

## Understanding young people's experiences of their early obsessive-compulsive signs emerging at 4-10 years

### Participant Information Sheet (PIS)

You are being invited to take part in a research study which involves you being interviewed to understand your experiences of obsessive-compulsive styles of thinking and behaviour. Before you decide whether to take part, 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. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

### **About the research**

#### ➤ **Who will conduct the research?**

James Dilks is doing this project as part of a PhD. James has been DBS checked. This project is supervised by Dr Ming Wai Wan (Division of Psychology and Mental Health) and Dr Rebecca Pedley (Division of Nursing, Midwifery and Social Work) at the University of Manchester.

#### ➤ **What is the purpose of the research?**

Some young people with OCD are able to look back and identify signs in the early years of their life that OCD was starting to develop. Sometimes, these signs were noticed by family members but also sometimes not.

Currently there is a lack of knowledge surrounding what the early signs of OCD are at the earliest stage.

By being able to detect the early signs of OCD among young children better, it would allow these children to be given the appropriate diagnosis and treatment quicker. This would then lead to better outcomes for children with OCD during therapy which would improve life for both themselves and their families.

Research has also shown that family members can respond in different ways to the child's early OCD signs. Understanding the young person's experience of this can be used to in the future help further improve family therapy for young children with OCD.

The purpose of this research is to carry out interviews to understand these early stages of OCD from a young person's past experiences. This interview would be based on previous experience from when you were between the ages of 4 and 10.

#### ➤ **Am I suitable to take part?**

To take part, you must be a young person living in the UK who:

- Is aged between 16 and 22.
- Has a diagnosis of OCD.

- Started showing signs of having OCD by the age of 10.
- Is fluent enough in English to participate in an interview.

You must also be able to consent to taking part in the study.

➤ **Will the research be published?**

The information we find out will be reported in professional journals and presentations, and a summary of findings will be shared with charities and with participants in the study. However, it will be impossible to identify you from anything said in the interview. Any names used will be removed.

➤ **Who has reviewed the research project?**

The project has been reviewed by The University of Manchester Research Ethics Committee [1/2/3/5/](#) and has been approved (ref: 14260; date to be added later)

## **What would my involvement be?**

➤ **What would I be asked to do if I took part?**

Taking part will involve you being interviewed by the main researcher (James) at a time to suit you. The interview can take place in person, by Zoom, or by phone, whichever is most convenient to you, and will usually take about 45-60 minutes. Before the interview begins, you will complete a questionnaire which asks some questions about yourself, such as your age. The researcher will go through this questionnaire with you.

In the interview, we are interested in finding out about your experiences of your repeated thoughts and behaviours in early childhood (4-10 years). We are also interested in how your family manage/d these and how (if at all) these management strategies have changed over time. We will also ask if this has affected other family members, and any steps they took to find information or support. The interview will be audio recorded.

There are also 2 more questionnaires, which you can either complete online or a posted paper version taking about 30-45 minutes in total, or we can go through together. These questionnaires help us understand more about your mental health and behaviour. One is about current obsessive-compulsive tendencies, and the other one, autistic tendencies, just because there is sometimes (but also often not) an overlap.

– **What are the risks involved in participating?**

The interview involves discussion of your thinking and behavioural styles, and your mental health, which may be worrying to you. You will be asked questions of how this has affected your own life as well as the life of your family, which may be upsetting for some. While some young people will find it helpful to talk about these experiences, some may also find it challenging. If it you happen to find anything that is being discussed distressing, you can stop at any time and/or withdraw from the study (and any information you have provided up to that point will be destroyed if you wish for it to be destroyed). If taking part raises any concerns for you or your family, we have a list of recommended organisations for you to contact and/or find out trusted information. If you continue to have concerns, then we recommend that you contact your GP.

– **Will I be compensated for taking part?**

Participants will receive a £15 physical gift card for taking part. Participants will only receive the gift card once they have completed all aspects of the study (each of the three questionnaires and the interview). We regret that we are unable to cover any travel expenses or childcare costs that may be incurred while taking part. Please note that we will not be able to provide any information about diagnosis. Additionally, we will not be able to provide access to support or services which would otherwise not be available to you.

– **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time without giving a reason and without any issues being brought upon yourself. However, it may not be possible to remove your data from the project once it has been secured as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.

In order for your data to be used in the study, you must complete the interview which will be audio recorded. However, as a participant, you must be comfortable with the recording process at all times. Therefore, you are free to stop recording at any time.

## **Data Protection and Confidentiality**

– **What information will you collect about me?**

In order to participate in this research project we will need to collect information that could identify you, called “personal identifiable information”. Specifically we will need to collect:

- Your name
- Your email address
- Your address
- Your record of consent
- Details of your GP
- A recording of your voice (audio recording)

We will also collect the following information about you:

- Your ethnic group
- Any other diagnoses or disabilities which you may have
- Any history which you may have with mental health services

We will also collect the following information about your emergency contact:

- Their name

- Their relationship to you
- Their phone number

– **Under what legal basis are you collecting this information?**

We are collecting and storing this personal identifiable information in accordance with UK data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

– **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice for Research](#).

– **Will my participation in the study be confidential and my personal identifiable information be protected?**

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

The researcher at The University of Manchester will have access to your personal information. To keep this information secure, your name and any other identifying information will be removed and replaced with a random ID number. The researcher will have access to the key that links this ID number to your personal information. If you choose to complete a posted paper version of the consent form, your consent form will be retained for 5 years in a locked cabinet on UoM premises for audit purposes. If you choose to complete the consent from online or verbally, your completed online consent form or audio recording of you giving consent will be safely stored on UoM servers in a digital folder only accessible to the study team. With your consent, we would also like to retain your contact details until we are able to inform you of the study’s findings. This is so that we can provide you with a summary of the findings for this study and inform you about future studies that you may be interested in. If you provide consent for this, your details will be safely stored on UoM servers in a digital folder only accessible to the study team and used only for the purposes described above.

If you opt to complete your interview in Zoom, your personal data will be processed by Zoom. This may mean that your personal data is transferred to a country outside of the European Economic Area, some of which have not yet been determined by the United Kingdom to have an adequate level of data protection. Appropriate legal mechanisms to ensure these transfers are compliant with the Data Protection Act 2018 and the UK General Data Protection Regulation are in place. The

recordings will be removed from the above third party platform and stored on University of Manchester managed file storage as soon as possible following the completion of data collection.

The audio recordings will be transcribed. The personal identifiable information will be removed in the final transcript. Once the analysis of the transcript is complete, the audio recording will be deleted.

In accordance with the University of Manchester's Research Privacy notice and with your consent, we would like to be able to share your anonymised data with other University of Manchester researchers who are doing studies similar to ours.

### **Potential disclosures**

If during the study, you reveal details about your mental health or the mental health of others which are concerning, but are not an imminent risk (e.g. you indicate suicidal ideation and self-harm more generally), your GP will be contacted. Additionally, a trained clinician at the University of Manchester will be contacted so that the researcher can get advice on whether any further safeguarding actions are needed.

If, during the study, you disclose information about any current or future illegal activities, we have a legal obligation to report this and will therefore need to inform the relevant authorities.

Individuals from the University, the site where the research is taking place and regulatory authorities may need to review the study information for auditing and monitoring purposes or in the event of an incident.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

### **What if I have a complaint?**

If you have a complaint that you wish to direct to members of the research team, please contact

**Dr Ming Wai Wan (m.w.wan@manchester.ac.uk) and/or**

**Dr Rebecca Pedley (Rebecca.Pedley@manchester.ac.uk)**

If you wish to make a formal complaint to someone independent of the research team or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact:

The Research Ethics Manager, Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: [research.complaints@manchester.ac.uk](mailto:research.complaints@manchester.ac.uk) or by telephoning 0161 306 8089.

If you wish to contact us about your data protection rights, please email

[dataprotection@manchester.ac.uk](mailto:dataprotection@manchester.ac.uk) or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioner's Office about complaints relating to your personal identifiable information](#) Tel 0303 123 1113

### **What do I do now if I wish to take part?**

If you have any questions about the study, or if you are interested in taking part, then please contact

**James Dilks (james.dilks@postgrad.manchester.ac.uk)** to discuss your suitability and arrange a time to be interviewed.

# Additional information in relation to COVID- 19

Due to the current COVID-19 pandemic, we have made some adjustments to the way in which this research study will be conducted that ensures we are following the latest government advice in relation to social distancing as well as taking all reasonable precautions in terms of limiting the spread of the virus. You should carefully consider all of the information provided below before deciding if you still want to take part in this research study. If you have any additional queries about any of the information provided, please speak with a member of the research team.

### **Are there any additional considerations that I need to know about before deciding whether I should take part?**

If you decide to be interviewed in person, this will pose the risk of you being infected by the interviewer during the study. If you decide to be interviewed at a location other than your home, this poses the risk of infection through travelling to and from the venue.

You should not take part if you are in a vulnerable group or if you have symptoms.

**What additional steps will you take to keep me safe while I take part?**

To reduce the chances of coming into contact with and/or spreading the virus, the use of facemasks will be strongly encouraged if taking part in person. The interviewer will take a lateral flow test to ensure he does not have the virus before interviewing you.

**What if the Government Guidance changes?**

If COVID restrictions are introduced again, in-person interviews will not go ahead. Instead, all interviews will be conducted over zoom or over the phone.

There are also a number of resources listed below that you can contact if you find any part of the study to be distressing:

Low distress:

- Contact a **family member or friend** for support.

Medium distress:

- Contact **Mind** on their helpline: 0300 123 3393 for non-urgent information about mental health support and services that may be available to you. Website; <https://www.mind.org.uk/>
- Talk to **your GP**

High/significant distress:

- **Shout** is a free and confidential text support service for anyone struggling to cope. Text 'Shout' to 85258, their support is available 24/7.
- Call **Samaritans** on 116 123 anytime, day or night for free. Visit their website for more details; <https://www.samaritans.org/how-we-can-help/contactsamaritan/>
- Go to your **local A&E department** if you feel you are unable to keep yourself safe

- Call the **emergency services** on 999.

Organisations which provide advice, information, and support services for those who have concerns surrounding OCD:

- **OCD-UK**

Visit <https://www.ocduk.org/> OR if you have a query about OCD, you can contact the OCDUK advice line on 01332 588112. This line is usually available between 9am – 12pm (Mon – Fri).

- **OCD Action**

Visit <https://ocdaction.org.uk/> OR for information and support surrounding OCD, you can contact the OCD Action help and information line on 0300 636 5478. This line is open between 9.30am – 8pm (Mon – Fri). Support from this organisation can also be obtained via email using the following email address: [support@ocdaction.or](mailto:support@ocdaction.or)



