



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 email address: elg25@sussex.ac.uk / 07472098132. 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 OCD therapies. In this study I am looking to understand the experience of those who have been involved in Cognitive Behavioural Therapy 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.

Study invitation:

- We invite you to take part in our research study which is looking to understand individuals' experiences of OCD therapy.
- Before you decide if you would like to take part, it is important that you understand why this research is being done and what taking part would involve for you.
- Please take the time to read this information carefully and discuss it with others if you wish. If there is anything which is not clear or you do not understand, please ask us.
- Please remember that it is entirely up to you if you would like to take part.

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 mental health researchers and qualified clinicians with experience of working with those with OCD).

What is the purpose of the study?

- We are looking to better understand the experience of receiving Cognitive Behavioural Therapy (CBT) for Obsessive-Compulsive Disorder (OCD).
- CBT is a type of therapy which looks at how you think and how you behave. This therapy involves examining, reflecting on, and re-evaluating distressing patterns of thinking and corresponding behaviours. CBT for OCD involves engaging in exposure work (often referred to as exposure and response prevention; ERP, or this might be referred to as 'behavioural experiments'). This involves deliberately triggering your obsessions whilst resisting the urge to engage in compulsive behaviours and then reflecting on what has been learned.
- If you received 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 contact Eilidh Grant (elg25@sussex.ac.uk/ 07472098132).
- If you wish to participate you will have the option of attending either an online focus group (a small group discussion in which you answer questions and give your thoughts on a topic, in this case CBT for OCD) with other people who have also received CBT for their OCD or an online individual interview with a PhD researcher from the University of Sussex. **It is very important to point out that there are no right or wrong answers, we are simply interested from hearing from you, about your experiences.**

Why have I been invited to participate?

- You have been invited to take part in this research as you have been offered or have received Cognitive Behavioural therapy (CBT) for your OCD symptoms.
- You are invited to take part whether you received CBT either online or in-person and whether this therapy was delivered in a group or individual setting.
- **We invite you to take part whether you decided to attend the full course of sessions or whether you decided, for whatever reason, to stop receiving therapy/attending sessions at any point, provided you attended at least one session of CBT for OCD.** We are aware that there are many possible reasons a person may have decided to stop attending therapy and very much welcome your involvement regardless of how you found therapy.

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

We are looking to recruit individuals who:

- Are currently aged 18 or over
- Are a current resident of England
- Received at least one session of CBT for OCD as an adult (if you have received this therapy as both a child/young person and as an adult then you are eligible to take part). If you are unsure whether the therapy, you received was CBT please see the above section ('what is the purpose of this study').
- This therapy should have been delivered in England

- Feel able to recall their experiences of receiving therapy in a sufficient level of detail that you feel able to discuss these experiences in a focus group or interview (depending on what you decide you would like to do).
- Received CBT for symptoms which were not exclusively hoarding behaviours/disorder as hoarding disorder is currently considered to be a separate diagnosis from OCD.
- Have sufficient English Language proficiency (ability) to enable you to take part in the focus groups or interviews.

There are no exclusion criteria regarding co-occurring mental health or neurodevelopmental (e.g. ADHD) diagnoses

If you are interested in taking part in our study but are not totally sure whether you are eligible or have any questions, please email a member of the research team (Eilidh Grant, elg25@sussex.ac.uk, Clara Strauss, clara.strauss@nhs.net or Frances Meeten, frances.meeten@sussex.ac.uk).

Do I have to take part?

- No, it is entirely up to you whether you decide you would like to be involved in this research project or not.
- It is important to note that withdrawing from or taking part in this study will not affect your clinical care. Likewise, whether you decide to take part or not, or later withdraw from, this study will not be shared with your clinical team.

What will happen to me if I take part?

Prior to the focus groups and interviews:

- If you decide that you would like to take part, you will be asked to sign a consent form (see below) and indicate your availability using the link provided at the end of the consent form.

If you decide to attend a focus group:

- We will run multiple online focus groups for service users and within each focus group there will be up to five participants.
- We will try and conduct these focus groups on different days and times of day to try and suit the different preferences of participants.
- Each focus group will have a duration of up to 90 minutes in length and will be hosted on Zoom (therefore you will not be required to travel anywhere).
- Eilidh Grant, a doctoral student from the School of Psychology at the University of Sussex, will be facilitating these focus groups, with Dr Frances Meeten and Professor Clara Strauss (both of whom are experienced clinical psychologists) taking turns to co-facilitate these groups.
- Should any questions or concerns arise during the duration of the focus group, please do not hesitate to use the message function which will be visible throughout the Zoom focus group to message any member of the

research team. Neither the content of your message nor the fact that you have messaged will be visible to other participants. You will be shown how to use the chat function at the beginning of the focus group

- **The focus groups will be based around exploring things you, and others who received the same treatment as you, found helpful or unhelpful in therapy and things that you may have found helped or hindered your experience of therapy.**
- Again, it is important to highlight that there will be no right or wrong answers, we are just interested in hearing about your opinions and experiences. Likewise, we will ask you to be respectful of the opinions and experiences of other members of the group.
- Nothing you say within the context of these focus groups will be relayed back to your clinical team.
- The focus groups will be audio recorded and transcribed (written up in text form), but nothing you say will be connected to your name, nor any identifying details instead all quotes will be attributed to participant X where the X is a number.
- Shortly before (e.g. the day before) you will be sent an email reminder for the focus group and asked to complete a short online survey which will just ask you to provide some basic information about yourself such as your gender identity and ethnicity. This data will be provided anonymously and will not be able to be linked to anything you say within the focus groups.
- Focus groups will begin with an outlining an overview of the focus groups including a restatement of the aims. Then clear ground rules for the focus group will be established, including making clear to attendees that what is said within the focus group must remain in the focus group.
- The focus group will then proceed and there will be a short 5-minute break in the middle.
- At the end of the focus group, you will be thanked for your time and participation and given another opportunity to ask any questions which you may have.
- You will be sent debrief materials via email which will provide you with links to help sites and offer you the chance to claim your £10 gift card to thank you for your participation. You will also be given the option to be sent a copy of the research (including a plain English summary of the research) once it has been written up for publication.

If you decide to attend an individual interview:

- Interviews will be around 60 minutes in length, and they will take place over Zoom or telephone if you prefer (so you will not be required to travel anywhere).
- Eilidh Grant, a doctoral student from the School of Psychology within the University of Sussex, will be the person who conducts the interviews.
- Interviews will be focused around your experiences of CBT for OCD therapy and things you found helpful or unhelpful about this therapy.

- It is important to note that nothing you say within the context of these interviews will be relayed back to your clinical team, and that there are no right or wrong answers we are just interested in hearing from you about your experiences.
- Your interview will be audio recorded and transcribed (written up in text form). Nothing you say will be connected to your name or any identifiable data. Instead, all quotes will be attributed to participant X where the X is a number.
- Shortly before (e.g. the day before) you will be sent an email reminder for the interview and asked to complete a short Qualtrics survey which will just ask you to provide some basic demographic questions such as your gender identity and ethnicity. This data will be provided anonymously.
- At the end of the interview, you will be thanked for your time and participation given another opportunity to ask any questions you may have.
- You will be sent debrief materials which will provide you with links to help sites and offer you the chance to claim your £10 gift card to thank you for your participation.

What are the possible disadvantages and risks of taking part?

- We will be discussing your experiences of therapy, 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 the focus group 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 by email once the interview or focus group is over.
- Additionally, the research team will remain in the Zoom call after the focus group or interview to answer any questions or concerns anyone may have or to talk through anything you may wish to talk through.

What are the possible benefits of taking part?

- Your knowledge and experience is invaluable; you will be helping to contribute towards and extend current knowledge of CBT for OCD and this research will be used to inform if and how CBT for OCD could be improved.
- You will have the opportunity to reflect upon and discuss your experiences of CBT for OCD with someone outside of your social circle and clinical team in a friendly, non-judgemental environment.
- Additionally, all individuals who decide to take part in either an interview or a focus group will be reimbursed for their time by receiving a £10 voucher from a range of choices.

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?

- Excerpts of things you share in the interview or focus group may be used in the write up of this research study but will be attributed to participant X, where X represents a number. No identifying data will be linked to these quotes which may be used.
- When you complete the short online surveys IP address tracking will be disabled and your demographic information will be stored in a separate, password protected file from the rest of your data
- This research project involves the use of our University Zoom account. Details of the platform's privacy notice can be found here: [Zoom Privacy Policy](#). All data collected will be stored securely on a University of Sussex managed system.
- All identifiable data will be deleted once the research has been written up and accepted for publication in a scientific journal. The audio recordings of the focus groups/interviews will be deleted once the transcripts have been written up.

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 (only the transcripts; the original audio recordings will be deleted). 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/
- at <https://www.sussex.ac.uk/about/website/privacy-and-cookies/privacy>
- our leaflet available from: www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to 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 relevant consent form (i.e. either the interview consent form or the focus group consent form) and on this form use the link to indicate your availability.

- 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, or text or call using the phone number [07472098132](tel:07472098132) (working hours: 10am-6pm) and we can arrange an alternative way of you accessing the consent forms.
- If you would like to take part but have any remaining questions, please do not hesitate to contact a member of the research team with anything you would like to ask or have clarified.

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 anticipated that when this study is written up it will be published in a scientific journal and presented at relevant conferences. Once I have written up the results of the study and vouchers have been given out, all identifiable data will be deleted.

Who is organising and funding the research?

- This study will be conducted and funded as part of a PhD project within 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).

How have patients and the public been involved in this study?

- We have received input from the NHS Sussex Partnership Lived Experience Advisory Panel (LEAP).
- LEAP members have been involved in reading through forms you will be given (including this information sheet) and we have shared the focus group questions with these individuals.
- In both instances, we asked LEAP members to provide their feedback and suggestions for improvement which we have implemented.
- After the focus groups and interviews have been conducted and our data has been analysed, the LEAP group will also be presented with the preliminary findings and again asked for their feedback.

Contact for Further Information

- If you have any questions relating to this project please contact Eilidh Grant (principle investigator, elg25@sussex.ac.uk/ phone number: 07472098132, working hours 10am-6pm), Professor Clara Strauss (clara.strauss@nhs.net; co-investigator and academic supervisor) or Dr Frances Meeten (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; co-investigator and academic supervisor) or Dr Frances Meeten (frances.meeten@sussex.ac.uk; co-investigator and academic supervisor) to voice these concerns.
- If you would prefer to talk someone outside of the research team, please email the please email the Universities' sponsor representative, Vanessa Cuthill (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:

4th 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 note that you can also speak to your general practitioner (your GP).

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_9u9RKaKe91oLsI6