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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	☐ Prospectively registered ☐ Protocol
Registration date 05/03/2025	**Overall study status** Completed	☐ Statistical analysis plan ☐ Results
Last Edited 04/09/2025	**Condition category** Mental and Behavioural Disorders	☐ Individual participant data ☒ 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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Public

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

Integrated Research Application System (IRAS)
355869

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
Nil known

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

Study design
Observational cross-sectional study

Primary study design
Observational

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
Adult

Lower age limit
18 years

Upper age limit
100 years

Sex
All

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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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

The data-sharing plans for the current study are unknown and will be made available at a later date

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