

Participant information sheet

Title of Study: An insight into the experiences of young people with Obsessive Compulsive Disorder.

I am a Sociology undergraduate student at the University of Surrey carrying out my final year dissertation project on exploring the experiences of OCD sufferers. Living with OCD myself has triggered my interest in understanding how others experience the symptoms of this disorder. I would therefore like to invite you to participate in this research project which forms part of my dissertation research project. You must only participate if you want to and choosing not to take part will not discredit you in any way. Before deciding whether to participate in this study, it is important that you understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

Please ensure that you have read and fully understood this information before proceeding with the research process. You will be provided with a copy of this Information Sheet to refer to throughout the research process.

What will happen if I take part?

The aim of this study is to explore the everyday experiences of OCD sufferers; you do not have to have a clinical diagnosis of OCD to participate. I am specifically interested in exploring your experiences of dealing with intrusive thoughts, seeking help and how you perceive yourself.

To develop an understanding of how you experience OCD I aim to carry out semi-structured interviews that will last around 50 minutes. These interviews will be conducted at the University of Surrey Starbucks with Skype being used as an alternative. Interviews will encourage you to openly tell me about the important aspects of your OCD experience. I may, at times, ask you to expand on certain events mentioned or ask you to talk about OCD in relation to specific topics. This interview, however, involves a series of open ended questions to encourage you to give me an understanding of how you experience OCD as a young person.

Why have I been invited to take part?

I am inviting you to take part in this study because you have been identified as a young person suffering from OCD symptoms and you may be interested in discussing your experiences.

Do I have to take part?

Please note that participating in this study is voluntary and by no means should you feel obliged to take part. Taking part is entirely voluntary and you would be free to withdraw at any point, although it will not be possible to withdraw data already collected after the point at which the dissertation is submitted (April 2018) The interview will take place at a time and place of your choosing.

What will happen to me if I take part?

If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. I will then contact you asking when you would be free to participate in an interview. Once the interview (lasting around 50 minutes) has been conducted and recorded, your response will be transcribed and analysed.

What are the possible benefits and risks of taking part?

The data that is generated on young people's everyday experiences of OCD will add to the sociological research that has been conducted around OCD. The benefits of participating in this study could be that you may find it enjoyable reflecting upon how you have experienced living with OCD. The disadvantage of taking part in the study may be that when talking about your experiences of OCD upsetting events and emotions may be triggered. However, if you feel as though reflecting upon certain experiences may be harmful to your wellbeing, I would advise you to not talk about them; I do not want this study to hinder you in any way.

Will my taking part be kept confidential?

What is said in the interview and/or data collected is regarded as strictly confidential and will be held securely until the research is finished. All data for analysis will be anonymised. In reporting on the research findings, I will not reveal the names of any participants or the organisation where you work.

A statement saying that privacy/confidentiality cannot be guaranteed when interview is conducted in a public setting (such as Starbucks) where conversation may be overheard has been included

All project data related to the administration of the project, (e.g. consent form) will be held for at least 6 years and all research data for at least 10 years in accordance with University policy. Your personal data will be held and processed in the strictest confidence, and in accordance with current data protection legislation. All information gathered will be held for long-term storage on University secure servers. Hard files will be kept in locked cabinets within the Sociology department at the University of Surrey.

No identifiable data will be accessed by anyone other than me, members of the research team and authorised personal from the University and regulatory authorities for monitoring purposes. Anonymity of the material will be protected by The Data Protection Act 1998. The data collected will not be able to be linked back to the participating parties. However, should you disclose that you or someone else is at risk then the researcher may need to report this to an appropriate authority.

How is the project being reviewed?

This study has been given a favourable ethical opinion by the FASS Research Ethics Committee.

What will happen to the results of the study?

The study is being used as the basis of my undergraduate dissertation.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Full address:

University of Surrey Department of Sociology

Guildford

GU2 7XH

Email: ap00355@surrey.ac.uk

What if something goes wrong?

If you wish to make a complaint about the conduct of the study you can contact:

Dissertation supervisor, Dr Rob Meadows

Full address:

University of Surrey Department of Sociology

Guildford

GU2 7XH

Email: r.meadows@surrey.ac.uk

Head of Sociology department, Professor Jon Garland

Full address:

University of Surrey Department of Sociology

Guildford

GU2 7XH

Email: j.garland@surrey.ac.uk

The University has in force the relevant insurance policies which apply to this study. In addition, the Sponsor has decided, in the event of harm where no legal liability arises, for “non-negligent harm” claims. If you wish to complain, or have any concerns about any aspect of the way you have been treated during this study then you should follow the instructions given above.

If you would like to seek further advice about dealing with OCD or just to have a chat in general about your mental health after or before the interviews, please contact these helpline numbers:

OCD Action:

020 7253 2664

support@ocdaction.org.uk

OCD-UK:

0345 120 3778

support@ocduk.org

The Samaritans:

01483 505555

jo@samaritans.org

Thank you for reading this information sheet and for considering taking part in this research.