Patient Information Sheet

Experiencing Obsessions and Compulsions in Daily Life

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of this study?
We want to find out more about how people with OCD experience their symptoms in the context of daily life. We would like to collect information to see whether symptoms change over time in a meaningful way and how this may relate to (i) personal aspects (e.g., age, mood) and (ii) to clinical aspects (e.g., the kind of OCD symptoms experienced).

Why have I been chosen?
You have been chosen because we are looking for individuals who experience symptoms of OCD to take part in this study and you have agreed to consider participating in this research. You have also stated that you own, have access to and are comfortable using an **Android smartphone** where you can install an app that will ask you about your everyday experiences of OCD for the duration of the study.

Do I have to take part?
It is up to you to decide. We will describe the study and can answer any questions you may have. We will ask you to complete a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive now or in the future.

What does the procedure involve? What will happen to me if I take part?

- You will be asked to complete a series of questionnaires online asking about yourself, your personality and habits. Completing these questionnaires typically takes 20-30 minutes. All the information will be kept in a way as to not include any personal, identifiable details.
- You will also download a special research app from Google Play Store that will be linked to this study. You will be asked to keep your phone close by for the duration of the study. In this study, the app will ask you to rate your symptoms, experiences and feelings a few unpredictable times a day (about 4-8) between 8 am and 10 pm, for up to 10 days. For example, you will be asked to rate the following statement for yourself "I am experiencing obsessions" using multiple choice options ranging from "None at all" to "Extremely severe". You may also complete a multiple choice question as to your current location, (e.g., "at home", "work", etc.).

Each time, answering the questions should only take 30 seconds to 2 minutes. The app will collect only the questionnaire data. Data on your smartphone is encrypted so that even if the device gets lost, nobody can access it. This data will be uploaded automatically to a secure server using SSL encryption when a wireless connection will be available. You will need to keep the app running in the background for the duration of the study, but it should not affect your smartphone in any way. After the study is over, you will be notified and you can remove the app.

- In the end, you will be asked to complete a final survey online about your experience.

What are the possible risks/side effects of taking part?
This study will help us to understand how you experience OCD in daily life. There are no risks associated with participating in this study, you are free to stop at any point. You can stop and/or remove the app at any point. The app will not use your data allocation and will not appreciably slow down your phone. However, if not enough data is collected from you, we will not be able to use your data in the study.

What are the possible benefits of taking part?
You will receive £20 Amazon Vouchers for your participation. You will also have the benefit of knowing that you have made a contribution to our understanding of OCD. If you wish, we can provide a file with the data about your symptom severity over the course of the study. We hope that by collecting information from you, we may be able to help with the development of better treatment and support for people with OCD.

Will my taking part in the study be kept confidential?
Yes. We will not inform anyone of your participation in the study without your consent. All information gathered about you during the study will be kept confidential. The details are included in Part 2.

Part 2

What will happen if I don't want to carry on with the study?
You are free to withdraw at any time, without explaining why. This would not affect the standard of care you receive.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (contact: Dr Davis Mpavaenda, 01707 364055, davis.mpavaenda@hpft.nhs.uk; Dr Sharon Morein, 01223 698418, sharon.morein@anglia.ac.uk). If you remain unhappy and wish to make a complaint, you can contact Professor Peter Bright, Chair of the Faculty Research Ethics Panel of Anglia Ruskin University (peter.bright@anglia.ac.uk, tel: 01223 363271). If you remain unhappy you can contact the Patient Advice and Liaison Service (tel: 01707 253916).

Will my taking part in this study be kept confidential?
All information collected about you during the course of the research will be kept strictly confidential. Any information about you will be linked to a subject code and will have your name and contact information removed so that you cannot be recognized from it. Documents linking your name with the subject code will be stored securely in a locked cabinet or password protected file in the investigator's office in the Psychology Department. Only members of the study team and regulatory authorities (who monitor the quality of the research) will have access

to identifiable data. As per established guidelines, research data will be stored for 10 years after the end of the study.

What will happen to the results of the research study?
When data from several volunteers are collected, they will be analysed and written up for publication in a scientific journal. The results may also be presented at scientific meetings, and in talks and in lay summaries available to service users and the public. All data will be have any personal information removed before they are analysed, and the results will always be presented in a way that data from individual volunteers cannot be identified.

What if I would like to participate in additional research?
If you have agreed to be contacted for optional future research, you may be contacted in future by the team for follow-up research. You can let the team know at any time if you are not interested or have any questions about this. If and when you may be contacted for follow-up research, you will be provided with relevant information enabling you to decide whether or not you may be interested.

Who is organising and funding the research?
This study is being organised and funded by the Department of Psychology at Anglia Ruskin University.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been approved by a Research Ethics Committee. Prior to that, this study was reviewed by patient volunteers at the Hertfordshire Partnership University NHS Foundation Trust.

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Thank you for considering taking part in this study. Our research depends on the goodwill of potential volunteers such as you. If you require any further information, we will be pleased to help you in any way we can.