Understanding parental experiences of 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 parents being interviewed to understand their experiences of parenting a child who has (or had, if since diagnosed) what may be considered as early 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 conducted 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 conducting this project in part fulfilment of a postgraduate qualification (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?

We know from research that some children can show styles of thinking and behaviour that are repeated often, and which the child struggles to control. This can start to happen at primary school age or earlier, and may (or may not) be recognised as ‘obsessive-compulsive’.

While some of these children later become diagnosed with a mental disorder (such as obsessive-compulsive disorder, OCD), others are not. Either way, these kinds of recurring thoughts and compulsive behaviours (to try to get rid of the thoughts) are likely to be challenging and distressing for families. Research in child mental health shows that early prevention is most effective, so this research seeks to understand the support such families need.

The purpose of this research is to carry out interviews to understand these early stages from the parents’ experience. This may be based on your current experience as a parent of a young child, or previous experience if your child is now older (11+ years).

➢ Am I suitable to take part?

To take part, you must be a parent (mother, father or guardian) living in the UK and have a child who:

- Lives with you.
- Does not have a diagnosis of OCD but who is showing or showed ‘obsessive-compulsive’ thoughts/behaviours by the age of 10.
- Your child is currently 4-16 years of age.
- You are fluent enough in English to participate in an interview.
OR

- Lives with you.
- Is diagnosed with OCD and showed ‘signs’ of this by the age of 10.
- Your child is currently 4-17 years of age.
- You are fluent enough in English to participate in an interview.

You must also be able to provide informed consent to take 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 one parent being interviewed by the main researcher (James) at a time to suit them. The interview can take place in person, by video call, 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 your family such as your child’s age. The researcher will go through this questionnaire with you.

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

While it’s ideal to find a quiet time when any children are not around (e.g. in school or looked after by someone else), we understand that this may not always be possible. We will do our best to accommodate any disruptions. It is, however, important that older children are not within listening range during the interview to prevent any possible distress to the child.

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 child’s 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 child’s thinking and behavioural styles, and their mental health, which may be worrying to you. We will be asked questions of how this has affected your own parenting and family life, which may be upsetting for some. While some parents 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 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 child’s GP.

➢ Will I be compensated for taking part?

Participants will receive a £15 physical gift card for taking part. However, 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 detriment to yourself. However, it may not be possible to remove your data from the project once it has been anonymised 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 your child:

- Their ethnic group
- Any other diagnoses or disabilities which they may have
- Any special educational needs which they may have
- Any history which they may have with mental health services
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 study team at The University of Manchester will have access to your personal information and they will anonymise it as soon as possible. Your name and any other identifying information will be removed and replaced with a random ID number. The research team 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, we have concerns about your safety or the safety of others, we will inform your GP.

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 or by telephoning 0161 306 8089.

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

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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 adhering to 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, over Microsoft teams 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.
- For online parent support resources go to the Care For The Family website; [https://www.careforthefamily.org.uk/family-life/parent-support](https://www.careforthefamily.org.uk/family-life/parent-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/](https://www.mind.org.uk/)
- Contact Family Lives on their helpline: 0808 800 2222 from Monday – Friday, 9am-9pm and 10-3pm on weekends for emotional support, information, advice and guidance on any aspect of parenting and family life. Website; [https://www.familylives.org.uk/](https://www.familylives.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/contact-samaritan/](https://www.samaritans.org/how-we-can-help/contact-samaritan/)
- Go to your local A&E department if you feel you are unable to keep yourself or your child 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/](https://www.ocduk.org/) OR if you have a query about OCD, you can contact the OCD-UK advice line on 01332 588112. This line is usually available between 9am – 12pm (Mon – Fri).

• **OCD Action**

  Visit [https://ocdaction.org.uk/](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.org.uk**.