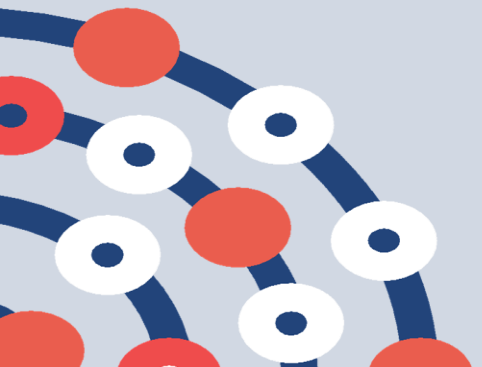




Children with OCD: Identifying Acceptable Support Strategies for Parents (CO-ASSIST)

Rebecca Pedley & Debra Robinson

Twitter: @COASSIST_OCD



Research team

- Dr Rebecca Pedley – Principal Investigator
- Professor Penny Bee – co-applicant
- Professor Karina Lovell – co-applicant
- Ms Debra Robinson – parent co-researcher
- Dr Emma Sowden – project researcher
- Ms Abi Brown – ARC research assistant

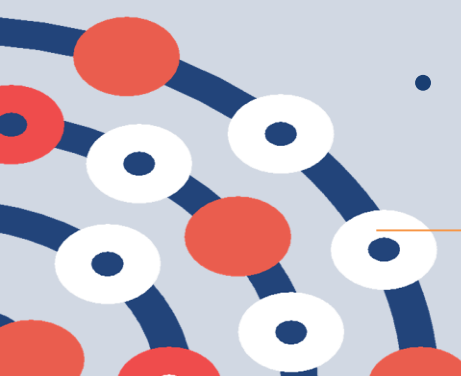
Consultants:

- Ashley Fulwood (CEO OCD UK)
- Zoe Wilson (Children, Young People and Parents lead, OCD UK)
- Nicky Lidbetter (CEO Anxiety UK)

Background



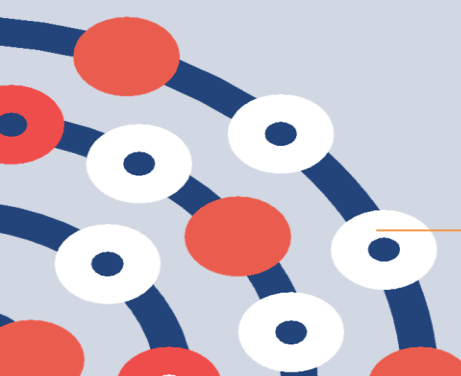
- Obsessive-compulsive disorder (OCD) often develops in childhood or adolescence (Geller et al, 2021)
- Relatives experience high levels of carer burden and distress (Cicek et al, 2013)
- Family accommodation is highly prevalent in paediatric OCD
- Parents of children with OCD perceive greater responsibility for the person with OCD in terms of ensuring treatment progress than other relative types (Stengler-Wenzke et al, 2014)
- Parents/carers currently receive little or no support in their caring role
- Urgent need for effective interventions to support parents in their caregiving role
- Lack of evidence on parent support needs and preferences



CO-ASSIST

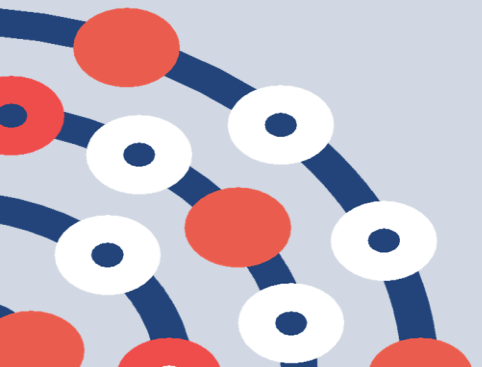
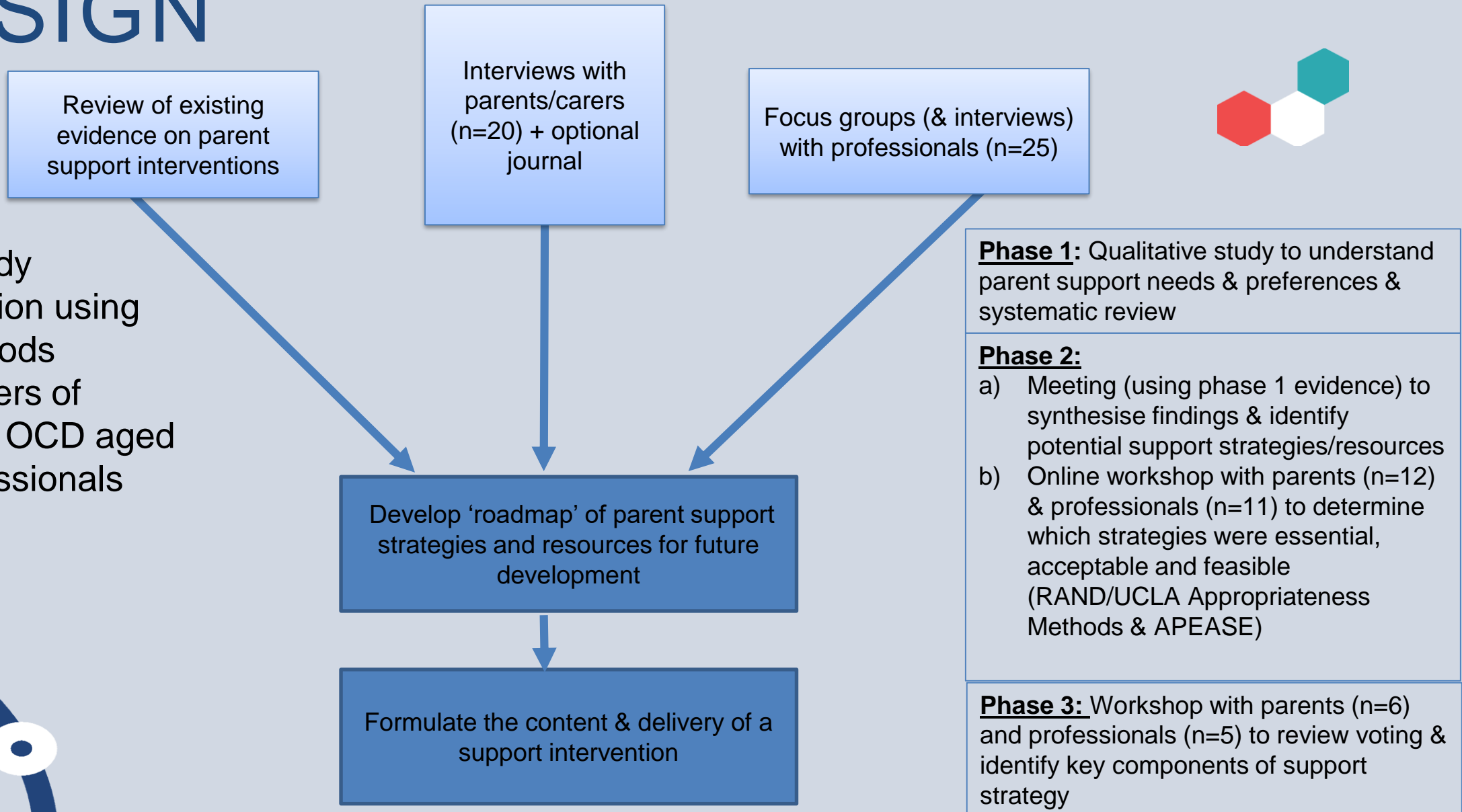


- **Aim: To undertake development work for better support of parents/carers of children with OCD**
- April 2020- Nov 2021
- Ethical approval Research Ethics Committee: North West Scotland 3
- Host organisation: Greater Manchester Mental Health Foundation Trust



DESIGN

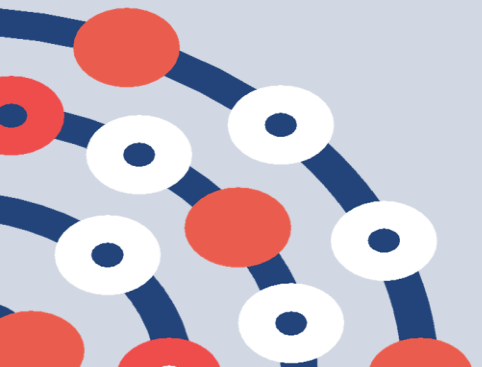
- 3 phase study
- Data collection using remote methods
- Parents/carers of children with OCD aged 8-18 & professionals



Lived experience & co-design



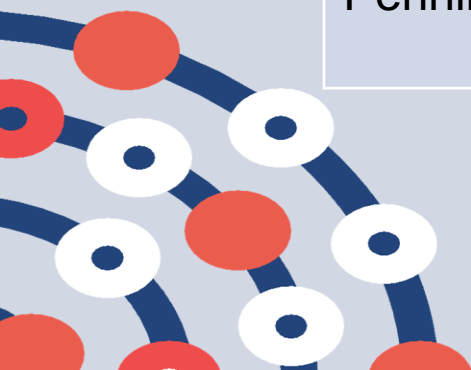
- Study designed with parents and OCD UK
- Co-researcher (Debbie) with lived experience of parenting a child with OCD employed throughout study
- 3 senior staff from OCD UK and Anxiety UK (national service user-led mental health charities) acted as consultants.
- Co-design workshops with parents/carers and professionals to identify support strategies



Recruitment



NHS CAMHS	Third sector & community
<p>Greater Manchester Mental Health NHS Foundation Trust (GMMH)</p> <p>Manchester University NHS Foundation Trust (MFT)</p> <p>North Staffordshire Combined Healthcare NHS Trust</p> <p>Dorset Healthcare University NHS Foundation Trust</p> <p>Berkshire Healthcare NHS Foundation Trust</p> <p>Pennine Care NHS Foundation Trust</p>	<p>OCD UK</p> <p>Anxiety UK</p> <p>OCD Action</p> <p>42nd Street</p> <p>Caribbean & African Health Network (CAHN)</p> <p>E-ACT</p> <p>SEND online channels</p> <p>Parents of children with OCD Facebook group</p>



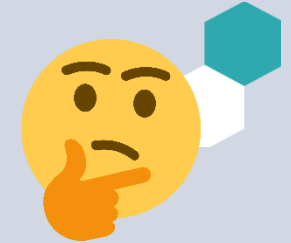
Qualitative study findings



**Coping with the
impact of OCD**

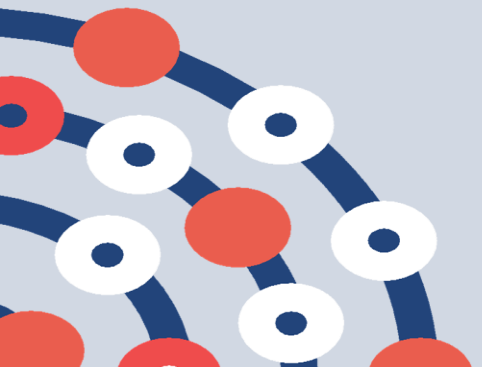
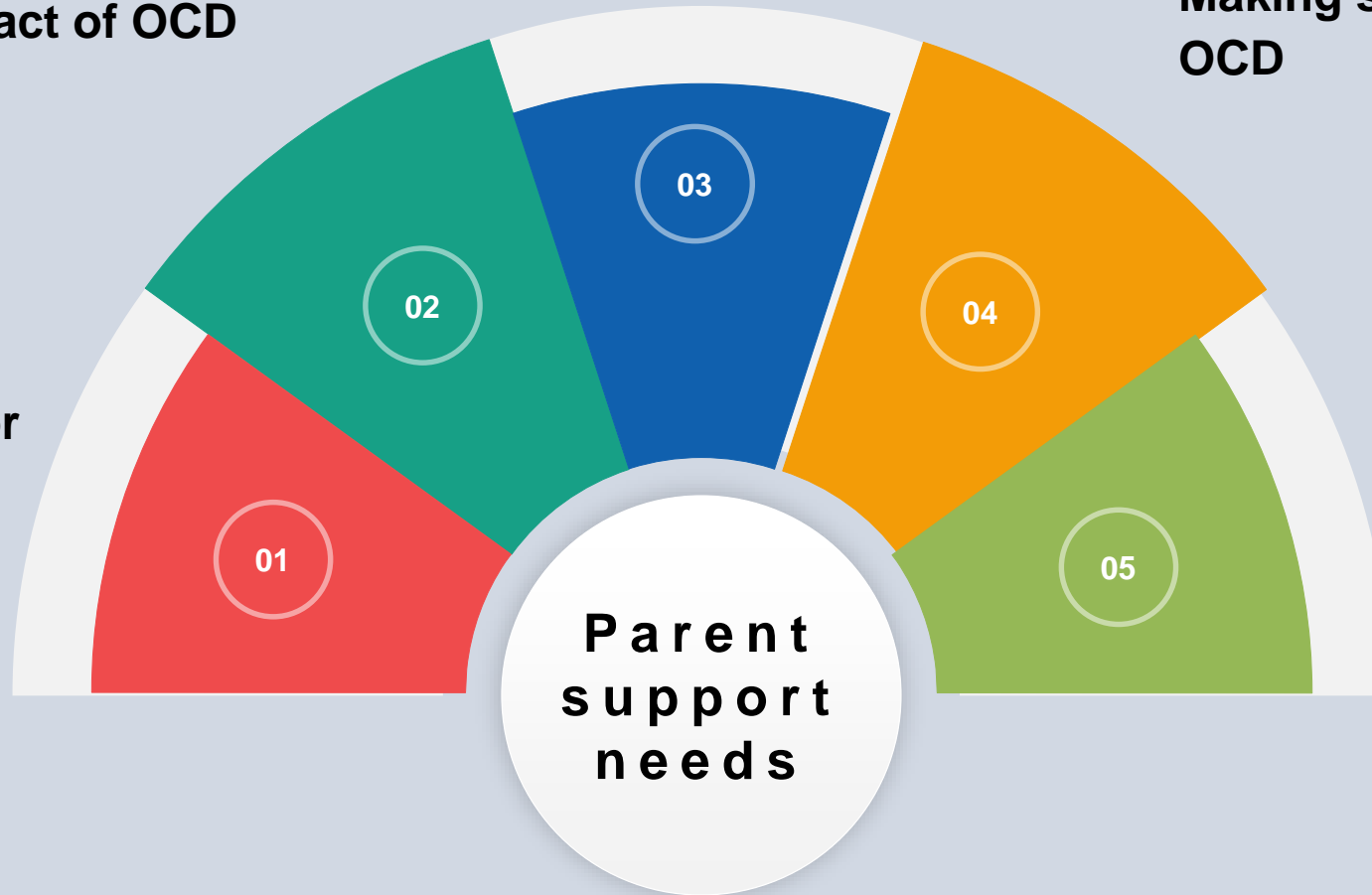
**Understanding
parents' role**

**Making sense of
OCD**



**Getting help for
my child**




Joined-up care



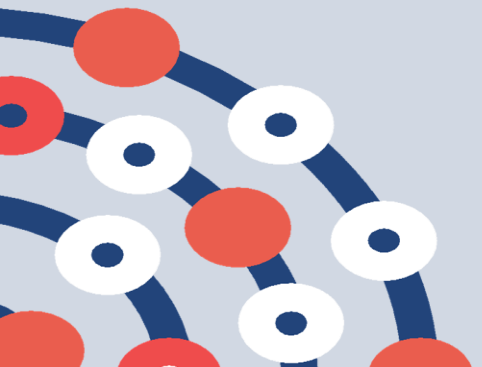
Phase 2 findings

- 22 support strategies/resources were rated highly (score 7-9) by parents and professionals on 'essentiality' = 'roadmap' to improving support for parents and carers of children with OCD



1-3  = **low score**
4-6  = **medium score**
7-9  = **high score**

Description of strategy or resources	Middle (median) score
An earlier approach to assessment for children & young people with possible OCD, involving a telephone assessment (to facilitate earlier diagnosis)	8
A group-based mixed face-to face & online workshop or short course for parents on the waiting list including education about OCD & emotional support for parents	8
Online support/mentoring for parents (by trained individuals) so they have a point of contact to ask any questions & gain reassurance about specific challenges as they arise (e.g. troubleshooting & sharing strategies)	8
Education for school staff (including teaching staff & school nurses) to develop better understanding & awareness of OCD, particularly around the severity of its impact and how to support the child in a joined-up way (parents, professionals and the child working	8
Campaigns through social media / schools / GPs to raise awareness of OCD and help it to be taken more seriously (similar to 'hidden disabilities' campaigns and sunflower lanyards). Example of an advert showing how someone can't leave the house because things aren't right and links to OCD information.	8

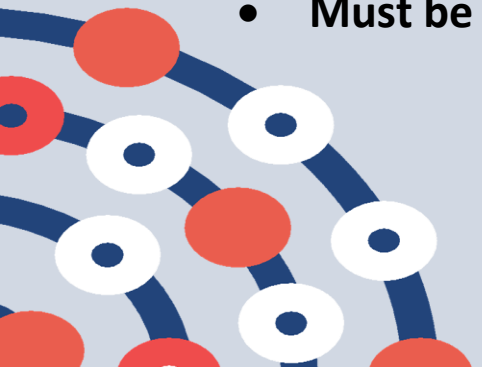


Phase 3 - the agreed intervention

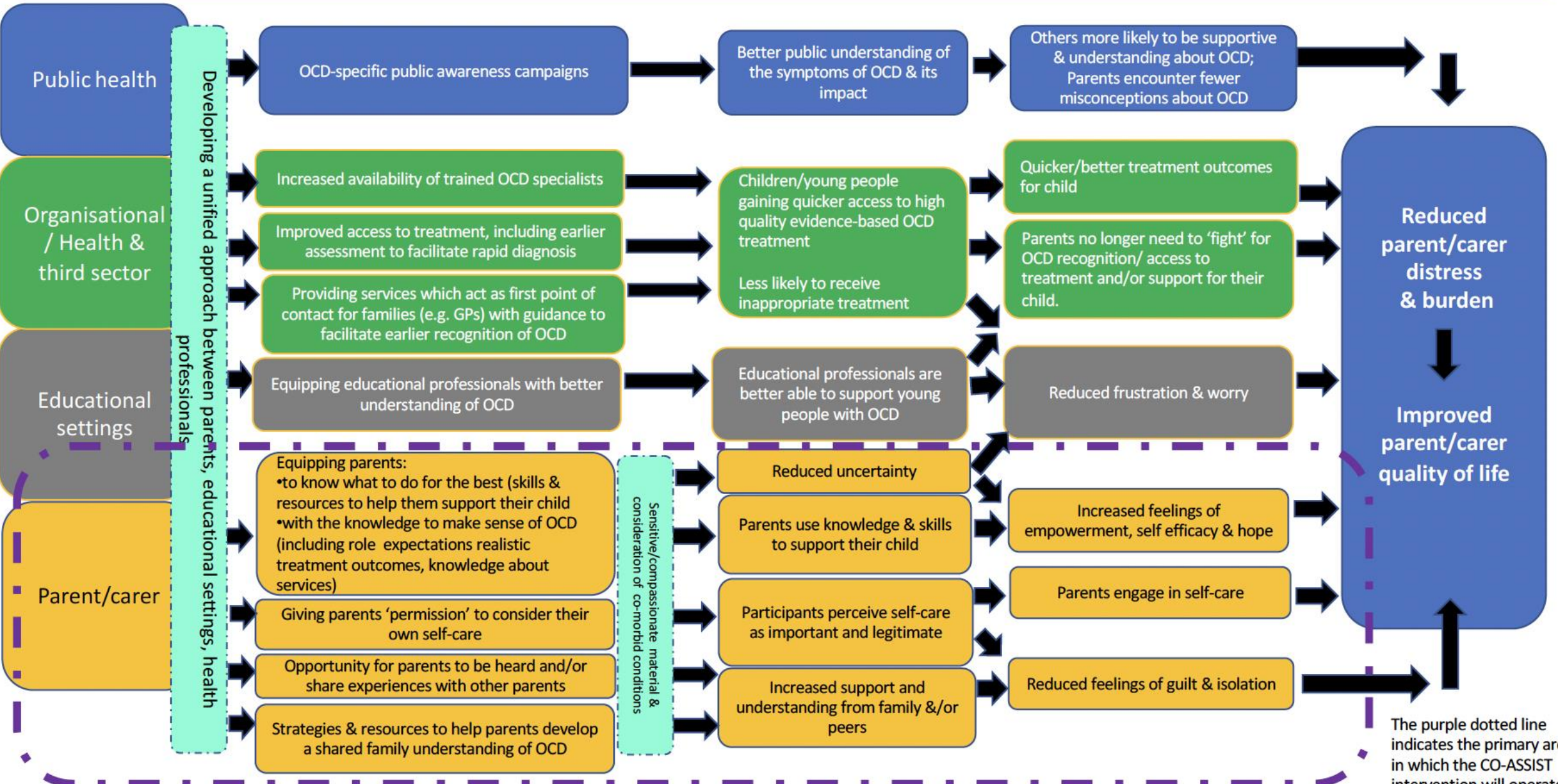
An accessible parent-focused **online platform** (a website and/or mobile app) with the following content:



- Anonymised 'parenting a child with OCD' lived-experience stories
- Q & A style parent-focused informational resource (including podcasts & videos)
- A step-by-step flowchart on where to go & what to expect when accessing treatment
- Signposting to existing support & pathways to services
- Resources which parents, children and wider family can look through together, (e.g. stories)
- 'Quick-guide' about what OCD is and isn't; overlap with other conditions
- Parents' troubleshooting feature for specific challenges
- Opportunity for parents to connect, share stories and interact
- Pre-recorded webinars (or signposting to those created by other organisations)
- **Must be accessible to families at different stages of the treatment pathway and accessible to outside of CAMHS**



Levels.....Change mechanisms.....Short/med-term impacts.....Long-term impacts.....Success

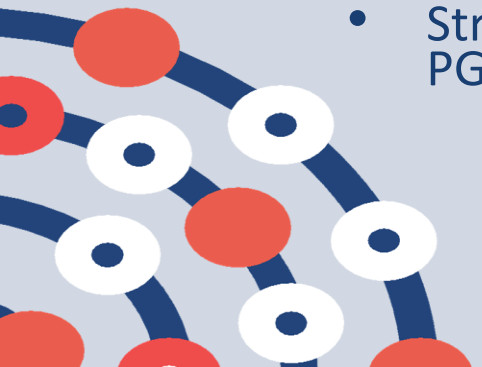


The purple dotted line indicates the primary area in which the CO-ASSIST intervention will operate.

Next steps



- NIHR Programme Development Grant submitted Jan 2023
- **Aim:** To undertake the necessary preparatory work for a future programme to reduce burden and distress for parents and carers of children with OCD
- **Objectives**
 - Develop a measure suitable for use in a future project to evaluate the online platform, to capture the specific burdens associated with being a parent/carer of a child with OCD
 - Co-design a high-fidelity design prototype of the digital platform
 - Establish a diverse Lived Experience Advisory Panel (LEAP) of parents to refine our PGfAR
 - Strengthen our multidisciplinary project team and refine the design of our future PGfAR



More information

Animation: <https://youtu.be/1S4WbShVQAk>

Podcast: <https://camhs.digital/category/podcasts/>

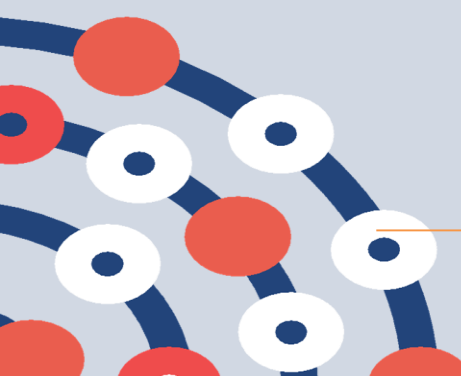
Publication: Sowden, E., Robinson, D., Lovell, K., Bee, P., Fulwood, A., Lidbetter, N., Wilson, Z., Brown, A., & Pedley, R. (in press). Understanding the support needs of parents of children with obsessive-compulsive disorder: a qualitative descriptive study in the UK. *BMC Psychiatry*.



Thank you for listening



Thank you to our research recruitment sites & all the participants
who made CO-ASSIST possible



SUPPORT FOR PARENTS & CARERS



CHILDREN WITH OCD