

PARTICIPANT INFORMATION LETTER

PROJECT TITLE: OCD Unacceptable/Taboo Thoughts in Youth: A Qualitative Analysis

APPLICATION NUMBER: (2023-3225)

PRINCIPAL INVESTIGATOR: Associate Professor Keong Yap

CO-INVESTIGATOR: Michelle Laving

STUDENT RESEARCHER: Lauren Moody-Stone

STUDENT'S DEGREE: Master of Psychology (Educational and Developmental)

Dear Participant,

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

1. What is the project about?

The current study seeks to explore the lived experiences of young adults with OCD Unacceptable/taboo obsessions across adolescence and young adulthood. These obsessions manifest as intrusive and unwanted thoughts, impulses, or mental images involving themes of aggression and violence, scrupulosity (moral or religious), or themes of a sexual nature. The main purpose of this project is to gain an understanding of your individual experiences living with Unacceptable/taboo thoughts during adolescence and young adulthood, with emphasis on your personal experiences seeking treatment for these concerns.

2. Who is undertaking the project?

This research project is being conducted by student researcher Lauren Moody-Stone, as part of her Master of Psychology (Educational and Developmental) degree at ACU Melbourne. Lauren has an Honours degree in Psychological Science and is currently provisionally registered as a psychologist. Lauren is guided by the expertise of her supervisors, PhD Candidate Michelle Laving and Associate Professor Keong Yap.

Michelle Laving is a registered counsellor with over 18 years of experience, currently pursuing her PhD at ACU Strathfield. Her research focuses on OCD and shame, particularly how shame relates to OCD type unacceptable thoughts. Her prior research includes interviews with adults living with OCD. Associate Professor Keong Yap is a registered clinical psychologist and the national Master of Psychology course coordinator at ACU. His research primarily focuses on clinical psychology, specifically obsessive-compulsive and related disorders which he has published numerous peer-reviewed papers within these areas.

3. Research Funding

This research project is partially funded by the ACU Faculty of Health Sciences. The allocated funds are specifically designated for participant remuneration.

4. Who can take part in this study?

Before you participate, we need to confirm your eligibility. While we strive for inclusivity in participant recruitment, there are certain eligibility criteria in place to minimise potential risks and ensure voluntary participation.

To be **included** for the study, you need to meet the following requirements:

- You must be between the ages of 19 and 23.
- You must be proficient in English.
- You must have a diagnosed case of obsessive-compulsive disorder (OCD), characterised by "unacceptable" or "taboo" thoughts, impulses, or mental images centred around themes of aggression, violence, religious/moral concerns (scrupulosity), or sex.
- The initial onset of your OCD symptoms (specifically the onset of Unacceptable/taboo intrusive thoughts) must have taken place when you were between the ages of 14 and 17.

You will be **excluded** from participating in the study if you:

- Have a history of self-harm, suicidal ideation, or suicide attempts.
- Have been diagnosed with another psychological disorder, with the exception of depression.
- Possess a cognitive impairment or disability that might hinder your full understanding of the study's purpose, tasks, and your role, including comprehending the terms of consent, privacy, and your right to withdraw at any point.

5. What will I need to do to participate in this study?

If you believe you satisfy the eligibility criteria for this study, please reach out to the student researcher to express your interest in participating. You will be given the opportunity to ask any questions you may have about the study and will be asked to complete the relevant privacy and consent forms. Once the researcher has been provided the relevant documentation, you will be invited to partake in the following screening process:

1. **Screening Interview (approx. 30 mins)**

- This task involves a 30-minute online interview with the student researcher to confirm your eligibility. The interview will be conducted over Microsoft Teams with audio-only—no camera will be required.
- You will receive an invitation via email to arrange a suitable date and time. You will **not** need a Microsoft Teams account to participate. For joining instructions, please follow this link: [Microsoft Teams Joining Instructions](#).
- To maintain confidentiality, you will be asked to choose a pseudonym or nickname for yourself at the beginning of this interview, which will be used for the rest of your participation in the study to identify you.

2. Screening Survey (approx. 30 to 40 mins)

- After your screening interview, you will receive a follow-up email containing a link to an online survey via Qualtrics. This survey will collect demographic information and will involve a self-assessment of your OCD symptoms, including the nature and severity of your obsessive-compulsive symptoms.
- Upon completion of the screening survey, your responses will be sent directly to the research team. The completion of the screening survey should take you approximately 30 to 40 minutes to complete.

Upon the completion of both the screening interview and survey, **should you meet the eligibility criteria for this study, you will be contacted by the student researcher again via email.** The purpose of this correspondence will be to arrange a convenient time for both parties to complete an in-depth interview. If your responses indicate that you **do not** meet the eligibility criteria for this study, you will not receive any further communication from the student researcher related to this study. Importantly, any identifiable information provided during your involvement in the research project will be promptly and securely deleted to uphold your privacy.

3. In-depth Interview (approx. 60 to 90 mins)

- You will receive an email invitation to schedule a 60-to-90-minute audio only interview with the student researcher via Microsoft Teams, arranged at a mutually convenient time.
- Your participation in this study will involve sharing your personal experiences with OCD and its impact on your life. This audio-only interview will involve the researcher asking questions about your experiences with OCD type unacceptable thoughts during adolescence and early adulthood.
- The interview will be audio-recorded to facilitate transcription and analysis. Transcription means the interview will be typed word-for-word to accurately capture your experiences and thoughts.
- The student researcher will de-identify the audio recording and promptly delete the recording once the interview transcription is completed. De-identified audio recordings and transcriptions will be securely stored on a password-protected, multi-factor authenticated OneDrive.

6. Do I have to take part in this research?

There is no obligation to participate in this research and if you do not wish to take part, you do not have to. Your participation is completely voluntary, and you may withdraw without consequence and reason at any stage. Before deciding to take part in this research study, please read the information carefully, ask any questions, or talk things over with a relative, friend, or another support person. If you express an interest to participate, we will ask you to complete an online consent and privacy form via email. This is a way for you to formally express your informed understanding of the study and your willingness to participate.

7. Are there any risks associated with participating in this project?

While participating in this study, it is possible that you *may* experience discomfort or distress, particularly as you reflect on your own experiences of OCD. If this occurs, you can decide to stop participating in this study at any time or take a break. This research is entirely voluntary, and your decision to participate, take a break, or withdraw will not affect your relationship with OCD Action UK or the ACU research team. If you need any assistance or have any concerns at any stage of the research process, we encourage you to let us know as soon as possible.

If needed, we would also recommend that you access the list of services provided on the OCD Action UK website here: <https://ocdaction.org.uk/i-need-support/>

Please note that the OCD Action UK helpline is not able to provide ‘clinical’ support like coping strategies, diagnosis, or personal advice about therapy or medication. All information they provide is general and based on official treatment guidelines and research.

If you or someone you know is experiencing a crisis, please see the information below:

<p>National Suicide Helpline UK</p>	<p>National Suicide Helpline UK offers a supportive listening service to anyone throughout the UK with thoughts of suicide or thoughts of self-harm. They are open 24/7.</p> <p>Tel: 0800 689 5652</p> <p>For more information about this service click here: https://www.spuk.org.uk/national-suicide-prevention-helpline-uk/</p>
<p>Samaritans UK & Ireland</p>	<p>Samaritans UK & Ireland offers 24-hour emotional support to anyone in distress or at risk of suicide throughout the UK & Ireland. They have 201 branches open 365 days a year, where people can also talk in person.</p> <p>Tel: 116123</p>

	<p>For more information about this service click here: https://www.samaritans.org/how-we-can-help/if-youre-having-difficult-time/</p> <p>For information about the Samaritan's Welsh Language Line, click here: https://www.samaritans.org/how-we-can-help/contact-samaritan/welsh-language-phone-line/</p>
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It is not a crime to have unwanted obsessions or intrusive thoughts. We want to reassure you that we will maintain confidentiality around your involvement in this research project. We recognise that unwanted obsessions may involve thoughts of illegal activities. We want participants to feel comfortable talking about these thoughts, and knowing 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.

To ensure the protection of your personal information, we will implement stringent data handling procedures. Your data will be de-identified, stored securely, and treated with strict confidentiality within the research team. Your identifiable information will be stored separately from any data (i.e., interviews, survey responses, audio recordings and transcriptions) to avoid any potential identification.

After the data collection (interview and transcription) is completed, your contact information will be deleted promptly. However, if you have indicated that you wish to receive a copy of the final de-identified project results, we will retain your email address solely for this purpose, we will then delete your email from our records. These steps are taken to reinforce your privacy and uphold the confidentiality of your participation in our study.

8. Are there any costs or reimbursements involved?

Participation in this study will not incur any costs for you. To express our gratitude for your time and contribution, we will provide a \$20 Amazon e-gift card to eligible participants upon completion of the 60-to-90-minute interview **only**. This e-gift card will be emailed to you and will be in your local currency.

9. What are the benefits of the research project?

While there may be no direct benefits for you participating in this research, your contribution can significantly add to the understanding of lived experiences of OCD and OCD Unacceptable/taboo

thoughts. Your involvement could potentially inform the development of more compassionate, effective, and person-centric treatment methods and health policies.

10. 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 prior to and during the study, without adverse consequences. If you wish to withdraw, please reach out to the student researcher via email, and your data will be deleted upon your request. Please be assured that your decision to withdraw, or to not participate, this will in no way affect your existing relationship with either the ACU research team or OCD Action UK.

11. Will anyone else know the results of the project or have access to my information?

ACU will manage your personal information in accordance with its [Privacy Policy](#) and in line with our privacy obligations under the Privacy Act, 1988, the Australian Privacy Principles (APPs) and, where applicable, international regulations, such as the EU/UK’s General Data Protection Regulation (GDPR).

Providing ACU with personal information is not required by law. You can choose not to participate and provide your information. However, once you have submitted your information, it cannot be identified as yours and withdrawn. Your information will not be shared with Third Parties without your consent or unless authorised by law. Your personal information will be stored securely in an ACU-controlled environment in Australia.

Please contact lauren.moodystone@myacu.edu.au to withdraw consent, access or correct. If you have a privacy enquiry or complaint or, if GDPR applies to you, and you wish to erase, request portability or restrict/object to processing, please contact privacy@acu.edu.au.

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

The de-identified results of this project will be included in the final research thesis as part of the student researcher's master's degree. There is also a possibility that we may seek to publish the de-identified results in a peer-reviewed journal.

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

If you have any further questions or concerns about the project, please contact the student researcher.

Research Team Contact

Name	Lauren Moody-Stone
Position	Student Researcher (ACU Melbourne)
Email	lauren.moodystone@myacu.edu.au

What if I have a complaint or any concerns about the research study?

The study has been reviewed by the Human Research Ethics Committee at Australian Catholic University (review number 2023-3225). If you have any complaints or concerns about the conduct of the project, you may write to the Manager of Research Ethics and Integrity, the Office of the Deputy Vice Chancellor (Research and Enterprise).

Name	Manager, Ethics and Integrity
Address	c/o Office of the Deputy Vice Chancellor (Research and Enterprise) Australian Catholic University North Sydney Campus PO Box 968, North Sydney, NSW 2059
Telephone	02 9739 2519
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.

14. I want to participate, what do I have to do?

If you would like more information or are interested in participating in the study, please send an expression of interest email to Lauren Moody-Stone on the details listed below.

Name	Lauren Moody-Stone
Position	Student Researcher
Email	lauren.moodystone@myacu.edu.au

Yours sincerely,

Student Researcher Lauren Moody-Stone

PhD Candidate Michelle Laving

A/Prof Keong Yap