

Information about the research

Children with OCD: Identifying Acceptable Support Strategies for Parents (CO-ASSIST) – Phase 2 Workshop Event

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. During an earlier phase of the study, we spoke to parents/carers and professionals who support children with OCD and their families to help understand how we might improve the support available to parents and carers. We have used this information together with published evidence, and feedback from key stakeholders including parents/carers, professionals, charity representatives and OCD researchers to put forward a list of strategies and resources to better support parents/carers. We now need your help to help us decide which strategies/resources are likely to be most helpful to parents, while also being feasible to provide.

Why have I been invited?

We are inviting representatives from various stakeholders (including parents/carers, charity representatives, clinicians and OCD researchers) to help gain insights into this topic.

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
- You are a professional who provides support to families with children/young people with OCD.
- You are a researcher or charity representative with an interest in developing services for families with OCD

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 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 informed of our findings. When we write up the results, all personal details will be removed so that no-one will know who you are.

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?

If you decide you would like to participate, we would like to invite you to take part in a 2 ½ hour remote workshop event, (regular breaks will be provided). Before the day, we will send you some information with findings from our previous stages of research to consider. During this event, you will be invited to share your views on support strategies and resources to meet parent/carer needs, through a series of activities, including discussion and voting. An experienced team of facilitators who have experience in OCD research will support the event. Before starting the workshop, all members will contribute to devising a proposed group agreement to enable meaningful discussions and the safeguarding of confidentiality.

The workshop will involve

- Listening to a presentation of possible strategies and resources to enhance parental/carer support in CYP OCD identified by combining the findings from our previous stages of research (including talking to parents/carers and professionals and existing literature). You will be sent some information about the proposed strategies/resources before the event so you have more time to consider them.
- Taking part in a series of small group discussion activities to share views on the potential support strategies.
- Taking part in anonymised electronic voting (full guidance will be given) to rate potential future support strategies and resources for parents

The discussions and activities will take place in real-time using video-conferencing (e.g. Zoom or Teams). For individuals who are not able to participate on the day, there will be an opportunity for individuals to contribute electronically in their own time.

We will not be recording the workshop but we will keep any design work produced during the workshop to inform our intervention development. Workshop materials will include comments added to the chat box during discussions, notes taken during the workshop, details of support strategies, or voting. All workshop material, will be anonymised, and any potentially identifying details will be removed from any design work produced during the workshop.

Will I be compensated for taking part?

Parent/carer participants will be compensated for their time and will receive £75 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 to take part; your participation is 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 2 ½ hour workshop, we will invite you to complete an electronic consent form accessed via secure University approved software. You will be provided with a reference document of the consent details. Once you have completed the consent form, you will be invited to answer some background questions (via the same secure software). This information will be used to help inform our understanding of the findings and there will be a 'prefer not to answer' option for each question. We will send you an email detailing how to access the electronic consent form and background questions, including a unique participant ID (required to access the form). To help prevent your data from being identifiable, your consent will be stored separately to your interview.

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 contribution to the workshop, 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.

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 workshop will provide you with an opportunity to inform the development of future support strategies for parents and carers of children with OCD, and we do not anticipate any major risks. However, sometimes reflecting on difficult experiences 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 workshop at any point. We would encourage you to speak to the study researcher if you are feeling upset after the workshop. 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?**

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)
- Background information- we will invite you to answer some background questions via a secure weblink (which can only be accessed via a unique ID 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 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.

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: http://documents.manchester.ac.uk/display.aspx?DocID=37095](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.
- All study data including- background information and electronic and paper-based notes collected during the workshop (will be converted to electronic files where necessary) and will be labelled 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 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.
- We will ensure that all members of the workshop are aware of the importance of safeguarding the confidentiality of participants. Facilitators will ensure that everything you tell us during the workshop is 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, 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	emma.sowden-2@manchester.ac.uk

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 3068089
 EMAIL research.complaints@manchester.ac.uk

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 dataprotection@manchester.ac.uk

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

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 emma.sowden-2@manchester.ac.uk