

UNIVERSITY OF EAST LONDON

Ethics and Integrity Sub-Committee (EISC)

University of East London

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Consent to Participate in a Research Study

The purpose of this Participant Information Sheet is to provide you with the information that you need to consider in deciding whether to participate in this research project.

Research Integrity

The University adheres to its responsibility to promote and support the highest standard of rigour and integrity in all aspects of research, observing the appropriate ethical, legal and professional frameworks.

The University is committed to preserving your dignity, rights, safety and wellbeing and as such it is a mandatory requirement of the University that formal ethical approval, from the appropriate Research Ethics Committee, is granted before research with human participants, human data human material, personal and/or sensitive data, or non-human animal commences.

Project Title

Toward acceptance of unwanted intrusive thoughts: Exploring the impact of metacognitive rationales for obsessive-compulsive phenomena on experiential avoidance

Principal Investigator/Director of Studies

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Project Description

This project seeks a small group of participants who are familiar with experiencing exposure and response-prevention (ERP), the preferred treatment protocol for obsessive-compulsive phenomena. We are interested in people (a) whose lived experience includes such phenomena and (b) whose past psychotherapy sessions included an introduction to the habituation exercises used in ERP. This would be the case regardless of whether or not you describe yourself as having obsessive-compulsive disorder (OCD).

If you are interested and aged 18 or over, we will firstly ask you to undergo an initial screening, which would involve filling in some basic demographic information and brief questionnaires using the secure hyperlink provided in the email used to send this Information Sheet. You will do so using a 'participant code' assigned by the researcher (in other words, without providing your name). This will typically take you less than 15 minutes to complete. We refer to this as **Stage 1** of the project, which we ask you to complete **on or before [date]**. Before embarking on Stage 1, we ask you to firstly read all the information outlined in this document. If you then have any questions about the detail of the full study, please contact the Student Researcher.

On completion of the Stage 1 questionnaires, we will give you an opportunity to listen to and, if you wish to do so, give brief typed-in feedback on a series of up to three related podcasts (of approximately 5 to 15 minutes' length). Each podcast includes potentially helpful 'metacognitive' ways of thinking about obsessive-compulsive phenomena, which may contrast with unhelpful metacognitions such as 'I am upset by unpleasant thoughts that come to my mind against my will' (where 'metacognitions' refer to second-order thoughts about everyday thoughts).

Stage 2 of the project involves an online Focus Group discussion, as we would like to hear your shared responses to these podcasts, which are intended to serve as a self-help resource. Selection for the Focus Group discussion may be determined randomly but may also involve some pre-screening. By **[date]**, selected individuals for Stage 2 will be contacted by email to arrange a brief (i.e., 15 minute) telephone or online 'check-in' with the researcher. This gives you an opportunity to (a) ask questions about what is expected in the Focus Group discussion, then (b) confirm your willingness and consent to take part in it.

To permit us to produce an accurate transcript of the Focus Group discussion, this recorded online meeting would be arranged using the Microsoft Teams platform. Aside from the researcher (who will serve as the moderator), you would be joined by between two and five other participants also participating in the discussion. Before joining others online at the scheduled time, you would be asked to choose an alias or 'nickname', so that your identity remains unknown to the other participants. The discussion will be timetabled to last 90 minutes. For this **Stage 2** of the project, we would need to know that you were available to attend an actual online group discussion at some stage **on or before [date]**, the intended cut-off date.

Aims and Objectives of the Project

The aim of this project is to further an understanding of the potential merits of augmenting, using metacognitive rationales, the psychoeducation which is preparatory to embarking on treatment using exposure and response-prevention (ERP).

The objectives of the project are (a) to incorporate an array of metacognitive frames-of-reference into a set of podcasts as 'inductions', and (b) to give you an opportunity to provide feedback and responses to them, given your familiarity with experiencing ERP as a treatment protocol. If invited to Stage 2 of the project, you would be asked questions such as:

- What was your first impression of the induction?
- What one thing did you like best/least about the induction?
- Which of the metaphors you were presented with in the induction resonated the most?

Safeguarding Your Wellbeing

Some of the Stage 2 Focus Group discussions may include reference to personal instances of living with symptoms common to OCD. As well, sometimes being on the internet makes a person feel uncomfortable, which can be more noticeable due to lack of 'in person' contact.

If you were to notice that you had feelings of psychological discomfort or stress during the Focus Group discussions, then one of the 'ground rules' would be that you can ask at any time for a 'time-out'. There will also be planned 'comfort breaks' throughout the discussion.

When the Focus Group interviews are transcribed, your alias or 'nickname' will be replaced with a code, then the audio-visual recording of the meeting you attended will be destroyed. This arrangement means that there will be no record of the meeting itself, and that your contribution, as well as that of others, will have been made in confidence.

If at any point during or after your participation in this project, you were to experience what you deem to be severe after-effects (such as prolonged or intense psychological discomfort and distress, or repetitive thinking-patterns which are unusual for you), then you will be provided with information on various organisations which can provide you with appropriate after-care support.

There are instances in which you would be ineligible to participate in this project. For example, we would not permit you to participate if you are defined as 'vulnerable' by the British Psychological Society's Code of Human Research Ethics, or if you report as being under care of a mental-health practitioner for **any of the following**: (a) major depressive disorder (MDD) or high suicidal risk, severe anxiety disorder, psychotic disorder and/or bipolar disorder for which you are presently in treatment, (b) mental impairment or evidence of organic brain disorder, (c) substance-misuse issues requiring specialist treatment, (d) a change in prescribed medication type or dose during the six weeks prior to participating in the project, (e) obsessive-compulsive disorder (OCD) during the twelve weeks prior to participating in the project.

Confidentiality of the Data

Your confidentiality will be maintained wherever possible, but there are exceptions to such confidentiality. If we believe that you or someone else is at serious risk of harm, we may be obliged to report such disclosures to relevant authorities.

Because the main part of this project is a Focus Group discussion, and because you will not be the sole participant, the situation requires certain measures to maintain your confidentiality within the group (as well as that of others). It is for this reason that we ask you to choose and use an alias or 'nickname' when in the Focus Group discussions.

The data relevant to this project includes your Stage 1 questionnaire responses alongside any brief typed-in feedback on the podcasts and (if selected for Stage 2) the recorded audio, visual, and transcription content generated using the Microsoft Teams platform. Data will be stored on the University of East London secure networked storage, and any devices which are used to access this data will be encrypted, password-protected, and kept under lock and key. After the transcription of the Focus Group recording, the student researcher will destroy the audio and visual record, and only the transcript (with each participant de-identified) will be retained. The transcript and any data analysis arising from it will be reviewed for disposal after every five-year timeframe has elapsed, from the time of the completion of the overall research programme.

Data generated during the research will be retained in accordance with the University of East London's Data Protection Policy.

In compliance with the General Data Protection Regulation (GDPR) the University's lawful basis for the processing of personal data collected, used, and retained for research purposes is the 'public task' condition. Therefore, the University does not rely on consent to process your personal data. However, the University will seek your consent to participate in this research project. Please see the following link for more information: [Data protection – University of East London \(UEL\)](#)

Location

The project will take place using the University of East London's online communications platform Microsoft Teams, using its 'scheduled meeting' functionality.

Remuneration

No payment or remuneration of any kind is associated with participation in this project.

Disclaimer

Your participation in this study is voluntary, and you are free to withdraw at any time during the research. Should you wish to withdraw from the study (i.e., at Stage 1 and/or Stage 2), you may do so without disadvantage to yourself and without an obligation to give a reason. Please note that your data can be withdrawn up to the point of data analysis (i.e., two weeks after the date of the Focus Group discussion), after which it may not be possible.

If you are in a dependent relationship with any of the researchers (e.g., as a student of one of the researchers), please be aware that your participation in the project will have no impact on assessment, treatment, service-use, or other support. If you are under the care of a mental-health practitioner, please be clear that this research does not form part of your treatment, and that no benefit should be expected to be gained from your participation.

Ethical Approval for the research project has been granted by the Ethics and Integrity Sub-Committee (EISC).

If you have any concerns regarding the conduct of the research in which you are being asked to participate, please contact:

Catherine Hitchens, Ethics, Integrity and Compliance Manager, Office for Postgraduates, Research and Engagement, University of East London, Docklands Campus, London, E16 2RD. Telephone: 020 8223 6683. Email: researchethics@uel.ac.uk

For general enquiries about the research please contact the Principal Investigator on the contact details at the top of this sheet.

Remember to access the Stage 1 questionnaires **using the secure hyperlink sent by email**, if you are interested in participating in this project.

Annexe 2

UNIVERSITY OF EAST LONDON

Online Consent to Participate in a Programme Involving the Use of Human Participants

(To be presented prior to accessing the Stage 1 questionnaires)

Project Title

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Mr Max Eames

Using an online interface, you will be asked to provide ‘informed consent’ by indicating YES to each item outlined below. Please retain this documentation (i.e., Annexe 2) as a record of what will be presented online.	YES	NO
I have read the Participant Information Sheet relating to the research project in which I have been asked to participate, and I have been given a copy to keep. The nature and purposes of the research project have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.		
I understand that secure online communication (using a proprietary form-creation interface such as Microsoft Forms) will be used to confirm my consent, and that consent will precede access to the Stage 1 submission of brief surveys and questionnaires. I understand that the submission will involve my using a ‘participant code’ provided by the researcher (meaning that my name will not be associated with the submission), and I consent to the capture and storage of such submissions. This means that data will be obtained from, and mediated by, my online or mobile communications device (such as a PC or mobile phone).		
I understand that secure online communication (using a proprietary form-creation interface such as Microsoft Forms) will be used to enable my submission of brief		

<p>surveys and questionnaires. I understand that the submission will involve my using a 'participant code' provided by the researcher (meaning that my name will not be associated with the submission), and I consent to the capture and storage of such submissions. This means that data will be obtained from, and mediated by, my online or mobile communications device (such as a PC or mobile phone).</p>		
<p>I understand that I may be contacted to participate in a Focus Group discussion and, if so, my contribution to the discussion is to be audio and video recorded, and I consent to such recordings. This means that data will be obtained from, and mediated by, my online or mobile communications device (such as a PC or mobile phone).</p>		
<p>I understand that my involvement in the research project, and particular data from this research, will remain strictly confidential as far as possible. Only the student researcher will have access to the audio-visual recording data, which will be deleted once transcription is complete.</p>		
<p>I understand that maintaining strict confidentiality is subject to the following limitations:</p> <p>(a) Confidentiality will be maintained wherever possible, but there are exceptions to such confidentiality. If we believe that you or someone else is at serious risk of harm, we may be obliged to report such disclosures to relevant authorities.</p> <p>(b) Because the main part of this project is a Focus Group discussion, and because I will not be the sole participant, the situation requires certain measures to maintain my confidentiality within the group (as well as that of others). It is for this reason that I agree to choose and use an alias or 'nickname' when in the Focus Group discussions.</p>		
<p>I understand that proposed methods of publication and dissemination of the research findings of this project may include dissertations or theses, peer-reviewed journals, internal reports, conference presentations, presentations to participants or relevant community groups, books or chapters, and the University of East London research repository.</p>		
<p>I understand that the data collected for the research project will be anonymised/pseudonymised before it is written up and/or published.</p>		
<p>I understand that only anonymised quotation will be used in any write-up of the results and subsequent publications, and that I will not be directly identifiable in any way.</p>		

I understand that I do not have the option to be named in any write-up of the results and subsequent publications.		
I understand that the University's lawful basis for processing my personal data collected, used, and retained for research purposes is the 'public task' condition and the University does not rely on consent to process my personal data.		
I understand that the published results of the research project will be accessible in the public domain and may be deposited in an open access data repository.		
I understand that the published results of the research project will be accessible in the public domain and may be re-used, republished, or reanalysed by others in future research.		
I give my permission for the research team to use the data that I have provided in future research projects which may be made publicly available.		
It has been explained to me what will happen once the research project has been completed.		
I understand that my participation in this study is entirely voluntary, and I am free to withdraw at any time during the research without disadvantage to myself and without being obliged to give any reason. I understand that my data can be withdrawn up to the point of data analysis, and that after this point it may not be possible if the data is anonymised.		
I hereby freely and fully consent to participate in the study which has been fully explained to me and for the information obtained to be used in relevant research publications.		