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Participant Information Sheet

Title of study: The cognitive profile of early-onset obsessive-compulsive disorder

We would like to invite you to take part in our research study. Before you decide whether or not to take part, we would like you to understand why the research is being done and what it would involve. Please take time to read it carefully and discuss it with your parent or guardian, who we have also given an information sheet to. Ask us if there is anything that is not clear or if you would like more information.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the study.

Part 1

What is the purpose of this study?

We are interested in studying the mental functions and behaviours of young people with obsessive-compulsive disorder. We would like you to complete a few computer tasks that assess these functions and behaviours. The tasks are like games or puzzles. We would like you to complete these tasks in order to help us with our research. We would also like you to complete a few questionnaires that will help us gather information about the symptoms of obsessive-compulsive disorder you experience. We are interested in studying the connection between your symptoms and how you complete the tasks. In addition, we will also invite your parents/siblings to complete the same tasks, if you give consent.

Why have I been chosen?

You have been chosen because you are a young person who has obsessive-compulsive disorder.

Do I have to take part?

It is up to you to decide to join the study. We will describe the study to you and go through this information sheet with you. If you decide to take part, we will ask for your permission to have your parent or guardian to sign a consent form for you. You are free to withdraw from the study at any time, without giving a reason. If you do decide to withdraw, your treatment would not be affected.

What will happen to me if I take part?

If you decide to take part, then your parent/guardian will speak on the telephone with a psychiatrist, who will ask your parent/guardian questions in order to make sure that you are a good fit for this study. If you are, then we will invite you to participate, and together we will choose a date and time for testing. On the day of testing, you will first have a conversation with a psychiatrist. He or she will ask you questions to help us gather information about the symptoms of obsessive-compulsive disorder you experience. Then, you will be asked to complete simple computer tasks that are like games or puzzles. They will involve viewing letters, numbers, or pictures on a computer screen and responding to them by pressing buttons. For example, you may see two abstract pictures and have to learn by trial-and-error which picture is the correct choice. Lastly, you will be asked to complete several questionnaires that will help us gather information about the symptoms of obsessive-compulsive disorder you experience.

If you travel to Cambridge for the study, then it will take place in a testing room in the Behavioural and Clinical Neuroscience Institute, Downing Site, Cambridge, CB2 3EB or in the Herchel Smith Building, Addenbrooke's Site, Cambridge, CB2 0SZ. If you would rather not travel to Cambridge, then the study will take place in a private testing room on the NHS Trust site where you normally go. After the interview with the psychiatrist, computerised tests and questionnaires will be intermixed. After you have completed 2 tests (or after about 45 minutes), we will let you have a 5-10 minute break. For example, you will complete 1 tests on the computer, then 1 questionnaire, then you will have a break. The testing session will be no longer than 3 hours.

Expenses and payments

Each family will be compensated for their time at the rate of £8 per hour (one person), and your parent or guardian will be reimbursed for travel expenses.

What are the possible risks and disadvantages of taking part?

In the unlikely event that you become upset during the testing session, then we will stop the session, and the researcher or psychiatrist will discuss with you what has caused you to become upset. We will continue only if you wish to.

What are the possible benefits of taking part?

You will have the pleasure of knowing that you made a contribution to the understanding of obsessive-compulsive disorder.

What happens when the research study stops?

When data from several participants have been collected, they will be analyzed and the results will be written up and published in a scientific journal. The results may also be presented at scientific meetings. The results will be presented without mention of your name or other information that could identify you.

What if there is a problem?

Any complaints you have will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will keep all information about you private and safe. Only the members of the study team will have access to it. The details are included in Part 2.

Part 2

What will happen if I don't want to carry on with the study?

You are free to withdraw at any time, without giving a reason. If you do decide to withdraw, your treatment would not be affected, and any data that has been collected from you will be destroyed.

What if there is a problem?

If you have a concern about any part of this study, you can bring it immediately to the attention of the experimenter, Aleya Marzuki (telephone: 07845667907; email: aa2017@cam.ac.uk). Or, you or your parent or guardian can contact the Chief Investigator, Professor Barbara Sahakian, whose contact information can be found on the last page of this information sheet.

Will my taking part in this study be kept confidential?

All information that is collected from or about you during the study will be kept private and safe. All data will be labelled by a participant identification number, not by your name or any other information that could identify you. The data will be stored in a safe location and will be accessible only to the members of the study team. Some of the questionnaires that you fill out may also be shared with other psychiatrists and researchers at your local NHS Trust. The only questionnaires that may be shared with them are ones that they would have had you fill in anyway as part of your treatment.

We will not tell anyone what you say to the psychiatrist or researcher unless you tell us something that suggests that you or someone else is at risk of harm. If that happens, then we will have to speak to the appropriate authority (such as your GP) straightaway.

Will my GP be informed?

Your GP will not be informed unless you want us to or unless you tell us something that suggests that you or someone else is at risk of harm.

What will happen to the results of the research study?

The results will be written up and published in a scientific journal or presented at scientific meetings. You will not be identified in any of the above. The results of the study will contribute to the understanding of obsessive-compulsive disorder.

Who is organising and funding the research?

This study is being organised by the Departments of Experimental Psychology and Psychiatry at the University of Cambridge and in part fulfilment of an MPhil. (Aleya Marzuki). It is being funded by a Wellcome Trust Programme Grant.

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The Patient Advice and Liaison Service

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Thank you for considering taking part in our study. Our research depends on volunteers like you. Please let us know if you would like any more information.