ISRCTN18589885 https://doi.org/10.1186/ISRCTN18589885

# Co-developing an online resource to support parents and carers of children with obsessive-compulsive disorder (OCD)

**Submission date**
04/03/2025

**Recruitment status**
No longer recruiting

**Registration date**
05/03/2025

**Overall study status**
Completed

**Last Edited**
07/10/2026

**Condition category**
Mental and Behavioural Disorders

[ ] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[X] Record updated in last year

## Plain English summary of protocol

Background and study aims
The development of a new questionnaire to capture the experiences of caring for a child with obsessive-compulsive disorder (OCD) is part of a wider study CORuS (Co-developing an Online ResoUrce to Support parents and carers of children with OCD). In order to evaluate whether an online resource is helpful to parents/carers who use it, a suitable questionnaire or 'measure' that captures the experience of caring for a child with OCD needs to be chosen. In previous consultations, parents felt that current questionnaires aimed at measuring the consequences of a carer/caregiver role do not adequately capture the difficulties parents/carers can experience when supporting a child with OCD. This study aims to develop a new questionnaire specifically for parents/carers of children aged 8-18 years with OCD.
We have developed a preliminary questionnaire by looking at data from a previous project -CO-ASSIST (including interviews and journals with parents of children with OCD) and a consultation workshop with parents/carers.
This study aims to recruit a minimum of 300 parents/carers to complete a 10-15-minute anonymised online pilot survey so we can refine the questionnaire using research methods (i.e., psychometric and statistical techniques) into a valid and reliable measure of the impact of caring for a child with OCD. The new measure will be used to evaluate an online platform in a future study. It may also be used clinically, for example, to better understand the impact of OCD on the family.

Who can participate?
Parent or carers (adults with parental responsibility) for a child aged 8-18 years with OCD who live in the UK

What does the study involve?
Participants will be invited to complete an online anonymous questionnaire hosted on a secure platform called Qualtrics. The online questionnaire will take approximately 10-15 minutes and contains 60 questions (statements). Each statement will capture thoughts and feelings that parents/carers of a child with OCD can have. Participants will be asked to rate each statement on a scale of 'never', 'rarely', 'sometimes', 'often', or 'always' according to how they have felt over

the last 2 weeks.
Before completing the questionnaire, participants will be invited to complete some screening questions to ensure they are eligible to take part. They will then be invited to answer some background questions about themselves and their child with OCD, including age, ethnicity, and gender. This information will provide a detailed description of how representative our sample is.

What are the possible benefits and risks of participating?
There will be no immediate direct benefit to those taking part. However, taking part will inform the development of a new outcome measure to understand the impact of caring for a child with OCD. The researchers do not anticipate any major risks. However, reflecting on your caring experiences over the last 2 weeks may be potentially distressing. If this happens, you may wish to use the contact numbers of support organisations provided in a debrief document, which can be accessed via a link at the end of the questionnaire, or you may wish to speak with a member of the research team

Where is the study run from?
The research team includes researchers from The University of Manchester and The University of Liverpool (UK), representatives from two national OCD and anxiety charities, clinicians and a parent with lived experience of parenting a child with OCD. The questionnaire has been created on a secure platform at the University of Manchester.

When is the study starting and how long is it expected to run for?
March 2023 to October 2025

Who is funding the study?
National Institute for Health and Care Research (NIHR) (UK)

Who is the main contact?
Dr Emma Sowden, parent.OCD.research@manchester.ac.uk

# Contact information

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# Additional identifiers

**Integrated Research Application System (IRAS)**
355869

# Study information

**Scientific Title**

Development of a programme to reduce burden and distress in parents and carers of children with obsessive-compulsive disorder (OCD)

## Acronym
CORuS

## Study objectives
Rationale:
While carer or caregiver burden is widely acknowledged as a theoretical construct and carer burden measures exist, a review of the literature found none specific to the context of parenting a child with obsessive-compulsive disorder (OCD). In addition, consultation with parents in preparation for this programme development grant highlighted the need for a new measure to capture parent/carer experiences of supporting a child with OCD, as no current individual measure exists for this group of carers.

We anticipate that this new measure will be employed in our future evaluation of the online platform and could also have useful applications beyond the proposed study. Consultation with clinical professionals indicates that the measure would be useful during assessment and follow-up within clinical practice to better understand the impact of OCD on the family and to monitor any changes during the child's treatment.

## Ethics approval required
Ethics approval required

## Ethics approval(s)
Approved 04/03/2023, University of Manchester UREC 2 (University of Manchester, Manchester, M19 9PY, United Kingdom; +44 (0)161 3066000; urec2@manchester.ac.uk), ref: 18774-33276

## Primary study design
Observational

## Study design
Observational cross-sectional study

## Study type(s)
Other

## Health condition(s) or problem(s) studied
Obsessive-compulsive disorder

## Interventions
Participants will be required to complete an online anonymised questionnaire which will take approximately 10-15 minutes to complete

## Intervention Type
Other

## Primary outcome(s)
Experiences of caring for a child with OCD, measured using a preliminary questionnaire containing 60 items at one specified point in time

### Key secondary outcome(s)
There are no secondary outcome measures

### Completion date
01/10/2025

## Eligibility

### Key inclusion criteria
1. Parent or carer (adult with parental responsibility) of a child aged 8-18 years with OCD
2. Living in the UK

### Participant type(s)
Carer, Other

### Healthy volunteers allowed
No

### Age group
Mixed

### Lower age limit
18 Years

### Upper age limit
100 Years

### Sex
All

### Total final enrolment
400

### Key exclusion criteria
1. Parents/carers who do not live in the UK

### Date of first enrolment
09/12/2024

### Date of final enrolment
01/10/2025

## Locations

### Countries of recruitment
United Kingdom

England

**Study participating centre**
**University of Manchester**
Division of Nursing, Midwifery & Social Work
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176 Oxford Road
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# Sponsor information

**Organisation**
Greater Manchester Mental Health NHS Foundation Trust

**ROR**
https://ror.org/05sb89p83

# Funder(s)

**Funder type**
Government

**Funder Name**
National Institute for Health and Care Research

**Alternative Name(s)**
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

**Funding Body Type**
Government organisation

**Funding Body Subtype**
National government

**Location**
United Kingdom

# Results and Publications

**Individual participant data (IPD) sharing plan**

## IPD sharing plan summary

Data sharing statement to be made available at a later date

## Study outputs

| Output type | Details | Date created | Date added | Peer reviewed? | Patient-facing? |
|---|---|---|---|---|---|
| Participant information sheet | Link to survey (containing participant information sheet) | | 05/03/2025 | No | Yes |
| Participant information sheet | Participant information sheet | 11/11/2025 | 11/11/2025 | No | Yes |