INFORMATION SHEET FOR PARTICIPANTS

Ethical Clearance Reference Number: 20/LO/0677

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET



AN INVESTIGATION INTO THE PHENOMENOLOGY OF SEXUAL THOUGHTS AND IMAGES

South London and Maudsley NHS Foundation Trust

I would like to invite you to participate in this research project which forms part of my Doctorate in Clinical Psychology research. 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. Please ask me if there is anything that is not clear or if you would like more information.

What is the purpose of the project?

The experience of intrusive sexual thoughts, doubts and images is very common. However, there are many differences in the personal understanding and response to these thoughts, but little is known about this. The purpose of the study is to investigate the experience of sexual thoughts, doubts and images about children in a wide cross-section of people. This will provide a background to further the understanding of psychological processes in those individuals who experience various difficulties with sexual thoughts.

Why have I been invited to take part?

We are inviting people who have a diagnosis of obsessive-compulsive disorder (OCD) who, as part of this problem, experience unwanted intrusive sexual thoughts, doubts, urges or images about children under the age of consent to participate in a more detailed study of those experiences.

We are looking for people to take part in the study who meet the following inclusion criteria. Those who:

- Have a diagnosis of OCD
- Experience current intrusive sexual thoughts or images about children under the age of consent
- Have not been convicted of a sexual offence against a child under the age of consent

The exclusion criteria are as follow:

- People who do not understand written English and cannot complete a questionnaire
- People who do not have the capacity to consent
- People under the age of 18

What will happen if I take part?

If you choose to take part in the project you will be asked to consent to taking part. You may be able to sign a consent form with your therapist if you are accessing an NHS service or you can do this online via a link that will be sent to you.

Telephone interview

King's College London - Research Ethics May 2018

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A member of the research team will then contact you by telephone to complete an interview. This will involve the researcher asking you some questions to check if you are eligible to take part (15 minutes) and semi-structured interview which will focus on your experience of sexual thoughts about children (20-25 minutes). The telephone interview will take around 35-40 minutes.

Online questionnaires

Once you have completed the interview, the researcher will send you a link to complete the online questionnaires. The questionnaires will take approximately 20 minutes to complete.

Further information

You can complete the online questionnaires anywhere that you have access to a computer, at a time that suits you. Participation in the interview can take place anywhere that is comfortable for you. We would suggest that this is somewhere where it is quiet and private where you are able to speak freely. You will be asked whether you are happy for your interview to be audio recorded on an encrypted device. However, the interview will only be recorded with your consent, and it is OK if you do not want your interview audio recorded.

The questions asked in the interview and on the questionnaires relate to your experience of sexual thoughts, doubts, urges and images. Some of the questions we ask are sensitive in nature, but you do not have to answer any question that you are not comfortable with. We are asking these questions to gain an understanding of the psychological processes that are present in individuals who experience various difficulties with sexual thoughts. This may help contribute to the development of psychological assessment and therapies that may be helpful for people who experience difficulties with sexual thoughts. The researcher who will complete the telephone interview with you has talked to lots of people who have experienced sexual thoughts about children and will be able to help you with any concerns or questions you have.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway and will not affect your present or future treatment in the National Health Service. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part.

Incentives

We would like to give you a £20 amazon voucher for taking part in the study and to thank you for your time.

What are the possible risks of taking part?

Some of the questions included in the questionnaires and the interviews are sensitive in nature. It is possible that some questions may make you feel uncomfortable or upset. You do not have to answer any questions that you don't feel comfortable with during the interview or as part of the online questionnaires. You can let the researcher know at any point that you do not want to answer questions in the interview or that you would like to stop the interview. You can contact the researcher if you feel uncomfortable or upset about the questions at any point in the study. If you are receiving treatment, you can also discuss this with your therapist. If you are not currently accessing therapy, you will be able to discuss what additional support you may need with the researcher.

What are the possible benefits of taking part?

There are no direct benefits of taking part. However, this research will enable a better understanding of sexual thoughts and images in those who experience difficulties with such

thoughts. This may contribute to the development of future psychological assessment and treatment for people who experience difficulties with these thoughts.

Data handling and confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR).

- We will need to use information from you in this project. This information will include your name and contact details, so we are able to get in touch with you about the study.
- All data collected as part of this study will be stored electronically in password protected documents which will be saved on the Institute of Psychiatry, Psychology and Neuroscience's secure server. Computers are password protected and ID cards are needed to access buildings where computers are used.
- All information that you give as part of the research will be kept entirely confidential and will
 only be accessed by the researchers. We will only break confidentiality if you disclose a
 previously unknown illegal act (such as harming someone else) or plans to harm yourself
 and/or others. In this case, we may need to inform a service who are can to support you to
 keep yourself and/or others safe (e.g. your GP, emergency services).
- We will ask you for some very brief demographic information such as your gender and age.
 We will ask you to provide us with an email address and contact number, so we are able to contact you to complete the study.
- All materials and data will be given an anonymous code that is used in data analysis. No identifiable information will be included in the write up of this study.
- Once the study has finished, we will keep your anonymised data for up to three years. Any
 personal identifiable information (such as your contact email or consent forms) will be
 destroyed 6-12 months after the study has ended (no later than December 2021).
- All information you give as part of this study will only be accessed by the researchers and will not be shared with any third parties.
- Both the South London and Maudsley NHS Trust and King's College London will act as Data Controllers.

Data Protection Statement

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). If you would like more information about how your data will be processed in accordance with GDPR please visit the link below:

https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research

If you would like a printed version of the above, please contact the researcher.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team, or
- by sending an email to OCDthoughts@kcl.ac.uk

What if I change my mind about taking part?

You are free withdraw at any point of the project, without having to give a reason. Withdrawing from the project will not affect you in any way. You are able to withdraw your data from the project up until 31st March 2021 after which the results will be written up and it will no longer be possible to withdraw your data. If you choose to withdraw from the project, we will not retain the information you have given us and all of your information will be deleted.

How is the project being funded?

This study forms part of a main research project conducted as part of the Doctorate in Clinical Psychology at The Institute of Psychiatry, Psychology and Neuroscience. This project is being funded by King's College London.

What will happen to the results of the project?

The results of the project will be summarised in my dissertation as part of the Doctorate in Clinical Psychology and will be published in scientific journals and in presentations. Please let the researcher know if you would like a copy of the results. With your permission, we may use short anonymous quotations from the interview for illustration of the main findings. No personal information whatsoever will be identified in any publication of the results.

Who should I contact for further information?

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

Jess Simmonds - OCDthoughts@kcl.ac.uk or 07525237306

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

If this project has harmed you in any way or if you wish to make a complaint about the conduct of the project, you can contact the researcher on OCDthoughts@kcl.ac.uk. If this has not been resolved after contacting the researcher and you would like further advice, you can contact SLaM PALS using the freephone number 0800 731 2864 (Option 2) or by emailing pals@slam.nhs.uk. If you would like further advice, you can contact Gill Dale, Director of Research Quality on gill.dale@kcl.ac.uk.

Insurance cover

In the event that something does go wrong and you are harmed during the research you may have grounds for legal action for compensation against King's College London and/or SLaM NHS Foundation Trust, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

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