**Hoarding Disorder – investigating the development of beliefs about possessions**

**PARTICIPANT INFORMATION SHEET**

Central University Research Ethics Committee Approval Reference: R77237/RE001

## Introductory paragraph

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

## Why is this research being conducted?

We would like your help in learning more about the link between past experiences of losing possessions and how people relate to things now.

We are interested in hearing from people who identify either as having problems with collecting and keeping clutter **or** those without such problems.

If you do have problems with collecting and keeping clutter, we are interested in hearing from you if before developing these problems, you had a childhood/adolescent experience of sudden (occurring in under a year) material deprivation resulting in the loss of all or nearly all of your and/or your family’s possessions. We are also interested in hearing from you if you have problems with collecting and keeping clutter but have not had this experience of material deprivation. If you don’t have problems with collecting and keeping clutter, we are interested in hearing from you whether or not you have any experience of material deprivation.

We hope that this research will help us to develop a deeper understanding of factors that may impact the relationship with possessions, and improve treatments for individuals having problems with collecting and keeping clutter.

## Why have I been invited to take part?

We are keen to hear from a full range of people aged 18 years old and above (with no upper age limit) and who are able to read, write and speak English. We wish to include people from the following three groups in our study:

1. Individuals who consider themselves to have a **significant problem with collecting and keeping clutter and** who have an experience in their early life (so during childhood/adolescence) of sudden (occurring in under a year) **material deprivation** resulting in the loss of all or nearly all of their and/or their family’s possessions, where this experience happened before they developed difficulties with collecting and keeping clutter.
2. Individuals who consider themselves to have a **significant problem with collecting and keeping clutter** but do not have an experience in their early life (so during childhood/adolescence) of sudden (occurring in under a year) material deprivation resulting in the loss of all or nearly all of their and/or their family’s possessions.
3. Individuals **who do not consider** themselves to have a **significant problem with collecting and keeping clutter** (whether or not they have a childhood/adolescent experience of the sudden loss of all or nearly all of their and/or their family’s possessions).

We aim to include the views of 75 individuals in this research project.

## Do I have to take part?

No. It is up to you to decide whether or not to take part. You can withdraw yourself from the study at any time, without giving a reason, by advising us of this decision. Once you complete the study you will be unable to withdraw your data. If you decide to withdraw whilst your participation in the study is ongoing, your data will be destroyed.

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

We would like you to email the researcher at fahreen.walji@hmc.ox.ac.uk so that you can be sent a unique identifying code and an online link to complete a consent form if you are happy to do this, and answer a question that asks you about hoarding behaviour. When you email the researcher please also provide your telephone number.

If you complete the consent form and answer the question about hoarding behaviour, you may then be contacted by the researcher to undertake a telephone/digital interview in which you will be asked some questions around hoarding behaviours, and you will be asked about any experiences of sudden (occurring in under a year) material deprivation you may have. This will take about 10-15 minutes. Whether or not you complete the telephone/digital interview, you will be asked to complete an online questionnaire pack containing some questions about your behaviours and beliefs around collecting and keeping clutter, demographic information and your mental health. This will involve being asked some detail about current and past psychological symptoms, including measures of psychological distress, and about your past experiences of material deprivation. This will take about 30-45 minutes.

In total, participation in the study will take about 30-60 minutes.

You can log in and log out of the program at your convenience if you would like to take a break from the questionnaires. If you would rather complete the online materials in hard copy, we will post them to you for you to complete.

As noted above, you can stop taking part in the research at any time or decline to answer any questions. Also, the information you provide will be kept strictly confidential except in rare circumstances in which it is judged that you or someone else is at risk of serious harm.

## What are the possible disadvantages and risks in taking part?

Some of the questionnaire measures, inviting you to reflect on your mental health and your experiences of losing possessions, may be difficult to think about. The questions around experiences of losing possessions have been designed with feedback from people with personal experience of this, in order to minimise the potential for distress. However, it is possible that you might find answering the questions upsetting.

As mentioned above, you can take a break from the study and return to it later.

At the end of the study, or if you withdraw at any point during completion, you will be provided with contact details of services and third-party organisations that will be able to offer support and guidance if you experience distress.

## Are there any benefits in taking part?

While there are no immediate benefits for those people participating in the project, it is hoped that this research will lead to a better understanding of individuals who have a significant problem with collecting and keeping clutter, and the development of better treatment for this difficulty.

## What information will be collected and why is the collection of this information relevant for achieving the research objectives?

During the study, you will be asked to provide the following information: your name, email address, telephone number, demographic information, information about your past and current psychological wellbeing, and your experiences of material deprivation of possessions.

The information you provide during the study is the **research data**. Any research data from which you can be identified (i.e. email address, telephone number and home address, should you request the consent form and questionnaires by post) is known as **personal data**.

**Personal data** (including consent forms) will be stored on a password protected Oxford University Computer, accessible only on University sites. Personal data will be stored for 3 months after the study has concluded and then permanently deleted. Once the research data has been checked your personal data will be detached from the research data, making it anonymous. This means that the data can no longer be withdrawn beyond this point as we will no longer know which is your data.

**Other research data** (including the questionnaire data that you fill in using a unique participant identifier) 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 researchers involved in this study will have access to the research data. Responsible members of the University of Oxford may be given access to the data for monitoring and and/or audit of the research. De-identified research data may be shared either directly with others or via a platform (so 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 ways including writing in academic journals, and presenting to relevant charities and to health professionals at conferences. The findings will also contribute to Fahreen Walji’s Doctorate in Clinical Psychology. You will not be identified in any reports or publications arising from the study.

## Will the research be published? Could I be identified from any publications or other research outputs?

As above, the findings from the research will be written up as part of a thesis, and reported in other ways possibly including academic publications, presentations including conference presentations, and on websites. It will not be possible for participants to be identifiable from these outputs. Some of these outputs will include written comments made by you in the study, with your consent.

## 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>.

## Who has reviewed this study?

This study has received ethics approval from a subcommittee of the University of Oxford Central University Research Ethics Committee (Ethics reference: R77237/RE001).

## Who do I contact if I have a concern about the research or I wish to complain?

If you have a concern about any aspect of this study, please contact Fahreen Walji (fahreen.walji@hmc.ox.ac.uk) or Professor Paul Salkovskis (paul.salkovskis@hmc.ox.ac.uk, (0)1865 226 369/431), 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.

## 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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