



## **PARTICIPANT INFORMATION SHEET**

### **Understanding the service user and clinician experience of Cognitive Behavioural Therapy (CBT) for Obsessive-Compulsive Disorder (OCD).**

#### **Equality & Diversity Statement**

We want our research materials to be as accessible and inclusive as possible regardless of age, disability, gender, ethnicity, religion or sexual orientation. If you have any individual needs concerning this information sheet e.g. larger print or printed on yellow paper for instance, please speak to or email Eilidh Grant who is leading this research, using the contact details: [elg25@sussex.ac.uk](mailto:elg25@sussex.ac.uk)/ 07472098132, working hours (10am-6pm). Unfortunately, we do not have a budget to allow us to translate this information sheet or other research materials into other languages.

#### **About the researcher:**

My name is Eilidh Grant, and I am a PhD student at the University of Sussex researching therapies for Obsessive-Compulsive Disorder (OCD). In this study I am looking to understand the experience of those who have been involved in Cognitive Behavioural Therapy (CBT) for obsessive compulsive disorder, both as a service user or as a clinician. I hope that my work will help to increase understanding of things that make therapy easier or more difficult for some people with OCD.

#### **Invitation paragraph**

*You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.*

#### **What is the purpose of the study?**

- The purpose of this study is to understand why people with Obsessive-Compulsive Disorder (OCD) may not take up cognitive-behavioural therapy (CBT) when it is offered to them. We understand that there are many reasons people may not wish to take up CBT for their OCD, and these may include practical reasons (e.g. not having childcare) or reasons to do with the therapy itself (e.g. feel anxious about engaging in this therapy).
- **It is important to stress that there are no right or wrong answers, we are simply interested in hearing from you about your experiences and opinions.**

### **Who is conducting this research?**

- This research is being conducted by researchers from the School of Psychology at the University of Sussex. The research team for this study is made up of Eilidh Grant (PhD student), Dr Frances Meeten and Prof Clara Strauss (both of whom are researchers at the University of Sussex and work within the local NHS mental health trust).

### **Why have I been invited to participate?**

- **We are looking for adults (aged eighteen or over) who have been offered cognitive-behavioural therapy in England for their obsessive-compulsive disorder when they were aged eighteen or older, but who decided for any reason that they did not want to take part in this therapy.**
- **You are welcome and encouraged to participate whether you declined CBT as soon as you were offered this therapy or whether you initially accepted the invitation to receive this type of therapy but later decided not to attend the sessions.**
- CBT for OCD is a type of therapy which looks at how you think and how you behave. This therapy involves examining, reflecting on, and evaluating distressing patterns of thinking and corresponding behaviours to explore alternative ways of thinking and behaving. CBT for OCD involves engaging in exposure work (often referred to as exposure and response prevention; ERP). Exposure work looks to break the cycle of obsessive thoughts and subsequent compulsive behaviours which maintains OCD by exposing oneself to situations which bring on obsessive thoughts and/or compulsive behaviours but whilst resisting the urge to carry out these compulsions.
- If you were offered therapy for your OCD but you are unsure whether this therapy would be classed as CBT and would be interested in being a part of this research, please email Eilidh Grant ([elg25@sussex.ac.uk](mailto:elg25@sussex.ac.uk)/07472098132).

### **How do I know if I am eligible (suitable) to take part in this research study?**

We are looking to recruit individuals who:

- Are currently over 18 and were aged 18 or above when they were offered CBT for their OCD (if you have been offered this therapy as both an adult and as a child/adolescent then you are welcome to take part)
- Are current residents of England and were offered CBT for OCD in England
- Have sufficient English language proficiency to enable them to read, understand and respond to the online survey questions
- Were offered CBT for OCD symptoms which were not limited to hoarding symptomology (as hoarding is now considered to be a separate disorder, hoarding disorder)
- There are no exclusion criteria regarding co-occurring mental health or neurodevelopmental (e.g. ADHD) diagnoses

If you are interested in taking part in this research but are not sure if you are eligible or have any outstanding questions please do not hesitate to contact a member of the research team (contact details provided at the end of this form).

### **Do I have to take part?**

- *It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to electronically give consent on a consent form displayed on the next page.*
- *If you decide to take part, you are still free to withdraw at any time and without giving a reason by simply closing the web browser you are using. As data is provided anonymously, you will not be able to withdraw your data once you have submitted it.*

### **What will happen to me if I take part?**

- All data collection will happen online using an online survey platform called Qualtrics
- If you decide that you would like to take part you will first be asked to provide consent and then you will be asked to complete a very short set of multiple-choice questions which will just ask you to select from a list about your gender identity, ethnicity and education.
- Then you will be asked to answer a single question about why you felt that CBT for OCD might not have been right for you in an open text box (answers can be as short or long as you like).
- You will then be shown a debrief form which will thank you for your time and provide you with links to help sites which might be useful. In this debrief form there will also be the option to enter a £25 prize draw. To enter this there will be a link in the debrief email address which will take you to a separate survey which will just ask you to enter your email address. As this will be a separate survey your email address will not be linked to your answers to the main survey and so your responses will remain anonymous.
- You will also be given the option to be sent a copy of the research (including a plain English summary of this research) once it has been written up for publication.

### **What are the possible benefits of taking part?**

- You will be contributing to existing knowledge about CBT for OCD and reasons why people might not want to or be able to engage in this therapy
- You will have the opportunity to reflect upon and share your reasons as to why CBT for OCD
- You will have the option to take part in a prize draw for a £25 'love2shop' voucher

### **What are the possible risks of taking part?**

- We will be asking about your experiences of being offered CBT for OCD, so please only take part if this is something you feel comfortable discussing in either a group or individual setting.
- We also encourage you to think of someone you would talk to should you feel you need to after Qualtrics survey and we provide links to help websites at the

end of this information sheet and in the debrief form which you will be presented with after completing the Qualtrics questionnaire.

### **What are your choices about how your information is used?**

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

### **Will my information in this study be kept confidential?**

- You will not be asked to provide any identifiable information such as your name or address. You will have the option to provide your email address for the prize draw but this will be recorded and stored separately to the rest of your answers (the demographics and your answers to the main question) and therefore your email address will not be able to be linked to any of these answers.
- Your email addresses will be stored in password protected files and all your data will be deleted once the project has been completed and written up. Email addresses will be deleted as soon as the prize draw winner has been selected and notified.
- For both Qualtrics surveys, IP address tracking will be disabled.
- Quotes of the responses you give to the open question (the one about why you decided not to take part in CBT for OCD) may be used in the write up of this study but with no identifiable information. Quotes will be written up in the following form: "RESPONSE HERE" (participant X), where X will represent a number.

### **How will we use information about you?**

We will need to use information from you for this research project.

This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

## **Where can I find out more about how my information is used?**

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- at <https://www.sussex.ac.uk/about/website/privacy-and-cookies/privacy>
- our leaflet available from: [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
- by asking one of the research team
- by sending an email to [elg25@sussex.ac.uk](mailto:elg25@sussex.ac.uk), or
- by ringing us on 07472098132.

## **What should I do if I want to take part?**

- If you found out about this study online (e.g. via social media or charity website) and decide you would like to take part in this study, please complete the consent form on the next page.
- If you are reading a paper copy of this information sheet and would like to take part, please use the link at the end of this information sheet to complete the relevant consent form.
- If you would like to take part but cannot complete the consent form online for any reason, please contact Eilidh Grant using the email address [elg25@sussex.ac.uk](mailto:elg25@sussex.ac.uk) or text or phone using the number 07472098132 between the hours of 10am to 6pm and we can arrange an alternative way of you accessing the consent forms.
- If you have any outstanding questions or anything you would like clarified, please do not hesitate to get in contact with a member of the research team.

## **What will happen to the results of the research study?**

- Your results will be used as part of Eilidh Grant's doctoral thesis. It is hoped that when this study is written up it will be published in a scientific journal. Once I have written up the results of the study and given out the prize for the prize draw, all data will be deleted.

## **Who is organising and funding the research?**

- I am conducting this research as a PhD student from the School of Psychology at the University of Sussex.

## **Who has approved this study?**

This study has been approved by the Pre-Sponsorship Review Panel (PSRP), the University of Sussex Sponsorship Sub-Committee (SSC), West London & GTAC Research Ethics Committee and the Health Research Authority (HRA).

## **Contact for Further Information**

- If you have any questions relating to this project please contact Eilidh Grant ([elg25@sussex.ac.uk](mailto:elg25@sussex.ac.uk); 07472098132 (working hours: 10am-6pm; principle investigator), Professor Clara Strauss ([clara.strauss@nhs.net](mailto:clara.strauss@nhs.net); co-investigator and academic supervisor) or Dr Frances Meeten ([frances.meeten@sussex.ac.uk](mailto:frances.meeten@sussex.ac.uk); co-investigator and academic supervisor).

### **Contact for if you have concerns relating to this study:**

- Should you have concerns relating to this study, please contact Professor Clara Strauss ([clara.strauss@nhs.net](mailto:clara.strauss@nhs.net); co-investigator and academic supervisor) or Dr Frances Meeten ([frances.meeten@sussex.ac.uk](mailto:frances.meeten@sussex.ac.uk); co-investigator and academic supervisor) to voice these concerns.
- If you would prefer to talk someone outside of the immediate research team, please email the Universities' sponsor representative, Vanessa Cuthill ([researchsponsorship@sussex.ac.uk](mailto:researchsponsorship@sussex.ac.uk)).

### **Insurance**

- The University of Sussex has insurance in place to cover its legal liabilities in respect of this study.

### **Thank you**

- Thank you so much for taking the time to read this information sheet and for considering taking part in our study.

### **Date:**

- 4<sup>th</sup> April 2023

### **Help websites:**

NHS OCD page: <https://www.nhs.uk/mental-health/conditions/obsessive-compulsive-disorder-ocd/overview/>

MIND (for information and support about a range of mental health conditions including OCD): <https://www.mind.org.uk/>

OCD specific charitable organisations offering advice and support: OCD action <https://ocdaction.org.uk/> (OCD Action helpline: 0300 636 5478) and OCD-UK <https://www.ocduk.org/> (OCD UK helpline: 01332 588112)

If you are concerned about your own mental health, please see your general practitioner (your GP) in the first instance.

You can also refer yourself to your local NHS talking therapies service (<https://www.nhs.uk/service-search/mental-health/find-a-psychological-therapies-service/>)

### **Link to consent form:**

[https://universityofsussex.eu.qualtrics.com/jfe/form/SV\\_czOHmemK9ISWPBQ](https://universityofsussex.eu.qualtrics.com/jfe/form/SV_czOHmemK9ISWPBQ)