

An Exploration of the Lived Experience of Pure O (primarily obsessional OCD): A Qualitative Survey

Participant Information Sheet

Who are the researchers and what is the research about?

Thank you for your interest in this research project focusing on understanding the experiences of individuals with Pure O (including those with or without a formal OCD diagnosis). My name is Virginia Guy and I am a trainee counselling psychologist in the Department of Health and Social Sciences, at the University of the West of England (UWE). I am completing this research for my doctoral thesis. My research is supervised by Dr Nikki Hayfield and Dr Zoe Thomas (see below for their contact details). Pure O is an important topic but there is currently limited research looking into the lived experience of this specific type of OCD. It is hoped that the findings from this study will increase current knowledge and understanding in this area.

What does participation involve?

You are invited to take part in an online qualitative survey (where you write answers to questions in your own words, rather than ticking boxes). The survey should take no more than 30 minutes to complete. There are no right answers – I am interested in the range of opinions and thoughts that people have. You can write as much as you want in response to the survey questions, but I would be appreciative if you could provide detailed answers. If you do not wish to answer certain questions but are happy for the partial data from the survey to be submitted simply leave blank the question(s) you do not want to answer and click submit when the other questions are complete. After you have completed the survey questions, there are also some demographic questions for you to answer (some of these will be tick box questions). This is for me to gain a sense of who is taking part in the research. You also need to complete a consent question, to confirm that you agree to participate, before beginning the survey.

Who can participate?

Adults over 18 who self-define as having Pure O or have been diagnosed with OCD without overt compulsions.

How will the data be used?

The data will be anonymised (i.e., any information that can identify you will be removed) and analysed for my research project. This means that anonymous (non-identifiable) extracts from your survey responses may be quoted in my thesis and in any publications and presentations arising from the research. The demographic data for all participants will be collected together and compiled into a summary table and included in my thesis and in any publications or presentations arising from the research. The information you provide will be treated confidentially and personally identifiable details will be stored separately from the data. Any personal and identifiable details provided during the research process will be deleted or destroyed after the final project has been submitted. If you contact me, I will have your email address. This will be treated as confidential and used only for the purposes of this research. When our correspondence is complete, I will delete your emails from my inbox, sent items, and deleted items folder.

What are the benefits of taking part?

I hope that participants will find it interesting taking part and by participating in this research, you will be contributing to the developing understandings of an important psychological issue.

How do I withdraw from the research?

If you decide you want to withdraw from the research please contact me via email Virginia2.Guy@live.uwe.ac.uk quoting the unique participant code you will be asked to create before completing the survey. Should you wish to withdraw, all answers, personal details and any email correspondence will be permanently deleted. If you wish to withdraw during the survey process you will be able to simply exit the survey before completion and no data will be saved. Please note that there are certain points beyond which it will be impossible to withdraw from the research – for instance, when I have submitted my thesis. Therefore, I strongly encourage you to contact me within a month of participation if you wish to withdraw your data. I'd like to emphasise that participation in this research is voluntary and all information provided is anonymous where possible.

Are there any risks involved?

We don't anticipate any particular risks to you with participating in this research; however, there is always the potential for research participation to raise uncomfortable and distressing issues. For this reason, we have provided websites with information about how to seek support online, over the phone and/or face-to-face in your local area, see:

For **emergency support**, if you or someone else is at risk of immediate harm please call **999**.

Support can be sought through your **GP** or **GP out-of-hours service**.

Mind - Offers information and advice about seeking support for OCD and other mental health concerns.

<https://www.mind.org.uk/information-support/types-of-mental-health-problems/obsessive-compulsive-disorder-ocd/treatments-for-ocd/>

NHS Website - Provides information about how to access local mental health support services. <https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/how-to-access-mental-health-services/>

OCD Action – Offers information and support specific to OCD through their website, forum and helpline. <https://www.ocdaction.org.uk/>

Anxiety UK- Provides information about accessing mental health support and offers specialised helpline support for individuals diagnosed with anxiety-related disorders. <https://www.anxietyuk.org.uk/>

No Panic – Offers help and support to individuals with anxiety-related disorders including a confidential helpline. <https://nopic.org.uk/contact-us/>

Support Outside the UK:

For help in an **emergency** in Europe please call **112** or in the USA call **911**.

International OCD Foundation- Provides information about accessing support for

individuals with OCD.

<https://iocdf.org/>

NAMI, the National Alliance on Mental Illness- Offers help and support resources to individuals experiencing mental health problems in America.

<https://www.nami.org/home>

Anxiety and Depression Association of America- An international organisation that helps people experiencing mental health problems to find resources and support.

<https://adaa.org/>

If you have any questions about this research, please contact me in the first instance:

Virginia Guy Email: Virginia2.guy@live.uwe.ac.uk

Or if you would like to contact my supervisors:

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This research has been approved by the Faculty Research Ethics Committee (FREC) HAS.20.06.184