



## Participant Information Sheet

Thank you for your interest in taking part in this study.

We are inviting you to take part in a research study. Before you decide if you wish to take part, it is important that you understand why this research is being carried out and what it will involve.

Please read the following information carefully.

### What is the purpose of the study?

We want to investigate what happens when a family member is needed or asked to become involved in their loved one's OCD symptoms and the impact this can have on both individuals. We are primarily interested in investigating this by utilising a novel data collection method that allows us to monitor this information on a daily basis.

Previous research has found that it is common for family members or friends to help out with their loved one's OCD behaviours (sometimes referred to as 'Accommodation'), although it is also known that at times individuals becoming involved in this way can mean that it is difficult for sufferers to benefit from psychological treatment. In this programme of research we wish to explore some of the factors that encourage family members to help out with OCD symptoms or behaviours, and the impact of these accommodation behaviours.

We also know that currently existing research depends on individuals' perception of accommodation after the events and an overall evaluation of the behaviours and feelings around it. This novel research will attempt to capture the behaviours in a more immediate and direct way by asking participants to give us a brief snapshot of their experiences on a daily basis. It has been ascertained by a previous study that this approach has been found to be acceptable and feasible by previous participants.

### Who can participate in the study?

We are looking for individuals with OCD and family members of individuals with OCD to participate in the study. Individuals with OCD and family members of individuals with OCD must be aged 18 or over in order to take part. If you are a family member of an individual experiencing OCD you must spend a significant amount of time with that individual (at least one hour a day) and must also not be involved in the care of another relative experiencing severe physical or mental health difficulties. If there is more than one individual who

supports an individual with an OCD, it is recommended that the person who supports you the most on a daily basis.

## Do I have to take part?

No. Your participation in this research is voluntary and you can withdraw from the research at any time. You do not have to provide a reason if you wish to withdraw from the research. You do not have to complete the questionnaire once you have started it. If you choose not to complete the entire survey, the information you have provided may still be used in the data analysis unless you specifically request that your information be withdrawn as mentioned below.

You can withdraw from the research after you have participated. If you wish to withdraw from the research after completing the survey, please get in touch with our research team within two weeks of completing the questionnaire using the contact details provided. Please note that if you wish for your data to be removed from the study, you will need to have provided an email address when completing the survey so we can identify which data belongs to you.

## What is involved in the study?

If you decide that you wish to take part in the study, you will first be asked some questions to determine whether you are eligible to participate in this study. This includes whether you consider yourself someone suffering from OCD or consider yourself an individual who supports someone with OCD, your age and whether you have access to a mobile smartphone. Following the essential criteria for eligibility into the study, there will be a few further questions gathering demographic information and information regarding accommodation behaviours. In total, this set of questions should take no longer than approximately 20 minutes, and will help us to ensure you are able to take part in the study.

If you are willing and able to participate, we can arrange an optional phone call or email from a member of the research team to discuss the study in more detail, answer any questions you may have and talk through the practicalities of participating.

The requirements of the study are that we will ask you (as an individual with OCD or as an individual who supports an individual with OCD) to answer a very brief survey (no longer than 5-10 minutes on each occasion) at several points throughout the day over a period of **14 days**. We will ask you to complete the surveys using a smartphone. The questions will primarily be related to accommodation, or helping out with, OCD behaviours.

All data that is collected will be anonymised. The data will be used for research purposes only and will be stored in accordance with the Data Protection Act (1998) and General Data Protection Regulation (GDPR; 2017) and the policies of Newcastle University and Northumberland, Tyne and Wear NHS Trust. Only the research team will have access to this data. Only the research team will have access to email addresses and telephone (if disclosed) that are provided, which will be securely stored, separate from the data.

## **What will happen if I become upset?**

It is unlikely that you will feel upset as a result of taking part in this research. However, if you do become upset you can withdraw from the research immediately. You will not be asked why you have withdrawn from the study. Following completion of the study, you will be provided with a debrief sheet which will provide information on charities and national services that you can contact should you require any further support. You will also be provided with contact details for the research team should you have any questions or concerns regarding the study specifically.

## **What are the benefits of participating in the study?**

By taking part in this research you will be contributing to the knowledge base which aims to further our understanding of accommodation in OCD and to develop further research into the assessment and treatment of OCD. Each participant that completes the study will be compensated for their time with a £10 voucher.

## **How do I find out more about the study?**

If you have any questions about the research, please get in contact with the researchers, at [OCD.Research@newcastle.ac.uk](mailto:OCD.Research@newcastle.ac.uk) and a member of the research team will contact you very shortly.