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An Investigation into Social Support, Possessions & Obsessions

PARTICIPANT INFORMATION SHEET

Central University Research Ethics Committee (CUREC) Approval Reference:
R74797/RE001

My name is Victoria Edwards 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 victoria.edwards@hmc.ox.ac.uk*

1. Why is this research being conducted?

The amount of social support people receive (or don't receive) can have a big impact on their thoughts and experiences. We are interested in the amount and type of social support experienced by people who have difficulties with a) over acquiring and keeping possessions, b) obsessional and compulsive problems, and c) those without problems with either. From this research, we hope to develop a greater understanding of factors that may make someone more vulnerable to difficulties with obsessions and compulsions or hoarding belongings, 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 problems and those who have hoarding difficulties.

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, from these 3 groups:

1. Consider themselves to have a significant problem with over acquiring and keeping possessions

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 or not 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. As the data collected is anonymous we will be unable to withdraw your data once you complete the study.

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 Hoarding 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 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 levels of social support and sense of belonging as well as any significant life events. This portion of the study may take approximately 30 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 if you could complete the questionnaires within a week.

You will also be asked whether you consent for your 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. 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 group.

5. Are there any potential risks in taking part?

Taking part could take up to approximately 45-60 minutes of your time in total.

All questionnaires are standardised measures and have been included with feedback from people with lived experience of having problems with their personal possessions 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, a password-protected database on an encrypted, password-protected device will store the data (details below).

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 their possessions. 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?

Data protection regulation requires that we state the legal basis for processing information about you. In the case of research, this is 'a task in the public interest.' The University of Oxford is the data controller and is responsible for looking after your information and using it properly.

The information you provide during the study is the research data. Any research data from which you can be identified (i.e. 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, encrypted Oxford Health NHS Foundation trust Ipad. Personal data will be stored for 3 months after the study has concluded itself and then permanently deleted.

Other research data (including consent forms and sensitive data obtained from questionnaires such as your racial or ethnic origin or information regarding your mental health) will be stored for at least 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 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. This archive includes digital copies of student theses successfully submitted as part of a University of Oxford postgraduate degree programme. Holding the archive online gives easy access for researchers to the full text of freely available theses, thereby increasing the likely impact and use of that research.

The research will be written up as part of Victoria Edwards' 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 Hoarding UK and OCD UK charities.

9. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: R74797/RE001).

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

Every care has been taken to ensure your safety during the course of the study. If you have a concern about any aspect of this study, please contact Victoria Edwards (victoria.edwards@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 Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible: Chair, **Medical Sciences Inter-Divisional Research Ethics Committee**; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

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 <http://www.admin.ox.ac.uk/councilsec/compliance/gdpr/individualrights/>.

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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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 Bream, Clinical Psychologist University of Oxford)
victoria.bream@hmc.ox.ac.uk

I'm Interested! What's Next?

If you would like to participate, please email Victoria Edwards to set up a telephone interview:
victoria.edwards@hmc.ox.ac.uk

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