

## **Information about the research**

### **Children with OCD: Identifying Acceptable Support Strategies for Parents (CO-ASSIST) – Phase 1**

We would like to invite you to take part in a research study, which aims to understand how we can better support parents and carers of children with obsessive-compulsive disorder (OCD). 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 before deciding whether to take part 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. Thank you for taking the time to read this.

### **About the research**

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

The research will be conducted by- Dr Rebecca Pedley, Dr Emma Sowden, Professor Karina Lovell and Professor Penny Bee, who are based at the Division of Nursing Midwifery and Social Work at The University of Manchester. A parent co-researcher and two UK charities will also be collaborating on the research study.

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

Obsessive-compulsive disorder (OCD) frequently begins in childhood or adolescence. Parents and carers supporting a child or young person with OCD often find their support role difficult. UK OCD charities and parent/carers, tell us that despite parents'/carers' important role, they are often given little or no support.

There is currently little evidence about how we can effectively support parents and carers of children with OCD. We want to speak to 25-30 parents/carers to understand the difficulties they face in their role and the ways we might go about better supporting them in the future. As part of this work, we will also speak to professionals who support children with OCD and their families.

You may have been invited for one of the following reasons:

- Your child attends a service who provide support to children/young people with OCD.
- You have responded to one of our study advertisements

#### **Will the outcomes of the research be published?**

At the end of the research, the results will be made available in reports and academic papers. A summary of the findings and a weblink to a podcast will be sent to you. We will also send a copy of our reports and academic papers to relevant charities including OCD UK to ensure that people with experiences of OCD are of aware of findings. When we write up the results, all-personal details will be removed so that no-one will know who you are. We may use direct quotes from your interview/group discussion, but no real names will be used.

## **Disclosure and Barring Service (DBS) Check**

All researchers involved in the study have undergone an appropriate level of DBS check.

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

This study has been reviewed by an independent group of people, called the Research Ethics Committee, to protect your safety, rights, well-being and dignity. The study has been given a favourable opinion by West of Scotland Research Ethics Committee 3 (Ref: 20/WS/0131).

## **Who is funding the research project?**

This study is organised and sponsored by the University of Manchester. The funder is the National Institute for Health Research.

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

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

#### ***Taking part in an interview***

If you decide to take part, we would like to invite you to take part in an interview where you will be given the opportunity to share your views and opinions. This can take place over the phone or video chat using Zoom or Microsoft Teams at a place that is convenient for you. The interview will last approximately 60 minutes, and you may end the conversation at any point.

We will invite you to discuss topics including:

- Your views and experiences of current services and available help for parents and carers who support a child or young person with OCD.
- Your support needs and the barriers and enablers to accessing support.
- Your preferences and priorities for the sorts of support that would help you in your role as a parent or carer of a child or young person with OCD.

At the beginning or at the end of the interview, the researcher will invite you answer some background questions about yourself. This information will be used to help inform our understanding of the overall findings. The researcher will go through these questions with you first to make sure you are happy to answer them and you are free to decline any of these questions

Interviews will be digitally audio-recorded – this means we will record the sound content of the interview. We audio record interviews because it is hard for the researchers to take notes on what people say, listen carefully and think all at the same time. If you take part using videoconferencing we will only use University of Manchester approved software (Microsoft Teams/Zoom) and we will only use your audio files for this study. Video files, which are automatically created during the recording process (within Microsoft Teams/Zoom), will be deleted immediately after the interview has ended and only the audio files will be saved for the purposes of this study.

If you take part using videoconferencing software (Microsoft Teams/Zoom) your personal data will be processed by Zoom or Microsoft, 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 European Commission to have an adequate level of data protection. Appropriate legal

mechanisms to ensure these transfers are compliant with the UK General Data Protection Regulation are in place. Teams/Zoom will only have access to the data that you log in with and you will have access to their privacy statements before proceeding. Note that the University of Manchester has contractual arrangements with Microsoft / Zoom offering additional safeguards as opposed to free versions. 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. After the interview, the whole interview is typed up by a university-approved supplier.

### ***Completing a daily journal (optional)***

In addition to taking part in the interview, we would also like to invite parents/carers to complete a 7-day journal in advance of the interview. The journal will include spaces for you to record the challenges and needs you have faced in your parenting or caring role during the day. You will also be asked to record suggestions about what might have helped you to manage the situation at that moment.

This part of the study is entirely optional, and you are free to take part in an interview without also completing a journal. Even if you agree to take part in this part of the study, there is no obligation to complete the journal each day if you don't manage to or change your mind – you will still be able to take part in the interview. You will be free to write down as little or as much as you would like, but we do not expect you to spend more than 10 minutes per day filling this in. In order to protect your confidentiality, we do not want you to use any names or personal identifiable information in the journal entries.

If you agree to complete a journal, you will have the option to visit a weblink each day at a time that suits you. If you prefer to fill in the journal using pen and paper, we will send a form for you to fill in at home and return in a self-addressed envelope (or alternatively, you can return the forms by scanning/photographing and then returning via email). We will label your form with a unique ID number so you won't need to send your name together with this information. If you are interested in completing a journal we will send you some more details in a letter (email or postal).

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

You will receive a £25 high street gift voucher for taking part.

### **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; your participation is entirely voluntary. Please contact the research team if you would like to take part. You do not need to contact the research team if you do not want to take part.

If you do decide to take part, you will be given this information sheet to keep. Before you go ahead with the study, we will ask you to record your 'verbal consent' – this means that we will ask you to verbally confirm whether or not you agree to the study. So that we have a record of your consent, we will take an audio recording of your consent, and we will provide you with a reference copy of the consent details. To help prevent your data from being identifiable, your consent will be recorded and stored separately to your interview and journal data (if completed).

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 will 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.

Although it is preferable for us to audio record the interview (so that we have a clear record of the data) if you don't want to be recorded, you can still take part, if two researchers can be present during the interview, one to conduct the interview and one to take accurate written notes. Please let the researcher know if this is the case. Even if you agree to being recorded; you are free to ask for the recording to be stopped at any time.

### **What are the possible risks and benefits of taking part**

We have designed the study so there will be no face-face contact to mitigate risks associated with COVID-19. We are hoping the interviews will provide you with an opportunity to share your experiences, and we do not anticipate any major risks. However, sometimes interviews may bring some quite strong emotions to the surface, in this situation we will be guided by your preferences and you can take a break at any time or decline to answer any questions or stop taking part in the interview at any point. We would encourage you to speak to the study researcher if you are feeling upset after the interview. We hope this study will benefit parents and carers of children with OCD in the future. We cannot claim there will be a direct benefit for individuals that take part, but many people find that taking part in studies of this sort useful because they have a chance to share their views on things.

## **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 contact details - name, address, phone number and email address (if available)
- With your consent, we will also audio record your phone/video chat interview - this will involve the recording of your voice only.
- We will invite you to answer some background questions at the beginning or the end of the interview.

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

We are collecting and storing this personal identifiable information in accordance with data protection law which protects 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 which can be found at <http://documents.manchester.ac.uk/display.aspx?DocID=37095>

**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:

- Personal contact details will be stored separately from study data, until the end of the study, or after the point of forwarding study, findings (if requested) at which point they will be destroyed.
- Study data (including - the interview, journal and background information) will be labelled immediately following collection with a unique ID number (known as pseudonymised). This means your name and any other identifying information will be removed and replaced with a random ID number. Only the research team will have access to the key that links this ID number to your personal information, which will be stored separately to your study data.
- The audio recording of your interview will be encrypted and stored on a secure University server. The audio recording of your consent will be stored separately from your study data. The recording of your interview will be typed up by a research team member or by a University of Manchester approved contracted transcription service. All personal identifiable information will be removed from your transcribed interview. The audio recording of your interview will be destroyed when the transcribed interview has been checked for accuracy and the early stage of the analysis has been completed.
- The key that links your ID number to your personal information will be destroyed once the analysis is complete. Only consent details and anonymised (non-identifiable) data will be archived as essential documents for the minimum required retention period of 5 years and then will be destroyed.
- Everything you tell us during the interview/group discussion is completely confidential. The only exception to this would be if you share something with us, which reveals that a vulnerable person is at risk of harm. In this case, we may be required to act on this information, but we would not do this without involving you in the process.
- All information that is collected is strictly confidential, and only members of the research team at The University of Manchester will have access to your personal information. All data will be stored securely on a password-protected and encrypted University operated server or in a locked filing cabinet.
- When you agree to take part in a research study, your anonymised data may be provided to researchers running other research studies outside of the CO-ASSIST study. The future research will be of a similar nature to this research project and will concern research about supporting parents and carers of children with mental health problems. Your information will only be used by this organisation and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research which can be found at

<https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/> This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of healthcare research and cannot be used to contact you regarding any other matter.

- Please also note that individuals from The University of Manchester, or regulatory authorities or participating NHS Trusts 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 concern about any aspect of this study, you should ask to speak to the Lead Investigator Rebecca Pedley (email: [Rebecca.Pedley@manchester.ac.uk](mailto:Rebecca.Pedley@manchester.ac.uk), tel: 0161 306 7331) who will do their best to answer your questions.

### *Minor complaints*

If you have a minor complaint, then you need to contact the researcher in the first instance:

NAME	Emma Sowden
ADDRESS	The University of Manchester, Division of Nursing Midwifery and Social work Jean McFarlane Building, Oxford Road, Manchester, M13 9PL
TELEPHONE	07795 612178
EMAIL	<a href="mailto:emma.sowden-2@manchester.ac.uk">emma.sowden-2@manchester.ac.uk</a>

### *Formal complaints*

**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:**

NAME	The Research Ethics Manager
ADDRESS	Research Office, Christie Building, The University of Manchester, Oxford Road, Manchester, M13 9PL
TELEPHONE	0161 275 2674
EMAIL	<a href="mailto:research.complaints@manchester.ac.uk">research.complaints@manchester.ac.uk</a>

If you wish to contact us about your data protection rights, please contact the Information Governance Office, and we will guide you through the process of exercising your rights.

NAME	The Information Governance Office
ADDRESS	Christie Building, The University of Manchester, Oxford Road, M13 9PL
EMAIL	<a href="mailto:dataprotection@manchester.ac.uk">dataprotection@manchester.ac.uk</a>

You also have a right to complain to the Information Commissioner's Office [about complaints](#)

relating to your personal identifiable information. Further details can be accessed at <https://ico.org.uk/make-a-complaint/> Tel 0303 123 1113

## Contact Details

If you have any queries about the study or if you are interested in taking part, then please contact the researcher(s)

NAME	Emma Sowden
ADDRESS	The University of Manchester, Division of Nursing Midwifery and Social work Jean McFarlane Building, Oxford Road, Manchester, M13 9PL
TELEPHONE	07795 612178
EMAIL	<a href="mailto:emma.sowden-2@manchester.ac.uk">emma.sowden-2@manchester.ac.uk</a>