

Participant Information Sheet

Understanding OCD Symptoms and Family Factors: A Study of Adults with OCD and their Caregivers.

Thank you for taking the time to consider taking part in this study. My name is Saba Meky, I am a clinical psychologist in training at the University of Bath.

Before you decide to take part in this study, it is important for you to understand why the research is being done and what it would involve. Please take time to read the following information carefully and, if you wish, discuss it with friends, relatives, or anyone else who you think would be a good person to advise you.

Please feel free to contact me via email (ocdresearch@bath.ac.uk) if there is anything that is not clear or if you would like more information.

What is this project about?

This project aims to help us better understand how family factors can affect symptoms OCD symptoms. Some research shows that some factors within family's can impact adults with OCD, their treatment and symptom severity. However, we still need more research to know which factors psychologists should be aware of to make treatments better for people with OCD. This study hopes to look into how different "family factors" are related to OCD symptoms. When we say "family factors", what we mean are things like the relationship styles of people with OCD and their caregivers, how people within the family handle and cope with upsetting and uncomfortable emotional situations, and how families may or may not interact with OCD rituals and/or compulsions. We are asking adults with OCD and their caregiver, partner, or parent to complete several online questionnaires and questions looking at these areas. These responses will help us to see if and how factors are connected, and guide future OCD therapy and research.

What does the project involve?

You will be asked to complete a series of questionnaires online. This may take up to 20-30 minutes. The questionnaires will ask about your demographics (such as your age and gender identity) and your experiences with others, uncomfortable emotional situations, and living with OCD.

Who can take part?

We are looking for 2 people 18 years of age of older to take part in this study:

- 1. One person with a diagnosis of OCD and / or identify OCD to be their main difficulty.
- 2. And one loved one and / or caregiver (e.g. parent, partner, spouse, sibling) who has lived with or is living with the person with OCD in the past year.



It is really important that you are **both (person with OCD and caregiver) able and consenting to participate** in this project.

Both members of your dyad will need to be willing to participate to meet our study criteria. Therefore, prior to taking part in the online survey, we ask that you discuss the study with your dyad, and ask if they are happy and consent for you to pass their email address onto us so that we can send them an invitation to consider taking part (their email address must be different to yours).

To confidentially link responses of both the person with OCD and their caregiver, you will need to create a unique code together before completing the questionnaires. For example, a combination of your initials and meaningful number (e.g., NE56). This code will be entered by both participants separately at the beginning of the questionnaires, and ensures that your data remains anonymous. At this point we will also ask for an email address that can be used to send an invitation to your the other person in your dyad so they can consider taking part.

What are the benefits of taking part?

By participating in this study, you will be helping us to learn more about how family factors impact OCD. This could lead to better psychological treatments for people with OCD. On completion of the questionnaire, you have the option to receive £5 cash payment for your participation if you wish. We will require your email address for receipt of this, and it will be sent via Paypal. Your email address will be stored securely separate to your questionnaire responses, so it is not identifiable or linked to your data.

Are there risks involved?

The questionnaire will be asking sensitive questions about your mental health, which might bring up difficult thoughts and feelings and could potentially be upsetting. If you are in any way concerned that the questionnaire might cause distress or negatively impact your wellbeing, we recommend that you do not participate in the study. Equally, if you feel happy to continue now but later find that completing the questionnaire is upsetting, please stop immediately. Whether or not you participate in the study, we recommend that you book an appointment with your GP if you have any non-urgent questions or concerns about your mental health or wellbeing. You can also seek support from a relevant mental health organisation, some examples of which are listed below:

• Reat

Website: www.beateatingdisorders.org.uk

Helpline: 0808 801 0677

• OCD-UK

Website: www.ocduk.org Helpline: 0333 212 7890



OCD Action

Website: www.ocdaction.org.uk Helpline: 0845 390 6232

Anxiety UK

Website: www.anxietyuk.org.uk

Helpline: 03444 775 774

Mind

Website: www.mind.org.uk Helpline: 0300 123 3393

If you have urgent concerns about your mental health, or are feeling suicidal, you should call 999 or contact the Samaritans for support:

Samaritans

24-hour helpline: 116 123 Website: <u>www.samaritans.org</u>

Do I have to take part?

No, it is entirely up to you to decide if you wish to take part or not. After you have read this page you will be asked to complete a consent form. If you consent to take part, you are free to withdraw from the study at any point, without having to give a reason, by simply closing the browser. If you have completed the questionnaires and wish to withdraw your responses, you can contact the researcher via email and provide them with your unique code and confirm if you are the person with OCD or the caregiver. This can be done without giving any reason and the other person will not be notified of a withdrawal. However, please note that 14 days after completing the questionnaires, all responses will be completely anonymised meaning that I won't be able to tell whose responses are whose anymore. From this point, you will not be able to withdraw your responses as they won't be identifiable.

Will my taking part in the study be kept anonymous and confidential?

Yes, your data will be kept secure and your real name will not be used in the study at any time, in line with the Data Protection Act and the University of Bath research requirements. Your consent form and questionnaire responses will initially be stored at an encrypted electronic data centre, only accessible to the researchers via a password-protected online account.

At the end of data collection (no later than 1st May 2026) your data will be securely transferred to a password-protected, encrypted file on a secure storage drive at the University of Bath, where it will be held during data analysis and only accessible to the researchers. This will involve looking for statistical trends in data provided by all study participants.

Following data analysis, the study will be written up as a research paper. The paper will describe the overall findings of the study, which might include examples from your questionnaire



responses for illustrative purposes, but you will not be identifiable in any write up. This paper will be submitted to the University of Bath as a part of the requirements of the Doctorate in Clinical Psychology. The paper will also be submitted for publication in a peer-reviewed journal.

Once the paper has been written up, the questionnaire data from all study participants will be securely transferred to and stored in the University of Bath's research data archive for at least 10 years, in line with the University of Bath Research Data Policy, after which it will be securely deleted. A completely anonymised dataset from this study will be saved on the University of Bath Data Archive. It is possible that the University of Bath will use this data for another research project, but the conditions of anonymity, confidentiality and secure storage outlined on this information sheet will still apply.

Who has reviewed this project?

This project has been given a favourable ethics opinion by the University of Bath, Biomedical Sciences Research Ethics Committee, reference 7262-15049

If you have any questions or concerns about the study, you can contact the lead researcher or academic supervisor using the details below. However, please note that these contact details should <u>only</u> be used for queries relating to the study. The researchers are <u>not</u> able to deal with queries regarding mental health, and their email inbox is only checked sporadically, meaning that any emails might not be replied to immediately.

Lead Researcher:

Saba Meky (Trainee Clinical Psychologist)

Email: ocdresearch@bath.ac.uk

Supervisors:

Dr Josie Millar, Dr Jennifer Allen and Dr Rowena Pagdin (Clinical Psychologists and Research Supervisors)

Email: ja980@bath.ac.uk <u>ifam20@bath.ac.uk</u>

University of Bath Ethics Committee: research-ethics@bath.ac.uk
University of Bath "Ethics@Bath" Privacy Notice: this can be found here https://www.bath.ac.uk/legal-information/university-of-bath-privacy-notice-for-research-participants/

Thank you very much for taking the time to read this information sheet.

We would be delighted if you would be willing to consider taking part.



If you decide you would like to take part, please read and complete the consent form on the next page.