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Appendix C: Participant information sheet

Study Title: *Understanding the impact of adverse life experiences on mental health difficulties, OCD, PTSD and anxiety.*

This is an invitation to take part in our research study exploring life experiences in individuals with no mental health difficulties, or those who experience OCD, PTSD and anxiety specifically. Our names are Torileigh Matthews and Amy Lunn and we are Trainee Clinical Psychologists at the University of Oxford working alongside Professor Paul Salkovskis.

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 to discuss it with others if you wish to. If there is anything that is not clear, or if you have questions and would like more information, please email stressresearch@oxfordhealth.nhs.uk.

1. What is this study about?

For this study we are interested in hearing from people with OCD, generalised anxiety, panic disorder, PTSD and people who have no mental health difficulties to understand the impact of experiencing different life events. This study aims to be able to understand the impact of life experiences on mental health difficulties, so that we can contribute to the evidence around how to best support affected individuals.

The study has received ethical approval from the University of Oxford Central University Research Ethics Committee (CUREC Approved Reference R89339/RE001) and you can find all information about it below. Please read through this information below before agreeing to participate (if you wish to) by ticking the 'yes' box below. You may ask any questions before deciding to take part by contacting the researcher (details below).

2. Who can take part in this study?

We are happy to hear from anyone who has heard about the study and is interested in finding out more information about participating. In some instances, you may have been asked to participate. We are particularly interested in hearing from anyone aged 18 years or older, living in the UK or Ireland who identifies as having no mental health difficulties, or experiences of Obsessive Compulsive Disorder (OCD), Generalised Anxiety Disorder (GAD),

Panic Disorder (PD), or Post-traumatic Stress Disorder (PTSD).

3. Do I have to take part?

No. You don't have to participate if you don't want to. You can ask questions about the research before deciding whether you wish to take part. If you do agree to take part, you may withdraw from the study, without giving a reason without any consequences. However, after completing the online questionnaires, all collected data is anonymised, meaning that we will be unable to withdraw your data.

4. Who is conducting this study?

This study is being conducted by Psychology Researchers at the University of Oxford (Oxford Institute of Clinical Psychology Training and Research) with extensive experience in psychological research and clinical work:

Professor Paul Salkovskis, Principal Investigator and Primary Supervisor

- *Torileigh Matthews* Trainee Clinical Psychologist
- *Amy Lunn* Trainee Clinical Psychologist
- *Dr Sam French*, Clinical Psychologist (External Supervisor)

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

Participation involves two parts:

- 1) A discussion with either Torileigh or Amy via Microsoft Teams or over the telephone undertaking a short interview
- 2) Filling out a series of online questionnaires

Part 1: The Teams/ Telephone call will take around 15-20 minutes and will be arranged for a time that is convenient for you. The researcher will talk through the study procedures and give you a chance to ask any questions. If you would like to take part, you will be asked to give verbal consent, this will be documented by the researcher. You will then be asked a series of questions about experiences of Generalised Anxiety Disorder, Obsessive Compulsive Disorder, Panic Disorder or Post Traumatic Stress Disorder or to confirm you are not currently experiencing mental health problems. This semi-structured interview is used widely in psychological research and clinical practice. You can pause or stop at any time. We will let you know at the end of the interview if it is appropriate for you to continue to the online questionnaires.

Part 2: Following the telephone/Microsoft Teams interview, if appropriate for you, you will be emailed a link to complete an online questionnaire along with your unique ID Code . You will be reminded of the details of the study and asked to provide your consent to take part in

this second part of the study. The questionnaire will include questions about your mental health, your experiences of anxiety, and your beliefs about responsibility. This part of the study should take approximately 30 minutes although for some people it may take longer (up to 45 minutes). You can log in and log out of the programme at your convenience using your allocated ID Code, if you would like to take a break from completing the questionnaires. We would appreciate if you could complete the questionnaires within one week. If you wish to withdraw from the study, this can be done by exiting the browser you are completing the questionnaires on.

6. Is there any potential risk in participating?

All the questionnaires within the study are commonly used in psychological research. Some of the questions may ask you to think about previous experiences that may be challenging or upsetting to think about. You can take a break from the study and return to it later or withdraw from the study completely at any point.

At the beginning of the study, once you have completed the interview, you will be provided with contact details of services and third-party organisations that will be able to offer you further support and guidance if needed. To ensure confidentiality, you will be provided with a unique personal identification number (PIN) to access the questionnaires. This PIN will be used to link the response from your interviews to the questionnaire. The PIN and your name will be stored on a separate password protected file.

7. Are there any benefits to taking part?

There will be no direct benefit to you from taking part in this research, but learning from your experiences is highly important for us. Having your voice heard in research is central to the development of interventions that are compassionate, supportive, and effective. By participating in our study, you will be helping us to build the evidence base for interventions in the context of OCD, PTSD and anxiety experiences. We hope this might then continue to the development and improvement of psychological support for people affected by these difficulties.

8. How will my data be used?

The data we will collect that could identify you will include consent records, contact details, age, gender, sex and ethnicity. Consent records taken during the online interview will be stored via a secure university server and will be kept for 3 years following publication. Information collected from the questionnaires are needed to answer our research question, and responses will be linked to a unique ID Code. The linkage file which holds the ID Code and personal information (such as name/email) will be stored on a separate password protected excel spreadsheet on university servers. Your ID code will be linked to your responses within three months of completing the questionnaire, however, this may occur sooner. Once your information has been linked, your personal information will then be removed. Once we anonymise your data, we will no longer be able to delete them, as it will

not be possible to identify which responses are yours (due to their anonymity). The linkage sheet will be deleted, as soon as feasibly possible, following the completion of the project. Your IP address will not be stored.

The anonymised data set will be retained and stored for 3 years following the study's completion. This will all be stored on the University of Oxford Secure servers.

Anonymised [non-identifiable] research data will be made publicly available after all relevant scientific papers are published (in the online platform Open Science Framework). This is extremely important for scientific scrutiny, transparency, and for reuse of data by the scientific community. *Your contact details & identifiable data will not be shared with anyone.* Once we anonymise your data, we will no longer be able to delete them, as it will not be possible to identify which responses are yours (due to their anonymity).

9. Will the research be published?

The University of Oxford is committed to the dissemination of its research for the benefit of society and the economy and, in support of this commitment, has established an online archive of research materials.

The research will be written up as part of Torileigh Matthews and Amy Lunn's Doctorate in Clinical Psychology. A copy of my thesis/ dissertation will be deposited both in print and online in the [Oxford University Research Archive](#) where it will be publicly available to facilitate its use in future research. The thesis will be openly accessible, and the research will also be written up for publication in a peer-reviewed scientific journal. The research team also aims to disseminate findings to UK & Ireland charities, services, and commissioners, and individuals involved in supporting people with anxiety, and in line with good practice for Open Science, we plan to deposit anonymised data online in the Open Science Framework (OSF) depository.

10. Who has reviewed this study?

This study has been reviewed and approved in different stages by:

- Project Approval Session (PAS) panel of the Oxford Institute of Clinical Psychology Training and Research;
- Senior Research Tutor at the Oxford Institute of Clinical Psychology Training and Research;
- University of Oxford Central University Research Ethics Committee (Reference number: R89339/RE001).

11. 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 Torileigh Matthews or Amy Lunn at stressresearch@oxfordhealth.nhs.uk. You may also contact our supervisor, 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, Headington, Oxford OX3 7GB

12. 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 research. 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 the University's Information Compliance web site at <https://compliance.admin.ox.ac.uk/individual-rights>.

13. Further Information and Contact Details

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

Torileigh Matthews

Trainee Clinical Psychologist

Oxford Institute of Clinical Psychology Training and Research

Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX.

Oxford University telephone number: +44 (0)1865 226431

Torileigh.matthews@hmc.ox.ac.uk

Amy Lunn

Trainee Clinical Psychologist

Oxford Institute of Clinical Psychology Training and Research

Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX.

Oxford University telephone number: +44 (0)1865 226431

Amy.Lunn@hmc.ox.ac.uk

You can also speak to the Principal Investigator (supervisor) of the project about any questions or concerns using the details below:

Professor Paul Salkovskis (University of Oxford)
Consultant Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research
Isis Education Centre, Warneford Hospital, Oxford, OX3 7JX.
Oxford University telephone number: +44 (0)1865 226431
paul.salkovskis@hmc.ox.ac.uk

I am interested in taking part! What do I do now?

If you would like to participate, please:

Click [HERE](#) to book your interview (Link to Teams Booking)

OR

Contact Torileigh Matthews or Amy Lunn to set up a telephone/ MS Teams
interview: stressresearch@oxfordhealth.nhs.uk

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