



Consent Information Statement

Project Title: Evaluation of a psycho education program to identify and treat family accommodation in relatives of patients with a diagnosis of Obsessive Compulsive Disorder.

Principal Investigator(s): Dr Richard Moulding (Swinburne University of Technology), Dr Sunil Bhar (Swinburne University of Technology), Dr Anna Thomas (Swinburne University of Technology), Samantha Beeken (Swinburne University of Technology)

Introduction to Project and Invitation to Participate

Thank you for your interest in this project. The research involves the completion of an interview regarding your experiences of living with an adult who has been diagnosed with OCD. The interview responses will form a large part of gathering information which will be used to develop a treatment support program for family members or carers of people living with an adult with OCD. If, once you have read the information contained in this statement you would like to participate in this research there is a consent form attached. The consent form outlines that you are free to withdraw your consent to participate at any time. We hope you feel able to participate and we assure you that your answers will be very valuable to the construction of the treatment support program.

What this project is about and why it is being undertaken

This research is being undertaken in order to develop a treatment program to support family members or carers of adults living with a diagnosis of OCD. There is a considerable body of evidence which acknowledges the difficulty that someone with OCD and their loved one experience in managing the disease. The purpose of the interview is to find out, from those living with someone with OCD, the following information;

- What their experiences are of being involved in their family members' OCD behaviour.
- What information or education they feel would be helpful for them to know.
- What they would like to see addressed in any support program that may help them to manage the challenges they face in not becoming involved in the rituals of their family member*.

*Family member is anyone living with, or in a supportive relationships with, someone suffering from OCD.

The researcher has chosen to interview those who live with someone with OCD to develop the treatment program as they feel it is important to find out the views of service users and allow people who may take part in any form of treatment to have an input into what would be most useful for them. Once all the interviews are completed they will be reviewed for common themes which will inform the researchers knowledge on what should be incorporated into the development of a treatment support program. In conjunction with current best practice and research the treatment program will then be developed.

Project and researcher interests

This project will form the requirements of a thesis in support of a Doctor of Psychology (Clinical Psychology) undertaken by Samantha Beeken at Swinburne University of Technology.

What participation will involve – time, effort, resources, costs, compensatory payments, etc.

To participate in this research you must be over 18 years of age and the person with OCD must also be over 18 years of age. For the comfort of those who choose to take part in the interview there are two options for completion. You can choose to meet with the researcher at a mutually agreed location or you can choose to complete the interview by telephone. If you choose to complete the interview by telephone the researcher will bear the cost of the telephone call. You will be asked to choose a day and time of your convenience to be contacted. You will also be asked for permission to audio record your responses to the questions using a digital voice recorder; this is to ensure the accuracy of the information transcribed by the researcher. You can choose not to have your answers recorded and still participate; the researcher will ensure that answers are fully transcribed as the interview is conducted.

The interview will take approximately 30- 60 minutes to complete. There are a series of questions about different aspects of living with someone with OCD, what information you feel may be helpful for you to know and what information or practical skills you would like to see in any support program. Example questions include;

- Have you received any information about the causes of OCD?
- What aspects of OCD do you find the most difficult for you to manage?
- Could you please describe any strategies you use to help you manage the challenges of living with someone with OCD?
- What would you hope to see in a support program designed to assist you to manage, and support you in, living with someone with OCD?

Participant rights and interests – Risks & Benefits/Contingencies/Back-up Support

Whilst the interview is designed to find out information about your experiences and your recommendations for the treatment program it is recognised that discussing the impact of OCD on you and your loved ones may feel intrusive or difficult. The questions are designed to find out the most important information to be incorporated into the treatment program and are not trying to suggest any form of responsibility for treatment outcome on supportive family members.

Once the program is written it is anticipated that it will be available to the general public via the Swinburne Psychology Clinic and you will be very welcome to participate in the program should you choose to do so. You can choose to be contacted by the researcher when the program is scheduled to run by annotating this on your consent form.

Participant rights and interests – Free Consent/Withdrawal from Participation

Participation in the interview is purely voluntary. You may choose to read this information sheet and not participate, to participate via a telephone call or to talk directly with the researcher. It is most important that if you choose to participate the interview is completed in the format that is most comfortable for you. Each interview sheet has a code number which de-identifies all data to be used in the research project. Only the researcher and research supervisors will have access to the list which links the informed consent form to the interview

schedule, this is to ensure that anyone who wishes to remove their responses at a later date can do so. At any time after completing the interview you can still request to have your data removed from the research project by quoting the code number provided to you by the researcher.

Participant rights and interests – Privacy & Confidentiality

All interview responses will be handled with the upmost sensitivity and respect at all times. They will be securely locked away in a locked cabinet at all times in accordance with privacy arrangements and will be kept separate from the list coordinating consent forms and interview responses.

Research output

This research will form the thesis element of the requirements for the Doctor of Psychology (Clinical Psychology) program. Once reviewed the interview responses will inform the development of a treatment program. In order to provide education and enhance knowledge in the field of OCD research it is anticipated that the researcher will publish the findings of the themes of the interviews and present the findings at relevant conferences. All data will be completely de-identified by the use of code numbers only and no identifying information will be made available at any time in any publication or conference presentation.

Further information about the project – who to contact

If you would like further information about the project, please do not hesitate to contact:

Principal Coordinating Supervisor Dr Richard Moulding

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Swinburne University of Technology.

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Research student Samantha Beeken

Novell account applied for

Concerns/complaints about the project – who to contact:

This project has been approved by or on behalf of Swinburne's Human Research Ethics Committee (SUHREC) in line with the *National Statement on Ethical Conduct in Human Research*. If you have any concerns or complaints about the conduct of this project, you can contact:

Research Ethics Officer, Swinburne Research (H68),

Swinburne University of Technology, P O Box 218, HAWTHORN VIC 3122.

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