

INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number: HR/DP-20/21-21977



YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of study

A Qualitative study exploring Repetitive Negative Thinking in OCD

Invitation

I would like to invite you to participate in this research project which forms part of a wider programme of research investigating treatments for people with a diagnosis of obsessive compulsive disorder (OCD). Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

We are developing a new study looking at thinking patterns and processes that play a part in OCD. We know that OCD involves frequent and unwanted intrusive thoughts (or doubts, images, urges) which cause distress. However, we also know that many OCD sufferers can become caught up in negative and repetitive ways of thinking *about* these thoughts and what they mean or their implications. We call this *repetitive negative thinking* and it includes things like worrying, ruminating and analysing. These ways of thinking are not exclusive to OCD but we are interested in understanding more about how they happen in OCD as we hope it will help us to develop more effective treatments.

At this stage of the research we want to find out more about people's experiences of getting stuck in these ways of thinking in response to intrusive thoughts so that we develop better ways of helping people to engage in more helpful ways of thinking.

Why have I been invited to take part?

We would like to invite people who meet the criteria below to participate in our research:

- People over the age of 18 years old with normal or corrected to normal vision and hearing.

Who have:

- Previously been diagnosed with OCD.
- OCD that involves primarily worrying or ruminating about upsetting and unwanted intrusive thoughts or doubts, including people who identify as having Pure 'O' (pure obsessional) OCD.

Who are not:

- Currently in treatment for psychosis, personality disorder, bipolar disorder or substance use issues.

What will happen if I take part?

If you choose to take part in the study you will be asked to complete an interview with a member of the research team about your experience of rumination and worry in relation to distressing thoughts / images / doubts / urges in OCD. You will be asked about examples of these, when and how they occur, as well as demographic and mental health information. For example, you may be asked questions like:

- Do you have any experience of repetitive negative thinking (worry, rumination) about unwanted intrusive thoughts and doubts?
- Could you tell us about a time this happened recently?
- Do you tend to find yourself thinking in similar ways about other things (outside of OCD)?

The interview will take approximately 1 hour. You will have the option of being interviewed over the telephone or MS Teams.

You will be asked if you consent to recording of the interview as this will allow for more accurate data analysis. The recording of the interview will be stored securely and only accessed by the research team. This will be stored using your unique ID number, and will be completely anonymous.

Do I have to take part?

Participation is completely voluntary. You are under no obligation to take part and should only do so if you would like to. There are no negative implications should you choose to not take part. If you choose to take part, you will be asked to provide your consent. In doing so, you will be asked to indicate that you have read and understood the information provided and that you consent to your anonymous data being used for the purposes outlined to you.

After choosing to take part in this study, you are still free to withdraw at any point, without giving a reason. If you have started the training session, you can do this by closing the browser window. Withdrawing from the study will not have negative consequences for you in any way. Once you submit your responses, they will be fully anonymous, so it will not be possible to withdraw your data from the study. Please do not include any personal identifiable information in your responses.

You are free to withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You are able to withdraw your data from the study up until 31/05/2021 after which withdrawal of your data will no longer be possible due to the data being committed to the final report. If you choose to withdraw from the study we will not retain the information you have given thus far.

Incentives

Participants who chose to complete the interview will be offered compensation for their time in the form of an Amazon voucher to the value of £12.

What are the possible risks of taking part?

The interview will ask questions about your experiences of negative streams of thought that occur as part of OCD. It may be upsetting to talk about this. In our experience of conducting similar research we expect that any distress you experience is likely to be temporary. If you take part and become noticeably upset or distressed, you will be reminded that you can end the interview at any time or chose to move on to another question. If an interviewer is concerned about your mental well-being, they may advise that you contact your GP or community mental health team. Information will be provided at the end of the study about different resources and organisations that you can contact if you have any concerns about your mental health. If you do have concerns about your mental wellbeing, please contact your GP or other community health worker, who will be best placed to advise you about your local support options. We have also included some relevant information that might be helpful in the debrief sheet that you will receive at the end of the study.

What are the possible benefits of taking part?

You may find the study interesting and may find value in sharing your experiences of OCD. Many people report feeling satisfied and pleased to have contributed to mental health research.

Data handling and confidentiality

This research is anonymous. This means that nobody, including the researchers, will be aware of your identity, and that nobody will be able to connect you to the answers you provide, even directly. Your answers will be treated confidentially and the information you provide will not allow you to be identified in any research outputs/publications. Your data will be held securely on a shared drive only accessible to those in the research team for 7 years. After this time, your data will be destroyed.

The data controller for this project will be King's College London (KCL). The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'. Your data will be processed in accordance with the standards set out by the General Data Protection Regulation Act 2018 (GDPR). You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you.

Questions, comments and requests about your personal data can also be sent to the Kings College London Data Protection Officer via info-compliance@kcl.ac.uk. If you wish to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk.

In the unlikely event that during participation in the research, a participant makes a disclosure that leads the interviewer to believe a participant is at risk of harming themselves, a clinical member of the department will contact and assess the participant and take necessary action to mitigate risk. This could involve breaking confidentiality, for example to disclose risk to health or other emergency services.

What will happen to the results of the study?

The results of the study will be summarised in a dissertation for the MSc in Mental Health Studies. The results of the study may also be published in an academic journal and will be used to inform the next stages of our programme of research.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Clare Gallagher

Email: Clare.gallagher@kcl.ac.uk

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

Dr Colette Hirsch

Postal address:

P319

Inst. of Psychiatry

Institute of Psychiatry

United Kingdom

Telephone: +44 (0)20 7848 0697

E-mail: Colette.hirsch@kcl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

If you are in need of urgent mental health support, please call one of the numbers below immediately:

- The Samaritans: 08457 90 90 90
- MindinfoLine: 0300 123 3393 (open 9am-6pm)
- Rethink advice and information service: 0300 5000 927 (open 10am-1pm)
- If you are based in Croydon, Lambeth, Lewisham or Southwark, the South London and Maudsley NHS Foundation Trust (SLaM) has a new helpline: 0800 731 2864 (open 24 hours)
- HOPELineUK: For young people up to the age of 35, 0800 068 41 41 (10am - 5pm & 7pm - 10pm, Weekends 2pm - 5pm). Or text: 07786 209697 or email: pat@papyrus-uk.org