



Joel Lewin

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An investigation of fear of losing control and anxiety

PARTICIPANT INFORMATION SHEET

Central University Research Ethics Committee (CUREC) Approval Reference:
R87791/RE001

My name is Joel Lewin and I am a Trainee Clinical Psychologist at the University of Oxford, working with Paul Salkovskis and team. This is an invitation to take part in our research study.

Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve. Please take time to read this Information Sheet, and discuss it with others if you wish. *If there is anything that is not clear, or if you would like more information, please email joel.lewin@hmc.ox.ac.uk*

1. Why is this research being conducted?

In anxiety disorders, people experience a range of fears. These include fears of specific phobias, or fears of negative judgement in social anxiety. A fear that may be relevant for people experiencing panic disorder or Obsessive Compulsive Disorder (OCD) is the fear of losing control.

An important question is whether fear of losing control is similar across different disorders, or whether there are specific differences in the nature of this fear between different disorders. This research will involve testing a new questionnaire developed by the researchers which assesses differences in the nature of fear of losing control across different groups. From this research, we hope to develop a greater understanding of factors that may contribute to the development and maintenance of difficulties with obsessions and compulsions or panic, with the hope of tailoring and improving treatments.

We are keen to hear from a range of people including those who have no current mental health problems, those who have obsessional or compulsive problems and those who have difficulties with panic.

2. Why have I been invited to take part?

You are very kindly interested in helping with our research. We are happy to hear from anyone who has heard about the study and is interested in finding out more information about participation. In some instances, you may have been asked to participate, as we are keen to gather the thoughts of people 18 years and above who currently reside in the UK, from these 3 groups:

1. Consider themselves to have a significant problem with panic
2. Consider themselves to have Obsessive Compulsive Disorder
3. Have no current experience of mental health difficulties

3. Do I have to take part?

No. You can ask questions about the research before deciding whether you wish to continue and take part. If you do agree to take part, you may withdraw yourself from the study, without giving a reason, and without negative consequences by advising me of this decision.

4. What will happen to me if I take part in the research?

The study will involve two parts:

1. A discussion over the telephone or on video conferencing using Microsoft Teams,
2. Filling out a series of questionnaires online (or a paper copy as requested)

The telephone session will take approximately 15 minutes and will be arranged for a time convenient for you. The researcher will talk you through the study procedures and give you the chance to ask any questions. If you are still happy to take part, you will be asked to give oral consent. You will then be asked a series of questions to determine if you meet diagnostic criteria for Panic Disorder, Obsessive Compulsive Disorder, or to confirm you are not currently experiencing mental health problems. This semi-structured interview is used widely across the globe in psychological research and in clinical practice. You can ask to pause or stop the interview at any time. With your consent, I would like to take notes and audio record the conversation so that my supervisor can listen to a sample to ensure diagnostic criteria are being accurately recorded. Once this is checked the audio recordings will be deleted.

Following the telephone interview, you will be emailed a link to complete an online questionnaire along with your unique anonymised Personal Identification Number (PIN). Alternatively, you can request a paper copy of the questionnaires to be sent by post. You will be reminded of the details of the study. The questionnaire will include questions about your mental health and your beliefs about losing control. This portion of the study will take approximately 20-40 minutes although for some people it may take longer. You can log in and log out of the program at your convenience using your allocated PIN, if you would like to take a break from the questionnaires. We would appreciate it if you could complete the questionnaires within a week of receiving the link.

You will also be asked whether you consent for your contact details to be retained within a secure research database by the Clinical Research Group, which constitutes Trainee Clinical Psychologists and Research Staff from the Oxford Institute for Clinical Psychology Training. If you give your permission, your contact details and information from your

screening telephone call will be retained so that you can be contacted with information about similar research studies that you may wish to participate in. We would keep a copy of your consent form with this database, as your consent is our legal basis for re-contacting you under UK data protection law. This is optional and does not affect your ability to participate in the current study. You can also ask, at any stage, for your name to be removed from the database.

5. Are there any potential risks in taking part?

Taking part could take up to approximately 60 minutes of your time in total.

All of the questionnaires have been included with feedback from people with lived experience of panic and OCD in order to minimise the potential for distress. However, some of the content may feel difficult to think about and it is possible you might find answering the questions upsetting. You can take a break from the study and return to it later, or withdraw from the study at any point. At the end of the study, or if you withdraw at any point, you will be provided with contact details of services and third-party organisations that will be able to offer support and guidance.

To ensure confidentiality, you will be provided with a unique personal identification number with which to fill out the questionnaires. In order to link telephone and questionnaire data, we will use a password-protected database on an encrypted, password-protected device.

6. Are there any benefits in taking part?

We hope that your participation in this will help us understand people who are experiencing difficulties and distress related to panic and obsessions or compulsions. This may contribute to the development of treatments. However, there will be no direct or personal benefit to you from taking part in this research.

7. What happens to the data provided?

The information you provide during the study is research data. Any research data from which you can be identified (i.e. audio recordings, name, email address, telephone number and home address, should you request the questionnaires by post) are known as personal data. Personal data will be stored on a password-protected, Nexus365 OneDrive account. Personal data will be stored for 3 months after the study is complete and then permanently deleted.

Audio recordings of the screening interviews will be deleted as soon as a second member of the research team has reviewed a subsection to check these have been reliably scored.

You will be given the option for your contact details to be retained in a secure database so that the researchers can contact you about future studies. If you decide to do this, your contact information will be deleted immediately upon request by contacting the researchers, or after 3 years. We will keep a copy of your consent form with this database, as your consent is our legal basis for re-contacting you under UK data protection law.

Other research data (including consent forms and data obtained from questionnaires) will be stored for 3 years after publication or public release of the work of the research. This information will then be shredded or permanently deleted and destroyed.

The research team involved in this study will have access to the research data. Responsible members of University of Oxford may be given access to data for monitoring and/or audit of the research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public. Using the research data, we hope to report our findings in academic journals and present them to relevant charities, and to health professionals at conferences. The findings will also contribute to a research thesis. You will not be identified in any reports or publications arising from the study.

8. Will the research be published?

The research will be written up as part of Joel Lewin's Doctorate in Clinical Psychology. On successful submission of the thesis, it will be deposited both in print and online in the University archives to facilitate its use in future research. If so, the thesis will be openly accessible. The research is likely to be written up for publication in a peer-reviewed scientific journal.

The research team also aims to disseminate findings to No More Panic and OCD UK charities.

9. Who has reviewed this study?

This research has received ethics approval from a subcommittee of the University of Oxford Central University Research Ethics Committee (Reference number: R87791/RE001).

10. Who do I contact if I have a concern about the study or I wish to complain?

If you have a concern about any aspect of this study, please contact Joel Lewin (joel.lewin@hmc.ox.ac.uk, 01865 226431) or Professor Paul Salkovskis (paul.salkovskis@hmc.ox.ac.uk, 01865 226431) and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with.

If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible: Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Oxford OX3 7GB

11. Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that is performed in the public interest.

Further information about your rights with respect to your personal data is available from <https://compliance.admin.ox.ac.uk/individual-rights>.

12. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

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Isis Education Centre
Warneford Hospital
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OX3 7JX
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You can also speak to the supervisors of the project about any questions or concerns using the details below:

Professor Paul Salkovskis (University of Oxford) paul.salkovskis@hmc.ox.ac.uk
Dr Victoria Edwards, (Clinical Psychologist at Oxford Health NHS Foundation Trust)
Victoria.edwards@oxfordhealth.nhs.uk

I'm Interested! What's Next?

If you would like to participate, please email Joel Lewin to set up a telephone interview:
joel.lewin@hmc.ox.ac.uk

Thank you for taking the time to read this information sheet and for your interest in the project.