

PARTICIPANT INFORMATION LETTER

PROJECT TITLE: Understanding the experiences of shame related to OCD intrusive thoughts

PRINCIPAL INVESTIGATOR: Associate Professor Keong Yap

STUDENT RESEARCHER: Michelle Laving **RESEARCH ASSOCIATE:** Dr Oscar Modesto **STUDENT'S DEGREE:** Doctor of Philosophy

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

The research project seeks to better understand how feelings of shame may be related to OCD Intrusive Thoughts (i.e. unwanted thoughts, urges or mental images around harmful, violent, immoral, or sacrilegious themes) by investigating the subjective experience of people who live / or have lived with these concerns. We are also interested in understanding people's experience of sharing these concerns with health professionals or factors that contributed to this decision.

Who is undertaking the project?

This project is conducted by PhD candidate Michelle Laving and will form the basis for the degree of Doctor of Philosophy at Australian Catholic University under the supervision of Associate Professor Keong Yap. Michelle has a master's in social health degree and previous experience in conducting research interviews with adult participants.

Who should not participate in this study?

Although recruitment in studies aims to be inclusive, in some cases, additional eligibility criteria needs to be stated to minimise potential risks for participants and ensure their involvement is voluntary. You will not be eligible to participate in this study if any of the following relate to you.

- Current and severe suicidality
- Current mania or psychosis,
- Severe cognitive impairment or disability that may impact your ability to understand the purpose
 of the study, the procedures, your involvement in it, and your right to withdraw consent at any
 time.
- Non English speaking

Are there any risks associated with participating in this project?

It is possible that during the interview and review of the recording you may feel a level of discomfort in recalling and discussing your experiences related to the research topic. If this occurs, you can decide to stop participating in this study at any time or decide to take a break during the interview process.

We would also recommend that you access the list of support services on the **OCD Action UK website** https://ocdaction.org.uk/i-need-support/ On this page **OCD Action** note that if you need urgent support, please contact **Samaritans 24 hour support line on 116 123**. For more information about support offered by Samaritans click here https://www.samaritans.org/how-we-can-help/contact-samaritan/

It is not a crime to have unwanted intrusive thoughts and we want to reassure you that we will maintain confidentiality around our discussion and exploration of your intrusive thoughts by using pseudonyms in the interviews and audio recordings only.

We recognise that intrusive thoughts sometimes involve thoughts of illegal activities. We want participants to feel comfortable about talking about these thoughts and that your interview will remain confidential. Our research study is **not** about criminal behaviours, as such we will **not** be asking you to report to us any criminal behaviour which might require the breaking of confidentiality.

Your data will be de-identified and stored securely and confidentially. To further protect confidentiality, we will ask you to use a nickname instead of your full name in the study and we will store your contact details in a separate file from the data. This contact information will be deleted immediately after completion of the data collection.

What will I be asked to do?

After returning a signed copy of the consent form, you will be sent an email with a link and password to complete the first part of the screening eligibility process which should take approximately 20 minutes to complete.

This screening section will include five basic demographic questions, four exclusion criteria questions, a self-report Mood, Anxiety, or Obsessive- Compulsive and Related Disorders screener containing 30 yes/no questions, a shame measure and a self-report measure to gather information about the nature and severity of your obsessions and compulsions.

Once this has been returned, it will be reviewed by the Principal researcher and student researcher. If the inclusion and exclusion criteria are met in this first screening process, a 30 min zoom call will be scheduled for the participant and student researcher to complete a diagnostic interview to confirm a diagnosis of OCD.

If eligible, we will organise another mutually convenient time to conduct an online interview that will take approximately 60 to 90 minutes via ZOOM. You will be sent a link to join this ZOOM session.

This interview will include questions to explore the specific characteristics and experiences of shame related to OCD type unacceptable/ intrusive thoughts and your experiences of sharing these occurrences with health professionals. This interview will be audio recorded. After the interview, we will send you the audio recording of the interview via email to review within a two - week period. This will give you the

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opportunity to clarify any responses you have made. The student researcher may also send you an email to seek clarification around some of your responses in the audio recording within this two-week period.

All data gathered from you both in writing and via audio recording will be stored and analysed in Australia. Once the results from the study have been concluded, we will send you a summary of these findings as a final confirmation of consent.

You do not need to have a ZOOM account to join this interview. For step by step instructions on how to join the interview please click here

https://support.zoom.us/hc/en-us/articles/201362193-Joining-a-Meeting

How much time will the project take?

The initial screening process should take approximately 20 minutes and around 30minutes to complete the diagnostic interview via zoom. The online interview will take approximately 60 - 90 minutes. The suggested time for reviewing and providing feedback about the audio recording of the interview is two weeks from the interview date.

What are the benefits of the research project?

Although there are no direct benefits of this study for you, the study will contribute to our understanding of how shame may be related to OCD Intrusive Thoughts and form a basis for the development and validation of a shame measure that is specific to OCD intrusive thoughts. It is hoped this will provide health professionals with a better understanding of client's experiences and factors that contribute to the concealment of intrusive thoughts and feelings of shame that may accompany it.

Can I withdraw from the study?

Participation in this study is completely voluntary. You are not under any obligation to participate. If you agree to participate, you can withdraw from the study at any time without adverse consequences. Your participation or withdrawal will in no way impact on your association with OCD Action UK. Please note that your agreement to have any data (including screening information) to remain part of the study at the point of withdrawal will be included in the attached consent form.

Will anyone else know the results of the project?

The results of the study will be included in the final PhD thesis which will be presented to the university as part of the candidature requirements. We will seek to publish the results of this study in a peer-reviewed journal and present findings in scientific conferences. Participant confidentiality is a priority and your responses will be deidentified in the final thesis, conference presentations, and the peer-reviewed journal paper.

Will I be able to find out the results of the project?

You will have an opportunity to see a summary of the findings once they have been collated and analysed. A final version of the study findings will be emailed to you at the conclusion of the project.

Who do I contact if I have questions about the project?

Please contact Michelle Laving via email: Michelle.Laving@myacu.edu.au

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What if I have a complaint or any concerns?

The study has been reviewed by the Human Research Ethics Committee at Australian Catholic University (review number 2019-206H). If you have any complaints or concerns about the conduct of the project, you may write to the Manager of the Human Research Ethics Committee care of the Office of the Deputy Vice Chancellor (Research).

Manager, Ethics c/o Office of the Deputy Vice Chancellor (Research) Australian Catholic University North Sydney Campus PO Box 968 NORTH SYDNEY, NSW 2059

Ph.: 02 9739 2519 Fax: 02 9739 2870

Email: resethics.manager@acu.edu.au

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

Yours sincerely,

ML

PhD candidate Michelle Laving

A/Prof Keong Yap

Dr Oscar Modesto

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