Increasing Access to Psychological Treatments for Preadolescent Children with Obsessive Compulsive Disorder (OCD).

Submitted thesis for: Doctor of Philosophy

School of Psychology and Clinical Language Sciences

University of Reading

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September 2022

Declaration

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged.

Chloe Chessell

September 2022

Contributions to papers

The work described in this thesis aims to increase access to psychological treatments for children with Obsessive Compulsive Disorder (OCD) and consists of a systematic review identifying the maintenance mechanisms relevant to preadolescent children with OCD, a qualitative study examining parents' experiences of parenting a preadolescent child with OCD, and a preliminary evaluation of an adapted therapist guided, parent-led Cognitive Behavioural Therapy (CBT) treatment for preadolescent children with OCD. The overall framework for this thesis was developed by Dr Brynjar Halldorsson (BH) and Professor Cathy Creswell (CCr) who secured funding for the PhD.

I (CCh) was the lead researcher for all chapters included in this thesis. With the support of the supervisory team (BH, CCr, and Professor Kate Harvey – KH), I led the planning for each of the studies included in this thesis, obtained relevant NHS and University ethical approvals, collected and analysed study data, and drafted the study manuscripts. Individual contributions to each chapter are outlined below.

Chapter 1: General introduction

The general introduction aims to provide an overview of the relevant literature and outline the structure of this thesis. The introduction was written by CCh and refined following feedback from BH, CCr, and KH.

Chapter 2 (Paper 1): Systematic review

The overall aim of the systematic review (i.e., to identify the cognitive, behavioural, and familial maintenance mechanisms relevant to childhood OCD) was developed by BH and CCr as part of the initial funding application, and they provided regular supervision throughout the duration of this study.

I developed the research questions for this review and identified the relevant cognitive, behavioural, and familial maintenance mechanisms to examine. I identified relevant search terms and conducted electronic and hand searches. I developed and piloted the study inclusion and exclusion criteria and screened all abstracts and full texts. BH screened a subset of abstracts and additionally screened all full texts. Any discrepancies between myself and BH regarding the inclusion of full texts were discussed with CCr. I led the data extraction and quality assessments which were second coded by Carolina Guzman-Holst (CGH). Any discrepancies in quality ratings between myself and CGH were discussed with BH and CCr. I wrote the initial manuscript draft, and refined this following feedback from BH, KH, and CCr.

My estimated percentage contribution to the systematic review is 85%.

Chapter 3 (Paper 2): Qualitative study

The overall aim of this study (i.e., to explore parents' experiences of parenting a preadolescent child with OCD) was developed by BH and CC as part of the initial funding application, and they provided regular supervision throughout the planning and conduct of the study.

I refined the research questions for this study and identified an appropriate method of qualitative analysis to use. I led the planning of the study, including creating the necessary NHS and University ethics documents (i.e., study protocols, participant information sheets, consent forms, topic guide etc.) with regular feedback from BH, KH, CCr and Dr Alice Farrington (AF). I led the recruitment for the study and conducted all qualitative interviews, with regular feedback from BH, KH, and CCr. I transcribed each interview and led the qualitative analysis of the interviews, with regular meetings with BH, KH, AF, and CCr. I drafted and refined the study manuscript with feedback from BH, KH, AF, and CCR.

My estimated percentage contribution to the qualitative study is 85%.

Chapter 4: Development of the intervention

The aim to adapt an existing therapist guided, parent-led CBT intervention to ensure suitability for preadolescent children with OCD was developed by BH and CCr as part of the initial funding application. The original treatment “Overcoming your child’s fears and worries” consisted of a parent book (Creswell & Willetts, 2007) and therapist manual (Willetts et al., 2016) and has since been revised to include an updated book “Helping your child with fears and worries” (Creswell & Willetts, 2019) and therapist manual (Halldorsson et al., 2019), as well as an online version of the treatment known as “Online Support and Intervention” (OSI, Hill et al., 2022).

I led the adaptation of the existing treatment to ensure suitability for children with OCD. I used the online written materials from OSI, the therapist manual (Halldorsson et al., 2019), and parent book (Creswell & Willetts, 2019) to develop brief reading materials for parents, treatment session handouts, and a therapist manual. Where appropriate, the original text from OSI was retained, as this was copy edited by health journalists to ensure a low reading age. Furthermore, with the permission of CCr, where appropriate, original text from the therapist manual was retained. Throughout the adaptation of the treatment, I received regular supervision and feedback from BH and CCr, AF and Dr Sasha Walters (SW) also provided feedback on the adapted treatment and accompanying therapist manual.

In addition to the results of the qualitative study (Paper 2) being used to inform the adapted treatment, further qualitative research exploring parents’ views about parent involvement in CBT for their child also informed the adapted treatment and is reported in Chapter 4. This qualitative research was conducted at the same time as the main qualitative study (Paper 2) and thus, the contributions of each author are the same as above. In addition to this, I conducted Patient and Public Involvement (PPI) work with parents and representatives from national OCD charities to further inform the adapted treatment. I wrote the chapter outlining the development of the adapted intervention and revised this following feedback from BH and CCr.

My estimated percentage contribution to the adapted treatment is 85%.

Chapter 5 (Paper 3): Preliminary evaluation of the adapted treatment

The overall aim of this study (i.e., to conduct a multiple baseline case series to evaluate the initial efficacy of the treatment, and to examine the acceptability of the treatment) was developed by BH and CCr, and they provided regular supervision throughout the study.

I led the planning of the study, including deciding upon the baseline lengths within the multiple baseline design, identifying which measures to use and when to administer these, and developing the data analytic strategy. I developed the necessary documents (e.g., study protocols, study information sheets, consent forms etc.) for NHS and University ethical approvals and completed the required amendments, with regular feedback from BH, AF, and CCr. I was responsible for recruiting participants to the study, with support from AF in the identification of potential participants from Berkshire Healthcare NHS Foundation (BHFT). I conducted all diagnostic assessments, which were supervised by CCr and SW. I conducted all treatment sessions, which were supervised by BH and CCr. CCr provided risk cover for all assessment and treatment sessions. I led the quantitative and qualitative analysis for the study, with regular supervision from BH, KH, and CCr. I wrote the study manuscript and refined this following feedback from BH, KH, AF, SW, and CCr.

My estimated percentage contribution to this study is 85%.

Chapter 6: Further information regarding the acceptability of the intervention

The overall aim of this section (i.e., to examine parents' acceptability of the treatment) was developed by BH and CCr.

I led the planning of this section, including developing a brief questionnaire and topic guide to assess parents' acceptability, with feedback from BH, KH, and CCr. I conducted relevant PPI work to increase the acceptability of the questions. Hannah Nicolson (HN), a University of Reading undergraduate student who was undertaking a placement with BHFT, conducted the qualitative interviews. I transcribed the interviews and analysed the data, with input from BH, KH, and CCr. I wrote this section and refined this following feedback from BH, KH, and CCr.

My estimated percentage contribution to this section is 85%.

Chapter 7: General discussion

The general discussion aimed to reflect on the overall strengths and limitations of this research and its contribution to the wider field. The discussion was written by CCh and refined following feedback from BH, CCr, and KH.

Candidate's name and signature	Supervisor's name and signature
Chloe Chessell	Kate Harvey
September 2022	September 2022

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Firstly, I would like to thank the families who shared their experiences of parenting a preadolescent child with OCD. This provided an invaluable insight into the needs and wants of parents and directly shaped the intervention that was developed as part of this thesis. I would also like to thank the families who participated in therapist guided, parent-led Cognitive Behavioural Therapy (CBT) for OCD for the time and effort that they dedicated to the programme.

I would also like to thank my colleagues at the Anxiety and Depression in Young People (AnDY) Clinic for providing me with the opportunity to train in, and deliver, therapist guided, parent-led CBT for children with anxiety disorders. Colleagues at Berkshire Healthcare NHS Foundation Trust also provided me with a platform to develop my clinical skills through observing OCD assessment and treatment sessions and assisting with psychoeducational workshops for parents of young people with OCD.

Most importantly, I would like to thank my supervisory team, Professor Cathy Creswell, Dr Brynjar Halldorsson, Professor Kate Harvey, Dr Alice Farrington, and Dr Sasha Walters, without whom this work would have not been possible. I feel incredibly lucky to have benefited from their extensive clinical and research expertise and commitment to helping to increase access to services for children with mental health difficulties.

Abstract

Obsessive Compulsive Disorder (OCD) is a mental health disorder that often begins during preadolescence and can continue into adulthood in the absence of effective treatment. Cognitive Behavioural Therapy (CBT) including Exposure and Response Prevention (ERP) is an effective psychological treatment for preadolescent children with OCD, however, services often have considerable waitlists for treatment and there is a pressing need to increase access to treatments for this population.

This thesis aimed to increase access to CBT for preadolescent children with OCD by adapting an existing brief low-intensity therapist guided, parent-led CBT intervention for children with anxiety disorders so that it was suitable for preadolescent children with OCD. Specifically, this thesis consisted of (1) a systematic review to identify the cognitive, behavioural, and familial maintenance mechanisms relevant to childhood OCD that need to be targeted in a brief low-intensity intervention, (2) qualitative research to explore parents' experiences of parenting a preadolescent child with OCD and their views about parent involvement in CBT to ensure the adapted treatment reflected their experiences and needs, and (3) a non-concurrent multiple baseline case series to examine the preliminary efficacy and acceptability of the adapted intervention.

Preliminary findings indicate that brief low-intensity therapist guided, parent-led CBT may be an effective, efficient, and acceptable intervention for this population that could help to substantially increase access to evidence-based treatments for preadolescent children with OCD. Further evaluation (i.e., a feasibility study) of this intervention in a low-intensity setting is now warranted, prior to a definitive randomised controlled trial of this intervention, if indicated.

Table of Contents

Declaration I

Contribution to papers II

Funding VIII

Acknowledgements IX

Abstract X

Chapter 1: General Introduction 1

1.1 Thesis aims and structure 7

1.2 Chapter 2 (Paper 1): Cognitive, behavioural, and familial maintenance mechanisms in childhood obsessive compulsive disorders: A systematic review 10

1.3 Chapter 3 (Paper 2): Parents' experiences of parenting a preadolescent child with OCD: A qualitative study 13

1.4 Chapter 4: The development of a brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD. 14

1.5 Chapter 5 (Paper 3): Therapist guided, parent-led CBT for preadolescent children with OCD: a non-concurrent multiple baseline case series 14

1.6 Chapter 6: In-depth exploration of parents' experiences and acceptability of the treatment 15

1.7 Chapter 7: Overall discussion 15

1.8 References 16

Chapter 2: Paper 1 Cognitive, behavioural, and familial maintenance mechanisms in childhood obsessive compulsive disorders: A systematic review 28

2.1 Introduction to Chapter 2 (Paper 1) 29

2.2 Paper 1 30

2.3 Further information on methodological decision making 60

2.4 References 63

Chapter 3: Paper 2 Parents' experiences of parenting a preadolescent child with OCD: A qualitative study 67

3.1 Introduction to Chapter 3 (Paper 2) 68

3.2 Paper 2 69

3.3 Further information on methodological decision making 106

3.4 References 108

Chapter 4: Development of therapist guided, parent-led Cognitive Behavioural Therapy (CBT) for preadolescent children with OCD 111

4.1 Introduction to Chapter 4 112

4.2 Overview 113

4.3 Implications from the systematic review 116

4.4 Implications from the qualitative research 117

4.5 Further implications from the qualitative research 121

4.6 Implications from collaborative work with Berkshire Healthcare NHS Foundation Trust (BHFT) 136

4.7 Development of the intervention 136

4.8 References 145

Chapter 5: Paper 3 Therapist guided, parent-led Cognitive Behavioural Therapy (CBT) for preadolescent children with OCD: A non-concurrent multiple baseline case series 151

5.1 Introduction to Chapter 5 (Paper 3) 152

5.2 References 153

5.3 Paper 3 154

5.4 Further information on methodological decision making 248

5.5 References 251

Chapter 6: In-depth exploration of parents' experiences and acceptability of therapist guided, parent-led CBT for preadolescent children with OCD 254

6.1 Introduction to Chapter 6 255

6.2 Overview 256
6.3 Method 257
6.4 Results 264
6.5 Discussion 286
6.6 Conclusion 291
6.7 References 292
6.8 Appendices 296
Chapter 7: General Discussion 298
7.1 Overview of findings 298
7.2 Synthesis of findings and implications for future research 304
7.3 Strengths and limitations of this thesis 315
7.4 Conclusions 319
7.5 References 321
Chapter 8: Appendices 331
8.1 Ethical approval letters 332
8.2 Information sheets 357
8.3 Consent/assent forms 400
8.4 Study materials 410

Chapter 1: General Introduction

Obsessive Compulsive Disorder (OCD) is a heterogenous disorder characterised by obsessions (unwanted intrusive cognitions that cause considerable distress or anxiety) and/or compulsions (repetitive physical or mental behaviours that are performed to prevent a feared outcome and to reduce associated distress or anxiety, American Psychiatric Association, 2013). OCD can first emerge during preadolescent years[1], with studies reporting a mean age of OCD onset of around 10.5 years of age (ranging from approximately 7.5 years of age to 12.5 years of age) in paediatric populations (Geller, Biederman, Jones, Park et al., 1998; Geller, Biederman, Jones, Shapiro et al., 1998; Stewart et al., 2004). Prevalence estimates of OCD in preadolescent children (aged ≤12 years) specifically are scarce (Waite & Williams, 2009) and although prevalence estimates have been shown to increase considerably during adolescent years (Heyman et al., 2001), studies that have included preadolescent children in their sample have shown prevalence estimates from 0.17% (Costello et al., 1996) to 2.9% (Valleni-Basile et al., 1994). Affected preadolescent children often report multiple obsessions and compulsions (Garcia et al., 2009; Geller et al., 2001), with contamination and aggressive obsessions (Garcia et al., 2009; Geller et al., 2001; Mancebo et al., 2008), checking compulsions (Garcia et al., 2009; Geller et al., 2001; Mancebo et al., 2008), and compulsions involving other people (Garcia et al., 2009; Mancebo et al., 2008) among the most frequently reported.

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[1] The age ranges used to define preadolescence vary across the literature, however, in line with relevant research in this field (e.g., Thirlwall et al., 2013; Mancebo et al., 2008; Mathieu et al., 2020; Verhaak & de Haan, 2007), preadolescence was defined as ≤12 years of age for the purpose of this thesis.

Preadolescent children with OCD are often significantly impaired, with up to 90% of affected children and adolescents (aged 5- to 17-year-olds) identifying impaired school, home, or social functioning, and almost 50% reporting impairments across all three domains (effects which were largely consistent regardless of age; Piacentini et al., 2003). Similarly, Stewart et al. (2017) found impaired family functioning and negative emotional impacts on affected children and adolescents (aged 7- to 19-year-olds) – effects that were particularly heightened during the young person's "worst-ever" period of OCD. Furthermore, OCD often follows a chronic course, with individual studies and meta-analytic research examining long-term follow-ups of children and adolescents with OCD showing persistence rates of 41% (Micali et al., 2010; Stewart et al., 2004). Importantly, experiencing OCD at an earlier age (Stewart et al., 2004) and for a longer period of time (Micali et al., 2010; Stewart et al., 2004) predicts greater persistence of the disorder – highlighting the critical need to provide early access to evidence-based treatments for *preadolescent* children with OCD specifically.

Cognitive Behavioural Therapy (CBT) including Exposure and Response Prevention (ERP) is the psychological treatment of choice for preadolescent children with OCD (National Institute of Health and Care Excellence, 2005) and involves children being gradually exposed to their obsessions (e.g., for a child with a fear of contamination, this may include touching feared objects such as money, door handles, other children's belongings etc.) whilst refraining from performing their compulsions (e.g., repetitive handwashing, Wu et al., 2020). CBT including ERP has a considerable evidence-base for preadolescent children with OCD, with several meta-analyses demonstrating its efficacy and effectiveness (Ivarsson et al., 2015; McGuire et al., 2015; Öst et al., 2016; Reid et al., 2021; Rosa-Alcázar et al., 2015; Wu et al., 2016). Moreover, the longer-term benefits of CBT including ERP have also been shown, with Barrett et al. (2005) demonstrating that over 70% of children and adolescents (aged 8- to 19-years-old) who received CBT were diagnosis free at 12- and 18-

month follow-ups, and Melin et al. (2018) showing that over 85% of children and adolescents (aged 5- to 17-years-old) who received CBT (in some cases, augmented with medication) were treatment responders or remitters at a 3-year follow-up.

Despite the evidence-base for CBT for preadolescent children with OCD, there is a pressing need to increase the availability of CBT for affected children and their families. Drawing on the wider literature, research has shown that less than 3% of children with a diagnosable anxiety disorder receive CBT (Reardon et al., 2020) and families can wait over 66-weeks to receive their first Child and Adolescent Mental Health Service (CAMHS) appointment in the UK (Woodhouse, 2006). Therapist expertise and training in CBT is also limited (Stallard et al., 2007), with 46.4% of CAMHS professionals surveyed (n=427) having no CBT training (Baker & Waite, 2020) and 25% of mental health professionals surveyed (n=107) reporting insufficient training as a barrier to using CBT including ERP in the treatment of OCD in children and adolescents (Keleher et al., 2020).

“Stepped care” has been suggested as one way to increase access to limited psychological resources for children with OCD specifically (Lewin et al., 2014). This involves offering effective “low-intensity” interventions (typically “brief” interventions that require minimal therapist input and time) as first-line interventions so that “high-intensity” interventions (which require greater therapist input and time) can be reserved for those who do not respond to low-intensity support (Bower & Gilbody, 2005). To date, the literature has used inconsistent definitions of “brief” and “low-intensity” CBT interventions. Thus, Shafran et al. (2021) propose that the term “brief CBT” can refer to both “low-intensity” and “brief high intensity” CBT interventions, however, also outline clear distinctions between these two types of intervention. “Low-intensity” interventions are characterised by the use of self-help resources and less than 6 hours of support from a trained supporter (with each support session typically lasting less than 30 minutes; Shafran et al., 2021). In contrast, “brief high intensity”

CBT interventions involve the delivery of traditional CBT by a core mental health professional in around half the traditional therapeutic time (Shafran et al., 2021). To date, limited brief CBT interventions (including both low-intensity and brief high intensity CBT interventions) for preadolescent children with OCD exist, however, among the few studies that have examined this, promising outcomes have been shown. For example, Bolton et al. (2011) demonstrated that a 5-session manualised CBT treatment (with an additional workbook) for children and adolescents (aged 10- to 18-years-old) with OCD resulted in significant improvements in young people's obsessive-compulsive symptoms (OCS) that did not significantly differ from a 12-session version of the treatment. Similarly, Aspvall et al. (2018) found that an online CBT intervention for children (aged 7- to 11-years-old) with OCD and their parents resulted in significant improvements in children's OCS with an average of 4.5 hours of therapist support. Furthermore, when this treatment was delivered as the first "step" of a "stepped care" approach for children and adolescents (aged 7- to 17-years-old) with OCD, 54% of young people did not require any further psychological support (Aspvall et al., 2021). Taken together, these studies suggest that brief CBT interventions for preadolescent children with OCD may be an effective way to help increase access to CBT. However, these treatments have been delivered by highly specialised therapists, limiting our understanding of whether non-specialist therapists can effectively deliver brief CBT interventions.

In the UK, the Children and Young People's (CYP) Improving Access to Psychological Treatments (IAPT) initiative aims to develop a workforce of low-intensity clinicians, known as Children's Wellbeing Practitioners (CWPs) and Educational Mental Health Practitioners (EMHPs), to deliver brief low-intensity evidence-based treatments for children and adolescents with anxiety, depression, or behavioural difficulties in school settings (i.e., via Mental Health Support Teams), Child and Adolescent Mental Health

Services (CAMHS), local authorities, and voluntary organisations (Ludlow et al., 2020). For preadolescent children specifically, CWPs and EMHPs are trained to deliver brief, low-intensity therapist guided, parent-led CBT approaches (Ludlow et al., 2020). These approaches involve a therapist working with a parent to teach them tools and techniques that they can use at home with their child, to help their child to overcome their difficulties (Thirlwall et al., 2013), and are currently delivered to parents of preadolescent children with anxiety disorders and behavioural difficulties (Ludlow et al., 2020). To date, CWPs and EMHPs do not deliver therapist guided, parent-led CBT treatments to parents of preadolescent children with OCD.

Brief low-intensity therapist guided, parent-led CBT may be an appropriate first-line treatment for preadolescent children with OCD to help increase access to treatments for affected children and their families. Drawing on the wider anxiety literature, therapist guided parent-led CBT approaches have been shown to be effective for preadolescent children with anxiety disorders compared to waitlist control conditions (e.g., Cartwright-Hatton et al., 2011; Cobham, 2012; Lyneham & Rapee, 2006; Rapee et al., 2005; Thirlwall et al., 2013; Waters et al., 2009) and have shown comparable outcomes with active control conditions (e.g., Creswell et al., 2017; Waters et al., 2009) even when these control conditions have required double the amount of therapist input (Waters et al., 2009). In fact, some studies have demonstrated superior treatment outcomes for preadolescent children with anxiety difficulties following parent-led CBT compared to longer parent and child CBT treatments (e.g., Cobham, 2012; Leong et al., 2009) – however, this is not the case across all studies, with Chavira et al. (2014), Mendlowitz et al. (1999), and Monga et al. (2015) finding poorer treatment outcomes following parent-led CBT compared to combined parent and child CBT treatments. Importantly, brief low-intensity therapist guided parent-led CBT approaches have been shown to be cost-effective (Creswell et al., 2017) and deliverable by non-specialist therapists (Thirlwall et al., 2013), with treatment gains maintained at a 3- to 5-year follow-up (Brown et al., 2017). Furthermore, brief low-intensity parent-led approaches have been shown to be acceptable to participating parents (Allard et al., 2022). To date, no brief low-intensity therapist guided, parent-led CBT treatment for preadolescent children with OCD that has been designed to be delivered by non-specialist therapists exists. However, Rosa-Alcázar et al. (2017, 2019) have evaluated a more resource intensive parent-led CBT intervention (consisting of 12 hours of specialist therapist support) for young children with OCD (aged 5- to 7-years-old) which has been shown to result in significant improvements in children's OCS at post-treatment and at a 3-month follow-up. Specifically, Rosa-Alcázar et al. (2017) found that 60% of children met criteria for remission (defined as a score of ≤12 on the Children's Yale-Brown Obsessive Compulsive Scale, CY-BOCS) at post-treatment and 100% at follow-up, and Rosa-Alcázar et al. (2019) found that 20% of children met criteria for remission (defined as a score of <11 on the CY-BOCS) at post-treatment and 53% at follow-up following therapist guided, parent-led CBT.

Taken together, the literature discussed suggests that a brief low-intensity therapist guided, parent-led CBT intervention has potential to be an effective and efficient first-line treatment to help increase access to CBT for preadolescent children with OCD. Bower and Gilbody (2005) state that first-line interventions need to be effective, efficient, and acceptable to families who receive them. Thus, to develop a brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD that meets these requirements, it is essential to (i) identify the cognitive, behavioural, and familial mechanisms that maintain OCD in preadolescent children, so that these mechanisms can be specifically targeted in a brief low-intensity CBT intervention, (ii) understand the experiences of parents of preadolescent children with OCD and their views on parent involvement in CBT to enable the development of an acceptable intervention, and (iii) assess the outcomes for preadolescent children with OCD who receive therapist-guided, parent-led CBT.

1.1 Thesis aims and structure

The overall aim of this PhD is to increase access to psychological treatments for preadolescent children with OCD by adapting[2] an existing low-intensity therapist guided, parent-led CBT treatment that is routinely delivered as a first-line treatment for children with anxiety disorders in the UK (Thirlwall et al., 2013) to ensure suitability for children with OCD. To achieve this, this PhD aims to (i) conduct a systematic review to identify the cognitive, behavioural, and familial mechanisms that maintain OCD in preadolescent children and therefore need to be targeted in a brief low-intensity CBT intervention, (ii) conduct qualitative interviews to explore parents' experiences of parenting a preadolescent child with OCD and their views towards parent involvement in CBT for their child, to ensure the adapted treatment is sensitive to parents' experiences and needs, and (iii) conduct a preliminary evaluation of the efficacy and acceptability of the adapted therapist guided, parent-led CBT intervention.

This thesis consists of five core sections, including (i) a systematic review of relevant psychological and familial maintenance mechanisms in childhood OCS/OCD, (ii) a

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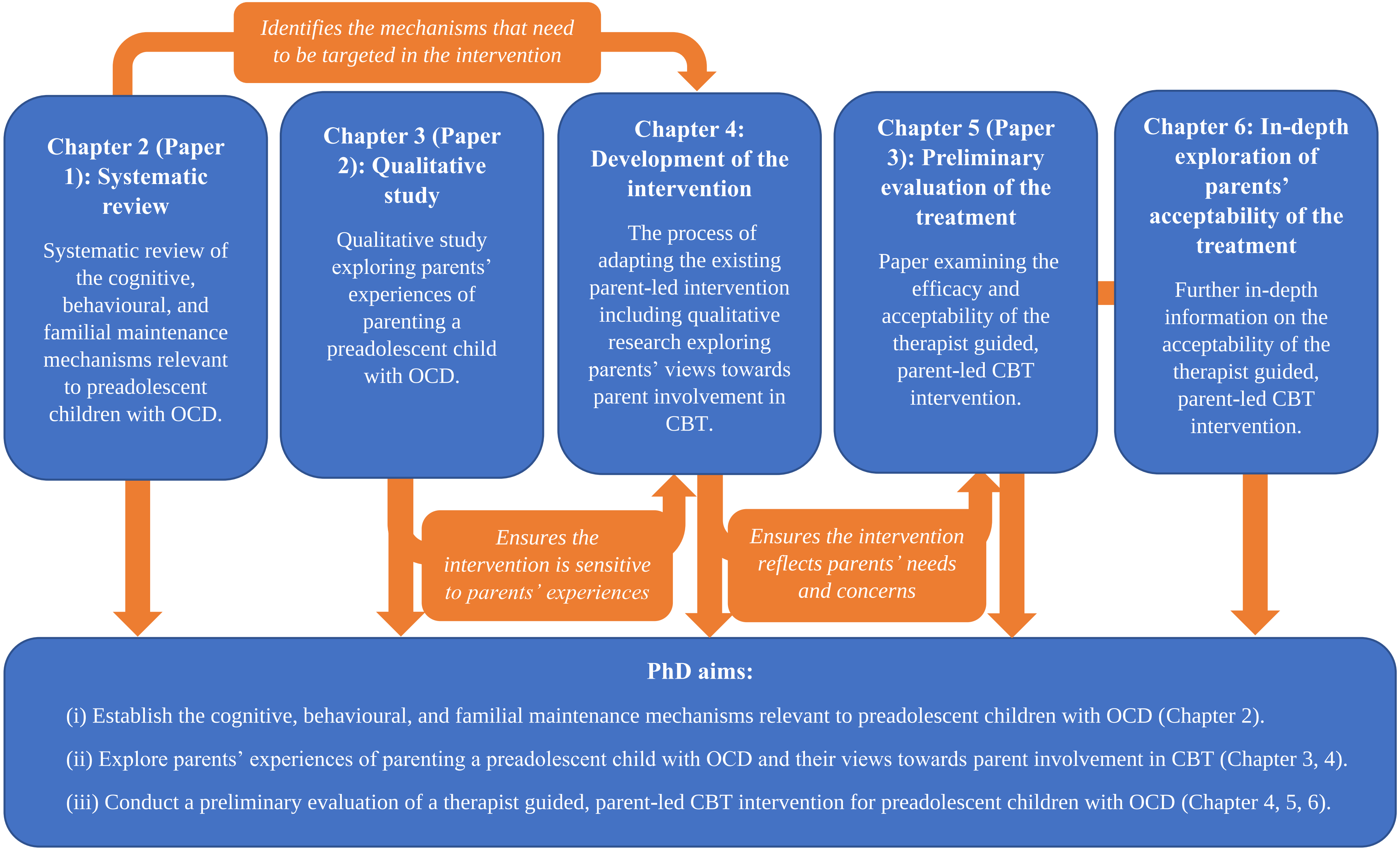
[2] The decision to "adapt" this existing intervention (i.e., to change aspects of the intervention to ensure that it was suitable for parents of preadolescent children with OCD; Bennett & Shafran, 2023) rather than to "modify" the existing intervention (i.e., to retain the original treatment and make small changes to the language and examples used in the treatment; Bennett & Shafran, 2023) was made to help maximise the potential efficacy and acceptability of the intervention for this population.

qualitative study examining parents' experiences of parenting a preadolescent child with OCD, (iii) a chapter outlining the development of the therapist guided, parent-led CBT intervention for preadolescent children with OCD, including further qualitative research exploring parents' views towards parent involvement in CBT treatment for their child, (iv) a preliminary evaluation of the efficacy and acceptability of the adapted therapist guided, parent-led CBT intervention, and (v) a chapter providing a further, in-depth exploration of parents' acceptability of the intervention. Figure 1 provides an outline of this thesis and highlights how each chapter contributes to the aims of this PhD. Further information on the aims of each chapter is outlined below.

Figure 1. Outline of thesis.



Identifies the mechanisms that need to be targeted in the intervention

Chapter 2 (Paper 1): Systematic review

Systematic review of the cognitive, behavioural, and familial maintenance mechanisms relevant to preadolescent children with OCD.

Chapter 3 (Paper 2): Qualitative study

Qualitative study exploring parents' experiences of parenting a preadolescent child with OCD.

Chapter 4: Development of the intervention

The process of adapting the existing parent-led intervention including qualitative research exploring parents' views towards parent involvement in CBT.

Chapter 5 (Paper 3): Preliminary evaluation of the treatment

Paper examining the efficacy and acceptability of the therapist guided, parent-led CBT intervention.

Chapter 6: In-depth exploration of parents' acceptability of the treatment

Further in-depth information on the acceptability of the therapist guided, parent-led CBT intervention.

Ensures the intervention is sensitive to parents' experiences

Ensures the intervention reflects parents' needs and concerns

PhD aims:

(i) Establish the cognitive, behavioural, and familial maintenance mechanisms relevant to preadolescent children with OCD (Chapter 2).

(ii) Explore parents' experiences of parenting a preadolescent child with OCD and their views towards parent involvement in CBT (Chapter 3, 4).

(iii) Conduct a preliminary evaluation of a therapist guided, parent-led CBT intervention for preadolescent children with OCD (Chapter 4, 5, 6).

1.2 Chapter 2 (Paper 1): Cognitive, behavioural, and familial maintenance mechanisms in childhood obsessive compulsive disorders: A systematic review.

To develop an effective and efficient brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD, it is crucial to understand the cognitive, behavioural, and familial mechanisms that maintain OCD in preadolescent children to ensure that these are appropriately targeted by the intervention.

Adult cognitive behavioural maintenance models of OCD exist and are based on the premise that how an individual interprets a normal intrusive cognition is key to the maintenance of the disorder (Reynolds & Reeves, 2008). For example, Salkovskis (1985, 1999) stated that "inflated responsibility", the idea that an individual interprets a normal intrusive cognition as a sign that they are responsible for causing and/or preventing harm to themselves and/or other people, is central to the maintenance of OCD. Similarly, Rachman (1993) identified the relevance of "thought action fusion" (TAF) to the maintenance of OCD. Here, individuals with OCD may hold beliefs that having a negative intrusive cognition increases the likelihood of a negative event occurring (known as "likelihood" TAF) and/or is morally the same as completing the action (known as "morality" TAF, Shafran & Rachman, 2004). Meta-cognitive models of OCD (e.g., Wells & Matthews, 1994) have also been proposed and emphasise beliefs about the meaning of normal intrusive cognitions and the need to complete compulsions as central in the maintenance of the disorder. To bring together the existing models, the Obsessive Compulsive Cognitions Working Group (OCCWG, 1997) identified six key belief domains hypothesised to be relevant to the maintenance of OCD in adults, including beliefs regarding (i) inflated responsibility, (ii) over importance of thoughts, (iii) overestimation of threat, (iv) the importance of controlling thoughts, (v) intolerance of uncertainty, and (vi) perfectionistic beliefs.

Although adult cognitive behavioural models of OCD exist, our understanding of whether these models apply to preadolescent children with OCD specifically is limited. One systematic review examined the applicability of inflated responsibility, TAF, and meta-cognitive beliefs to children and adolescents with OCD and concluded that these models were applicable to this age range (Reynolds & Reeves, 2008). However, this review largely failed to consider the strength of the research evidence (e.g., cross-sectional designs, non-clinical samples) when drawing their conclusions. Mantz and Abbott (2017) have since conducted a narrative review of the applicability of the six key belief domains identified by the OCCWG (1997) to children and adolescents and found inconclusive evidence regarding their applicability to this population. However, both reviews have considered children and adolescents as one group, limiting our understanding of the applicability of these models to preadolescent children with OCD specifically.

It is crucial to understand the applicability of these models to preadolescent children specifically, given that there are key cognitive and social differences between preadolescents and adolescents (Yurgelun-Todd, 2007) that may influence the maintenance of the disorder. For example, Farrell and Barrett (2006) suggest that the cognitive processes identified in adult models of OCD may be less influential during preadolescence, given that preadolescent children with OCD endorse significantly fewer inflated responsibility and probability of harm beliefs than adolescents with OCD. Furthermore, there are differences in the clinical presentation of OCD among affected children and adolescents. For example, preadolescent children (aged ≤12 years) with OCD report significantly fewer sexual (Geller et al., 2001), religious (Geller et al., 2001), and aggressive obsessions (Mancebo et al., 2008) than adolescents with OCD, and report significantly fewer mental compulsions (Mancebo et al., 2008). Finally, families have considerably more influence over preadolescent children than adolescents (Freeman et al., 2003), highlighting the importance of considering family factors in the maintenance of the disorder among preadolescent children specifically.

To date, there are no maintenance models that consider how the family may contribute to maintenance of OCD in preadolescent children. However, some family factors, including family members' cognitions and behaviours, have been suggested to contribute to the maintenance of the disorder in children. For example, how parents interpret and respond to anxious stimuli is thought to be relevant to the maintenance of OCD in children (Freeman et al., 2003), as parental reactions may reinforce children's negative interpretations of anxious stimuli and/or promote avoidance of feared situations (Barrett et al., 1996; Creswell et al., 2010). Furthermore, family accommodation (i.e., participating or assisting in compulsions and/or modifying family routines to avoid children's distress) has been proposed to have a strong role in the maintenance of the disorder in children, as these attempts to relieve children's symptoms can inadvertently reinforce children's symptoms and compulsions (Waters & Barrett, 2000).

Thus, to develop an effective and efficient therapist guided, parent-led intervention for preadolescent children with OCD, further examination of the relevant cognitive, behavioural, and familial mechanisms that may contribute to the maintenance of OCD in preadolescent children is required. In Chapter 2 (Paper 1), I therefore systematically reviewed quantitative studies examining the association between the proposed maintenance mechanisms (identified from adult maintenance models of OCD and the broader literature considering the role of the family in the maintenance of OCD and anxiety disorders) and children's obsessive compulsive symptoms (OCS)/OCD. Studies using correlational, experimental, or between-group designs were included, as well as treatment studies examining changes in proposed maintenance mechanisms and children's OCS/OCD across treatment.

1.3 Chapter 3 (Paper 2): Parents' experiences of parenting a preadolescent child with OCD: A qualitative study.

To develop a brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD that is acceptable to parents, an understanding of parents' experiences of parenting their child is essential. To date, limited research has examined parents' experiences of parenting a preadolescent child with OCD specifically, and existing research has predominantly relied on questionnaire measures. For example, Storch et al. (2009) administered questionnaires to parents of children, adolescents, and adults (aged 6- to 20-years-old) with OCD and found that parents experienced high levels of distress and uncertainty surrounding their child's OCD. Furthermore, Wu et al. (2018) found significant, positive correlations between children and adolescent's (aged 7- to 17-years-old) OCD severity and parent-reported caregiver burden and reduced quality of life. Futh et al. (2012) extended previous research and used qualitative methods to explore how parents understand and manage their child/adolescents' (aged 9- to 18-years-old) OCD. Analyses identified that parents find it hard to understand their child's OCD, experience OCD as having a "powerful" influence on their child and family, and experience "tension" when deciding whether or not to accommodate their child's OCD. Although Futh et al. (2012) provide a valuable insight into the experiences of parents of children and adolescents with OCD, given that preadolescent children are more dependent on the family (Freeman et al., 2003), parents of preadolescent children with OCD may have distinct experiences and challenges that need to be considered when developing a therapist guided, parent-led intervention. In Chapter 3 (Paper 2), I therefore conducted in-depth, semi-structured qualitative interviews which aimed to explore parents' experiences of parenting a preadolescent child with OCD. Twenty-two parents of 16 children with OCD were interviewed and the data were analysed using reflexive thematic analysis (Braun & Clarke, 2022). To capture a diverse range of parental experiences, purposive sampling was used to interview mothers and fathers at different stages of the help-seeking process for their child, including those whose children were waiting to receive treatment, were currently receiving treatment, and who had previously received treatment.

1.4 Chapter 4: The development of a brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD.

In Chapter 4, I aimed to bring together the results of Chapter 2 (Paper 1) and Chapter 3 (Paper 2) to adapt the existing brief low-intensity therapist guided, parent-led CBT intervention (Thirlwall et al., 2013) to ensure suitability for preadolescent children with OCD. This chapter documents the process of adapting the intervention, including the results of further qualitative research which examined parents' views towards parent involvement in CBT for preadolescent children with OCD (using the same sample and methodology as Paper 2). Furthermore, reflections from relevant clinical work conducted with Berkshire Healthcare NHS Foundation Trust (BHFT), the collaborative partner in this PhD, are also drawn on. Finally, this chapter discusses how Patient and Public Involvement (PPI) from parents of children with and without OCD and national OCD charities informed the adapted intervention.

1.5 Chapter 5 (Paper 3): Therapist guided, parent-led CBT for preadolescent children with OCD: a non-concurrent multiple baseline case series.

Following on from the development of the therapist guided, parent-led CBT intervention for preadolescent children with OCD (Chapter 4), in Chapter 5 (Paper 3) I conducted a preliminary evaluation of the efficacy and acceptability of this intervention to examine whether this treatment has the potential to be a first-line intervention for preadolescent children with OCD. As is appropriate for novel interventions, a multiple baseline approach was used to evaluate the treatment (Horner et al., 2005), where 10 families of preadolescent children (aged 5- to 12-years-old) with OCD were randomised to no-treatment baseline periods of 3-, 4-, or 5- weeks before receiving the intervention. Semi-structured diagnostic interviews were conducted at pre-treatment, post-treatment (i.e., within a week of completing treatment), and at a one-month follow-up period, and weekly parent-reported questionnaires were completed during the baseline and intervention periods. Parents' acceptability of the intervention was assessed using a questionnaire and optional semi-structured qualitative interview.

1.6 Chapter 6: In-depth exploration of parents' experiences and acceptability of the treatment.

Bower and Gilbody (2005) state that first-line interventions for mental health difficulties need to be acceptable to users. Thus, in Chapter 6, I provide a further, more detailed exploration of the acceptability of the brief low-intensity therapist guided, parent-led CBT intervention to participating parents. All parents who participated in the treatment were invited to take part in an optional semi-structured qualitative interview which aimed to explore parents' experiences and acceptability of the intervention. Qualitative interviews were chosen as this method can provide a detailed insight into how newly developed interventions are received (Locock & Boaz, 2019). Parents from eight of the 10 families who received the treatment participated in the qualitative interview. The themes generated from reflexive thematic analysis (Braun & Clarke, 2022) are discussed, alongside implications for future iterations of the treatment.

1.7 Chapter 7: Overall discussion

In Chapter 7, I provide an overview of the findings from each chapter and consider the results in relation to the wider literature and Bower and Gilbody's (2005) criteria for first-line interventions. The strengths and limitations of this body of work are discussed and directions for future research to establish whether brief low-intensity therapist guided, parent-led CBT has the potential to increase access to CBT for preadolescent children with OCD are identified.

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Chapter 2: Paper 1

Cognitive, behavioural, and familial maintenance mechanisms in childhood obsessive compulsive disorders: A systematic review.

Published in *Journal of Experimental Psychopathology*.

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2.1 Introduction to Chapter 2 (Paper 1)

In Chapter 1, I identified the necessary background research required to develop an effective, efficient, and acceptable brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD, including (1) the identification of relevant cognitive, behavioural, and familial maintenance mechanisms in childhood OCD that need to be targeted in a brief low-intensity intervention, and (2) an understanding of parents' experiences of parenting a preadolescent child with OCD to ensure the development of an intervention that reflects parents' experiences and needs.

In Chapter 2 (Paper 1), I therefore aimed to address the first stage in developing this intervention and used a systematic approach to review literature examining the role of cognitive, behavioural, and familial mechanisms in the maintenance of obsessive compulsive symptoms (OCS)/OCD in preadolescent children.

Review Paper

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Cognitive, behavioural and familial maintenance mechanisms in childhood obsessive compulsive disorders: A systematic review

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Abstract

Cognitive Behavioural Therapy (CBT) for preadolescent children with obsessive compulsive disorder (OCD) is typically derived from adult cognitive behavioural models of OCD; however, it is unknown whether these adult models apply to preadolescent children. This systematic review examined whether 11 cognitive, behavioural and familial maintenance mechanisms identified from adult cognitive behavioural models of OCD and descriptions of how family factors may maintain OCD applied to preadolescent children with obsessive compulsive symptoms/disorder (OCS/OCD; Prospero: CRD42019153371). PsycINFO, MEDLINE and Web of Science Core Collection were searched in March 2019, with forward citation handsearching conducted in March/April 2020. Twenty-nine studies were synthesised. Studies were identified for only six of the 11 proposed maintenance factors. Of the cognitive and behavioural factors, only inflated responsibility and meta-cognitive beliefs showed evidence of independent and/or specific associations with childhood OCS. Of the family factors, only less frequent displays of parental confidence, positive problem solving and rewarding of children's independence showed some evidence of specificity to childhood OCD. Notably, findings across studies were inconsistent and existing studies have considerable methodological limitations. Experimental and prospective longitudinal studies are needed to determine whether the proposed factors maintain childhood OCS/OCD, to improve the effectiveness and efficiency of CBT for preadolescent children with OCD.

Keywords

Obsessive compulsive disorder, cognitive behavioural models, preadolescence

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Introduction

Obsessive compulsive disorder (OCD) is a highly debilitating mental health disorder characterised by the presence of obsessions (intrusive, unwanted thoughts, images or urges which cause significant distress or anxiety) and/or compulsions (repetitive behaviours or mental acts an individual feels compelled to perform to reduce distress or anxiety, or to prevent a feared outcome; American Psychiatric Association, 2013). OCD often has its onset between the ages of 7.5 and 12.5 years old (Geller et al., 1998) and is estimated to affect between 1% and 4% of the paediatric population (Flament et al., 1988; Heyman et al., 2001). Childhood OCD is also commonly comorbid with other mental health disorders (Heyman et al., 2001; Pediatric OCD Treatment Study (POTS) Team, 2004) and often continues into adulthood if appropriate treatment is not provided (Pinto et al., 2006).

Cognitive Behavioural Therapy (CBT) including Exposure and Response Prevention (ERP) is the recommended psychological treatment for childhood OCD (National Institute of Health and Care Excellence - NICE, 2005), and has been shown to be superior to pharmacological treatment (Ivarsson et al., 2015) and active psychological control conditions (Freeman et al., 2014). Despite this, up to 60% of children and adolescents do not experience clinical remission of obsessive compulsive symptoms (OCS) following CBT (Barrett et al., 2008; Pediatric OCD Treatment Study (POTS) Team, 2004). To date, treatment studies have often failed to distinguish between preadolescent and adolescent populations (e.g. Franklin et al., 2011; Piacentini et al., 2011; Williams et al., 2010) despite key differences among these populations (i.e. cognitive maturation, clinical presentation and family factors) which may influence the maintenance of the disorder. To improve the effectiveness of CBT for preadolescent children with OCD specifically, an understanding of the psychological processes which maintain the disorder in preadolescence is required.

There are a number of reasons to anticipate that the processes that maintain OCD in preadolescents may differ to those that occur in adolescence or adulthood. First, Farrell and Barrett (2006) suggested that the cognitive processes hypothesised to maintain OCD may be particularly important during adolescent and adult years – bringing a lack of clarity about the processes which maintain the disorder in preadolescence. For example, Farrell and Barrett (2006) found that adolescents and adults with OCD reported significantly higher responsibility beliefs, probability of harm beliefs, and engaged in more thought suppression than preadolescent children with OCD. However, ratings of thought-action fusion (TAF), doubt, severity of harm and cognitive control were comparable across preadolescents, adolescents and adults with OCD. Second, the clinical presentation of OCD differs with age. For example, Nakatani et al. (2011) found that children with early onset OCD (defined as <10 years old) reported significantly more repeating and ordering compulsions compared to children with late onset OCD (defined as 10 to 18 years old). Furthermore, Geller et al. (2001) found that preadolescent children (<12 years) with OCD reported significantly fewer aggressive and sexual obsessions than adults with OCD and were less likely to report multiple obsessions and compulsions than adults with OCD. Moreover, preadolescent children with OCD reported significantly fewer religious and sexual obsessions than adolescents (≥12 years) with OCD and had poorer ‘insight’. Similarly, Mancebo et al. (2008) found that preadolescent children (6–12 years) with OCD reported significantly fewer aggressive obsessions than adolescents (13–18 years) and adults with OCD, and significantly fewer mental rituals than adolescents with OCD. However, in this study, no significant age differences were found on reports of sexual or religious obsessions. Third, preadolescent children are immersed in the family in a distinct manner to adolescents and adults (Freeman et al., 2003). Children are heavily reliant on the family and spend considerable time in the family environment (Freeman et al., 2003). Thus, researchers have emphasised the importance of understanding the role of the family in the maintenance of OCD among preadolescent children specifically (Freeman et al., 2003; Smorti, 2012; Waters & Barrett, 2000).

To date, treatment for childhood OCD has typically involved CBT with ERP as the core treatment component – in line with the existing evidence base (NICE, 2005). However, there is evidence to suggest that the psychological processes implicated in cognitive models of adult OCD also apply to children and adolescents (Reynolds & Reeves, 2008), suggesting that cognitive approaches to CBT treatment for young people with OCD may add further value. The most widely cited cognitive behavioural model of adult OCD was proposed by Salkovskis (1985) which proposes that the central difference between individuals with and without OCD is the interpretation assigned to the incidence and/or content of normal intrusive cognitions. Individuals with OCD interpret intrusive cognitions as indicating that they may be responsible for harm and/or the prevention of harm to themselves and/or others (Salkovskis et al., 1996). This interpretation results in a plethora of effects, including (i) mood changes, such as increased distress, anxiety and low mood; (ii) attentional biases, whereby individuals place greater attention on intrusive cognitions and related stimuli; (iii) increased accessibility of intrusive cognitions and (iv) maladaptive cognitive and behavioural

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strategies, such as compulsive checking and/or washing, reassurance seeking, avoidance and thought suppression (Salkovskis, 1999). These effects are proposed to maintain the individual's negative interpretation of the intrusive cognitions, prevent belief disconfirmation and increase the likelihood of future intrusive cognitions (Salkovskis, 1999).

Other cognitive models of adult OCD share the central feature that an individual's interpretation of an intrusive cognition is crucial to the development and maintenance of OCD (Reynolds & Reeves, 2008). For example, Rachman (1993) proposed the construct of TAF, a cognitive process where individuals interpret thoughts and actions as equivalent. TAF consists of two elements; (i) likelihood TAF – the belief that experiencing an unwanted, intrusive cognition increases the probability of an adverse event occurring to oneself and/or others and (ii) morality TAF – the belief that experiencing an unwanted, intrusive cognition is morally equivalent to performing the action (Shafran & Rachman, 2004). A related construct, which has also been proposed to contribute to the maintenance of OCD (Bolton et al., 2002), is 'magical thinking', the belief that one's thoughts or actions can affect causally unrelated events (Zusne & Jones, 1989). Furthermore, Wells and Matthews' (1994) meta-cognitive model of adult OCD emphasises the role of beliefs about thinking in the maintenance of OCD. Specifically, this model highlights the potential maintaining role of (i) beliefs regarding the meaning and consequences of experiencing an intrusive cognition, and (ii) beliefs regarding the need to perform compulsions and the negative effects of not doing so (Fisher & Wells, 2008). To consolidate research examining cognitive models of OCD, the Obsessive Compulsive Cognitions Working Group (1997) identified six belief domains considered to be critical to the development and maintenance of adult OCD. These include (i) inflated responsibility – the belief that one has capability to cause or prevent negative outcomes; (ii) over importance of thoughts – the belief that the appearance of a thought means that the thought is important; (iii) importance of controlling thoughts – the belief that it is possible and desirable to have complete control over one's thoughts; (iv) overestimation of threat – beliefs about the likelihood or severity of negative events; (v) intolerance of uncertainty – beliefs about the need to be certain, and one's inability to cope in uncertain situations and (vi) perfectionism – beliefs about the necessity of perfectionism and the consequences of mistakes (Obsessive Compulsive Cognitions Working Group, 1997).

To date, there has been limited research to examine the applicability of adult cognitive behavioural models of OCD to childhood OCD, and studies have typically examined preadolescents and adolescents together. For example, Reynolds and Reeves (2008) conducted a systematic review examining the relevance of adult cognitive models of OCD to children and adolescents more broadly (aged < 18 years old), with a particular focus on inflated responsibility, TAF and meta-cognitive beliefs. Of 122 studies identified, only 11 met inclusion criteria. Ten studies provided preliminary support for the applicability of adult cognitive models of OCD among children and adolescents; however, many studies used cross-sectional designs and non-clinical samples. Only one study (with young people aged 7–17 years) used an experimental design, and as such was the only study able to examine directionality among a clinical sample, and failed to support the applicability of a causal role of responsibility beliefs on OCD-related constructs (e.g. avoidance and ritualising) in children and adolescents. Mantz and Abbott (2017) have since conducted a (non-systematic) literature review of research examining the Obsessive Compulsive Cognitions Working Group's (1997) six key OCD belief domains which included (combined) child and adolescent populations. The authors highlighted that there is inconclusive evidence regarding the relationship between cognitive appraisals and the maintenance of OCD among children and adolescents. In addition to an absence of consideration of the specific evidence for preadolescent children, reviews to date have failed to examine other maintenance mechanisms identified in adult models of OCD such as attentional biases and maladaptive coping strategies. Furthermore, the role of the family in the maintenance of childhood OCD has been largely overlooked.

Despite the need to understand the role of family factors in the maintenance of OCD among preadolescent children specifically (Freeman et al., 2003), to our knowledge, there is no maintenance model which outlines the role of the family in the maintenance of childhood OCD. However, some family factors have been proposed to be relevant to the maintenance of childhood OCD and anxiety more broadly, including family members' cognitions (Freeman et al., 2003) and behaviours (Smorti, 2012; Waters & Barrett, 2000). Family members' cognitions (e.g. interpretations of anxious stimuli) may be relevant to the maintenance of childhood OCD (Freeman et al., 2003) through direct or indirect effects on family members' behaviours (e.g. by reinforcing threatening interpretations of anxious stimuli or promoting avoidance behaviours; Barrett et al., 1996; Creswell et al., 2010). Moreover, family members' behaviours, in particular, family accommodation (e.g. assistance/participation in rituals and/or modification of routines to minimise child distress; Waters & Barrett, 2000) are thought to maintain childhood OCD through inadvertently reinforcing children's OCS and behaviours through attempts to provide symptom relief to the child (Waters & Barrett, 2000). Thus, the role of the family in the maintenance of OCD among preadolescent children warrants further attention.

Objectives

This systematic review aims to critically examine whether the cognitive and behavioural maintenance mechanisms

Table 1. Hypotheses derived from adult cognitive behavioural models of OCD and descriptions of how family factors may maintain childhood OCD.

Inflated responsibility

There will be a significant positive association between childhood OCS/OCD and beliefs regarding personal responsibility for harm and/or its prevention (Obsessive Compulsive Cognitions Working Group, 1997; Salkovskis, 1985).

Over importance of thoughts

There will be a significant positive association between childhood OCS/OCD and beliefs that the appearance of a thought means that the thought is important, including beliefs regarding thought-action fusion and magical thinking (Obsessive Compulsive Cognitions Working Group, 1997; Rachman, 1993).

Importance of controlling thoughts

There will be a significant positive association between childhood OCS/OCD and beliefs that (i) it is possible and desirable to control thoughts and (ii) failure to control thoughts will have serious consequences (Obsessive Compulsive Cognitions Working Group, 1997).

Overestimation of threat

There will be a significant positive association between childhood OCS/OCD and beliefs about (i) the probability of harm and (ii) the severity of harm (Obsessive Compulsive Cognitions Working Group, 1997).

Intolerance of uncertainty

There will be a significant positive association between childhood OCS/OCD and beliefs about (i) the need for certainty, (ii) an inability to cope with unanticipated change and (iii) an inability to cope with ambiguous situations (Obsessive Compulsive Cognitions Working Group, 1997).

Perfectionism

There will be a significant positive association between childhood OCS/OCD and beliefs that (i) it is possible and necessary to achieve perfection and (ii) the absence of perfection will have serious consequences (Obsessive Compulsive Cognitions Working Group, 1997).

Emotional responses

There will be a significant positive association between childhood OCS/OCD and emotional responses to intrusive unwanted cognitions and related stimuli (in particular, increased distress, anxiety and/or mood changes; Salkovskis, 1985).

Attentional biases

There will be a significant positive association between childhood OCS/OCD and attention to intrusive unwanted cognitions and related stimuli (Salkovskis, 1985).

Neutralising actions

There will be a significant positive association between childhood OCS/OCD and engagement in neutralising behaviours in response to intrusive unwanted cognitions and related stimuli (in particular, compulsions, reassurance seeking and/or mental argument; Salkovskis, 1985).

Counterproductive safety strategies

There will be a significant positive association between childhood OCS/OCD and engagement in counterproductive safety strategies in response to intrusive unwanted cognitions and related stimuli (in particular, thought suppression, impossible criteria and/or avoidance; Salkovskis, 1985).

Family factors

There will be a significant positive association between childhood OCS/OCD and family member's cognitions and/or behaviours (in particular, family member's interpretations of anxious stimuli and/or family accommodation; Barrett et al., 1996; Creswell et al., 2010; Smorti, 2012; Waters & Barrett, 2000).

Note. Due to the conceptual overlap between neutralising actions and counterproductive safety strategies, for clarity, we have classified neutralising actions as restorative behaviours (i.e. behaviours which an individual performs to reduce harm that has been caused, such as washing compulsions) and have classified counterproductive safety strategies as verification behaviours (i.e. behaviours performed when an individual fears they may cause harm in the future, such as checking compulsions, Cougle et al., 2007).

identified in adult models of OCD are applicable to childhood OCS/OCD and to examine the potential role of family factors (specifically, family members' cognitions and/or behaviours) in the maintenance of childhood OCS/OCD. The main hypotheses are outlined in Table 1 and were derived from adult cognitive behavioural models of OCD (e.g. Obsessive Compulsive Cognitions Working Group, 1997; Rachman, 1993; Salkovskis, 1985; Wells & Matthews, 1994), and descriptions of how family factors may maintain childhood OCD (e.g. Barrett et al., 1996; Creswell et al., 2010; Smorti, 2012; Waters & Barrett, 2000). Each hypothesis refers to the association between childhood OCS/OCD and the proposed maintenance factor. The term 'association' refers to comparisons between groups of children with or without high OCS/OCD (here comparison groups might be healthy controls and/or psychiatric controls) or correlations between childhood OCS and the proposed maintenance factor.

Method

A systematic review was conducted in accordance with PRISMA guidelines (Moher et al., 2009) and was pre-registered with PROSPERO (ID: CRD42019153371, accessible from https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=153371).

Search strategy

Three electronic databases, PsycINFO, MEDLINE and Web of Science Core Collection, were searched from 1985 to March 25, 2019, with backward and forward citation hand searching conducted in March/April 2020 for all studies included in the review, to identify further papers of interest not identified from the electronic search. The former date was chosen to reflect the introduction of the adult cognitive behavioural model of OCD (Salkovskis, 1985). The following search strategy was implemented: (Obsessi* or compulsi* or OCD) AND (Child* or p?ediatric or juvenile or young or youth or school) AND (Cogniti* or belief* or thought* or threat or responsibility or perfect* or magic* thinking or uncertain* or safety behavio* or neutrali* or avoid* or coping or reassur* or ritual* or suppress* or emotion* or attention* or attend or family or parent or carer or guardian or accommodation or antagonising). No other restrictions were applied to the search strategy.

Eligibility criteria

The inclusion and exclusion criteria were piloted and refined by two review authors (CCh and BH) using a subsample of papers. Studies were deemed eligible for inclusion if they met the following criteria:

1. The paper was available in English, in a peer-reviewed journal.
2. The paper reported on humans.
3. *The paper reported novel findings.* Papers reporting reviews, meta-analyses, biographies, clinical guidelines, commentaries or summaries of previously reported research were not included in this review.
4. *The paper reported on preadolescent children aged between 5 and 12 years old (inclusive).* Due to the scarcity of research in the preadolescent population, studies including participants with an upper age limit of 14 years were included, if the average age of the sample was less than 13 years. Papers reporting on other age ranges (e.g. 7–17 years) were included, if sub-group analyses of preadolescent children (aged 5–14 years, with a mean <13 years) could be extracted. Where studies examined children and adolescents as one group, we contacted authors to request re-conducted analyses for participants who met our core age criteria (i.e. participants aged 5–12 years old). Authors were only contacted to re-conduct analyses when papers satisfied all other eligibility criteria and presented no extractable data for participants in our specified age range.
5. *The paper included a standardised measure of OCS/OCD.* Papers were required to include a standardised measure of OCS/OCD. Diagnostic interviews were required to be structured or semi-structured and conducted with the child, parent or both. Questionnaire measures were required to show evidence of adequate psychometric properties and to have been designed specifically for children. Studies using a questionnaire subscale to measure OCS/OCD were included, if the above criteria were satisfied.
6. *The paper included a measure of one or more potential maintenance factors*. This review focused on potential cognitive, behavioural and familial maintenance factors (i.e. children's and/or family member's specific cognitions and/or behaviours). Papers with questionnaire, observation or equivalent measures of potential maintenance factors were included.
7. The paper was required to meet at least one of the following study designs:
    1. Study examining (i) associations between potential maintenance factors and continuous measures of OCS/OCD and (ii) independent or specific associations between potential maintenance factors and continuous measures of OCS/OCD, compared with other anxiety symptoms/disorders and/or non-anxious controls.
    2. Study examining (i) differences in potential maintenance factors and categorical measures of OCS/OCD and (ii) differences in potential maintenance factors and categorical measures of OCS/OCD, compared with other anxiety symptoms/disorders and/or non-anxious controls.
    3. Prospective or experimental study examining the direction of effects between potential maintenance factors and OCS/OCD, including experimental studies using treatment designs.
    4. Study examining change in a potential maintenance mechanism and change in OCS/OCD.

Papers were excluded if the study was a single case report, or if the study specifically examined OCS/OCD in the context of other comorbid conditions (e.g. autism spectrum disorders (ASDs), attention deficit hyperactivity

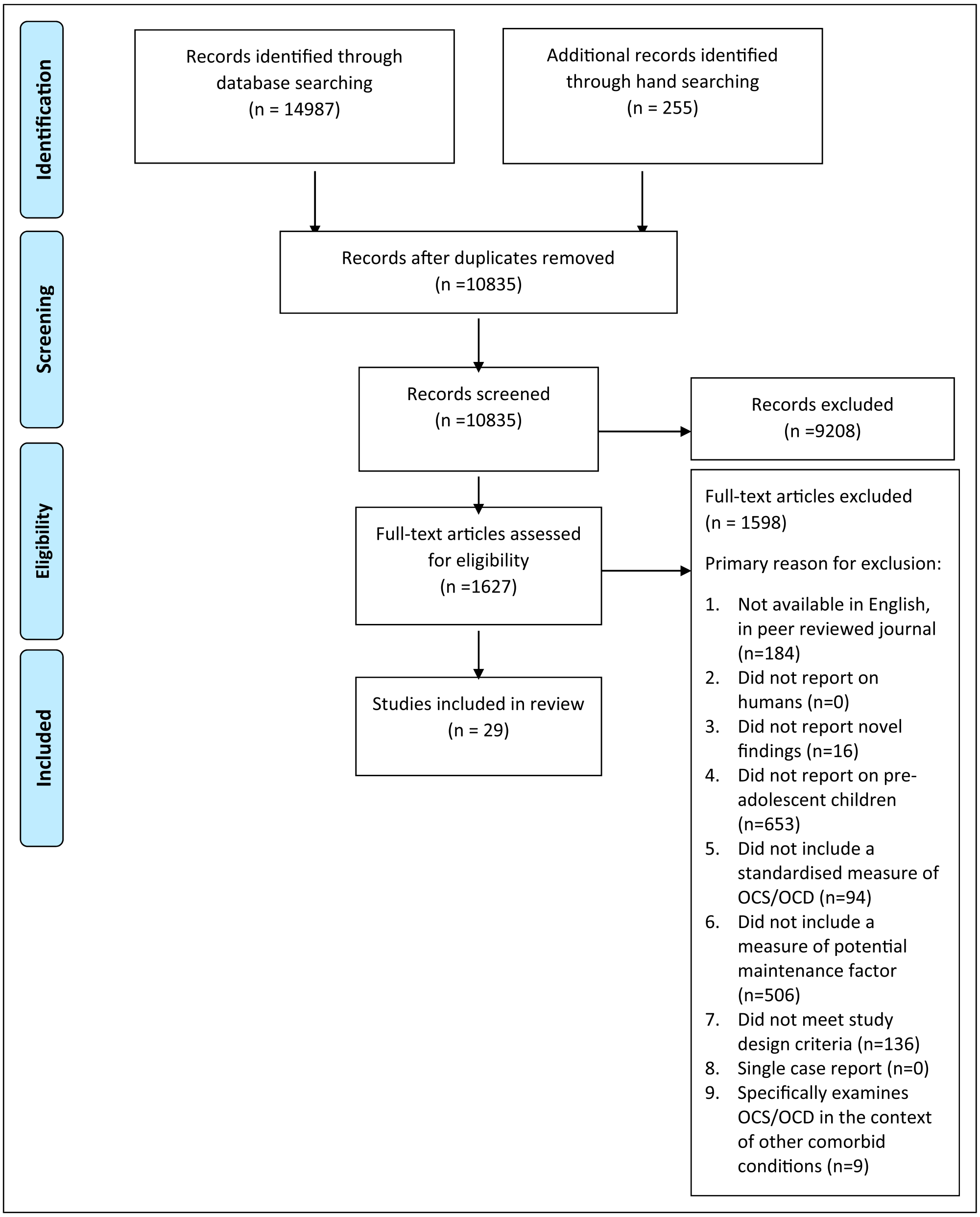

Figure 1. PRISMA flowchart of study selection process.

disorder (ADHD), eating disorders or physical health conditions).

Study selection

A flow chart of the study selection process is shown in Figure 1. Electronic database searches retrieved 14,987 records. Backward and forward citation hand searching retrieved a further 255 potentially eligible papers. A total of 10,835 records were retained after duplicates were removed. The titles and abstracts of a subset of records (*n* = 200) retrieved from the electronic database searches were independently screened by two review authors (CCh and BH) to identify records for full text screening. Inter-rater reliability between the two review authors was calculated and classified as 'almost perfect agreement' (k = .86; Landis & Koch, 1977). The titles and abstracts of the remaining records were screened by one review author (CCh). Two review authors (CCh and BH) then independently screened 1627 full texts to determine eligibility for inclusion in the review. Ninety-nine records were identified which examined children and adolescents as one group (i.e. they presented no extractable data for participants in our specified age range). As these records met all other eligibility criteria, we emailed the authors of 96 records (n = 3 were not contactable) to request re-conducted analyses on participants within our age range. Seven authors responded with the requested analyses or provided data for re-analysis. Any disagreements among reviewers were initially discussed by the two review authors (CCh and BH) and if consensus was not reached, a third review author (CCr) was consulted to reach a final decision.

Data extraction

A data extraction sheet was developed and refined through initial piloting. The data extraction sheet included: details of the publication (e.g. authors, title and year of publication); participant characteristics (e.g. number of participants, age range, gender, diagnostic information and comorbidity); study design (e.g. questionnaire, observation, prospective, experiment and intervention); standardised measure of OCS/OCD (e.g. questionnaire, interview, informant, evidence of construct validity and appropriateness for age of child); measure of potential maintenance factors (e.g. questionnaire, observation and informant); control/comparison group (if applicable); method of data analysis; sub-group analyses (if applicable, e.g., age); study results (including effect sizes); and information relevant to the quality assessment. Data extraction was independently conducted by two review authors (CCh and CGH) and reviewed to ensure accuracy. Any discrepancies were initially discussed by the two review authors (CCh and CGH), and if consensus was not reached, a third review author (CCr or BH) was consulted to reach a final decision. Authors were contacted for missing data where necessary.

Quality ratings

The quality of included studies was assessed using a modified version of the Checklist for Assessing the Quality of Quantitative Studies (Kmet et al., 2004). We modified the wording of the criterion 'Outcome and exposure measures well defined and robust to misclassification bias?' and measured this for both OCS/OCD measures ('OCS/OCD measure(s) well defined and robust to misclassification bias?') and proposed maintenance factor measures ('Proposed maintenance factor measure(s) well defined and robust to misclassification bias?'). Two review authors (CCh and CGH) independently rated the quality of all included studies. Studies were only rated on the criteria which were applicable to the specific study design; thus, the possible total score for each study varied, so percentage scores were calculated to show the total score as a proportion of the potential total for each study. Studies where analyses were re-conducted to fit our specified age criteria were rated twice; once for the overall quality of the paper and once for the re-conducted analyses. This approach was chosen to reflect that re-conducted analyses may differ in quality (i.e. sample size, control for confounding variables and estimates of variance) from the original paper. Any discrepancies were initially discussed by the two review authors (CCh and CGH) and a third review author (CCr or BH) was consulted if consensus was not reached.

Data synthesis

Due to considerable heterogeneity among the studies included in this review, we adopted a descriptive approach to data synthesis. Studies are organised according to (i) specific hypotheses identified from adult cognitive behavioural models of OCD, and descriptions of how family factors may maintain childhood OCD; (ii) sample characteristics (e.g. non-clinical and clinical populations); and (iii) methodological approach, to indicate the extent to which findings aid our understanding of whether the proposed maintenance factors are independently and/or specifically associated with childhood OCS/OCD. Thus, we presented studies examining the association between childhood OCS/OCD and proposed maintenance factors (i.e. studies examining differences between children with OCD and non-clinical controls on proposed maintenance factors, or associations between childhood OCS/OCD and proposed maintenance factors). If the study provided evidence of a significant association between childhood OCS/OCD and the proposed maintenance factor, we then presented study findings (where applicable) on the *independent* association between childhood OCS/OCD and the proposed maintenance factor (i.e. associations between childhood OCS/OCD and the proposed maintenance factor whilst controlling for other psychiatric symptoms) and/or the *specific* association between childhood OCS/OCD and the proposed maintenance factor (i.e. differences between children with OCD and psychiatric controls on the proposed maintenance factor or lack of associations between other psychiatric symptoms and the proposed maintenance factor). If the study provided no evidence for a significant association between childhood OCS/OCD and the proposed maintenance factor, then no analyses regarding independent or specific associations from that study were presented. A summary of the strength of the existing evidence for each proposed maintenance factor is shown in Figure 2.

The results of this review are evaluated based on significance testing and effect sizes. In recognition that many studies used small sample sizes and/or were insufficiently powered to detect potentially meaningful effects, effect sizes (Cohen's d) were calculated to aid interpretation of the results in the discussion section. Cohen's d is reported for all studies where this could be extracted, calculated or converted (using https://www.psychometrica.de/effect_size.html). Where effect sizes were not reported, Cohen's d was calculated using means and standard deviations. If this data was not available, effect sizes were calculated using F values or t-statistics. Where there was insufficient

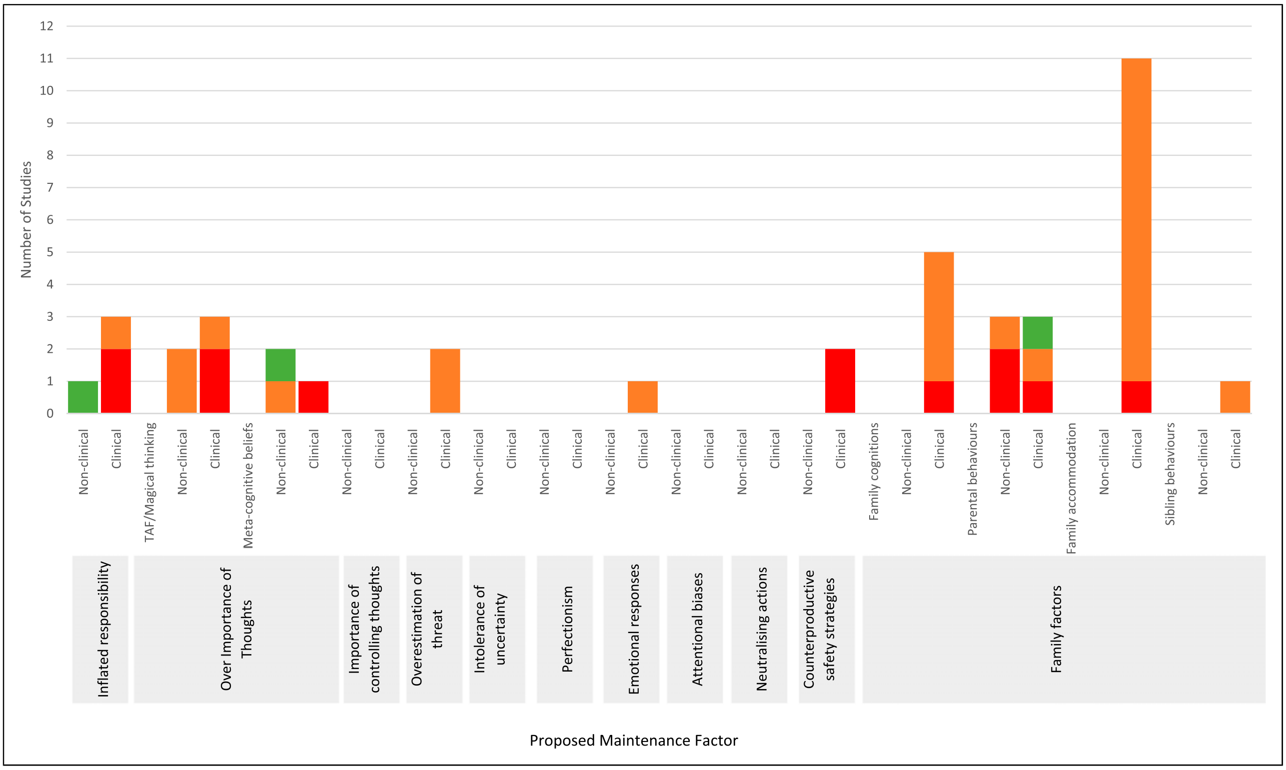

Figure 2. Summary of the strength of the available evidence. *Note.* Studies are represented once for each investigated maintenance factor, for the highest degree of evidence shown. Red = The study has found no evidence to support the hypothesised association between childhood OCS/OCD and the proposed maintenance factor; Orange = The study has found some evidence to support the hypothesised association between childhood OCS/OCD and the proposed maintenance factor; Green = The study has found some evidence to support the hypothesised independent and/or specific association between childhood OCS/OCD and the proposed maintenance factor.

information to calculate effect sizes, authors were contacted to provide the required data. However, the required data was not always available to calculate effect sizes; in these circumstances, we interpreted the results based on significance testing only. For consistency, the effect sizes reported in this paper were calculated by the review authors unless indicated. Any discrepancies between review authors' calculations and the original papers are indicated. Effect sizes were coded as positive or negative to aid interpretation of the data. For correlational studies, a positive effect size indicates that increases in childhood OCS/OCD are associated with increases in the proposed maintenance factor. For studies examining between-group differences, a positive effect size indicates that children with OCD have a higher score on the proposed maintenance factor than the control group. For treatment studies examining the statistical association between change in childhood OCS/OCD and change in proposed maintenance factors, a positive effect size shows the measures changed in the same direction (e.g. reductions in both childhood OCS/OCD and the maintenance factor). Where treatment studies did not directly examine this association, but just reported change in childhood OCS/OCD and proposed maintenance factors over time, a positive effect size indicates increases in childhood OCS/OCD or the proposed maintenance factor across time. Effect sizes were interpreted using Cohen's (1988) conventions of small (d = 0.20), medium (d = 0.50) and large (d = 0.80). Where there was insufficient information to determine the direction of the effect, this is indicated.

Results

Description of included studies

Study characteristics and results are presented in Tables 2 and 3, respectively. In total, 29 studies published between 1998 and 2020 were included in the review. Studies were diverse in sample size (ranging from 3 participants to 202 participants); participant age (ranging from 5 to 14 years); percentage of female participants (ranging from 25% to 75%); recruitment setting (including schools and mental health settings); and country (including UK $n = 3$; USA $n = 6$; Australia $n = 9$; Sweden $n = 1$; Spain $n = 2$; Canada $n = 2$; the Netherlands $n = 3$; Iceland $n = 1$; Serbia $n = 1$ and India $n = 1$).

Table 2. Study characteristics.

Citation	*n**	Age in years (mean, range)*	Sex (% Female)*	Country	OCS/OCD measure(s)	Potential maintenance factor measure(s)	Quality rating (sub-group analyses)
Aspvall et al. (2018)	11	9.5 (8–11)	63.6%	Sweden	CY-BOCS; OCI-CV; ChOCI-R-P	Family Accommodation Scale – Self Rated (FAS-SR)	73.1%
Barney et al. (2017)	3	10.3 (10–11)	33.3%	US	CY-BOCS; NIMH-GOCS	Parental Acceptance and Action Questionnaire (PAAQ)	65.4%
Barrett and Healy (2003)	59	10.1 (7–13)	49.2%	Australia	ADIS-P	Cognitive Assessment of Salkovskis Theory; Cognitive Assessment of Thought Action Fusion (TAF) and self-doubt	83.3%
Barrett et al. (2000)	4	12.3 (10–13)	75.0%	Australia	ADIS-P; CY-BOCS	Sibling Accommodation Scale (SAS); Sibling Relationship Questionnaire (SRQ)	38.5%
Barrett et al. (2002)	83	9.6 (6–14)	51.8%	Australia	ADIS-P	Macro-coding Schedule for Parent and Child Behaviours (MPCB)	83.3%
Belschner et al. (2020)**	13	10.3 (6–12)	69.2%	Canada	CY-BOCS-PR	Parental Tolerance of Child Distress (PT-OCD); FAS	76.9% (63.6%)
Bipeta et al. (2013)**	15	9.9 (7–12)	53.3%	India	CY-BOCS	Family Accommodation Scale – Parent Report (FAS-PR)	87.5% (80.0%)
Bolton et al. (2002)	86	Not reported (5–13)	Not reported	UK	SCAS OSC subscale	Magical Thinking Questionnaire (MTQ)	58.3%
Challacombe and Salkovskis (2009) [a]	61	9.9 (7–14)	54.1%	UK	Child OCI	Observed Mother-Child Interactions; Five Minute Speech Sample (FMSS)	66.7%
Farrell et al. (2013)	28	9.9 (8–12)	39.3%	Australia	ADIS-P	Family Discussion Task	83.3%
Farrell et al. (2015)	48	9.7 (8–12)	45.8%	Australia	ADIS-P	Interpretation Bias Task	87.5%
Farrell et al. (2012)	26	Not reported (7–11)	Not reported	Australia	CY-BOCS	Responsibility Attitudes Scale (RAS); Revised TAF scale; White Bear Suppression Inventory (WBSI); Meta-Cognition Questionnaire for Adolescents (MCQ-A)	87.5%
Grüner et al. (1999)	117	10.4 (9–12)	51.3%	The Netherlands	SCAS OCS subscale	Modified My Memories of Upbringing for Children (EMBU-C)	79.2%
Lebowitz (2013)	6	11.3 (10–13)	33.3%	US	CY-BOCS-PR	Family Accommodation Scale (FAS)	30.8%
Lebowitz et al. (2014)**	54	10.1 (7–12)	58.7%	US	CY-BOCS	FAS; Family Accommodation Scale – Anxiety (FASA)	87.5% (80.0%)
Magnúsdóttir and Smári (2004)	202	11.7 (10–14)	53.0%	Iceland	LOI-CV	Responsibility Attitudes Scale for Children (RAS-C)	70.8%
Mathieu et al. (2020)	79	10.4 (7–12)	Not reported	Australia	CY-BOCS	Modified EMBU-C; Obsessive Beliefs Questionnaire – Child Version (OBQ-CV)	62.5%
Muris and Merckelbach (1998)	45	9.8 (8–12)	57.8%	The Netherlands	SCARED OCD subscale	Modified EMBU-C	50.0%

(continued)

Table 2. (continued)

Citation	*n**	Age in years (mean, range)*	Sex (% Female)*	Country	OCS/OCD measure(s)	Potential maintenance factor measure(s)	Quality rating (sub-group analyses)
Rosa-Alcázar et al. (2017)	20	6.6 (5–7)	35.0%	Spain	CY-BOCS	FAS	85.7%
Rosa-Alcázar et al. (2019)	44	6.7 (5–7)	25.0%	Spain	CY-BOCS	FAS	92.9%
Selles, Franklin, et al. (2018b)	46	6.9 (5–8)	56.5%	US	CY-BOCS; CY-BOCS-PR	Measure of Distress Tolerance	82.1%
Selles, Belschner, et al. (2018a)**	32	11.3 (7–12)	71.9%	Canada	CY-BOCS; CY-BOCS-PR	FAS	65.4% (59.1%)
Simonds et al. (2009)	102	7.7 (5–10)	52.9%	UK	SLOI-CV; SCAS OCS subscale	MTQ	79.2%
Stevanovic et al. (2016)**	66	12.0 (12–12.5)	51.5%	Serbia	RCADS OCD subscale	Metacognitions Questionnaire for Children (MCQ-C)	79.2% (75%)
Verhaak and de Haan (2007)	18	Not reported (8–12)	61.1%	The Netherlands	CY-BOCS	MTQ	58.3%
Waters et al. (2001)	7	Not reported (10–13)	Not reported	Australia	CY-BOCS	FAS	57.7%
White and Hudson (2016)	187	10.6 (7–12)	31.3%	Australia	SCAS OCS subscale	Revised MCQ-C (MCQ-CR)	83.3%
Whiteside et al. (2014)**	10	9.8 (7–12)	40.0%	US	ADIS-C; CY-BOCS	Family Accommodation Items (FAI)	80.8% (72.7%)
Wu et al. (2014)**	24	10.6 (7–12)	25.0%	US	CY-BOCS	FAI	83.3% (80.0%)

Note. OCS = Obsessive compulsive symptoms; CY-BOCS = Children's Yale-Brown Obsessive Compulsive Scale; CY-BOCS-PR = Children's Yale-Brown Obsessive Compulsive Scale – Parent Report; OCI-CV = Obsessive Compulsive Inventory – Child Version; ChOCI-R-P =Children's Obsessional Compulsive Inventory – Revised – Parent Report; NIHM GOCS = National Institute of Mental Health Global Obsessive Compulsive Scale; ADIS-P = Anxiety Disorder Interview Schedule – Parent Report; ADIS-C = Anxiety Disorder Interview Schedule – Child Report; SCAS = Spence Children's Anxiety Scale; Child OCI = Child Obsessive Compulsive Inventory; LOI-CV = Leyton Obsessive Inventory – Child Version; SLOI-CV = Short Leyton Obsessive Compulsive Inventory – Child Version; SCARED = Screen for Child Anxiety Related Disorders; RCADS = Revised Children's Anxiety and Depression Scale. FAS = Family Accommodation Scale; FAS-SR = Family Accommodation Scale – Self Report; FAS-PR = Family Accommodation Scale – Parent Report; FASA = Family Accommodation Scale for Anxiety; FAI = Family Accommodation Items; SAS = Sibling Accommodation Scale; PAAQ = Parental Acceptance and Action Questionnaire; SRQ = Sibling Relationship Questionnaire; MPCB = Macro-coding Schedule for Parent and Child Behaviours; PT-OCD = Parental Tolerance of Child Distress; FMSS = Five Minute Speech Sample; MTQ = Magical Thinking Questionnaire; RAS = Responsibility Attitudes Scale; RAS-C = Responsibility Attitudes Scale for Children; TAF = Thought action fusion; WBSI = White Bear Suppression Inventory; MCQ-C = Metacognitions Questionnaire for Children; MCQ-A = Metacognitions Questionnaire for Adolescents; MCQ-CR = Revised Metacognitions Questionnaire for Children; OBQ-CV = Obsessive Beliefs Questionnaire – Child Version; Modified EMBU-C = My Memories of Upbringing – Child Version.

* The number, age and gender of participants have been extracted for analyses which met our inclusion criteria, rather than the total sample of participants. ** Denotes where authors have provided data for re-analysis or provided re-conducted analyses within our specified age range.

[a] Indicates where parents included in the study were selected on the presence of particular mental health conditions.

Table 3. Results and effect sizes.

				Study design			
Citation	OCS/OCD Measure(s)	Proposed maintenance factor measure(s)	Age range (Years)	Association between proposed maintenance factor and OCS/OCD using non-clinical sample	Association between proposed maintenance factor and OCS/OCD using a clinical sample	Differences between proposed maintenance factors and OCD, compared with other anxiety disorders and/or non-anxious controls	Change in proposed maintenance factors and change in OCS/OCD
Inflated responsibility							
Magnúsdóttir and Smári (2004)	LOI-CV	RAS-C	10–14	$d = 0.68$			
Farrell et al. (2012)	CY-BOCS	RAS	7–11		$d = -0.32$		
Mathieu et al. (2020)	CY-BOCS	OBQ-CV	7–12		$d = 0.32$		
Barrett and Healy (2003)	ADIS-P	Cognitive Assessment of Salkovskis Theory–Responsibility for Harm	7–13			OCD-relevant threat: $d = 1.01$* (OCD > NCC) $d = 0.24$ (OCD > AD) Non-OCD threat: $d = -0.25$ (OCD < NCC) $d = 0.29$ (OCD > AD)	
Over importance of thoughts							
Simonds et al. (2009)	SCAS OCS subscale; SLOI-CV	MTQ	5–10 5–6 7–8 9 – 10	SCAS OCS: $d = 0.59$* (total) $d = 0.55$* (thought) $d = 0.48$* (action) SLOI-CV: $d = 0.81$* (total) $d = 0.74$* (thought) $d = 0.66$* (action) SCAS OCS: $d = 0.72$ (total) SLOI-CV: $d = 1.62$* (total) SCAS OCS: $d = -0.08$ (total) SLOI-CV: $d = 0.47$* (total) SCAS OCS: $d = 0.75$* (total) SLOI-CV: $d = 0.35$ (total)			
Bolton et al. (2002)	SCAS OCS subscale	MTQ	5–6 7–8 10–11 12–13	Not reported Not reported Not reported Spearman's $p = .65$*[a]			
White and Hudson (2016)	SCAS OCS subscale	MCQ-CR	7–12	$d = 1.32$*			

(continued)

Table 3. (continued)

				Study design			
Citation	OCS/OCD Measure(s)	Proposed maintenance factor measure(s)	Age range (Years)	Association between proposed maintenance factor and OCS/OCD using non-clinical sample	Association between proposed maintenance factor and OCS/OCD using a clinical sample	Differences between proposed maintenance factors and OCD, compared with other anxiety disorders and/or non-anxious controls	Change in proposed maintenance factors and change in OCS/OCD
Stevanovic et al. (2016)**	RCADS OCD subscale	MCQ-C	12–12.512	d = 2.67* (controlling for depression)			
Verhaak and de Haan (2007)	CY-BOCS	MTQ	8–12		d = 0.12 (total)d = 0.12 (thought)d = 0.10 (action)		
Farrell et al. (2012)	CY-BOCS	Revised TAF Scale;MCQ-A	7–11		d = −0.28 (TAF Likelihood Self)d = −0.30 (TAF Likelihood Other) d = 0.39 (TAF Morality)d = −0.26 (MCQ-A)		
Barrett and Healy (2003)	ADIS-P	Cognitive Assessment of TAF	7–13			d = 0.81* (OCD > NCC) d = 0.46 (OCD > AD)	
Importance of controlling thoughts							
No eligible studies identified							
Overestimation of threat							
Farrell et al. (2015)	ADIS-P	Interpretation Bias Task	8–12			Difficulty ratings: d = 0.86*(OCD > NCC) Open threat interpretation ratings: d = 0.39[b] (OCD vs. NCC)Closed threat interpretation rating: d = 0.37 (OCD > NCC) Appraisals of coping: d = −0.21 (OCD < NCC)Coping plans: d = −0.39 (OCD < NCC)	
Barrett and Healy (2003)	ADIS-P	Cognitive Assessment of Salkovskis Theory –Severity of Harm;Probability of Harm	7–13			Severity of Harm: OCD-relevant threat: d = 1.07* (OCD > NCC) d = 0.71 (OCD > AD) Non-OCD threat: d = 0.48 (OCD > NCC) d = −0.07 (OCD < AD) Probability of Harm: OCD-relevant threat: d = 1.25 (OCD > NCC) d = 0.55 (OCD > AD) Non-OCD-relevant threats: d = 0.27 (OCD > NCC) d = 0.06 (OCD > AD)	
Intolerance of uncertainty							
No eligible studies identified							
Perfectionism							

(continued)

Table 3. (continued)

Citation	OCS/OCD Measure(s)	Proposed maintenance factor measure(s)	Age range (Years)	Study design			
				Association between proposed maintenance factor and OCS/OCD using non-clinical sample	Association between proposed maintenance factor and OCS/OCD using a clinical sample	Differences between proposed maintenance factors and OCD, compared with other anxiety disorders and/or non-anxious controls	Change in proposed maintenance factors and change in OCS/OCD
No eligible studies identified							
Emotional responses							
Selles, Franklin, et al. (2018b)	CY-BOCS;CY-BOCS-PR	Measure of Distress Tolerance	5–8				$d = -1.32^{*c}$ (CY-BOCS) $d = -0.90$ (CY-BOCS-PR)
Attentional biases							
No eligible studies identified							
Neutralising actions							
No eligible studies identified							
Counterproductive safety strategies							
Farrell et al. (2012)	CY-BOCS	WBSI	7–11		$d = 0.22$		
Barrett and Healy (2003)	ADIS-P	Cognitive Assessment of Self-Doubt	7–13			$d = -0.10$ (OCD < NCC) $d = -0.04$ (OCD < AD)	
Family members' cognitions							
Farrell et al. (2012)	CYBOCS	Maternal RAS; Revised TAF Scale; WBSI; MCQ	7–11		$d = 2.08^{*}$ (RAS) $d = 1.19^{*}$ (WBSI) $d = 0.87^{*}$ (MCQ) $d = 0.77$ (TAF Likelihood Self) $d = 0.52$ (TAF Likelihood Other) $d = -0.04$ (TAF Morality)		
Farrell et al. (2015)	ADIS-P	Interpretation Bias Task	8–12			Closed threat interpretation rating: $d = 0.68^{*}$(Mothers of OCD>NCC) Open threat interpretation ratings: $d = 0.23^{b}$(Mothers of OCD vs. NCC) Difficulty ratings: $d = 0.69^{*}$(Mothers of OCD>NCC) Appraisals of coping: $d = -0.54$ (Mothers of OCD<NCC) Coping plans: $d = -0.29$ (Mothers of OCD<NCC)	
Selles, Franklin, et al. (2018b)	CY-BOCS; CY-BOCS-PR	Measure of Distress Tolerance	5–8				Maternal: $d = -0.58$ (CY-BOCS) $d = -0.52$ (CY-BOCS-PR) Paternal: $d = -1.00^{*}$ (CY-BOCS) $d = -0.85$ (CY-BOCS-PR)

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Table 3. (continued)

				Study design			
Citation	OCS/OCD Measure(s)	Proposed maintenance factor measure(s)	Age range (Years)	Association between proposed maintenance factor and OCS/OCD using non-clinical sample	Association between proposed maintenance factor and OCS/OCD using a clinical sample	Differences between proposed maintenance factors and OCD, compared with other anxiety disorders and/or non-anxious controls	Change in proposed maintenance factors and change in OCS/OCD
Belschner et al. (2020)**	CY-BOCS-PR	PT-OCD	6–12				$d = -0.29$ (Pre-Post intervention period CY-BOCS-PR) $d = 0.94$*(Pre-Post intervention period PT-OCD)
Barney et al. (2017)	CY-BOCS; NIHM GOCS	PAAQ	10–11				$d = -2.61$ (Pre-Post CY-BOCS) $d = -5.87$ (Pre-Post NIMH-GOCS) $d = -0.70$ (Pre-Post PAAQ)
Family member's behaviours							
Grüner et al. (1999)	SCAS OCS subscale	Modified EMBU-C	9–12	Maternal: $d = 0.52$*(control) $d = 0.54$*(anxious parenting) $d = 0.90$*(rejection) $d = -0.32$ (emotional warmth)Paternal: $d = 0.47$* (control) $d = 0.49$* (anxious parenting) $d = 0.85$*(rejection) $d = -0.22$ (emotional warmth)			
Muris and Merckelbach (1998)	SCARED OCD subscale	Modified EMBU-C	8–12	Not reported			
Challacombe and Salkovskis (2009)	Child OCI	Observed Mother-Child Interactions; FMSS	7–14	Not reported			
Mathieu et al. (2020)	CY-BOCS	Modified EMBU-C	7–12		$d = -0.43$ (overprotection) $d = -0.35$ (anxious parenting) $d = 0.35$ (rejection)		
Bipeta et al. (2013)**	CY-BOCS	FAS-PR	7–12		$d = 7.84$* (Total) $d = 3.37$* (Avoidance of triggers)		
Wu et al. (2014)**	CY-BOCS	FAI	7–12		$d = 1.81$* (Total) $d = 1.19$* (Participation) $d = 1.58$* (Modification)		

(continued)

Table 3. (continued)

				Study design			
Citation	OCS/OCD Measure(s)	Proposed maintenance factor measure(s)	Age range (Years)	Association between proposed maintenance factor and OCS/OCD using non-clinical sample	Association between proposed maintenance factor and OCS/OCD using a clinical sample	Differences between proposed maintenance factors and OCD, compared with other anxiety disorders and/or non-anxious controls	Change in proposed maintenance factors and change in OCS/OCD
Barrett et al. (2002)	ADIS-P	MPCB	6–14			Maternal control: $d = -0.15$ (OCD < AD) $d = 3.05$ (OCD > ED) $d = 2.45$ (OCD > NCC)Maternal warmth: $d = -0.75$*(OCD < AD) $d = 0.60$ (OCD > ED) $d = -1.24$*(OCD < NCC) Maternal doubt: $d = -10.40$*(OCD < AD) $d = -8.61$*(OCD < ED) $d = -3.04$ (OCD < NCC) Maternal avoidance: $d = -0.82$ (OCD < AD) $d = -0.63$ (OCD < ED) $d = -0.53$ (OCD < NCC) Maternal problem solving: $d = -2.40$*(OCD < AD) $d = -1.45$*(OCD < ED) $d = -1.95$*(OCD < NCC) Maternal confidence: $d = -4.03$*(OCD < AD) $d = -1.22$*(OCD < ED) $d = -6.82$*(OCD < NCC) Maternal reward independence: $d = -2.89$*(OCD < AD) $d = -1.22$*(OCD < ED) $d = -3.38$*(OCD < NCC) Paternal control: $d = -0.16$ (OCD < AD) $d = 0.49$ (OCD > NCC)Paternal warmth: $d = -0.59$ (OCD < AD) $d = -2.08$*(OCD < NCC) Paternal doubt: $d = -1.53$*(OCD < AD) $d = 0.02$ (OCD > NCC)Paternal avoidance: $d = -0.71$ (OCD < AD) $d = 0.24$ (OCD > NCC)Paternal problem solving: $d = -2.18$*(OCD < AD) $d = -2.22$*(OCD < NCC)	

(continued)

Table 3. (continued)

				Study design			
Citation	OCS/OCD Measure(s)	Proposed maintenance factor measure(s)	Age range (Years)	Association between proposed maintenance factor and OCS/OCD using non-clinical sample	Association between proposed maintenance factor and OCS/OCD using a clinical sample	Differences between proposed maintenance factors and OCD, compared with other anxiety disorders and/or non-anxious controls	Change in proposed maintenance factors and change in OCS/OCD
						Paternal confidence: $d = -3.32$*(OCD < AD) $d = -7.87$*(OCD < NCC) Paternal reward independence: $d = -2.40$*(OCD < AD) $d = -4.56$*(OCD < NCC)	
Farrell et al. (2013)	ADIS-P	Family Discussion Task	8–12			Autonomy (vs. Control): $d = -0.40$ (Mothers of OCD<NCC) Confidence (vs. doubt): $d = -0.07$ (Mothers of OCD<NCC) Warmth (vs. dismissive): $d = -0.69^{d}$ (Mothers of OCD<NCC) Enhancement of child's responsibility not reported	
Lebowitz et al. (2014)**	CY-BOCS	FAS; FASA	7–12			Accommodation: $d = 0.40$ (OCD > AD) $d = 1.45$* (OCD > NCC) Participation: $d = 0.30$ (OCD > AD) $d = 1.25$* (OCD > NCC) Modification: $d = 0.31$(OCD > AD) $d = 1.35$* (OCD > NCC) Parent distress: $d = 0.22$ (OCD > AD) $d = 1.41$ (OCD > NCC)	
Aspvall et al. (2018)	CY-BOCS; OCI-CV; ChOCI-R-P	FAS-SR	8–11				$d =- 1.86$* (Pre-Post CY-BOCS) $d = -0.30$ (Post-3 m FU CY-BOCS) $d = -1.65$*(Pre-Post OCI-CV) $d = -0.03$ (Post-3 m FU OCI-CV) $d = -2.15$*(Pre-Post ChOCI-R-P) $d = 0.06$ (Post-3 m FU ChOCI-R-P)

(continued)

Table 3. (continued)

Citation	OCS/OCD Measure(s)	Proposed maintenance factor measure(s)	Age range (Years)	Study design Association between proposed maintenance factor and OCS/OCD using non-clinical sample	Association between proposed maintenance factor and OCS/OCD using a clinical sample	Differences between proposed maintenance factors and OCD, compared with other anxiety disorders and/or non-anxious controls	Change in proposed maintenance factors and change in OCS/OCD
							$d = -2.67$* (Pre-Post FAS-SR) $d = -0.04$ (Post-3 m FU FAS-SR)
Selles, Belschner, et al. (2018a)**	CY-BOCS; CY-BOCS-PR	FAS	8–13				$d = -1.74$* (Pre-Post CY-BOCS) $d = -0.05$ (Post-1 m FU CY-BOCS) $d = -1.58$* (Pre-Post CY-BOCS-PR) $d = -0.09$[e] (Post-1 m FU CY-BOCS-PR) $d = -1.51$* (Pre-Post FAS) $d = -0.23$ (Post-1 m FU FAS)
Lebowitz (2013)	CY-BOCS-PR	FAS	10–13				Not reported
Rosa-Alcázar et al. (2017)	CY-BOCS	FAS	5–7				$d = -5.55$* (Pre-3 m FU CY-BOCS) $d = -4.55$* (Pre-3 m FU FAS)
Rosa-Alcázar et al. (2019)	CY-BOCS	FAS	5–7				$d \geq -7.29$* (Pre-3 m FU CY-BOCS) $d \geq -5.60$* (Pre-3 m FU FAS-Mother) $d \geq -5.60$* (Pre-3 m FU FAS-Father)
Waters et al. (2001)	CY-BOCS	FAS	10–13				$d = -3.62$* (Pre-Post CY-BOCS) Not reported for all other variables
Whiteside et al. (2014)**	ADIS-C; CY-BOCS	FAI	7–12				$d = -1.46$* (Pre-Post CY-BOCS) $d = -0.66$ (Pre-Post ADIS OCD) $d = -1.46$* (Pre-Post FAI)
Belschner et al. (2020)**	CY-BOCS-PR	FAS	6–12				$d = -0.29$ (Pre-Post intervention period CY-BOCS-PR) $d = 0.03$ (Pre-Post intervention period FAS)

(continued)

Table 3. (continued)

Citation	OCS/OCD Measure(s)	Proposed maintenance factor measure(s)	Age range (Years)	Study design Association between proposed maintenance factor and OCS/OCD using non-clinical sample	Association between proposed maintenance factor and OCS/OCD using a clinical sample	Differences between proposed maintenance factors and OCD, compared with other anxiety disorders and/or non-anxious controls	Change in proposed maintenance factors and change in OCS/OCD
Barrett et al. (2000)	ADIS-P; CY-BOCS	SAS; SRQ	10–13			Warmth: *d* = −0.37^{f} (Siblings of OCD<NCC) Dominance: *d* = 0.00 (Siblings of OCD vs. NCC) Conflict: *d* = 0.03 (Siblings of OCD>NCC) Rivalry: *d* = 1.17^{f} (Siblings of OCD>NCC)	*d* = −4.64 (Pre-Post CY-BOCS) *d* = 0.13^{f} (Pre-Post Warmth) *d* = −0.55 (Pre-Post Dominance) *d* = −0.25^{f} (Pre-Post Conflict) *d* = −2.25 (Pre-Post Rivalry) *d* = −1.89 (Pre-Post SAS total) *d* = −1.95^{f} (Pre-Post SAS participation) *d* = −1.61 (Pre-Post SAS modification) *d* = −0.64 (Pre-Post SAS Sibling distress)

Note. OCS = Obsessive compulsive symptoms; CY-BOCS = Children's Yale-Brown Obsessive Compulsive Scale; CY-BOCS-PR = Children's Yale-Brown Obsessive Compulsive Scale – Parent Report; OCI-CV = Obsessive Compulsive Inventory – Child Version; ChOCI-R-P =Children's Obsessional Compulsive Inventory – Revised–Parent Report; NIHM GOCS = National Institute of Mental Health Global Obsessive-Compulsive Scale; ADIS-P = Anxiety Disorder Interview Schedule – Parent Report; ADIS-C = Anxiety Disorder Interview Schedule–Child Report; SCAS = Spence Children's Anxiety Scale; Child OCI = Child Obsessive Compulsive Inventory; LOI-CV = Leyton Obsessive Inventory – Child Version; SLOI-CV = Short Leyton Obsessive Compulsive Inventory – Child Version; SCARED = Screen for Child Anxiety Related Disorders; RCADS = Revised Children's Anxiety and Depression Scale. FAS = Family Accommodation Scale; FAS-SR = Family Accommodation Scale – Self Report; FAS-PR = Family Accommodation Scale – Parent Report; FASA = Family Accommodation Scale for Anxiety; FAI = Family Accommodation Items; SAS = Sibling Accommodation Scale; PAAQ = Parental Acceptance and Action Questionnaire; SRQ = Sibling Relationship Questionnaire; MPCB = Macro-coding Schedule for Parent and Child Behaviours; PT-OCD = Parental Tolerance of Child Distress; FMSS = Five Minute Speech Sample; MTQ = Magical Thinking Questionnaire; RAS = Responsibility Attitudes Scale; RAS-C = Responsibility Attitudes Scale for Children; TAF = Thought action fusion; WBSI = White Bear Suppression Inventory; MCQ = Metacognition Questionnaire; MCQ-C = Metacognitions Questionnaire for Children; MCQ-A = Metacognitions Questionnaire for Adolescents; MCQ-CR = Revised Metacognitions Questionnaire for Children; OBQ-CV = Obsessive Beliefs Questionnaire – Child Version; Modified EMBU-C = My Memories of Upbringing – Child Version. NCC = Non-clinical controls; AD = Anxiety disorder; ED = Externalising disorder; MDD = Major depressive disorder; ADHD = attention deficit hyperactivity disorder; CD = Conduct disorder; TD = Tic disorder; Pre = Pre-treatment; Post = Post-treatment; FU = Follow-up; 1 m = 1 month; 3 m = 3 month.

Please refer to the data synthesis section to aid interpretation of positive and negative effect sizes. * Indicates a significant result. ** Denotes where authors have provided data for re-analysis or provided re-conducted analyses within our specified age range.

[a] Indicates where review authors were unable to convert data to Cohen's d.

[b] Insufficient information to determine the direction of the effect size.

[c] This effect size was calculated according to the formula provided by Peterson and Brown (2005); however, the original standardised regression coefficient (r = 0.51) marginally exceeded the recommended values for applying this formula (r = +/−0.50).

[d] Original author effect size calculation (d = 0.72).

[e] Original author effect size calculation (d = 0.08).

[f] Discrepancies between original author and review author calculation of means from raw data (original author warmth OCD group M = 3.05, review author calculation M = 3.03; original author warmth control group M = 3.29, review author calculation M = 3.23; original author rivalry OCD group M = 3.50, review author calculation M = 3.40; original author rivalry control group M = 3.01, review author calculation M = 3.07; original author post-treatment warmth M = 3.10, review author calculation M = 3.12; original author pre-treatment conflict M = 2.80, review author calculation M = 2.82; original author pre-treatment SAS participation subscale M = 1.87, review author calculation M = 1.67).

Eligible studies were identified for six of the 11 proposed maintenance factors. Among the cognitive and behavioural mechanisms, studies most commonly examined inflated responsibility beliefs (*n* = 4) and over importance of thoughts (*n* = 7). Studies were also identified for overestimation of threat (*n* = 2), emotional responses (*n* = 1) and counterproductive safety strategies (*n* = 2). No eligible studies were identified which examined the association between childhood OCS/OCD and the remaining cognitive/behavioural mechanisms, that is, importance of controlling thoughts, intolerance of uncertainty, perfectionism, attentional biases or neutralising actions. Among the familial mechanisms, studies most commonly examined family members' behaviours (*n* = 18) – including 12 different parental behaviours, family accommodation and sibling behaviours. Five studies examined family members' cognitions. The strength of the available evidence for each proposed maintenance factor is summarised in Figure 2.

Quality ratings

As shown in Table 2, the quality of included studies varied considerably (from 30.8% to 92.9%). Studies often scored highly for sufficiently described research questions, study design, participant characteristics and appropriate conclusions. Lower scores were typically allocated for participant recruitment (recruitment strategies were often unclear/could introduce bias); sample size (studies often failed to provide power analyses); data analysis (studies provided little evidence statistical assumptions were met) and estimates of variance (confidence intervals and/or standard errors for results were infrequently reported).

1. Inflated responsibility

Four studies (three with clinical samples) used cross-sectional designs to examine the association between inflated responsibility and childhood OCS/OCD.

Non-clinical populations

Magnúsdóttir and Smári (2004) provided evidence of a significant positive association between childhood OCS and inflated responsibility in a non-clinical sample (*N* = 202, 10–14 years, *d* = 0.68). Regarding specificity, although a significant association between children's depression symptoms and inflated responsibility was found (*d* = 0.63), there was a significant independent association between childhood OCS and inflated responsibility after controlling for children's depression symptoms (*d* = 0.45).

Clinical populations

There is some, albeit limited, evidence that inflated responsibility is significantly associated with childhood OCS/OCD in clinical samples but no evidence that inflated responsibility is independently associated with, or specific to, children with OCD. While there was not a significant association between OCD severity and responsibility beliefs in general within groups of children with OCD (*N* = 26, 7–11 years, *d* = −0.32, Farrell et al., 2012; *N* = 79, 7–12 years *d* = 0.32, Mathieu et al., 2020), Barrett and Healy (2003) found that children with OCD (*N* = 28, 7–13 years) reported significantly higher responsibility ratings for OCD-relevant (but not non-OCD-relevant) threats compared to non-clinical controls (*N* = 14, *d* = 1.01 and *d* = −0.25, respectively). However, regarding specificity, Barrett and Healy (2003) found no evidence that children with OCD (*N* = 28) reported significantly higher responsibility ratings for OCD-relevant threats compared to children with anxiety disorders (*N* = 17, *d* = 0.24).

2. Over importance of thoughts

Five studies (three with clinical samples) employed cross-sectional designs to examine the association between over importance of thoughts and childhood OCS/OCD. Specifically, three studies examined 'magical thinking' and two studies examined TAF. Additionally, three studies (one with a clinical sample) were identified which examined the association between meta-cognitive beliefs and childhood OCS/OCD. Although meta-cognitive beliefs are not fully encompassed by the construct of over importance of thoughts, the meta-cognitive model of adult OCD emphasises beliefs about the meaning and importance of intrusions in the maintenance of OCD (Wells & Matthews, 1994); thus, these studies are also presented here.

Non-clinical populations

Magical thinking and thought-action fusion. There is evidence that 'magical thinking' is significantly associated with childhood OCS in non-clinical populations; however, the size of the associations differs depending on child age and the OCS measure used. Furthermore, there is no evidence that this association is independent or specific to childhood OCS. For example, Simonds et al. (2009) found that increased 'magical thinking' beliefs were significantly associated with increased OCS on two measures of OCS (*N* = 102, 5–10 years, SLOI-CV and MTQ total *d* = 0.81, MTQ thought subscale *d* = 0.74, MTQ action subscale *d* = 0.66; SCAS OCS subscale and MTQ total *d* = 0.59, MTQ thought subscale *d* = 0.55, MTQ action subscale *d* = 0.48). However, when analyses were conducted for three specific age groups (i.e. 5–6 years, 7–8 years and 9–10 years), the magnitude of the effect varied considerably dependent on the measure of OCS used (d's ranged from $d = -0.08$ to $d = 1.62$, see Table 3 for further details), with significant positive associations found between 'magical thinking' and SLOI-CV scores for 5–6 year olds ($d = 1.62$), and 'magical thinking' and SCAS OCS subscale scores for 9–10 year olds ($d = 0.75$). Consistent with these findings, Bolton et al. (2002) also only found significant positive associations between 'magical thinking' and OCS for older children (i.e. 10–11 years and 12–13 years, Spearman's $p = .65$[1]) and not for younger children (i.e. <10 years old) when using the SCAS OCS subscale. Regarding independence, 'magical thinking' has not been found to significantly predict higher scores on two measures of OCS after controlling for other anxiety symptoms (male participants only, SLOI-CV $d = 0.56$; SCAS OCS subscale $d = 0.49$, Simonds et al., 2009). Similarly, 'magical thinking' does not appear to be specific to childhood OCS as significant associations between 'magical thinking' and other anxiety symptoms have been found for 12–13 year olds (Bolton et al., 2002) and 5–10 year olds (d's ranged from $d = 0.50$ to $d = 0.68$, Simonds et al., 2009).

Meta-cognitive beliefs. There is evidence that meta-cognitive beliefs are significantly and independently associated with childhood OCS in non-clinical populations. However, evidence of specificity in this relationship is mixed. White and Hudson (2016) found that increased meta-cognitive beliefs were significantly associated with increased OCS ($N = 187$, 7–12 years, $d = 1.32$). Extending this, Stevanovic et al. (2016) provided evidence of independence in this relationship, as increased meta-cognitive beliefs were significantly associated with increased OCS, after controlling for children's depression symptoms ($N = 66$, 12 years old, $d = 2.67$). Regarding specificity, although children's depression symptoms were not significantly associated with children's meta-cognitive beliefs (after controlling for anxiety symptoms, $d = -0.18$), significant associations have been found between meta-cognitive beliefs and all RCADS anxiety subscales (after controlling for depression symptoms, d's ranged from $d = 0.75$ to $d = 2.14$, Stevanovic et al., 2016) and all SCAS subscales (d's ranged from $d = 0.68$ to $d = 1.28$, White & Hudson, 2016).

Clinical populations

Magical thinking and thought-action fusion. There is limited evidence of an association between 'magical thinking' or TAF and childhood OCS/OCD in clinical populations, and there is currently no evidence that 'magical thinking' or TAF is independently associated with, or specific to, children with OCD. While there was not a significant association between OCD severity and 'magical thinking' or TAF within groups of children with OCD ($N = 18$, 8–12 years, MTQ Total $d = 0.12$, MTQ Thought $d = 0.12$, MTQ Action $d = 0.10$, Verhaak & de Haan, 2007; $N = 26$, 7–11 years, TAF Likelihood Self $d = -0.28$, TAF Likelihood Other $d = -0.30$, TAF Morality $d = 0.39$, Farrell et al., 2012), Barrett and Healy (2003) found that children with OCD reported significantly higher levels of TAF than non-clinical controls ($d = 0.81$). However, concerning specificity, no significant differences between children with OCD and anxiety disorders on ratings of TAF have been shown ($d = 0.46$; Barrett & Healy, 2003).

Meta-cognitive beliefs. There is no evidence that meta-cognitive beliefs are significantly associated with childhood OCS/OCD in clinical samples. For example, Farrell et al. (2012) did not find a significant association between increased meta-cognitive beliefs and increased OCD severity within a sample of children with OCD (7–11 years, $d = -0.26$).

3. Importance of controlling thoughts

No studies were identified which met our eligibility criteria and examined the association between importance of controlling thoughts and childhood OCS/OCD in non-clinical or clinical samples.

4. Overestimation of threat

Two studies (with clinical samples) employed cross-sectional designs to examine the association between overestimation of threat and childhood OCS/OCD

Clinical populations

There is mixed evidence regarding the association between overestimation of threat and childhood OCS/OCD in clinical samples, and no evidence of an independent or specific association to children with OCD. Farrell et al. (2015) found that children with OCD ($N = 22$, 8–12 years) interpreted ambiguous scenarios (including mildly-positive, neutral and mildly-aversive scenarios) as significantly more difficult than non-clinical controls ($N = 26$, $d = 0.86$). However, no significant between-group differences were found for children's open or closed threat interpretations ($d = 0.39$[2] and $d = 0.37$, respectively) appraisals of coping ($d = -0.21$) or coping plans ($d = -0.39$) for ambiguous scenarios. Further, Barrett and Healy (2003) found that children with OCD (7–13 years) reported significantly higher severity of harm ratings for OCD-relevant threats compared to non-clinical controls ($d = 1.07$), yet there were no significant between-group differences for children's ratings of the probability of harm for OCD-relevant threats (d = 1.25). As expected, there were no significant differences for children's ratings of the probability or severity of harm for non-OCD-relevant threats (d = 0.27 and d = 0.48, respectively). Regarding specificity, children with OCD did not report significantly higher severity of harm ratings for OCD-relevant threats compared to children with anxiety disorders (d = 0.71, Barrett & Healy, 2003). Similarly, regarding independence, no significant differences were found between children with OCD and non-clinical controls' difficulty ratings for ambiguous scenarios when controlling for children's comorbid anxiety symptoms (d = 0.17, Farrell et al., 2015).

5. Intolerance of uncertainty

No studies were identified which met our eligibility criteria and examined the association between intolerance of uncertainty and childhood OCS/OCD in non-clinical or clinical populations.

6. Perfectionism

No studies were identified which met our eligibility criteria and examined the association between perfectionism and childhood OCS/OCD in non-clinical or clinical populations.

7. Emotional responses

One study (with a clinical sample) examined the association between emotional responses and childhood OCS/OCD.

Clinical populations

Selles, Franklin, et al. (2018b) provided evidence of a significant association between improvements in children's (N = 46, 5–8 years) distress tolerance throughout treatment and reductions on clinician (but not parent) reported OCD severity at post-treatment (d = −1.32 and d = −0.90, respectively). No research has examined whether this association is independent or specific to children with OCD.

8. Attentional biases

No studies were identified which met our eligibility criteria and examined the association between attention to intrusive, unwanted cognitions or related stimuli and childhood OCS/OCD in non-clinical or clinical populations.

9. Neutralising actions

No studies were identified which examined the association between neutralising actions and childhood OCS/OCD in non-clinical or clinical populations.

10. Counterproductive safety strategies

Two studies (with clinical samples) employed cross-sectional designs to examine the association between counterproductive safety strategies and childhood OCS/OCD.

Clinical populations

There is no evidence that counterproductive safety strategies are significantly associated with childhood OCS/OCD in clinical samples. For example, Farrell et al. (2012) did not find a significant association between OCD severity and thought suppression within a group of children (7–11 years) with OCD (d = 0.22). Similarly, Barrett and Healy (2003) found no evidence that children with OCD (7–13 years) had significantly higher ratings for responses to self-doubt (i.e. by repeating rituals/checking) compared to non-clinical controls (d = −0.10).

11. Family factors

Family member's cognitions

Five studies (with clinical samples) examined the association between family member's cognitions and childhood OCS/OCD; two studies employed cross-sectional designs and three studies used treatment designs.

Clinical populations

There is mixed evidence regarding the association between family members' cognitions and childhood OCS/OCD in clinical samples, and no research has examined whether these associations are independent or specific to children with OCD. For example, when examining the association between family members' cognitions and OCD severity within a sample of children (N = 26, 7–11 years) with OCD, Farrell et al. (2012) found significant positive associations for maternal responsibility attitudes (d = 2.08), thought suppression (d = 1.19) and meta-cognitive beliefs (d = 0.87) but not for maternal TAF (TAF Likelihood Self d = 0.77; TAF Likelihood Other d = 0.52; TAF Morality d = −0.04). Furthermore, Farrell et al. (2015) found that mothers of children (8–12 years) with OCD perceived ambiguous scenarios (including mildly-positive, neutral and mildly-aversive scenarios) as significantly more threatening (on responses to closed, but not open questions, d = 0.68 and d = 0.23[2], respectively) and more difficult (d = 0.69) than mothers of non-clinical controls. However, the between-group differences in mother's appraisals of coping (d = −0.54) or coping plans (d = −0.29) for ambiguous scenarios were not significant.

Regarding the association between parents' distress tolerance or acceptance of their child's emotions and childhood OCS/OCD specifically, inconsistent findings have been found.

For example, whilst Selles et al. (2018b) found that improvements in fathers' tolerance of their child's distress throughout treatment was significantly associated with reductions on clinician (but not parent) report of children's (5–8 years) OCD severity at post-treatment (d = −1.00 and d = −0.85, respectively), no significant associations between improvements in mother's distress tolerance and children's post-treatment OCD severity were shown (CY-BOCS d = −0.58; CY-BOCS-PR d = −0.52). Similarly, although Belschner et al. (2020) did not directly examine the association between changes in parental distress tolerance and changes in children's (N = 13, 6–12 years) OCS/OCD across treatment, analyses showed that despite parents' tolerance of their child's distress significantly increasing through a caregiver-focussed, mindfulness-based intervention (d = 0.94), children's OCD severity did not significantly decrease across this period (d = −0.29). In contrast, Barney et al. (2017) found mean improvements in both parents' acceptance of their child's (N = 3, 10–11 years) emotions and children's OCD severity following Acceptance and Commitment Therapy (ACT; CY-BOCS d = −2.61; NIMH-GOCS d = −5.87; PAAQ d = −0.70).

Family member's behaviours

Eighteen studies (15 with clinical samples) examined the association between family member's behaviours (including 12 different parental behaviours, family accommodation and sibling behaviours) and childhood OCS/OCD. Nine studies employed cross-sectional designs and nine studies used treatment designs to examine the association of interest.

Non-clinical populations

Parental behaviours. There is limited evidence of a significant association between parental behaviours and childhood OCS in non-clinical populations, and there is no evidence that particular parental behaviours are independently or specifically associated with childhood OCS. For example, Grüner et al. (1999) found significant positive associations between children's (N = 117, 9–12 years) reports of maternal and paternal control, anxious parenting and rejection (but not emotional warmth) and children's OCS, after controlling for children's age and gender (maternal control d = 0.52; anxious parenting d = 0.54; rejection d = 0.90; emotional warmth d = −0.32; paternal control d = 0.47; anxious parenting d = 0.49; rejection d = 0.85; emotional warmth d = −0.22). In contrast, Muris and Merckelbach (1998) found no evidence that children's (N = 45, 8–12 years) reports of maternal and paternal behaviours (i.e. warmth, rejection, control or anxious parenting) were associated with children's OCS when using the SCARED OCS subscale. Similarly, Challacombe and Salkovskis (2009) found no evidence that maternal promotion of autonomy, maternal warmth or high levels of expressed emotion were significantly associated with children's (N = 61, 7–14 years) OCS. Regarding specificity, it is noted that significant positive correlations were also found between parental control, anxious rearing and rejection, and all other SCAS subscales (d's ranged from d = 0.39 to d = 0.93, Grüner et al., 1999).

Family accommodation. No eligible studies were identified which examined the association between family accommodation and childhood OCS in non-clinical populations.

Clinical populations

Parental behaviours. There is mixed evidence regarding the association between parental behaviours and childhood OCS/OCD in clinical samples, and no research has examined the independence of these associations. However, there is some evidence that particular parental behaviours are specifically associated with childhood OCS/OCD. When parental behaviours have been examined within a sample of children (7–12 years) with OCD, no significant associations have been found between children's OCD severity and children's reports of parental overprotection (d = −0.43), anxious parenting (d = −0.35) or rejection (d = 0.35, Mathieu et al., 2020). In contrast, Barrett et al. (2002) found that compared to parents of non-clinical controls (N = 22, 7–13 years), mothers and fathers of children with OCD (N = 18; 8–14 years) displayed significantly less warmth (d = −1.24, d = −2.08, respectively), confidence (d = −6.82, d = −7.87, respectively), positive problem solving (d = −1.95, d = −2.22, respectively) and rewarding of children's independence (d = −3.38, d = −4.56, respectively) based on observations of a Family Discussion Task. However, there was no evidence that parents of children with OCD significantly differed from non-clinical controls on observations of maternal/paternal control (d = 2.45, d = 0.49, respectively), maternal/paternal doubt (d = −3.04, d = 0.02, respectively) or maternal/paternal avoidance (d = −0.53, d = 0.24, respectively). Furthermore, Farrell et al. (2013) found no evidence that mothers of children (8–12 years) with OCD significantly differed to mothers of non-clinical controls on displays of autonomy granting (vs. control d = −0.40) confidence (vs. doubt d = −0.07) or warmth (vs. dismissiveness d = −0.69). However, Farrell et al. (2013) did show that mothers of children with OCD displayed significantly greater enhancement of their child's (rather than their own) responsibility for action during a Family Discussion task, compared to mothers of non-clinical controls (who did not differ in enhancement of their own or their child's responsibility for action[1]).

Regarding specificity, although Barrett et al. (2002) found that mothers of children with OCD (N = 18, 8–

14 years) displayed significantly less warmth than mothers of children with anxiety disorders (N = 22, 6–14 years, d = −0.75), no significant differences were found between mothers of children with OCD and externalising disorders (N = 21, 7–12 years, d = 0.60). Furthermore, no significant differences in paternal warmth were found for fathers of children with OCD and anxiety disorders (d = −0.59). Overall, only less frequent displays of parental confidence, positive problem solving and rewarding of children's independence were specific to parents of children with OCD, compared to parents of children with anxiety disorders (maternal confidence d = −4.03; problem solving d = −2.40; reward independence d = −2.89; paternal confidence d = −3.32; problem solving d = −2.18; reward independence d = −2.40) and externalising disorders (maternal confidence d = −1.22; problem solving d = −1.45; and reward independence d = −1.22, Barrett et al., 2002).

Family accommodation. Family accommodation has consistently been found to be significantly associated with childhood OCS/OCD in clinical samples; however, no research has examined the independence of this association, and in the only study to examine disorder specificity, there was no evidence that this association was specific to children with OCD. For example, Lebowitz et al. (2014) found that compared to mothers of non-clinical controls (N = 16, 7–12 years), mothers of children with OCD (N = 21) reported significantly greater levels of overall family accommodation (d = 1.45), participation in rituals (d = 1.25), modification of family routines (d = 1.35) and parental distress when accommodating (d = 1.41). Similarly, when examining the association between OCD severity and family accommodation within groups of children (7–12 years) with OCD, strong significant associations have been found (N = 15, FAS Total d = 7.84, FAS Avoidance of Triggers d = 3.37, Bipeta et al., 2013; N = 24, FAS total d = 1.81, FAS Participation d = 1.19, FAS Modification d = 1.58, Wu et al., 2014). Furthermore, although no eligible treatment studies have statistically examined the association between changes in children's OCD severity and changes in family accommodation across treatment, studies have consistently shown significant improvements in both children's OCD severity and family accommodation from pre-to post-treatment, including following internet-delivered CBT (N = 11, 8–11 years, CY-BOCS d = −1.86, OCI-CV d = −1.65, ChOCI-R-P d = −2.15, FAS d = −2.67, Aspvall et al., 2018); group CBT (N = 32, 7–12 years, CY-BOCS d = −1.74, CY-BOCS-PR d = −1.58, FAS d = −1.51, Selles et al., 2018a); parent-led CBT (N = 6, 10–13 years, Lebowitz, 2013; N = 20, 5–7 years, Rosa-Alcázar et al., 2017; N = 44, 5–7 years, Rosa-Alcázar et al., 2019); and family-based CBT treatments (N = 7, 10–13 years, CY-BOCS d = −3.62, Waters et al., 2001; Rosa-Alcázar et al., 2017; Rosa-Alcázar et al., 2019), with some studies showing maintenance of these effects at 1-month (CY-BOCS d = −0.05, CY-BOCS-PR d = −0.09, FAS d = −0.23, Selles et al., 2018a) and 3-month follow-up periods (CY-BOCS d = −0.30, OCI-CV d = −0.03, ChOCI-R-P d = 0.06, FAS d = −0.04, Aspvall et al., 2018; Rosa-Alcázar et al., 2019; Rosa-Alcázar et al., 2017). Furthermore, Whiteside et al. (2014) also found significant improvements in both children's CY-BOCS (but not ADIS OCD severity) and family accommodation scores following intensive CBT treatment (N = 10, 7–12 years, CY-BOCS d = −1.46; ADIS OCD d = −0.66; FA d = −1.46). In contrast to this overall pattern, Belschner et al. (2020) found no evidence that children's (6–12 years) OCD severity or family accommodation significantly improved across the intervention period of a caregiver-focussed, mindfulness-based intervention (CY-BOCS-PR d = −0.29; FAS d = 0.03). Regarding specificity, Lebowitz et al. (2014) found that mothers of children with OCD (N = 21) did not report significantly greater levels of overall family accommodation (d = 0.40), participation in rituals (d = 0.30), modification of family routines (d = 0.31) or parental distress (d = 0.22) than mothers of children with anxiety disorders (N=17).

Siblings' behaviours. There is some evidence of an association between siblings' behaviours and childhood OCS/OCD in clinical samples; however, no research has examined the independence or specificity of this association to childhood OCS/OCD. Barrett et al. (2000) found that on average, siblings of children with OCD (N = 4, 10–13 years) reported less warmth and greater rivalry in their sibling relationship compared to siblings of non-clinical children (N = 5, 8–12 years; d = −0.37 and d = 1.17, respectively); however, there were no mean differences in sibling dominance or conflict (d = 0.00 and d = 0.03, respectively). Furthermore, Barrett et al. (2000) also found evidence of mean improvements in both children's OCD severity (d = −4.64) and sibling warmth (d = 0.13), dominance (d = −0.55), conflict (d = −0.25), rivalry (d = −2.25), overall accommodation (d = −1.89), participation in rituals (d = −1.95), modification of routines (d = −1.61) and distress when accommodating (d = −0.64) following CBT treatment.

Robustness of data synthesis

According to liberal thresholds suggested by Kmet et al. (2004), three studies were defined as poor quality (i.e. <55% quality ratings; Barrett et al., 2000; Lebowitz, 2013; and Muris & Merckelbach, 1998). Although studies were not excluded on this basis, re-examination of the results without these studies provides greater confidence that some parental behaviours (i.e. parental control, anxious parenting and rejection) are significantly associated with childhood OCS in non-clinical populations. However, there continued to be a lack of evidence that this association was specific to childhood OCS. Furthermore, without the inclusion of Barrett et al. (2000) there is no evidence on the potential role of sibling behaviours in the maintenance of childhood OCS/OCD. Overall, the main results of this review remain unchanged.

Discussion

This review synthesised 29 studies examining the association between childhood OCS/OCD and proposed maintenance factors identified from adult cognitive behavioural models of OCD, and descriptions of how family factors may maintain childhood OCS/OCD.

As shown in Figure 2, no eligible studies were identified for the importance of controlling thoughts, intolerance of uncertainty, perfectionism, attentional biases or neutralising actions. Furthermore, although there was evidence of cross-sectional associations between childhood OCS/OCD and all other cognitive and familial maintenance factors (but not behavioural factors, i.e., counterproductive safety strategies), findings were often inconsistent between and within studies. Notably, however, there were large, independent associations between childhood OCS and two cognitive factors, that is, inflated responsibility and meta-cognitive beliefs, after controlling for children's depression symptoms (Magnúsdóttir & Smári, 2004; Stevanovic et al., 2016, respectively). Similarly, large, specific associations between childhood OCS/OCD and three (of the 12) parental behaviours examined were found (i.e. less frequent displays of parental confidence, positive problem solving and rewarding of children's independence; Barrett et al., 2002). However, the association between parental confidence and childhood OCS/OCD was not consistently found across studies, with Farrell et al. (2013) not finding a significant association between reduced maternal confidence and childhood OCS/OCD. Finally, there was some, albeit limited evidence, that meta-cognitive beliefs may be specific to childhood OCS, on the basis that there was a significant association between children's meta-cognitive beliefs and OCS (whilst controlling for depression symptoms), but no evidence of a significant association between children's meta-cognitive beliefs and depression symptoms (whilst controlling for anxiety symptoms, Stevanovic et al., 2016). Crucially, there were no experimental studies and no studies which examined longitudinal associations directly, limiting any conclusions which can be drawn about the direction of any associations identified.

This review focused specifically on preadolescent children with OCD, and the results are both consistent with and contradictory to previous reviews examining the relevance of adult cognitive models of OCD to child and adolescent populations. Consistent with our findings, Mantz and Abbott (2017) concluded there was insufficient evidence to support a link between children (and adolescents') cognitive beliefs and the maintenance of OCS/OCD. In contrast, Reynolds and Reeves (2008) concluded that there was broad support for the application of adult cognitive models of OCD to child and adolescent populations. Several reasons for these contradictory conclusions exist. First, Reynolds and Reeves (2008) placed less emphasis on whether cognitive beliefs were independently or specifically associated with OCS/OCD in young people than the current review. For example, correlational studies (not controlling for other psychopathological symptoms) were used as evidence to support the application of adult cognitive models of OCD to young people. Second, Reynolds and Reeves (2008) considered a broader age range of participants (i.e. <18 years old) and notably the older samples within this range provided greater evidence that cognitive beliefs are specific to young people with OCD (i.e. Libby et al., 2004) than was available for preadolescent samples. Finally, in contrast to the current review, Reynolds and Reeves (2008) included a broader range of papers (i.e. papers which did not examine the association between a measure of childhood OCS/OCD and a proposed maintenance factor measure) to inform their conclusions.

Limitations of the existing literature

The studies included in this review have several limitations to consider, including the heterogeneity of measures used, research designs employed and study power. These will now be considered in turn.

Variability in OCS/OCD measures. There was considerable variability in the measures of OCS/OCD employed, and their psychometric properties. Ten different measures of childhood OCS/OCD were used, which may account for the inconsistent findings both between and within studies (Brakoulias et al., 2014). This was illustrated by Simonds et al. (2009) who found substantially different effect sizes for the association between children's OCS and 'magical thinking' when using two different OCS measures. Furthermore, the psychometric properties of the OCS/OCD measures varied. For example, whilst some studies have shown the LOI-CV significantly correlates with the CY-BOCS (e.g. Scahill et al., 1997) – which is considered the gold standard measure of OCD for young people (Lewin & Piacentini, 2010), other studies have not (e.g. Stewart et al., 2005; Storch et al., 2011). Future research would benefit from using measures of OCS/OCD which are specifically designed and validated for preadolescent children.

Variability in maintenance measures. There was also considerable diversity in the measures of proposed maintenance factors used, limiting our ability to compare and synthesise existing knowledge in the field. For example, of the four studies examining inflated responsibility, four different measures were used, including assessments individualised to children's most frequent intrusions (e.g. Barrett & Healy, 2003); RAS (e.g. Farrell et al., 2012); RAS-C (e.g. Magnúsdóttir & Smári, 2004); and OBQ-CV (e.g. Mathieu et al., 2020). Furthermore, the cognitive measures used (e.g. RAS; revised TAF scale; WBSI) were often adapted from adult cognitive measures and lack sufficient validation for younger populations (Mantz & Abbott, 2017). As such, it is unclear whether these measures examined the intended mechanisms, due to differences in adults' and children's cognitive development (Casey et al., 2005). The development and validation of valid and reliable measures that can be used consistently to examine the proposed maintenance factors specifically among preadolescent children is urgently required.

Research design. Our knowledge of the mechanisms which maintain childhood OCS/OCD is limited by the research designs employed. Critically, no experimental or prospective longitudinal studies were identified in this review, which are crucial to determine the direction of effects between childhood OCS/OCD and proposed maintenance factors. Instead, studies most commonly used correlational designs. This was particularly problematic in studies where the sample consisted only of children with OCD, as there was a restricted range of OCS. This meant that the non-significant associations found between children's OCS and proposed maintenance factors within samples of children with OCD may have resulted from insufficient variability in OCS, rather than the absence of a maintenance effect. Furthermore, few treatment studies statistically examined the association between changes in children's OCS and changes in proposed maintenance factors, considerably limiting the conclusions which can be drawn from these studies. Finally, few studies compared children with OCD to children with other mental health disorders, such as anxiety disorders, limiting our understanding of whether the proposed maintenance factors are specifically associated with OCD in children.

Study power. Studies conducted with clinical populations often had small sample sizes and either failed to report power analyses or were insufficiently powered to detect potentially clinically meaningful effects. This limits our understanding of whether the proposed maintenance factors apply to preadolescent children, as non-significant associations could often be attributed to limited power. Thus, researchers need to ensure future studies are sufficiently powered to detect meaningful effects.

Strengths and limitations of the review

This is the first review to examine the applicability of adult cognitive behavioural models of OCD exclusively to preadolescent children and extends previous reviews by examining a broader range of mechanisms in the maintenance of childhood OCS/OCD. An extensive electronic search using broad search terms was conducted, and forward citation handsearching was carried out to identify recently published papers. Furthermore, the authors of 96 papers were contacted to request re-conducted analyses for participants within our specified age range. Nonetheless, a number of limitations need to be considered. First, of the studies where data was re-analysed (n = 7), sample sizes were often small and/or insufficiently powered to detect potentially meaningful differences through significance testing, limiting the conclusions which can be drawn from these studies. For example, where the results of re-conducted analyses differed to the original papers (e.g. Belschner et al., 2020; Whiteside et al., 2014), it is unclear whether this was due to the age of the participants. Second, the scope of this review was limited by our classification of maintenance measures during the screening stages (see Prospero CRD42019153371 for full details). For example, the CY-BOCS was only classed as a measure of OCS/OCD and not a measure of maintenance. This meant that papers using specific items of the CY-BOCS (e.g. avoidance and doubt) to measure maintenance were not included in this review. Furthermore, given that some of the proposed maintenance factors identified from adult models of OCD are also core features of the disorder (e.g. emotional and behavioural responses), there was overlap in the measures of OCS/OCD and some of the maintenance factor measures used (e.g. measures of counterproductive safety strategies) – limiting the conclusions which can be drawn. Third, this review was limited by our study design criteria. We required studies to examine the association between a proposed maintenance factor and a measure of childhood OCS/OCD, and not, for example a measure of an element of OCS/OCD. This meant that we did not include studies such as Reeves et al. (2010), who experimentally manipulated non-clinical youths' perceived responsibility for a task and examined the effect on variables including checking, hesitation and state anxiety. Thus, some studies which may contribute to our understanding of the relevance of adult models of OCD to youth were not eligible for the review. Fourth, we used effect size calculators which assumed statistical independence between proposed maintenance factor and OCS/OCD scores at different timepoints (i.e. pre- and post-treatment study scores), which may have resulted in inaccurate calculations in some circumstances. We also extrapolated the recommended values for converting standardised regression coefficients to Pearson's r. Finally, this review focused on proposed maintenance factors derived from theoretical accounts of the development and maintenance of OCD – however, it may be necessary to derive hypotheses about the mechanisms which maintain childhood OCD directly from children themselves, for example, through qualitative research. This approach has facilitated the understanding of other psychological disorders (e.g. psychosis, Isham et al., 2019) and has the potential to advance clinical interventions (Isham et al., 2019).

Conclusion

This systematic review examined the putative maintenance mechanisms for childhood OCS/OCD as identified from theoretical models of adult OCD and descriptions of how family factors may maintain childhood OCS/OCD. While there was some evidence of cross-sectional associations between childhood OCS/OCD and certain proposed maintenance factors, there is currently limited evidence that these associations are independently or specifically associated with childhood OCS/OCD. Inflated responsibility and meta-cognitive beliefs have been shown to be independently associated with childhood OCS (when controlling for children's depression symptoms). Similarly, meta-cognitive beliefs may be specific to childhood OCS, as significant associations have been found between children's meta-cognitive beliefs and OCS but not between children's meta-cognitive beliefs and depression symptoms (when controlling for children's anxiety symptoms). Finally, certain parental behaviours (e.g. reduced confidence, positive problem solving and rewarding of children's independence) have showed evidence of specificity to children with OCD (when compared to children with anxiety disorders and children with externalising disorders). However, findings are often inconsistent both between and within studies and there is currently no evidence that can allow conclusions about the direction of these associations, and, as such, whether these factors do in fact have a *maintaining* role. Given the detrimental impacts of childhood OCD, future research urgently needs to use experimental and prospective longitudinal designs to elucidate whether the proposed maintenance mechanisms *maintain* childhood OCD, to improve the efficacy of CBT for preadolescent children with OCD.

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Notes

1. Insufficient information to calculate Cohen's *d*.
2. Insufficient information to determine the direction of Cohen's *d*.

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2.3 Further information on methodological decision making

Due to the nature and scope of journal articles, I was unable to comment on the rationale for all decision making processes in the systematic review paper. Thus, information on decisions not discussed in the paper are presented here.

Given that multiple cognitive behavioural maintenance models of OCD exist (Franklin & Foa, 2011), I had to decide which models to focus on in this systematic review. Salkovskis' (1985) model of OCD was chosen as this is the most widely cited cognitive behavioural maintenance model of OCD. The Obsessive Compulsive Cognitions Working Group (OCCWG)'s (1997) six key belief domains were also chosen as this work brings together a number of relevant models of OCD. For example, the belief domain 'over importance of thoughts' encompasses the concept of Thought Action Fusion (Rachman, 1993) and 'magical thinking' (Zusne & Jones, 1989). Similarly, 'over importance of thoughts' and 'importance of controlling thoughts' share commonalities with the meta-cognitive model of OCD (Wells & Matthews, 1994). Moreover, the work of both Salkovskis (1985) and OCCWG (1997) can also be considered to encompass other models of OCD not discussed in this paper, including the models proposed by Wilheim and Steketee (2006) and Foa and Kozak (1986), which also emphasise the role of maladaptive interpretations of intrusive cognitions (Wilheim & Steketee, 2006) and beliefs regarding the probability and severity of harm (Foa & Kozak, 1986) as central to the maintenance of OCD.

In line with other recent systematic reviews relating to child and adolescent mental health (e.g., Lawrence et al., 2019; Plaisted et al., 2021; Reardon et al., 2017), I decided to only include peer-reviewed journal articles that were available in English in the systematic review. This decision was made as the peer-review process aims to assess and improve the quality of research prior to publication (Burnham, 1990; Kelly et al., 2014). Furthermore, the inclusion of non-English studies has been shown to considerably increase the resources required to conduct a systematic review (Hartling et al., 2017) and would have resulted in practical challenges (i.e., payment for translation services) beyond the remit of this studentship. Despite this rationale, the decision to exclude ‘grey’ literature (i.e., materials that have not been academically peer-reviewed, such as dissertations, pre-prints, and conference abstracts, Adams et al., 2017) and non-English articles means that not all studies relevant to this review may have been identified (Blackhall, 2007) and the review may be subject to publication bias, whereby null results are less likely to be published in English peer-reviewed journals (Egger & Smith, 1998; Heres et al., 2004).

I also decided to exclude papers that examined obsessive compulsive symptoms (OCS) or disorder (OCD) in the context of other comorbid conditions such as autism, attention deficit hyperactivity disorder (ADHD), eating disorders, and physical health conditions. This decision was made as this systematic review aimed to identify the maintenance mechanisms relevant to childhood OCS/OCD that could be targeted in a brief low-intensity first-line psychological intervention, whereas treatments for children with these comorbid difficulties may require additional adaptions and/or longer treatments (e.g., Jassi et al., 2021; Lock, 2015).

Finally, I assessed the quality of eligible studies to enable us to draw conclusions that reflected the quality of the existing evidence-base (Siddaway et al., 2019). I decided to use Kmet et al.’s (2004) quality assessment tool, as this tool facilitates a comprehensive assessment of studies that are methodologically diverse. However, given the plethora of quality assessment tools that exist (Siddaway et al., 2019), I considered a range of possible tools. The Cochrane Risk of Bias Quality Assessment Tool (Higgins et al., 2016) is the recommended quality assessment tool for randomised controlled trials (Jørgensen et al., 2016), however, this tool was deemed inappropriate for the current review, given the broad range of study designs that needed to be assessed. There is a lack of agreement regarding the recommended tool for non-randomised studies (Quigley et al., 2019), however, the most commonly used are the Newcastle Ottawa Scale (which assesses study quality in three domains: study selection, control, and outcomes, Wells et al., 2000) and the Risk of Bias in Non-Randomised Studies – of Interventions (ROBINS-I, which facilitates the assessment of study characteristics and reporting of results, Sterne et al., 2016). Although some of the assessment domains of both scales can be applied to broad study designs, these scales were predominantly designed to assess cohort studies, and thus lacked sufficient breadth for the current review. Furthermore, in contrast to Kmet et al. (2004), neither scale facilitated the assessment of authors' rationale for their chosen statistical analyses or the quality of authors' conclusions.

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Chapter 3: Paper 2

Parents’ experiences of parenting a preadolescent child with OCD: A qualitative study

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[1] Minor changes have been made to this manuscript (i.e., adoption of APA referencing style and inclusion of tables and figures in the text) for the purpose of this thesis.

3.1 Introduction to Chapter 3 (Paper 2)

Chapter 2 (Paper 1) consisted of a systematic review examining the cognitive, behavioural, and familial mechanisms in the maintenance of obsessive compulsive symptoms (OCS)/OCD in preadolescent children to help inform the content of a brief low-intensity therapist guided, parent-led CBT intervention.

Following this, it was necessary to understand parents' experiences of parenting their preadolescent child with OCD to ensure the developed intervention was sensitive to parents' experiences and needs. In Chapter 3 (Paper 2), I therefore used semi-structured qualitative interviews to facilitate the collection of rich data surrounding parents' experiences of parenting a child with OCD to further inform the development of the intervention.

Parents' experiences of Parenting a Preadolescent Child with OCD: A qualitative study

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Abstract

Obsessive Compulsive Disorder (OCD) has negative impacts on affected preadolescent children; however, little is known about parents' experiences of parenting a preadolescent child with OCD, and limited provision exists to help parents to support their children. This study aimed to explore parents' experiences of parenting a preadolescent child with OCD using semi-structured, qualitative interviews to inform the development of such provision. Twenty-two parents (15 mothers; 7 fathers) of 16 children (7- to 14-years-old) who had experienced OCD were interviewed. Reflexive thematic analysis was used to generate two overarching themes: (1) challenge and frustration, and (2) helplessness, and five themes: (1) the journey to understanding and coming to terms with OCD, (2) the battle for support, (3) navigating how to respond to OCD, (4) OCD is in control, and (5) the emotional turmoil of parenting a preadolescent child with OCD. The need for clear, accessible, and scalable support for parents of preadolescent children with OCD was identified.

Key words:

Obsessive Compulsive Disorder; Qualitative; Parents; Children

Introduction

Obsessive Compulsive Disorder (OCD) is characterised by obsessions and/or compulsions (American Psychiatric Association, 2013) and commonly first occurs during preadolescent years (Geller et al., 1998). Experiencing OCD during preadolescence has also been associated with greater persistence of the disorder overtime (Stewart et al., 2004).

In addition to the obvious negative impacts on affected children, parents of preadolescent children with OCD report impairments to wider family functioning (Garcia et al., 2010; Piacentini et al., 2003), high levels of parental distress and anxiety (Stewart et al., 2017; Storch et al., 2009), and often feel helpless as to how to help or respond to their child's difficulties (Futh et al., 2012). Furthermore, parenting a child with OCD may have distinct challenges, given that family accommodation (i.e., participation and/or facilitation of rituals, provision of reassurance, and/or facilitating avoidance of OCD triggers, Waters & Barrett, 2000) is frequently reported among parents in this population (Monzani et al., 2020; Peris et al., 2008). This highlights the need to provide support and guidance to parents of preadolescent children with OCD, which may alleviate distress both for the parents and also for their children with OCD. Indeed, parents have been shown to be able to effectively help their child to overcome OCD when supported by a therapist (e.g., Rosa-Alcázar et al., 2019). However, parent-focused programmes to date have provided levels of support for parents which may not be easily disseminated at a large scale (e.g., approximately 12 hours of individual therapist input in Rosa-Alcázar et al., 2019).

To develop ways of supporting parents of preadolescent children with OCD that can be delivered at scale, we need to understand parents' experiences of parenting a child with OCD, to ensure that the support provided reflects parents' experiences, needs, and wishes. To date, limited research has explored this qualitatively. One exception is Futh et al. (2012) who used written narratives to explore mothers' and fathers' understanding and management of their children and adolescents' (9- to 18-years-old) OCD. Using thematic analysis, they generated four themes: (i) parents' finding it hard to 'make sense' of their child's OCD, (ii) OCD having 'power' over their child and others (resulting in parental helplessness and frustration), (iii) the 'impact' OCD had on their child and family, and (iv) parents' 'engagement' in accommodation/resisting accommodation of OCD. Although providing useful insights, the use of written narratives may have limited richness compared to, for example, interviews which allow the researcher to explicitly respond to and probe participants' responses to obtain a rich, detailed understanding of their experiences (Smith, 2015). Kerby (2018) extended this by conducting in-depth qualitative interviews with nine parents of adolescents (12- to 15-years-old) with OCD to explore their cognitive, behavioural, and emotional experiences of parenting their child. Interpretative Phenomenological Analysis (IPA) was used to identify eight themes, including 'relief' at their child's OCD diagnosis, 'fear', 'anxiety', 'sadness', 'anger', 'guilt', and 'judgement' in relation to their child's OCD, and 'joy' when their child overcame OCD. Although Kerby (2018) provides a useful insight into parents' experiences of parenting an adolescent with OCD, to date, no studies have specifically explored parents' experiences of parenting a *preadolescent* child with OCD. This is crucial, given that preadolescent children are more reliant than adolescents on their parents (Freeman et al., 2003; Hill et al., 2007) and thus, parents of preadolescent children with OCD may experience unique challenges. This study therefore conducted in-depth, semi-structured qualitative interviews to build on the existing literature and explore experiences of parenting a preadolescent child (7- to 12-years-old) with OCD. Reflexive Thematic Analysis (TA) was used to analyse the data, as this enables the researcher to generate patterns of shared meaning across a diverse range of participants (Braun & Clarke, 2020a).

Method

This study was approved by London Bridge NHS Research Ethics Committee (19/LO/0514) and the University of Reading Research Ethics Committee (UREC 19/09) and is reported in accordance with the COREQ checklist (Tong et al., 2007).

Recruitment

We recruited parents of children (7- to 12-years) who were suspected of having OCD or currently diagnosed with OCD, and parents of children (7- to 14-years) who were previously diagnosed with OCD (when aged 7- to 12-years) by a mental health professional. Parents were recruited from two Child and Adolescent Mental Health Services (CAMHS) in Southeast England, UK-based mental health charities, social media, and UK-based private treatment providers.

For those recruited through CAMHS, families completed semi-structured diagnostic interviews to identify the child's presenting problem following routine procedures in both CAMHS settings. Where OCD was diagnosed, a clinical team member approached parents to provide them with study information and to seek consent for their contact details to be shared with the research team.

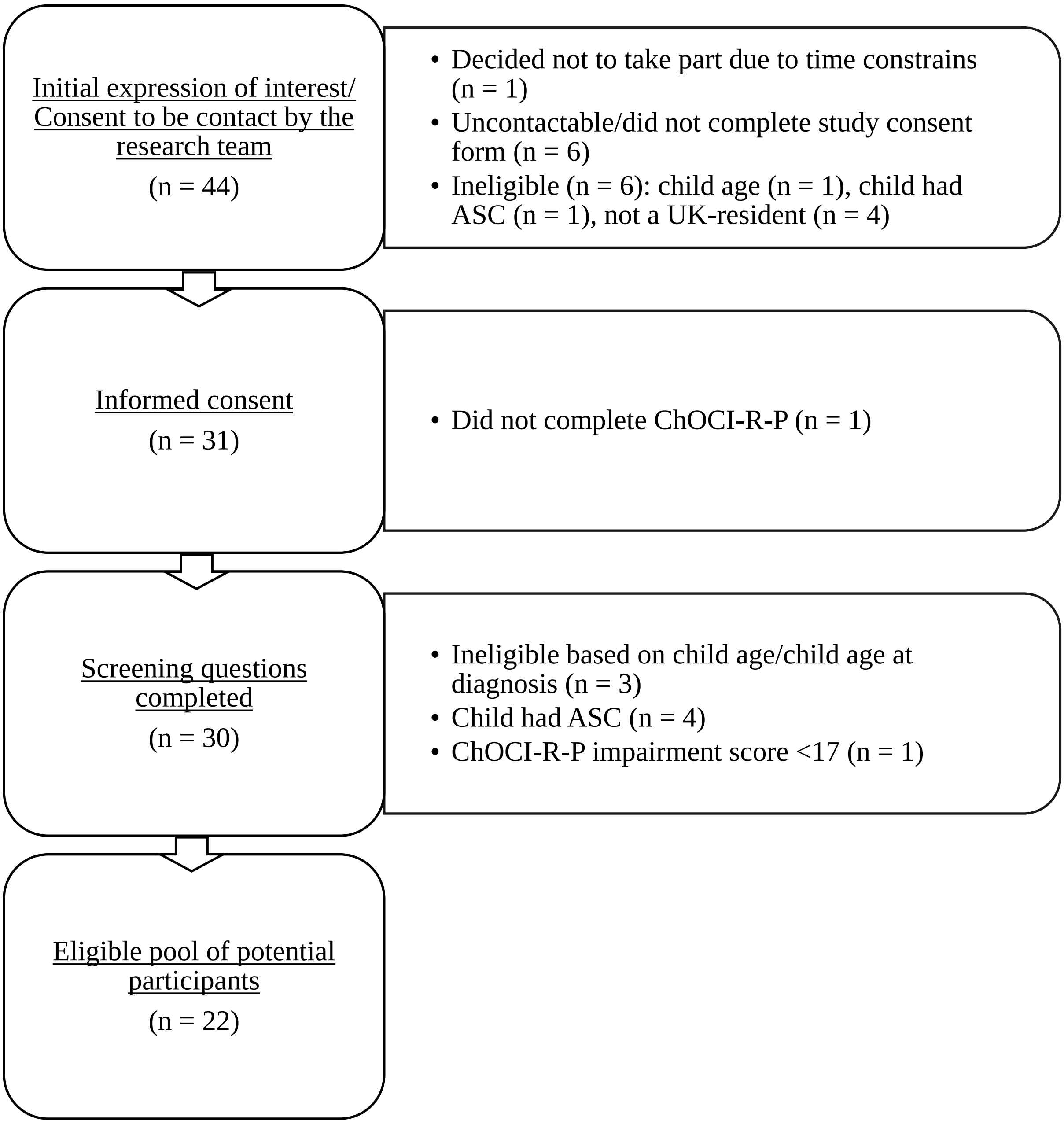
Parents could also refer themselves into the study using an online link. Information was made available through posters displayed in the participating CAMHS waiting rooms and were distributed to charities, private treatment providers, and across social media sites. The study researcher (CCh) contacted interested parents via telephone and/or email to discuss the study and seek written informed consent from parents to participate. After providing informed consent, parents completed a screening questionnaire collecting demographic information and information about their child's mental health diagnoses and stage in the help-seeking process. If children were suspected to have OCD (but did not have a diagnosis provided by a mental health professional), parents were asked to complete the Children's

Obsessional Compulsive Inventory Revised Parent report (ChOCI-R-P) to determine their eligibility for the study. Parents were eligible for the study if their child had an impairment score >17 on the ChOCI-R-P. Parents of children (aged 7- to 14-years) who had previously been diagnosed with OCD (when aged 7- to 12-years) were only eligible for the study if their child's diagnosis had been provided by a mental health professional.

Parents were not eligible for the study if their child had a diagnosis of an Autism Spectrum Condition (ASC) or a significant learning disability, as treatments for these populations often require specific adaptations (Sze & Wood, 2007). Similarly, parents were not eligible for the study if they did not live in the UK, could not speak sufficient English, or had an intellectual impairment that would interfere with their ability to complete measures or participate in an interview.

Eligible parents formed a pool of potential participants ahead of purposive sampling (see Figure 1). Parents who were selected for interview were provided with a £10 voucher.

Figure 1. Recruitment of participants.



Note. ASC = Autism Spectrum Condition; ChOCI-R-P = Children's Obsessional Compulsive Inventory Revised Parent report

Measures

Screening Questionnaire

Parents completed a brief screening questionnaire measuring parent and child age, gender, self-reported ethnicity (in accordance with the categories outlined by the Office for National Statistics, 2022), parental employment status (i.e., unemployed, employed full-time or part-time or other), parental education status (i.e., school completion, further education, higher education, or postgraduate qualification), caregiver status (i.e., primary, secondary, shared caregiver, or other) and parental relationship status (i.e., single, married, remarried, divorced, separated, living with partner, widowed, or not applicable) as it was anticipated that these demographic factors may influence parents' experiences of parenting their child. Children's diagnostic and treatment history and stage in the help-seeking process was also collected.

Children's Obsessional Compulsive Inventory – Revised, Parent Report (ChOCI-R-P, Uher et al., 2008)

The ChOCI-R-P is a parent-report measure to assess OCD symptoms and severity in children and adolescents. It consists of two sections assessing obsessions and compulsions. Each contains 16 questions: 10 to assess the presence of symptoms using a 3-point scale, and six to assess the associated impairment using a 5-point scale. Parent reported impairment scores are summed to produce a total impairment score (out of a total of 48). A total impairment score >17 on the ChOCI-P (which derives the impairment score in the same way) has been shown to have adequate sensitivity and specificity to determine an OCD diagnosis (Shafran et al., 2003).

Participants

We used a purposive sampling approach to capture diversity in parents' experiences and views, and thus, invited parents to interview who varied according to: (1) child age and gender, (2) parent gender and caregiving role, (3) stage in the help-seeking process, and (4) demographic characteristics. We used an *information power* approach to determine our sample size, which considers factors such as breadth of the research questions and diversity of participants (Malterud et al., 2016). Given that we aimed to examine breadth of experiences across a diverse range of parents, we anticipated that between 10 and 20 interviews would be required to generate a rich, complex dataset. Twenty parents (14 mothers, 6 fathers) of 14 children were initially interviewed. As recommended by Braun and Clarke (2021) and Malterud et al. (2016), we used the data collected to decide upon our final sample size, based on its richness and complexity. Towards the end of interviewing, we noted that parents of younger children and parents from non-White backgrounds were providing additional complexity and insights – thus, we sought to recruit two additional parents who either had a younger child and/or who identified as being from a non-White background. The final sample consisted of 22 parents (15 mothers, 7 fathers) of 16 children (see Table 1 for participant characteristics). Twelve parents were recruited through CAMHS, and 10 parents were recruited from charities, private treatment providers, or social media. The sample was predominantly White British, with some parents identifying themselves and/or their children from other White, Mixed, or Asian backgrounds. Eighteen parents had completed at least an undergraduate degree and twenty parents were employed either full-time or part-time. All families had sought professional support for their child's difficulties. Many families were either waiting to receive treatment with their local CAMHS (n = 7) or specialist service (n = 1) and/or were receiving treatment with CAMHS (n = 4) or private treatment providers (n = 4). Five families had previously received treatment for their child's OCD.

Table 1. Participant Characteristics

Child	
n	16
Mean age (range), years	11.8 (8 – 14)
Mean age of diagnosis (range), years	10.3 (6 – 12)
Female, n (%)	9 (56.3%)
Ethnicity[a]	
White British, n (%)	13 (81.3%)
Any other white background, n (%)	1 (6.3%)
Mixed background, n (%)	1 (6.3%)
Asian background, n (%)	1 (6.3%)
Parent	
n	22
Mean age (range), years	44.6 (35 – 56)
Mother, n (%)	15 (68.2%)
Ethnicity	
White British, n (%)	16 (72.7%)
Any other white background, n (%)	2 (9.1%)
Asian background, n (%)	2 (9.1%)
Not stated	2 (9.1%)
Caregiving role	
Primary caregiver, n (%)	9 (41.0%)
Secondary caregiver, n (%)	3 (13.6%)
Shared caregiver, n (%)	10 (45.5%)
Parent education	
School completion, n (%)	1 (4.5%)
Further education (e.g., college, vocational courses), n (%)	3 (13.6%)
Higher education (e.g., undergraduate degree), n (%)	12 (54.5%)
Postgraduate education, n (%)	6 (27.3%)
Parent employment status	
Unemployed, n (%)	2 (9.1%)
Employed (part-time), n (%)	9 (41.0%)
Employed (full-time), n (%)	10 (45.5%)
Other (self-employed), n (%)	1 (4.5%)
Help-seeking	
Not sought treatment, n (%)	0
Waitlist for treatment, n (%)	8 (50%)
Currently receiving treatment, n (%)	8 (50%)
Previously received treatment, n (%)	5 (31.3%)
Recruitment source	
CAMHS	12 (54.5%)
Other (e.g., charities, social media, private treatment providers)	10 (45.5%)

Note. [a] Ethnicity categories taken from Office for National Statistics (2022).

Procedure

A topic guide was developed based on relevant research evidence (e.g., Futh et al., 2012; Storch et al., 2009; Wu et al., 2014) and the authors' clinical experience of working with families of children with anxiety disorders and OCD. Its aim was to broadly explore parents' experiences of parenting a child with OCD. Two Public and Patient Involvement (PPI) members, with experience of parenting a child with OCD, reviewed the topic guide and participated in a practice interview to increase the acceptability of the questions to families. Interviews were conducted by the first author (CCh) who is a female PhD student trained in qualitative methods and qualified Psychological Wellbeing Practitioner (PWP) with experience of delivering brief low-intensity CBT interventions with parents of children with anxiety disorders. The interviewer had briefly encountered two participants prior to the study (one at a national conference where the study was advertised and one during her honorary clinical role where she introduced the study to a participant). Participants were told that the purpose of the study was to improve understanding of the experiences of parenting a child with OCD so that the research team to might design treatments that better support families. Participants were able to ask questions about the researcher and their research interests if they chose to. Interviews were conducted via telephone (n = 19) or face-to-face (n = 3) at the University of Reading. Face-to-face interviews took place in a quiet room with only the interviewer and participant present except for one interview where a participant's child (who did not have OCD and who wore headphones for the duration of the interview) attended. Interviews lasted an average of 73 minutes (range 45 – 121 minutes) and were audio-recorded. Interviews were transcribed verbatim, with identifying information removed. Field notes were made during and after each interview.

Data analysis

Reflexive Thematic Analysis (TA) was used to generate patterns of shared meaning across the dataset (Braun & Clarke, 2020a). We adopted an essentialist/realist epistemological approach to data analysis, which assumes that language allows participants to express their experience and meaning (Potter & Wetherell, 1987; Widdicombe & Wooffitt, 1995). Reflexive TA values the researchers' subjectivity in the analytic process and encourages researchers to be aware of and reflect on their assumptions and biases (Braun & Clarke, 2020a, 2020b). CCh conducted this study as part of doctoral research that aimed to increase access to psychological treatments for children with OCD. CCh (who is a PWP), AF, CCr and BH (who are Clinical Psychologists) have experience of delivering therapist guided, parent-led CBT to parents of children with anxiety disorders, a treatment developed by CCr that is routinely delivered in NHS services. CCh, AF, CCr, and BH also have experience of delivering psychological treatments to children and adults with a range of mental health difficulties, and AF and BH have particular expertise in assessment and treatment for OCD. CCr, BH, and KH all have considerable experience of conducting and supervising qualitative research.

Data analysis followed the six-stages of reflexive TA outlined by (Braun & Clarke, 2022) and was led by CCh. CCh met regularly with the research team during the initial code generation to facilitate interpretation of the data. Two in-depth coding meetings with CCh, CCr, BH and KH were held during theme development and refinement to consider alternative understandings of the data and ensure the credibility of the final interpretation. NVivo (Bazeley & Jackson, 2013) was used to store data and support data analysis. Participants were not provided with an opportunity to give feedback on the findings but were given the option of receiving a summary of the study results.

Results

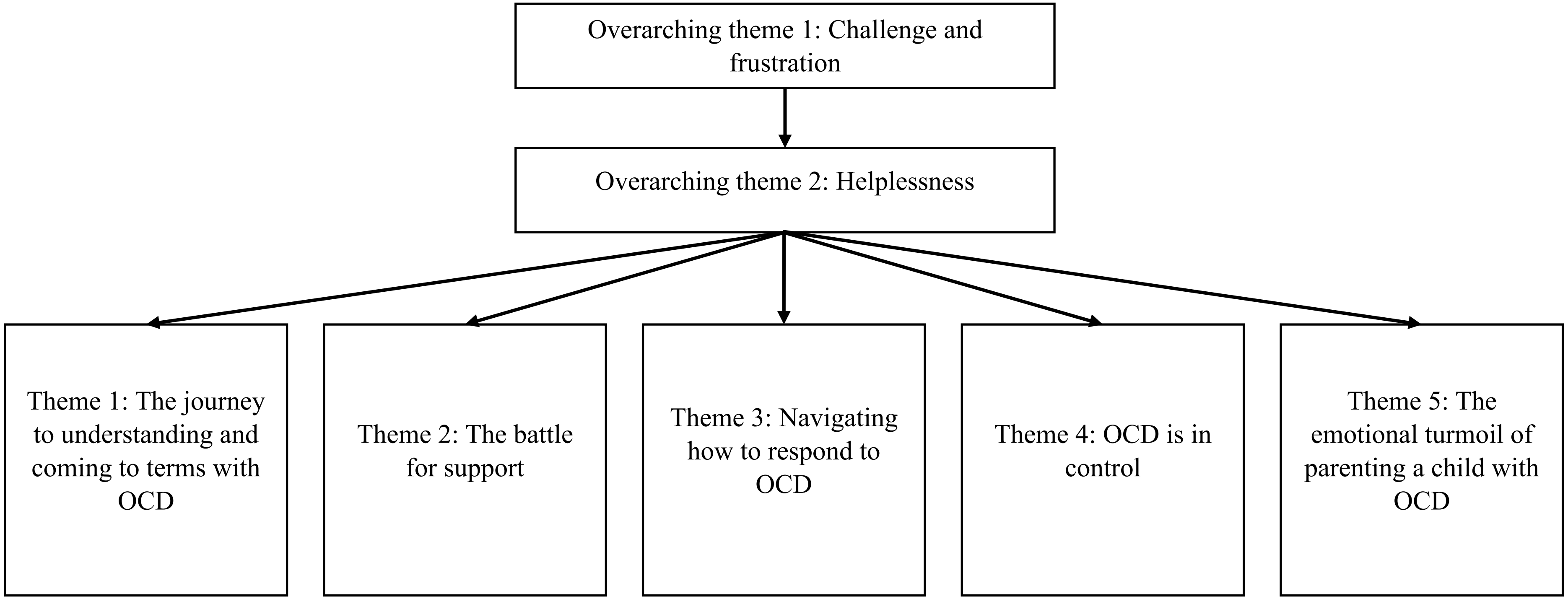
A thematic map of the results is shown in Figure 2. Table 2 reports individual participant characteristics to aid interpretation of the results.

Table 2. Individual participant characteristics

Participant ID	Caregiver	Child age	Child gender	Received any treatment
15	Mother	7 – 11	Female	No
17	Mother	7 – 11	Female	No
18	Mother	12 – 14	Male	No
19	Mother	7 – 11	Female	Yes
23	Mother	12 – 14	Male	Yes
24	Mother	12 – 14	Female	Yes
25	Mother	12 – 14	Female	Yes
30	Mother	12 – 14	Female	Yes
31	Mother	7 – 11	Male	Yes
33	Mother	12 – 14	Female	Yes
35	Mother	12 – 14	Male	Yes
37	Mother	12 – 14	Male	Yes
38	Mother	12 – 14	Male	No
40	Mother	12 – 14	Female	Yes
44	Mother	7 – 11	Female	Yes
22	Father	7 – 11	Female	No
26	Father	7 – 11	Female	No
27	Father	12 – 14	Male	No
28	Father	7 – 11	Female	Yes
34	Father	12 – 14	Male	Yes
39	Father	12 – 14	Female	Yes
43	Father	12 – 14	Female	Yes

Note. To preserve the anonymity of participants, child age is reported as 7- to 11-years or 12- to 14-years and child and parent ethnicity are not reported.

Figure 2. Thematic map.



Theme 1: The journey to understanding and coming to terms with OCD

Subtheme: *'I just didn't know what was going on with my child' [ID31, mother]*

Parents often found it challenging when they were unaware that their child was experiencing OCD. For some, there was a sense of unfamiliarity, *'didn't even know it was OCD ... it just didn't make any sense' [ID43, father],* whereas others struggled to differentiate between normative childhood development and disordered behaviour.

- *'I think a lot of it I didn't really notice for a while because ... kids are always running their hands along walls and tapping things and touching things, that's what kids do when they are young' [ID28, father]*

Even when parents knew their child had OCD, they found it hard to identify what was OCD versus other difficulties – for example, other mental health problems or hormonal changes.

- *'It's difficult to know how much of it is hormones, how much of it is a typical teenage tantrum, or it's a teenage tantrum with OCD or it's OCD. It's really hard to distinguish between those three possibilities, which are every possibility when he is kicking off' [ID23, mother]*

Furthermore, parents found it challenging to relate to their child's difficulties. They perceived OCD to be *'really quite irrational' [ID17, mother]* and found it *'immensely frustrating' [ID37, mother].*

- *'There's things like, we have been out for a walk, where she has ... touched a branch or something [and] you find out that there is dirt on it somewhere, or there might have been dogs gone near it ... and she gets really upset about that, the thought that she could have touched dirt or poo or something like that, um even when it's ...*

ridiculous that it could even, you know, that it's so remote the chance of that happening' [ID39, father].

Despite this, understanding OCD was seen as *'the key' [ID34, father]* to supporting their child. Parents' understanding of OCD often shifted over time, helping to ease their frustrations.

- *'I think it's helped that we understand her better, so I think overtime because all of us have sort of experienced a shift in how much we understand and how much we know about OCD, we are not having so many difficult situations' [ID17, mother]*
- *'I think um, what made a big difference to me, is ... to try to understand how OCD works ... it's like if somebody had a swimming pool full of sharks and somebody said put your foot in it, no one in their right mind would do it, but ... that's what OCD does to you, it tells you stories, which are, we all know they are not true, but for that person, they are true, and that, that's the thing which is ... the hardest thought to understand' [ID34, father]*

Subtheme: *'I have got to accept this' [ID38, mother]*

The importance of coming to terms with their child's difficulties was also stressed by many parents.

- *'just getting parents feeling comfortable with the whole condition and making them realise that they need help and that they need, the child needs some sort of assistance ... it's nobody's fault, it's not bad parenting, it's not the child being inadequate ... it's just the way it is' [ID39, father]*

Through this journey, some parents were able to identify the *'silver linings' [ID30, mother]* of OCD.

- *'I think there are positives you know…just to see how, how resilient she is … how strong she is you know, yes she will have her moment but … she has become far more stronger than I ever thought [ID30, mother]'*

Despite this, the majority of parents remarked that *'I can't see any positives' [ID44, mother]* to OCD, with some parents describing coming to terms with OCD as a long, challenging journey.

- *'I don't see that there's positives in having a child with OCD, he doesn't want it, he is so unhappy, he really doesn't like it, he's like "what's wrong with me … I don't like OCD monster" … there is nothing good about it, the poor little boy he's struggled' [ID31, mother]*
- *'it's taken me like a year, or something like that, to go from a point of going what the shit is happening to my family, to my daughter, what's going on, the whole world has come to an end, type feeling, um, to getting to a point of acceptance and going okay, she has got this condition, it's not nice, you know … and being a little bit more centred and stable about the whole thing, that's taken some serious work for me' [ID43, father]*

Some parents identified barriers to coming to terms with their child's difficulties, particularly when they didn't understand that it was OCD, resulting in some parents feeling embarrassed by their child's behaviour.

- *'it's also a bit embarrassing, because your child is, so completely different from her friends … so she's saying all these really weird things, that, I would pretty much only like tell my best friend … how can you say to people "does your child think they have weed on light bulbs?", of course they don't because, it's not normal [laughs], so yeah, it's, it's embarrassing, it's secretive' [ID44, mother]*

Moreover, many parents (particularly participating mothers) perceived their child's difficulties to be misunderstood by others (e.g., family, school, mental health services, and/or the public), adding to their frustration.

- *'she's said things like "couldn't you just get a book", or ... "why do you think he's like that?" ... "do you think that's because you're worried?" and you know, just unhelpful, and she doesn't mean any harm, but that's difficult, you know that causes friction…like anyone would pretend to have a child with OCD, or make it up or you know, want to diagnose' [ID19, mother]*
- *'Because so many people joke about OCD, "Oh I'm OCD I check for this, I check for that" no you're not OCD, you just like to check because you are slightly anxious. It's a big discrepancy and it's that sort of semantics of what is OCD and what is OCD, I think society portrays it as being a little bit organised. It's not.' [ID23, mother]*

Among participating parents who identified from non-White British backgrounds, there appeared to be a disparity between their own, and their wider culture's views of mental health difficulties, adding to their challenges.

- *'it's not really recognised no, they see it as, I wouldn't say a sign of weakness, they just see it as, just get on with it ... it's not really spoken about ... it's a very different way of thinking' [ID withheld to preserve anonymity]*

Theme 2: The battle for support

Participating parents frequently described challenges obtaining support from mental health services and, in some cases, schools. This resulted in parental desperation, helplessness, and frustration, with parents describing *'getting through that waiting list and just waiting and waiting, that is like, the worst time of your life' [ID31, mother]* and *'soul destroying' [ID15, mother]*.

- *'I suppose the ridiculousness of the fact that ... you have diagnosed someone with a mental health condition and you're expected to wait 2 years for the next, next appointment, because there is no one available ... if he'd had a brain tumour would they have left him for two years ... you know that would be seen as unacceptable' [ID28, father]*
- *'well I was given a telephone number and told if there was a crisis then, then, but the thing is, what constitutes a crisis? I mean, my day, every day was a crisis. And, and it's like "okay, well you are still on the waiting list, maybe you could go down to 6 months", well hey well that still doesn't help me today. That still doesn't help me get her into school when she is hiding under the bed refusing to put her clothes on. That still doesn't help me when she is trying to ... run into the middle of the road. That still doesn't help me when ... she won't eat anything whilst we are out, and she is physically losing weight.' [ID15, mother]*

As a result, parents often had to rely on themselves to help their child or seek alternative support, including private treatment, alternative (often non-evidence based) therapies, school support, and ad-hoc information from friends.

- *'any input would have been useful because we did it all, off our own back, we didn't have any support with any of it so you know everything we did was, was just sort of what we had read on the internet' [ID25, mother]*

Even when parents were able to access support (either NHS or private), the battle persisted, with some parents perceiving their therapist and/or assessment and treatment as inadequate.

- *'It's quite insulting when like someone like that [CAMHS professional], who hasn't been there at 3 o'clock in the morning, every morning when your child is, you know,* *blinking at the ceiling otherwise she is going to be, a lesbian, telling me that she hasn't got OCD' [ID40, mother]*

- *'again with hindsight, after the first session or two [of treatment] I should have gone, "what the shit is this?" but um, I think you know at the time I didn't know, um you just go well maybe you know, maybe she [the therapist] knows what she is doing, I'm going to run with this, uh cos I didn't exactly have an alternative strategy, so you just do it' [ID43, father]*

However, many parents valued the support they received and the benefits this brought to their child.

- *'until you then start, your child gets seen, and then it's like a light bulb moment, because suddenly there's people who do understand and do get it, and actually you can see the improvements' [ID31, mother]*

Theme 3: Navigating how to respond to OCD

Subtheme: *'It's the whole feeling of wanting to help, but not knowing how to' [ID38, mother]*

Many parents didn't know *'what is the right thing to do' [ID25, mother]* when responding to their child's OCD. Parents typically accommodated OCD (either knowingly or unknowingly), often feeling that they had no choice but to do this, to keep their child functioning.

- *'well we could stop doing everything [i.e., accommodating the child's OCD] and we have thought about that, but then, I am very keen to keep [child's name] at school you see, and functioning' [ID24, mother]'*

Some parents experienced an internal conflict about whether to accommodate their child's OCD. They often knew that accommodation would perpetuate their child's difficulties, but they did not know how else to respond in these situations, particularly when there was a perceived time pressure (e.g., before school or bedtime).

- *'it was real conflict with myself because I knew it wasn't helpful, but ... especially in the morning, I needed to get him to school, he wouldn't leave, you know, if I didn't do it, well I had one morning where I wouldn't reassure him about putting his clothes on ... I said "no, that's enough, I am not doing this, it is ridiculous ... you weren't doing this a week ago, you are suddenly doing it" ... went downstairs to deal with the other [children], came upstairs 15 minutes later and he's got no clothes on and he's crying, what do you do? I need to get him to school, you know, I've got the other [children], I can't have a stand-off, plus he is distressed, you know, which as a parent, you don't want to see' [ID19, mother]*

Some parents also experienced conflict with other caregivers about the best way to respond to their child.

- *'my husband just was not impre[ssed]: "that's pandering to it, that's just not going to help him because the more you do that kind of thing, the more he is going to expect you to do that kind of thing, and then we are going round in a vicious circle"' [ID23, mother]*

Subtheme: *'maybe next time, I will only give you three reassurances…rather than thirty' [ID15, mother]*

Despite not knowing how best to respond, over half of the participating parents described attempts to fight back at their child's OCD, either by resisting accommodation, trying to rationalise their child's fears, or encouraging their child to face their fears, which had varying success.

- *‘she was scared of petrol stations, and uh, I need petrol, so that’s life, um and so every time we went, her panic attack was like, 10 and now it’s completely gone because she just realised that nothing is going to happen at a petrol station, but that took a lot of determination’ [ID40, mother]*
- *‘we try and do um logical thinking … let’s go back to that example of where he said, “are you overdosing me” and I said to him, “do you think I would, I am your mum?” and he said “no, I know you wouldn’t but my head keeps tell me that you would, that you are doing it” … and I asked him “do you understand what overdosing means? And that it’s against the law?” and “why would I want to hurt my child?” … and he said fine, and then the next day he said it again’ [ID38, mother]*

Some parents perceived particular OCD presentations to be easier to help their child with than others. For example, *‘physical things’* or *‘smaller’ [ID15, mother]* compulsions were viewed as easier than the *‘internal stuff, you know, the things that are going round in his head’ [ID38, mother]*.

- *‘but to be honest, it’s counting which worries me the most, because um, it doesn’t really have a, physical manifestation which you can deal with’ [ID35, mother]*

Theme 4: OCD is in control

Subtheme: *‘it was controlling her, she couldn’t control it’ [ID15, mother]*

Participating parents frequently described how OCD completely controlled their child. Children were perceived to be in a *‘constant battle’ [ID25, mother]* with OCD, resulting in impaired daily functioning and physical damage, with children washing their hands until *‘they were raw, bleeding from here to here’ [ID23, mother]*.

- *'it's just constant ... to get her out of bed in the morning sometimes it can take her two hours because she can't face getting out of bed, because she has so many thoughts and rituals like, things like gulping, long blinks, saying a chain of thoughts without blinking and then blinking at the end ... and then that's just getting out of bed' [ID24, mother]*

Parents also felt that OCD had changed their child's behaviour, describing how OCD made their child angry, explosive, and aggressive.

- *'I think surprising as well because, um he has gone from being a very placid, very affectionate child to being quite aggressive, and angry, really angry' [ID23, mother]*

Subtheme: '*I was doing everything for him' [ID31, mother]*

Parents identified that OCD controlled their own lives – for example, through the need to provide constant reassurance or to vigilantly monitor their child's difficulties. In some cases, their child was reliant on them for basic functioning (e.g., eating).

- *'everything he did, he needed to check really whether that was okay "Is it okay if I put this shoe on first? Is it okay if I do these laces up? Is it okay if I don't take this book to school today because I am not going to need it?" ... it started first thing in the morning, and it went through probably just about everything he did really' [ID37, mother]*
- *'you have to, kind of be on high alert, knowing you have a child with OCD, you can't let things go, if she is behaving a bit weirdly, it's OCD, so what's happening, we need to find out' [ID44, mother]*
- *'I mean there have been times when we have had to feed her, because she wasn't eating' [ID24, mother]*

Many parents identified that OCD became their top priority, with some parents describing particular impacts on their ability to work.

- *'trying to work in a full-time job with additional respons[ibilites] ... was just not possible ... so now I have got a job that's home-based ... but I can only do part-time as well, to fit in, well you've got to fit in CAMHS appointments, fit in making sure that you are doing some of the exercises with her and having some of the conversations with her between times, when she has got a full schedule of school and sport and all the other activities that teenagers do, and then you have got to fit in, managing an illness as well, then I think as a parent, you have got to be there a lot more' [ID33, mother]*

Overall, OCD appeared to control mothers' lives to the greatest extent.

- *'a lot of these things happened, kind of before school ... so it was affecting [partner's name] a lot more than me because I had already gone to work by then' [ID28, father]*

Subtheme: *'it obviously impacts the whole family' [ID22, father]*

Most parents felt that OCD negatively impacted wider family life. For example, OCD prevented family plans from being made, disrupted arrangements, and/or dictated the logistics of family activities.

- *'we can't plan anything on a weekend because she won't be able to get ready ... and we have just cancelled a holiday to [location] because it was too stressful to think about going ... that's just a small thing the holidays but um, well it's just everyday living' [ID24, mother]*

- *'if we plan something and she'll have an outburst, you know the plan, you can just forget it, um so, you know it will just go out of the window so it's just so difficult' [ID30, mother]*

Parents described how OCD created *'a tension in the air at home' [ID26, father]* and disrupted family dynamics.

- *'it's wrecked the family life … the way everybody used to interact changed an awful lot, and it's you know, as parents you try to keep harmony between everybody, and it was very difficult to get that' [ID34, father]*

Parents also perceived siblings to be negatively impacted, identifying that they had to *'just sit on the side-lines and wait until we could be there' [ID17, mother]*, which some parents felt resulted in sibling frustration.

- *'it was more about the length of time … that I would spend with him that I couldn't then spend with other children, and I think that's the main thing that I noted and seemed to certainly affect one of the other [children] definitely' [ID37, mother]*
- *'the oldest one, is very, she doesn't like it because she perceives she is being dictated to by his OCD. And to a greater or lesser degree, an awful lot of the stuff we do do at the moment is dictated to us by his OCD' [ID23, mother]*

However, a minority of parents identified minimal impacts of OCD on family life. Although there are many plausible explanations for this, one notable reason could be parental characteristics (e.g., parents being less likely to accommodate or not perceiving small accommodations to negatively impact family life).

- *'his OCD doesn't affect our family life in a negative way … it didn't prevent us from doing anything which we wanted to do' [ID35, mother]*

Theme 5: The emotional turmoil of parenting a child with OCD

Participating parents frequently highlighted the emotional challenges of parenting a child with OCD, *'generally, if you have got a kid with OCD, your parents, I would say are, are emotionally distraught' [ID43, father]*. Parents' emotions ranged from feeling *'sad that your child is having to deal with something on top of daily challenges' [ID18, mother]* and *'really scared' [ID31, mother]* to finding OCD *'really upsetting and difficult' [ID25, mother], 'extremely stressful' [ID37, father], 'exhausting emotionally' [ID33, mother]* and *'all overwhelming, you are struggling to, just cope with, you know, on a day-to-day basis' [ID43, father]*. Parents also felt anxious about their child's OCD, both now and in the future *'well it's worrying now, and it's worrying whether it will go worse … because I am not sure, uh, from what I had read, if it ever goes away, and um, how he will manage' [ID35, mother]*, exacerbating their sense of helplessness.

Moreover, parents commonly experienced blame, either self-blame (e.g., feeling they had caused/exacerbated their child's difficulties or not sufficiently helped them) and/or blame from their wider community.

- *'you feel a bit of a failure, like you haven't done the best for your child, I do, I feel a real failure' [ID33, mother]*
- *'but it's trying to live with other people's accepting it, so, members of my family you know, first thing that's, coming from an Asian culture, the first thing somebody said to me was, "oh, what did you do to him?"' [ID withheld to preserve anonymity]*

These emotional challenges meant that some parents felt isolated, perceiving themselves as the only family experiencing these difficulties. Consequently, some parents searched for belonging by trying to connect with other families of children with OCD or mental health difficulties.

- *'immediately as soon as a parent, understands that their child has got OCD, I think they should be put in a room with other parents with children with OCD, because immediately it's really, it's such a lonely experience … and then, you know, at the point when you actually meet some other parents with children with OCD you go shit, they are going through exactly the same thing, they have to wash the clothes twenty times a day, their kid does this … that makes that experience a whole lot less lonely' [ID43, father]*

Overarching theme: Challenge and frustration

Parents identified that parenting a child with OCD was *'really really tough' [ID33, mother]*. Challenge was present across all themes and resulted in parents finding OCD *'obviously just really frustrating' [ID24, mother]*. Some parents' experience of challenge and frustration improved over time, *'we have had um a massive success in in tackling it … life is much easier, for everyone' [ID19, mother]*, however for others, this persisted even when they were able to access treatment *'cos I didn't know what to do [before treatment], and then when I did know how to do it, it was still really difficult because then you have go to try and tell the whole family this is how to do things' [ID31, mother]*.

Overarching theme: Helplessness

Parental helplessness stemmed from the challenge and frustration of parenting a child with OCD. Helplessness was present across all themes, particularly where parents did not know how to support their child, *'I just feel like what can I do? What can I do? If it was like a cut or if it was, even a broken arm, you know you can plaster it over but this, it's all inside him, I don't know how I can, other than hug him and love him and give him all the cuddles, these worries every night are the same and I just come away feeling sick in my stomach, thinking how can I help my child?' [ID38, mother]*. Similarly, for some parents, helplessness improved over time, whereas for others, this persisted *'so now … we are not sending her to any therapist … because she'll get therapy um fatigue, and um, we need to just make sure … it's going to be, as useful as it possibly can be, you know, otherwise we don't want another wasted eight sessions' [ID43, father]*.

Discussion

This study used in-depth, semi-structured interviews to explore parents' experiences of parenting a preadolescent child with OCD. We used reflexive thematic analysis to generate themes which captured the breadth of parents' experiences, allowing us to identify key implications for the development of support for parents of preadolescent children with OCD that can be widely disseminated.

Consistent with previous research (e.g., Futh et al., 2012; Kerby, 2018), we identified clear challenges that parents experienced in trying to understand their child's difficulties, navigating how to respond to their child's OCD, the control that OCD had on their family, and the emotional difficulties of parenting a child with OCD. Extending Futh et al. (2012), our findings provided further insights into the specific difficulties parents experienced understanding and coming to terms with their child's OCD. For example, parents often experienced frustration due to OCD being misunderstood, either by other family members and/or by wider society. This mirrored the findings of Kerby (2018) who identified the 'anger' that parents experienced at other family members/wider society's misunderstandings of OCD. Interestingly, in the current study, this frustration appeared to be particularly relevant for parents from non-White British backgrounds who identified differences between their own and their wider communities' cultural beliefs surrounding mental illness. This highlights the need to sensitively consider possible family or cultural barriers to understanding OCD when developing support for parents.

Building on previous research (e.g., Futh et al., 2012; Kerby, 2018), our study provided detailed insights into how parents navigated responding to OCD. Parents frequently accommodated OCD, despite some parents experiencing conflict within themselves (and in some cases, their partners) as to the best way to respond to OCD. Parents typically felt they had no choice but to accommodate their child's OCD, particularly when they perceived this as necessary to enable their child to function (e.g., to eat, to go to school) and when there was a perceived time pressure (e.g., mornings, bedtimes). This latter finding is similar to Kerby (2018) who identified that parents of adolescents with OCD were more likely to accommodate OCD during 'stressful' or 'chaotic' moments and when parents perceived emotional resources were lower. Thus, support for parents needs to provide clear and manageable alternatives to accommodation, that can be shared by caregivers, to empower parents to respond in ways that help to reduce their child's OCD. Given that parents may already be blaming themselves or feel blamed by others for their child's difficulties (as highlighted in this study and Kerby (2018)), this support clearly needs to be provided in a non-judgemental way. The in-depth interviews conducted during this study also provided further insight into the control that OCD had on parents and the wider family. Although Kerby (2018) also identified such impacts (e.g., parents reporting an inability to go on holiday as a family and having less time to spend with other children), parents of *preadolescent* children with OCD appeared to report these impacts to a greater extent (e.g., OCD resulted in some parents having to give up their job, having to wash, dress, and feed their child and resulted in perceiving sibling frustration at having to adhere to OCD's demands). The extent of this control may be particular to families of preadolescent children with OCD, given that preadolescent children are heavily reliant on their parents and family environment (Freeman et al., 2003). Such insights are crucial to be aware of when developing support for parents to ensure this reflects their experiences and needs.

Notably, we identified the battle that parents experience in accessing appropriate treatment for their child. In contrast to Futh et al. (2012) and Kerby (2018) (who also did not explicitly ask parents about their experiences of accessing support), parents who participated in this study frequently and spontaneously described challenges accessing treatment. Such difficulties are unsurprising, given that only around ⅓ families who seek treatment for anxiety disorders receive any kind of mental health support, and less than 3% receive evidence-based treatment (Reardon et al., 2020). These challenges often led to a sense of parental helplessness, frustration, and desperation – highlighting the need to develop support for parents which is accessible and scalable.

Strengths of this study include the use of in-depth, semi-structured qualitative interviews to provide rich meaningful insights into parents' experiences of parenting a preadolescent child with OCD. The use of a purposive sampling approach enabled us to capture diversity in parents' experiences, allowing us to generate a complex dataset that captured a range of parents' experiences. Specifically, we were able to capture the experiences of mothers and fathers, parents who were at different stages of the help-seeking process for their child, and parents whose children had received different types of treatment/treatment providers. We also sought to ensure high-quality data analysis by following the recommendations of Braun and Clarke (2022). For example, we reflected on the research team's knowledge and experience and considered how this shaped the data analysis and actively considered alternative possible interpretations of the data during coding meetings. This was further aided by a research team that included a member (KH) who brought both qualitative expertise and different research interests to the more clinical oriented members, and from obtaining feedback on preliminary data analyses from wider research teams and at conferences. Moreover, the team worked together throughout the study to ensure high quality interviews, to review initial coding, and to review analytic writing. This use of a paper trail also ensured the study was conducted in a systematic and thorough way (Braun & Clarke, 2022). However, a limitation of the study is that we did not conduct diagnostic interviews to establish current or past OCD but relied on parental report regarding previous clinical diagnoses and/or children meeting clinical cut-offs on a screening measure. This meant that we could not formally confirm whether children had met diagnostic criteria for OCD (and any comorbid diagnoses). Furthermore, given that we did not ask all parents to complete a standardised measure of their child's OCD symptoms or severity, nor did we purposively sample parents according to their child's type of OCD or severity, we were unable to explore whether these variables impacted parents' experiences of parenting their child. This is a particular limitation of this study, as these variables may impact the support that families need. Moreover, although parents from non-White ethnic backgrounds did participant, over 80% of the parents that were interviewed identified as White British or Other White backgrounds and the majority of parents (81.8%) had at least an undergraduate degree. This may have been the result of our recruitment pathways, as parents may have had to overcome several barriers to access CAMHS support (Anderson et al., 2017; Reardon et al., 2017) or be in a financial position to pay for private treatment. Thus, the transferability of this research to other settings may be limited (Braun & Clarke, 2022) and further research is warranted that specifically addresses the experiences of parents of children with OCD identified through wider community settings. Finally, although the purpose of this research was to understand *parents'* experiences of parenting a preadolescent child with OCD, future research may also benefit from interviewing other key stakeholders (e.g., affected preadolescent children and clinicians who support families of preadolescent children with OCD) to further ensure the development of acceptable support for families.

Conclusion

This study highlights a number of key aspects of the experiences of parents with a preadolescent child with OCD. Parental challenges and frustrations were widespread and commonly resulted in a sense of helplessness. Parents found it difficult to understand and respond to their child's OCD, to access appropriate treatment for their child, and to cope with the emotional challenges and control that OCD imposed on their families' lives. Going forward, it is important that support is provided for parents of preadolescent children with OCD that recognises (and is sensitive to) the challenges and frustrations that parents experience. Clear practical guidance on how to respond to OCD is needed to reduce parental helplessness and to empower parents to respond to their child's requests for accommodation/reassurance in ways that are both helpful for the children and manageable for the parents. Critically, this support must be able to be delivered at scale and accessible early on when families first need support, to help prevent the battle that parents often experience to access appropriate support for their child.

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Disclosure statement

The authors report there are no competing interests to declare.

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3.3 Further information on methodological decision making

In this section I will elaborate on the methodological decision making processes that I was unable to comment on (due to word limit constraints) in the qualitative paper.

In designing this qualitative study, I explored whether to conduct one-to-one interviews or focus groups. One-to-one interviews are the most commonly used method to collect qualitative data (Nunkoosing, 2005) and allow the researcher flexibility to explore and clarify participants' responses to generate a rich insight into their views and experiences (Morgan et al., 1998; Smith, 2015). In contrast, focus groups (i.e., where a group of participants are invited to discuss a research topic of interest, Powell & Single, 1996) use group interactions (i.e., where participants question or comment on other participants' views) to generate rich data (Duggleby, 2005; Guest et al., 2017). Despite the potential utility of focus groups in exploring parents' experiences of parenting a preadolescent child with OCD, focus groups have been identified as inappropriate when the aim of the research is to explore individual narratives of sensitive topics (Smithson, 2008) and some (but not all) research has shown that participants are less likely to discuss personally sensitive information during focus groups than one-to-one interviews (e.g., Kaplowitz, 2000; Kaplowitz & Hoehn, 2001; Wight, 1994; Wutich et al., 2010). Furthermore, focus groups have been shown to be more time consuming and logistically challenging than one-to-one interviews (e.g., Coenen et al., 2012; Thomas et al., 1995). Thus, I opted to use one-to-one interviews given the sensitive nature of the research and due to the reduced time burden/greater logistical flexibility that one-to-one interviews could offer.

I also considered the use of different qualitative approaches to this study, in particular interpretative phenomenological analysis (IPA), as IPA can be used to address research questions that aim to explore individuals' experiences and sense-making of a particular phenomenon (Smith, 2019) and thus could have been an appropriate method to explore parents' experiences of parenting a preadolescent child with OCD. Furthermore, IPA is similar to reflexive thematic analysis in that researcher reflexivity is at the core of the method (Braun & Clarke, 2020). Despite this, IPA typically recruits a small number of participants with similar characteristics (e.g., Smith & Osborn, 2007) and thus reflexive thematic analysis has been deemed more appropriate when the research aims to capture a diverse range of participant views (Braun & Clarke, 2020). Furthermore, reflexive thematic analysis is also considered more appropriate than IPA when the researchers intend to use the findings to identify relevant clinical implications (Braun & Clarke, 2020; Sandelowski & Leeman, 2012). Thus, given that this qualitative study aimed to explore a *diverse* range of experiences of parenting a preadolescent child with OCD to *inform* the development of a psychological intervention, I selected reflexive thematic analysis as the most appropriate method.

Finally, when I first developed the study protocol (Chessell et al., 2019), I intended to use 'data saturation' (i.e., where no additional information or insights are obtained from the collection of further data, Lincoln & Guba, 1985) to determine our final sample size. However, in line with updates in the field that have more clearly defined reflexive thematic analysis (Braun & Clarke, 2019) and questioned the applicability of 'data saturation' to this particular approach (given that reflexive thematic analysis recognises the role of the researcher in interpreting the data – thus, new insights and interpretations are always plausible, Braun & Clarke, 2021), I decided to use an 'information power' approach (Malterud et al., 2016) to determine our final sample size (as discussed in the paper).

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Chapter 4: Development of therapist guided, parent-led Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD).

4.1 Introduction to Chapter 4

So far in this thesis, I have discussed the underpinning work necessary to develop an effective, efficient, and acceptable brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD. In Chapter 4, I discuss the implications of Chapter 2 (Paper 1) and Chapter 3 (Paper 2) for the development of the intervention and provide a detailed account of how the intervention was developed. In this chapter, I also draw on how additional qualitative research which (using the same sample and methodology as Chapter 3, Paper 2) explored parents' views about how and whether parents should be involved in CBT for their child, relevant reflections from clinical work, and contributions from Patient and Public Involvement (PPI) representatives informed the developed intervention.

4.2 Overview

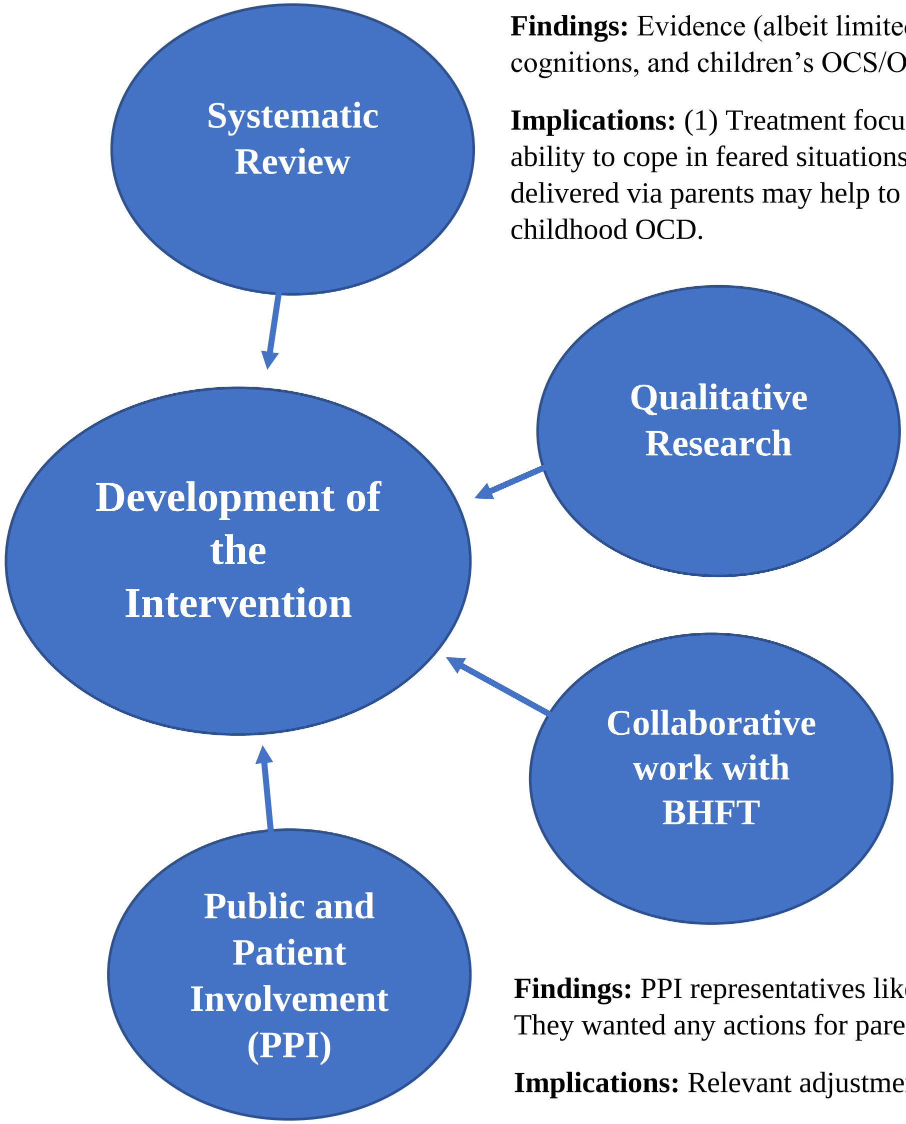
Obsessive Compulsive Disorder (OCD) often begins during preadolescent years (Geller et al., 1998) and has detrimental impacts on affected children (Lack et al., 2009; Piacentini et al., 2003; Stewart et al., 2017) and their parents/caregivers (Chessell et al., 2022; Stewart et al., 2017; Storch et al., 2009; Wu et al., 2018). Access to treatments for preadolescent children with OCD are limited (O’Neill & Feusner, 2015) and there is a need to develop brief, accessible, and scalable support for this population (Chessell et al., 2022).

Therapist guided parent-led CBT treatments offer one potential way to increase access to treatment for preadolescent children with OCD. Here, therapists work with parents/carers (rather than children directly) to empower parents/carers to use CBT techniques with their child to help them to overcome their difficulties (Thirlwall et al., 2013). Therapist guided, parent-led CBT treatments require considerably less therapist input than traditional (i.e., face-to-face, weekly sessions) CBT approaches (Thirlwall et al., 2013) and have been shown to be effective (e.g., Chavira et al., 2014; Cobham, 2012; Waters et al., 2009) and cost-effective (e.g., Creswell et al., 2017) for preadolescent children with anxiety difficulties. Moreover, this approach can be effectively delivered by non-specialist therapists (Thirlwall et al., 2013) and is routinely delivered by low-intensity clinicians (i.e., Children’s Wellbeing Practitioners (CWPs) and Educational Mental Health Practitioners (EMHPs)) in a range of settings (i.e., Mental Health Support Teams in schools, Child and Adolescent Mental Health Services, local authorities, and voluntary sectors; Ludlow et al., 2020) – helping to further increase the numbers of families who can benefit from this intervention.

The therapist guided parent-led CBT treatment delivered as part of this PhD was adapted from an existing evidence-based parent-led treatment for preadolescent children (7- to 12- years old) with anxiety disorders (Creswell et al., 2017; Hill et al., 2022; Thirlwall et al., 2013). The original treatment consisted of eight treatment sessions (four face-to-face and four telephone calls) accompanied by a therapist manual (Willetts et al., 2016) and parent book (Creswell & Willetts, 2007) and has since been revised to consist of six treatment sessions (four face-to-face and two telephone calls), an updated therapist manual (Halldorsson et al., 2019) and parent book (Creswell & Willetts, 2019). The core treatment components include: (1) psychoeducation on the development and maintenance of childhood anxiety disorders, (2) identifying treatment goals, (3) using open questions to identify what the child needs to learn to overcome their anxiety and achieve their treatment goals, (4) a step-by-step approach to facing fears (with a focus on helping children to learn new information about their fears and their ability to cope in feared situations), and (5) problem-solving.

To ensure the adapted treatment was effective, efficient, and acceptable to parents of preadolescent children with OCD, we used the results of the systematic review (Paper 1) to ensure the treatment targeted any cognitive, behavioural, or familial maintenance mechanisms relevant to childhood OCD, and the results of the qualitative research (Paper 2 and Chapter 4) to ensure parents' experiences of parenting a child with OCD, and their views as to how and whether parents should be involved in CBT, were at the forefront of the treatment adaptation (Locock & Boaz, 2019). Reflections from clinical work conducted with Berkshire Healthcare NHS Foundation Trust (BHFT) as part of this collaborative PhD, and Patient and Public Involvement (PPI) from parents and national charities further informed the adapted treatment and helped to ensure that key stakeholder views were considered during this process (Palmer et al., 2019). Figure 1 highlights the key implications of the research, clinical, and PPI work that informed the adapted treatment.

Figure 1. Implications of research, clinical, and PPI work that informed the adapted treatment.



Findings: Evidence (albeit limited) of significant associations between children's OCS/OCD and particular cognitions, and children's OCS/OCD and parents' cognitions and behaviours.

Implications: (1) Treatment focused on helping children to learn new information about their fears and their ability to cope in feared situations is appropriate to address a range of possible cognitions. (2) Treatment delivered via parents may help to address parental cognitions and behaviours relevant to the maintenance of childhood OCD.

Findings: (1) Parents experience practical and emotional challenges and often feel helpless as to how best to support their child. (2) Parents perceive knowledge as key in helping their child and view themselves as essential in their child's treatment. However, parents have understandable concerns about their involvement in treatment.

Implications: (1) Treatment needs to be sensitive to the challenges parents face and provide parents with clear, simple, and practical tools to help reduce parental helplessness. (2) Treatment should acknowledge parents' concerns and collaboratively troubleshoot any challenges encountered to empower parents to help their children to overcome OCD.

Findings: Parents emphasised the need for clear, simple information. They valued the opportunity to speak with other parents and liked the use of analogies and videos to help understand OCD.

Implications: (1) Include optional videos for parents to learn more about OCD. (2) Signpost parents to place where they can connect with other parents of children with OCD if they wish.

Findings: PPI representatives liked the colour/layout of the materials and found the information easy to read. They wanted any actions for parents to be made clearer and suggested additional troubleshooting ideas.

Implications: Relevant adjustments were made to the treatment materials to maximise treatment acceptability.

4.3 Implications from the systematic review

The systematic review provided a narrative synthesis of 29 studies examining the cognitive, behavioural, and familial maintenance mechanisms relevant to childhood obsessive compulsive symptoms (OCS)/OCD in preadolescent children (Chessell et al., 2021). Studies examined six (of 11) hypothesised maintenance mechanisms identified from adult cognitive and behavioural models of OCD (e.g., Obsessive Compulsive Cognitions Working Group, 1997; Rachman, 1993; Salkovskis, 1985) and literature on possible family factors (e.g., Barrett et al., 1996; Creswell et al., 2010; Freeman et al., 2003; Waters & Barrett, 2000), specifically (1) inflated responsibility, (2) over-importance of thoughts, (3) overestimation of threat, (4) emotional responses, (5) counter-productive safety strategies, and (6) family factors (i.e., family members' cognitions and behaviours). No eligible studies were identified for (1) the importance of controlling thoughts, (2) intolerance of uncertainty, (3) perfectionism, (4) attentional biases, (5) neutralising actions. The studies included in this review had substantial methodological limitations and all were cross-sectional. Moreover, no eligible experimental or longitudinal studies were identified, meaning that no conclusions could be drawn regarding the direction of the associations between childhood OCS/OCD and the proposed maintenance factors. Thus, we are currently unable to determine whether the proposed maintenance factors do have a *maintaining* role in childhood OCS/OCD, limiting our understanding of the mechanisms that need to be targeted in treatment to ensure an effective and efficient treatment for preadolescent children with OCD. Despite this, included studies provided some evidence of significant associations between childhood OCS/OCD and cognitive factors (i.e., inflated responsibility, over-importance of thoughts, and overestimation of threat) – thus, keeping the focus of treatment on helping children to learn new information about their fears and worries was deemed appropriate. A significant association was also shown between children's post-treatment CY-BOCS scores and improved distress tolerance across treatment – highlighting the importance of including a focus on helping children to learn new information about their ability to cope in feared situations in treatment. Furthermore, evidence of significant associations between childhood OCS/OCD and some parental cognitions and behaviours (including family accommodation) were found – therefore, delivering treatment via parents may help to address parental factors that may be inadvertently contributing to the maintenance of children's difficulties (Murray et al., 2009). Finally, specific associations between childhood OCD and reduced parental confidence, reduced rewarding of children's independence, and reduced use of problem solving were found – providing a rationale for keeping the existing treatment content on promoting and praising children's independence and problem solving (Thirlwall et al., 2013).

4.4 Implications from the qualitative research

In the qualitative study, semi-structured interviews were conducted to explore parents' experiences of parenting a preadolescent child (aged 7- to 14- years old) with OCD (Paper 2). The themes generated from this study were used to adapt the existing treatment to ensure that parents' experiences were central to the adapted treatment and to help maximise the acceptability of the treatment to parents. Table 1 outlines each theme, the key points within each theme, and the implications for the adaptation of the treatment. Treatment implications are colour coded as follows: green = rationale for keeping an existing treatment component, purple = considerations to be aware of when delivering the treatment, and red = elements of the existing treatment which need to be adapted.

Table 1. Implications from Chessell et al. (2022)

Themes	Key points within themes	Implications for treatment adaptations
The journey to understanding and coming to terms with OCD	Parents find it **challenging to understand** and come to terms with OCD. Parents often perceived OCD as **irrational** and find it **hard to relate to** OCD, which can result in parental **frustration**. Despite this, parents perceive **understanding OCD as key** to helping their child.	• Adapt the existing treatment content to normalise intrusive thoughts and provide psychoeducation on the development and maintenance of OCD to promote understanding of OCD. Explore and normalise any parental frustrations as a response to OCD. • Include information on externalising OCD and viewing OCD 'as a bully' to help parents (and children) to understand OCD. • Adapt the content of the case studies to cover four different OCD presentations to help provide insight into OCD. • Include optional videos for parents to watch to further aid their understanding of OCD.
	Parents **feel OCD is misunderstood by others**, including family members, therapists, and wider society. **Cultural differences** in perceptions of mental health can add to the frustrations and challenges faced by some parents.	• Be aware of possible societal and cultural differences in perceptions of mental health difficulties and how this may add to the challenges experienced by some parents.
The battle for support	Parents experience **helplessness**, **frustration**, and **desperation** at the lack of support, and often have to **rely on themselves** to find information on how to help their child.	• Adapt the parent book to develop short, clear, and simple reading materials so that parents do not feel overwhelmed by information and to ensure parents have all of the information they need for the treatment.
	Some parents perceive therapists/services as providing **inadequate support** for their child/**misunderstanding** their child's OCD.	• Adapt the treatment content to provide information on the existing evidence-base for treatment of childhood OCD and how the current treatment aligns with this. • Ensure parents feel their child's difficulties are understood through the use of reflection, normalising, and summarising the child's difficulties during assessments and treatment sessions.

Navigating how to respond to OCD	Parents often **do not know how to respond** to their child's OCD. They often feel they **need to accommodate** their child's OCD to enable their child to function, and experience **blame** from themselves or others for accommodating their child's OCD.	• Adapt the treatment content to provide psychoeducation on family accommodation and reassurance giving in the maintenance of OCD. • Explicitly recognise accommodation/reassurance is a normal response to a distressed child and ensure parents do not feel blamed for their understandable responses. • Provide clear, manageable alternatives to family accommodation and reassurance provision. • Normalise that in some situations, parents may need to accommodate their child's OCD (and that parents should not blame themselves for this) but encourage parents to reduce accommodation where they can.
	Parents **feel more able to help with some OCD presentations**/characteristics than others.	• The use of a step-by-step plan to ensure helping children to face their fears is manageable for both the parent and the child. • Explore if parents have any concerns about helping their child to overcome OCD/specific OCD presentations.
OCD is in control	Children are perceived to be in 'constant battle' with OCD and can experience **aggressive outbursts**.	• Develop additional reading materials to provide psychoeducation on OCD and anger (and how to respond to this).
	OCD **impacts parents** (e.g., parents may have to assist children with basic daily functioning, impacts to parental employment) and **the wider family** (e.g., parents perceiving siblings as overlooked, impact on family outings.)	• Be aware of, and sensitive to, the challenges parents are experiencing. • Ensure collaborative homework setting so that parents are not overwhelmed/to be responsive to existing demands placed upon parents.
The emotional turmoil of parenting a child with OCD	Parents experience a **range of emotions** including sadness, anxiety, stress, frustration, blame, emotional exhaustion.	• Be aware of, and sensitive to, the emotional challenges parents may be experiencing.

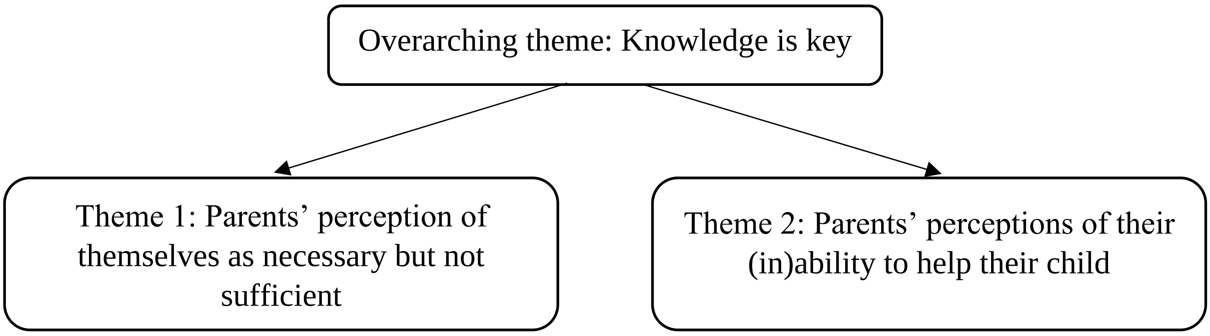
	Some parents experience a sense of **isolation**.	- Adapt the treatment content to provide extra information/signposting on self-care for parents and charities where parents can connect with other parents of children with mental health difficulties/OCD.
Challenge and frustration	Parents experience OCD as **challenging** and **frustrating**.	- Be aware of, and normalise, parents' experiences of challenge/frustration during appointments.
Helplessness	Parents **feel helpless** as they do not know how to best support their child and find it challenging to access appropriate support for their child.	- Provide clear, manageable techniques parents can implement with their child that reduce parental helplessness and empower parents to support their child.

Note. Treatment implications are colour coded as follows: Green = Rationale for keeping an existing treatment component, Purple = Considerations to be aware of when delivering the treatment, and Red = Elements of the existing treatment which need to be adapted.

4.5 Further implications from the qualitative research

In addition to exploring parents' experiences of parenting a preadolescent child with OCD (Paper 2), we also explored parents' views on parental involvement in CBT for children with OCD. Parents were provided with a factsheet one-week before their interview that contained information on CBT for OCD and four different ways parents could be involved in treatment (based on the existing literature and team's clinical experience). This included: (1) child sessions with no parent involvement, (2) child sessions with limited parent involvement (i.e., parents attend the beginning and/or end of the child's treatment session), (3) child sessions and additional parent sessions (i.e., parents receive separate, additional therapist input to their child), and (4) therapist guided, parent-led CBT. Parents were asked about their views of each approach, including the perceived benefits and challenges, and how they thought their child would respond to each approach. Reflexive thematic analysis was used to generate one overarching theme and two themes (see Figure 2). A description of each theme, along with illustrative quotes, is provided below. To help ensure that the adapted treatment was acceptable to parents and responsive to their view, key parental concerns regarding parental involvement in CBT and their implications for the adapted treatment are outlined in table 2. Treatment implications are colour coded as follows: green = rationale for keeping an existing treatment component, purple = considerations to be aware of when delivering the intervention, and red = elements of the existing treatment which need to be adapted.

Figure 2. Thematic map.



Theme 1: Parents' perception of themselves as necessary but not sufficient

Parents perceived themselves as essential in their child's treatment – they saw themselves as a key team member to help their child to overcome OCD and wanted to be part of the therapy process.

'I definitely think they [parents] should be involved. Because, it's to create a unit, it is just as important to create an environment for your child where they can practice the techniques they are taught ... because it's hard, it's going to be hard to do' [ID18, mother]

Parents felt they needed to be involved in their child's treatment sessions to be able to support their child to make progress at home and to reinforce key therapeutic messages.

'Our therapist talked about um ... the climate and the weather, and you know the clouds, and how mood is like clouds, you know, they come and go, all these things that we could then use the same language and reinforce that, but ... if I hadn't been there, um he would have just got that for that hour and, I am not sure how, how much he would have hung on to without the, someone else there reminding him, of, what had been said and supporting' [ID19, mother]

Parents also felt that they had important knowledge to share with the therapist, which some parents (particularly parents of younger children) felt their child lacked ability to disclose.

'I guess, the bit it is missing [individual child sessions with additional parent sessions] is the little bit from above [individual child sessions with limited parent involvement] where the parents might be able to talk to the therapist, because, especially with a child that's ... at sort of the young age group ... they are not always able to vocalise what, what has been going on, and in fact my, my child ... could have quite happily of sat there and said barely anything in the session' [ID25, mother]

As a result, some parents felt that treatment approaches with greater parent involvement (i.e., parent-led treatment) would be appropriate for their family and enable them to support their child both now, and in the future, if necessary.

'and the nice thing about that as well ... I know sometimes, children don't carry it into adulthood but often they do, but if you've got that treatment plan and you've used it and you've had success, you can nip it in the bud again when things start coming back up, you've got the strategies there to try and minimise them early on, rather than get back on the waiting list and wait again for however long, to see somebody again' [ID19, mother]

However, other parents felt that their involvement in treatment should be minimal, identifying that parent-led treatment approaches may have limited utility without their child being involved.

'I wouldn't say it is a complete waste of time as a method of dealing with it, as you've got in there, treatment work books and passing on as much knowledge as you can. There would definitely be value over doing nothing, of course, but um I think it would be minimal' [ID22, father]

This was often because parents felt their child needed to be the central focus of treatment, emphasising that their child needed to be seen by a therapist and take ownership of their recovery.

'I think it's important that the child has the individual time with the therapist, to say and do and learn away from the parent' [ID19, mother]

'there'd be more um, ownership by the child, and there does have to be a lot of ownership by the child, at the end of the day, they are the only ones who can really really do it' [ID33, mother]

Some parents identified that other approaches (e.g., individual child sessions with limited parent involvement or individual child sessions with additional parent sessions) may offer a more balanced approach and would, for example, allow their child to speak more freely with the therapist.

'In this way [individual child sessions with limited parent involvement], the parents are involved and they are interested but at the same time, it gives the children the freedom to go and explore their thoughts and processes, without feeling they have got the pressure of their parents being there and hearing things they probably wouldn't want them to hear or think or feel' [ID38, mother]

Furthermore, many parents expressed a preference for a holistic approach to treatment, combining two or more of the four treatment approaches discussed. They felt that combining approaches would capitalise on the benefits of each approach and allow the therapist to have a greater understanding of how to support the family.

'It has to be, you have to do a combination of, with the child, without the child ... I'd say [treatment approach] two, three and four ... you know, all of those together, not one or the other' [ID31, mother]

'because I think all the elements in there have their own merit, and have their own benefit and so to, why leave anyone of those out' [ID43, father]

Similarly, some parents felt that treatment should involve wider family members too, to help promote knowledge across family members and ensure a consistent approach to helping their child.

'I think it might not just even be parents, I think it might be worth considering whether that is also wider family, so um, you know, if there is a member of the family like a grandmother that spends a lot of time with the child ... so yeah, fundamentally parents but it

could be um whoever is really caring for the child, to, to have that time, to learn about it, and … like you said there, how the family can influence the OCD' [ID33, mother]

'so everyone is coming from the same angle, also the parents could be doing contradictory things to what the therapist wants them to do, or what has been said to the child. If it is not a joined up approach it's not going to work' [ID15, mother]

Theme 2: Parents' perception of their (in)ability to help their child

Parents typically identified facilitators and barriers to their perceived ability to help their child with OCD.

Subtheme: 'they weren't complicated things to do so, um that made things easy' [ID28, father]

Many parents stressed the importance of information being clear, simple, easy to incorporate in their day-to-day lives, and in accessible formats, to facilitate helping their child.

'like a step by step, this is what you would do to help your child not scratch their cheek. You'd ask them to do this then that then that, wait five minutes and then do this then that then that. So it would be … a step-by-step, like following a recipe' [ID18, mother]

'I read it [a self-help book] years ago but I remember it was easy to be read, or maybe it was so incorporate in my life I can't remember it anymore you know, but it was easy, it wasn't thick to digest so it was easy to implement' [ID30, mother]

'like a little video or something, they could send a link via email so you could watch it from home … that would have helped me a little video that I could just click on my phone, in the comforts of my own home, and be able to educate myself' [ID40, mother]

Crucially, parents felt that the information they received needed to be specifically tailored to their child and family so that they could support their child with their specific difficulties.

'I have read books and things, but because they are not necessarily all his type of OCD, you can't, that doesn't help him' [ID18, mother]

'as for, how the family can influence OCD, so that's not something you can get from a book, and you can, but it's going to be general, and … I would um suggest needs to be specific, so yeah your kid, manifest, or exhibits OCD symptoms like this, these are the triggers, so these are the things that you need to do and not do, that are specific … to your um situation' [ID43, father]

Subtheme: 'just having access to a therapist where you can say actually, this is what is going on, what do you suggest, and having an action plan' [ID15, mother]

Parents identified they needed an external professional to *'tell me what I needed to do' [ID19, mother]* to help their child. Parents wanted guidance broadly on how to support their child, as well as troubleshooting difficulties that may arise. Parents' desire for external guidance often stemmed from their experience of helplessness at not knowing how to support their child.

'If somebody is giving you support to deal with the situation, on a regular basis, that would be invaluable' [ID15, mother]

'like I said, when there's, in terms of physical health, if my son was cut himself, I know I can help him by putting a plaster on it … but this I can't do anything, I can't put a plaster over it, it's not something that is going to go away after a couple of days, so and it's something that you, that seems to be there, and you think, what can I do? what can I do? These kind of sessions [individual child sessions with additional parent sessions] would really give you that support' [ID38, mother]

Furthermore, around half of the parents identified that receiving advice from a therapist would help them to feel supported with the emotional challenges of parenting a child with OCD, which they perceived to impact on their ability to help their child.

'cos the thing is, if the parent is completely going under as well they are not going to be any help to the child, and it just exacerbates the situation … that's the situation we were in, we were in such a low place as well, because of everything that was going on, it just made it harder to stay positive, and actually deal with it in a positive way' [ID15, mother]

Subtheme: 'um obviously it requires more commitment and time from the parents to um accommodate the sessions' [ID22, father]

Parents frequently identified practical challenges to being involved in their child's treatment, particularly where greater parental involvement was required (i.e., additional parent sessions and parent-led treatment). Many parents (particularly fathers) therefore stressed the need for flexibility in treatment delivery (e.g., mode of delivery, time of day) to facilitate parental involvement in treatment.

'because you know, for example my [children] were out at [activity] today so they are out of the way, the house is quiet … so the flexibility of me having a conversation with a, a, a medical profession and I could feed back to them and they could maybe talk to me about it, whereas if it is very inflexible then, you know, you are not going to get people involved in the same way' [ID28, father]

'it would be useful to dial in just for the, the adult ones, yeah, and I would say, for, for you know, because that makes it more flexible' [ID27, father]

Subtheme: 'initially it was tricky cos I knew it would upset her, but I wanted her OCD gone more than I minded her being temporarily upset' [ID44, mother]

Some parents identified the importance of understanding the rationale for treatment and experiencing treatment gains to facilitate them helping their child. Where parents were unable to see the long-term benefits (over the short-term distress their child may experience) they struggled to help their child to engage in treatment tasks.

'it wasn't the easiest but I could see the end point in a way, so I could see it was worth doing, had it gone on longer, I may have found it harder, if it hadn't worked I wouldn't have seen the use in it, therefore, my involvement might have not been as, cos, like I say, you just want to make sure your child is okay, and you don't like to see them upset, so it was quite difficult at times' [ID37, mother]

Subtheme: 'sometimes we go through a phase thinking does he really want help?' [ID38, mother]

Parents' perception of their ability to help their child was somewhat impacted by their child's willingness to engage in treatment or techniques that parents were using at home to support their child. Some parents identified that using developmentally appropriate language and reviewing previous treatment successes helped them to engage their child.

'you properly got them on board when you are talking about "oh well look at all these things that are in your rubbish bin, you know, go and have a look in your rubbish bin, what can you see in there?" and things like that, and they are on board, because you are not saying "oh well you have this intrusive thought" ... it's a fun book, and then you relate it to, the unwanted, unnecessary unneeded thoughts' [ID44, mother]

However, other parents felt that their child was not currently receptive to help, which they perceived as a barrier to helping their child themselves.

'the next step is for him to actually want to stop. Because it's like an alcoholic giving up drink isn't it, it's, the process of stopping is not pleasant and won't be pleasant for him.

And he is studious enough to know it won't be pleasant, so he has got to really want to do it, or even going on a diet or something, you have really got to want to do it for it to be successful'. [ID18, mother]

Subtheme: 'most children look at their parent and say, that's my parent … they wouldn't take on board the lessons you are teaching them' [ID39, father]

Parents described how their child perceived them as less credible than a therapist. Parents felt their child would be less receptive to their attempts to help them and would be resistant to receiving their support (particularly in the absence of the child meeting with the therapist).

'it's coming from somebody else who is a specialist, so he's got that in his head that if you are a doctor, if you are a specialist in the area then you must be right. If we were to do it, he would probably just think "oh god here they go, what are they doing now, what are they implementing now, it's just another parent thing"' [ID38, mother]

Subtheme: 'We are not mental health professionals' [ID23, Mother]

Many parents lacked confidence in their own and other parents' ability to help their child (particularly in a parent-led treatment approach) and felt that their child should receive direct help from a mental health professional.

'um, so I think that that, that's difficult, this, this assumes for this to work, it would assume, a, that the parents can, can understand what the therapist has said, first of all, you know, um and be able to then implement that therapy with their child' [ID43, father]

'I can't see, out of a few sessions, I can't see how a parent can be, qualified to do that, um, because, because to be a therapist, you need to study quite a lot, and it, and I find it a bit

worrying and it's a bit like um, you know, somebody give you a recipe and then you become a Michelin starred chef, it doesn't really work like this' [ID34, father]

In part, some parents felt unable to take an integral role in helping their child, due to their emotional attachment with their child.

'a therapist just isn't emotionally involved in the same way, so can suggest things that they know the child will find tricky, and, expect them to do it, where as a parent, it's a bit like, oh god no, that's really going to upset them or distress them if, if they do that, so I am not going to ask them … I don't want to see them distressed' [ID44, mother]

Whilst other parents did not want the responsibility of supporting their child (in a parent-led treatment approach) as this would add to the emotional challenges they were already experiencing.

'parents are supporting the child so much anyway, that to put that extra I hate to use the word burden, but the extra responsibility and the extra pressure and stress that it's up to the parent then to perform as a therapist, and it's up to the parent whether the child gets better or not, ultimately, I think would be really quite hard, cos you might feel like a failure' [ID33, mother]

However, parents often stressed the importance of early access to information and treatment to support their child. In some cases, this sense of urgency meant that parents would be more willing to try other treatment approaches (e.g., parent-led treatment approaches) that could be more readily available, particularly if this meant being able to support their child when their difficulties were less severe.

'if we had had something like this [parent-led approach], even early on this time you know because [child's name] mentioned to me in [month] … you know the things with the numbers and the counting I have started doing it again, and if we had been able to access

something at that point, I think that could have worked really well … um that could be really successful early on, I think that, the point we got to by the time we saw somebody, we would have struggled because I think [child's name] needed to hear if from someone else' [ID19, mother]

Overarching theme: Knowledge is key

Common across parents was the sense that *'information is power. The more a parent knows, the more they can help' [ID18, mother]* and *'educating the parents is, crucial, absolutely crucial' [ID44, mother]*. Parents perceived knowledge as the key to increasing their self-efficacy to help their child, which could be achieved through various methods, including books, therapist support, attending their child's treatment sessions, or learning through previous successes of helping their child.

'oh that sounds fantastic [individual child sessions with additional parent sessions] …if we had that, that would I think help us, a great deal … because additional information on how to manage OCD, would help, uh with … supporting your child, on that journey of OCD management. Additional information is always good, basically, that's my answer' [ID35, mother]

'well because obviously, learning from her [the therapist], she was like a teacher for me to see, how, how do I do this stuff' [ID31, mother]

'and then for me to realise, actually no he can do this, he is going to be able to do this, gave me kind of the strength to go right we have got to do this hard one now and it's going to be horrible but we have just got to grit out teeth and get through it because he will be able to do it' [ID37, mother]

Table 2. Implications from further qualitative research.

Parental concern	**Implications for treatment adaptation**
The child needs to be the central focus of treatment (i.e., children need to be seen by a therapist and take ownership of their recovery).	• Maintain involving the child in the diagnostic assessments. • Adapt the treatment to include an externalising OCD handout for children, where children can draw/name their child to help them feel more included in the treatment. • Adapt the reading materials to explicitly recognise the importance of the therapist, parents, and child working 'as a team' to overcome OCD. • Be aware of and re-iterate the importance of involving the child throughout the treatment (e.g., encourage parents to finalise/choose goals and finalise the step-by-step plan with their child. Encourage parents to allow their child to input ideas into possible reward systems and to give their child choice over which independent activities to try).
Parents identified the importance of information needing to be clear, simple, and in accessible formats.	• Adapt the reading materials to provide clear, bite-sized information (e.g., examples of OCD maintenance cycles and step-by-step plans built up one step at a time). • Avoid using specialist terms e.g., 'family accommodation' to keep information simple/easy to understand. • Use case examples to illustrate key principles/techniques (e.g., maintenance cycles, setting SMART goals, step-by-step plans). • Provide explicit examples of how to talk to children about their fears. • Adapt the treatment content to provide clear alternatives to family accommodation and reassurance provision (e.g., instead of saying 'X', try 'Y'). • Provide the option to receive audio-recordings of the reading material to increase accessibility.
Parents identified that to be able to support their child, information needs to be specifically tailored to their child and family.	• Continue developing personalised maintenance cycles with each family. • Continue developing personalised step-by-step plans with each family. • Adapt the treatment content to provide case studies of different OCD presentations to help parents think about how these examples might apply to their child.

Parents identified the importance of having guidance on how to support their child and how to troubleshoot difficulties which arise.	• Maintain regular pacing of sessions to provide consistent guidance and support to parents. • Adapt the reading materials to include “what if” sections which pre-empt possible parental concerns/challenges and how to overcome these. • Adapt the reading materials to provide a section on common experiences and challenges implementing the step-by-step plan for children with OCD. • Continue to provide worked examples of problem solving.
Parents identified that emotional challenges/emotional attachment to their child makes it hard for them to support their child.	• Keep space for parents to share how their child’s OCD has been over the past week. • Adapt the treatment content to include an additional handout on self-care for parents. Be aware of the emotional challenges and give parents permission to practice self-care if needed. • Adapt the reading materials to provide explicit guidance on what parents can do if they are finding ERP emotionally challenging.
Parents identified the importance of treatment being delivered flexibly.	• Adapt the treatment manual to allow greater flexibility on the use of videocalls or telephone calls depending on parent preference. • Allow remote delivery to allow two parents to separately join the appointment. • Allow greater flexibility in timings of assessment and treatment sessions (e.g., evening appointments).
Parents identified the importance of understanding the rationale for treatment.	• Continue to emphasise the key concepts of helping children to learn new information about their fears and their ability to cope in feared situations throughout the treatment.
Parents identified concerns that their child may not be willing to engage in treatment or techniques implemented by parents.	• Adapt the treatment to include developmentally appropriate analogies (e.g., OCD as a bully, elephants on the train track) that parents can use at home to engage their child. • Adapt the treatment so that ERP steps can include ways to test out non-threatening magical thinking/thought action fusion beliefs as a first step, to help engage children who are reluctant to participate in ERP. • Continue to encourage parents to identify appropriate rewards to help engage their child. • Continue to encourage parents to involve their child’s hobbies/interests throughout treatment.

	• Adapt the reading materials to include “what if”/troubleshooting sections targeted at overcoming challenges engaging children.
Parents identified the importance of involving wider family members in treatment to help increase others’ knowledge of OCD and to promote a consistent approach to managing their child’s OCD.	• Enable more than one parent/caregiver to attend the treatment sessions if they wish. • Discuss with parents how/whether/to what extent to include other family members in the treatment.
Parents perceive themselves as less credible than a therapist.	• Continue involving the child at the diagnostic assessments to enable the child to meet the therapist. Explain to the child that the therapist will be giving parents tools/tips on how to help they can help them. • Encourage parents to talk about treatment sessions/attribute homework tasks to the therapist if helpful. • Adapt the reading materials to list this as a common concern and normalise parents’ concerns about this.
Parents are not mental health professionals.	• Adapt the reading materials to include clear, simple, bite sized information, and worked examples throughout. • Avoid using specialist terms e.g., ‘family accommodation’ to keep information simple/easy to understand. • Help parents to learn simple skills and techniques that are easy to incorporate in their day-to-day life.
Parents lack confidence in their ability to help child.	• Adapt the reading materials to include clear, simple, bite sized information, and worked examples throughout. • Ensure there are opportunities for parents to ask questions and to review key information if needed. • Adapt the treatment measures to explicitly monitoring parents’ confidence. Explicitly review parents’ confidence at each treatment session and collaboratively troubleshoot areas where parents may lack confidence. Continue to praise parents’ efforts/achievements to boost their confidence.

	• Adapt the reading materials to list this as a common concern and normalise parents' concerns about this.
Parents may not want the responsibility of treating their child.	• Adapt the reading materials to emphasise a team approach to overcoming OCD. Emphasise the team approach throughout the treatment and the expertise that parents bring to the team about their child's difficulties. Explicitly recognise that parents are not wholly responsible for their child's treatment. • Adapt the reading materials to list this as a common concern and normalise parents' concerns about this.
Parents recognise that knowledge is key to helping their child.	• Adapt the treatment content to provide relevant psychoeducation on OCD to help empower parents to help their child.

Note. ERP = Exposure and Response Prevention; Treatment implications are colour coded as follows: Green = Rationale for keeping an existing treatment component, Purple = Considerations to be aware of when delivering the treatment, and Red = Elements of the existing treatment which need to be adapted.

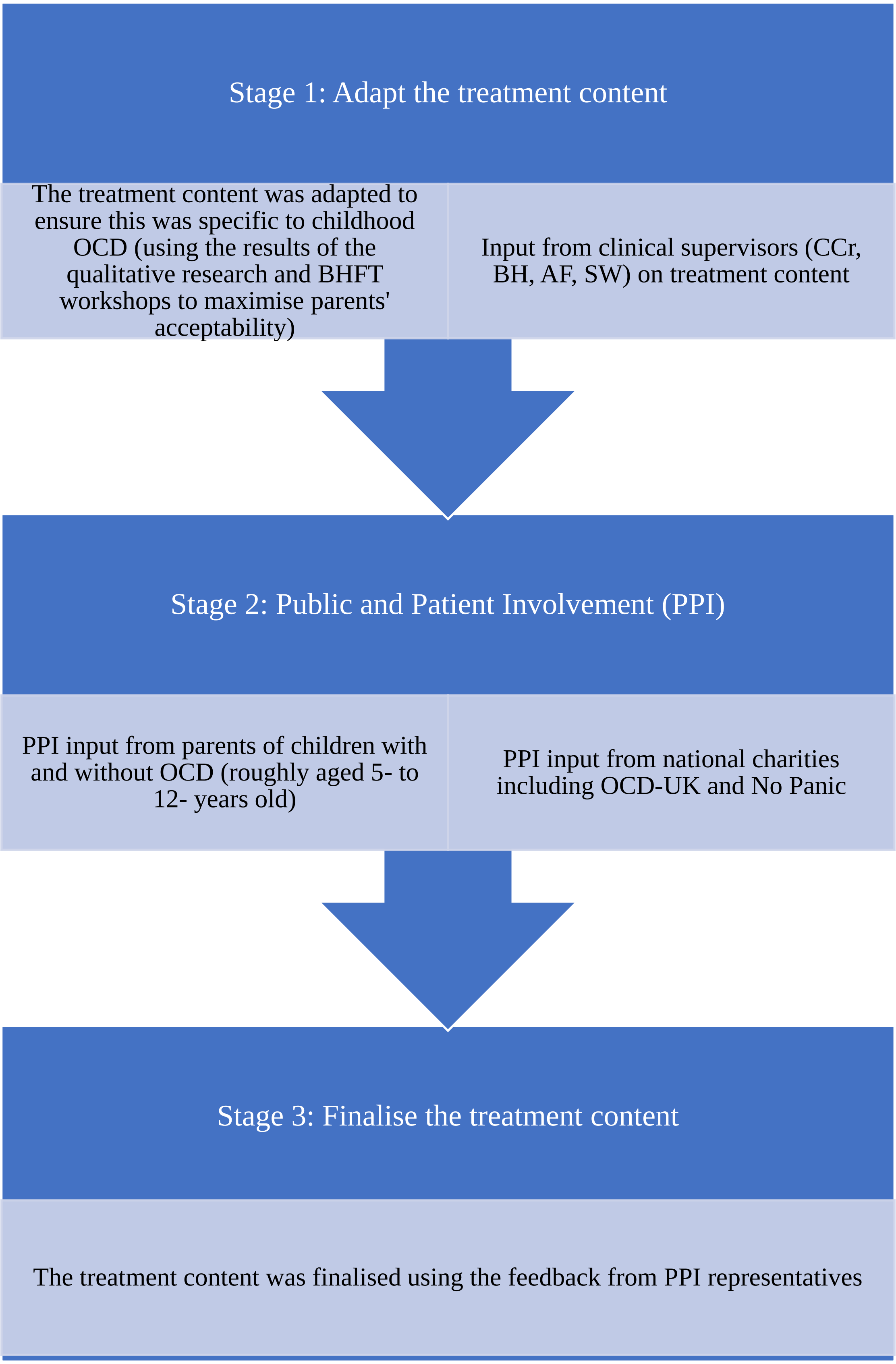
4.6 Implications from collaborative work with Berkshire Healthcare NHS Foundation Trust (BHFT)

As part of this collaborative PhD studentship with BHFT, I helped to facilitate a series of psychoeducational workshops for parents of children and adolescents with OCD whose children were either waiting to receive or currently receiving treatment within the service. Four workshops were conducted across four months and provided psychoeducation on OCD (including the development and maintenance of OCD, family accommodation, reassurance provision, and the impact of OCD on family and siblings), evidence-based treatments for OCD, how parents can support young people receiving CBT, and self-care for parents. Parents completed a feedback questionnaire assessing the acceptability of the workshops. Consistent with the findings of the qualitative research, parents found it helpful to understand what OCD is and to learn that unwanted thoughts are normal. Parents liked the analogy of OCD 'as a bully' and found it helpful to watch videos which provided further insight into what OCD is. Parents identified the importance of information being presented in clear, simple ways and liked the use of case examples. Some parents found it challenging to not reassure their child or struggled to engage their child in the suggested techniques when their child was not receiving therapist support. I used parents' feedback from these workshops to identify key implications for the adapted treatment that reflected parents' experiences and views, including: the importance of helping parents to understand OCD (using analogies and videos to assist with this); the need to provide parents with clear and simple information; providing relevant case examples; giving parents clear alternatives to reassurance provision (and recognising this can be hard for parents to do); and troubleshooting with parents how to engage children in treatment techniques.

4.7 Development of the intervention

The adapted treatment was developed using the revised treatment materials for parents of preadolescent children with anxiety disorders (e.g., Creswell & Willetts, 2019; Halldorsson et al., 2019) and an online version of this treatment (Hill et al., 2022), both of which focus on empowering parents to help their children to engage in exposure tasks that help them to learn new information about their fears and their ability to cope in feared situations to overcome their anxiety difficulties. This treatment was adapted using the results of the qualitative research (Chapter 2, and Chapter 4), existing OCD treatment manuals (e.g., Bream et al., 2017; Turner et al., 2019), relevant OCD measures (e.g., Scahill et al., 1997), and the team's clinical expertise. Families were offered 6- to 8- individual treatment sessions to enable adequate time to cover the treatment content and to provide families with opportunities to implement the treatment techniques (and collaboratively troubleshoot any barriers to implementation) prior to the final treatment session. The adapted treatment materials consisted of a therapist manual, reading materials for parents, and session handouts. An overview of each stage of the treatment adaptation is shown in Figure 3 and summarised below. Table 3 provides a brief comparison of the original (Creswell & Willetts, 2019; Halldorsson et al., 2019) and adapted treatment content.

Figure 3. Development of the intervention



Stage 1: Adapt the treatment content

The treatment content was adapted to ensure this was specific to childhood OCD (using the results of the qualitative research and BHFT workshops to maximise parents' acceptability)

Input from clinical supervisors (CCr, BH, AF, SW) on treatment content

Stage 2: Public and Patient Involvement (PPI)

PPI input from parents of children with and without OCD (roughly aged 5- to 12- years old)

PPI input from national charities including OCD-UK and No Panic

Stage 3: Finalise the treatment content

The treatment content was finalised using the feedback from PPI representatives

Stage 1: Adapt the treatment content

Given that parents stated the importance of information being clear and simple, I adapted the reading materials developed by Hill et al. (2022) for the basis of this intervention, as these reading materials had been developed using a co-design process and were copy edited by health journalists to ensure that they were clear and easy for parents to understand and had a low reading age. I systematically worked through these reading materials and considered where relevant adaptations to the content and/or delivery of the content needed to be made. Adaptations were made using the results of the qualitative research (Chapter 2, and Chapter 4), reflections from BHFT workshops (Chapter 4), existing OCD treatment manuals (e.g., Bream et al., 2017; Turner et al., 2019), relevant OCD measures (e.g., Scahill et al., 1997), and input from clinical supervisors (CCr, BH, AF, SW) who are Clinical Psychologists with considerable expertise in parent-led treatments and the assessment/treatment of OCD. Bream et al.’s (2017) manual was used to provide inspiration for how to explain the OCD maintenance cycle to parents in a simple step-by-step fashion (i.e., by presenting each aspect of the maintenance cycle one stage at a time) and for its use of metaphors to help parents to understand the rationale for externalising OCD (i.e., using the bully metaphor) and for exposure (i.e., the elephants on the train track metaphor). Turner et al.’s (2019) treatment manuals were used to gauge how much content was typically covered in a treatment session and how concepts (in particular, externalising OCD) were explained to young people. Given that Turner et al.’s (2019) treatment manual is based on a habituation model of exposure (rather than exposure with a focus on helping children to learn new information about their fears and their ability to cope in feared situations, as is the case in Creswell and Willetts (2019)), this manual was mainly used for the above purposes. Similarly, other manuals for the treatment of OCD in children and adolescents (e.g., March & Mulle, 1998) were also not used to adapt this treatment given their focus on habituation based exposure. This decision was made following recent literature suggesting that exposure focused on helping individuals to learn new information about their fears and their ability to cope in feared situations may enhance treatment outcomes compared to habituation based exposure (Craske et al., 2014).

Stage 2: Public and Patient Involvement (PPI)

Given the importance of ensuring that key stakeholder views are heard during intervention development (Palmer et al., 2019), PPI feedback was sought from key stakeholders (including parents of children with and without OCD and two national charities who regularly support families affected by OCD) to ensure that the adapted reading materials and treatment handouts were understandable, acceptable, and reflective of families' needs (Locock & Boaz, 2019). Specifically, respondents were asked to provide feedback on (1) whether the reading materials and handouts were clear and easy to understand, (2) whether the optional 'activity boxes' would be useful for parents to complete, (3) whether the proposed formatting of the reading materials and treatment handouts were clear and engaging, and (4) whether the written information was sensitive to parents' experiences.

Parents of children without OCD thought that the reading materials were easy to read and understand. Parents liked that minimal abbreviations were used and liked the use of metaphors to explain key concepts. They liked the use of case examples and particularly valued the information on parents' experiences of implementing step-by-step plans with their child. Parents also liked the worked example of an OCD maintenance cycle, particularly how this was built up step-by-step, and thought that the "what if"/trouble-shooting sections would be helpful for parents. Parents liked the layout and colours of the reading materials and handouts. Parents suggested making any actions that parents need to complete clearer/in a distinct colour and identified the importance of the therapist reviewing/providing feedback on any activity boxes the parents complete. They suggested reducing unnecessary repetition (i.e., only saying “what if” once during the “what if”/trouble-shooting section) and normalising that it might seem scary/uncomfortable to externalise OCD and providing a rationale for why externalising OCD is helpful.

Parents of children with OCD also thought the information was clear, simple, and easy to read. They liked the use of bold text to emphasise key points and liked the colours used throughout the materials. They suggested having a ‘checklist’ at the end of each section to make it clear to parents what they needed to work on over the next week. They suggested having less pictures and including arrows from one box of information to another to make this easier for parents to follow. One mother felt that the information on the causes of OCD was parent blaming and suggested keeping this information broader to avoid this. They thought the step-by-step approach to reducing reassuring seeking was particularly helpful and valued the clear alternatives to reassurance provision. Parents felt it was important that the rationale for not providing reassurance needed to be made clearer and suggested that it is helpful for parents to work together to reduce reassurance provision where possible. They suggested emphasising that ERP can focus on one goal at a time so that parents do not feel overwhelmed. They also suggested dividing the information on ERP and parents’ experiences of this into two separate sections that are given to parents over two separate weeks, as they felt the existing format was overwhelming and hard to absorb. Finally, they suggested adding additional tips for parents on how to cope if they find ERP emotionally challenging, including working as a team with another adult and walking away if needed.

The treatment materials were additionally reviewed by representatives from OCD-UK and No Panic. The charity representatives thought that the materials were helpful and appropriate for parents of preadolescent children with OCD. They thought that the language used would be acceptable to families and thought that the use of pictures and colours would be engaging for parents. They suggested highlighting action points in red, using more distinct colours in the OCD maintenance cycle to make this clearer if parents print out the materials, adding page numbers, and having a notes page for parents. They liked the use of case examples, however felt it was important to add a note to say that OCD presents differently for each child and that parents should not be concerned if they cannot relate to the case examples provided. They thought that providing links to optional videos for parents would be helpful if parents have different learning styles. No Panic suggested adding information about their charity on the resources page as this would provide a way for parents to connect with other parents of children with OCD if they wished.

Stage 3: Finalise the adapted treatment

PPI input was used to finalise the treatment materials to help maximise parental acceptability of the treatment.

Table 3. A brief comparison of the original (Creswell & Willetts, 2019; Halldorsson et al., 2019) and adapted treatments.

Session	Original Treatment (Creswell & Willetts, 2019; Halldorsson et al., 2019).	Adapted Treatment
1	*Content:* Psychoeducation on the development and maintenance of anxiety disorders (including how other people can contribute to the maintenance of anxiety disorders); setting realistic expectations; goal setting. *Handouts:* Maintenance of anxiety; goals. *Homework:* Complete maintenance of anxiety handout; discuss and finalise goals with child.	*Content:* Psychoeducation on the development and maintenance of OCD (including information on how other people can contribute to the maintenance of OCD); setting realistic expectations; goal setting. *Handouts:* Maintenance of OCD; goals. *Homework:* Complete maintenance of OCD handout; discuss and finalise goals with child.
2	*Content:* Open questioning skills to help parent(s) to identify what their child is worried about and what their child needs to learn to overcome their anxiety; identifying rewards; encouraging independent behaviour. *Handouts:* What is my child thinking; what does my child need to learn; rewards; encouraging independent behaviour. *Homework:* Practice using open questioning skills; collaboratively identify rewards with child; encourage independent behaviour.	*Content:* Open questioning skills to help parent(s) to identify what their child's obsessions are and what these obsessions mean to their child to identify what their child needs to learn to overcome their OCD; Encouraging parents to externalise OCD with their child; identify rewards; encouraging independent behaviour. *Handouts:* What are my child's obsessions and what do they mean to my child; what does my child need to learn; externalising OCD; rewards. *Homework:* Practice using open questioning skills; externalise OCD with child; collaboratively identify rewards with child; encouraging independent behaviour.
3	*Content:* Step-by-step exposure plan to help children to face feared situations in a gradual, manageable way. *Handouts:* Ideas for step-by-step plan; my child's step-by-step-plan; monitoring progress on the step-by-step plan. *Homework:* Finalise plan with child; begin implementing the plan.	*Content:* Step-by-step exposure and response prevention plan to help children to be exposed to their obsessions (without completing compulsions) in a gradual, manageable way; alternatives to reassurance provision. *Handouts:* What steps should be in my child's step-by-step plan; ideas for step-by-step plan; my child's step-by-step plan. *Homework:* Finalise plan with child; begin implementing the plan.

4	*Content:* Review progress of step-by-step plan; troubleshoot any difficulties. *Handouts:* My child’s step-by-step-plan; monitoring progress on the step-by-step plan. *Homework:* Continue implementing step-by-step plan.	*Content:* Review progress of step-by-step plan; troubleshoot any difficulties. *Handouts:* My child’s step-by-step-plan. *Homework:* Continue implementing step-by-step plan.
5	*Content:* Review progress of step-by-step plan; troubleshoot any difficulties; introduction of problem-solving technique. *Handouts:* My child’s step-by-step-plan; monitoring progress on the step-by-step plan; problem solving. *Homework:* Continue implementing step-by-step plan; implement problem solving if needed.	*Content:* Review progress of step-by-step plan; troubleshoot any difficulties; introduction of problem-solving technique. *Handouts:* My child’s step-by-step-plan; problem solving. *Homework:* Continue implementing step-by-step plan; implement problem solving if needed.
6	*Content:* Review progress of step-by-step plan; review of problem-solving; relapse prevention. *Handouts:* My child’s step-by-step-plan; monitoring progress on the step-by-step plan; things that have been helpful for my child; things to carry on working on. *Homework:* Continue implementing treatment techniques where needed.	*Content:* Review progress of step-by-step plan; review of problem-solving; (if final session, relapse prevention). *Handouts:* My child’s step-by-step-plan; problem solving. *Homework:* Continue implementing step-by-step plan; implement problem solving if needed.
7 (if needed)	N/A	*Content:* Review progress of step-by-step plan; (if final session, relapse prevention). *Handouts:* My child’s step-by-step-plan. *Homework:* Continue implementing step-by-step plan.
8 (if needed)	N/A	*Content:* Review progress of step-by-step plan; relapse prevention. *Handouts:* My child’s step-by-step-plan; maintaining progress and managing setbacks. *Homework:* Continue implementing treatment techniques where needed.

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Chapter 5: Paper 3

Therapist guided, parent-led Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD): A non-concurrent multiple baseline case series

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5.1 Introduction to Chapter 5 (Paper 3)

In Chapter 4, I detailed the development of a brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD. To determine whether this intervention may be a viable first-line treatment for this population, in Chapter 5 (Paper 3), I present the results of a preliminary evaluation of the efficacy and acceptability of this treatment. Given that this is a novel intervention with a clinical population, I used a non-concurrent multiple baseline approach to evaluate the treatment (Horner et al., 2005; Watson & Workman, 1981). This approach is particularly advantageous for evaluating newly developed interventions as it is less costly and time consuming compared to randomised controlled trials (Horner et al., 2005). In this Chapter, I also present a brief overview of a reflexive thematic analysis exploring parents' experiences and acceptability of the intervention, however, owing to the constraints of journal articles, I was unable to discuss this analysis in great depth. Therefore, in Chapter 6, I provide further detailed information related to this aspect of the study.

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Therapist guided, parent-led Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder: a non-concurrent multiple baseline case series.

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Abstract

Cognitive Behavioural Therapy (CBT) including Exposure and Response Prevention (ERP) is an effective treatment for preadolescent children with OCD, however, there is a need to increase access to this treatment for affected children. This study is a preliminary evaluation of the efficacy and acceptability of a brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children (5- to 12-years-old) with OCD using a non-concurrent multiple baseline approach and qualitative interviews. Parents of 10 children with OCD were randomly allocated to no-treatment baselines of 3-, 4-, or 5-weeks before receiving 6-to-8- individual treatment sessions with a Psychological Wellbeing Practitioner. Diagnostic measures were completed prior to the baseline, one-week post-treatment, and at a one-month follow-up and parents completed weekly measures of children's OCD symptoms/impairment. Seventy percent of children were 'responders' and/or 'remitters' on diagnostic measures at post-treatment, and 60% at the one-month follow-up. At least 50% of children showed reliable improvements on parent-reported OCD symptoms/impairment from pre- to post-treatment, and from pre-treatment to one-month follow-up. Crucially, the intervention was acceptable (albeit demanding) to parents. Brief low-intensity therapist guided, parent-led CBT has the potential to be an effective, acceptable, and *accessible* first-line treatment for preadolescent children with OCD, subject to the findings of further evaluations.

Keywords

Obsessive Compulsive Disorder; Cognitive behavioural therapy; Preadolescence; Parent-led interventions.

Introduction

Obsessive Compulsive Disorder (OCD) typically first starts between 7.5 and 12.5 years of age (Geller et al., 1998) and is associated with substantial impairment to the child's home, school, and leisure time (Piacentini et al., 2003; Stewart et al., 2017). Younger onset of OCD is associated with a more chronic course (Stewart et al., 2004), however the sooner that treatment is provided, the better the outcomes (Mancebo et al., 2014) – highlighting the need for timely access to evidence-based treatment for preadolescent children with OCD.

Cognitive Behavioural Therapy (CBT) including Exposure and Response Prevention (ERP) is an effective, gold-standard psychological treatment for preadolescent children with OCD (Ivarsson et al., 2015; McGuire et al., 2015; National Institute of Health and Care Excellence [NICE], 2005; Öst et al., 2016), however limited numbers of mental health professionals are trained to deliver CBT treatments (Baker & Waite, 2020; Stallard et al., 2007), resulting in substantial waits for services (O'Neill & Feusner, 2015). Existing CBT treatments for preadolescent children with OCD typically consist of at least 10 hours of therapist support (Barrett et al., 2008; Franklin et al., 2015) – limiting the number of children who can benefit from such treatments. Indeed, Chessell et al. (2022a) highlighted the "battle" that parents describe in trying to access CBT treatment for preadolescent children with OCD.

Brief, low-intensity parent-led treatments have been used to increase access to treatments for preadolescent children with anxiety difficulties and behavioural problems (Ludlow et al., 2020) and may be a potential way to increase access to CBT for preadolescent children with OCD. Brief, low-intensity parent-led treatments involve a therapist working directly with a parent to empower them to apply CBT techniques at home with their child (Creswell et al., 2017) and can increase access to treatments as although this approach still requires access to a therapist, parent-led treatments can be delivered effectively (e.g., Chavira et al., 2014; Cobham, 2012; Thirlwall et al., 2013) and cost-effectively (e.g., Creswell et al., 2017) with good outcomes achieved when delivered by non-specialist therapists (Thirlwall et al., 2013). To date, limited research has explored the potential for parent-led treatments to increase access to CBT for preadolescent children with OCD, however, one research group has examined the efficacy of this approach for young children (aged 5- to 7-years-old) with OCD (Rosa-Alcázar et al., 2017, 2019). Although this research has demonstrated significant improvements in children's OCD severity (Rosa-Alcázar et al., 2017, 2019), the treatment consisted of 12 hours of individual support with specialist therapists, limiting the potential reach of the treatment. Thus, there is a need to develop and evaluate a brief, low-intensity parent-led CBT treatment that can help to increase access to treatments for preadolescent children with OCD and that is acceptable to parents.

The current study is a preliminary evaluation of a brief, low-intensity parent-led CBT treatment for preadolescent children with OCD using a non-concurrent, multiple baseline approach. The treatment was adapted from an existing, evidence-based parent-led treatment for preadolescent children with anxiety disorders (Thirlwall et al., 2013) to ensure suitability for parents of preadolescent children with OCD. In addition to adapting treatment materials to reflect CBT (including ERP) approaches for the treatment of childhood OCD, adaptations reflected themes that were identified from recent qualitative work on the experiences of parents of preadolescent children with OCD (Chessell et al., 2022a). These adaptations included the need for guidance to be sensitive to the challenges and emotional difficulties that parents experience, and the need to provide clear, manageable advice for parents on how they should respond to their children's OCD to reduce parental helplessness and to empower parents in their ability to support their children. Specifically, this study aimed to examine: (1) the clinical outcomes for children whose parents participated in a brief, low-intensity parent-led CBT treatment and (2) acceptability of the treatment to parents (using both quantitative and qualitative methods).

Materials and Methods

This article is written in accordance with the recommended reporting guidelines for multiple baseline approaches (Tate et al., 2016) and qualitative research (Tong et al., 2007). For brevity, information relating to the COREQ checklist (Tong et al., 2007) is reported in supplementary analyses (see Table S4).

Participants

Participants were ten children aged 9- to 12-years-old (M= 10.9 years, SD= 1.1 years, 70% female) and their parent(s). Inclusion criteria required children to be UK-residents, aged 5- to 12-years-old, and to meet DSM-5 criteria for OCD as assessed using the Anxiety Disorder Interview Schedule – Parent report (ADIS-P). Children were excluded if they were currently receiving psychological interventions or psychotropic medication (where the dosage had not been stable for 2 months). Children were also excluded if they had a confirmed autism diagnosis, were suspected to have autism (indicated by a score of ≥ 15 on the Social Communication Questionnaire), had a profound learning disability (indicated by attending a specialist school), or if there were significant safety concerns (i.e., current suicidal intent, recurrent or potentially life limiting self-harm, child protection plan/child protection register). Parents were required to be UK-residents and were excluded if they had a significant intellectual impairment or were unable to understand written English. Participant characteristics are shown in Table 1. Eight children were White British, one child was White and Asian, and one child was White and Black African. Nine parents identified as White British and one parent identified as British Indian. Children's ADIS-P Clinical Severity

Rating (CSR) scores ranged from moderate (n = 6) to severe (n = 4) and half of the children met criteria for at least one additional disorder.

Study design

A non-concurrent multiple baseline approach was used to evaluate the treatment, as this approach is appropriate when evaluating novel treatments (Horner et al., 2005) with clinical populations, where it is unlikely that referrals will be received at the same timepoint (Watson & Workman, 1981; Ollendick et al., 2021). A series of AB replications were conducted across participants and consisted of a no-treatment baseline phase (A) and a treatment phase (B). Families were randomly allocated (using block randomisation) to one of three pre-determined baseline lengths of 3-, 4-, or 5-weeks to control for the confound of time (Kratochwill & Levin, 2010) and to ensure that the minimum recommended number of data points per phase was met (Kratchowill et al., 2010). Treatment commenced immediately after the baseline phase.

Procedure

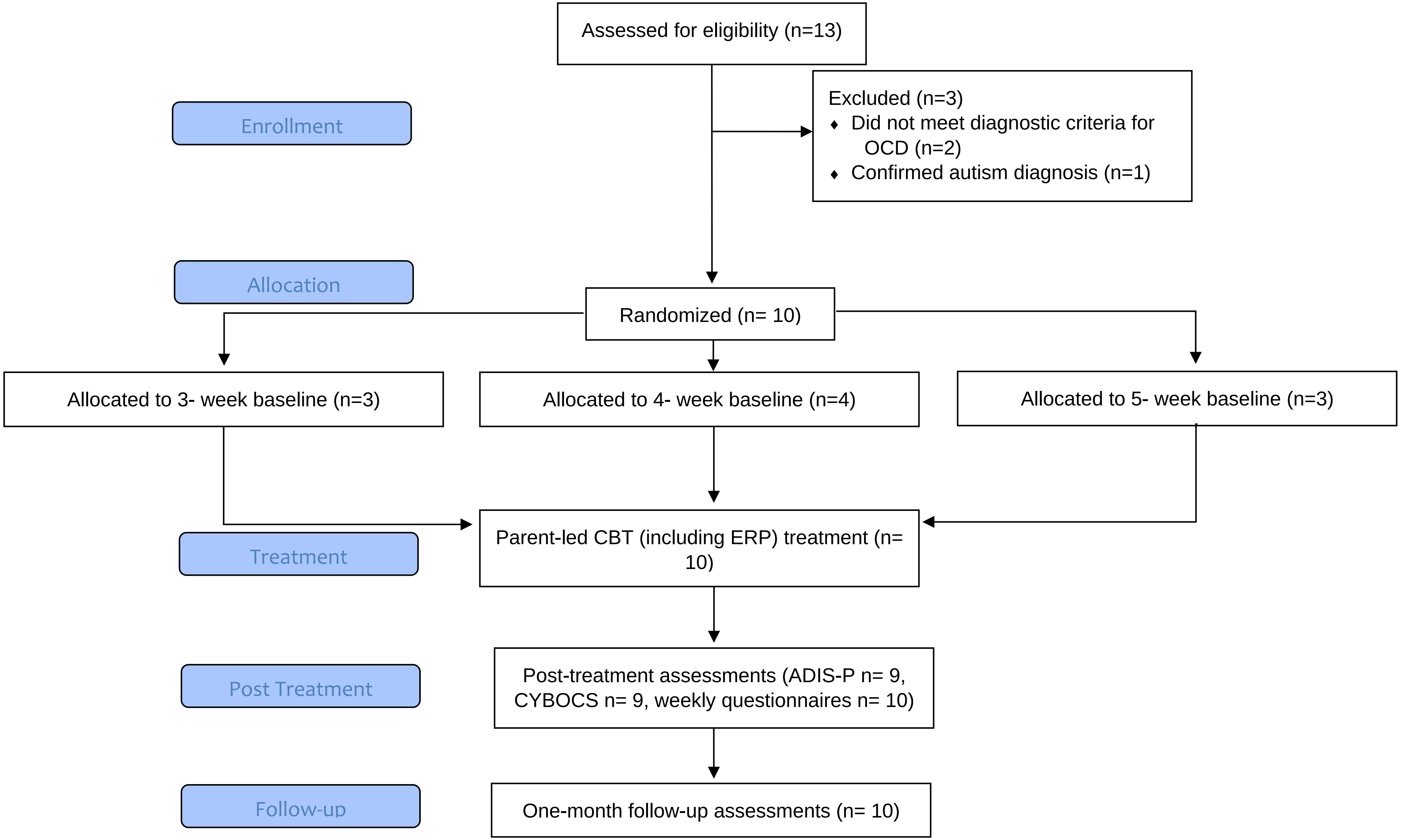
Ethical approval was obtained from West Midlands – South Birmingham Research Ethics Committee (REC Reference: 21/WM/0077) and the University of Reading Research Ethics Committee (UREC: 21/27). Potential participants were recruited from a local Child and Adolescent Mental Health Service (CAMHS) in South East England (n = 2) and advertisements distributed via social media and mental health charities (n = 11) (see Figure 1). Advertisements contained a link where parents (and their children) could access online study information and complete online consent (and optional child assent) forms. Adverts listed the contact details of the study researcher (CCh) to enable parents to ask questions before providing informed consent. Consenting parents completed an online screening questionnaire (see Measures) to determine potential eligibility for the study. Potentially eligible parents then completed the Social Communication Questionnaire (SCQ) and if indicated, the Anxiety Disorder Interview Schedule – Parent report (ADIS-P). Children who met criteria for OCD on the ADIS-P then completed the CY-BOCS (if child assent had been obtained) with their parent(s) present to add further information where applicable (Scahill et al., 1997). Parents then attended a videocall appointment with the study researcher to discuss the outcomes of the ADIS-P and CY-BOCS and to be randomised to a baseline length. Parents completed weekly online questionnaires during the baseline and treatment phases. Parents (and their child if assent was obtained) completed briefer versions of the ADIS-P (i.e., the OCD section only) and CY-BOCS (i.e., a review of pre-treatment symptoms, identification of any new symptoms, and completion of post-treatment severity ratings) within one-week of completing treatment, and full versions of these measures one-month after completing treatment. Parents attended a final appointment to discuss the outcomes of these assessments and recommendations for further external support, if needed. Parents completed a feedback questionnaire and were invited to participate in an optional qualitative interview to share their experiences of the treatment.

Table 1. Participant characteristics

ID	Child Age (at intake, years)	Child Gender	Primary Parent	Parent Age (years)	ADIS-P OCD Pre-treatment CSR	CY-BOCS Pre-treatment score	Comorbid diagnoses pre-treatment (CSR)
1	11 – 12	Male	Father	40 – 49	5	22	N/A
2	5 – 10	Female	Mother	40 – 49	6	28	N/A
3	5 – 10	Female	Mother	40 – 49	5	26	N/A
4	5 – 10	Female	Mother	30 – 39	4	22	Generalised anxiety disorder (4)
5	11 – 12	Female	Mother	40 – 49	6	18	Social anxiety disorder (5)
6	11 – 12	Male	Father	40 – 49	6	25	N/A
7	11 – 12	Female	Mother	40 – 49	4	24	N/A
8	11 – 12	Male	Mother	Missing	4	28	Separation anxiety disorder (5); Generalised anxiety disorder (4); Tourette's disorder[1]
9	5 – 10	Female	Mother	50 – 59	4	19	Generalised anxiety disorder (4)
10	11 – 12	Female	Mother	40 – 49	6	20	Social anxiety disorder (4)

Note. To preserve anonymity, parent and child age are presented as ranges, and parent and child ethnicity are not reported here; [1] = One parent identified that their child was diagnosed with Tourette's disorder, however, this was not formally assessed as part of this study; ADIS-P = Anxiety Disorder Interview Schedule – Parent report; CSR = Clinical Severity Rating; CY-BOCS = Children's Yale Brown Obsessive Compulsive Scale.

Figure 1. Flow of participants.



Treatment

The treatment was adapted from an existing parent-led CBT treatment for children with anxiety disorders (Creswell & Willetts, 2019; Halldorsson et al., 2019; Hill et al., 2022) to ensure suitability for children with OCD (see Table 2 for treatment adaptations and Table 3 for treatment content). Adaptations reflected the existing literature on possible maintenance mechanisms relevant to childhood OCD (Chessell, Halldorsson, Harvey, et al., 2021), parents' experiences of parenting a preadolescent child with OCD (Chessell et al., 2022a), the research teams' clinical experience, existing OCD treatments/manuals (e.g., Bream et al., 2017; Turner et al., 2019), and Public and Patient Involvement (PPI) with mental health charities and parents of children with OCD. The treatment emphasised ERP with a focus on helping children to learn new information about their fears/worries/obsessions and their ability to cope in feared situations without performing compulsions (Craske et al., 2014). Although the adult literature suggests that varying the difficulty/intensity of exposure tasks can optimise new learning (Craske et al., 2014), in line with the original treatment (Creswell & Willetts, 2019), a step-by-step approach to exposure was chosen (i.e., starting with easier ERP tasks and gradually progressing towards harder ERP tasks) to ensure that this was attainable for parents and their children. Parents attended 6- to 8- individual treatment sessions. As the study took place during the COVID-19 pandemic all sessions were conducted remotely and comprised 4 videocall sessions lasting 1 hour, and 2 – 4 shorter telephone/videocall review sessions (mode dependent on parent preference) lasting 30 minutes. The total amount of therapist input was 5 – 6 hours per family. The first 6 sessions were typically delivered weekly and the remaining 2 sessions (if needed) were delivered over a 2- to 6- week period (based on clinical judgement and families' preferences). Parents were provided with material to read prior to the first 5 sessions and the final session and completed between-session tasks with their child. Treatment was delivered by a qualified Psychological

Wellbeing Practitioner (PWP graduate psychological therapist; CCh) with experience of delivering parent-led CBT for anxiety disorders.

Table 2. Summary of treatment adaptations

Original treatment (Creswell & Willetts, 2019; Halldorsson et al., 2019; Hill et al., 2022)	Adapted treatment	Rationale for adaptation
Content		
Psychoeducation on development and maintenance of childhood anxiety	Psychoeducation on development and maintenance of childhood OCD, including information on (and alternatives to) family accommodation and reassurance provision; Externalising OCD.	Psychoeducation on OCD (including optional videos) to ensure relevant treatment content and to promote parental understanding of OCD (Chessell et al., 2022a); psychoeducation on family accommodation and reassurance provision due to the association between family accommodation and childhood OCS/OCD (Chessell, Halldorsson, Harvey, et al., 2021) and to enable parents to know how to respond in helpful ways to their child's OCD (Chessell et al., 2022a); externalising OCD to facilitate child involvement in treatment and to promote parents and children working as a team to overcome OCD (Chessell et al., 2022b).
Step-by-step exposure to feared stimuli with a focus on helping children to learn new information about their fears/worries and ability to cope in feared situations	Step-by-step exposure (with response prevention) to feared stimuli with a focus on helping children to learn new information about their fears/worries/obsessions and their ability to cope in feared situations without performing compulsions.	ERP is the gold-standard recommended psychological treatment for children with OCD (NICE, 2005).
Reading materials		
Accompanying book	Brief reading materials	Brief reading materials were developed to ensure information was concise, simple, and did not overwhelm parents (Chessell et al., 2022a, 2022b, and PPI). Reading materials recognised and addressed common parental concerns about parent-led treatment for OCD and incorporated case studies (with a range of OCD presentations) to ensure materials were relatable to families (Chessell et al., 2022b).

Measures		
RCADS, ORS, CAIS, GBOs, SRS	ChOCI-R-P, FAS-PR, Items assessing parental knowledge /confidence, items assessing child learning, GBOs, SRS	ChOCI-R-P included to specifically track OCD symptoms; FAS-PR to monitor family accommodation; items assessing parental knowledge/confidence were included as parents commonly feel ill-equipped to support their child at the start of treatment (Allard et al., 2022; Chessell et al., 2022a, 2022b); items assessing child learning to help enhance exposures (Craske et al., 2014).

Note. RCADS = Revised Child Anxiety and Depression Scale; ORS = Outcome Rating Scale; CAIS = Child Anxiety Interference Scale; GBOs = Goal Based Outcomes; SRS = Session Rating Scale; ChOCI-R-P = Children’s Obsessive Compulsive Inventory – Revised – Parent report; FAS-PR = Family Accommodation Scale – Parent Report; PPI = Patient and Public Involvement.

Table 3. Treatment content

Session	Content	Between-session tasks
1 (Videocall, 1 hour)	Psychoeducation on OCD, including the development and maintenance of OCD. Identification of 3 goals.	Prior to session 1, read Section 1 of the reading materials. After session 1, complete maintenance of OCD handout; discuss and refine treatment goals with child; read Section 2 of reading materials.
2 (Videocall, 1 hour)	Externalising OCD; rehearsal of skills on how to talk to their child about OCD to identify what their child needs to learn to overcome OCD. Identifying rewards.	Discuss externalising OCD with child; use questioning skills to identify what child needs to learn to overcome OCD; identify rewards with child; read Section 3 of reading materials.
3 (Videocall, 1 hour)	Development of provisional step-by-step (ERP) plan to work towards one treatment goal. Step-by-step ERP plans gradually progressed from easier to harder ERP tasks (as perceived by the parent/child).	Discuss and refine step-by-step plan with child. Implement step 1 of the plan; read Section 4 of the reading materials
4 (Telephone/ videocall, 30 minutes)	Review of step-by-step plan	Continue implementing step-by-step with child; read Section 5 of the reading materials.
5 (Videocall, 1 hour)	Review of step-by-step plan; worked example of problem solving	Continue implementing step-by-step with child; use problem solving approach with child if applicable. If session 6 is final session, read Section 6 of reading materials
6 (Telephone/ videocall, 30 minutes)	Review of step-by-step plan; review of problem solving. If final session, relapse prevention plan developed.	Continue implementing step-by-step plan with child. If session 7 is final session, read Section 6 of reading materials
7 (if needed, telephone/ videocall, 30 minutes)	Review of step-by-step plan. If final session, relapse prevention plan developed	Continue implementing step-by-step plan with child. If session 8 is final session, read Section 6 of reading materials
8 (if needed, telephone/ videocall, 30 minutes)	Review of step-by-step plan; relapse prevention plan developed	Continue implementing treatment techniques where necessary.

Measures

Screening Measures

Screening Questionnaire. To determine parents' potential eligibility for the study, all parents completed an initial screening questionnaire. This included parent/child demographic information, confirmation of UK residency, prescribed psychotropic medication, current/previous psychological support, confirmed autism diagnosis/learning disabilities, and brief questions to determine whether the child may be experiencing obsessions and/or compulsions.

Social Communication Questionnaire (SQC; Rutter et al., 2003). To identify if children had suspected autism, parents completed the 40-item SCQ. The SCQ is a screening measure for autism and has good psychometric properties (Berument et al., 1999). Individuals who score ≥ 15 may have autism and further assessment is recommended (Berument et al., 1999).

Diagnostic Outcome Measures

Anxiety Disorder Interview Schedule – Parent Report (Silverman, 1996). The ADIS-P is a parent-report, semi-structured interview which assesses DSM-IV anxiety, mood, and externalising disorders in young people aged 7- to 16-years-old and is considered a 'gold standard' measure in research settings (Creswell et al., 2020). Small adjustments to the ADIS-P were made to ensure alignment with the DSM-5. Clinician Severity Ratings (CSRs) were allocated on a scale from 0- to 8- for each diagnosis, with a CSR of ≥ 4 indicating diagnostic criteria had been met. A qualified PWP (CCh) administered the full ADIS-P with the same parent(s) of each child prior to the baseline phase and one-month after the treatment phase. The OCD section of the ADIS was additionally conducted within one-week of completing the treatment phase. CCh and CCr (a Clinical Psychologist with extensive experience with the ADIS-C/P) discussed cases during clinical supervision and independently assigned diagnoses and CSRs based on parent-report and clinical judgement, prior to reaching a consensus clinical judgement (Creswell et al., 2021). The ADIS-P has good test re-test reliability (Silverman et al., 2001), concurrent validity (Wood et al., 2002), and is sensitive to treatment change (Barrett et al., 2004). Percentage agreement on the presence or absence of diagnoses across raters (CCh and CCR) was 94.4% and inter-rater reliability for CSRs was moderate to excellent (κ = 0.7; ICC = 0.9[1]).

Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS; Scahill et al., 1997) The CY-BOCS is a semi-structured, clinician-administered measure assessing OCD symptom severity for young people aged 6- to 17-years-old. The CY-BOCS is considered the 'gold standard' assessment for OCD in young people (Lewin & Piacentini, 2010) and is routinely used in OCD treatment trials (e.g., Bolton et al., 2011; Farrell et al., 2022; Melin et al., 2020) and was therefore selected as the primary outcome measure for this study. The severity of obsessions and compulsions are each assessed using 5 scales measuring: (1) time consumed, (2) interference caused, (3) level of distress experienced, (4) effort to resist, and (5) extent of control. A total score ranging from 0 – 40 is calculated, with higher scores indicating greater OCD severity. CCh administered the CYBOCS with each child (and their parent) prior to the baseline phase and one-month after the treatment phase. A briefer version of the CYBOCS (where obsessions/compulsions were reviewed, and the 5-item scales were readministered) was conducted within one-week of completing the treatment phase. CCh and SW (a Clinical Psychologist with extensive experience with the CY-BOCS) discussed cases during clinical supervision and independently assigned ratings for each 5-item scale, prior to

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[1] The ICC is presented as this is commonly reported in other published papers. However, given that we did not use the full range of CSRs when assessing whether children met diagnostic criteria for a given disorder, we also present Cohen's Kappa.

reaching consensus clinical judgement. The CY-BOCS has good test re-rest reliability (Storch et al., 2004), convergent and divergent validity (Scahill et al., 1997) and can reflect treatment change (Scahill et al., 1997). Inter-rater reliability across all assessments was excellent (ICC = 1.0).

Weekly Baseline and Treatment Phase Measures

Children's Obsessive Compulsive Inventory – Revised – Parent Report (Uher et al., 2008). The ChOCI-R-P is a 32-item questionnaire measuring the presence and severity of children's obsessions and compulsions. Twenty items assess symptom presence, and 12 items assess symptom severity (with the latter corresponding to the five scales used to assess symptom severity on the CY-BOCS; Shafran et al., 2003). Scores are summed to produce a total symptom score (out of 40) and a total impairment score (out of 48) whereby higher scores indicate greater number of OCD symptoms and impairment. A total impairment score >17 has shown sufficient sensitivity to indicate an OCD diagnosis on the ChOCI-R (which uses the same items to calculate the impairment score as the ChOCI-R-P; Shafran et al., 2003). The ChOCI-R-P has been shown to have good internal consistency and convergent validity with the CY-BOCS (Uher et al., 2008) and is sensitive to treatment change (Aspvall et al., 2018).

Family Accommodation Scale – Parent Report (Flessner et al., 2011). Based on the findings of Chessell et al. (2022a) and the high reported prevalence of family accommodation in this population (Monzani et al., 2020), parents completed a weekly measure of family accommodation. The FAS-PR is a 12-item questionnaire measuring the frequency and severity of parental accommodation of OCD over the past month and has good psychometric properties (Flessner et al., 2011). The frequency of accommodation is assessed on a 5-point scale (0 = Never, 1 = 1- to 3-times per month, 2 = 1- or 2-times per week, 3 = 3- to 6-times per week, 4 = daily) as is accommodation severity (0 = No, 1 = Mild, 2 = Moderate, 3 = Severe, 4 = Extreme). To ensure suitability for *weekly* administration, we adapted the frequency of accommodation items accordingly (0 = Never, 1 = 1- or 2-times per week, 2 = 3- to 6-times per week, 3 = Daily).

Items assessing parents' knowledge and confidence to help their child to overcome OCD. Based on the findings of Chessell et al. (2022a) we administered 3 items to assess the effects of the parent-led intervention on parents' knowledge and confidence to help their child to overcome OCD. Parents were asked to complete the following items to reflect their experiences over the past week: (1) *I have learned new information about my child's OCD,* (2) *I have learned new information about how to help my child to overcome OCD,* (3) *I feel confident in my ability to help my children to overcome OCD*, and were measured on a 5-point scale from 1 (*I have learned no new information about my child's OCD/how to help my child to overcome OCD/I do not feel confident in my ability to help my child overcome OCD*) to 5 (*I have learned a lot of new information about my child's OCD/how to help my child overcome OCD/I feel very confident in my ability to help my child to overcome OCD*).

Additional Treatment Phase Measures

Goal-based Outcomes (GBOs, Law & Jaboc, 2015). In line with routine practice in services that offer low-intensity interventions, parents identified up to 3 therapeutic goals for their child to work towards during the treatment phase (Ludlow et al., 2020). Goals were collaboratively identified in-session with the therapist, and parents were encouraged to discuss and refine these goals at home with their child. Parents rated their child's progress towards the goals each week from 0 (no progress towards goal) to 10 (goal achieved).

Items assessing children's learning about their fears and their ability to cope in feared situations. Given that this treatment was designed to create opportunities for children to learn new information about their fears and their ability to cope in feared situations without performing compulsions, parents were asked to complete the following items after each treatment session, with reference to the past week: (1) *My child has learned new information about their fears/worries/obsessions (e.g., information about the probability of their fears/worries/obsessions happening, or how bad it would be if their fears/worries/obsessions came true),* and (2) *My child has learned new information about their ability to cope in feared situations,* which were assessed on a 5-point scale from 1 (*no new learning*) to 5 (*a lot of new learning*).

Treatment Acceptability Measures

To assess the acceptability of the treatment to parents, parents completed a post-treatment questionnaire, a weekly measure of their experience of the treatment sessions, and an optional post-treatment qualitative interview.

Post-treatment questionnaire. Parents who attended at least one treatment session were invited to complete a feedback questionnaire consisting of 10 questions. Six questions assessed acceptability of the approach to parents (e.g., 'I am satisfied with the number of treatment sessions I received' 'This treatment equipped me to help my child overcome OCD') on a 5-point scale from strongly disagree to strongly agree. Four open-ended questions invited parents to comment on aspects of the treatment they liked, disliked, suggestions for improvement, and any other feedback.

Session Rating Scale (SRS; Miller et al., 2000). The SRS is an established measure of the therapeutic alliance and has adequate psychometric properties (Campbell & Hemsley, 2009; Duncan et al., 2003). Respondents are required to indicate their experience of each treatment session by placing a mark along four 10cm lines (i.e., a visual analogue scale) measuring (1) therapeutic relationship, (2) topics covered, (3) therapeutic approach, and (4) overall satisfaction. Items are scored by measuring the respondent's mark to the closest centimetre, producing a total score ranging from 0- to 40- (with higher scores corresponding to a better therapeutic alliance). Scores <36 may indicate a problematic therapeutic alliance and should be explored by the therapist (Duncan et al., 2003). To ensure suitability for online completion, parents were asked to indicate their experience of each treatment session along a 10-point Likert scale.

Optional Qualitative Interview. The qualitative interviews aimed to explore parents' experiences and acceptability of the treatment. In particular, we aimed to capture the views of parents whose children did and did not "respond" and/or "remit" at the one-month follow-up, and parents who attended all treatment sessions (either alone or jointly with another caregiver) versus parents who only attended some treatment sessions (i.e., parents who were not the primary parent participating in the study), as it was anticipated that these variables may influence parents' experiences and views. Owing to the small scale nature of this study, we therefore invited all parents who attended at least one treatment session to participate in a qualitative interview to capture diversity in parents' experiences and views. A topic guide was developed based on relevant research (e.g., Reardon et al., 2022) and the research team's clinical experience and was refined following feedback from Public and Patient Involvement (PPI) parent and UK-based OCD charity representatives to ensure suitability for families. The interviews were conducted by a female University of Reading Undergraduate Student (HN) who was undertaking a placement at Berkshire Healthcare NHS Foundation Trust (BHFT) CAMHS. HN was not involved in any other aspect of the study to enable parents to freely discuss their views of the treatment. HN did not have any formal qualitative training, however CCh (who has completed Master's level training and conducted qualitative research as part of her doctoral research) provided training and supervision for HN whilst she conducted the interviews. All interviews were conducted via Microsoft Teams or telephone and were video and/or audio-recorded. Where two parents jointly attended the treatment sessions, parents had the option to participate in an individual or joint interview.

Data Analysis

The study data analytic plan was pre-registered on the Open Science Framework (see Chessell, Halldorsson, Walters, et al., 2021) and deviations from this protocol are outlined in the footnote below[2]. The primary outcome measure for this study was the CY-BOCS; all other measures were secondary outcome measures (Chessell, Halldorsson, Walters, et al., 2021). Quantitative data were analysed using a combination of statistical and visual analyses, in line with recommended guidelines (Tate et al., 2016; Manolov et al., 2014). Rates of clinical ‘response’ and ‘remission’ were calculated according to international consensus guidelines (Mataix-Cols et al., 2016) whereby clinical ‘response’ is defined as ≥35% reduction in CY-BOCS scores for at least one week, and clinical ‘remission’ is defined as no longer meeting diagnostic criteria for OCD on the ADIS-P for at least one week. Reliable change was calculated for the CY-BOCS, ChOCI-R-P, and FAS-PR from pre-treatment (final baseline scores) to post-treatment, and pre-treatment to one-month follow-up (Jacobson & Truax, 1991). Effect sizes (Cohen’s d) were calculated for the CY-BOCS, ChOCI-R-P, and FAS-PR from pre-treatment (final baseline scores) to post-treatment, and pre-treatment to one-month follow-up to ensure comparability with other treatment studies (Lakens, 2013). Cohen’s d was calculated using https://www.psychometrica.de/effect_size.html which subtracts the later mean from the baseline mean and divides this by the pooled SD.

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[2] We intended to calculate reliable change indices using the mean baseline score and effect sizes using the first baseline score, however, we opted to use the final baseline score to account for the different baseline lengths and to ensure consistency across analyses. We also planned to calculate reliable change indices and effect sizes for the ADIS-P, however, following recent international consensus guidelines which recommend using CSRs to primarily decide upon diagnoses and the statistical problems with averaging CSRs across participants (Creswell et al., 2020), we decided not to calculate reliable change indices or effect sizes for this measure. Finally, we intended to include participants’ responses to post-treatment acceptability questionnaires in our qualitative analyses, however, these responses did not contribute additional insights beyond the qualitative interviews and thus were not included in these analyses.

Visual analyses were used to assess the extent to which observed gains were likely to be the result of the treatment programme. Due to the treatment being delivered over a varying number of weeks for each family (ranging from 8- to 13-weeks), visual analyses focused on questionnaire data that corresponded to the eight treatment sessions to ensure a consistent approach across participants. Following recommended guidelines (e.g., Kratchowill et al., 2010; Manolov et al., 2014) *systematic* visual analysis was conducted using the protocol outlined by Kratochwill et al. (2010). This involved examination of within- and between-phase changes in: (1) level, (2) trend, (3) data stability, (4) onset of change, (5) overlapping data, and (6) consistency of observations across participants (Kratchowill et al., 2010). Systematic visual analysis was assisted by https://manolov.shinyapps.io/Overlap/ (Manolov, 2018). Here, the trend line was fitted using statistical techniques (i.e., the Mean Absolute Scaled Error (MASE) method), which is an appropriate method to identify the best-fitting line, and stability was assessed using the trend stability envelop (Manolov, 2018). Lane and Gast (2014) suggest that stability is shown when 80% of the data points fall within 25% of the median trend stability envelope. Individual participant outputs from https://manolov.shinyapps.io/Overlap/ are shown in the supplementary analyses. We used these systematic visual analyses collectively to determine whether the intervention showed a "clear" effect, a "possible" effect, or "little-to-no" effect on participants' outcomes, with particular weight given to comparisons of observed and projected intervention values (i.e., where the trend of the baseline data is extrapolated across the intervention phase). A "clear effect" was based on the data pattern in the intervention phase being sufficiently different to what would be expected from the baseline phase data (Horner et al., 2005). A "possible" effect of the intervention was concluded when visual analyses showed improvements in participants' outcomes, however, these improvements were not superior to the improvements projected from the baseline data. "Little-to-no" effect was concluded when visual analyses showed limited improvements or a deterioration in participants' outcomes following the introduction of the intervention. For brevity in the results section, plots illustrating trend stability, overlapping data, and observed and projected intervention phase values are shown in the supplementary analyses, and Tables S1, S2, and S3 provide further information on how effects were categorised for each participant on each outcome measure.

Qualitative data were analysed using reflexive thematic analysis to enable the research team to generate shared patterns of meaning across the dataset (Braun & Clarke, 2022) and to identify implications for future iterations of the treatment. *Reflexive* thematic analysis was specifically chosen as this method values the subjectivity of the research team in the analysis and encourages researchers to critically reflect on how their experiences shape data collection and analysis (Braun & Clarke, 2019). This study formed part of CCh's doctoral research which aimed to increase access to CBT for preadolescent children with OCD. The original parent-led CBT intervention (on which the adapted version is based) was developed by CCr, and CCh, CCr, and BH all have considerable experience in delivering this treatment approach. Given that CCh, CCr, and BH are invested in parent-led CBT interventions, KH contributed to the study design and analysis as KH is not a clinician and has not contributed to the development of the treatment. CCh led the qualitative analysis and engaged in the six-stages of reflexive thematic analysis outlined by Braun and Clarke (2022). CCh met regularly with the research team during the initial coding and generation of themes to ensure an interpretative approach to data analysis and to consider other possible interpretations of the data (Braun & Clarke, 2022). Where two parents of the same child jointly participated in an interview, the interview transcript was analysed once, and parents were given separate participant IDs to differentiate their responses. NVivo (Version 12.0, Bazeley & Jackson, 2013) was used to store and analyse the data. For brevity in the results section, we present a thematic map and a table providing an overview of each theme along with illustrative quotes. Further, in-depth descriptions of each theme are provided in the supplementary analyses.

Results

Missing Data

One participant (P4, who was randomly allocated to a 4-week baseline) did not complete their final baseline questionnaire. We therefore analysed their data as if they were allocated to a 3-week baseline. One family (P1) did not complete the post-treatment ADIS-P and CY-BOCS due to child illness, and one family (P10) completed their follow-up ADIS-P and CY-BOCS two months after completing treatment (rather than one month) due to parent and child illness. One participant (P4) had missing SRS data for two treatment sessions and only eleven (of fifteen) parents completed the post-treatment acceptability questionnaire. Where there was missing data for diagnostic measures, we present both intent-to-treat (ITT) and completer analyses where appropriate. Where there was missing data for acceptability measures, analyses were based on the available data.

Clinical Response and Remission

On the primary outcome measure (i.e., the CY-BOCS), forty percent (n=4/10, ITT; 44%, n=4/9, completer) of children met criteria for ‘clinical response’ (i.e., ≥35% reduction in CY-BOCS scores, Mataix-Cols et al., 2016) at post-treatment, and 40% (n=4/10, ITT; 40%, n=4/10, completer) at the one-month follow-up. On the secondary outcome measure (i.e., the ADIS-P), sixty percent (n=6/10, ITT; 67%, n=6/9, completer) of children met criteria for ‘clinical remission’ (i.e., no longer meeting diagnostic criteria for OCD for a minimum of one week, Mataix-Cols et al., 2016) at post-treatment, and 50% (n=5/10, ITT; 50%, n=5/10, completer) at the one-month follow-up assessment. Forty percent (n=4/10, ITT; 40%, n=4/10, completer) of children met criteria for one or more comorbid diagnoses on the ADIS-P at the one-month follow-up, specifically social anxiety (n = 2), separation anxiety (n = 1), specific phobia (n = 1), and attention deficit hyperactivity disorder (n = 1).

Reliable Change (Jacobson & Truax, 1991)

On the primary outcome measure (i.e., the CY-BOCS), sixty percent (n=6/10, ITT; 67%, n=6/9 completer) of children met criteria for reliable improvement at post-treatment, and 70% (n=7/10, ITT; 70%, n=7/10, completer) at the one-month follow-up assessment. On the secondary outcome measures, fifty percent (n=5/10, ITT; 50%, n=5/10 completer) of children showed reliable improvement on ChOCI-R-P symptom scores at post-treatment and at the one-month follow-up assessment. Sixty percent (n=6/10, ITT; 60%, n=6/10, completer) of children reliably improved on ChOCI-R-P impairment scores and no longer scored in the clinical range at post-treatment. These six children also scored in the non-clinical range at the one-month follow-up assessment, however, only five of these children evidenced a reliable change on impairment scores from the baseline phase. Forty percent (n=4/10, ITT; 40%, n=4/10, completer) of families evidenced reliable improvement in FAS-PR scores at post-treatment and at the one-month follow-up assessment.

Effect Sizes

Effect sizes (Cohen’s d) for the CYBOCS, ChOCI-R-P, and FAS-PR were calculated using completer data and are shown in Table 4. Large effect sizes (according to conventions: d = 0.8, Cohen, 1988) were observed for all measures at each time point.

Table 4. Means, standard deviations, and effect sizes for outcome measures[1]

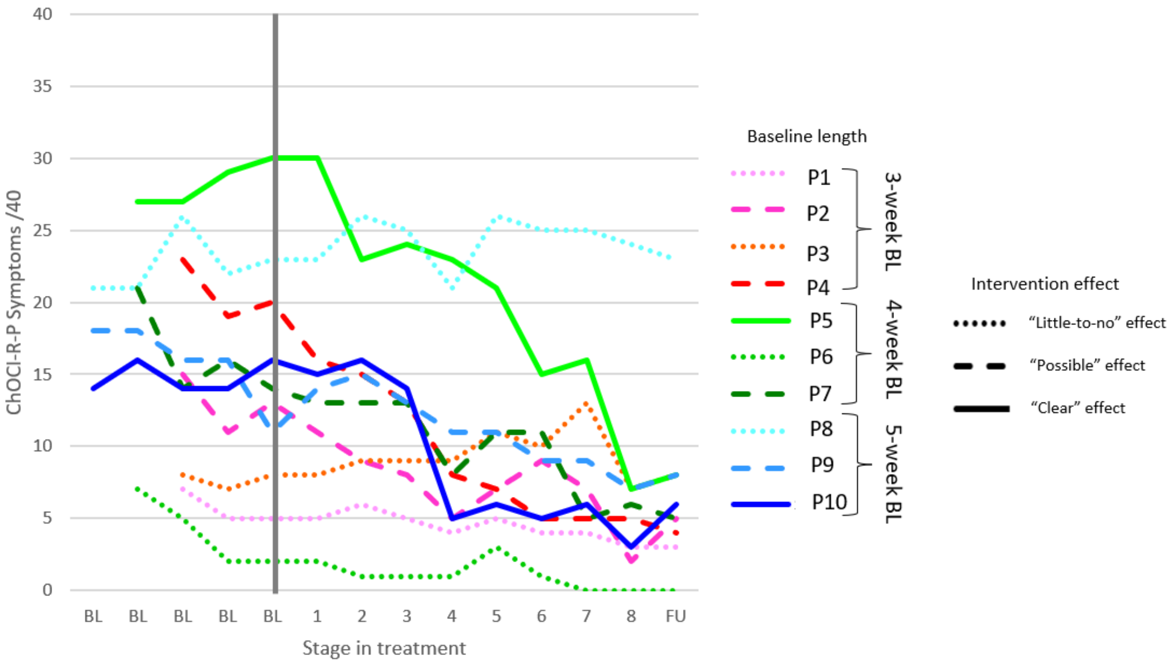
Measure	Pre-treatment (n=10)	Post-treatment (n=10)	Follow-up (one month) (n=10)	Pre-treatment to post-treatment Cohen's d	Pre-treatment to one-month follow-up Cohen's d
CY-BOCS	23.3 (3.6)	16.7[2] (5.4)	16.4 (5.8)	-1.4	-1.4
ChOCI-R-P Symptoms	14.2 (8.5)	6.4 (6.6)	7.0 (6.2)	-1	-1
ChOCI-R-P Impairment	25.2 (8.0)	15.4 (10.1)	16.2 (10.5)	-1.1	-1
FAS-PR	16.6 (10.7)	8 (10.0)	7.8 (9.2)	-0.8	-0.9

Note. [1]Effect sizes were calculated using completer data only. [2]n=9. CYBOCS = Children's Yale Brown Obsessive Compulsive Scale; ChOCI-R-P = Children's Obsessional Compulsive Inventory – Revised – Parent report; FAS-PR = Family Accommodation Scale – Parent Report.

Visual Analyses

Individual participant data for the ChOCI-R-P symptoms, ChOCI-R-P impairment, and FAS-PR is shown in Figure 1, 2, and 3 respectively.

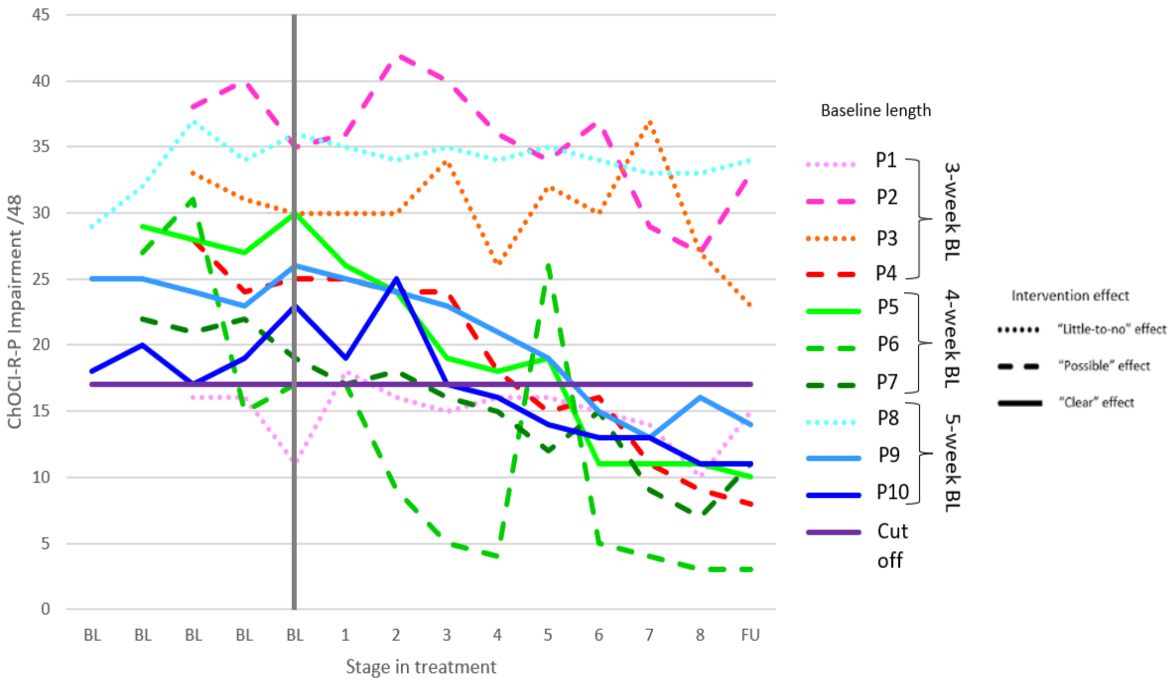
Figure 1. Individual ChOCI-R-P Symptoms.



Note. ChOCI-R-P = Children's Obsessional Compulsive Inventory – Revised – Parent report; BL = Baseline; FU = One-month follow-up. Dotted lines = "Little-to-no" effect of the intervention; Dashed lines = a "possible" effect of the intervention; Solid horizontal lines = a "clear" effect of the intervention; Solid vertical line = final baseline data point.

ChOCI-R-P Symptoms. Visual analyses revealed a "clear" effect of the intervention in reducing OCS for two participants (P5, P10), a "possible" effect for four participants (P2, P4, P7, P9) and "little-to-no" effect for four participants (P1, P3, P6, P8). Where there was a "clear" effect of the intervention, participants either had a deteriorating (i.e., an increase in OCS, P5) or a zero-celerating (i.e., neither improving nor deteriorating) baseline trend (P10) followed by an overall improving treatment trend and reduction in average OCS across phases. Where there was a "possible" effect of the intervention, all participants had improving baseline trends, which continued to improve (albeit, in most cases, at an overall slower rate) during the treatment phase (P2, P4, P7, P9). Among the four participants where "little-to-no" effect of the intervention was observed, two participants had improving baseline trends which continued to improve (at an overall slower rate) during the treatment phase (P1, P6). One participant had a deteriorating baseline trend but showed a small overall improving treatment trend (P8), and one participant had a zero-celerating trend in both phases (P3). Two participants (P1, P6) experienced limited reductions in their average OCS scores and two participants (P3, P8) experienced an increase in average OCS scores. The majority of participants experienced an initial reduction in OCS during the first four treatment sessions, irrespective of the length of their baseline phase.

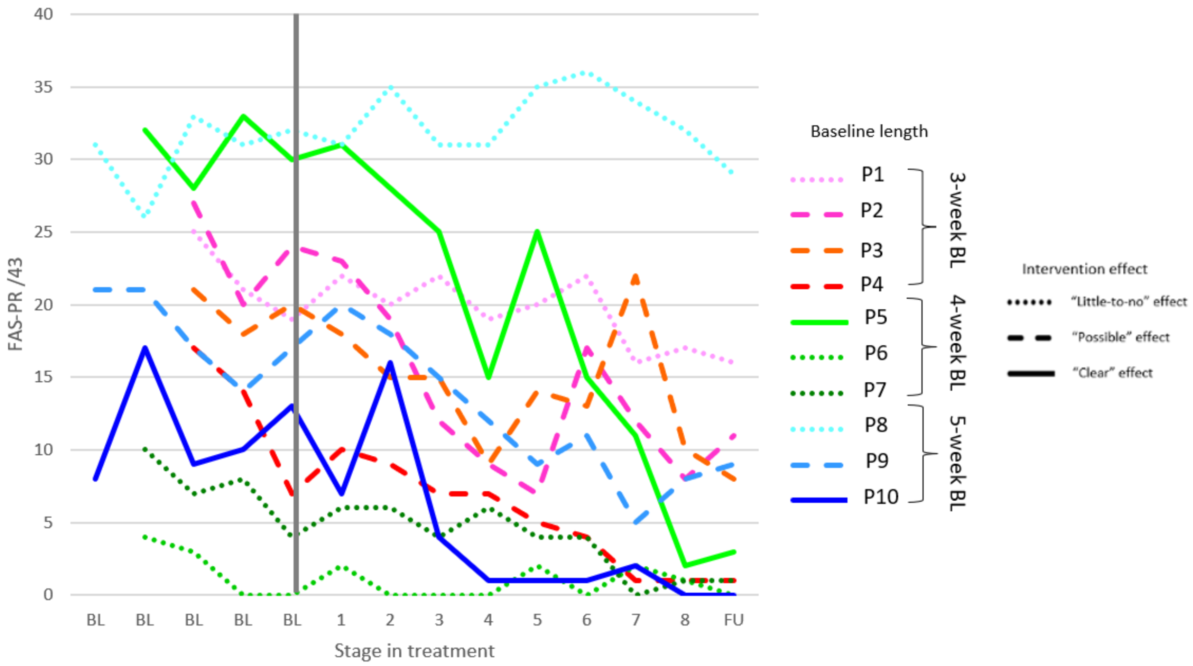
Figure 2. Individual ChOCI-R-P Impairment Scores.



Note. ChOCI-R-P = Children's Obsessional Compulsive Inventory – Revised – Parent report; BL = Baseline; FU = One-month follow-up. Dotted lines = "Little-to-no" effect of the intervention; Dashed lines = a "possible" effect of the intervention; Solid horizontal lines = a "clear" effect of the intervention; Solid vertical line = final baseline data point; Solid purple horizontal line = Clinical cut off for the ChOCI-R-P.

ChOCI-R-P Impairment. Visual analyses showed a “clear” effect of the intervention in reducing impairment scores for three participants (P5, P9, P10), a “possible” effect for four participants (P2, P4, P6, P7) and “little-to-no” effect for three participants (P1, P3, P8). Where a “clear” effect of the intervention was shown, participants either had a small improving baseline trend (P5, P9) or a deteriorating baseline trend (P10) followed by clear overall improving treatment trends and a reduction in average impairment scores across phases. Where there was a “possible” effect of the intervention, all participants had overall improving baseline and treatment trends and experienced a reduction in average impairment scores across phases. Where the intervention had “little-to-no” effect, two participants (P1, P3) had overall improving trends during the baseline and treatment phase, however one participant (P1) had an increase in average impairment scores during the treatment phase and one participant (P3) showed limited improvement in average scores across phases. One participant (P8) had a deteriorating baseline trend and a small improving treatment trend, however, experienced limited change in average impairment scores across phases. The majority of participants experienced an initial reduction in OCD impairment between the 2nd and 4th treatment sessions, irrespective of the length of their baseline phase.

Figure 3. Individual FAS-PR Scores.



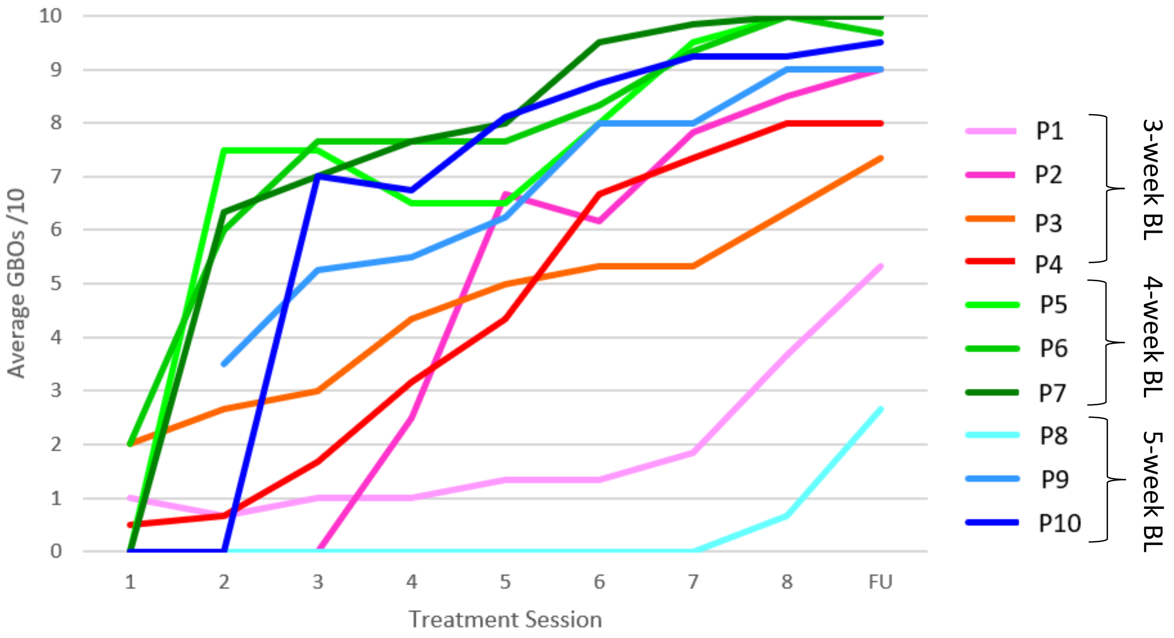
Note. FAS-PR = Family Accommodation Scale – Parent Report; BL = Baseline; FU = One-month follow-up. Dotted lines = "Little-to-no" effect of the intervention; Dashed lines = a "possible" effect of the intervention; Solid horizontal lines = a "clear" effect of the intervention; Solid vertical line = final baseline data point.

FAS-PR. Visual analyses showed a "clear" effect of the intervention in reducing family accommodation for 2 participants (P5, P10), a "possible" effect of the intervention for four participants (P2, P3, P4, P9) and "little-to-no" effect of the intervention for four participants (P1, P6, P7, P8). Where there was a "clear" effect of the intervention, participants either had a zero-celerating (P5) or a deteriorating baseline trend (P10) followed by an overall improving treatment trend and reduction in average family accommodation symptoms across phases. Where there was a "possible" effect of the intervention, all participants had overall improving baseline and treatment trends and experienced a reduction in average scores across phases (P2, P3, P4, P9). Where there was "limited" effect of the intervention, three participants had improving baseline trends (P1, P6, P7) that either continued to improve (but at an overall slower rate) during the treatment phase (P1, P7) or showed a zero-celerating treatment trend (P6). One participant (P8) had a deteriorating baseline phase and zero-celerating treatment trend. Three participants showed small average reductions in scores across phases (P1, P6, P7) and one participant showed an increase in average scores (P8). The majority of parents reported an initial reduction in family accommodation during the first four treatment sessions, irrespective of the length of their baseline phase.

Goal Based Outcomes (GBOs)

Participants' progress towards each of their treatment goals was averaged and is presented in Figure 4. All participants made progress towards their goals during the treatment, however two participants (P1, P8) made less progress than the others. Interestingly, participants with a four-week baseline appeared to make greater initial gains towards their treatment goals, particularly compared to participants with a three-week baseline.

Figure 4. Averaged goal-based outcomes (GBOs) for each participant.



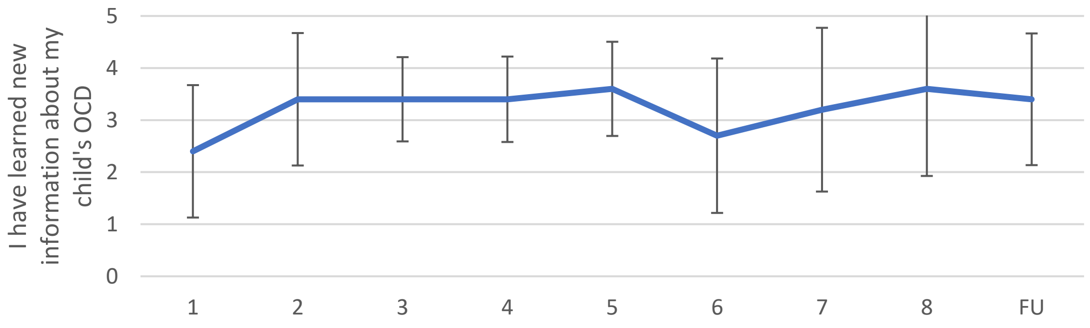
Note. BL = Baseline; FU = One-month follow-up.

Items assessing parents' knowledge and confidence to help their child to overcome OCD

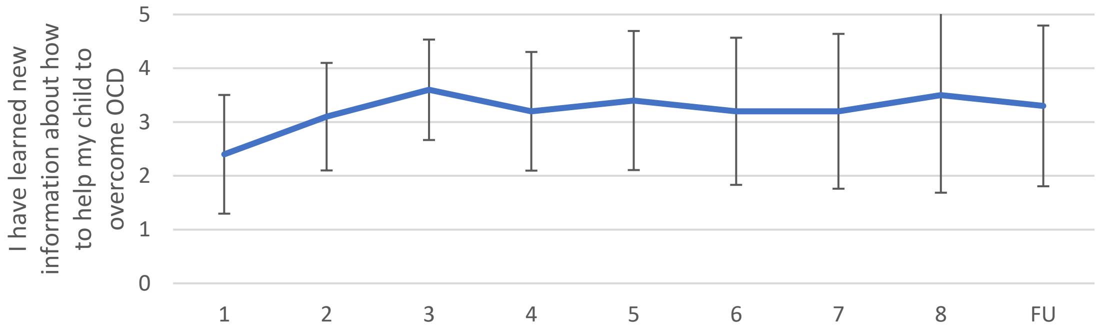
Averaged parental responses to items assessing their knowledge and confidence to help their child to overcome OCD are shown in Figure 5a, b, and c, respectively. Parents learned the most new information about their child's OCD from treatment session two to five, and session eight, corresponding to the sessions where the main treatment content and information on relapse prevention was covered. Similarly, parents consistently learned the most new information about how to help their child to overcome OCD from session three to the follow-up appointment, mirroring the introduction and monitoring of ERP tasks. Notably, parents consistently reported learning a reasonable amount of new information about their child's OCD and how to help their child to overcome OCD across treatment sessions (with the majority of treatment session means >3 out of 5). Parents' confidence to help their child to overcome OCD also gradually increased across the treatment programme.

Figure 5. Items assessing whether parents have learned new information about their child's OCD, whether parents have learned new information about how to help their child to overcome OCD, and parents' confidence in their ability to help their child to overcome OCD.

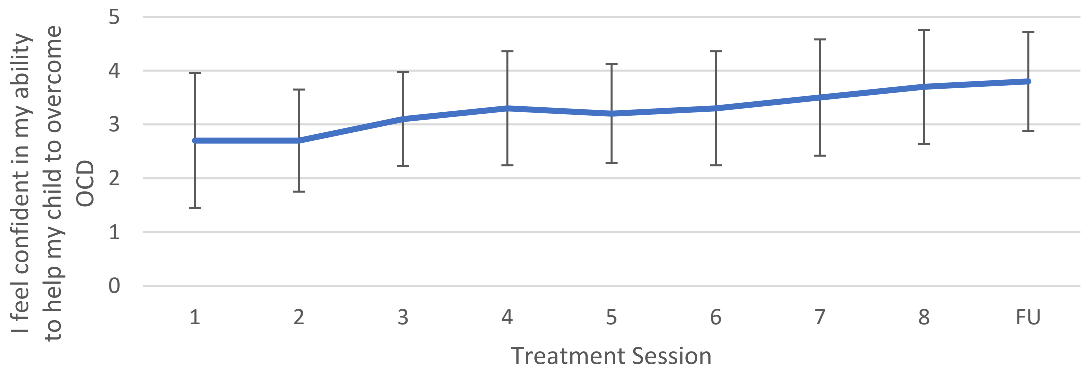
(a)



(b)



(c)

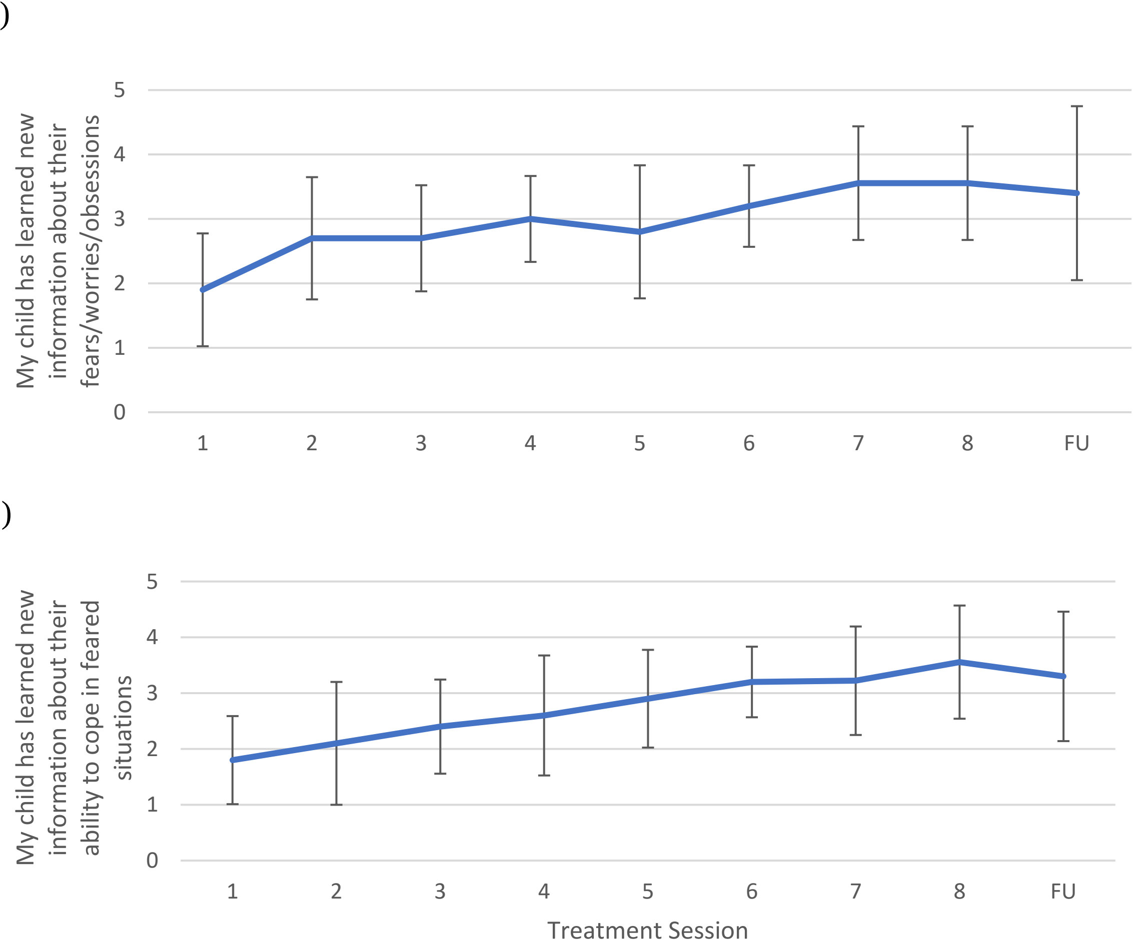


Note. Error bars represent the standard deviation for each treatment session score.

Items assessing children's learning about their fears and their ability to cope in feared situations.

Averaged parental responses to items assessing children's learning about their fears and their ability to cope in feared situations are shown in Figure 8a and b, respectively. Parents reported that their children gradually learned new information about their fears and their ability to cope in feared situations as the treatment progressed – however, the amount of new learning slightly subsided at the follow-up appointment.

Figure 8. Items assessing whether children have learned new information about their fears and their ability to cope in feared situations.



Note. Error bars represent the standard deviation for each treatment session score.

Treatment Acceptability

Treatment attendance. All families completed the treatment. Eight mothers and two fathers attended all assessment and treatment sessions (one father was unable to complete the post-treatment diagnostic assessments, however completed the one-month follow-up assessments). For five families, an additional parent (one mother and four fathers) attended one or more treatment sessions.

Session Rating Scale (SRS). Parents' average total SRS scores across all treatment sessions (M=38.7, SD=2.8) and each individual treatment session were above the cut-off of

36, indicating that the treatment was broadly acceptable to parents. However, parents' total SRS scores ranged from 28 to 40 across treatment sessions, with one parent's total SRS scores consistently below the cut-off for each treatment session (M=31.8, SD=1.8, Range=28-34) and another parent's total SRS scores were below the cut-off for the first treatment session, suggesting that the treatment/particular treatment sessions were less acceptable to these parents. No other parents' total SRS scores were below the cut-off for any treatment session.

Post-treatment questionnaire. Eleven parents (seven mothers and four fathers) completed the post-treatment questionnaire. All parents 'agreed' or 'strongly agreed' that they were satisfied with the treatment programme, the length of the treatment sessions, and would recommend the treatment to other families. Ten parents 'agreed' or 'strongly agreed' that they were satisfied with the number of treatment sessions, the outcomes of treatment, and felt equipped to help their child to overcome OCD; one parent 'neither agreed nor disagreed' with these statements and commented that they would prefer more sessions that were delivered face-to-face with a clearer expectation that treatment progress can be slow.

Optional qualitative interview. Ten parents (6 mothers, 4 fathers) of eight children participated in a qualitative interview (see Table S5 for overall participant characteristics and Table S6 for individual participant characteristics to aid interpretation of the data) approximately two- to three- months after completing their final treatment session. Where more than one parent of a child agreed to participate in the interview, parents opted to attend the interview together.

Four themes were generated to illustrate parents' experiences and their views on the acceptability of the treatment, including (1) 'feeling equipped and empowered', (2) 'the road to a new normal', (3) 'treatment is burdensome', and (4) 'the ingredients for success'.

Themes are presented in a thematic map (see Figure 9) and an overview of each theme is shown in Table 5. We present the thematic map as an adapted CBT ‘hot cross bun’ model (Greenberger & Padesky, 1995) to demonstrate the interlocking relationships between the themes. In this model, we propose that positive (or negative) change in one of these themes will either directly or indirectly have a positive (or negative) impact on the other themes. The themes ‘feeling equipped and empowered’, ‘the ingredients for success’, and ‘the road to a new normal’ are perceived to have a direct impact all other themes. In contrast, ‘treatment is burdensome’ is thought to have a direct impact on parents’ perceptions of feeling equipped and empowered and the ingredients for success, in turn, indirectly affecting families’ road to a new normal. For example, if the treatment is experienced as highly burdensome, then this may reduce parents’ sense of feeling equipped and empowered and the ingredients for success may not be met, in turn, inhibiting families’ progress towards a new normal. However, if we help parents to overcome the perceived burdens of the treatment (e.g., by collaboratively exploring with parents whether there are other caregivers/significant figures who could help implement the treatment and/or manage other responsibilities), this may result in the ingredients for success being met and help to ensure that parents feel equipped and empowered to support their child to overcome OCD, in turn, facilitating their journey to a new normal. Thus, when delivering parent-led CBT for preadolescent children with OCD, clinicians may only need to facilitate positive change in one of these themes to begin to see positive (direct or indirect) impacts on the other themes.

Figure 9. Thematic Map.

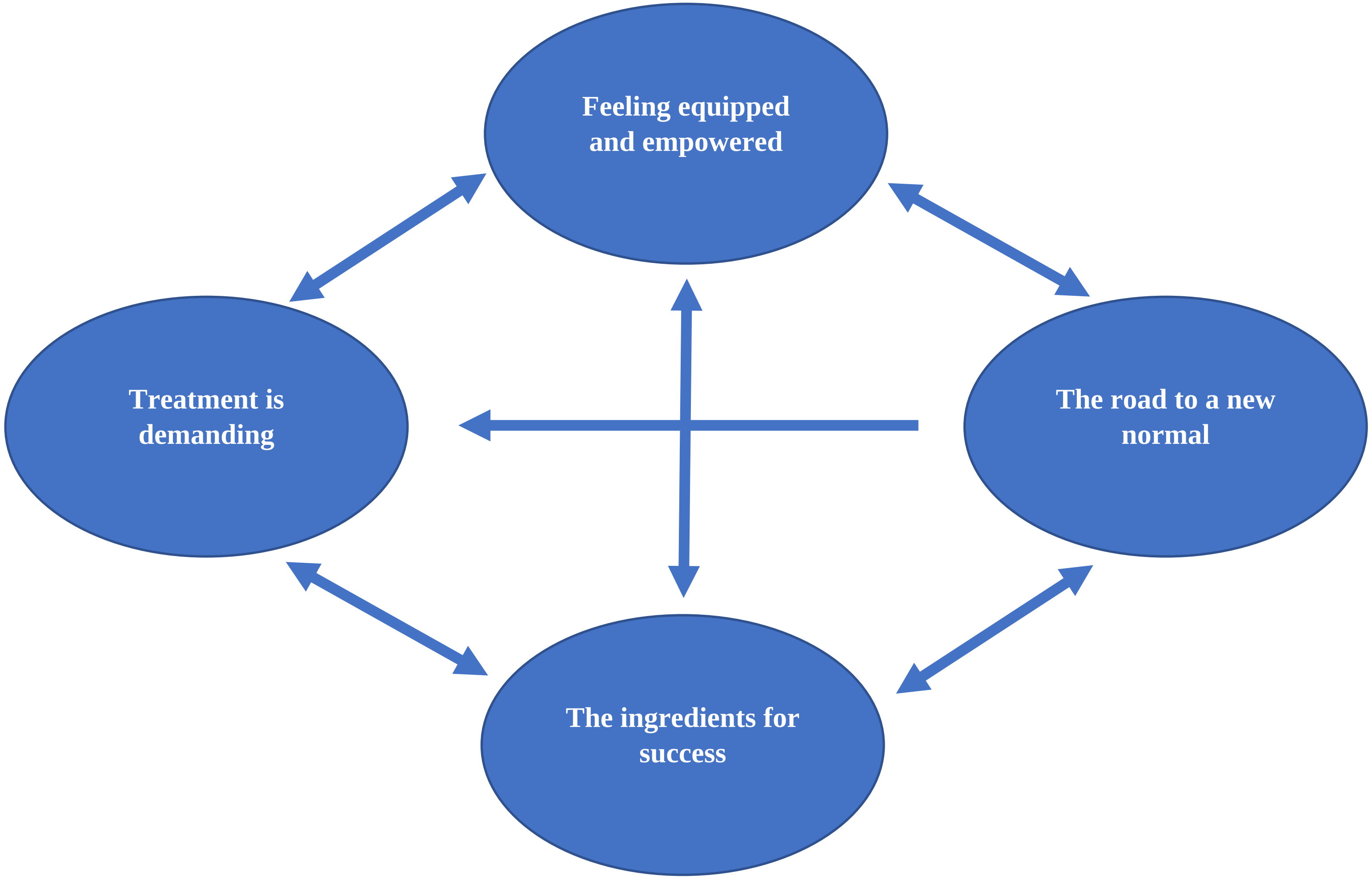


Table 5. Summary of themes generated from reflexive thematic analysis

Theme	Key points within the theme	Illustrative quote
Feeling equipped and empowered	• Parents were keen to help their child to overcome OCD, however typically felt ill-equipped to support their child at the start of the treatment and doubted their ability to successfully implement the treatment approach.	*"I didn't think that the approach was wrong, I just worried that I wouldn't be good enough to do it" [ID3A, Mother]*
	• Throughout the treatment, parents felt increasingly equipped and empowered (both practically and emotionally) to support their child now, and in the future.	*"but if ever something happens like she's had a bad day at school or I do notice that she's started doing something [i.e., a compulsion], I feel much more confident in having a calm and open conversation with her about it. And I'm confident that I will be able to say to her if ever we need to implement these techniques again, we can work together to do it." [ID7, mother]*
	• Parents' sense of feeling equipped and empowered was facilitated by the treatment being practical, straightforward, and providing them with a structure to support their child.	*"I'd say it was a really, um positive and practical and quite straightforward… because I mean none of it's really that complicated, which I think is the beauty of it … it's something that anybody can do." [ID9, mother]*
	• The extent to which parents felt equipped and empowered to support their child at the end of the treatment varied. Many parents felt confident to use ERP to help their child to overcome OCD, whereas a minority of parents only felt equipped to talk to their child about their OCD and perceived their own performance in treatment as inadequate and/or felt out of their depth to help their child.	*"we're confident with where we're going, we know we've got the tools to do it" [ID2B, father]* *"I think that's when I felt the panic [when implementing the first step of the step-by-step plan], because my son was like, "I've got hundreds [of compulsions], what are you gonna do?"." [ID8, mother]*

The road to a new normal	• Parents' experiences of the treatment evoked a sense of each family being on a road to a new normal. As part of this journey, parents' felt that their child increased their awareness of their OCD and felt increasingly understood and accepted.	*"I think now she doesn't feel quite so isolated and odd ... with how she sees things and and understand situations and, um, worries about things, so ... that's helpful, absolutely kind of, fundamentally helpful, I think to how she sees herself. So that's that's a really good thing." [ID9, mother]*
	• Moreover, as part of this journey, parents described positive change for their child (e.g., reductions in their child's OCD symptoms) and the wider family (e.g., improved family relationships, increased family freedom).	*"yeah, I mean first of all it's made a big difference to to to [child's name] and her anxieties ... she's able to, uh, do a lot more than she used to be able to ... M: ... and you know, since [the treatment] ... we've really noticed her laughing a lot more, she's playing with her [sibling] a lot more and just not squirreling herself away in her room ... so the benefits to her have been immense]." [ID3A/B, mother and father]*
	• However, the road to a new normal was not linear for many families, with around half of parents identifying fluctuations in their child's progress throughout treatment.	*"there was a couple of weeks again, as I say, I went backwards and I felt like we'd almost started again but it's like every time we went backwards we went six steps forwards afterwards" [ID5, mother]*
	• At the end of the treatment, families were at different stages in their journey towards a new normal. A minority of parents perceived their child as nearer the start of the journey, reporting increased awareness of OCD but limited improvements in their child's symptoms. The majority of families had experienced substantial improvements in their child's symptoms, however, identified persisting difficulties that their child still needed to overcome.	*"but ... we need to see improvements [I: yeah] in the behaviour and you know, a relaxing of his attitude, and then you know be more tolerant to incidents that trigger him. But we're not there yet, so I can't say it's been a benefit to know more about it until we've, push forward" [ID1, father].* *"I mean it's still, it's still lingering, um, um, yeah it's still popping its head up every now and again his OCD, but nothing like it was." [ID6, father]*

Treatment is burdensome	*Subtheme: Treatment as an additional responsibility*	
	• Around half of parents felt that the treatment was an additional burden on their life. This was particularly the case for parents who had other children, additional family responsibilities, and/or were the only parent implementing the treatment.	*"I found it really hard, cause having another child as well, and my [family member] was diagnosed with [medical illness] as well while this treatment was going on … and obviously both the children are really anxious, as it is, so there was a lot happening [ID8, mother]*
	• Perceiving the treatment as burdensome meant that some parents experienced fluctuations in their ability to implement the treatment techniques. This led to a minority of parents blaming themselves for not investing enough time in the treatment or feeling frustrated by the demands of treatment.	*"I mean, time just gets in the way. I mean, it's school runs, it's this, it's that. The pinch points in, with the OCD are always coming … when you're time constrained. So you're trying to get out of the house in the morning to get the school bus or something like that, so you don't have time to put in a process and sit down there and discuss things rationally, right? It doesn't work like that" [ID1, father]*
	Subtheme: The demands of engaging the child	
	• All parents described the demands of engaging their child in the treatment and often perceived their child as resistant to engage (e.g., resistant to talk about OCD, to engage in ERP tasks, to reflect on what they had learned from an ERP task). This meant that some parents experienced the treatment as emotionally burdensome.	*"I mean [child's name] was very reluctant um, to do the work it was, it was just hard just to get her to sit down to start to talk about how we would progress each week. So, I mean that was the hardest bit … getting [child's name] engaged" [ID2A, mother]* *"often she [the child] would say to us something like, you know, "well, you don't, you don't care [M: Yeah] if I'm going to die or you don't care that I'm going to, you know, be poisoned" … that was particularly hard, because obviously that's completely the opposite [M: mm] you know, we do care completely" [ID3B, father]*

	Subtheme: Treatment demands exceeded parents' expectations	
	• Some parents described how the demands of treatment were mismatched with their initial expectations. For example, for some families, the process of overcoming OCD was slower and harder than anticipated, and parents had to continue implementing treatment techniques after completing the treatment sessions. This meant that some parents wanted more clarity on the demands of helping their child to overcome OCD.	*"I think [therapist name] said it at the beginning, but it [overcoming OCD] could take much longer than the therapy [F: Yeah] to actually see real progress [F: that's a good point, oh 8 weeks and she'll be fixed, it's kind of, we weren't that naive] we were hoping, we weren't that naïve but we was hoping it would be a bit quicker" [ID2A/B, mother and father].* *"so I think explaining the time investment at the start of the study is really important, so not only are you going to have to invest time in your child, not only, as well as your hour's video call, but there will be additional reading, without scaring people off" [ID5, mother].*
Ingredients for success	*Subtheme: Learning to engage the self and the child*	
	• Parents identified the aspects of treatment they perceived as crucial to motivate themselves to continue implementing the treatment techniques, including the importance of experiencing and celebrating treatment success, and the therapist recognising their child's progress.	*"Seeing the victory, you know, so like [M: yeah] when we did that first exposure ladder with with her [item] and remembering at the start that she was basically saying "I'm never going to be able to do" [M: yeah] and actually then ... do the last thing on on on the ladder ... I mean that is just so encouraging" [ID3B, father]*
	• Parents described how, over time, they learned to engage their child in the treatment. This included learning when was the 'right' time to use the treatment techniques, learning how to best engage their child, and identifying the 'right' motivator for their child.	*"if we got the moments right and he was in the right headspace at that time, then he was very receptive to it [the treatment techniques]" [ID6, father]* *"and so finally we found that these little [characters] in [game name] ... you can dress them up, if you've got these [tokens]... it meant a lot to her that she could do these characters and she had things in mind that she really wanted to do" [ID2A, mother].*

Subtheme: Valuing flexibility	
• Parents perceived flexibility as crucial and valued the videocall and telephone appointments as this offered greater flexibility around parents' schedules than face-to-face support. Parents also valued the flexibility of the therapist in helping parents to adjust treatment techniques that did not work for their child and providing the option for parents to space out treatment sessions to allow parents more time to implement treatment techniques.	*"For the sake of convenience, it was quite good that it was done via [Microsoft] Teams ... it made it convenient for me, it meant I didn't have to arrange childcare ..., it's easier to fit them in [than face-to-face sessions]". [ID13, mother]* *"around sort of [time of year] time when … we'd done most of the key things, [therapist name] suggested leaving a bit longer gaps between meetings to give it a bit more time and that really, I felt that was really good as well … otherwise it might have been a bit quick, there might not have been time to see progress" [ID3A, mother]*
• However, a minority of parents identified the need for greater flexibility as to where and when the treatment sessions are delivered.	*"I suppose there was a few times where I was out and about, um and I, I had to change [the videocall appointment] and I suppose if it been over the phone, I might have been able to continue to do that appointment." [ID5, mother]*
Subtheme: The role of support	
• Parents recognised the role of regular support and guidance from the therapist as key to helping their child to overcome OCD.	*"yeah, 'cause I think we had our homework to do, didn't we [M: yeah] which was to come up with a plan but then if we if we found it difficult it was great then that in the next you know session, we could then just talk those things through [M: yeah] with [therapist name] [ID3B, father].*

• Parents also recognised the value of working as a 'team' with another parent/caregiver to help them to feel emotionally supported and to enable their child to receive consistent responses to their OCD. Among the parents who completed the treatment on their own, some of these parents had a desire for wider support (e.g., from other parents who had received parent-led CBT).	*“but actually, it was useful for [partner name] to be involved … there were certain things he could do where I wasn't there, so sort of certain things she’d do maybe on the getting ready to go to school or on the way to school … he could question her about” [ID9, mother]* *“I think it might be helpful if there was information about support, support groups, or like if you could have other parents that have been through it, that could, talk to you, you know, things like that might be really useful” [ID8, mother]*
Subtheme: The need to align the existing treatment with parents' needs	
• Although some parents felt that no changes were needed to the existing treatment, a minority of parents expressed a preference for greater therapist support (e.g., more sessions, longer-follow-ups) or greater therapist availability at times of distress.	*“if there's a possibility of um the parent not having to wait a week … um you know, having an opportunity to contact somebody and say, you know, I'm feeling overwhelmed and panicked.” [ID8, mother]*
• Some parents identified instances where they did not feel best placed to support their child (e.g., if their child's difficulties related to the parent's own difficulties, where parents felt too emotionally involved with their child, and/or where parents perceived their child to be more open with the therapist) and in these instances, a minority of parents had a preference for their child's assessments to be face-to-face and/or for there to be more appointments with their child.	*“I guess maybe as in a way as a parent, I'm almost sometimes too close, and I’m sort of absorbed into her fears or anxiety … so [it can be] quite hard for me to step back and uhm, really work what was going on for some of those” [ID9, mother]* *“um maybe some more meetings with [child’s name] would have been nice. Not many more as I know it’s obviously parent-led but even if it was just, it's maybe one to check in in the middle” [ID5, mother]*.

Discussion

We used a multiple baseline approach to evaluate the initial efficacy and acceptability of an adapted therapist guided, parent-led CBT intervention for preadolescent children with OCD. Promising outcomes were shown, with 70% (ITT; 78% completer) of children classed as ‘responders’ (on the CY-BOCS) and/or ‘remitters’ (on the ADIS-P) at post-treatment, and 60% (ITT; 60% completer) of children at the one-month follow-up. Moreover, the majority of children showed reliable improvements on the CY-BOCS, ChOCI-R-P symptom scores, and ChOCI-R-P impairment scores at post-treatment and at follow-up. Reductions in the number and severity of comorbid diagnoses across the sample were also observed from pre-treatment to the one-month follow-up. Parents’ knowledge and confidence to help their child to overcome OCD also gradually increased throughout the treatment, and the treatment was found to be acceptable to parents.

Notably, treatment outcomes varied depending on the measure and method of analysis. For example, on the primary outcome measure (i.e., the CY-BOCS), only 40% (ITT; 44% completer) of children met criteria for ‘response’ at post-treatment and at the one-month follow-up (40% ITT; 40% completer), whereas 60% (ITT; 67% completer) of children showed reliable change on this measure from pre- to post-treatment and 70% (ITT; 70% completer) from pre-treatment to the one-month follow-up. This discrepancy may be the result of using international consensus guidelines to classify ‘response’ on the CY-BOCS (i.e., ≥35% reduction, Mataix-Cols et al., 2016) which is a more conservative threshold compared to other guidelines (i.e., >25% reduction, Storch et al., 2010). Furthermore, discrepancies between ‘response’ rates on the CY-BOCS at post-treatment (i.e., 40% ITT; 44% completer) and at follow-up (40% ITT; 40% completer) and ‘remission’ rates on the ADIS-P at post-treatment (60% ITT; 67% completer) and follow-up (50% ITT; 50% completer) (which were notably higher than CY-BOCS ‘response’ rates) may be the result of the CY-BOCS being primarily conducted with the child (with the parent present to add additional information where necessary) versus the ADIS-P being conducted with parents only. Such parent-child discrepancies have been noted in other OCD treatment trials (e.g., Storch et al., 2006). Moreover, this discrepant finding may reflect the lack of research examining the convergent validity of the CY-BOCS and ADIS-P OCD section. Encouragingly, reliable change indices for parent-reported ChOCI-R-P symptom and impairment scores at post-treatment (symptoms: 50% ITT, 50% completer; impairment: 60% ITT, 60% completer) and at one-month follow-up (symptoms: 50% ITT, 50% completer; impairment: 50% ITT, 50% completer) closely reflected 'remission' rates on the ADIS-P (post-treatment: 60% ITT, 67% completer; follow-up: 50% ITT, 50% completer), suggesting that parents were reporting consistently across measures.

When examining the results of the visual analyses of the ChOCI-R-P symptom and impairment scales, six participants showed promising outcomes on both scales and seven participants showed improvements on at least one of these scales, however four participants had limited improvements on at least one of these scales. Of these four participants, the limited improvements observed for two participants may be due to floor effects, where parents reported low symptom (P1, P6) or impairment (P1) scores during the baseline period, meaning that there was limited scope for improvement on those scales during the treatment period. Some parents (P1, P8) appeared to find it challenging to engage their child in their step-by-step ERP plan. Whilst there are many plausible explanations for this, it is possible that these children were fearful of engaging in ERP – a common reason as to why individuals may refuse to engage in this treatment technique (Mancebo et al., 2011). Given that exposure has been identified as key to treatment change (Peris et al., 2015; Whiteside et al., 2020), the lack of improvements for these participants was unsurprising, and future evaluations of this treatment should consider additional ways to support parents to engage their child in this aspect of the treatment, for example, by providing parents with greater psychoeducation on the role of rewards in motivating children (Bouchard et al., 2004) and/or by encouraging parents to support their child to generate ideas for how they could start to put their fears to the test and praising their ideas and efforts (Barrett et al., 2002). For one participant (P8), comorbid diagnoses appeared to additionally contribute to difficulties engaging in the step-by-step ERP plan. Finally, despite the remaining participant (P3) experiencing over 40% reduction in their CY-BOCS scores at post-treatment, limited improvements were observed on their parent-reported ChOCI-R-P symptom and impairment scores, which may be the result of discrepancies in parent and child report.

Parent-reported improvements in family accommodation and children's learning about their fears and their ability to cope in feared situations were also observed across the treatment and may represent possible mechanisms of change in this intervention. Family accommodation has been proposed to have a powerful role in the maintenance of childhood OCD (Waters & Barrett, 2000) and was indirectly targeted in this intervention through psychoeducation and providing parents with alternatives to accommodation. Similarly, exposure focused on helping individuals to learn new information about their fears has been suggested to be key to enhance treatment outcomes (Craske et al., 2014). Future evaluations of this research should therefore examine whether family accommodation and new learning mediate treatment outcomes.

The outcomes of this research are encouraging when compared to other OCD treatment trials for children. In line with meta-analytic research (McGuire et al., 2015), we observed large effects on all outcome measures from pre- to post-treatment. Furthermore, these effect sizes were consistent with a brief individual CBT intervention for children and adolescents with OCD (consisting of 7 hours of therapist support, Bolton et al., 2011) and a parent-led CBT intervention for young children with OCD (consisting of 12 hours of therapist support, Rosa-Alcázar et al., 2017, 2019). However, notably, the pre-post treatment CY-BOCS effect sizes seen in Rosa-Alcázar et al. (2017, 2019) (d=-3.4 in both studies) were considerably larger than the current study due to smaller standard deviations and lower post-treatment mean CY-BOCS scores. Comparison of 'response' and 'remission' rates with other OCD trials is challenging, given that previous studies have used inconsistent criteria (Mataix-Cols et al., 2016). In this study, we defined 'response' as ≥ 35% reduction in CY-BOCS scores and 'remission' as no longer meeting diagnostic criteria on the ADIS-P for one week (Mataix-Cols et al., 2016). This differed to Rosa-Alcázar et al. (2017) who defined 'remission' as ≤12 on the CY-BOCS and found that 60% of children met this criteria after receiving parent-led CBT. Notably, 30% of children in the current study met Rosa-Alcázar et al.'s (2017) criteria for 'remission' at post-treatment, with half the amount of therapist support. However, Rosa-Alcázar et al. (2019) defined 'remission' as <11 on the CY-BOCS and found that only 20% of children who received parent-led CBT met this criteria at post-treatment. When applying this conservative criteria to the current study, no children met criteria for 'remission' at post-treatment.

Crucially, the treatment was acceptable to parents. Despite two parents' SRS scores being below the cut-off for one or more treatment sessions, all parents (including these two parents) who completed the post-treatment questionnaire agreed that they were satisfied with the treatment programme and would recommend the treatment to other families. Qualitative analyses highlighted that the treatment enabled parents to feel equipped and empowered to talk to their child about OCD, and in the majority of cases, able to use ERP to help their child to overcome OCD. Subsequently, many families reported experiencing positive changes for their child and/or their wider family as a result of the treatment. Moreover, parents valued receiving regular guidance from the therapist, as well as flexibility in the delivery of the treatment. Parents (where applicable) valued having another caregiver involved in the treatment to facilitate a consistent approach to responding to their child's OCD and to provide emotional support for the parent. In contrast, parents who completed the treatment alone identified the need for wider peer support – thus, this will be an important consideration for future iterations of the treatment. Notably, some parents experienced the treatment as an additional responsibility and all parents experienced some challenges engaging their child in the treatment. Thus, future iterations of the treatment should draw on parents' perceptions of the ingredients for success (e.g., greater flexibility, support from others, learning how to engage the self and child) to help address the perceived burdens of the treatment to parents and to help facilitate families' journeys to a new normal.

Strengths of this study include the evaluation of a brief low-intensity treatment for preadolescent children with OCD that was delivered by a non-specialist therapist. The promising outcomes achieved indicate that this treatment may be an appropriate first-line treatment for preadolescent children with OCD. In line with Bower and Gilbody's (2005) criteria for a first-line intervention, this treatment has shown encouraging outcomes compared to other traditional CBT treatments for children with OCD, requires considerably less therapist input than traditional CBT approaches, and shows promising acceptability to parents. Moreover, we included children with comorbid diagnoses (with the exception of autism/learning disabilities) and children who had previously received psychological support, increasing the generalisability of our findings to routine clinical services that offer low-intensity interventions (i.e., where this intervention is intended to be delivered). Furthermore, we were able to recruit six fathers who participated in at least one treatment session (four of whom attended all eight treatment sessions) which may be the result of the flexible nature (i.e., video/telephone appointments, evening appointments) of the treatment (Thurston & Phares, 2008). This is advantageous given that both maternal and paternal accommodation of OCD symptoms have been associated with children and adolescents' treatment outcomes

(Monzani et al., 2020) and the inclusion of fathers in the treatment enabled us to assess the acceptability of the intervention to both mothers and fathers. We also used gold standard diagnostic assessments, psychometrically valid symptom measures, and international consensus guidelines to determine children's treatment outcomes (Mataix-Cols et al., 2016), and a combination of statistical and systematic visual analyses to analyse the results in line with best-practice guidelines (Kratochwill et al., 2010; Tate et al., 2016). The use of a multiple baseline approach enabled us to examine the effect of the intervention whilst controlling for factors that may impact internal validity (e.g., time, external events that coincide with the introduction of the treatment etc., Kratochwill et al., 2010). Our results indicated that treatment gains were not influenced by baseline length (with the potential exception of treatment goals), strengthening the conclusions that can be made regarding the effect of the intervention on children's outcomes (Watson & Workman, 1981, Kazdin, 2019). Furthermore, the use of qualitative interviews enabled a rich insight into parents' experiences and acceptability of the treatment that will inform future iterations of the treatment.

Despite the strengths of this study, there are important limitations to consider. First, this study was limited by its sample size (n = 10 children). Although this is an appropriate sample size for this study design (Kratchowill et al., 2010), it will be crucial to examine this intervention on a larger scale to draw firm conclusions regarding treatment efficacy. Second, a number of participants had improving baseline trends, meaning that we could not infer with confidence whether there was a "clear" effect of the intervention, as there was a considerable overlap between the observed and projected treatment data. Given that OCD is often chronic in nature (Micali et al., 2010), we would not typically expect participants' improving baseline trends to continue in a linear fashion. Furthermore, we calculated participants' treatment trends based on all of their session-by-session data, despite not anticipating observing treatment effects during the first few treatments sessions (when sessions were mainly psychoeducational in nature). Thus, our approach to classifying treatment effects based on visual analyses was conservative. Third, due to the preliminary nature of this research, we were unable to use blind assessors to conduct and score diagnostic assessments. Although this is the case for other preliminary studies (e.g., Leigh & Clark, 2016; Vogel et al., 2012; Whiteside et al., 2008), lack of assessor blinding can result in overestimated treatment effects (Savović et al., 2018). While we also used parent-reported outcome measures to assess the effects of the intervention, the lack of assessor blinding means that the results of this study need to be interpreted with caution. Furthermore, unusually, we obtained greater ‘remission’ rates (as assessed by the ADIS-P) than ‘response’ rates (assessed by the CY-BOCS) in this study, which may be due to the ADIS-P being parent-reported and the CY-BOCS being predominantly child reported (with additional input from parents where necessary). Although international consensus guidelines suggest prioritising parent-report for preadolescent children with anxiety disorders (Krause et al., 2021), future evaluations of this treatment may benefit from combining the information obtained from parent and child diagnostic interviews. Fourth, we used a between-groups measure of Cohen’s d to calculate effect sizes that were comparable to other treatment studies – however, this effect size does not consider the relationship between pre- and post/follow-up treatment data and may therefore have resulted in inaccurate effect size calculations. Fifth, we only conducted a one-month follow-up of participants, limiting our understanding of the longer-term impacts of this intervention. Sixth, our sample predominantly consisted of White British children and parents, restricting our understanding of the efficacy and acceptability of this treatment for families from more diverse backgrounds. Finally, therapist adherence to the treatment manual was not formally assessed. Although in this study the treatment was delivered and supervised by the individuals who developed the treatment, the use of a therapist adherence measure will be particularly important for future evaluations of this treatment that will involve independent therapists and supervisors.

Conclusions

This study demonstrated promising outcomes for preadolescent children with OCD following a brief low-intensity therapist guided, parent-led CBT intervention that was delivered by a non-specialist therapist. The treatment was acceptable to parents and qualitative analyses highlighted key considerations for future iterations of the treatment. Further evaluation of this intervention is now warranted and should recruit a demographically diverse sample of children and parents and use independent blind assessors to increase confidence in the intervention effects. However, subject to the findings of further evaluations, our findings suggest that this brief low-intensity treatment, developed to be delivered by non-specialist therapists, may be a good candidate as a first-line treatment to ultimately substantially increase access to evidence-based treatments for preadolescent children with OCD.

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Declaration of interest

CCr receives royalties for the sale of the original treatment book ‘Helping your child with fears and worries’, however, does not receive royalties for any of the treatment materials used in this study.

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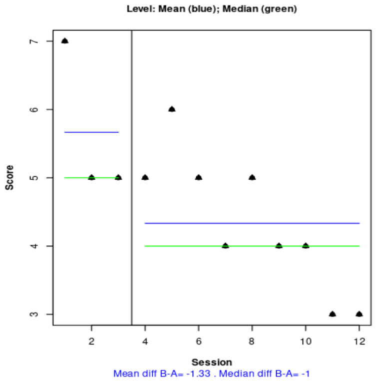
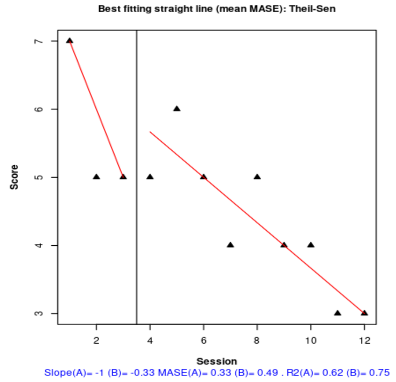
Supplementary Materials

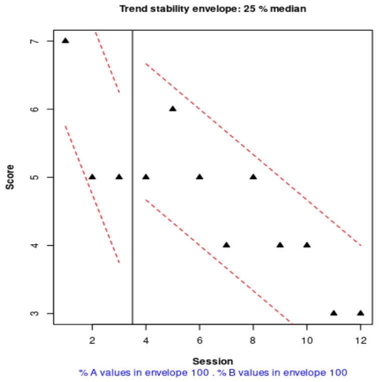
Note. Table S5, S6, and the full qualitative analyses were submitted as supplementary analyses alongside this paper, however, are not listed here, as this information is provided in Chapter 6 (where Table S5 = Table 1, Table S6 = Table 2, and the full qualitative analyses are written on pages 254 - 268).

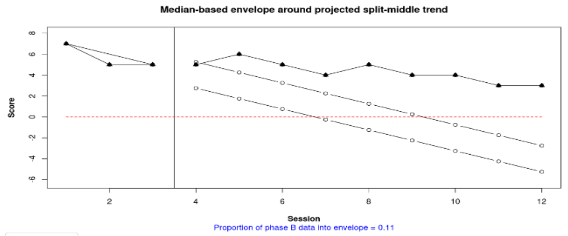
1. Visual analyses of ChOCI-R-P symptoms for each participant (including level, trend, variability, observed and projected values, percentage of non-overlapping data [PND]).

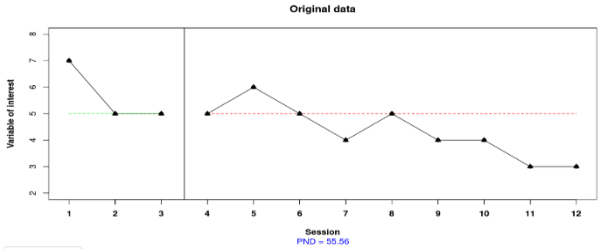
(a) Participant 1











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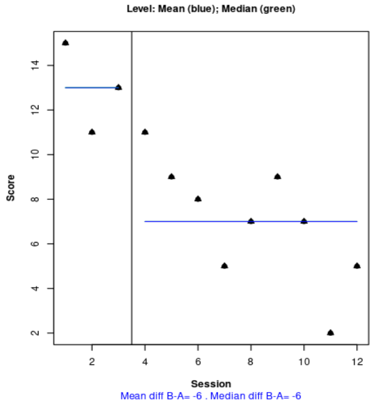
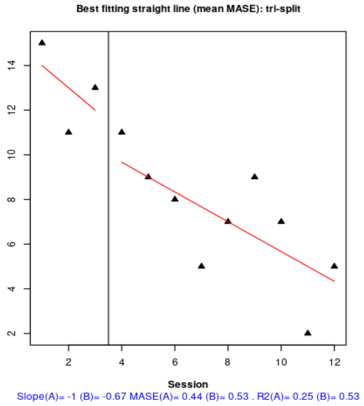
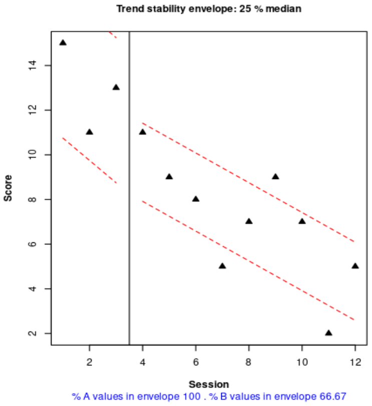
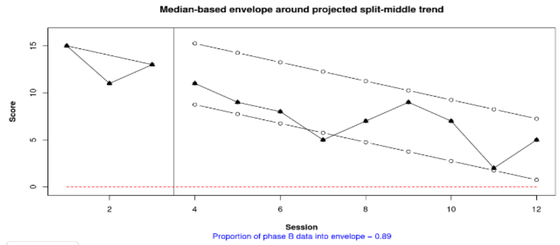
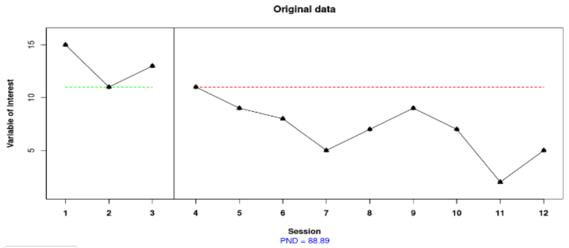


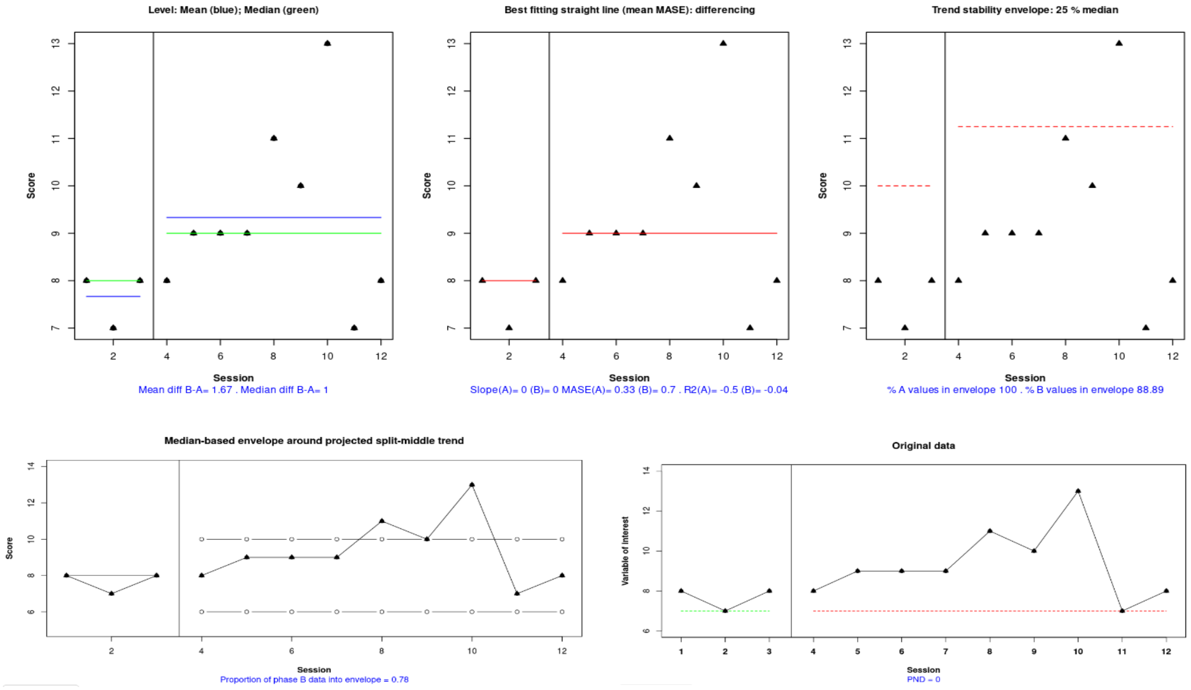




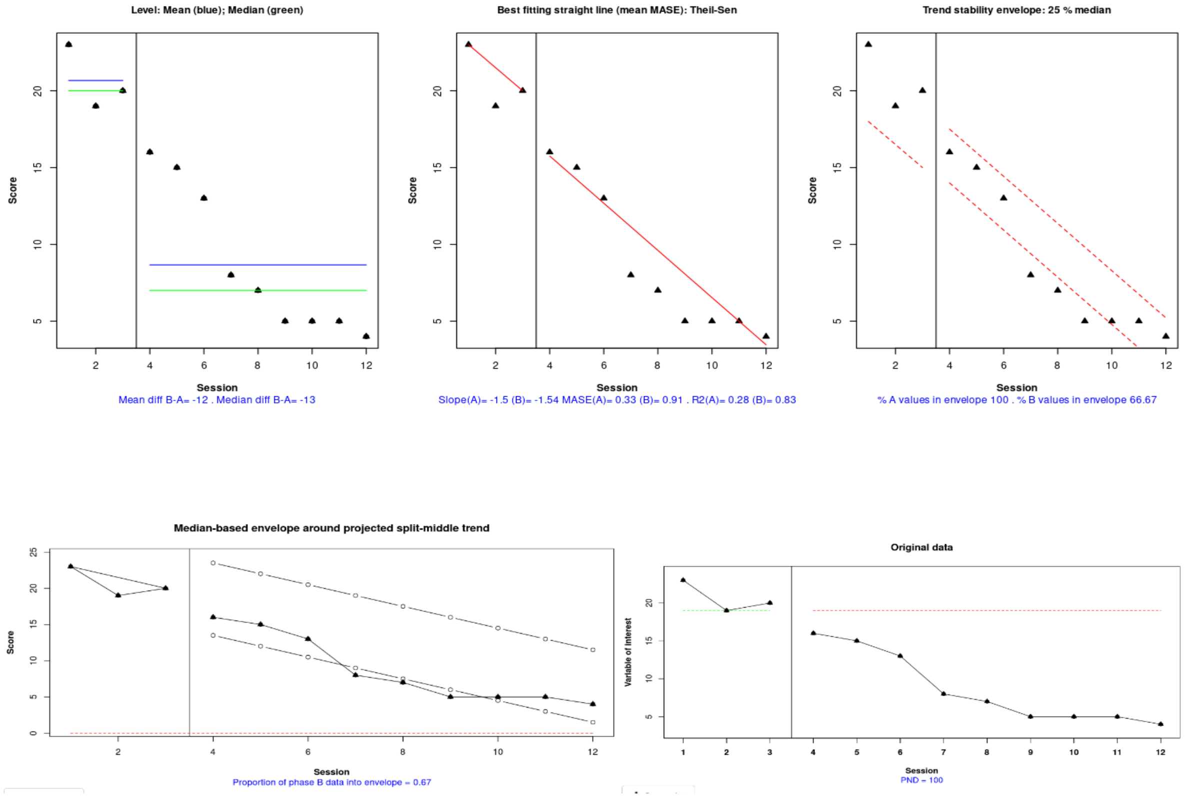




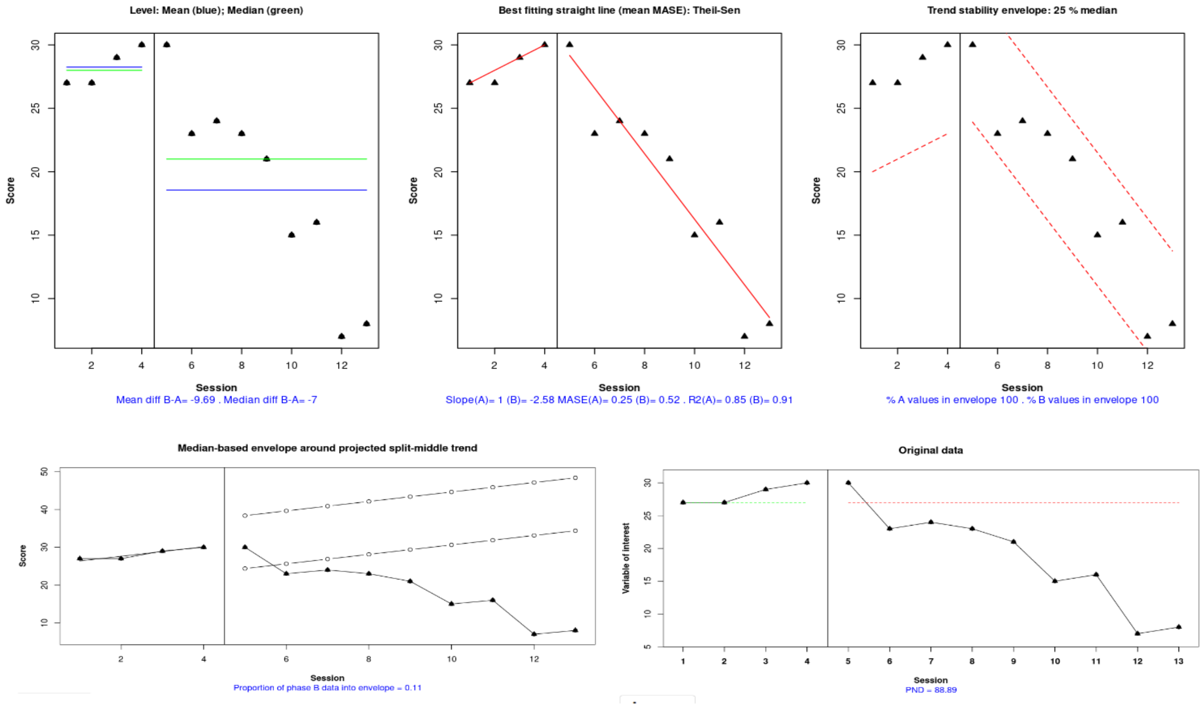
(c) Participant 3



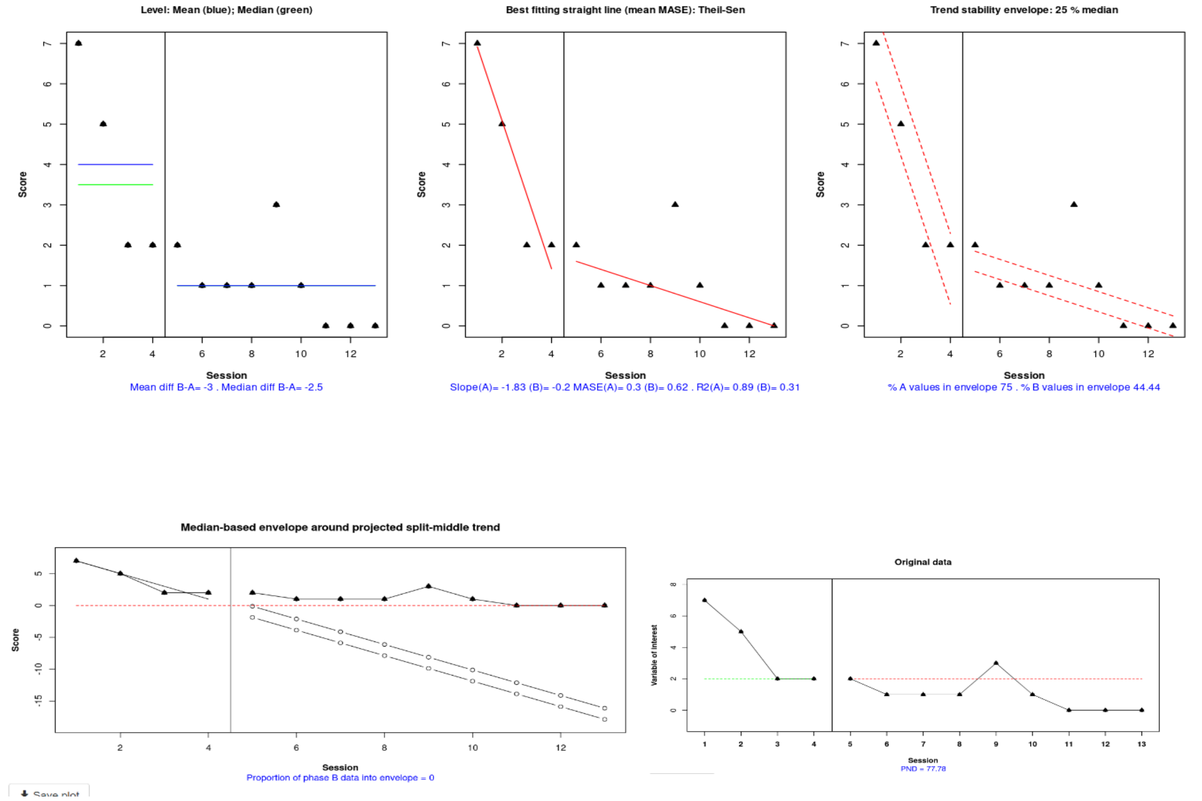
(d) Participant 4



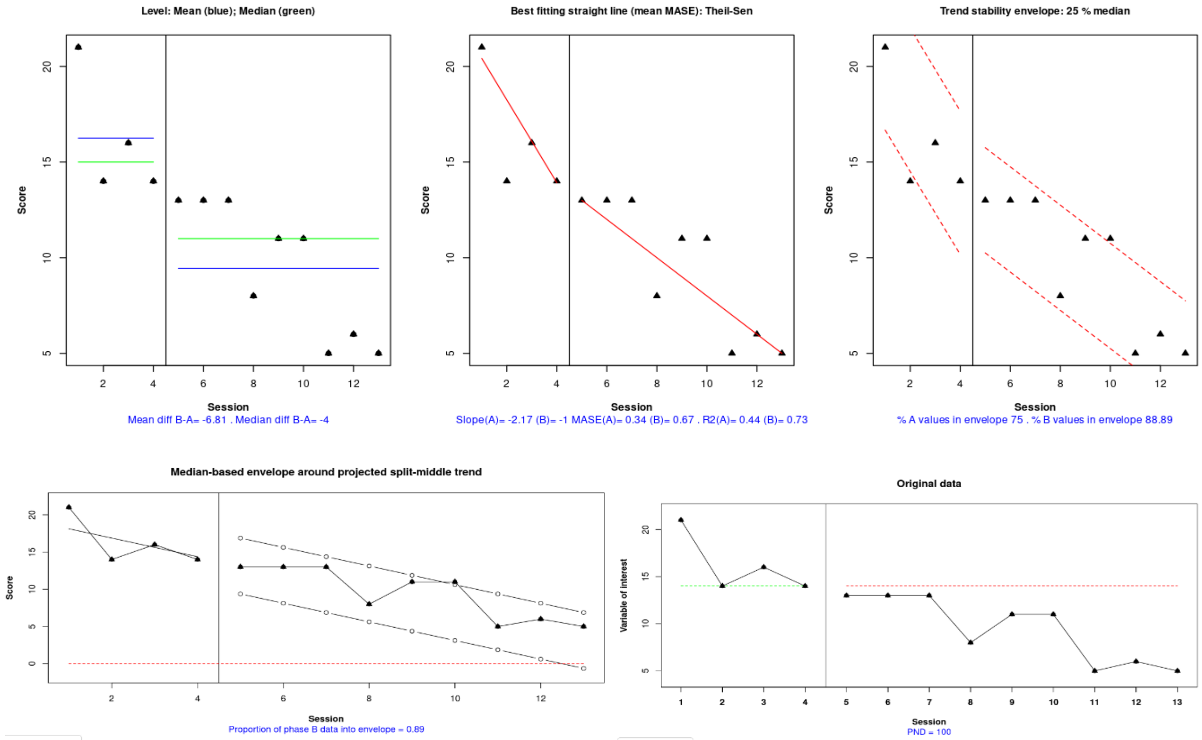
(e) Participant 5



(f) Participant 6



(g) Participant 7



Level: Mean (blue); Median (green)

Mean diff B-A= -6.81 . Median diff B-A= -4

Best fitting straight line (mean MASE): Theil-Sen

Slope(A)= -2.17 (B)= -1 MASE(A)= 0.34 (B)= 0.67 . R2(A)= 0.44 (B)= 0.73

Trend stability envelope: 25 % median

% A values in envelope 75 . % B values in envelope 88.89

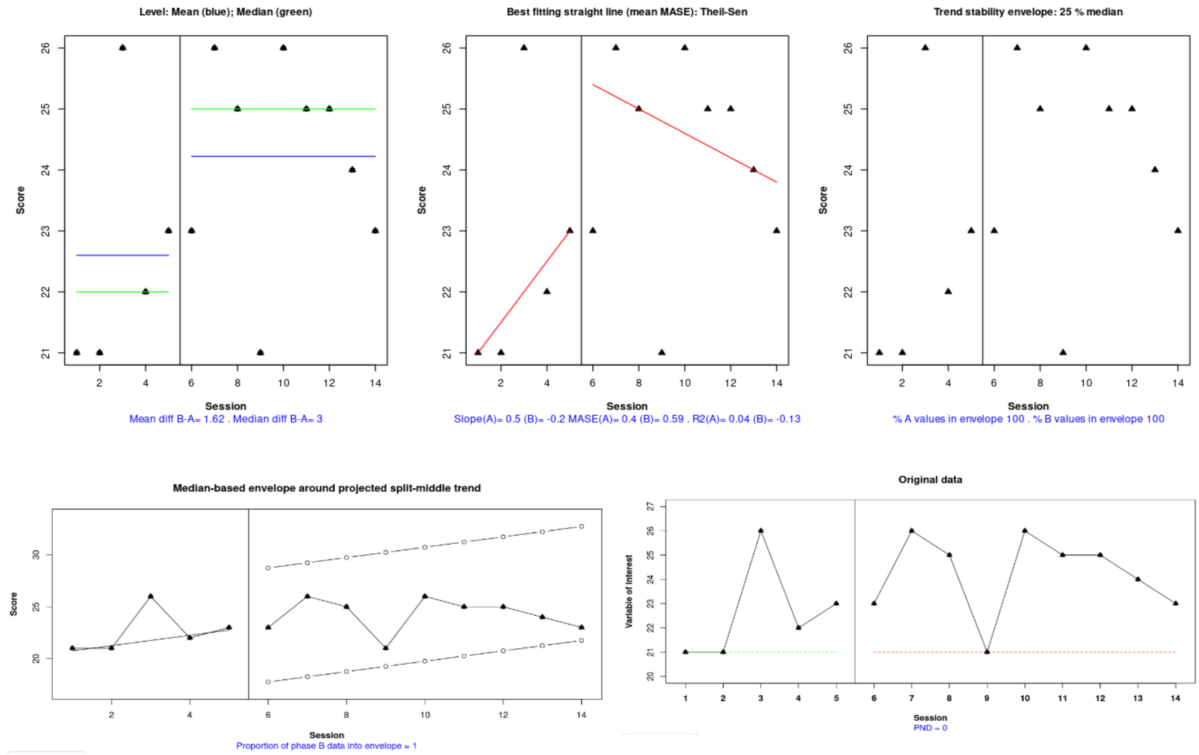
Median-based envelope around projected split-middle trend

Proportion of phase B data into envelope = 0.89

Original data

PND = 100

(h) Participant 8



Level: Mean (blue); Median (green)

Mean diff B-A= 1.62 . Median diff B-A= 3

Best fitting straight line (mean MASE): Theil-Sen

Slope(A)= 0.5 (B)= -0.2 MASE(A)= 0.4 (B)= 0.59 . R2(A)= 0.04 (B)= -0.13

Trend stability envelope: 25 % median

% A values in envelope 100 . % B values in envelope 100

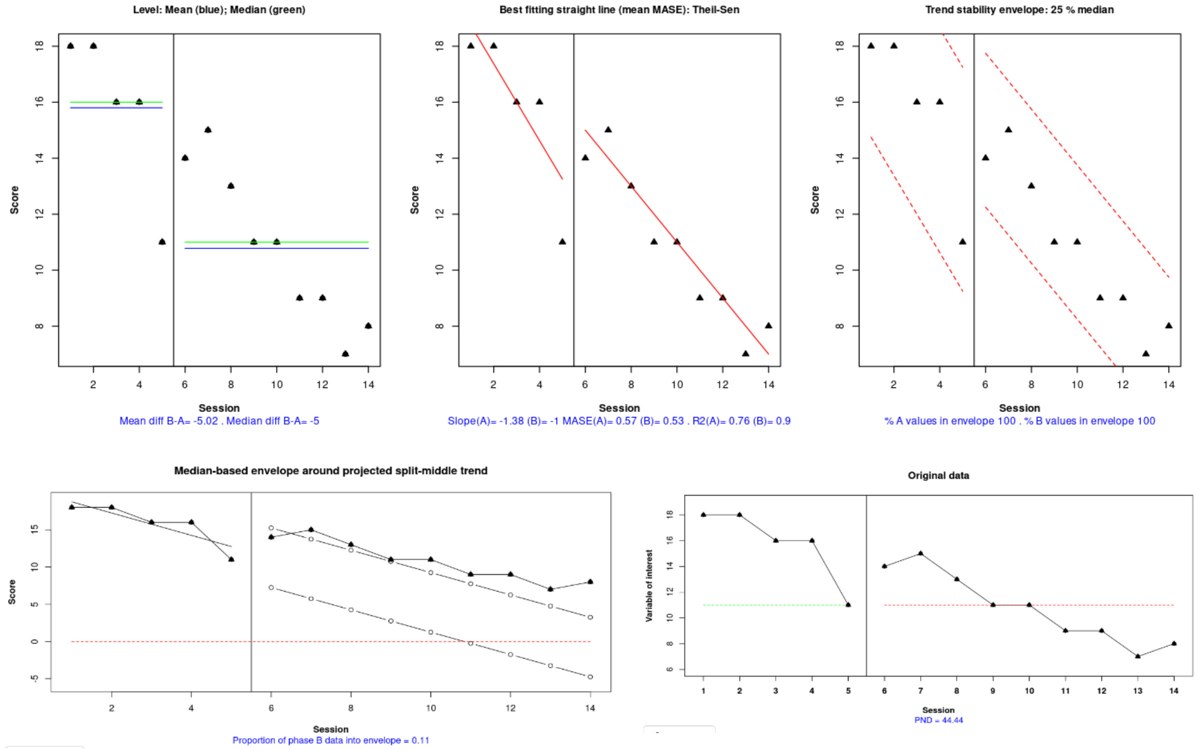
Median-based envelope around projected split-middle trend

Proportion of phase B data into envelope = 1

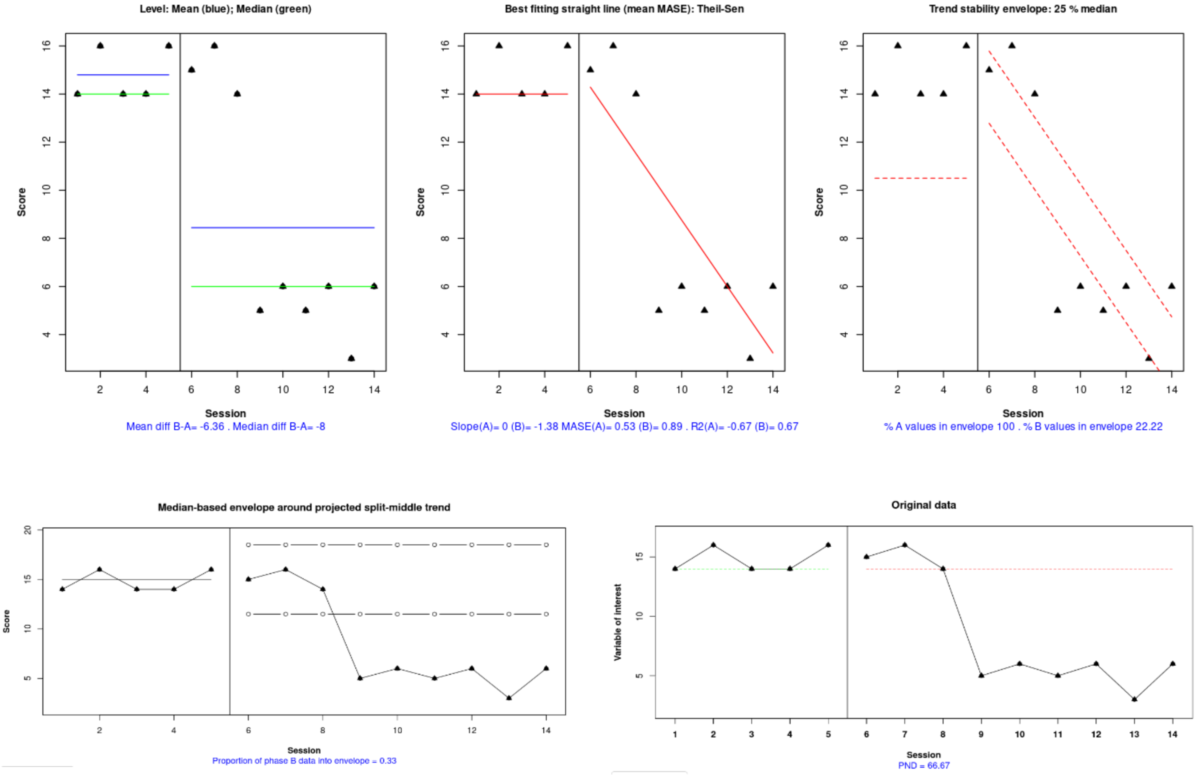
Original data

PND = 0

(i) Participant 9

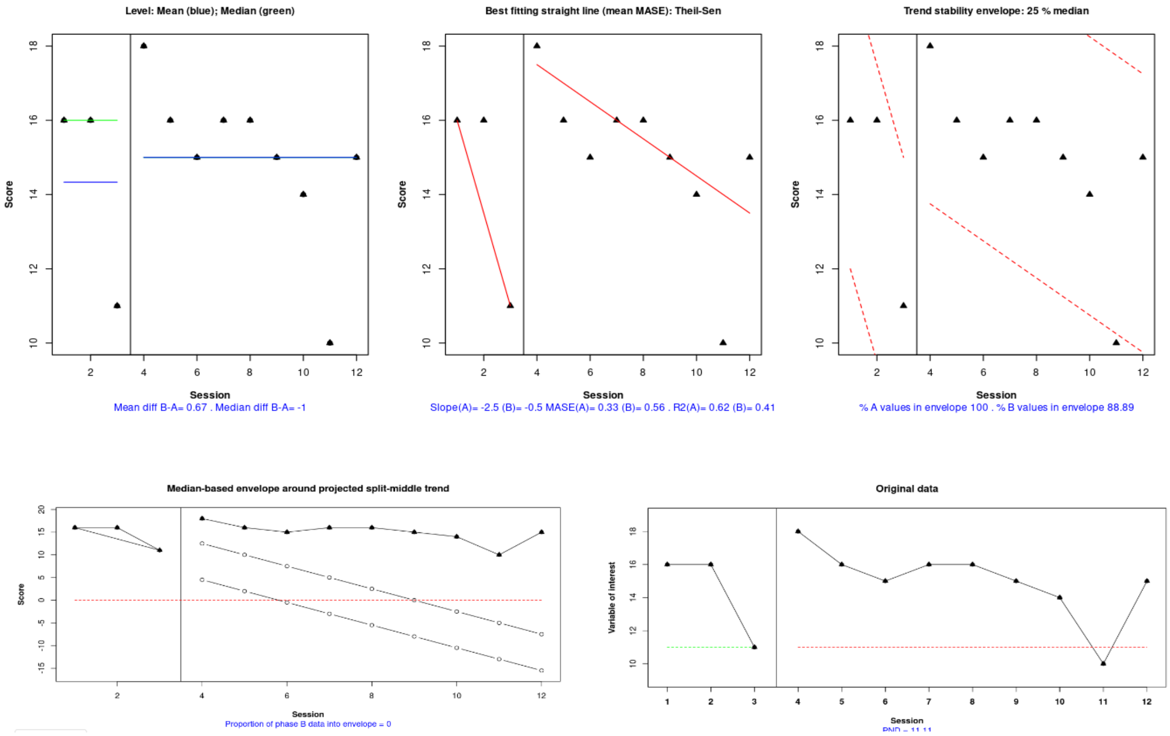


(j) Participant 10

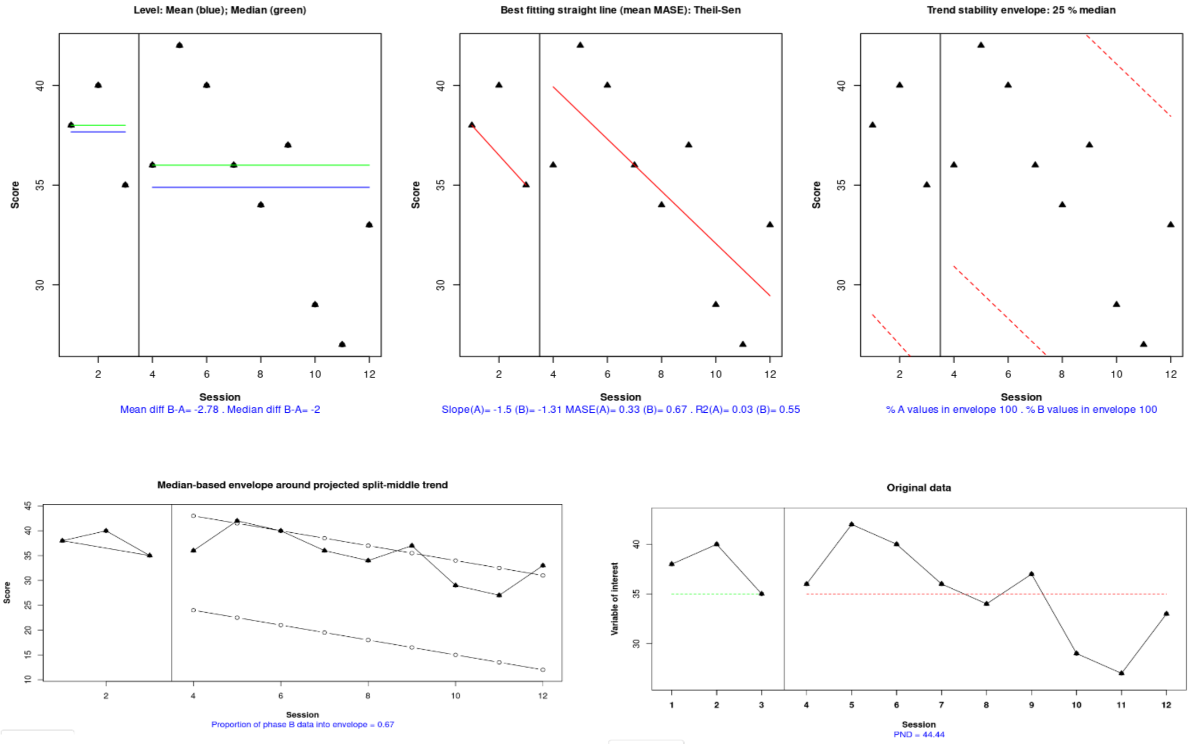


2. Visual analyses of ChOCI-R-P impairment for each participant (including level, trend, variability, observed and projected values, percentage of non-overlapping data [PND]).

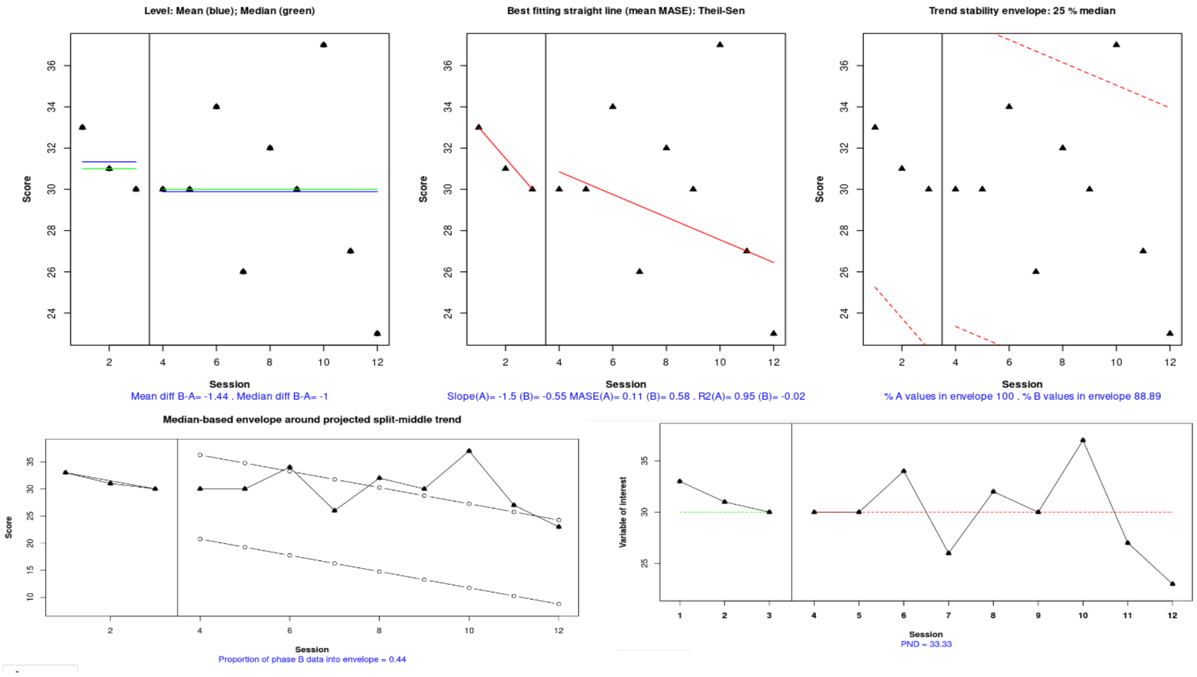
(a) Participant 1



(b) Participant 2



(c) Participant 3


Level: Mean (blue); Median (green)

Mean diff B-A= -1.44 . Median diff B-A= -1

Best fitting straight line (mean MASE): Theil-Sen

Slope(A)= -1.5 (B)= -0.55 MASE(A)= 0.11 (B)= 0.58 . R2(A)= 0.95 (B)= -0.02

Trend stability envelope: 25 % median

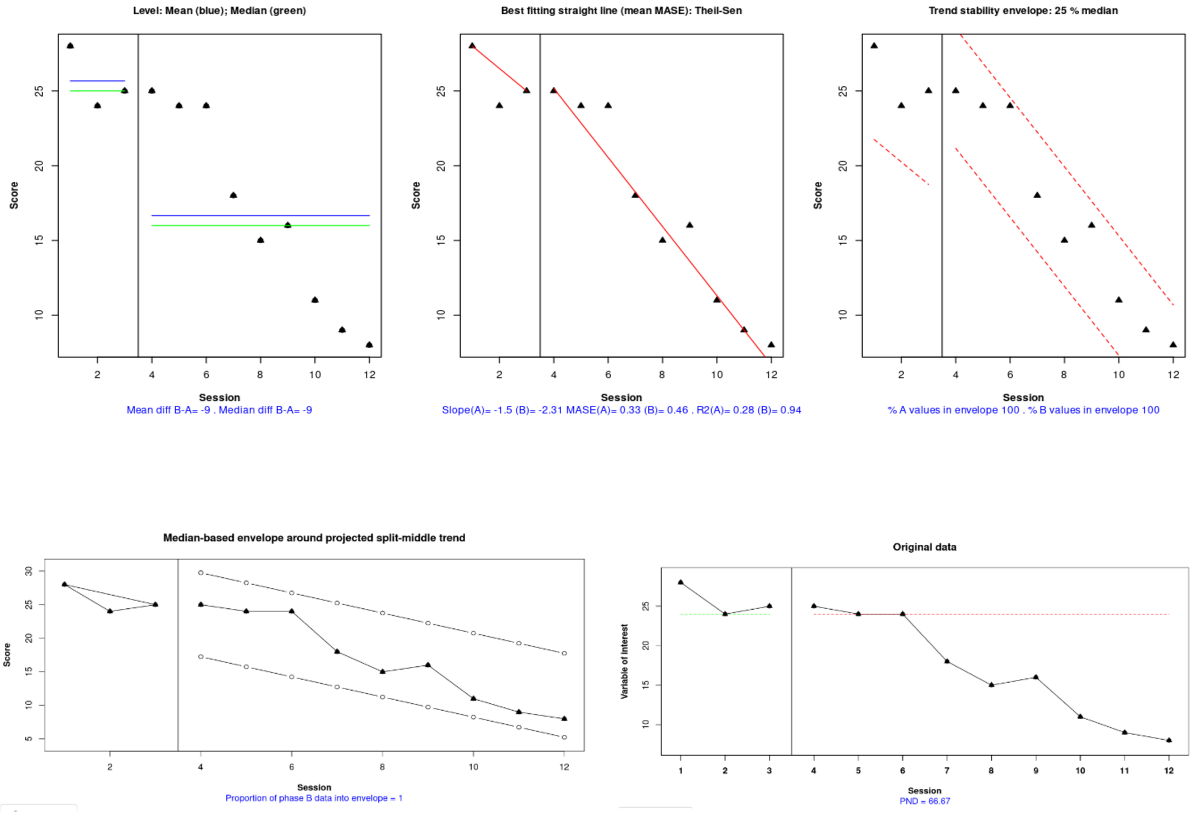
% A values in envelope 100 . % B values in envelope 88.89

Median-based envelope around projected split-middle trend

Proportion of phase B data into envelope = 0.44

PND = 33.33

(d) Participant 4


Level: Mean (blue); Median (green)

Mean diff B-A= -9 . Median diff B-A= -9

Best fitting straight line (mean MASE): Theil-Sen

Slope(A)= -1.5 (B)= -2.31 MASE(A)= 0.33 (B)= 0.46 . R2(A)= 0.28 (B)= 0.94

Trend stability envelope: 25 % median

% A values in envelope 100 . % B values in envelope 100

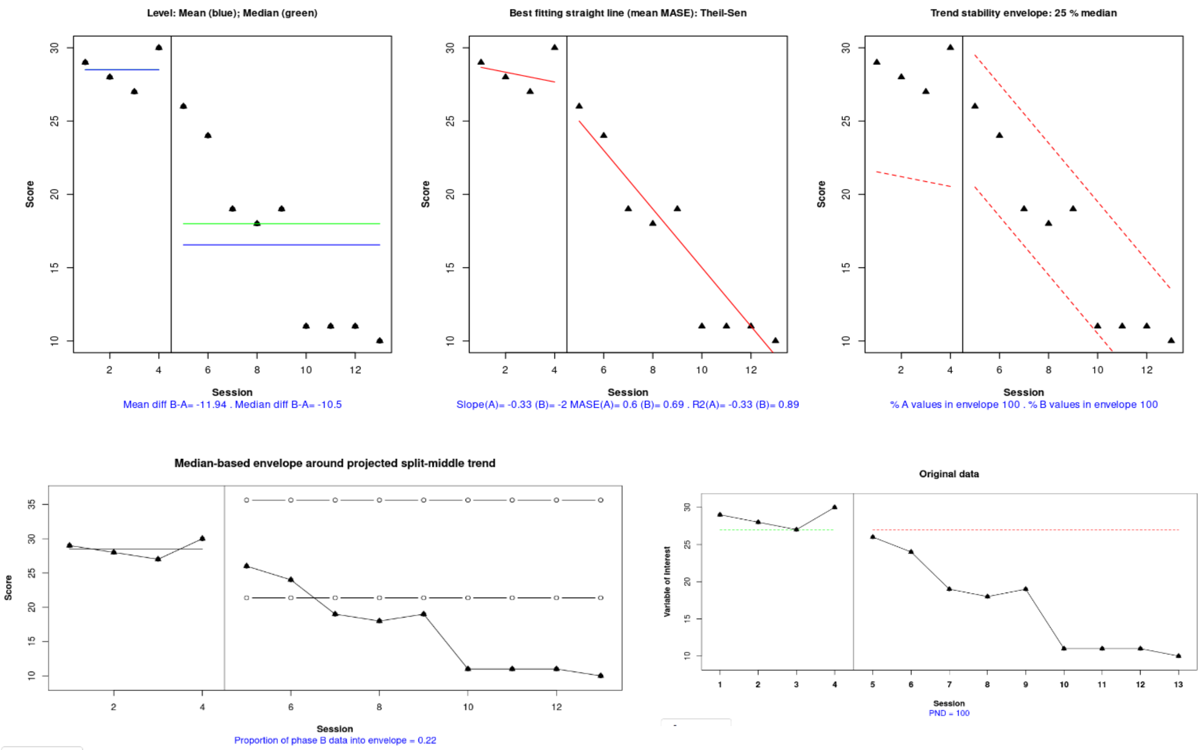
Median-based envelope around projected split-middle trend

Proportion of phase B data into envelope = 1

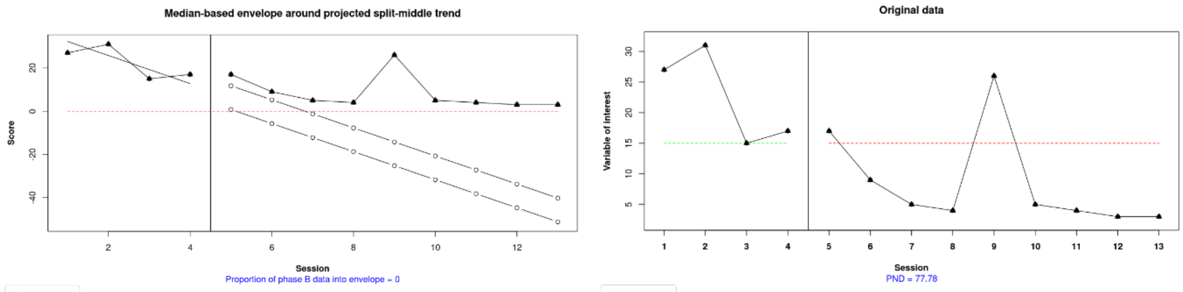
Original data

PND = 66.67

(e) Participant 5



(f) Participant 6[1]



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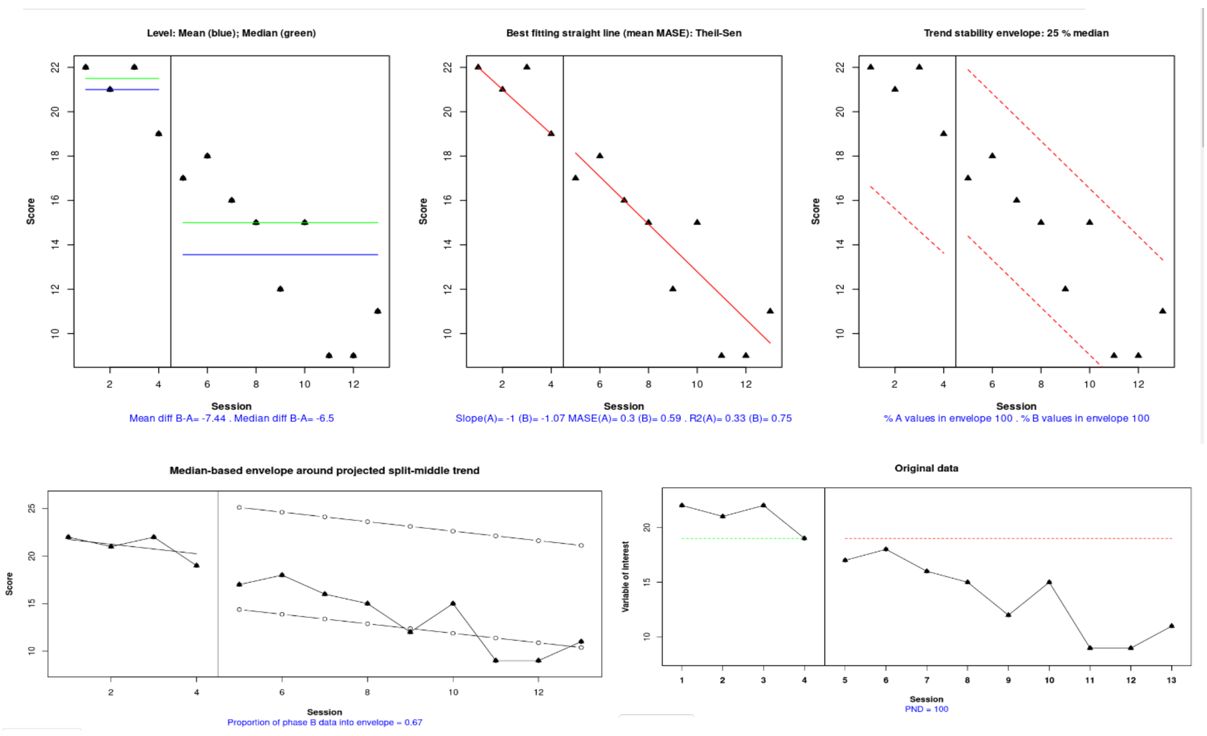
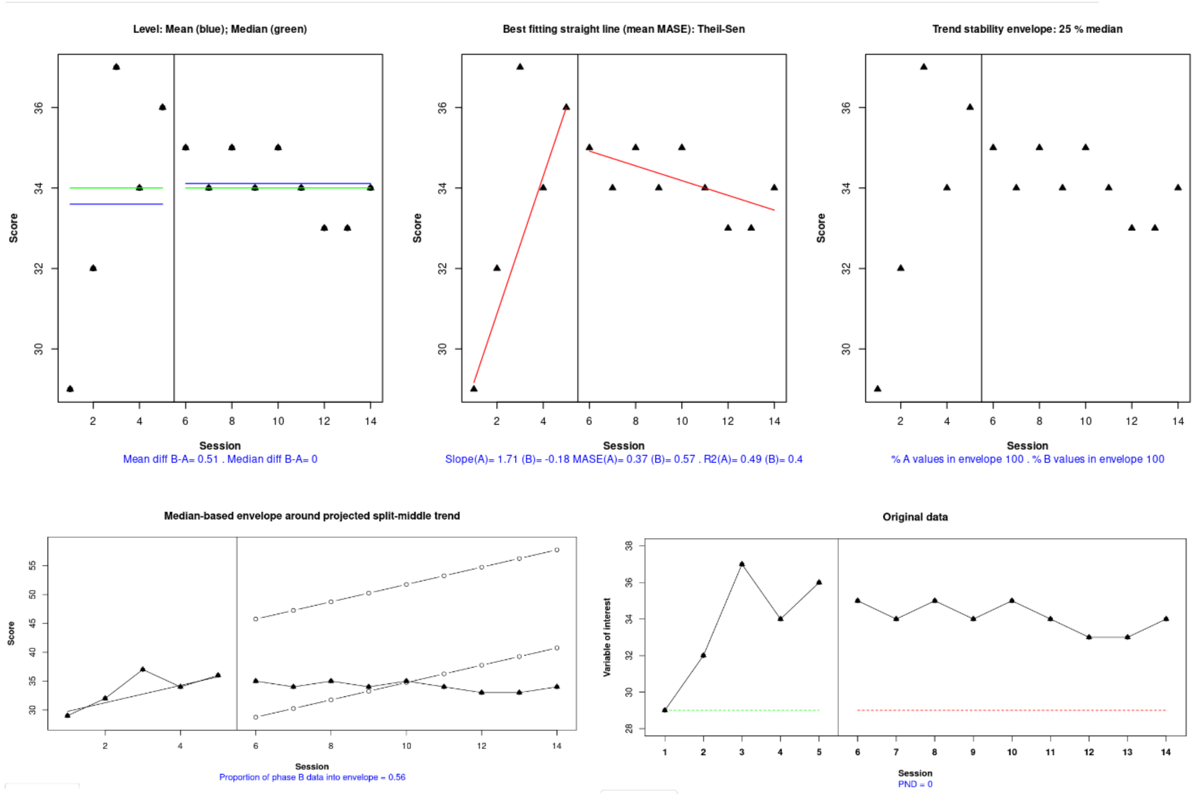
[1] Mean, trend, and data stability were assessed by eye for this participant, as this data could not be analysed in https://manolov.shinyapps.io/Overlap/

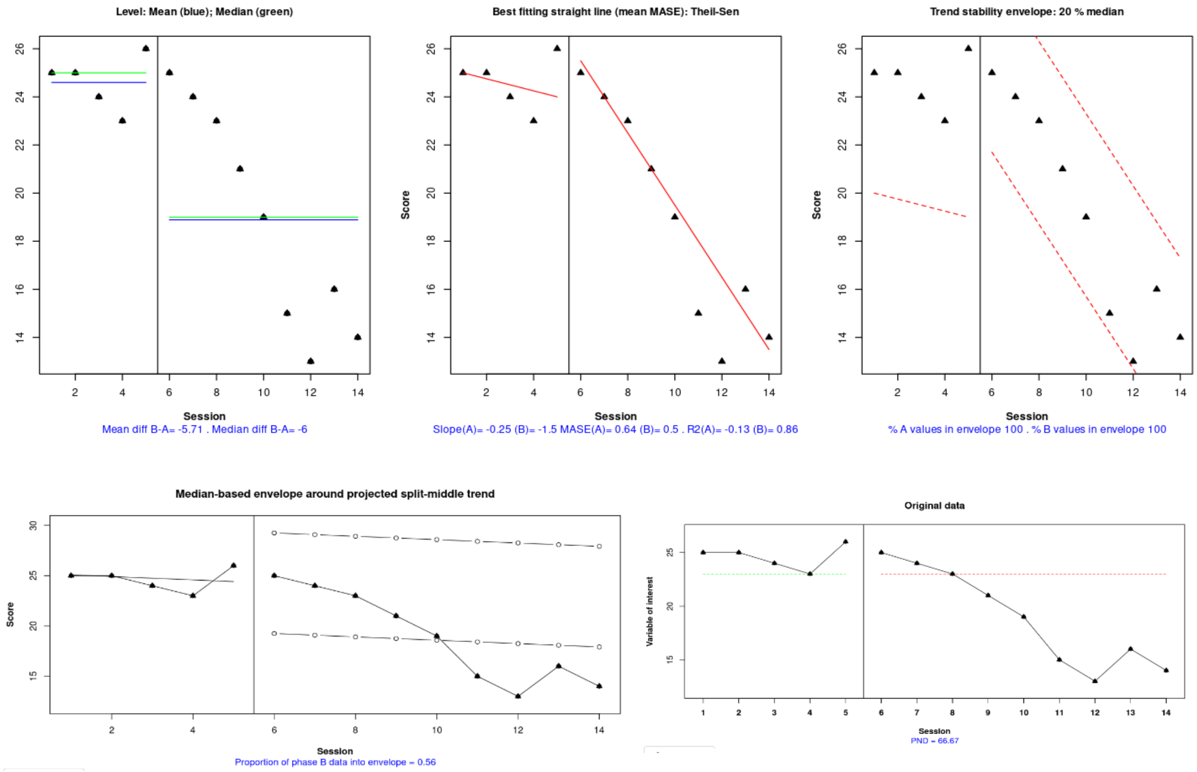
(g) Participant 7



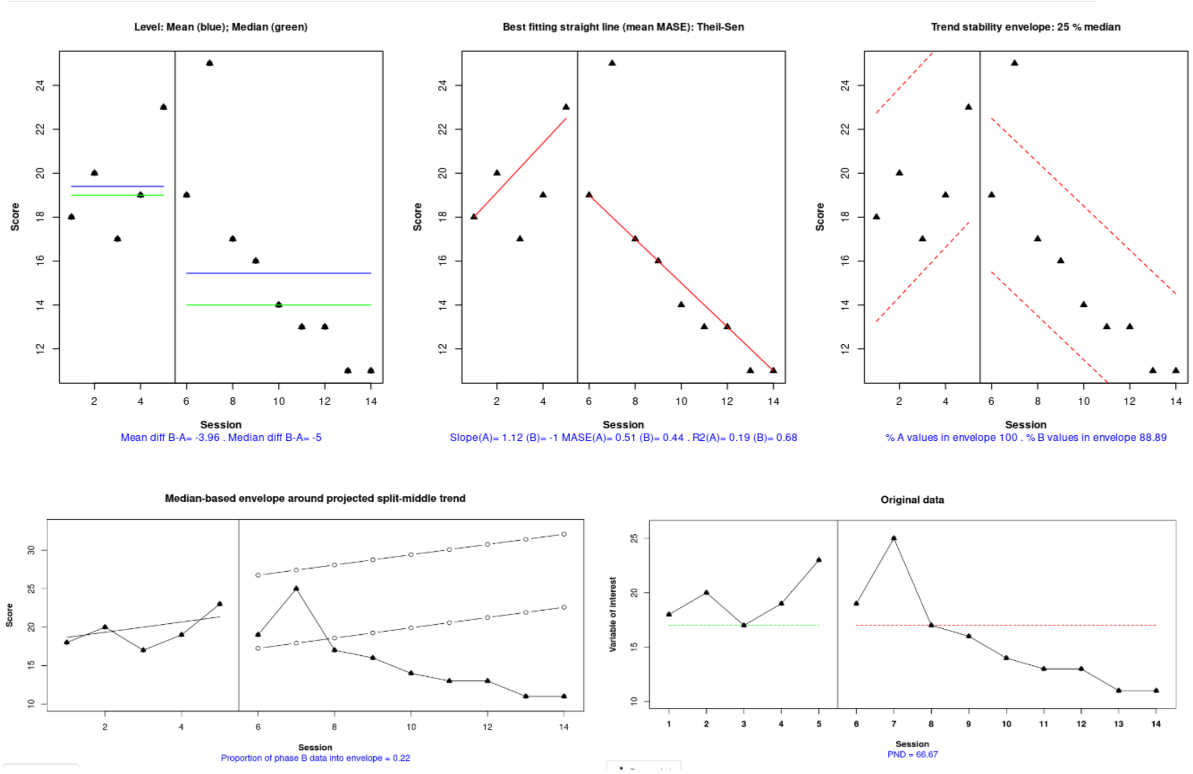
(h) Participant 8



(i) Participant 9

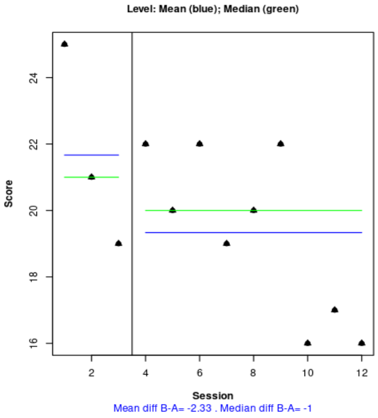


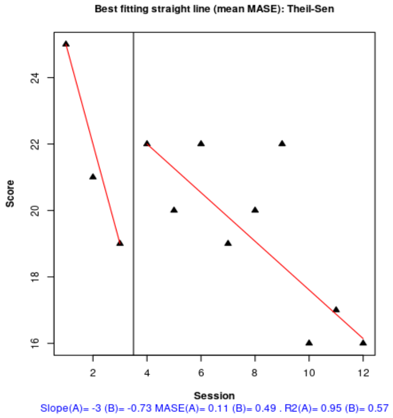
(j) Participant 10

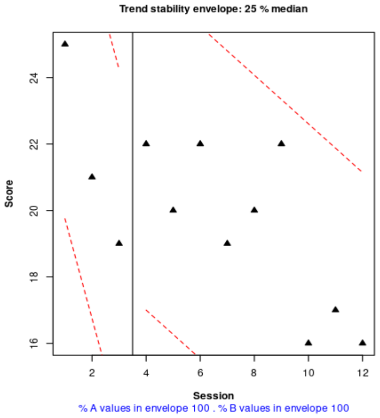


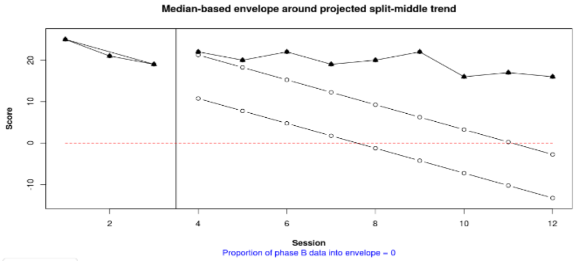
3. Visual analyses of FAS-PR for each participant (including level, trend, variability, observed and projected values, percentage of non-overlapping data [PND]).

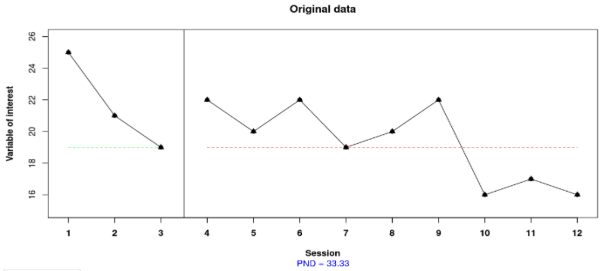
(a) Participant 1



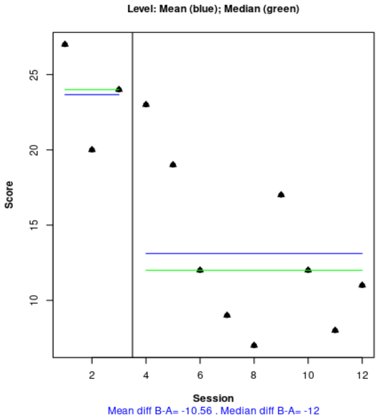


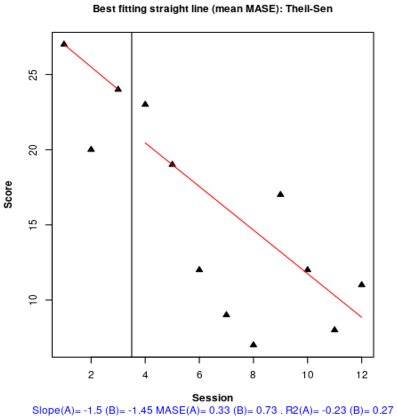


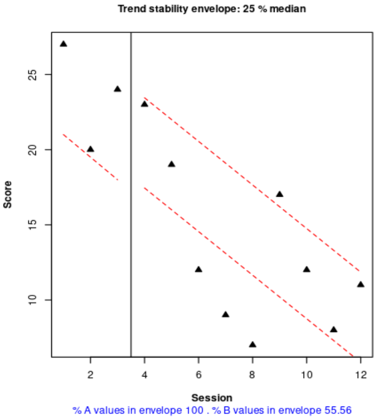


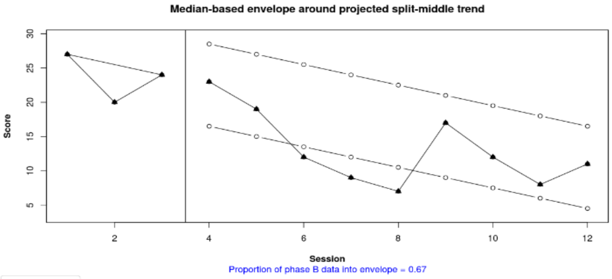


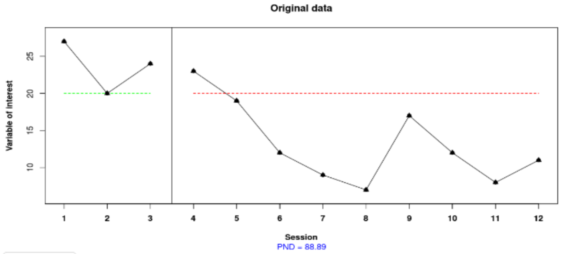
(b) Participant 2



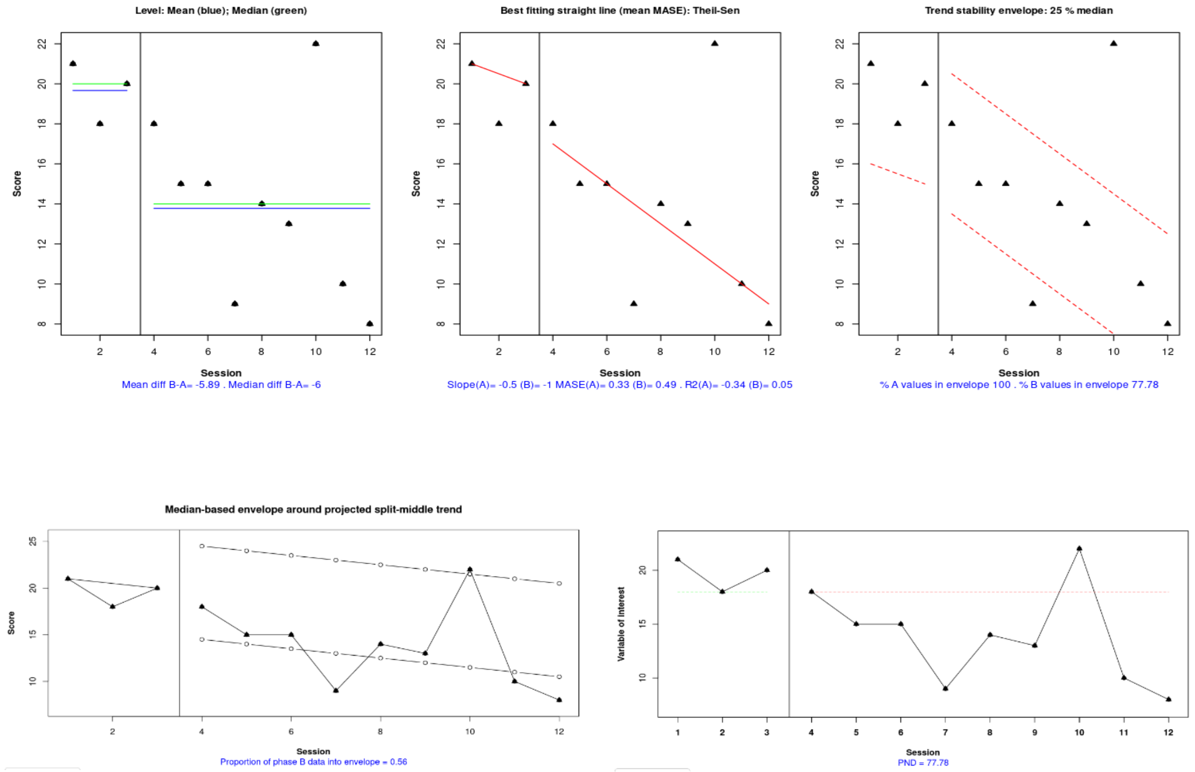




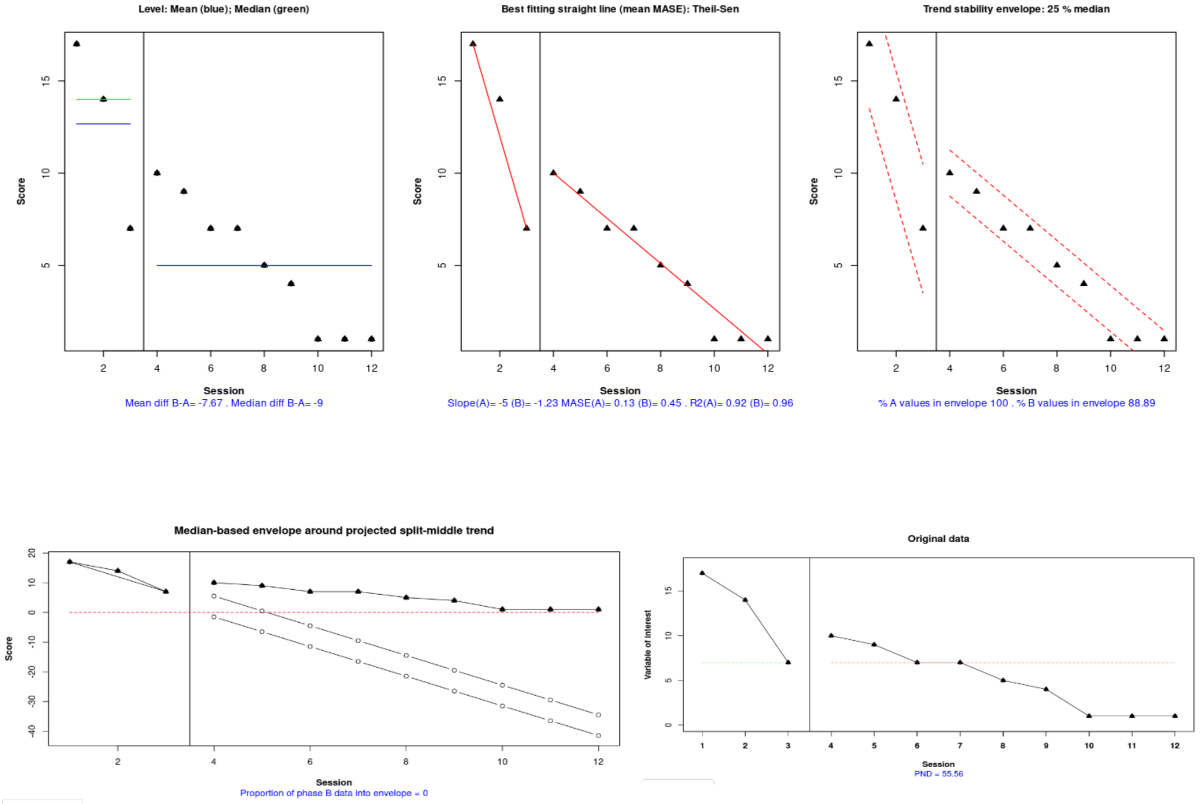




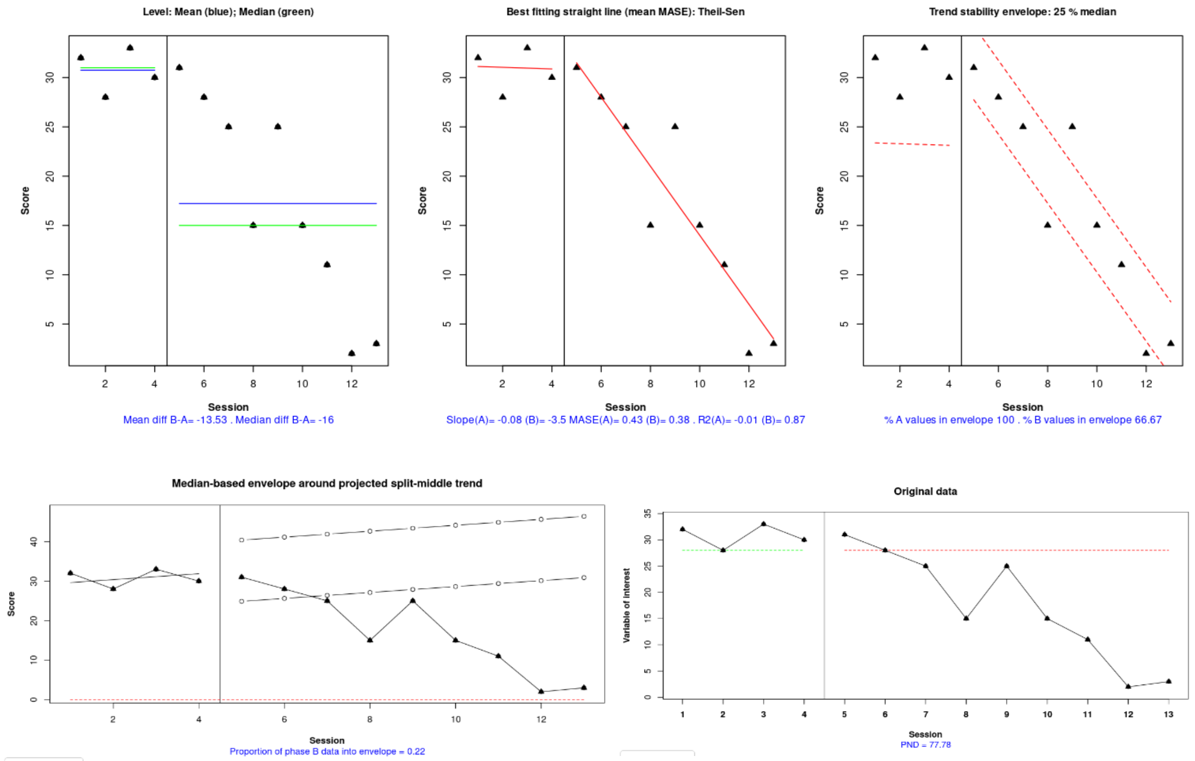
(c) Participant 3



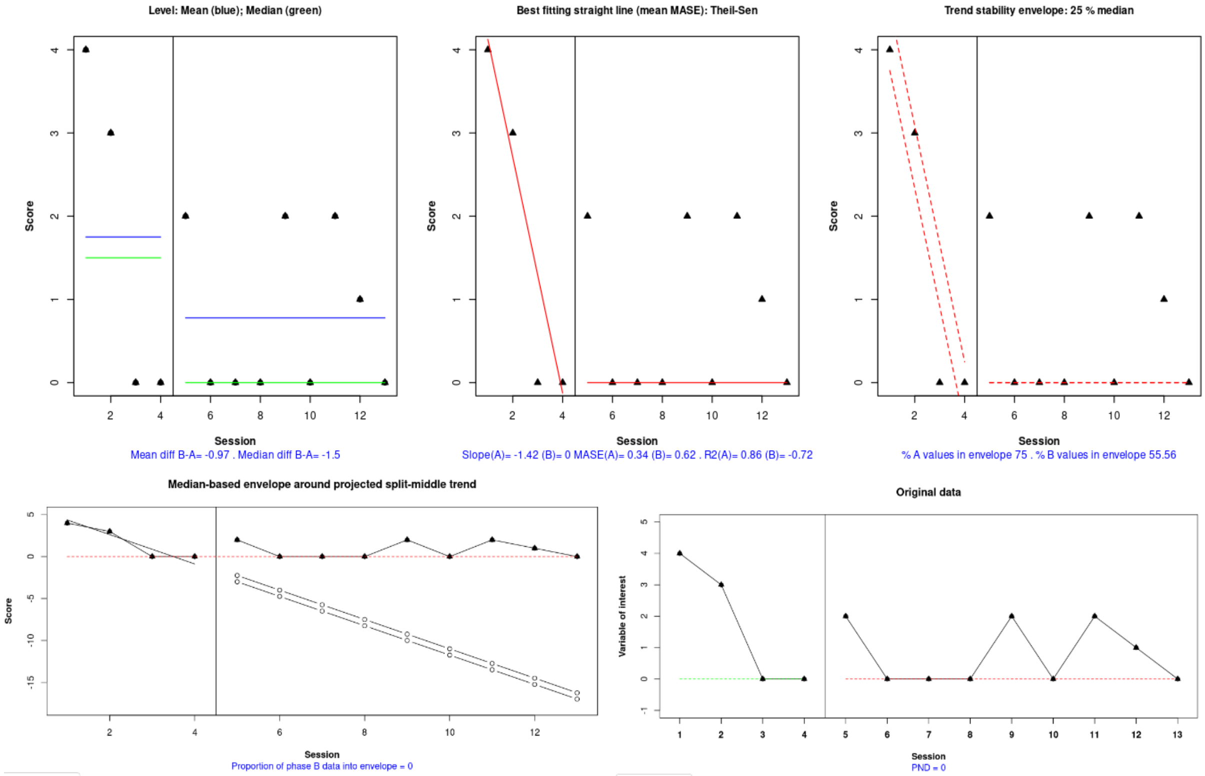
(d) Participant 4



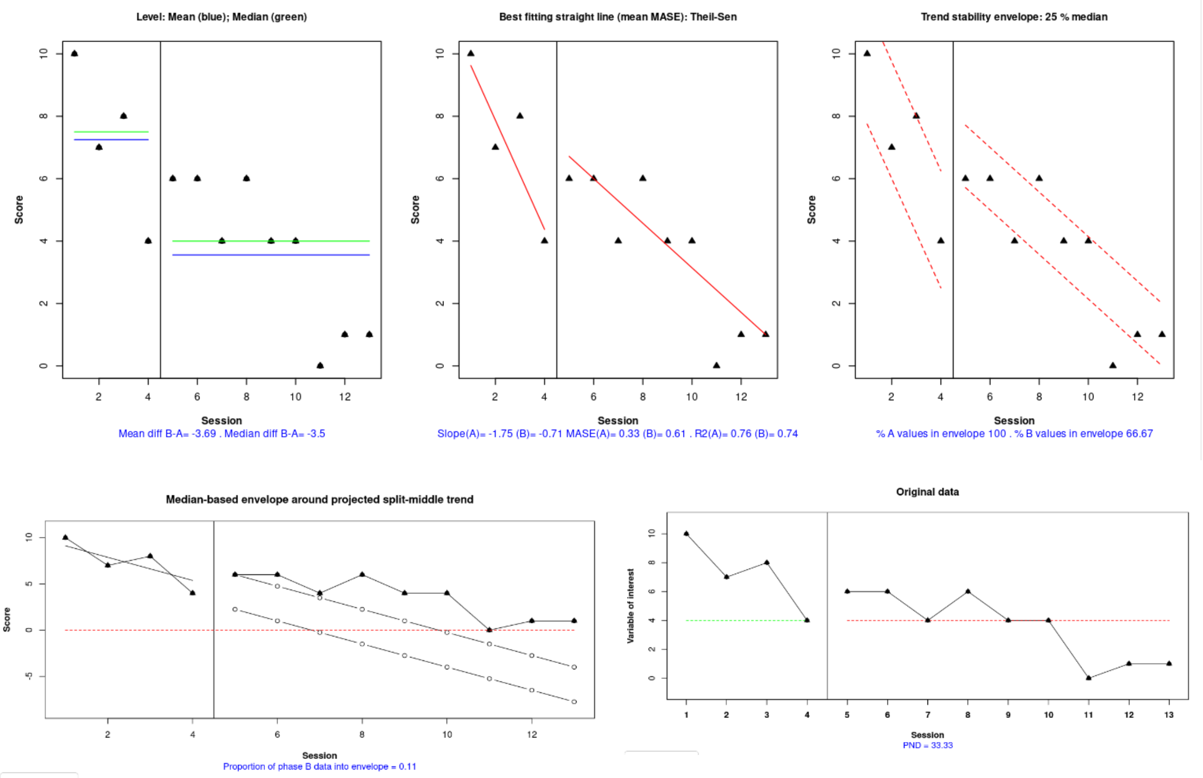
(e) Participant 5



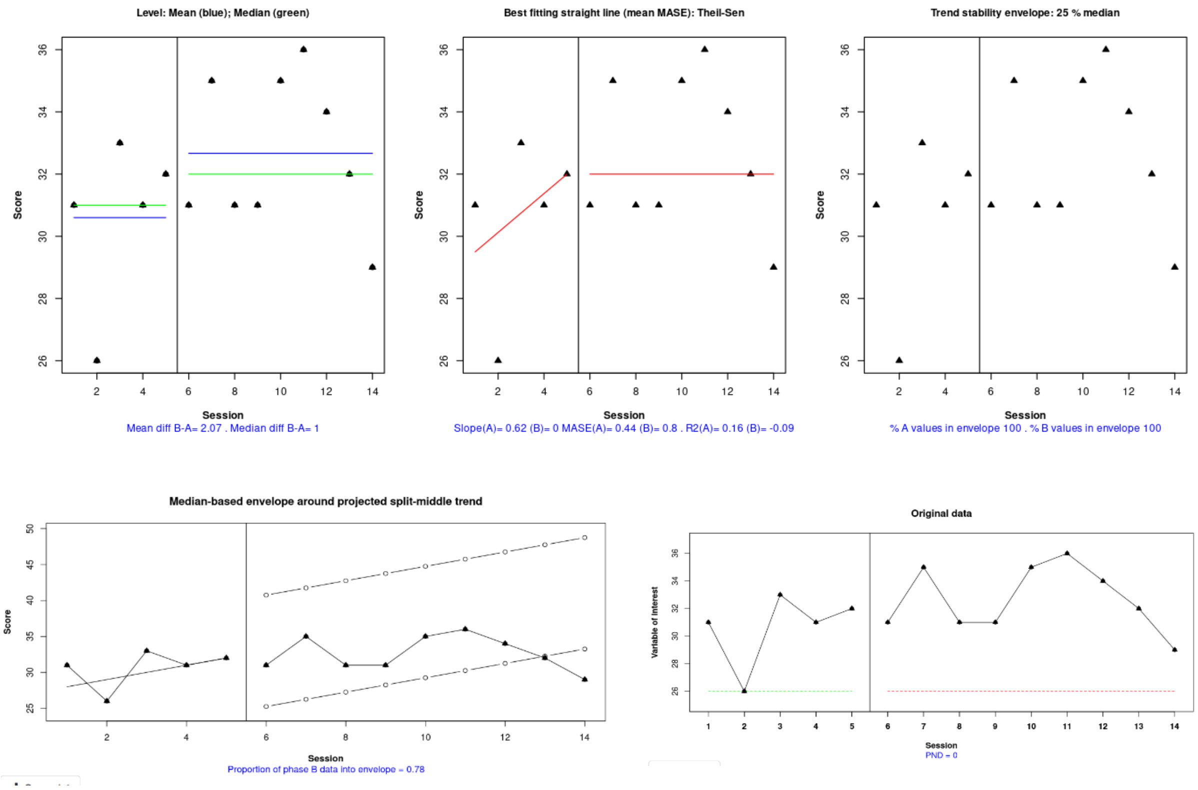
(f) Participant 6



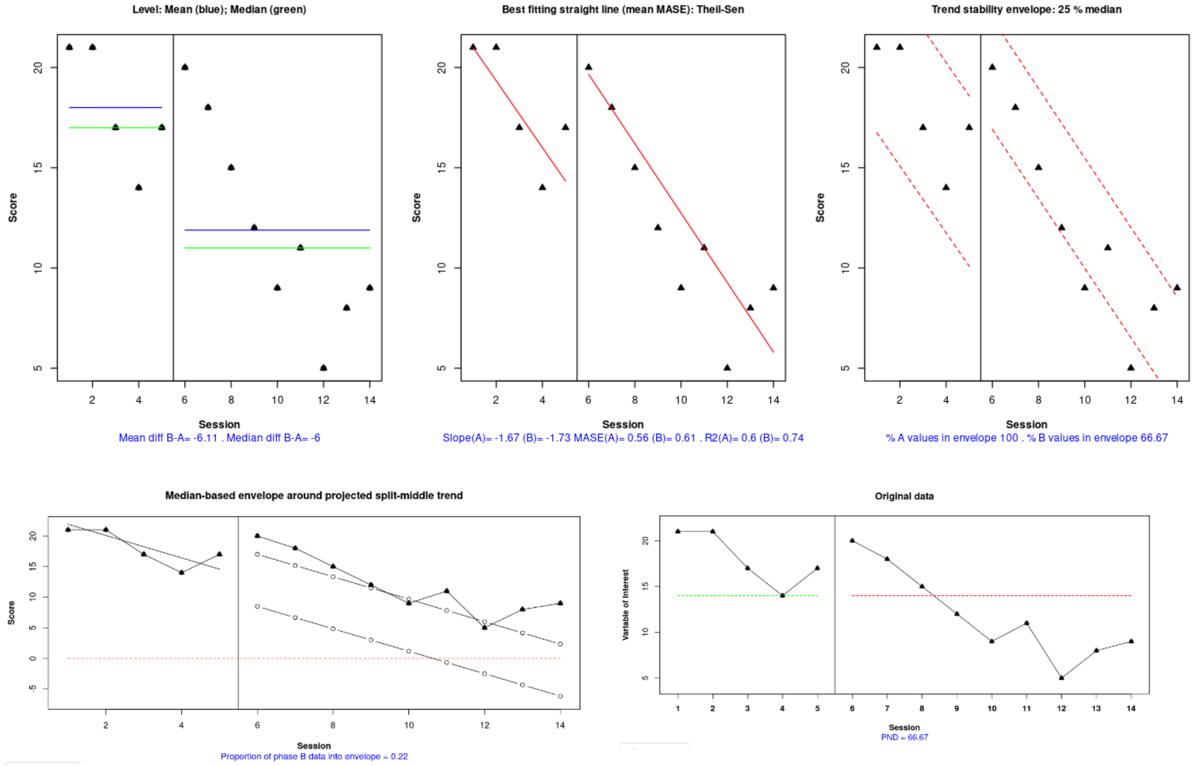
(g) Participant 7



(h) Participant 8



(i) Participant 9



(j) Participant 10

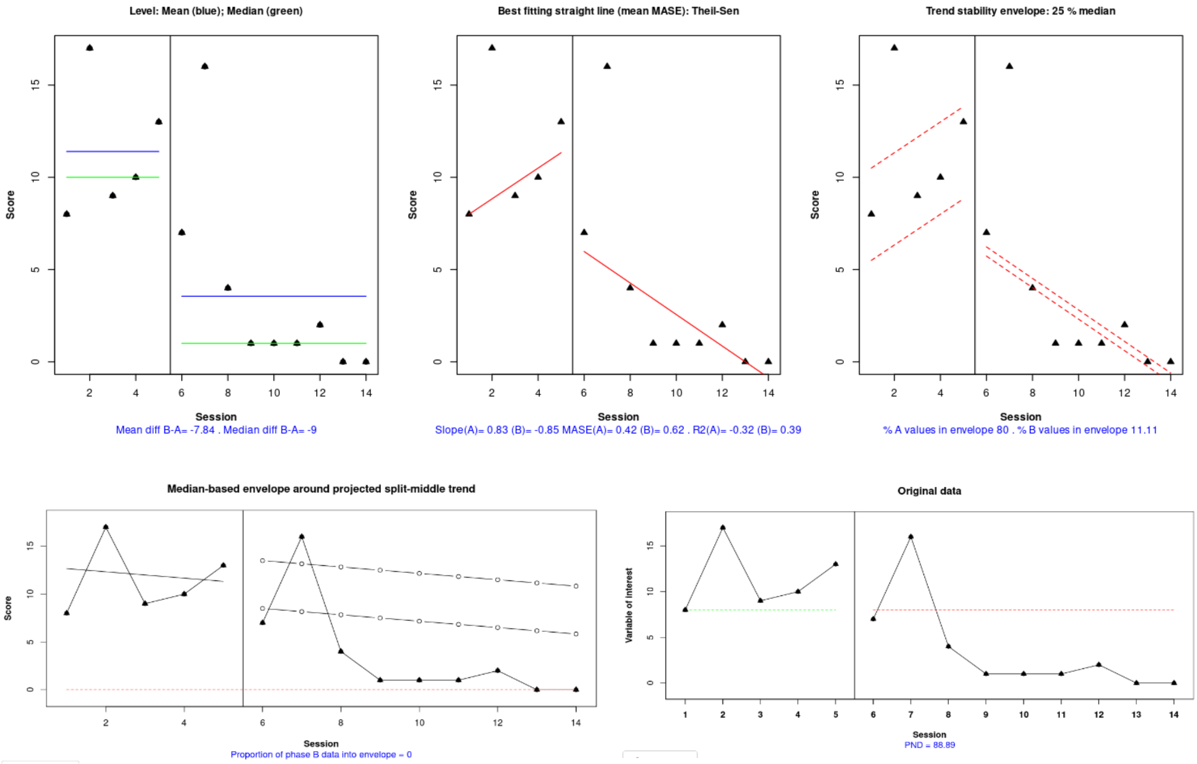


Table S1. Individual ChOCI-R-P symptom scores classification of “clear”, “possible” and “little-to-no” effects

ID	Classification	Rationale
1	Little-to-no effect	Stable improving baseline trend; stable improving treatment trend (although at a slower overall rate than the baseline trend); limited change in average symptoms across (average baseline symptoms = 5.7, average treatment symptoms = 4.3); 56% non-overlapping data across phases; observed treatment values are higher than projected treatment values (although there are floor effects).
2	Possible effect	Stable improving baseline trend; variable improving treatment trend (although at a slower overall rate than the baseline trend); change in average symptoms across phases (average baseline symptoms = 13, average treatment symptoms = 7); 89% non-overlapping data across phases; observed treatment values overlap with projected treatment values.
3	Little-to-no effect	Stable zero-celerating baseline trend; stable zero-celerating treatment trend; increase in average symptoms across phases (average baseline symptoms = 7.7, average treatment symptoms = 9.3); 0% non-overlapping data; observed treatment values either overlap with or are higher than the projected treatment values.
4	Possible effect	Stable improving baseline trend; variable improving treatment trend; change in average symptoms across phases (average baseline symptoms = 20.7, average treatment symptoms = 8.7); 100% non-overlapping data; observed treatment values mostly overlap with projected treatment values.
5	Clear effect	Stable deteriorating baseline trend; stable improving treatment trend; change in average symptoms across phases (average baseline symptoms = 28.3, average treatment symptoms = 18.6); 89% non-overlapping data; minimal overlap between observed and projected treatment values
6	Little-to-no effect	Variable improving baseline trend; variable improving treatment trend (although at an overall slower rate than the baseline trend); limited change in average symptoms across phases (average baseline symptoms = 4, average treatment symptoms = 1); 78% non-overlapping data; observed treatment values are higher than projected treatment values (although there are floor effects).
7	Possible effect	Variable improving baseline trend; stable improving treatment trend; change in average symptoms across phases (average baseline symptoms = 16.3, average treatment symptoms = 9.4); 100% non-overlapping data; observed treatment values overlap with projected treatment values.
8	Little-to-no effect	Stable deteriorating baseline trend; stable improving treatment trend; increase in average symptoms across phases (average baseline symptoms = 22.6, average treatment symptoms = 24.2); 0% non-overlapping data; observed treatment values overlap with projected treatment values.

9	Possible effect	Stable improving baseline trend; stable improving treatment trend (although at a slower overall rate than the baseline trend); change in average symptom scores across phases (average baseline symptoms = 15.8; average treatment symptoms = 10.8); 44% non-overlapping data; observed treatment values either overlap or are higher than projected treatment values.
10	Clear effect	Stable zero-celerating baseline trend; variable improving treatment trend; change in average symptoms across phases (average baseline symptoms = 14.8; average treatment symptoms = 8.4); 67% non-overlapping data; minimal overlap between observed and projected treatment values.

Note. ChOCI-R-P = Children's Obsessional Compulsive Inventory – Revised – Parent report.

Table S2. Individual ChOCI-R-P impairment scores classification of “clear”, “possible” and “little-to-no” effects

ID	Classification	Rationale
1	Little-to-no effect	Stable improving baseline trend; stable slightly improving treatment trend (although at a slower overall rate than the baseline trend); increase in average impairment scores across phases (average baseline impairment = 14.3, average treatment impairment = 15.0); 11% non-overlapping data across phases; observed treatment values are higher than projected treatment values (although there are floor effects).
2	Possible effect	Stable improving baseline trend; stable improving treatment trend; slight reduction in average impairment scores across phases (average baseline impairment = 37.7, average treatment impairment = 34.9); 44% non-overlapping data across phases; observed treatment values mostly overlap with projected treatment values.
3	Little-to-no effect	Stable improving baseline trend; stable improving treatment trend (although at a slower overall rate than the baseline trend); slight reduction in average impairment scores across phases (average baseline impairment = 31.3, average treatment impairment = 29.9); 33% non-overlapping data; observed treatment values either overlap with or are higher than the projected treatment values.
4	Possible effect	Stable improving baseline trend; stable improving treatment trend (at an overall faster rate than the baseline trend); reduction in average impairment scores across phases (average baseline impairment = 25.7, average treatment impairment = 16.7); 67% non-overlapping data; observed treatment values overlap with projected treatment values.
5	Clear effect	Stable slightly improving baseline trend; stable improving treatment trend (at an overall faster rate than the baseline trend; reduction in average impairment scores across phases (average baseline impairment = 28.5, average treatment impairment = 16.6); 100% non-overlapping data; minimal overlap between observed and projected treatment values.
6	Possible effect	Variable improving baseline trend; variable improving treatment trend; reduction in average impairment scores across phases (average baseline impairment = 22.5, average treatment impairment = 8.4); 78% non-overlapping data; observed treatment values are higher than predicted treatment values (although there are floor effects).
7	Possible effect	Stable improving baseline trend; stable improving treatment trend; reduction in average impairment scores across phases (average baseline impairment = 21, average treatment impairment = 13.3); 100% non-overlapping data; observed treatment values mostly overlap with projected treatment values.
8	Little-to-no effect	Stable deteriorating baseline trend; stable very slightly improving treatment trend; increase in average impairment scores across phases (average baseline impairment = 33.6, average treatment impairment = 34.1); 0% non-overlapping data; 50% of observed treatment values overlap with projected treatment values.

9	Clear effect	Stable slightly improving baseline trend; stable improving treatment trend; reduction in average impairment scores across phases (average baseline impairment = 24.6; average treatment impairment = 18.9); 67% non-overlapping data; 56% of observed treatment values overlap with projected treatment values (however the degree of overlap lessons as the treatment progresses).
10	Clear effect	Stable deteriorating baseline trend; stable improving treatment trend; reduction in average impairment across phases (average baseline impairment = 19.4; average treatment impairment = 15.4); 67% non-overlapping data; minimal overlap between observed and projected treatment values.

Note. ChOCI-R-P = Children's Obsessional Compulsive Inventory – Revised – Parent report.

Table S3. Individual FAS-PR scores classification of “clear”, “possible” and “little-to-no” effects

ID	Classification	Rationale
1	Little-to-no effect	Stable improving baseline trend; stable improving treatment trend (although at a slower overall rate than the baseline trend); slight reduction in average family accommodation scores across phases (average baseline FA = 21.7, average treatment FA = 19.3); 33% non-overlapping data across phases; observed treatment values are higher than projected treatment values (although there are floor effects).
2	Possible effect	Stable improving baseline trend; variable improving treatment trend; reduction in average family accommodation scores across phases (average baseline FA = 23.7, average treatment FA = 13.1); 89% non-overlapping data across phases; observed treatment values mostly overlap with projected treatment values.
3	Possible effect	Stable improving baseline trend; variable improving treatment trend (at a faster overall rate than the baseline trend); reduction in family accommodation across phases (average baseline FA = 19.7, average treatment FA = 13.8); 78% non-overlapping data; observed treatment values mostly overlap with projected treatment values.
4	Possible effect	Stable improving baseline trend; stable improving treatment trend (at an overall slower rate than the baseline trend); reduction in average family accommodation across phases (average baseline FA = 12.7, average treatment FA = 5.0); 56% non-overlapping data; observed treatment values are higher than projected treatment values (however there are floor effects).
5	Clear effect	Stable zero-celerating baseline trend; variable improving treatment trend; reduction in average family accommodation scores across phases (average baseline FA = 30.8, average treatment FA = 17.2); 78% non-overlapping data; minimal overlap between observed and projected treatment values
6	Little-to-no effect	Variable improving baseline trend; variable zero-celerating treatment trend; slight reduction in average family accommodation scores across phases (average baseline FA = 1.75, average treatment FA = 0.8); 0% non-overlapping data; observed treatment values are higher than projected treatment values (however, there are floor effects)
7	Little-to-no effect	Stable improving baseline trend; variable improving treatment trend (at a slower overall rate than the baseline trend); reduction in average family accommodation scores across phases (average baseline FA = 7.3, average treatment impairment = 3.6); 33% non-overlapping data; observed treatment values are higher than projected treatment values (however, there are floor effects).
8	Little-to-no effect	Stable deteriorating baseline trend; stable zero-celerating treatment trend; increase in average family accommodation scores across phases (average baseline FA= 30.6, average treatment FA = 32.7); 0% non-overlapping data; observed treatment values overlap with projected treatment values.

9	Possible effect	Stable improving baseline trend; variable improving treatment trend (at a faster rate than the baseline trend); reduction in average family accommodation scores across phases (average baseline FA = 18.0; average treatment FA = 11.9); 67% non-overlapping data; observed treatment values overlap with or are higher than projected treatment values.
10	Clear effect	Stable deteriorating baseline trend; variable improving treatment trend; reduction in average family accommodation across phases (average baseline FA = 11.4; average treatment FA = 3.6); 89% non-overlapping data; minimal overlap between observed and projected treatment values.

Note. FAS-PR = Family Accommodation Scale – Parent Report; FA = Family accommodation.

Table S4. COREQ Checklist (Tong et al., 2007)

Topic	Description
Domain 1: Research Team and Reflexivity	
Personal Characteristics:	
1. Interviewer/facilitator	1. All interviews were conducted by HN.
2. Credentials	2. HN is a University of Reading Undergraduate Student.
3. Occupation	3. HN was undertaking a year-long placement at Berkshire Healthcare NHS Foundation Trust (BHFT) when she conducted the interviews.
4. Gender	4. HN identified as female.
5. Experience and training.	5. As part of HN's role in BHFT, she had experience of working with families affected by mental health difficulties. HN did not have any formal training or qualifications in qualitative research, however CCh (who has completed Master's level training in qualitative methods and undertaken qualitative research for her doctoral thesis) conducted two training sessions with HN to familiarise HN with qualitative interviewing and the interview topic guide and to provide HN with an opportunity to practice the interview. CCh then listened to each participant interview conducted by HN and met with HN after each interview to discuss strengths of the interview and to identify areas where further probes could be used to generate richer data.
Relationship with participants:	
6. Relationship established	6. HN had not been involved in any other aspects of the study and therefore was not known to participants.
7. Participant knowledge of the interviewer	7. Participants were told that the purpose of the interview was to understand their experiences of receiving the treatment to enable the research team to improve the treatment for families in the future.
8. Interviewer characteristics.	8. Participants were made aware that HN's role in the research team was to conduct the qualitative interviews so that participants could openly discuss their views of the treatment.
Domain 2: Study Design	
Theoretical Framework:	

9. Methodological orientation and theory.	9. We used reflexive thematic analysis to analyse the data so that we could identify patterns of shared meaning across a diverse range of participants (Braun & Clarke, 2019), which, in turn, would enable us to draw conclusions regarding the acceptability of the treatment to parents and identify implications for future iterations of the treatment. *Reflexive* thematic analysis in particular was chosen as this approach values the subjectivity of the research team in the analysis and provides an opportunity for researchers to critically reflect on and consider how their experiences and expertise shape the research process (Braun & Clarke, 2019). An essentialist/realist epistemological approach to the data, whereby we assumed that language enables participants to communicate their experiences and meaning (Potter & Wetherell, 1987; Widdicombe & Wooffitt, 1995).
Participant Selection:	
10. Sampling	10. Participants for this qualitative interview study were recruited from the families who participated in the parent-led CBT intervention. All parents (n=15) who attended at least one treatment session were invited to take part in the qualitative interview, forming a pool of potential participants. We aimed to capture the views of parents whose children did and did not “respond” and/or “remit” at the one-month follow-up, and parents who attended all treatment sessions (either alone or jointly with another caregiver) versus parents who only attended some treatment sessions (i.e., parents who were not the primary parent participating in the study), as it was anticipated that these variables may influence parents’ experiences and views. Owing to the small scale nature of the treatment study, we therefore invited all parents in the pool to participate in the qualitative interview to capture diversity in parents’ experiences and views.
11. Method of approach	11. The study clinician (CCh) introduced the optional interview to parents during the final feedback appointment of the study (i.e., where the clinician provided information on the child’s treatment outcomes and made recommendations for further support if necessary) and emailed interested parents a link to the study information and consent form. CCh then sent follow-up emails and/or telephoned interested parents who did not complete the study consent forms to see if parents had any questions and/or were still interested in participating in the interview.

12. Sample size	12. All fifteen parents were sent the link to access information about the interview and consent forms. Eleven parents provided informed consent to participate in the interview and ten parents (6 mothers, 4 fathers) of eight children participated in the interview. Where more than one parent of a child agreed to participate in the interview, parents had the option to complete the interview together, or separately. Where this was the case, all parents opted to complete the interview together.
13. Non-participation.	13. One parent was unable to attend the scheduled interview with her partner due to childcare difficulties and declined to participate in a re-scheduled interview. Four other potential participants declined to participate and/or did not respond to follow-up emails/telephone calls.
Setting:	
14. Setting of data collection	14. All interviews were conducted remotely via Microsoft Teams or telephone.
15. Presence of non-participants	15. Only HN and the participating parent(s) were present for the interviews.
16. Description of the sample.	16. Demographic characteristics of the sample are shown in Table S4.
Data collection:	
17. Interview guide	17. A topic guide was developed based on relevant previous research (e.g., Reardon et al., 2022) and the team's clinical expertise and broadly explored (i) parents' initial views of the treatment approach, (ii) parents' experiences of receiving the treatment, (iii) parents' views about the mode, content, and structure of the treatment, and (iv) parents' overall views about the treatment. Individual questions were refined following Public and Patient Involvement (PPI) feedback from 2 parents of a child with OCD and UK-based OCD charity representatives to maximise the acceptability of the questions to participating parents.
18. Repeat interviews	18. Interviews were conducted once with each parent(s).
19. Audio/visual recording	19. Interviews were audio and/or video-recorded on Microsoft Teams and automatically transcribed by Microsoft Teams.
20. Field notes	20. CCh made field notes whilst reviewing each interview.
21. Duration	21. Interviews lasted an average of 48 minutes (range 34 – 59 minutes).
22. Data saturation	22. It is argued that data saturation is not as a useful concept for defining sample size in reflexive thematic analysis, as this approach emphasises the active role of the researcher in generating shared patterns of meaning across the dataset (and thus, different interpretations of the data are always possible, Braun & Clarke, 2021).

23. Transcripts returned.	23. Transcripts were not returned to participants.
Domain 3: Analysis and Findings	
Data analysis:	
24. Number of data coders	24. CCh led the analysis of the interview data and met regularly with the wider research team (KH, CCr, BH) to aid an interpretative approach to data analysis and to consider other possible interpretations of the data.
25. Description of coding tree	25. The six-stages of data analysis outlined by Braun and Clarke (2022) were followed and thus, a coding tree was not provided.
26. Derivation of themes	26. The data was coded inductively (i.e., data driven) and codes were continually reviewed and refined as further interviews were coded.
27. Software	27. Data were stored and analysed using NVivo.
28. Participant checking.	28. Participants were not provided with an opportunity to give feedback on the findings but were given the option of receiving a summary of the study results.
Reporting:	
29. Quotations presented	29. Illustrative participant quotes were presented for each theme (see Table 5).
30. Data and findings consistent	30. Participant quotes were used to provide evidence of each theme (see Table 5).
31. Clarity of major themes	31. Major themes were presented visually using a thematic map.
32. Clarity of minor themes.	32. Diverse and discrepant data among participants was reported.

References for supplementary analyses

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Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, *13*(2), 201–216. https://doi.org/10.1080/2159676X.2019.1704846

Braun, V., & Clarke, V. (2022). *Thematic Analysis A Practical Guide*. SAGE Publications.

Potter, J., & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behaviour.* SAGE Publications.

Reardon, T., Dodd, H., Hill, C., Jasper, B., Lawrence, P. J., Morgan, F., Rapee, R. M., Ukoumunne, O. C., Violato, M., Davey, E., Halliday, G., Jones, B., Martineau, L., McCall, A., Niekamp, N., Placzek, A., Potts, R., Weisser, T., & Creswell, C. (2022). Minimising young children's anxiety through schools (MY-CATS): Protocol for a cluster randomised controlled trial to evaluate the effectiveness and cost-effectiveness of an online parent-led intervention compared with usual school practice for young children identified as at risk for anxiety disorders. *Trials*, *23*(1), 149. https://doi.org/10.1186/s13063-022-06010-8

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Widdicombe, S., & Wooffitt, R. (1995). *The language of youth subcultures: Social identify in action*. Harvester Wheatsheaf.

5.4 Further information on methodological decision making

Due to word limit constraints of journals, in this section I will present additional information regarding methodological decision making for the case series paper here.

I decided to use a non-concurrent multiple baseline approach to evaluate the preliminary efficacy of this treatment, as this approach is a critical first step in evaluating the feasibility, efficacy, and effectiveness of novel interventions (Chambless & Ollendick, 2001; Horner et al., 2005; Morgan, 2009). Multiple baseline approaches are also more cost and time effective than Randomised Controlled Trials (RCTs) and offer greater internal validity (e.g., control for maturation and history) than pre-post intervention designs (Tate et al., 2016). Despite these advantages, there is large variability in how single case experimental designs (SCEDs) are designed and analysed. For example, I opted to have a minimum of three data points per phase. Although this is sufficient for the design to ‘meet standards with reservations’, a minimum of five data points per phase is necessary to ‘meet standards without reservations’ (Kratchowill et al., 2010). Despite this, I opted to use ≥3 data points per phase to balance the need between having sufficient baseline data to conduct a visual analysis and the ethical concerns of withholding treatment from participants for longer periods of time (Kazdin, 2019). Similarly, given that there is no consensus on recommended effect sizes for SCEDs (Kratchowill et al., 2010; Kazdin et al., 2021), I considered a range of possible effect sizes for this study, including non-overlapping pair indices (e.g., Non-overlap of all pairs [NAP] and TAU-U). Although NAP and TAU-U have been specifically designed for SCEDs (Parker et al., 2011), these indices are not without limitations, and are heavily influenced by characteristics of study designs (e.g., number of baseline observations, type of observations; Pustejovsky, 2016; Chen et al., 2016), making comparisons across studies difficult (Barton et al., 2019). I therefore chose to use Cohen’s d, as although this index also has limitations for use in SCEDs (see Paper 3 for a further discussion of this), this effect size is more easily comparable with the outcomes of between-groups research.

I conducted diagnostic interviews with parents to determine their families' eligibility for the study. I decided to determine eligibility based on parent-report only (rather than combined parent and child report) as international consensus guidelines recommend prioritising parent-report for preadolescent children with anxiety disorders (Krause et al., 2021) and to reduce the time burden for ineligible families. However, some parents found it challenging to answer questions assessing their child's possible obsessions – thus, myself and CCr (who provided clinical supervision for parent-reported diagnostic assessments) may have failed to identify OCD in some cases. Rapp et al. (2016) highlight the importance of combined parent and child report in the assessment of childhood OCD, stating that parents are typically superior informants of overt compulsions, accommodation, and/or symptom impairment, whereas children are typically superior informants of obsessions and impairment outside of the home. Thus, future research may benefit from combined parent-child report (in cases where parents are unaware of their child's obsessions) to determine study eligibility.

I included a number of measures to evaluate the outcomes of the treatment, including the Family Accommodation Scale – Parent Report (FAS-PR, Flessner et al., 2011). I decided to routinely track family accommodation as our treatment protocol provided psychoeducation on family accommodation and alternative responses to family accommodation, in light of qualitative research highlighting the challenges that parents' experience in knowing whether or not to accommodate their child's OCD (Chessell et al., 2022). Furthermore, family accommodation has been proposed to have a key role in the maintenance of childhood OCD (Waters & Barrett, 2000) – thus, this was deemed important to assess as part of this treatment study. Interestingly, individual family accommodation scores appeared to align with individual OCD symptom and impairment scores across the treatment. For example, increases in OCD symptom/impairment scores at a given treatment session often corresponded with increases in family accommodation scores at the same time point. Despite this, it was not clear whether changes in family accommodation preceded changes in OCD symptoms/impairment or vice versa, and future research should examine whether family accommodation mediates treatment outcomes.

Finally, when I first wrote our study protocol (see Chessell et al., 2021), I intended to include parents' responses to open-ended questions in the post-treatment questionnaires in our qualitative analyses. However, parents' responses to these open-ended questions were often limited, and comparisons between participants' questionnaire and interview responses did not add any new information beyond what was discussed (in more detail) in the qualitative interviews. I therefore did not include these responses in our qualitative analyses, however used the responses (where necessary) to provide further information on why one parent may have 'neither agreed nor disagreed' with particular statements on the questionnaire. This decision meant that the views of two parents (one father who attended half of the treatment sessions with the primary participating parent, and one mother who attended all treatment sessions with her partner present for three treatment sessions) who completed the post-treatment questionnaire and did not participate in the qualitative interview were not explicitly represented in the qualitative analyses.

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Chapter 6: In-depth exploration of parents' experiences and acceptability of therapist guided, parent-led CBT for preadolescent children with OCD.

6.1 Introduction to Chapter 6

In Chapter 5 (Paper 3), I outlined the results of a preliminary evaluation of the efficacy and acceptability of therapist guided, parent-led CBT for preadolescent children with OCD. Due to the constraints of journal articles, I was unable to provide detailed information on the qualitative work conducted as part of this study which explored parents' experiences and acceptability of the treatment. Given that treatment acceptability is crucial when developing first-line interventions (Bower & Gilbody, 2005), in Chapter 6, I provide an in-depth account of the methodology, results, and implications of this qualitative work for future iterations of the treatment.

6.2 Overview

This chapter provides a detailed account of parents' experiences and acceptability of the therapist guided, parent-led CBT intervention for preadolescent children with OCD. Understanding parents' experiences and acceptability of the intervention is crucial, given that parents are "gate-keepers" to their child accessing mental health support (Stiffman et al., 2004) and have a key role in deciding on their child's mental health treatment (Lewin et al., 2014). Furthermore, Bower and Gilbody (2005) state the importance of ensuring treatment acceptability when developing first-line interventions, as it has been suggested that interventions that are acceptable to users are more likely to result in improved treatment adherence and outcomes (Galea et al., 2022).

Qualitative interviews offer a valuable method to explore parents' experiences and acceptability of an intervention, as these interviews have been suggested to facilitate greater reflection from participants compared to brief post-treatment questionnaires (McLeod, 2011). Moreover, qualitative interviews can facilitate the collection of rich, complex data, as the interviewer can probe participants' responses to gain a deeper understanding of their experiences (Smith, 2015). This data can also be integrated with quantitative treatment outcomes to provide a greater understanding of the 'real world' impact of an intervention to individuals' lives (Johnson & Schoonenboom, 2016), to help understand the reasons why some individuals may or may not benefit from an intervention (Richards et al., 2019; Johnson & Schoonenboom, 2016), and to facilitate future iterations of an intervention (Dorgan et al., 2022; Davis et al., 2019).

This chapter therefore provides an in-depth exploration of parents' experiences and acceptability of the therapist guided, parent-led CBT intervention through a detailed discussion of the methods and analysis of eight qualitative interviews that were conducted with 10 parents who participated in the treatment study.

6.3 Method

The information presented in this chapter is reported in line with the COREQ checklist (Tong et al., 2007).

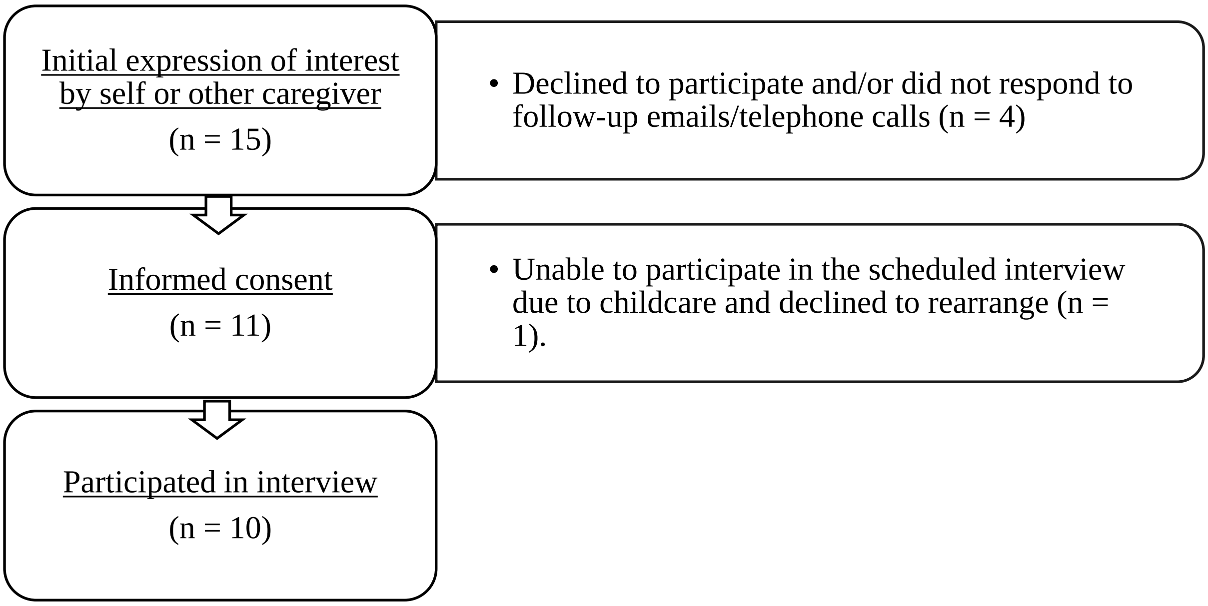
Recruitment and participants

Participants for this qualitative interview study were recruited from the families who participated in the therapist guided, parent-led CBT treatment study (Chapter 5). Further information on the original sources of participant recruitment can be found in Chapter 5. All parents (n = 15) who attended at least one treatment session were invited to take part in the qualitative interview study, forming a pool of potential participants. We aimed to capture the views of parents whose children did and did not “respond” and/or “remit” at the one-month follow-up, and parents who attended all treatment sessions (either alone or jointly with another caregiver) versus parents who only attended some treatment sessions (i.e., parents who were not the primary parent participating in the study), as it was anticipated that these variables may influence parents’ experiences and views. Owing to the small scale nature of the treatment study, we therefore invited all parents in the pool to participate in the qualitative interview to capture diversity in parents’ experiences and views.

The study clinician (CCh) introduced the optional interview to potential participants during the final feedback appointment of the study (i.e., where the clinician provided information on the child’s treatment outcomes and made recommendations for further support if necessary). If potential participants expressed an interest in the interview, the study clinician emailed the parent(s) a link to the study information and consent forms. If only one parent (from a family where two parents had attended at least one treatment session) was present during the final feedback appointment, and this parent expressed an interest in the interview, then the study clinician emailed both of the parents a link to the study information and consent forms. The study clinician sent follow-up emails and/or telephoned interested parents who did not complete the study consent forms to see if parents had any questions and/or were still interested in participating in the interview. The recruitment of participants is shown in Figure 1.

Eleven parents provided informed consent to participate in the qualitative interview, however, one parent was unable to attend the scheduled interview with her partner due to childcare difficulties and declined to participate in a re-scheduled interview. Thus, the final sample consisted of 10 parents (6 mothers, 4 fathers) of eight children (see Table 1 for participant characteristics). Parents who participated in the qualitative interview study (and their children) were predominantly White British (n = 9 and n= 6, respectively), however, one parent identified as British Indian, one child was identified by their parent as White and Asian, and one child was identified by their parent as White and Black African. Of the five potential participants (n = 3 mothers, n = 2 fathers) who did not provide informed consent and/or declined to participate in the interview, demographic data was only available for two of the mothers. The demographic characteristics of one mother (aged 40 – 49 years, White British, with an undergraduate degree) were reflected in the interviewed sample, however, the demographic characteristics of the other mother (aged 30 – 39 years, White British, and school completer) were less well reflected in the interviewed sample.

Figure 1. Recruitment of participants.



Measures

Demographic Questions. Parents who provided informed consent to participate in the interview and had not completed information regarding their demographics as part of the treatment study were asked to complete relevant demographic questions. This included parental age, gender, relationship to their child, caregiver status (i.e., primary, secondary, shared caregiver, or other), parental relationship status (i.e., single, married, remarried, divorced, separated, living with partner, widowed, or not applicable), parental education status (i.e., school completion, further education, higher education, or postgraduate qualification), parental employment status (i.e., unemployed, employed full-time or part-time or other), and self-reported ethnicity (in accordance with the categories outlined by the Office for National Statistics, 2022), as it was anticipated that these demographic factors may impact parents' experiences and acceptability of the treatment.

Procedure

A topic guide was developed based on relevant previous research (e.g., Reardon et al., 2022) and the team's clinical expertise. It was refined following Public and Patient Involvement (PPI) feedback from 2 parents of a child with OCD and an OCD-UK charity representative to maximise the acceptability of the interview questions to participating parents. The topic guide broadly explored (i) parents' initial views of the treatment approach, (ii) parents' experiences of receiving the treatment, (iii) parents' views about the mode, content, and structure of the treatment, and (iv) parents' overall views about the treatment.

The interviews were conducted by HN who is a female University of Reading Undergraduate Student undertaking a year-long placement at Berkshire Healthcare NHS Foundation Trust (BHFT) and who had not been involved in any other aspects of the study and therefore was not known to participants. As part of HN's role in BHFT, she had experience of working with families affected by mental health difficulties. HN did not have any formal training or qualifications in qualitative research, however CCh (who has completed Master's level training in qualitative methods and undertaken qualitative research for her doctoral thesis) conducted two training sessions with HN to provide HN with information on qualitative methods, semi-structured interviews, the key skills needed for conducting semi-structured interviews, an overview of the interview topic guide, examples of previous qualitative interviews, and the opportunity to conduct practice interviews with CCh. CCh also listened to each interview conducted by HN and met with HN after each interview to discuss strengths of the interview and to identify areas where further probes could be used to generate richer data.

All interviews were conducted remotely via Microsoft Teams or telephone with only HN and the participating parent(s) present. Participants were told that the interviews aimed to understand their experiences of receiving the treatment to enable the research team to improve the treatment for families in the future. Where more than one parent of a child agreed to participate in the interview, parents had the option to complete the interview together, or separately. Where this was the case, all parents opted to complete the interview together. On average, interviews were 48 minutes in length (range 34 – 59 minutes) and all interviews were video and/or audio-recorded and automatically transcribed by Microsoft Teams. CCh listened to each interview and corrected the auto-transcription where necessary. All participants received a £20 voucher for participating in the interview.

Table 1. Participant Characteristics

Child	
N	8
Mean age (range), years	11.0 (10 – 12)
Female, n (%)	5 (62.5)
Ethnicity[a]	
White British, n (%)	6 (75)
Mixed background, n (%)	2 (25)
Treatment “responder” at one-month follow-up (i.e., ≥35% reduction on the CY-BOCS), n (%)	3 (37.5)
Treatment “remitter” at one-month follow-up (i.e., no longer meeting DSM-5 criteria for OCD on the ADIS-P), n (%)	3 (37.5)
Parent	
N	10
Mean age (range), years[b]	46.0 (41 – 52)
Mother, n (%)	6 (60)
Ethnicity	
White British, n (%)	9 (90)
Asian background, n (%)	1 (10)
Caregiving role	
Primary caregiver, n (%)	5 (50)
Secondary caregiver, n (%)	0 (0)
Shared caregiver, n (%)	5 (50)
Parent relationship status	
Married, n (%)	8 (80)
Living with partner, n (%)	1 (10)
Separated, n (%)	1 (10)
Parent education	
School completion, n (%)	0 (0)
Further education (e.g., college, vocational courses), n (%)	1 (10)
Higher education (e.g., undergraduate degree), n (%)	6 (60)
Postgraduate education, n (%)	3 (30)
Parent employment status	
Unemployed, n (%)	1 (10)
Employed (part-time), n (%)	2 (20)
Employed (full-time), n (%)	4 (40)
Employed (part-time/full-time not stated), n (%)	2 (20)
Other (self-employed), n (%)	1 (10)
Treatment attendance	
One parent attended all treatment sessions alone	4 (40)
Two parents attended one or more treatment sessions together	6 (60)

Note. [a] Ethnicity categories taken from Office for National Statistics (2022). [b] Data missing for one female participant.

Data analysis

We used reflexive thematic analysis to analyse the data obtained from the semi-structured interviews and adopted an essentialist/realist epistemological approach to the data, whereby we assumed that language enables participants to communicate their experiences and meaning (Potter & Wetherell, 1987; Widdicombe & Wooffitt, 1995). We used thematic analysis so that we could identify patterns of shared meaning across a diverse range of participants (Braun & Clarke, 2019), which, in turn, would enable us to draw conclusions regarding the acceptability of the treatment to parents and identify implications for future iterations of the treatment. *Reflexive* thematic analysis in particular was chosen as this approach values the subjectivity of the research team in the analysis and provides an opportunity for researchers to critically reflect on and consider how their experiences and expertise shape the research process (Braun & Clarke, 2019).

This study formed part of CCh's doctoral research which aimed to increase access to CBT for preadolescent children with OCD. Three members of the research team have experience of delivering CBT to families affected by mental health problems, particularly delivering therapist guided, parent-led CBT approaches – CCh in her role as an Honorary Psychological Wellbeing Practitioner (PWP) and Professor Cathy Creswell and Dr Brynjar Halldorsson in their roles as Clinical Psychologists. The original therapist guided, parent-led CBT intervention (on which the adapted version was based) was developed by CCr, and CCr, BH, and CCh all contributed to the adapted version of the treatment. Given that CCh, CCr, and BH have considerable experience and investment in delivering parent-led treatments to families, Professor Kate Harvey (KH) contributed to the study design and analysis as KH is not a clinician and has not contributed to the development of the treatment. KH, CCr, and BH also have considerable qualitative expertise.

CCh led the analysis of the interview data and engaged in the six-stages of data analysis outlined by Braun and Clarke (2022). Analysis began with data familiarisation, whereby CCh engaged in repeated listening and reading of the interview transcripts. CCh then generated initial codes using an inductive (i.e., data driven) approach and continually reviewed and refined these codes as further interviews were coded. CCh discussed initial codes with the wider research team to aid an interpretative approach to data analysis. Codes were then combined to form initial themes which were refined by examining the coded data within each theme and by re-reading the entire dataset. The generation of initial themes was an iterative process, whereby CCh met regularly with the research team to discuss patterns of meaning within the dataset and to consider other possible interpretations of the data. Themes were then defined and named, and a final report was written. Data were stored and analysed using NVivo (Version 12.0, Bazeley & Jackson, 2013).

6.4 Results

A thematic map is shown in Figure 1. We present the thematic map as a CBT ‘hot cross bun’ model (Greenberger & Padesky, 1995) to demonstrate the interlocking relationships between each of the themes. This representation will be discussed in further detail after the presentation of each theme. To facilitate interpretation of the data, Table 2 presents individual participant characteristics. Key implications from the qualitative analysis for future iterations of this treatment are shown in Table 3. Implications are colour coded as follows: green = rationale for keeping the treatment component as it is; purple = considerations to be aware of when next delivering the treatment; red = treatment component needs adjusting for future iterations of the treatment.

Figure 1. Thematic Map

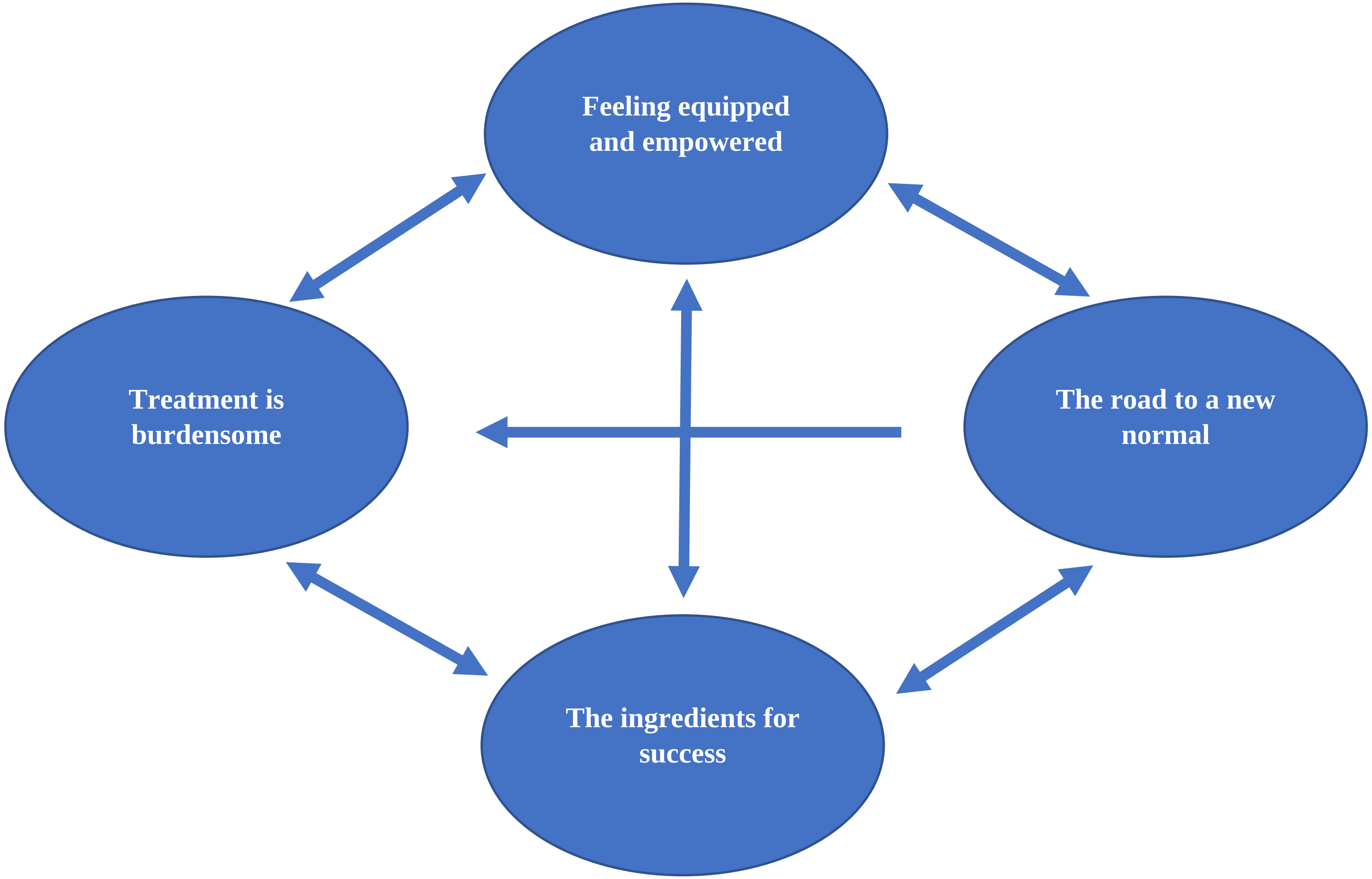


Table 2. Individual participant characteristics

Child ID	Parent ID	Child Age (at intake, years)	Child Gender	Child 'responder' status at one-month follow-up	Child 'remitter' status at one-month follow-up	Parent Gender	Parent Age (years)	Attended treatment alone vs. jointly with another caregiver[1]
1	1	11 - 12	Male	Non-responder	Non-remitter	Male	40 - 49	Alone
2	2a	5 - 10	Female	Non-responder	Non-remitter	Female	40 - 49	Jointly
	2b					Male	40 - 49	Jointly
3	3a	5 - 10	Female	Responder	Non-remitter	Female	40 - 49	Jointly
	3b					Male	40 - 49	Jointly
5	5	11 - 12	Female	Responder	Remitter	Female	40 - 49	Alone
6	6	11 - 12	Male	Responder	Remitter	Male	40 - 49	Jointly
7	7	11 - 12	Female	Non-responder	Non-remitter	Female	40 - 49	Alone
8	8	11 - 12	Male	Non-responder	Non-remitter	Female	Missing	Alone
9	9	5 - 10	Female	Non-responder	Remitter	Female	50 - 59	Jointly

Note. To preserve anonymity, parent and child age are presented as ranges, and parent and child ethnicity are not reported; Where two parents of the same child participated in the qualitative interview, mothers are indicated by ‘a’ and fathers are indicated by ‘b’; ‘Responder’ = ≥35% reduction in Children’s Yale Brown Obsessive Compulsive Scale (CY-BOCS) scores; ‘Remitter’ = no longer meeting diagnostic criteria on the Anxiety Disorder Interview Schedule – Parent Report (ADIS-P); [1]Jointly with another caregiver refers to families where one parent attended all treatment sessions and another parent jointly attended one or more treatment sessions.

Theme 1: Feeling equipped and empowered

Before starting the treatment, over half of participating parents had initial concerns about the treatment approach. Many parents felt ill-equipped to engage in a parent-led treatment *"I didn't think that the approach was wrong, I just worried that I wouldn't be good enough to do it" [ID3A, mother]* as this type of treatment *"wouldn't be something I would normally go for, especially on behalf of my child" [ID2A, mother]*. Parents described how they felt overwhelmed and *"really emotional about it [the child's difficulties] all" [ID3A, mother]* before starting treatment and had concerns regarding the efficacy of the approach *"um to be honest, I just thought, this is never gonna work [laughs] um and it felt like a steep hill that I had, that we had to climb" [ID5, mother].*

Despite this, parents were invested in supporting their child and viewed the parent-led approach as an opportunity to gain knowledge and skills, at a time when many were struggling to access any professional support.

"Well, with an elder child having experienced some issues and we tried to go through CAMHS in lockdown, it was a pretty pointless exercise, waiting list, lack of resource facilities, etc. so ... we just thought great, it's [the treatment] a free resource, you're getting lots of attention ... so it's just a question of getting as much exposure to it so I can build my understanding, and try and help alleviate the situation" [ID1, father]

Through engaging in the treatment, parents described feeling increasingly equipped and empowered (both practically and emotionally) to support their child now, and in the future.

"It really helps with your parental resilience, you know, so when you encounter these situations further down the line, you feel more resilient, you feel more able to calm the situation down" [ID2A, mother]

"but if ever something happens like she's had a bad day at school or I do notice that she's started doing something [i.e., a compulsion], I feel much more confident in having a calm and open conversation with her about it. And I'm confident that I will be able to say to her if ever we need to implement these techniques again, we can work together to do it." [ID7, mother]

Furthermore, parents increasingly recognised their powerful role in being able to bring about positive change for their child and became confident to adapt the treatment techniques to best suit their child's needs.

"yeah, 'cause obviously there's the the step-by-step ladder was was broken down, but we we just recognized as we were doing it, that some of the steps on the ladder just need to be broken down [M: Yeah] you know further so ... M: .... that again, was one of the benefits of being parent-led was because we could break it down without having to wait to go back to therapist and say is it OK?" [ID3A/B, mother and father]

Moreover, parents felt that the treatment provided them with a *"real structure" [ID2B, father]* and was *"about the right length" [ID2B, father]* to develop skills and confidence to support their child. The straightforward nature of the treatment also facilitated parents feeling equipped and empowered, with all parents identifying that the treatment concepts, reading materials, and/or explanations from the therapist were clear and easy to understand.

"I'd say it was a really, um positive and practical and quite straightforward... because I mean none of it's really that complicated, which I think is the beauty of it, is that it's just getting the basic premise of of what you're trying to do with your child, which is to support them through facing their fears and um testing that out and getting them to

understand that what's happened when you have tested it. I think it's all it's it's something that anybody can do." [ID9, mother]

"Yeah, I really enjoyed them [the reading materials]. They were very easy to understand. They were, you know, well written. Nothing too complicated." [ID7, mother]

However, the extent to which parents felt equipped and empowered to support their child by the end of the treatment varied. While most parents felt confident to use ERP techniques to help their child to overcome OCD (and in some cases, other related difficulties) a minority only felt equipped to talk to their child about OCD and were hesitant in their ability to implement Exposure and Response Prevention (ERP) techniques.

"but the thing is, we, we're confident, we're confident with where we're going, we know we've got the tools to do it" [ID2B, father]

"I think that's when I felt the panic [when implementing the first step of the step-by-step plan], because my son was like, "I've got hundreds [of compulsions], what are you gonna do?"." [ID8, mother]

Among the minority of parents who felt less equipped and empowered to implement ERP techniques, they perceived their own performance in treatment as inadequate *"I, probably, haven't quite followed the steps maybe as or as methodically as I should have done, but it's just hard" [ID1, father]* and/or felt *"out of my depth" [ID8, mother]* to help their child with their difficulties. This sense of feeling minimally equipped and empowered appeared to be related to difficulties engaging their child in the treatment techniques. This sense of inadequacy was less of a feature of interviews with parents who did feel empowered.

Theme 2: The road to a new normal

Parents' experiences of the treatment often evoked a sense of each family being on a road to a new normal. As part of this journey, parents felt that the treatment had helped their child to feel increasingly understood and accepted and had enabled their child to increase their awareness of OCD.

"I think now she doesn't feel quite so isolated and odd … with how she sees things and and understand situations and, um, worries about things, so … that's helpful, absolutely kind of, fundamentally helpful, I think to how she sees herself. So that's that's a really good thing." [ID9, mother]

"yeah, so part of the research process … was around supporting my son to name it, and he decided to just call it OCD [laughs], um so that was helpful because then it would, it gave us, him in particular an opportunity to recognize it wasn't him. So some of these intrusive thoughts that, he wasn't sharing with anyone, he was keeping to himself, but were really distressing for him, now he had the language to say and now he does say sometimes, "I think this is my OCD", and that was really powerful". [ID8, mother]

Moreover, as part of this journey, many families experienced positive change, including a reduction in their child's OCD symptoms, and a feeling that they had *"got our old [child's name] back, so it's amazing" [ID2B, father].* Wider positive changes for the family were also reported by many participating parents, with parents identifying improved parent-child relationships, improved relationships with siblings, and increased freedom for the whole family.

"yeah, I mean first of all it's made a big difference to to to [child's name] and her anxieties … she's able to, uh, do a lot more than she used to be able to, you know, so there's a lot of things that she just wasn't able to touch. You know touching things is not an issue anymore, is at all? [M: No, and she just she wasn't happy. You know she wasn't laughing.

She wasn't enjoying things. Or if she did it was only for a little bit of time. And you know, since [the treatment] … we've really noticed her laughing a lot more, she's playing with her [sibling] a lot more and just not squirreling herself away in her room … so the benefits to her have been immense].” [ID3A/B, mother and father]

“so, I think it [the treatment] has slightly evolved and developed our relationship into potentially a more um constructive and positive one, that will be helpful going forward” [ID9, mother]

“we're now talking about planning holidays again and all those sorts of things” [ID2A, mother]

However, the road to a new normal was not linear for many families, with around half of participating parents identifying fluctuating progress when supporting their child to overcome OCD.

“there was a couple of weeks again, as I say, I went backwards and I felt like we'd almost started again and I just thought this is, you know, when, we’re never, I'm never gonna get this done, but it's like every time we went backwards we went six steps forwards afterwards” [ID5, mother]

Furthermore, at the end of the treatment, some families were further along their journey to a new normal than others. A minority of parents could be perceived as nearer the start of their journey, as these parents reported limited improvements in their child’s symptoms *“but it we need to see improvements [I: yeah] in the behaviour and you know, a relaxing of his attitude, and then you know be more tolerant to incidents that trigger him. But we're not there yet, so I can't say it's been a benefit to know more about it until we've, push forward” [ID1, father]*. However, the majority of parents could be perceived as well on their way to a new normal, despite many parents identifying persisting difficulties that their child still needed to overcome *"I mean it's still, it's still lingering, um, um, yeah it's still popping its head up every now and again his OCD, but nothing like it was." [ID6, father]*

Theme 3: Treatment is burdensome

Subtheme: Treatment as an additional responsibility

Despite most parents describing a *"positive experience" [ID7, mother]* of the treatment, around half of parents perceived the treatment to be an additional burden on their life. This was particularly the case for parents who had other children (in some cases with mental health difficulties themselves), additional family responsibilities, or where there was only one parent implementing the treatment approach.

"I found it really hard, cause having another child as well, and my [family member] was diagnosed with [medical illness] as well while this treatment was going on … and obviously both the children are really anxious, as it is, so there was a lot happening um, and like I said, school was really hard as well, so [child's name] was coming home from school and having massive meltdowns and it was quite a challenging, period." [ID8, mother]

Perceiving the treatment as burdensome meant that some parents experienced fluctuations in their ability to engage in, and implement, the treatment techniques, which in turn, led to a minority of parents blaming themselves for not investing enough time in the treatment and/or feeling frustrated by the demands of treatment. In the latter case, this frustration meant that one parent had a preference for individual child support (rather than a parent-led approach).

"I mean, time just gets in the way. I mean, it's school runs, it's this, it's that. The pinch points in, with the OCD are always coming when you're, as I said, said [therapist name], it's always when you're time constrained. So you're trying to get out of the house in the morning

to get the school bus or something like that, so you don't have time to put in a process and sit down there and discuss things rationally, right? It doesn't work like that". [ID1, father]

"so there was certainly no one trying to put guilt on me about anything ... it's just one of those, parent things, where you're juggling lots of stuff and feel that you, can't fully do anything, you know, to its full potential sometimes, and I didn't want to waste the experience, so I did really want to, um, you know give everything a go as much as we could" [ID9, mother]

Furthermore, although most parents identified that the weekly questionnaires were useful and relatively quick to complete, parents often viewed them as adding to the demands of the treatment approach.

"and obviously there was all the surveys ... so that felt like quite well, gosh, yeah, I must do the questionnaires. I must do the, you know, the, to get those done. And again, it's just time really." [ID9, mother]

Subtheme: The demands of engaging the child

All parents described difficulties engaging their child in the treatment. Parents often perceived their child as resistant to engaging in the treatment – for example, some parents felt their child was resistant to 'letting go' of OCD, described their child's difficulties (or refusal) to talk about OCD, and/or described difficulties encouraging their child to engage in ERP tasks.

"but we've reached this impasse and this is the problem, he doesn't want to change, "I can't be bothered changing", "we'll don't you think it'll be beneficial to..." "yeah, but I don't want to". You just can't engage him." [ID1, father]

"I mean [child's name] was very reluctant um, to do the work it was, it was just hard just to get her to sit down to start to talk about how we would progress each week. So, I mean that was the hardest bit, wasn't it? Out of the whole treatment? [seeking agreement from father] Getting [child's name] engaged" [ID2A, mother]

More specifically, some parents found it difficult to communicate the rationale for the treatment techniques to their child and over half of parents found it particularly challenging to help their child to reflect on what they had learned from completing an ERP task.

"the biggest challenge was, uh, taking the information from [therapist name] and um passing it on to [child's name], um that was the difficulty" [ID6, father]

"I think she has always found it really hard to fill in the 1st and the last bit [of the step plan], you know "what I was I thinking?", "what do I think will happen now?". To start off with she was she would always write "well, I haven't died, yet" um and things like that and but we just had to go with it really at the start" [ID3A, mother]

As a result of these difficulties engaging their child in the treatment, some parents experienced the treatment as emotionally burdensome, identifying that the treatment was *"pretty tough going" [ID2B, father]* and at times *"a bit distressing" [ID8, mother].*

Subtheme: Demands exceeded parents' expectations

Some parents described how the demands of treatment (and beyond) were mismatched with their initial expectations. For example, some parents' experience of helping their child to overcome OCD was a slower and harder process then they anticipated, *"I think [therapist name] said it at the beginning, but it [overcoming OCD] could take much longer than the therapy [F: Yeah] to actually see real progress [F: that's a good point, oh 8 weeks and she'll be fixed, it's kind of, we weren't that naive] we were hoping, we weren't that naïve but we was hoping it would be a bit quicker" [ID2A/B, mother and father]*, which in part, appeared to be due to the nature of OCD, whereby targeting one obsession/compulsion could result in a new obsession/compulsion arising, *"sometimes, um, when [child's name] would make progress, she'd eliminate an OCD behaviour, but she'd end up replacing it with something else like a compulsion … um, so that was a bit of a challenge." [ID7, mother].* This meant that many families needed to continue implementing treatment techniques after completing the treatment, which was perceived to be an additional burden for some parents, *"the difficulty we have is remembering it all to be honest, it's, it's yeah, we keep saying to ourselves we need to sit down and read through all of the um handouts again just to keep familiarizing ourselves with with the information" [ID6, father].* This mismatch between the anticipated and actual demands of treatment meant that a minority of parents called for more clarity over what is expected of parents in a parent-led treatment approach, *"so I think explaining the time investment at the start of the study is really important, so not only are you going to have to invest time in your child, not only, as well as your hour's video call, but there will be additional reading, without scaring people off" [ID5, mother].*

Theme 4: The ingredients for success

Subtheme: Learning to engage the self and the child

Parents reflected on the aspects of treatment that they perceived as crucial to motivate themselves to continue implementing the treatment techniques. Most commonly, parents expressed the importance of experiencing and celebrating treatment success, as well as the therapist recognising their child's progress, as key to keeping them engaged in the treatment.

"Seeing the victory, you know, so like [M: yeah] when we did that first exposure ladder with with her [item] and remembering at the start that she was basically saying "I'm never going to be able to do" [M: yeah] and actually then within you know however many weeks it was, you know, to … do the last thing on on on the ladder and now you know that's

not a problem for her at all [M: no], I mean that is just so encouraging, isn't it … I guess it's where we sort of said yeah, clearly this is, this is the right approach for her." [ID3B, father]

"she [the therapist] pointed out that the progress we've made… that was important ... because when you're in the thick of it, you can't see things changing, but she's [the therapist] like, "well, actually you know, couple weeks ago you were this and now she's doing this" and it's just you know, celebrating small victories sort of thing. She [the therapist] helped us with that each week um and that got, kept us going ... because ... there were many times we wanted to give up" [ID2A, mother]

Parents also frequently described how, over time, they learned to engage their child in the treatment. This commonly involved parents learning how and when to use particular treatment techniques with their child, *"if you picked the wrong moment then you know with with lots of things you know it's timing when you speak to kids you've got to pick your moments, so if we, if we got the moments right and he was in the right headspace at that time, then he was very receptive to it" [ID6, father]*, learning how to best engage their child (e.g., through involving their child in the decision making, being curious, reminding the child of their previous successes), *"yeah so, if um, encouraging her, like I would remind her "do you remember how good it felt, like how accomplished you felt when you managed this two weeks ago … let's just try and aim to get that feeling back again… do you remember how relaxed you felt when you hadn't worried about such and such thing?" [ID7, mother]*, and crucially (as perceived by parents), identifying the right motivator for their child, *"and so finally we found that these little [characters] in [game name] … you can dress them up, if you've got these [tokens], and it was kind of like 89 pence for like 400 [tokens] or something … it was it was a small amount of money, but it meant a lot to her that she could do these characters and she had things in mind that she really wanted to do" [ID2A, mother]*.

Subtheme: Valuing flexibility

Parents commonly perceived flexibility to be crucial in treatment. Parents typically valued videocall and telephone appointments, as these were perceived to be less time consuming and easier to fit around parents' schedules than face-to-face support. Some parents also recognised how the parent-led approach facilitated them being able to "*go at our own pace." [ID7, mother]*

"I mean it was obviously convenient that we, you know we could fit it into a lunch break. You know, obviously if it was, you know, going to visit someone, then obviously that would have taken a lot more time" [ID3B, father].

Many parents also valued the flexibility of the therapist – for example, helping parents to adjust techniques that did not work for their child and offering the option to space out appointments to allow parents more time to implement the treatment techniques.

"'cause the researcher suggested saying, talking about OCD, that it was a bully and that didn't work for him at all, and again, the researcher was really helpful ... so we changed the language around that a little bit and that that helped a little bit more" [ID8, mother]

"around sort of [time of year] time when ... we'd done most of the key things, [therapist name] suggested leaving a bit longer gaps between meetings to give it a bit more time and that really, I felt that was really good as well ... otherwise it might have been a bit quick, there might not have been time to see progress" [ID3A, mother]

However, a minority of parents identified the need for greater flexibility as to where and when the treatment is delivered.

"as long as there's flexibility around the sessions. I mean, she [the therapist] was quite insistent about when they [the treatment sessions] were, and that's fine, to a degree, but

there has to be, you know it's a two way, approach to it so you know input on both sides". [ID1, father]

"I suppose there was a few times where I was out and about, um and I, I had to change [the videocall appointment] and I suppose if it been over the phone, I might have been able to continue to do that appointment." [ID5, mother]

Subtheme: The role of support

Most parents recognised the role of support from the therapist as crucial to this treatment approach. Parents frequently described feeling *"very supported" [ID3A, mother]* by the therapist, and recognised the value of receiving regular guidance and support as key to helping their child to overcome OCD.

"yeah, 'cause I think we had our homework to do, didn't we [M: yeah] which was to come up with a plan but then if we if we found it difficult it was great then that in the next you know session, we could then just talk those things through [M: yeah] with [therapist name] and get her view on does it look OK? Or should you know is there anything else we should be doing?" [ID3B, father].

"having that regular touchpoints motivated us to do it and kept us going, and I think if we didn't have that and I'm sure for a lot of people you could easily slip focus and um [M: yeah] you know, and before you know it, you know you're not getting as far" [ID2B, father].

Parents also recognised the value of working as a 'team' with another parent/caregiver or wider family members. Parents felt that a 'team approach' enabled them to feel supported emotionally, enabled them to respond consistently to their child's OCD, and meant that they could troubleshoot difficulties with someone who was familiar with the treatment techniques, even if their partner/other caregiver was involved in the treatment to a lesser extent.

"and I think it worked really well with the two of us, because we could tag team if one of us was finding a bit frustrating, the other person could take over, and we often said to ourselves, you know, "did I did I handle that right? Did it, am I doing this? Am I reassuring or is this?" and working together on it, I think has been really helpful for us." [ID3B, father]

"but actually, it was useful for [partner name] to be involved even though he was maybe a little less involved than me … there were certain things he could do where I wasn't there, so sort of certain things she'd do maybe on the getting ready to go to school or on the way to school … he could question her about" [ID9, mother]

In fact, parents who had a partner/other caregiver involved in the treatment hypothesised about the difficulties that one parent could face in implementing this treatment alone, and among the parents who did complete the treatment alone, some of these parents had a desire for wider support (particularly from other parents who had received a parent-led treatment).

"yeah, I think to go through something like this on your own would just be almost insurmountable, really um, much, much harder" [ID2A, mother]

"I think it might be helpful if there was information about support, support groups, or like if you could have other parents that have been through it, that could, talk to you, you know, things like that might be really useful" [ID8, mother]

Subtheme: the need to align the existing treatment with parents' needs

Although some parents felt that no changes were needed to the existing treatment, a minority of parents expressed a preference for greater therapist support, either in terms of the number of sessions, the length of the follow-up appointment, or greater therapist availability at times of distress.

"if there's a possibility of um the parent not having to wait a week, maybe that that's something that's helpful, um you know, having an opportunity to contact somebody and say, you know, I'm feeling overwhelmed and panicked." [ID8, mother]

Furthermore, despite parents being onboard with the parent-led approach, there were a few instances where parents did not feel best placed to support their child. This included supporting their child with particular OCD symptoms, which typically tapped into the parent's own difficulties or emotional attachment with the child *"I guess maybe as in a way as a parent, I'm almost sometimes too close, and I'm sort of absorbed into her fears of anxiety, so I kind of feel it almost too much, so [it can be] quite hard for me to step back and uhm, really work what was going on for some of those" [ID9, mother]*, and finding it hard to support their child when they perceived and/or experienced their child being more open with the therapist, *"I was really, acutely aware of the fact that the things that she'd tell me there was a massive gap in what she was telling me and what she was telling [therapist's name]" [ID7, mother]*. In these instances, a minority of parents had a desire for their child's appointments to be face-to-face and/or for there to be more appointments with their child, *"um maybe some more meetings with [child's name] would have been nice. Not many more as I know it's obviously parent-led but even if it was just, it's maybe one to check in in the middle" [ID5, mother]*.

Relationship between the themes

We presented the themes as an adapted CBT 'hot cross bun' model (Greenberger & Padesky, 1995) to illustrate the relationships between each of the themes. Here, we propose that positive (or negative) change in one of these themes will either directly or indirectly have a positive (or negative) impact on the other themes. The themes 'feeling equipped and empowered', 'the ingredients for success', and 'the road to a new normal' are perceived to have a direct impact all other themes. In contrast, ‘treatment is burdensome’ is thought to have a direct impact on parents’ perceptions of feeling equipped and empowered and the ingredients for success, in turn, indirectly affecting families’ road to a new normal. For example, if the treatment is experienced as highly burdensome, then this may reduce parents’ sense of feeling equipped and empowered and the ingredients for success may not be met, in turn, inhibiting families’ progress towards a new normal. However, if we help parents to overcome the perceived burdens of the treatment (e.g., by collaboratively exploring with parents whether there are other caregivers/significant figures who could help implement the treatment and/or manage other responsibilities), this may result in the ingredients for success being met and help to ensure that parents feel equipped and empowered to support their child to overcome OCD, in turn, facilitating their journey to a new normal. Thus, when delivering parent-led CBT for preadolescent children with OCD, clinicians may only need to facilitate positive change in one of these themes to begin to see positive (direct or indirect) impacts on the other themes.

Table 3. Implications of the qualitative analysis for future iterations of the treatment

Theme	Key points within the theme	Implications for future iterations of the treatment
Feeling equipped and empowered	Many parents felt ill-equipped to support their child at the beginning of the treatment and had concerns regarding the efficacy of the approach.	Continue to normalise parents' initial treatment concerns and provide psychoeducation on the evidence-base for parent-led treatment approaches.
	Treatment helped parents to feel equipped and empowered (both practically and emotionally) to help their child now and in the future.	Continue to provide practical tools and techniques that parents can use at home to support their child. Continue to offer opportunities to practice key skills in the treatment sessions.
	Parents felt the treatment was straightforward and provided them with a structure to help their child. Most parents felt the treatment was the right length to develop skills and confidence.	Continue to keep the treatment materials brief and simple. Continue to offer 6 to 8 sessions for the majority of families.
	Some parents only felt equipped to talk to their child about OCD and felt less able to engage their child in ERP. In these cases, parents experienced frustration and/or felt out of their depth to help their child.	Continue to review parents' confidence to help their child to overcome OCD. Spend more time using the problem solving approach with parents to consider ways to build their confidence/engage their child in ERP techniques, where necessary.
The road to a new normal	Parents perceived that their children felt increasingly understood and accepted throughout the treatment and developed greater awareness of their OCD.	Continue to provide psychoeducation on OCD and normalise intrusive thoughts. Continue encouraging parents to externalise OCD with their child.
	Parents perceived that their child's OCD improved during treatment and noted wider changes to parent-child relationships, sibling relationships, and greater family freedom.	Continue to notice and communicate treatment successes to parents.
	Parents perceived the road to a new normal as non-linear and noted fluctuating progress towards overcoming OCD.	Adapt the treatment materials to normalise fluctuations in treatment progress. Continue to normalise this in treatment sessions.

	• Parents were at different stages in their road to a new normal at the end of treatment, with some parents at the beginning of their journey and others at the stage of overcoming OCD. Most parents identified persisting difficulties once treatment finished.	• Adapt the treatment to include more realistic expectations of treatment outcomes. Use the treatment data to provide estimates of how children may respond to treatment and note that some children may need further support at the end of the treatment. Ensure parents are aware that they are learning tools to help their child to start the process of overcoming OCD and are likely to need to use the tools once treatment finishes.
Treatment is demanding	• Parents perceived the treatment to be an additional demand to their existing responsibilities. Due to the perceived treatment demands, some parents experienced fluctuations in how engaged they were with the approach. For some parents the time demands led to frustration or self-blame.	• Continue to make parents aware of the time commitment before agreeing to take part in the treatment approach. Continue to normalise time constraints as a common experience in this treatment approach. Continue to problem solve with parents how they can integrate the treatment techniques into their daily life. Consider offering more flexibility (i.e., length between sessions, telephone instead of videocall) for parents when competing demands are high.
	• Parents felt the questionnaires added to the demands of the treatment.	• Continue to provide a rationale for the questionnaires and show parents graphs at each session to re-iterate the importance of gathering this data. Consider whether all questionnaires need to be completed weekly or whether some questionnaires could be completed pre-, mid-, and post-treatment.
	• Many parents perceived their child to be resistant to engaging in the treatment (e.g., talking about OCD, engaging in ERP, reflecting on what they had learned from ERP tasks).	• Continue to normalise and problem solve difficulties engaging children in treatment. Adapt the treatment manual to include more ideas on how to engage children in the treatment (e.g., starting off with non-threatening, fun/engaging experiments). Place greater emphasis on finding the right motivator for each child.
	• Parents can find treatment emotionally demanding.	• Continue to normalise parents' experiences and problem solve this challenge with parents.

	The demands of treatment exceeded parents' expectations.	Adapt the treatment to include more realistic expectations of treatment demands. Ensure parents are aware that they are learning tools to help their child to start the process of overcoming OCD and are likely to need to use the tools once treatment finishes.
The ingredients for success	Some parents identified the importance of experiencing and celebrating success (and the therapist communicating this) to stay engaged in the treatment.	Continue to start with small ERPs tasks so that families experience success. Continue to recognise and congratulate parents for treatment successes.
	Parents learned how to engage their child throughout treatment.	Adapt the treatment materials to emphasise that parents are experts in engaging their child. Include ideas of how other parents have engaged their child in treatment (e.g., involving children in decision making, reminding them of previous successes, identifying the right motivator for their child). Normalise a 'trial and error' approach to engaging their child in treatment.
	Parents valued the flexibility of videocall and telephone appointment and the ability to space out sessions if needed.	Continue to offer the option of videocall and telephone appointments, even when COVID-19 allows face-to-face appointments to resume. Continue to offer flexibility in the spacing of treatment sessions if needed/clinically appropriate.
	Some parents wanted greater flexibility (e.g., telephone rather than videocall, more time between sessions).	Consider on an individual basis how the treatment mode and frequency may work best for individual families.
	Parents valued regular therapist support.	Continue to provide therapist guided treatment sessions.
	Parents valued working as a team with another parent/carer/family member.	Continue to allow flexibility for more than one caregiver to join one or more treatment sessions. If helpful, encourage parents to involve other caregivers/figures in the child's life to lessen the demands of treatment on the parent. Signpost all parents to support groups in case relevant/helpful.

	- Some parents expressed a preference for greater therapist support, more (often face-to-face) treatment sessions with their child, particularly where parents did not feel best placed to support their child.	- Remind parents they can email if they feel they need additional support/advice during the week. Offer face-to-face sessions for the child's assessments. Explicitly check in with parents if there are particular obsessions/compulsions they are finding challenging and problem solving this with parents.

Note. ERP = Exposure and Response Prevention.

6.5 Discussion

We conducted semi-structured qualitative interviews to explore parents' experiences and acceptability of a brief, low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD. Reflexive thematic analysis was used to generate four themes reflecting parents' experiences and acceptability of the intervention, including (1) 'feeling equipped and empowered', (2) 'the road to a new normal', (3) 'treatment is burdensome', and (4) 'the ingredients for success', and to identify implications for future iterations of this treatment.

Similar to other qualitative studies exploring parents' experiences of parent-led CBT for child anxiety disorders (Allard et al., 2022; Dorgan et al., 2022), parents of children with OCD initially doubted their ability to engage in a parent-led treatment, however, the practical and straightforward nature of the approach enabled parents to feel increasingly equipped and empowered to support their child. Notably, this finding is also supported by the quantitative data reported in Chapter 5 which demonstrated average increases in parents' knowledge and confidence to support their child as the intervention progressed. Interestingly, the current study extended previous qualitative studies (e.g., Allard et al., 2022; Dorgan et al., 2022) by identifying the different extents to which parents can feel empowered – for example, many parents felt empowered to implement ERP, whereas a minority of parents only felt empowered to discuss OCD with their child (and felt less able to use ERP techniques). Among the parents who felt less able to use ERP, these parents found it challenging to engage their child in the treatment, struggled to learn how best to engage their child in the approach (which was perceived by many parents as crucial for treatment success), and (during the treatment sessions) reported some anxiety regarding the use of ERP with their child (i.e., parents were uncertain/apprehensive about how their child would respond to ERP). These qualitative findings help to explain the quantitative variation in parents' knowledge and confidence to help their child (as seen by the error bars in Figure 5 in Chapter 5) and identify the need for future iterations of this treatment to focus on helping parents to learn how to best engage their child in the treatment techniques and help parents develop their distress tolerance skills (Belschner et al., 2020) to ensure that all parents feel equipped and empowered to implement ERP to facilitate their families' journey to a new normal.

Notably, most parents perceived the parent-led treatment to be burdensome. This experience is in line with previous qualitative studies, which have also identified the challenges parents face finding the time to implement treatment techniques (Allard et al., 2022) alongside other competing demands (e.g., parents' own physical or mental health difficulties, employment, and/or needing to care for other children, Lundkvist-Houndoumadi et al., 2016). Extending previous studies, this study emphasised the emotional burden that the parent-led treatment can place on parents, with some parents experiencing the treatment (at times) as tough and distressing. The demands of treatment were also greater than parents' initial expectations, which may reflect the perceived ever changing nature of OCD, with many families having to continue to implement treatment techniques months after completing the treatment. Thus, future iterations of the treatment would benefit from providing parents with more realistic expectations about treatment demands both during and beyond the treatment (for example, updating the case studies to illustrate how children may progress through the treatment and beyond, to provide parents with more realistic expectations regarding recovery times and the need to continue implementing treatment techniques after completing the treatment) and explicitly discussing with parents (if needed) ways to reduce the perceived demands of the treatment.

Given that parents of children who did/did not 'respond' and/or 'remit' at the one-month follow-up were recruited, we were able to use parents' qualitative accounts to explore possible differences in parents' experiences of the treatment (depending on their quantitative treatment outcome) and understand the reasons why some families may have benefitted less from the treatment. Interestingly, parents of non-responders/remitters still experienced feeling equipped and empowered as a result of the treatment (albeit, in some cases, to a lesser extent than parents of responders/remitters), mirroring previous qualitative research which has also found that parents of anxious children who did not 'respond' to group parent-led CBT still felt empowered from the treatment (Dorgan et al., 2022). Furthermore, both parents of non-responders/remitters and responders/remitters experienced challenges engaging their child in ERP during the treatment. Whilst some non-responders/remitters learned how to engage their child in ERP (often through the identification of motivating rewards), two parents of non-responders/remitters experienced limited success engaging their child in ERP due to child reluctance and parental frustration/distress when supporting their child. Moreover, parents of non-responders/remitters often identified additional external life events that had a negative impact on their ability to engage in the treatment. For example, family illness, transitions (i.e., children moving schools), and having other children with additional needs created challenges for parents' ability to engage. Although this was also a feature of interviews with parents of responders/remitters, many of these families had more than one parent involved in the treatment, which may have helped to lessen the perceived burden of the treatment (alongside external life events) and provided additional support for parents to implement ERP. This hypothesis reflects the findings of Dorgan et al. (2022) who found that parents of non-responders received less support from their families in implementing the treatment compared to responders. Taken together, these potential differences in parental experiences highlight the importance of (1) having small, manageable ERP steps (accompanied by motivating rewards) to build parents' and children's confidence to use ERP, and (2) ensuring parents feel supported to implement treatment techniques alongside additional life events.

Critically, the themes generated from this reflexive thematic analysis were perceived to be interrelated. This is important clinically, as positive change in one of these themes has the potential to subsequently positively impact the other themes. For example, parents viewed treatment flexibility as a critical ingredient for treatment success. Thus, if clinicians are able to deliver treatment in a way that is flexible for families (whilst broadly adhering to the treatment manual), this may help to overcome the perceived burdensomeness of the treatment to parents, increase parents' sense of empowerment, and facilitate families' journey to a new normal. Future clinicians delivering this intervention should therefore hold this thematic map in mind to help them to collaboratively problem solve any barriers that parents may face implementing this treatment.

Strengths and limitations

The use of semi-structured qualitative interviews enabled us to gain greater insight into parents' experiences and acceptability of the treatment and the 'real world' benefits of the treatment for families (Johnson & Schoonenboom, 2016) that were less well captured by the quantitative data collected in Chapter 5. Similarly, the integration of qualitative and quantitative data facilitated our understanding as to why some parents felt more or less knowledgeable and able to help their child to overcome OCD and why some families (i.e., treatment 'non-responders' and/or 'non-remitters') may have benefited less from this treatment approach (Richards et al., 2019). However, despite our efforts to also recruit parents who only attended some of the treatment sessions, parents who participated in the interviews had attended all eight treatment sessions (either alone or jointly with another caregiver), limiting our understanding of whether parents' experiences and views towards the treatment differ if they only attend some of the treatment sessions. The parents who participated in this treatment were also predominantly White British (90%) and/or well educated (i.e., with 90% of parents having at least an undergraduate degree), limiting our understanding of how this treatment would be received by parents from more diverse backgrounds. Given that parents were predominantly recruited through social media advertisements (see Chapter 5 for information on participant recruitment), it is surprising that there was limited variability in parents' ethnicity and education status. However, it is possible that a parent-led intervention may be less appealing to parents from ethnic minority or less educated backgrounds, as research has shown that cultural factors can be a barrier to parents seeking mental health support for their child (Reardon et al., 2017) and that less educated individuals are less likely to seek mental health support (Steele et al., 2007). Thus, future evaluations of this treatment should aim to recruit a more varied sample of parents through working with relevant charities, agencies, and local support groups to deepen our understanding of the acceptability of this intervention to a diverse range of families. Moreover, future evaluations of this treatment would also benefit from conducting qualitative interviews with children whose parents have participated in this treatment approach. This would provide a valuable insight into children's experiences of being supported by their parents, help to delineate the reasons why some children find it challenging to engage in this approach, and facilitate iterations of the treatment to maximise treatment acceptability for both parents and their children.

We placed particular emphasis on the quality of the data collection and analysis to ensure a high quality report. For example, although the interviewer (HN) had no formal training in qualitative methods, HN had experience of working with families with mental health difficulties and therefore had common factor skills (e.g., empathy, summarising) that were directly applicable to qualitative interviewing. Furthermore, CCh conducted practice interviews with HN, and met with HN after each interview to reflect on the strengths of the interview and to identify areas to probe further in the future. This process meant that the richness and complexity of the interviews progressively increased. High quality data analysis was ensured through critically reflecting on the research team's experiences, to ensure that alternative interpretations of the data were considered (Braun & Clarke, 2022). For example, given CCh, BH, and CCr's investment in parent-led CBT as a means of increasing access to treatments for children with mental health difficulties, KH largely supervised the analysis and write-up of the qualitative data as KH brings different research experience and expertise, and thus facilitated the team's critical reflection and engagement with the data. This included discussing CCh's reflective notes throughout the analysis which detailed any tensions between an investment in parent-led CBT and the analysis being generated. CCh also worked closely with KH and CCr during the initial coding and initial theme generation to ensure an interpretative approach to data analysis and a paper trail (see appendix 1 for an example) was kept illustrating CCh's engagement with the six-stages of reflexive thematic analysis (Braun & Clarke, 2022).

6.6 Conclusion

This study explored parents' experiences and acceptability of a brief low-intensity parent-led CBT intervention for preadolescent children with OCD. In line with the requirements for first-line interventions (Bower & Gilbody, 2005), on the whole, this intervention can be deemed acceptable to participating parents. Parents described a largely positive experience of the treatment, felt increasingly equipped and empowered to support their child on a journey to a new normal, and identified the factors of treatment (i.e., learning about the self and child, flexibility, support, and aligning the treatment with parents' needs) they perceived as crucial for treatment success. Despite this, parents often perceived the treatment to be burdensome – thus, future iterations of this treatment need to help parents to address the perceived burdens of the treatment to further empower parents to help their child to overcome OCD.

6.7 References

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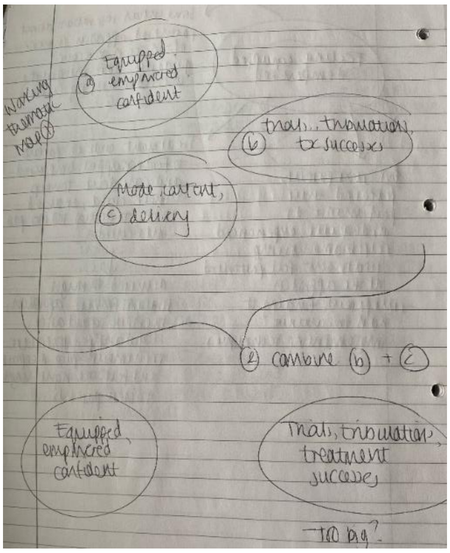
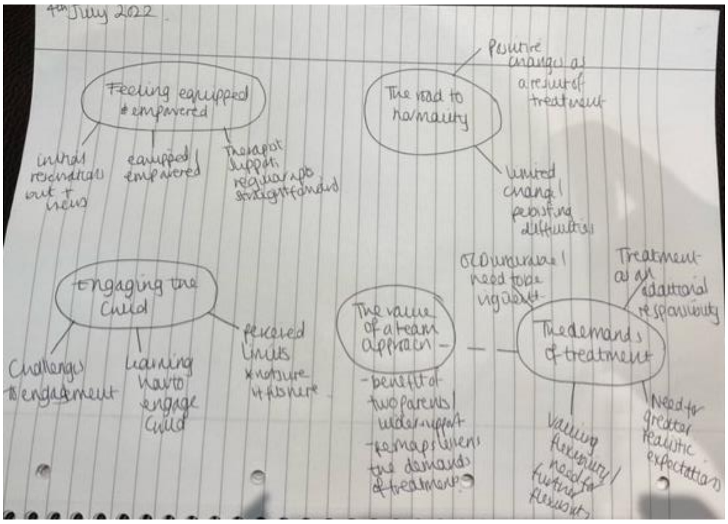
Appendices

1. Paper trail illustrating the development and refinement of themes.

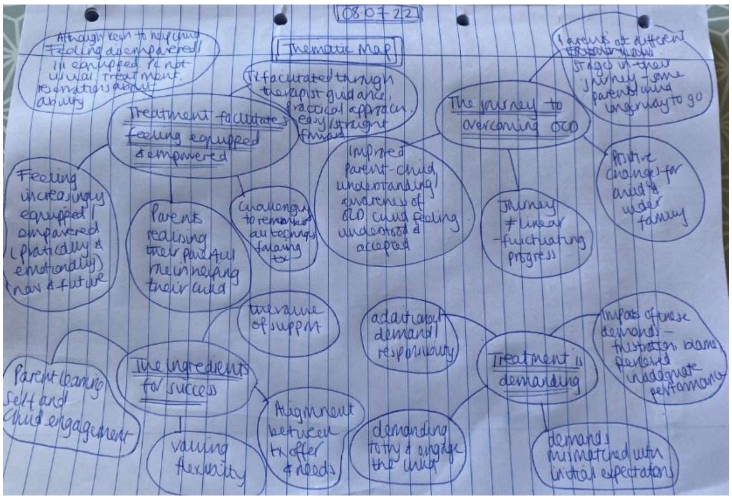
(a) Example of how I progressed between different initial ideas for themes/a thematic map.



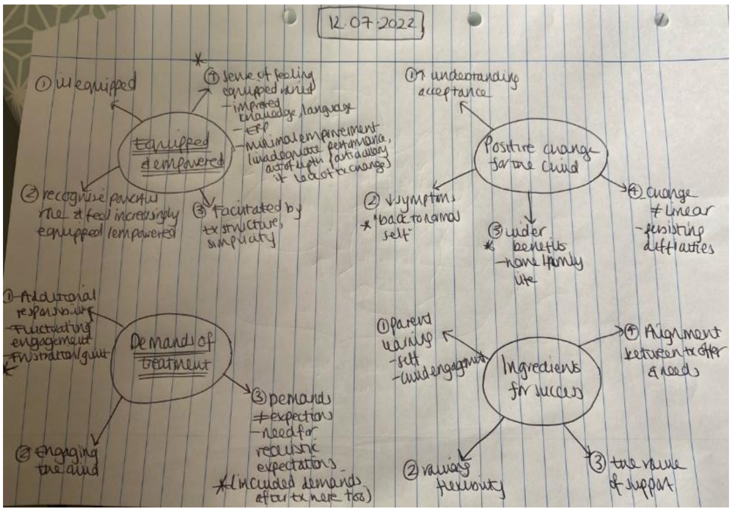
(b) Example of initial themes/thematic map.



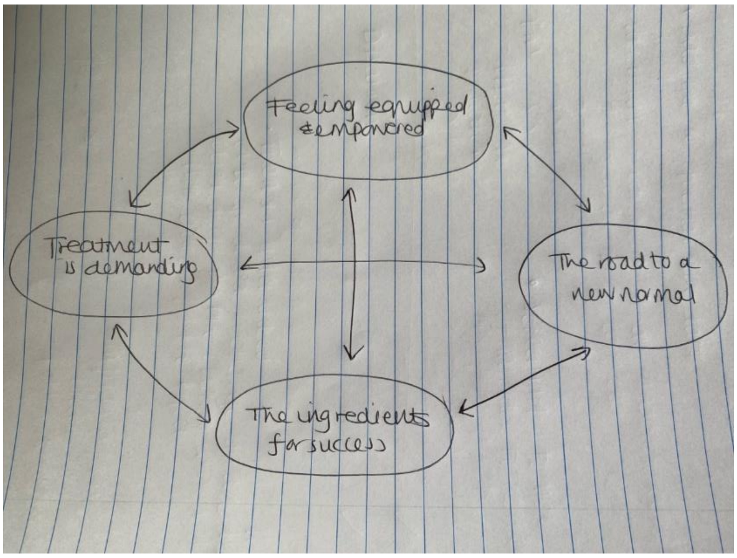
(c) Example of more developed themes/initial thematic map.



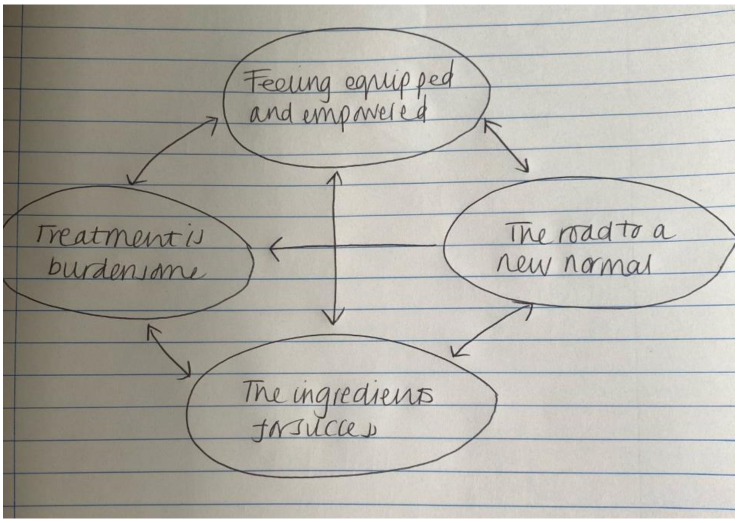
(d) Example of refined themes/thematic map.



(e) Example of further refined themes/thematic map.



(f) 'Finalised' themes/thematic map.



Chapter 7: General Discussion

This thesis aimed to develop a potential means of increasing access to psychological treatments for preadolescent children with OCD by adapting an existing evidence-based brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with anxiety disorders (e.g., Thirlwall et al., 2013) to ensure suitability for preadolescent children with OCD. To achieve this, this thesis specifically aimed to (i) identify the cognitive, behavioural, and familial mechanisms relevant to the maintenance of obsessive compulsive symptoms (OCS)/OCD in preadolescent children that need to be targeted in a brief low-intensity intervention, (ii) qualitatively explore parents' experiences of parenting a preadolescent child with OCD, and their views about parental involvement in CBT for their child's difficulties, and (iii) adapt and conduct a preliminary evaluation of a brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD. Bower and Gilbody's (2005) criteria for first-line interventions were used to evaluate whether brief low-intensity therapist guided, parent-led CBT may be a viable first-line intervention to help increase access to psychological treatments for preadolescent children with OCD. In this chapter, I provide an overview and synthesis of the main findings from this thesis, outline the associated clinical and research implications, and consider the strengths and limitations of this work.

7.1 Overview of findings

Paper 1: Systematic review

Bower and Gilbody (2005) state that first-line interventions need to be effective and efficient. Thus, to develop a brief low-intensity therapist guided, parent-led CBT intervention that met these requirements, it was crucial to understand the mechanisms that maintain OCS/OCD in preadolescent children, so that these mechanisms could be targeted in a brief low-intensity intervention. In Paper 1, I therefore conducted therefore conducted a systematic review and narrative synthesis of 29 quantitative studies that examined the association between proposed maintenance factors (identified from adult cognitive behavioural models of OCD and the wider literature examining the role family factors in the maintenance of OCD and anxiety disorders) and childhood OCS/OCD.

Eligible studies were identified for six of the 11 proposed maintenance factors. Specifically, (i) inflated responsibility, (ii) over importance of thoughts, (iii) overestimation of threat, (iv) emotional responses, (v) counter-productive safety strategies, and (vi) family factors (including family members' cognitions and behaviours). No eligible studies were identified for (i) importance of controlling thoughts, (ii) intolerance of uncertainty, (iii) perfectionism, (iv) attentional biases, or (v) neutralising actions. Where eligible studies were identified, studies provided some evidence of significant associations between the proposed maintenance factors (with the exception of counterproductive safety strategies) and childhood OCS/OCD, and a handful of studies provided evidence of specific and/or independent associations between inflated responsibility, meta-cognitive beliefs, and specific parental behaviours and childhood OCS or OCD, whilst controlling for and/or compared to other psychological symptoms/disorders.

Despite these findings, the review highlighted the scarcity of research examining maintenance mechanisms in this population and the reliance of the existing literature on cross-sectional and correlational designs, limiting our understanding of whether the proposed maintenance factors do *maintain* childhood OCS/OCD. However, the review did highlight a broad range of parent and child cognitions and parent behaviours that were significantly associated with childhood OCS/OCD, and a significant association between improvements in children's distress tolerance and more favourable treatment outcomes. Together, these findings suggested that an exposure-based treatment focused on helping children to learn new information about their fears (i.e., targeting relevant cognitions for each child) and their ability to cope in feared situations (i.e., increasing children's distress tolerance) without performing their compulsions would be appropriate. Moreover, delivering this treatment via parents was deemed appropriate to help indirectly target parental cognitions and behaviours that may be inadvertently maintaining the child's difficulties. Critically, the review highlighted the pressing need for future experimental and/or longitudinal studies to provide insight into the mechanisms that *maintain* OCS/OCD in preadolescent children to improve the efficiency and effectiveness of new and existing treatments for this population.

Paper 2: Qualitative study

In line with Bower and Gilbody's (2005) criteria for first-line interventions, Paper 1 examined the relevant maintenance mechanisms that need to be targeted to ensure an effective and efficient treatment. Paper 2 therefore sought to ensure that brief low-intensity therapist guided, parent-led CBT would be an acceptable intervention to this population (Bower & Gilbody, 2005) by qualitatively exploring parents' experiences of parenting a preadolescent child with OCD so that the developed intervention would reflect parents' experiences and needs. Twenty-two parents of 16 children (aged 7- to 14-years-old) with lived experience of OCD participated in semi-structured qualitative interviews and reflexive thematic analysis was used to generate themes capturing parents' experiences.

Two overarching themes and five themes were generated, including (1) challenge and frustration (overarching), (2) helplessness (overarching), (3) the journey to understanding and accepting OCD, (4) the battle for support, (5) navigating how to respond to OCD, (6) OCD is in control, and (7) the emotional turmoil of parenting a child with OCD. Themes captured the difficulties parents experience trying to understand and relate to their child's OCD, and the challenges of not knowing how to best respond to their child's distress. Parents also described how OCD dominates their child's, their own, and their wider family's lives and discussed the range of (predominantly negative) emotions they experience parenting a child with OCD. Notably, parents spontaneously and frequently described the battle they experience trying to access appropriate support for their child, and the associated helplessness they experience when they are unable to access this.

Paper 2 therefore enabled the identification of key implications for the development of support for parents of preadolescent children with OCD, including the need for *accessible and scalable* support that provides parents with (1) psychoeducation on what OCD is, (2) clear, manageable, and helpful ways that parents can respond to their child's OCD/distress, and (3) support that is sensitive to the emotional challenges parents experience.

Chapter 4: Further qualitative research

In Paper 2, qualitative methods were used to explore parents' experiences of parenting a preadolescent child with OCD to ensure the developed intervention reflected parents' experiences and needs. To further maximise the acceptability of brief low-intensity therapist guided, parent-led CBT for this population (Bower & Gilbody, 2005), qualitative methods were also used to explore parents' views about different ways parents can be involved in CBT for their child, to ensure the developed intervention reflected parents' views and addressed any parental concerns regarding parental involvement in treatment (see Chapter 4). As in Paper 2, twenty-two parents of 16 children with lived experience of OCD participated in semi-structured qualitative interviews exploring their views towards (1) individual child treatment sessions with no parental involvement, (2) individual child treatment sessions with parental attendance at the beginning and/or end of the sessions, (3) separate child and parent treatment sessions, and (4) therapist guided, parent-led CBT.

Reflexive thematic analysis was used to generate one overarching theme and two themes, including (1) knowledge is key (overarching), (2) parents' perception of themselves as necessary but not sufficient, and (3) parents' perceptions of their (in) ability to help their child. The results illustrated the degrees to which parents perceived their involvement in treatment to be essential, with many parents identifying that they had key knowledge to share with therapists and perceived themselves as crucial to help their child to implement treatment techniques at home, whereas other parents felt their involvement in treatment should be minimal. Parents often wanted their child to be the focus of the treatment and some parents valued a 'holistic' approach to treatment, stating a preference for a combination of the treatment approaches discussed. Parents perceived their ability to help their child to be increased if information is presented in clear, simple, and accessible formats, and is delivered flexibly. Therapist support and personalisation of treatment materials were also seen as key facilitators to parents being able to support their child. However, parents described lacking confidence and credibility (in their child's eyes) as barriers to their ability to support their child, as well as their emotional attachment to their child and the time commitments of being involved in therapy.

Similar to Paper 2, this qualitative work has key implications for developing support for parents of preadolescent children with OCD. The findings indicated that therapist guided, parent-led CBT could be an acceptable intervention to parents, given that parents perceive themselves as essential in their child's treatment. However, to maximise the acceptability of this treatment to parents, the treatment needed to capitalise on parents' perceived facilitators to their ability to support their child (e.g., the intervention needed to be simple, personalised, and delivered flexibly around parents' existing commitments) and address parents' perceived barriers to their ability to support their child (e.g., the intervention needed to focus on building parents' confidence, credibility, and provide parents with tools to manage their own emotions when supporting their child to overcome OCD).

Paper 3: Non-concurrent multiple baseline case series

The results of Paper 1, Paper 2, and the further qualitative research were used to adapt an existing brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with anxiety disorders (e.g., Thirlwall et al., 2013) to ensure suitability for preadolescent children with OCD. To assess whether this adapted intervention could be an effective and acceptable first-line intervention for this population (Bower & Gilbody, 2005), in Paper 3, a preliminary evaluation of the efficacy and acceptability of the intervention using a non-concurrent multiple baseline approach and qualitative interviews was conducted. Parents of 10 children with OCD were randomised to no-treatment baseline periods of 3-, 4-, or 5- weeks before receiving 6- to 8- individual treatment sessions. Diagnostic assessments were completed at three timepoints (pre-baseline, post-treatment, one-month follow-up) and parents completed weekly measures assessing their child's OCD symptoms, impairment, and family accommodation. Results showed that 70% of children were 'responders' and/or 'remitters' on diagnostic assessments at post-treatment and 60% at follow-up. Fifty percent of children showed reliable improvements on parent-reported OCD symptoms and impairment and 40% of parents reported reliable reductions in family accommodation from pre- to post-treatment, and from pre-treatment to one-month follow-up. Post-treatment questionnaires and semi-structured qualitative interviews indicated that the intervention was acceptable to parents. The results of Paper 3 therefore have clear implications for increasing access to psychological treatments as the findings suggest that brief low-intensity therapist guided, parent-led CBT may be an effective, efficient, and acceptable first-line intervention (subject to further evaluation) for this population.

Chapter 6: In-depth exploration of parents' experiences and acceptability of the treatment

Due to the nature and scope of journal articles, in Paper 3, I was unable to provide an in-depth account of parents' experiences and acceptability of the intervention. Thus, to assess parents' acceptability of the intervention (Bower & Gilbody, 2005), in Chapter 6, I provided a detailed account of semi-structured qualitative interviews conducted with 10 parents (6 mothers, 4 fathers) of eight children who participated in the treatment study. Interviews were conducted roughly two- to three-months after parents completed the treatment and were analysed using reflexive thematic analysis.

Four themes were generated including (1) feeling equipped and empowered, (2) the road to a new normal, (3) treatment is burdensome, and (4) the ingredients for success. These interlocking themes captured parents' experiences (on the whole) of feeling increasingly equipped and empowered to support their child to overcome OCD and experiences of positive change on their families' road to a new normal. Parents often valued therapist support and support from other parents/caregivers, as well as the flexibility of the treatment. Despite this, parents experienced the treatment as burdensome and, in some cases, identified the need for clearer initial expectations of the demands of the treatment.

This qualitative research has clear implications for increasing access to psychological treatments for preadolescent children with OCD, as it identifies that therapist guided, parent-led CBT is a broadly acceptable intervention to parents, however, highlights the need for therapists to help parents address the perceived burdens of the treatment to help maximise the acceptability of the intervention.

7.2 Synthesis of findings and implications for future research

A synthesis of the findings of this research and the associated implications for increasing access to psychological treatments for preadolescent children with OCD are presented below, with reference to the existing literature.

Establishing the cognitive, behavioural, and familial maintenance mechanisms relevant to OCS/OCD in preadolescent children.

Paper 1 (Systematic Review) provided some (albeit limited) evidence of potential mechanisms relevant to the maintenance of childhood OCS/OCD that could be targeted to ensure effective and efficient treatments to help increase access to psychological treatments for preadolescent children with OCD. However, the findings of Paper 1 were broadly consistent with other reviews (e.g., Mantz & Abbott, 2017) that have found insufficient evidence to draw conclusions regarding the applicability of adult cognitive models of OCD to child and adolescent populations. Paper 2 (Qualitative Study) may build on the findings of Paper 1 and provide additional insights into potential familial maintenance mechanisms in preadolescent children with OCD. Although this was not the aim of Paper 2, researchers have used qualitative research exploring patients' experiences of disorders to generate hypotheses regarding potential maintenance factors (e.g., Isham et al., 2019). In line with previous quantitative research (e.g., Monzani et al., 2020), Paper 2 highlighted that parents frequently accommodate their child's OCD. Family accommodation is thought to have a strong maintenance role in childhood OCD (Waters & Barrett, 2000) and the results of Paper 1 showed that reductions in family accommodation across treatment were consistently related to reductions in children's OCS (Chessell et al., 2021). The results of Paper 2 provide further insight on this, highlighting that parents often feel helpless when their child is distressed and feel they have no other choice but to accommodate their child's OCD to enable their child to function *"it was real conflict with myself [whether or not to accommodate] because I knew it wasn't helpful, but I suppose at that point, especially in the morning, I needed to get him to* *school, he wouldn't leave, you know, if I didn't do it"[ID19, mother]*. As a result of the findings of Paper 1 and 2, in Paper 3 family accommodation was indirectly targeted as part of the parent-led intervention and analyses demonstrated that 40% of families evidence reliable improvements in family accommodation across the treatment. Interestingly, examination of session-by-session treatment measures in Paper 3 indicated a close relationship between parent's reports of their child's OCD symptoms/impairment and family accommodation. For example, increases in children's OCD symptoms/impairment scores at a given session were typically accompanied by increases in family accommodation. Despite this, it was not possible to determine whether changes in children's OCD symptoms/impairment preceded changes in family accommodation or vice versa. Thus, given the potential role of family accommodation in the maintenance of childhood OCD, future evaluations of therapist guided, parent-led CBT should examine whether changes in family accommodation mediate treatment outcomes.

Implications for future research to establish the cognitive, behavioural, and familial maintenance mechanisms in childhood OCS/OCD.

As identified in Paper 1, there is a clear need for future research to use experimental and/or longitudinal designs to identify whether the proposed maintenance factors identified from adult models of OCD do have a *maintaining* role in childhood OCS/OCD. Experimental research in particular has been identified as critical to test theory-driven hypotheses and establish relevant maintenance mechanisms in psychological disorders (Blackwell & Woud, 2022; Ouimet et al., 2021). Single-case experimental designs (SCEDs) (i.e., experimental designs that involve continued monitoring of symptoms/behaviours of interest prior to and after the introduction of an intervention, Krasny-Pacini & Evans, 2018) may also be particularly useful to establish relevant maintenance mechanisms, as these designs can be used to manipulate proposed maintenance factors and examine the subsequent effects on relevant measures (Dallery et al., 2013). This approach has been used in the adult OCD literature, where Radomsky et al. (2020) used a SCED to demonstrate that behavioural experiments targeting inflated responsibility beliefs and memory distrust resulted in hypothesised improvements on relevant outcome measures. Based on reflections from delivering parent-led CBT for preadolescent children with OCD, SCEDs with exposures designed to target specific cognitive beliefs (i.e., inflated responsibility, magical thinking, and thought-action fusion) may be promising potential maintenance mechanisms to focus on. Furthermore, many of the children who participated in the treatment study (Paper 3) described 'not-just-right-experiences' (NJREs) where they felt they had to perform compulsions until it felt right (Coles et al., 2003). NJREs are not explicitly accounted for in the adult cognitive behavioural maintenance models of OCD examined in the systematic review and very little research has examined the role of NJREs in childhood OCD (Nissen & Parner, 2018). Despite this, Nissen and Parner (2018) have demonstrated that NJREs are commonly reported by children and adolescents with OCD and are associated with greater risk of relapse following CBT. Thus, SCEDs designed to examine the role of NJREs in the maintenance of OCD in preadolescent children may be of particular interest and may help to broaden our understanding of the potential mechanisms that maintain childhood OCD.

Ensuring the acceptability of interventions

The findings of Paper 2 (Qualitative Study), Chapter 4 (Qualitative work), and Chapter 6 (Qualitative work) provide key information for the development of acceptable interventions for parents with a preadolescent child with OCD. Paper 2 extended previous quantitative research (e.g., Storch et al., 2009; Wu et al., 2018) and qualitatively explored parents' experiences of parenting a preadolescent child with OCD and in Chapter 4, I presented the first exploration of parents' views about parent involvement in CBT for their child. This research provided an invaluable insight into parents' experiences and treatment views and directly shaped the development of the adapted treatment (e.g., specific alternatives to accommodation and reassurance were provided, treatment materials were specifically developed to be clear and simple and in accessible formats etc.) and the delivery of the treatment (e.g., ensuring the study clinician was sensitive to the emotional challenges parents may be experiencing, offering evening appointments to provide greater flexibility for parents etc.).

Given that it is crucial for first-line interventions to be acceptable to patients (Bower & Gilbody, 2005) and treatment acceptability has been linked to greater treatment adherence and outcomes (Galea et al., 2022), in Chapter 6, I qualitatively explored parents' experiences and acceptability of therapist guided, parent-led CBT for OCD. Similar to the findings of other qualitative studies that have explored parents' experiences of parent-led CBT for child anxiety disorders (e.g., Allard et al., 2022; Dorgan et al., 2022), parents of children with OCD were initially hesitant about their ability to deliver the treatment, however, felt increasingly equipped to support their child as the treatment progressed. Moreover, parents described challenges implementing the treatment alongside existing responsibilities, mirroring the challenges identified in previous research (e.g., Allard et al., 2022; Lundkvist-Houndoumadi et al., 2016). This appeared to be a particular challenge for some (but not all) parents of non-responders/remitters at the one-month follow-up. Interestingly, although this challenge was also reported by parents of responders/remitters, many of these families had more than one parent involved in the treatment, which may have helped to reduce the perceived burden of the treatment alongside existing responsibilities and enabled parents to work as a team to implement the treatment techniques. This is in line with Dorgan et al. (2022) who found that parents of anxious children who did not respond to group parent-led CBT reported less family support in implementing treatment techniques compared to parents of responders. Furthermore, whilst parents of non-responder/remitters and responders/remitters both reported challenges engaging their child in ERP in the current study, some (but not all) parents of non-responders struggled to overcome this challenge, resulting in limited improvements in their child's OCD symptoms. Based on reflections from delivering the treatment and the qualitative research, these families were often unable to identify motivating rewards to engage their child to have a go at ERP and were hesitant about how their child would respond to ERP tasks. Thus, these qualitative findings provide a detailed insight into parents' experiences and acceptability of the treatment (and how this may differ for parents of non-responders/remitters versus responders/remitters) which will help to inform future iterations of the treatment to further increase parents' acceptability of the approach.

Implications for future research to ensure the development of acceptable interventions

Qualitative research has been identified as critical for continued intervention development as it can provide unique insights into patients' experiences of an intervention and identify problematic areas that require further refinement (Gilgun & Sands, 2012). Thus, future research should refine brief low-intensity therapist guided, parent-led CBT for OCD using the results of the qualitative analyses (i.e., Chapter 6) to help maximise the acceptability of the intervention. For example, future iterations of this treatment should consider how to use parents' perceptions of the ingredients for success (e.g., the role of support from other caregivers/family members/support groups) to help address the perceived burdens of the treatment to parents, particularly for parents who are attending the treatment sessions alone. Furthermore, given that parents of non-responders/remitters struggled to engage their child in ERP and were hesitant about how their child would respond to ERP tasks, this re-iterates the importance of collaboratively identifying small, manageable initial ERP steps for the child, that are fun/engaging and accompanied by a motivating reward (Bouchard et al., 2004), to help build both parents' and children's confidence to engage in their step-by-step ERP plan. Conducting qualitative research and/or Patient and Public

Involvement (PPI) work to explore children's experiences and perceptions of low-intensity, therapist guided, parent-led CBT will also be crucial to understand why some children may find it challenging to engage in this treatment approach. For example, it is possible that this treatment may be more or less acceptable to children based on their OCD presentation. Research among adult populations has shown that harm-related and sexual obsessions are more highly stigmatised than NJREs and contamination-related obsessions (Cathey & Wetterneck, 2013; Homonoff & Sciutto, 2019). Thus, it will be important to explore the acceptability of this intervention to preadolescent children with different OCD presentations. Notably, the research that has contributed to the development and evaluation of the intervention to date has been predominantly conducted with White British and/or University educated parents. Thus, to truly have potential to increase access to treatments for preadolescent children with OCD, it will be critical to conduct further qualitative research and/or PPI work with a diverse range of parents and children to help ensure the treatment meets the needs of, and is acceptable to, diverse families.

Qualitative research can also facilitate the implementation of interventions in routine clinical practice (May & Finch, 2009). Expert Recommendations for Implementing Change (ERIC, Powell et al., 2015) suggest establishing services' readiness for the implementation of an intervention, as well as identifying potential facilitators or barriers to implementation before embarking on the implementation process (Kirchner et al., 2020). Thus, future qualitative research should be conducted with key stakeholders in the Children and Young People's (CYP) Improving Access to Psychological Therapies (IAPT) initiative (e.g., Children's Wellbeing Practitioners (CWPs), Educational Mental Health Practitioners (EMHPs), CWP/EMHP supervisors, service leads) to explore the perceived facilitators and barriers to the implementation of parent-led CBT for OCD in the range of settings that CWPs and EMHPs operate (i.e., Mental Health Support Teams (MHSTs), Child and Adolescent

Mental Health Services (CAMHS), local authorities, and voluntary organisations; Ludlow et al., 2020). For example, CWPs and EMHPs are not currently trained to treat OCD (Ludlow et al., 2020), thus, both they and their supervisors may require formal training and expert supervision to facilitate the successful delivery of parent-led CBT for this population (Kirchner et al., 2020). Identification of such training needs (alongside other barriers/facilitators to implementation) will be crucial to ensure the successful implementation (Powell et al., 2015) and uptake of the intervention by relevant clinicians who work within a framework designed to help increase access to treatments for children with mental health difficulties (Ludlow et al., 2020).

Brief low-intensity therapist guided, parent-led CBT has the potential to increase access to treatments for preadolescent children with OCD.

The findings from Paper 1 (Systematic Review), Paper 2 (Qualitative Study), and Chapter 4 (Qualitative work) directly informed the developed intervention delivered in Paper 3 (Treatment Study). Paper 3 extended the current field by conducting the first preliminary evaluation of the efficacy and acceptability of a brief low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD. This extended previous research as the intervention only required 5- to 6-hours of therapist support, which was half the therapist time required for an existing parent-led CBT intervention for very young children with OCD (e.g., Rosa-Alcázar et al., 2017, 2019). Encouragingly, the results from Paper 3 were largely in line with other brief and more intensive treatments for children and adolescents with OCD that have also found large effect sizes on outcome measures (Bolton et al., 2011; McGuire et al., 2015). This is particularly encouraging given that the therapy delivered in most OCD treatment trials (e.g., Bolton et al., 2011; Rosa-Alcázar et al., 2017, 2019) is delivered by highly specialised therapists, whereas the intervention evaluated in Paper 3 was delivered by a non-specialist, low-intensity therapist. This is promising for helping to increase access to psychological treatments for preadolescent children with OCD, as brief low-intensity therapist guided, parent-led CBT has the potential to be delivered by low-intensity CYP clinicians (who are trained and experienced in delivering parent-led CBT for anxiety disorders and behavioural problems, Ludlow et al., 2020) as part of the CYP IAPT initiative.

Implications for future research examining brief low-intensity therapist guided, parent-led CBT for preadolescent children with OCD

As discussed throughout this Chapter, to advance this field of research, it will be necessary to use the existing qualitative research (i.e., Chapter 6) and further qualitative research and/or PPI work with key stakeholders (i.e., diverse parents, preadolescent children with different OCD presentations, and CWPs, EMHPs, and clinical leads) to maximise the acceptability and deliverability of low-intensity, therapist guided, parent-led CBT for this population. This work should involve identifying ways to reduce the perceived burdens of the treatment to parents and exploring ways to increase children's engagement with this approach (including an exploration of possible barriers that particular OCD presentations may pose in therapist guided, parent-led CBT and possible ways to overcome this). It will also be important to consider with stakeholders whether therapist guided, parent-led CBT can in fact be an acceptable and deliverable first-line intervention for preadolescent children with OCD or whether a more flexible approach (e.g., that involves the child to some degree) may be required.

One possible way to reduce the perceived burden of this treatment and to offer a flexible way to increase children's engagement could be to adapt the existing treatment so that it can be delivered via an internet platform (i.e., a low-intensity, internet delivered, therapist guided, parent-led CBT intervention). Low-intensity, internet delivered, therapist guided CBT (consisting of 12 online chapters for children and parents to complete with minimal therapist support) has been shown to be effective and cost-effective for children and adolescents with OCD when delivered as part of a stepped care model (Aspvall et al., 2021) and thus shows considerable promise for helping to increase access to CBT for children and adolescents with OCD. The evidence-base for low-intensity, internet delivered, therapist guided, *parent-led* CBT interventions for children with anxiety disorders is emerging, with Hill et al. (2022) demonstrating the preliminary efficacy of this approach in a routine clinical setting. However, to date, no such intervention for preadolescent children with OCD exists. Future qualitative/PPI work should therefore consider whether a low-intensity, internet delivered, therapist guided, parent-led CBT treatment could help to reduce the perceived burden of the treatment (i.e., by reducing the amount of therapist support required and enabling parents to access treatment content at a time/place that is convenient for them) and help to promote children's engagement in treatment (e.g., by having optional content for parents with tips on how to engage younger/older children or children with more stigmatised OCD presentations, and having optional online content for children to understand more about OCD and CBT if necessary).

Upon conducting this further intervention development/refinement work, an appropriate next step would be to conduct a feasibility study in the context in which this intervention is aimed to be delivered (i.e., by CWPs and EMHPs in MHSTs, CAMHS, local authority, and voluntary settings) (Skivington et al., 2021). In line with previous research (e.g., Taylor et al., 2019; Waite, 2022), the purpose of this feasibility study would be to obtain the necessary information (i.e., likely recruitment rates in clinical settings, drop-out rates, retention to follow-up assessments, staff training and supervision needs) to inform the design of a definitive randomised controlled trial (RCT) of this intervention, if warranted (Skivington et al., 2021).

Broader considerations for increasing access to CBT for preadolescent children with OCD

The aim of this thesis was to develop a *brief*, low-intensity therapist guided, parent-led CBT intervention for preadolescent children with OCD. Autistic children were excluded from this research, given that CBT treatments for autistic individuals are often longer and/or require specific adaptations (e.g., Jassi et al., 2021; Sze & Wood, 2007). Despite this, around 30% of autistic young people experience OCD (Szmatari et al., 1989; South et al., 2005) - thus, the decision to exclude autistic children from this research limits the usefulness of this intervention to services accessed by families with autistic children with OCD (e.g., CAMHS; Martin et al., 2020). Therefore, to truly increase access to treatment for *all* preadolescent children with OCD, once the initial efficacy of this treatment approach (for neurotypical preadolescent children with OCD) has been established, future developments of this treatment should involve autistic children with OCD and their parents to explore whether this brief treatment approach may be appropriate for this population, and if indicated, identify any treatment adaptations that may be required (Skivington et al., 2021).

To further increase access to evidence-based psychological treatments for all preadolescent children with OCD, it will also be necessary to consider further ways to reduce the amount of therapist input and time required to support families. Such possibilities include the use of chatbots (i.e., automated [often text-based] systems that can be programmed to detect and appropriately respond to an individual's mental health needs, Torous et al., 2021), guidance-on-demand (i.e., self-help interventions which have no pre-scheduled therapist support, however, individuals can request therapist support as needed, Brog et al., 2021), as well as peer-delivered interventions (i.e., where individuals with previous experience of a mental health problem/treatment are trained to deliver an evidence-based treatment to their peers, O'Hara et al., 2021). A peer-delivered treatment model may be particularly relevant to this population, given that some parents describe their experiences of parenting a preadolescent child with OCD as lonely and isolating and express a desire for general peer support (Chessell et al., 2022a). Furthermore, given that parents can lack confidence in their ability to help their child at the start of treatment (Chessell, Halldorsson et al., 2022), parents may find it encouraging to receive the treatment from parents who have been able to support their child to overcome OCD. Trained peer-supporters may also be able to share their own reflections of the 'ingredients for success' in this treatment (e.g., by sharing their experiences of how they motivated their child to engage in the treatment) which may help to facilitate other families' treatment journeys. Despite these potential benefits, it would be interesting to explore whether a peer-delivered treatment model would be acceptable to parents, as although parents' experiences indicate that this model could be acceptable, parents have also stressed the importance of having a 'professional' to guide them on how to help their child (Chessell et al., 2022b) and valued regular therapist support during the treatment (Chessell, Halldorsson et al., 2022). Thus, for any of the above options to be an acceptable future possibility, it will be essential to conduct appropriate PPI and co-production work with all key stakeholders (Skivington et al., 2021; National Institute for Health and Care Research [NIHR], 2021).

7.3 Strengths and limitations of this thesis

Strengths of this thesis include the exclusive focus on preadolescent children with OCD. As highlighted throughout this thesis, the existing literature typically examines preadolescent children and adolescents as one group, despite key social and cognitive differences (Yurgelun-Todd, 2007) that may influence the maintenance and treatment of the disorder. The use of a mixed-methods approach to this thesis also helped to provide a more detailed understanding of OCD in preadolescent children (Doyle et al., 2016). For example, the results of the systematic review (Paper 1), qualitative study (Paper 2), and treatment study (Paper 3) all built on each other to help identify possible promising maintenance mechanisms to focus on in future research. Moreover, research conducted for this thesis lead to the development of an intervention that has the potential to be accessible and scalable within the existing NHS mental health system (i.e., the CYP IAPT programme) and thus, could substantially increase access to treatments for preadolescent children with OCD in the future. Furthermore, we involved key stakeholders throughout the development of the intervention. For example, we ensured that parents' experiences and treatment views (identified from the qualitative research) informed the developed intervention. We also conducted PPI work with parents more generally (whose children were roughly aged 5- to 12-years-old), parents of children with OCD (roughly aged 5- to 12-years-old) and national charities (who specialise in supporting individuals and families affected by OCD) to refine the treatment materials. Two NHS Clinical Psychologists were also involved in developing and refining the treatment materials.

Despite these strengths, it is important to consider the limitations of this thesis. First, this project would have benefited from the use of specific frameworks designed to aid intervention development, evaluation, and implementation. For example, the Medical Research Council (MRC) and NIHR framework for the development of complex interventions (Skivington et al., 2021). This framework consists of four phases (i.e., developing/choosing an intervention, feasibility, evaluation, and implementation) each with six core considerations (i.e., context, uncertainties, stakeholder views, intervention theory, intervention refinement, and economic considerations) (Skivington et al., 2021). Context is one core consideration and although this was considered during the intervention development (i.e., this intervention was developed with intention for it to be delivered by CWPs and EMHPs working in MHSTs, CAMHS, local authority, and voluntary settings), the use of the MRC/NIHR framework would have emphasised the need to consider context more heavily at the onset and throughout this project (e.g., by involving CWPs, EMHPs, and clinical leads throughout the intervention development and evaluation to ensure that this project addressed key research questions from their perspective, met their needs, and addressed any possible implementation barriers early on) (Skivington et al., 2021).

Relatedly, this project may have benefitted from being co-produced with key stakeholders. Co-produced research actively involves key stakeholders at the onset of the research project with the aim of developing interventions *with* rather than *for* affected individuals (Hodson et al., 2019). The National Institute for Health Research (NIHR, 2021) states that co-produced research should involve the perspectives of *all* relevant stakeholders, consist of *shared* decision-making, and *mutually benefit* all stakeholders involved. Whilst this project shares some features of co-production (i.e., by collaborating with Clinical Psychologists from Berkshire Healthcare NHS Foundation Trust, conducting qualitative interviews with parents with the aim of facilitating intervention development and evaluation, and conducting PPI work with relevant stakeholders), this project would have benefitted from involving additional key stakeholders throughout the project (e.g., preadolescent children with OCD and low-intensity practitioners). Moreover, although parents' experiences and views directly shaped the adapted intervention, parents were not given the opportunity to mutually decide upon the final treatment approach. Thus, moving forwards, it will be essential to consider relevant frameworks to help explore whether and how low-intensity therapist guided, parent-led CBT for preadolescent children with OCD can meet the needs of *all* relevant stakeholders, in turn, helping to maximise the adoption and use of this intervention in routine clinical practice (Skivington et al., 2021).

Furthermore, as highlighted throughout this thesis, although we aimed to recruit a diverse range of parents for both the qualitative study (Paper 2) and the treatment study (Paper 3) by advertising the study through a broad range of recruitment pathways (i.e., clinical services, social media, UK-based mental health charities), the parents who participated in these studies were predominantly White British and/or University educated. The lack of ethnic diversity in these studies is not dissimilar to the existing literature, as Williams et al. (2010) highlight the distinct lack of participation of ethnic minority individuals in adult and child OCD treatment trials. This is a limitation given that individuals from different cultural backgrounds may have different experiences of OCD symptoms (e.g., Cordeiro et al., 2015; Wheaton et al., 2013; Williams & Jahn, 2017; Wilson & Thayer, 2020) that may influence the maintenance and treatment of the disorder (Ouimet et al., 2021). Furthermore, the lack of non-University educated parents who participated in this research is a clear limitation, as parents from more diverse educational backgrounds may have specific needs that need to be addressed in order for a brief low-intensity therapist guided, parent-led CBT intervention to be successful.

Another notable limitation of this thesis is the research team's allegiance to therapist guided, parent-led CBT. Although I had no prior experience of parent-led CBT before commencing this research, I developed considerable experience in the delivery of parent-led CBT prior to conducting the qualitative interviews exploring parents' experiences and treatment views and prior to the developing the adapted intervention. CCr, BH, AF, and SW also had considerable expertise in parent-led CBT. Whilst this can be considered a strength, as the research team could draw on relevant clinical experiences and reflections to inform the development and delivery of the adapted treatment, the research team's allegiance to parent-led CBT had the potential to considerably shape this thesis and may have influenced the preliminary outcomes of the treatment. To help mitigate this, KH (who is not a clinician and does not have allegiance to parent-led CBT) was involved throughout this work given her impartiality. KH's involvement helped to ensure that the research team remained open minded that parent-led CBT may not be an acceptable intervention for parents of children with OCD when conducting the qualitative interviews in Paper 2 and Paper 3. This was achieved in Paper 2 (Qualitative Study) by exploring parents' views towards different ways parents can be involved in CBT for their child (rather than just their views towards parent-led CBT), to ensure that parents' broader treatment views were heard and could be used to determine whether parent-led CBT may be an acceptable intervention for this population. Furthermore, in Paper 3 (Treatment Study), the inclusion of KH in the qualitative analysis ensured that both positive and negative experiences of parent-led CBT received equal attention and were reflected in the qualitative results. Despite this, researcher allegiance may have impacted the treatment outcomes in Paper 3 (Munder et al., 2013). Specifically, given that it was not feasible to use blind assessors to conduct and score the diagnostic assessments (which were conducted by CCh, and scored by CCh/CCr/SW), it is possible that the effects of the intervention were overestimated (Savović et al., 2018). However, parent-reported questionnaire measures were completed on a regular basis to help mitigate this.

7.4 Conclusions

This thesis has demonstrated that brief low-intensity therapist guided, parent-led CBT may be an effective, efficient, and acceptable way to substantially increase access to CBT for preadolescent children with OCD. We adapted an existing evidence-based therapist guided, parent-led CBT intervention for children with anxiety disorders to ensure suitability for children with OCD using the findings of Paper 1 (Systematic Review), Paper 2 (Qualitative Study), and Chapter 4 (Qualitative work). Paper 1 identified the scarcity of research examining maintenance mechanisms relevant to childhood OCS/OCD and highlighted the clear need for future high quality research in this area to increase the efficacy and efficiency of new and existing paediatric OCD treatments. Paper 2 and Chapter 4 provided a detailed insight into parental experiences and treatment views that directly informed the necessary adaptations of the treatment. In Paper 3 (Treatment Study) an initial evaluation of the adapted treatment was conducted and provided preliminary evidence for the efficacy and acceptability of the treatment, and in Chapter 6 (Qualitative work) key ways to improve the acceptability of the intervention to parents were identified.

To further advance this line of research, future research should (1) use experimental and longitudinal designs to establish the maintenance mechanisms that need to be targeted in brief low-intensity therapist guided parent-led CBT for preadolescent children with OCD, (2) use relevant frameworks (i.e., Skivington et al., 2021; NIHR, 2021) to refine the intervention to reflect parents' experiences of receiving the intervention and conduct further qualitative and/or PPI work with diverse parents, preadolescent children with different OCD presentations, and CWPs, EHMPs, and clinical leads to ensure that the intervention is acceptable and deliverable in routine services and (3) use relevant frameworks (i.e., Skivington et al., 2021) to conduct a feasibility study of the refined intervention in an MHST and/or CAMHS service to gather necessary information to inform a definitive RCT of this intervention, if warranted.

7.5 References

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Chapter 8: Appendices

Appendix 1: Ethical Approval Letters

University of Reading Research Ethics Committee Approval (Paper 2)

NHS Research Ethics Committee Approval (Paper 2)

Health Research Authority Approval (Paper 2)

University of Reading Research Ethics Committee Approval (Paper 3)

NHS Research Ethics Committee Approval (Paper 3)

Health Research Authority Approval (Paper 3)

University of Reading Research Ethics Committee Approval (Paper 2)

University of Reading

Coordinator for Quality Assurance in Research
Dr Mike Proven, BSc(Hons), PhD

Academic and Governance Services
Whiteknights House
Whiteknights, PO Box 217
Reading RG6 6AH
phone +44 (0)118 378 7119
email urec@reading.ac.uk

Dr Kate Harvey
School of Psychology and Clinical Language
Sciences
University of Reading
RG6 6AL

1 May 2019

Dear Kate,

UREC 19/09: Parents' experiences of parenting a child with Obsessive Compulsive Symptoms/Disorder. *Favourable opinion*

Thank you for your application (emails, dated 3rd and 11th April 2019 and including attachments, from Liz White and Chloe Chessell refers) for review of the above project which was considered by a UREC Sub-committee on Wednesday 1 May 2019. I can confirm that the Chair is pleased to confirm a favourable ethical opinion on the basis of the information that was reviewed by the sub-committee.

Please note that the Committee will monitor the progress of projects to which it has given favourable ethical opinion approximately one year after such agreement, and then on a regular basis until its completion.

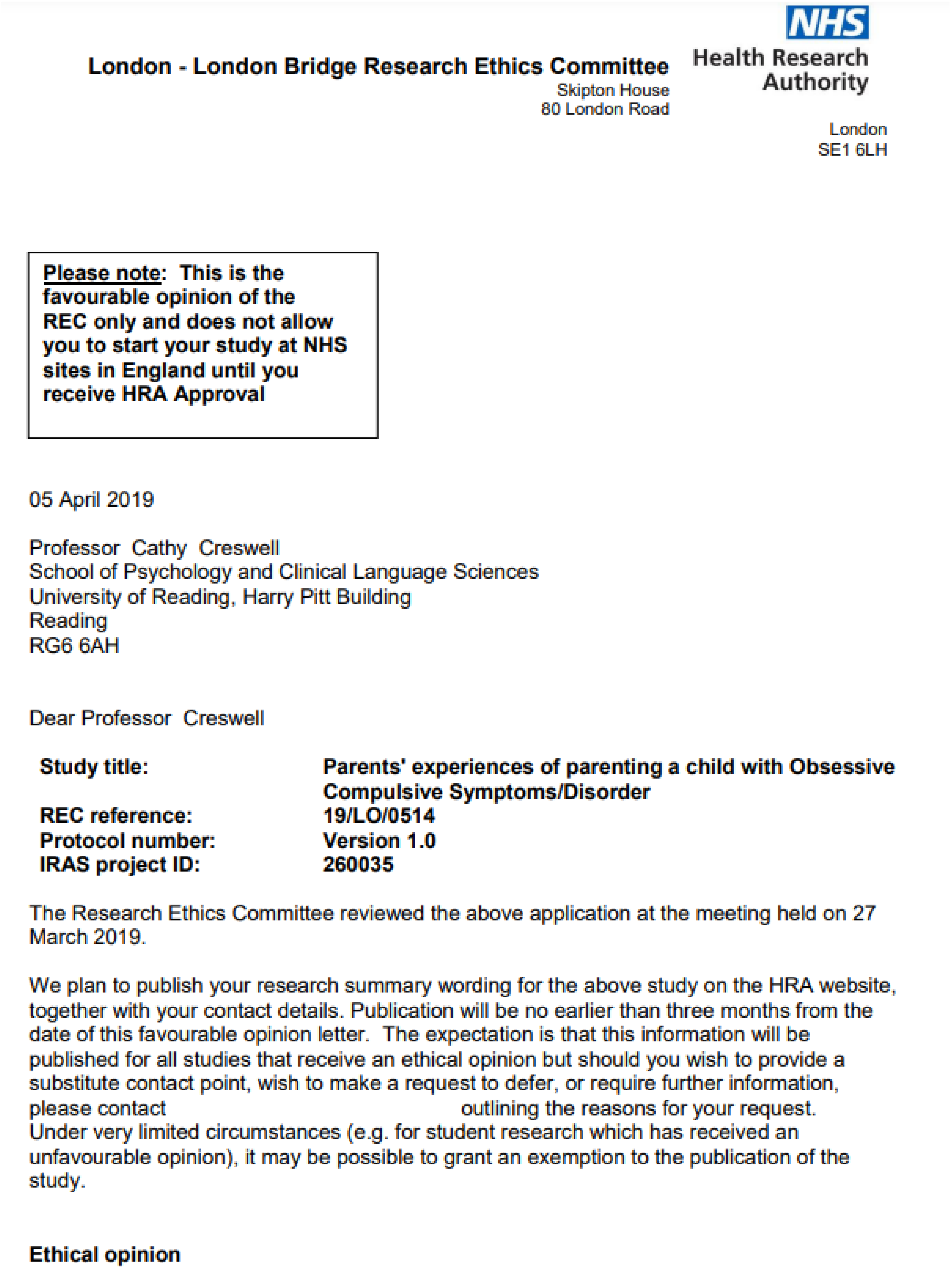
Please also find attached Safety Note 59: Incident Reporting in Human Interventional Studies at the University of Reading, to be followed should there be an incident arising from the conduct of this research.

The University Board for Research and Innovation has also asked that recipients of favourable ethical opinions from UREC be reminded of the provisions of the University Code of Good Practice in Research. A copy is attached and further information may be obtained here: https://www.reading.ac.uk/internal/academic-and-governance-services/quality-assurance-in-research/reas-RSqar.aspx
Yours sincerely

Dr M J Proven
Coordinator for Quality Assurance in Research (UREC Secretary)

cc: Dr John Wright (Chair); Dr Andrew Glennerster (SREC Chair); Ms Chloe Chessell (Researcher); Ms Liz White (Ethics Administrator);

NHS Research Ethics Committee Approval (Paper 2)



London - London Bridge Research Ethics Committee
Skipton House
80 London Road
London
SE1 6LH

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

05 April 2019

Professor Cathy Creswell
School of Psychology and Clinical Language Sciences
University of Reading, Harry Pitt Building
Reading
RG6 6AH

Dear Professor Creswell

Study title:	**Parents' experiences of parenting a child with Obsessive Compulsive Symptoms/Disorder**
REC reference:	**19/LO/0514**
Protocol number:	**Version 1.0**
IRAS project ID:	**260035**

The Research Ethics Committee reviewed the above application at the meeting held on 27 March 2019.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Advertisement]	Version 1.0	25 February 2019
Covering letter on headed paper [Cover_Letter]		25 February 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		25 February 2019
Interview schedules or topic guides for participants [Topic_Guide]	Version 1.0	25 February 2019
IRAS Application Form [IRAS_Form_26022019]		26 February 2019
Letter from funder [Funder_Letter]		25 February 2019
Letter from sponsor		25 February 2019
Non-validated questionnaire [Screening_Questions]	Version 1.0	25 February 2019
Other [Consent_To_Be_Contacted]	Version 1.0	25 February 2019
Other [Risk_Management_Protocol]	Version 1.0	25 February 2019
Other [Parent_Fact_Sheet]	Version 1.0	25 February 2019
Participant consent form [Participant_Study_Consent_Form]	Version 1.0	25 February 2019
Participant information sheet (PIS) [Participant_Information_Sheet]	Version 1.0	25 February 2019
Research protocol or project proposal [Research_Protocol]	Version 1.0	25 February 2019
Summary CV for Chief Investigator (CI) [Chief_Investigator_CV]		25 February 2019
Summary CV for student [Student_CV]		25 February 2019
Summary CV for supervisor (student research) [Supervisor_CV_Brynjar_Halldorsson]		25 February 2019
Summary CV for supervisor (student research) [Supervisor_CV_Cathy_Creswell]		25 February 2019
Validated questionnaire [ChOCI_Parent_Report]		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/LO/0514 **Please quote this number on all correspondence**

With the Committee’s best wishes for the success of this project.

Yours sincerely
PP:

Ms Jane Smith
Chair

E-mail:

London - London Bridge Research Ethics Committee

Attendance at Committee meeting on 27 March 2019

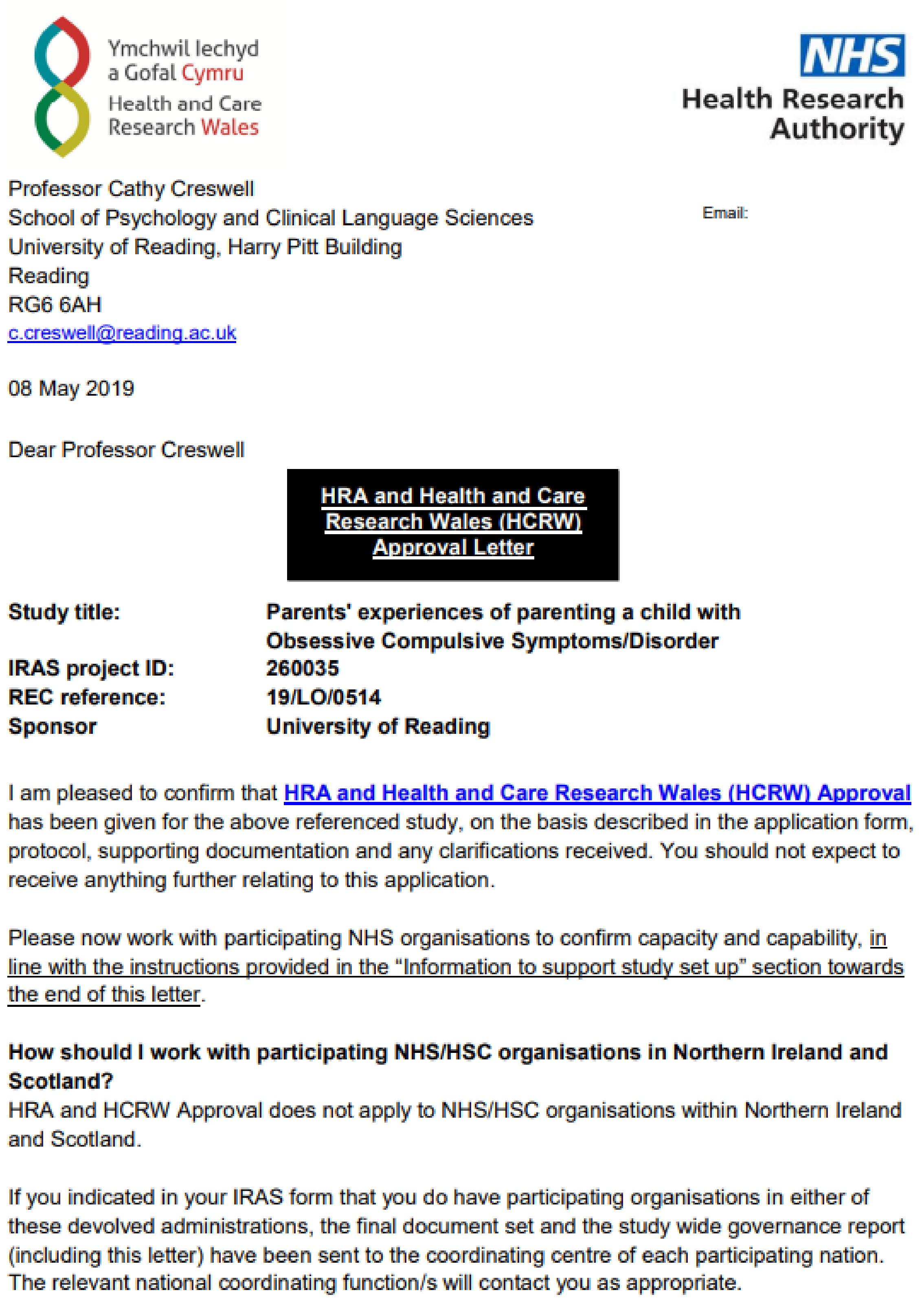
Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Ahmed Al-Nagar	Lead Pharmacist	Yes	
Dr Hilary Crowe	Student of Biomedicine at Birkbeck	No	
Mr David Gallacher	Consultant Physicist	Yes	
Miss Alice Glaser	Investigator Initiated Trials Coordinator	Yes	
Mr Nicholas Harper	Project Manager	Yes	
Dr Alex Hatziagorakis	Consultant Psychiatrist	Yes	
Ms Kate Melvin	Freelance Qualitative Researcher	Yes	
Mr Barry Moody	Retired solicitor/partner in law firm	Yes	
Bernadette Roberts	Retired Finance Manager	Yes	
Ms Jane Smith	Retired medical journal editor (BMJ)	Yes	
Miss Anna Stockwell	Early Phase Trials Coordinator	No	
Mrs Roberta Tucker	Senior Director Global Quality Assurance	Yes	
Dr Shelley Watcham	Medical Advisor	No	
Dr Ralph White	Pharmacist	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mr Connor Frost	Approvals Officer

Health Research Authority Approval (Paper 2)



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Professor Cathy Creswell
School of Psychology and Clinical Language Sciences
University of Reading, Harry Pitt Building
Reading
RG6 6AH
c.creswell@reading.ac.uk

Email:

08 May 2019

Dear Professor Creswell

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Parents' experiences of parenting a child with Obsessive Compulsive Symptoms/Disorder**
IRAS project ID:	**260035**
REC reference:	**19/LO/0514**
Sponsor	**University of Reading**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **260035**. Please quote this on all correspondence.

Yours sincerely,
Gemma Oakes

Approvals Specialist

Email:

Copy to: *Dr Mike Proven, University of Reading [Sponsor Contact]*
m.j.proven@reading.ac.uk

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

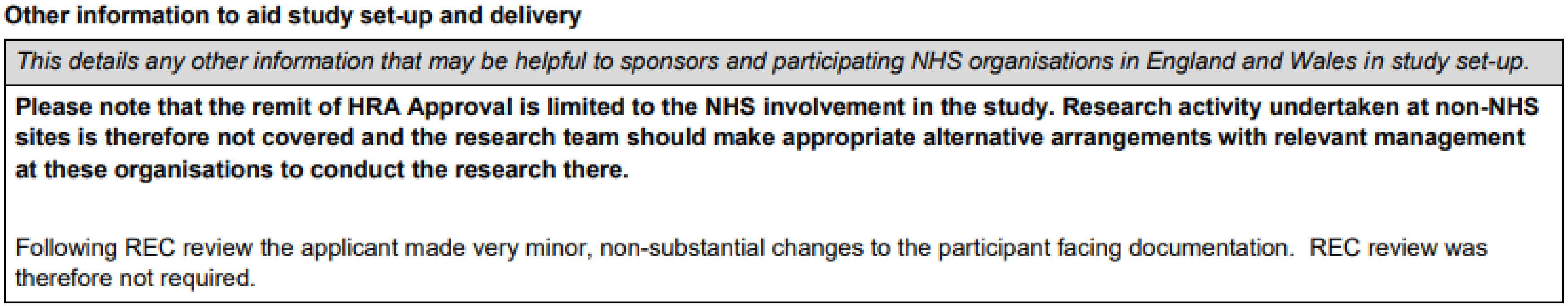
Document	*Version*	*Date*
Copies of advertisement materials for research participants [Advertisement]	Version 1.0	25 February 2019
Covering letter on headed paper [Cover_Letter]		25 February 2019
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only)		25 February 2019
HRA Schedule of Events [Recruiting Site]	3	30 April 2019
HRA Statement of Activities [Recruiting Site]	2	30 April 2019
Interview schedules or topic guides for participants [Topic_Guide]	Version 1.0	25 February 2019
IRAS Application Form [IRAS_Form_26022019]		26 February 2019
IRAS Application Form XML file [IRAS_Form_26022019]		26 February 2019
Letter from funder [Funder_Letter]		25 February 2019
Letter from sponsor		25 February 2019
Other [Consent_To_Be_Contacted]	Version 1.0	25 February 2019
Other [Risk_Management_Protocol]	Version 1.0	25 February 2019
Other [Parent_Fact_Sheet]	Version 1.0	25 February 2019
Other [Screening Questions]	**2**	**12 April 2019**
Participant consent form	**3**	**16 April 2019**
Participant information sheet (PIS)	**3**	**23 April 2019**
Research protocol or project proposal [Research_Protocol]	Version 1.0	25 February 2019
Summary CV for Chief Investigator (CI) [Chief_Investigator_CV]		25 February 2019
Summary CV for student [Student_CV]		25 February 2019
Summary CV for supervisor (student research) [Supervisor_CV_Brynjar_Halldorsson]		25 February 2019
Summary CV for supervisor (student research) [Supervisor_CV_Cathy_Creswell]		25 February 2019
Validated questionnaire [ChOCI_Parent_Report]		

IRAS project ID	260035

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

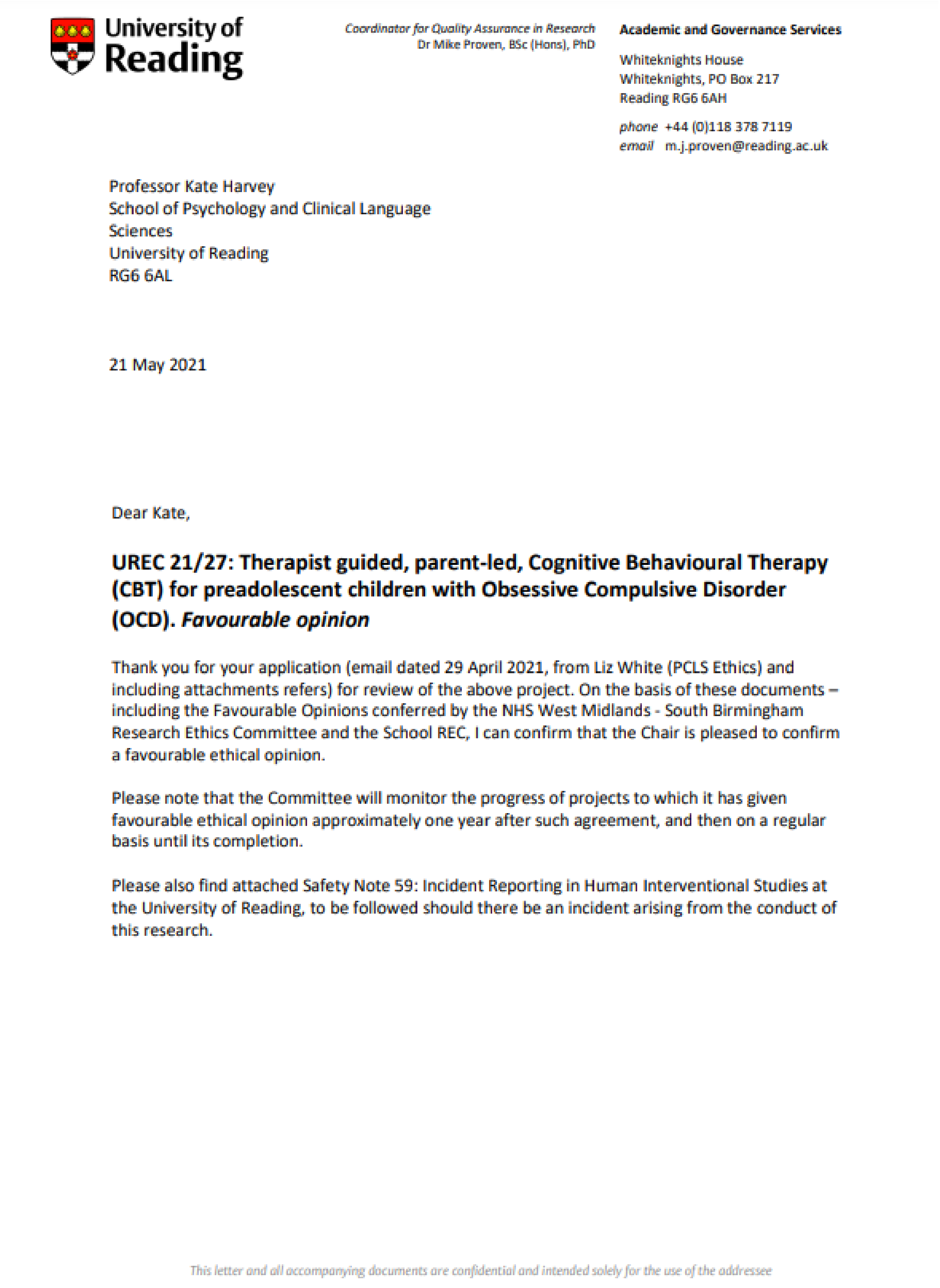
Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is one site type participating in the study. All research activities are the same at the participating NHS sites as detailed in the study protocol and supporting documentation, as follows: Local members of staff will identify and approach potentially eligible participants and obtain consent for them to be contacted directly by the research team.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	A statement of activities has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	The study is funded by Economic & Social Research Council. The sponsor has confirmed funding will **not** be provided to the participating NHS site.	A Local Principal Investigator is required at the participating NHS site, and has already been identified.	The activities at the participating NHS organisation will be undertaken by local clinical team therefore contractual relationships with the host organisation are in place. No additional arrangements (honorary research contracts or letters of access) are expected for this study.



Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
Please note that the remit of HRA Approval is limited to the NHS involvement in the study. Research activity undertaken at non-NHS sites is therefore not covered and the research team should make appropriate alternative arrangements with relevant management at these organisations to conduct the research there. Following REC review the applicant made very minor, non-substantial changes to the participant facing documentation. REC review was therefore not required.

University of Reading Research Ethics Committee Approval (Paper 3)



University of Reading

Coordinator for Quality Assurance in Research
Dr Mike Proven, BSc (Hons), PhD

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Professor Kate Harvey
School of Psychology and Clinical Language
Sciences
University of Reading
RG6 6AL

21 May 2021

Dear Kate,

UREC 21/27: Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD). ***Favourable opinion***

Thank you for your application (email dated 29 April 2021, from Liz White (PCLS Ethics) and including attachments refers) for review of the above project. On the basis of these documents – including the Favourable Opinions conferred by the NHS West Midlands - South Birmingham Research Ethics Committee and the School REC, I can confirm that the Chair is pleased to confirm a favourable ethical opinion.

Please note that the Committee will monitor the progress of projects to which it has given favourable ethical opinion approximately one year after such agreement, and then on a regular basis until its completion.

Please also find attached Safety Note 59: Incident Reporting in Human Interventional Studies at the University of Reading, to be followed should there be an incident arising from the conduct of this research.

The University Board for Research and Innovation has also asked that recipients of favourable ethical opinions from UREC be reminded of the provisions of the University Code of Good Practice in Research. A copy is attached and further information may be obtained here:

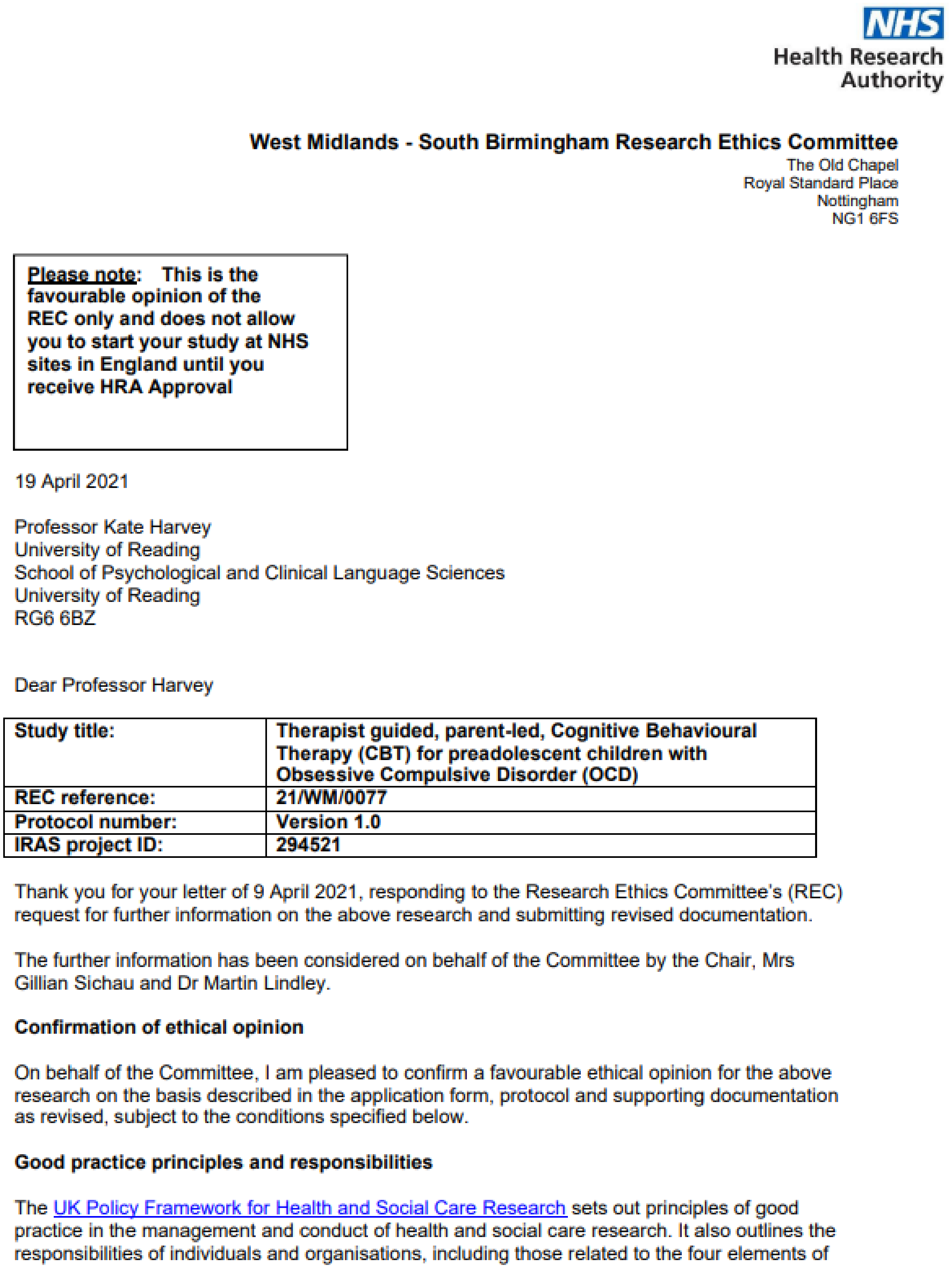
http://www.reading.ac.uk/internal/res/QualityAssuranceInResearch/reas-RSqar.aspx.

Yours sincerely

Dr M J Proven
Coordinator for Quality Assurance in Research (UREC Secretary)

cc PCLS ethics; Chloe Chessell (PhD student)

NHS Research Ethics Committee Approval (Paper 3)



NHS
Health Research
Authority

West Midlands - South Birmingham Research Ethics Committee
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

19 April 2021

Professor Kate Harvey
University of Reading
School of Psychological and Clinical Language Sciences
University of Reading
RG6 6BZ

Dear Professor Harvey

Study title:	**Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD)**
REC reference:	**21/WM/0077**
Protocol number:	**Version 1.0**
IRAS project ID:	**294521**

Thank you for your letter of 9 April 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair, Mrs Gillian Sichau and Dr Martin Lindley.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:
https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at:
https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Study_Advert_1]	1.0	23 February 2021
Copies of materials calling attention of potential participants to the research [Study_Advert_2]	1.0	23 February 2021
Copies of materials calling attention of potential participants to the research [Study_Advert_3]	1.0	23 February 2021
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Covering letter on headed paper [Cover_Letter]	1.0	23 February 2021
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Interview schedules or topic guides for participants [Topic_Guide]	1.0	23 February 2021
IRAS Application Form [IRAS_Form_02032021]		02 March 2021
Letter from funder [Funder_Letter]	1.0	23 February 2021
Letter from sponsor [Letter from sponsor]	1.0	24 February 2021
Non-validated questionnaire [Non_Validated_Questionnaire_Parent knowledge and confidence]	1.0	23 February 2021
Non-validated questionnaire [Non_Validated_Questionnaire_Child_Learning]	1.0	23 February 2021
Non-validated questionnaire [Non_Validated_Questionnaire_Treatment_Acceptability]	1.0	23 February 2021
Non-validated questionnaire [Screening_Questions]	1.0	23 February 2021
Non-validated questionnaire [Demographic_Questions_Qualitative_Interviews]	1.0	23 February 2021
Other [Application Clarification]		04 March 2021
Other [Responses to Provisional Opinion_09_04_2021]	1.0	09 April 2021
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Participant consent form [Child_Assent_Form]	1.0	23 February 2021
Participant consent form [Parent_Consent_Child_Participation_Form]	1.0	23 February 2021
Participant consent form [Parent_Consent_Form]	2.0	29 March 2021
Participant consent form [Parent_Consent_Qualitative_Interviews]	2.0	29 March 2021
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Summary CV for student [Student_CV]	1.0	23 February 2021

Summary CV for supervisor (student research) [Supervisor_1_CV]	1.0	23 February 2021
Summary CV for supervisor (student research) [Supervisor_2_CV]	1.0	23 February 2021
Summary CV for supervisor (student research) [Supervisor_3_CV]	1.0	23 February 2021
Summary CV for supervisor (student research) [Supervisor_4_CV]	1.0	23 February 2021
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study_Flow_Chart]	1.0	23 February 2021
Validated questionnaire [Validated_Diagnostic_Interview_CYBOCS]	1.0	23 February 2021
Validated questionnaire [Validated_Diagnostic_Interview_ADIS-P]	1.0	23 February 2021
Validated questionnaire [Validated_Questionnaire_ChOCI-R-P]	1.0	23 February 2021
Validated questionnaire [Validated_Questionnaire_FAS]	1.0	23 February 2021
Validated questionnaire [Validated_Questionnaire_SCQ]	1.0	23 February 2021
Validated questionnaire [Validated_Questionnaire_Session_Rating_Scale]	1.0	23 February 2021

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 294521 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

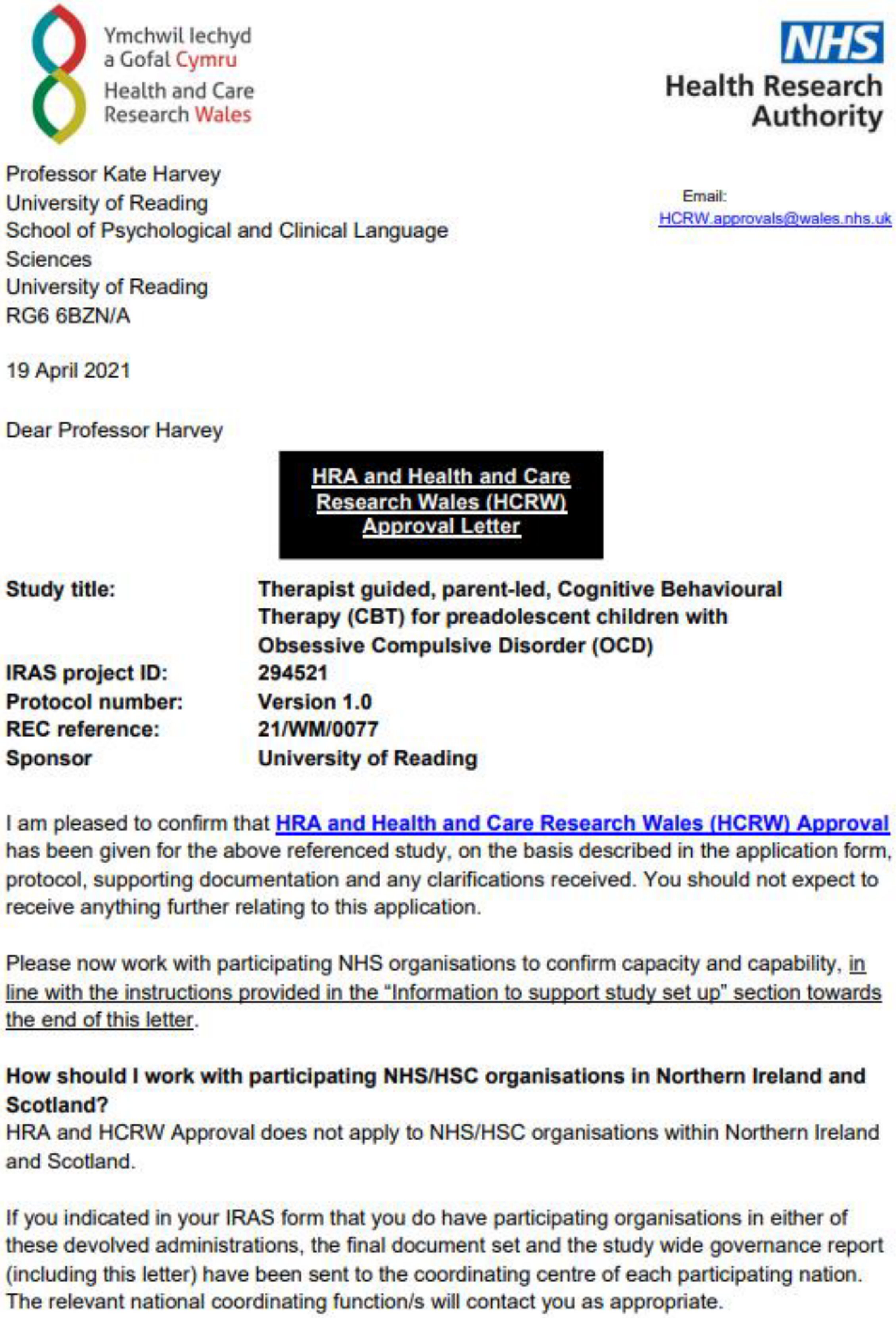
Yours sincerely

Professor Paula McGee
Chair

Email:

Copy to: Dr Mike Proven

Health Research Authority Approval (Paper 3)



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Professor Kate Harvey
University of Reading
School of Psychological and Clinical Language
Sciences
University of Reading
RG6 6BZN/A

Email:
HCRW.approvals@wales.nhs.uk

19 April 2021

Dear Professor Harvey

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD)**
IRAS project ID:	**294521**
Protocol number:	**Version 1.0**
REC reference:	**21/WM/0077**
Sponsor	**University of Reading**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Please quote this on all correspondence.

Yours sincerely,

Harriet Wood
Approvals Specialist
Email:
Copy to: *Dr Mike Proven*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

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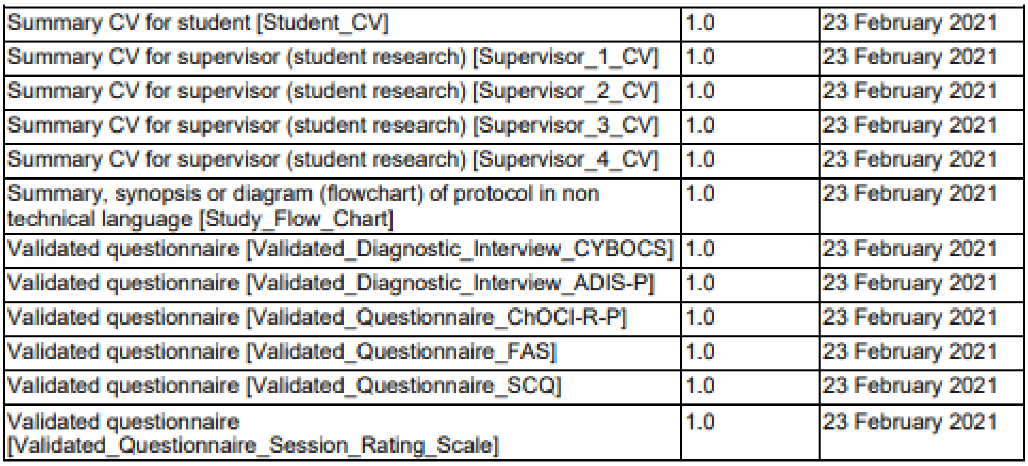
Summary CV for Chief Investigator (CI) [Chief_Investigator_CV]	1.0	23 February 2021



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Validated questionnaire [Validated_Questionnaire_SCQ]	1.0	23 February 2021
Validated questionnaire [Validated_Questionnaire_Session_Rating_Scale]	1.0	23 February 2021

IRAS project ID	294521

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is only one participating NHS organisation therefore there is only one site type.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used. The Sponsor was advised that we would normally expect a separate site agreement (the model Non-Commercial Agreement) to be used for studies which are interventional. The Sponsor has confirmed they intend to use the organisation information document as the agreement because the studentship for the PhD student involved in the study is a collaborative studentship with BHFT, and because the Protocol has been jointly developed with staff at	No study funding will be provided to sites as per the Organisation Information Document.	A Principal Investigator should be appointed at study sites.	Where arrangements are not already in place, network staff (or similar) undertaking any of the research activities listed in the IRAS form(except for administration of questionnaires or surveys), would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm enhanced DBS checks, including appropriate

		BHFT. The HRA and HCRW take no position on the acceptability of this proposal. Participating NHS organisations should now determine its acceptability and liaise with the sponsor to confirm whether this is acceptable or whether a separate agreement should be put in place.			barred list checks, and occupational health clearance. For research team members only administering questionnaires or surveys, a Letter of Access based on enhanced DBS checks and occupational health clearance would be appropriate.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 2: Information Sheets for Parents and Children

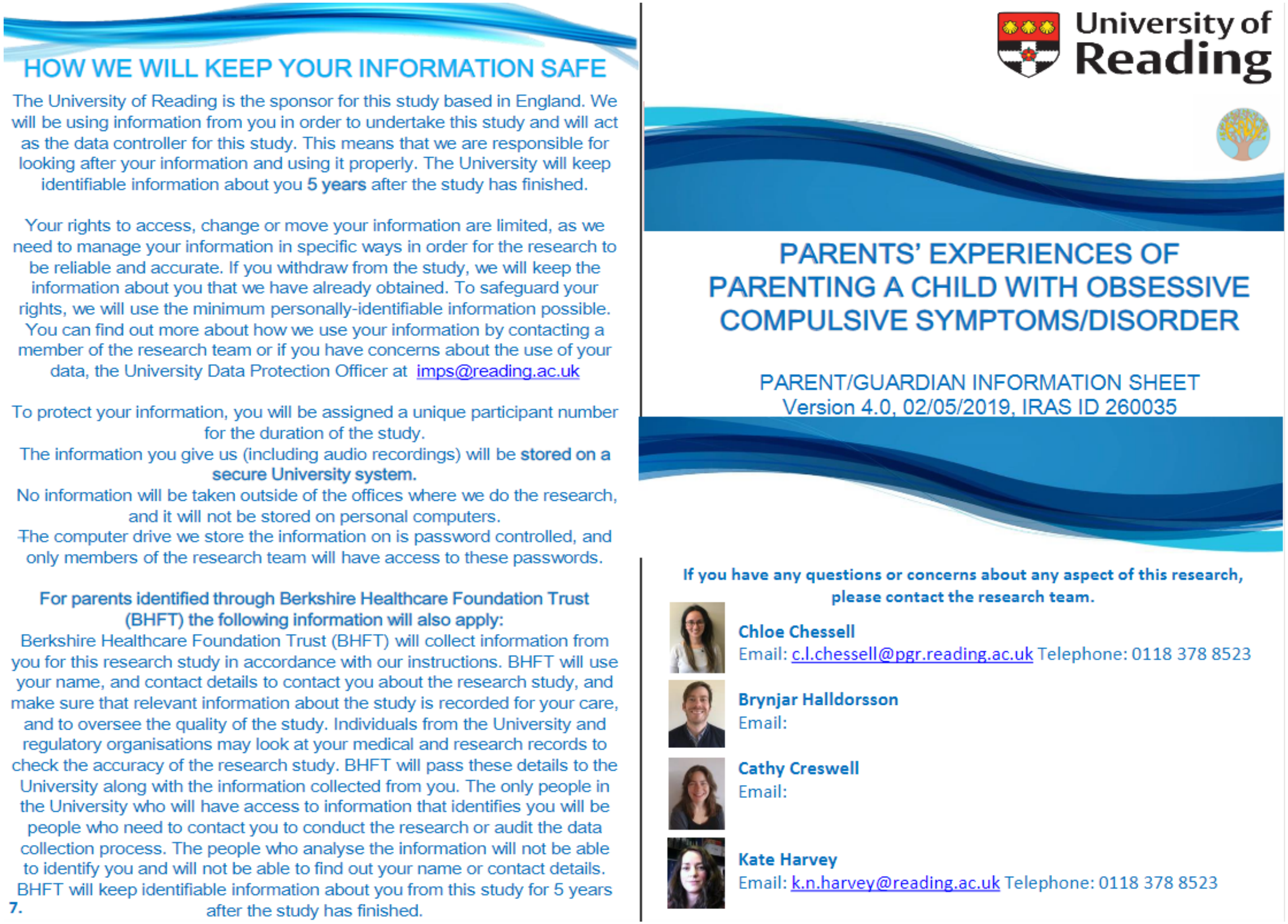
Information sheet for parents (Paper 2)

Information sheet for parents – treatment study (Paper 3)

Information sheet for children – treatment study (Paper 3)

Information sheet for parents – qualitative interview (Paper 3)

Information sheet for parents (Paper 2)



HOW WE WILL KEEP YOUR INFORMATION SAFE

The University of Reading is the sponsor for this study based in England. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University will keep identifiable information about you **5 years** after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information by contacting a member of the research team or if you have concerns about the use of your data, the University Data Protection Officer at imps@reading.ac.uk

To protect your information, you will be assigned a unique participant number for the duration of the study.
The information you give us (including audio recordings) will be **stored on a secure University system.**
No information will be taken outside of the offices where we do the research, and it will not be stored on personal computers.
The computer drive we store the information on is password controlled, and only members of the research team will have access to these passwords.

For parents identified through Berkshire Healthcare Foundation Trust (BHFT) the following information will also apply:
Berkshire Healthcare Foundation Trust (BHFT) will collect information from you for this research study in accordance with our instructions. BHFT will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from the University and regulatory organisations may look at your medical and research records to check the accuracy of the research study. BHFT will pass these details to the University along with the information collected from you. The only people in the University who will have access to information that identifies you will be people who need to contact you to conduct the research or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. BHFT will keep identifiable information about you from this study for 5 years after the study has finished.

7.

University of Reading

PARENTS' EXPERIENCES OF PARENTING A CHILD WITH OBSESSIVE COMPULSIVE SYMPTOMS/DISORDER

PARENT/GUARDIAN INFORMATION SHEET
Version 4.0, 02/05/2019, IRAS ID 260035

If you have any questions or concerns about any aspect of this research, please contact the research team.

Chloe Chessell
Email: c.l.chessell@pgr.reading.ac.uk Telephone: 0118 378 8523

Brynjar Halldorsson
Email:

Cathy Creswell
Email:

Kate Harvey
Email: k.n.harvey@reading.ac.uk Telephone: 0118 378 8523

OVERVIEW:
WHAT IS THIS ALL ABOUT?

We are carrying out a research project to find out about parents' experiences of parenting a child with OCD, and their views/preferences towards parent involvement in Cognitive Behaviour Therapy (CBT) for children with OCD.

We would like to invite you to take part.

Here, you will find information which we hope will help you to decide whether to take part in this research.

What you can find in this leaflet:

Page 2 An overview of the study

Page 3 Advantages of taking part in this study

Page 4 Disadvantages of taking part in this study

Page 5 What you will be asked to do

Page 6 Important points about this study

Page 7 How your information is stored and kept safe

IMPORTANT POINTS

You **do not have to take part** in this study, and you have the right to withdraw from the study at any time.

Taking part, or deciding not to take part, will **not affect your son/daughter's current or future treatment**.

All information and research data will be kept **confidential and secure**

Please see page 7 for more information about how we keep your information safe

The only time we share information without agreement, is if we believe someone is at risk of harm. In this case, we would speak to you first.

Interviews will be **audio recorded** so we can carry out a detailed analysis of what parents tell us.

When we write up our research, we will include some **quotes from the interviews** so people know the important things that were said. **We will not use any real names**, so people will not be able to identify who said what.

WHAT WE WILL BE ASKING YOU TO DO

We will ask you to complete some **short questionnaires** to confirm you are eligible for the study.

If you are **eligible** to take part in the study, you may be asked to take part in an **interview**

If you are **not eligible** to take part, you will be informed that you do not need to take part in an interview

The **interview** will be with a member of the research team, at a convenient time for you

You can choose whether the interview is held at the University of Reading, Berkshire Healthcare NHS Foundation Trust, your home, telephone or Skype

What happens now

- **If you would like to take part**: if you have provided permission for a member of the research team to contact you, you will be contacted by the research team and you can let them know you wish to take part.

- **If you do not want to take part:** you do not need to do anything.

AN OVERVIEW OF THE STUDY

We want to understand **parents' experiences** of parenting a child with Obsessive Compulsive Disorder (OCD), and **their views/preferences** towards parent involvement in Cognitive Behaviour Therapy (CBT) for children with OCD.

This study is relevant to you if your son/daughter:

- Is aged 7 to 12 years old and is suspected to have OCD, or has a current diagnosis of OCD, or is aged 7 to 14 years old and has previously been diagnosed with OCD (when aged between 7 and 12 years old).
- If you are yet to seek professional support for your child's OCD; if your child is on the waitlist or receiving any form of treatment for OCD, or if your child has previously received any form of treatment for OCD (when aged between 7 and 12 years old).

By hearing parents' experiences and views, we hope to develop treatments that families want and need.

We will ask you to complete **short questionnaires** to confirm you are eligible to take part in the study. These questionnaires will ask about your child's OCD, any treatment they have received, and general questions about your family. It is expected this will take approximately **10 to 25 minutes.**

If you are eligible to take part, **we may then ask you to attend an interview**. Before the interview, we will give you information on what CBT for OCD is, and how parents can be involved. During the interview, we will ask you about your experiences of parenting your child, and your views/preferences towards parent involvement in treatment.

We expect the interview will take approximately **45 minutes**

ADVANTAGES OF TAKING PART

By taking part in this research, you will be helping us to understand **how we can best support parents** whose children suffer from OCD, and **help us to design treatments** which are suited to families' experiences and needs.

During the interview, you will have the opportunity to **share your experiences** of parenting a child with OCD, and **share your views** about whether parents should be involved in treatment.

If you wish, we can send you a summary of the study and the findings once the research is completed.

You will be given a **£10 voucher** to thank you for taking part in the interview.

THE DISADVANTAGES OF TAKING PART

This interview may involve discussing sensitive topics

However, you will be **able to decide what you want to talk about**, and we will not ask you to discuss anything you do not wish to.

You can take breaks during the interview, and stop at any time. If you become upset, we will always ask if you want to continue the interview or not.

We **do not expect any harm to come to you** from taking part in this study. This study has been reviewed and given a **favourable ethical opinion** for conduct by the NHS Research Ethics Committee, and the University of Reading Ethics Committee.

If the topics discussed in the interview raise any concerns, there are **people you can talk to for support and advice:**

- National Organisations such as Young Minds (www.youngminds.org.uk; parent helpline or OCD-UK (https://www.ocduk.org/; advice helpline)
- The Chief Investigator (Professor Cathy Creswell) can also provide additional contacts.

If you take part, and wish to make a complain at any time, please contact:

- Professor Carmel Houston-Price or Dr Graham Schafer, Joint Heads of School of Psychology and Clinical Language Sciences at the University of Reading at: School of Psychology and Clinical Language Sciences, University of Reading, Harry Pitt Building, Early Gate, Reading, RG6 7BE (Telephone: 0118 978 8523; Email: c.houston-price@reading.ac.uk or g.w.schafer@reading.ac.uk)
- The NHS Patient Advice and Liaison service (PALs) on the NHS Choices website, by asking your GP, a member of the research term or calling NHS 111.

Information sheet for parents – treatment study (Paper 3)

1

University of Reading

Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD).

Parent/Carer Information Sheet
Version: 2.0 (29/03/2021) IRAS ID: 294521

If you would like to speak to a member of the research team, or request paper copies of this information please contact a member of the research team below:

Chloe Chessell is the main contact for this study.

Please email:

You can also contact one of the study supervisors:

Professor Cathy Creswell
[redacted]

Dr Alice Farrington

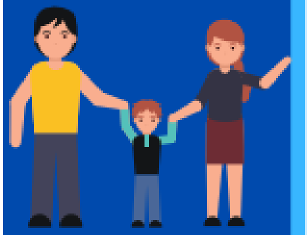
Professor Kate Harvey
k.n.harvey@reading.ac.uk

Dr Sasha Walters

Dr Brynjar Halldorsson
[redacted]

University of Reading

What is this all about?



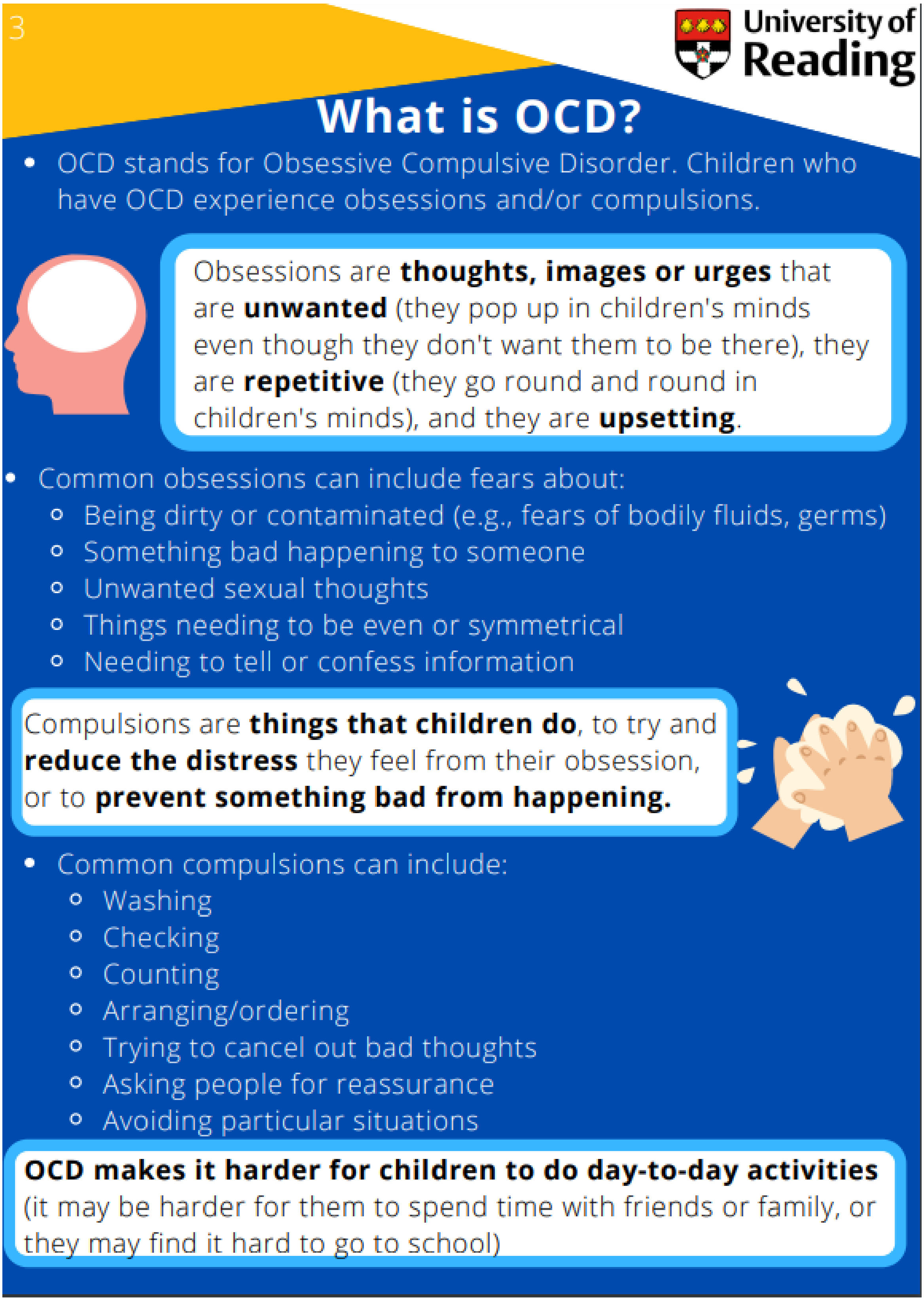
We are carrying out a study to see if a therapist guided, parent-led Cognitive Behavioural Therapy (CBT) treatment helps to improve symptoms of Obsessive Compulsive Disorder (OCD) in children. This means that **parents/carers will learn techniques with a therapist** that they can put in place at home to **help their child** to overcome OCD.

We would like to invite you to take part

We will provide you with some **information** that we hope will **help you to decide whether you would like to take part**.

We will also provide some **information for your child**.

- In this research study we will use information from you (and your child, if they decide to take part). We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.
- Everyone involved in this study will **keep your data safe and secure.** We will also follow all privacy rules. At the end of the study we will save some of the data in case we need to check it.
- We will make sure no-one can work out who you are from the reports we write.
- **The information pack tells you more about this.**



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What is OCD?

- OCD stands for Obsessive Compulsive Disorder. Children who have OCD experience obsessions and/or compulsions.

Obsessions are **thoughts, images or urges** that are **unwanted** (they pop up in children's minds even though they don't want them to be there), they are **repetitive** (they go round and round in children's minds), and they are **upsetting**.

- Common obsessions can include fears about:
  - Being dirty or contaminated (e.g., fears of bodily fluids, germs)
  - Something bad happening to someone
  - Unwanted sexual thoughts
  - Things needing to be even or symmetrical
  - Needing to tell or confess information

Compulsions are **things that children do**, to try and **reduce the distress** they feel from their obsession, or to **prevent something bad from happening.**

- Common compulsions can include:
  - Washing
  - Checking
  - Counting
  - Arranging/ordering
  - Trying to cancel out bad thoughts
  - Asking people for reassurance
  - Avoiding particular situations

OCD makes it harder for children to do day-to-day activities (it may be harder for them to spend time with friends or family, or they may find it hard to go to school)

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A brief overview

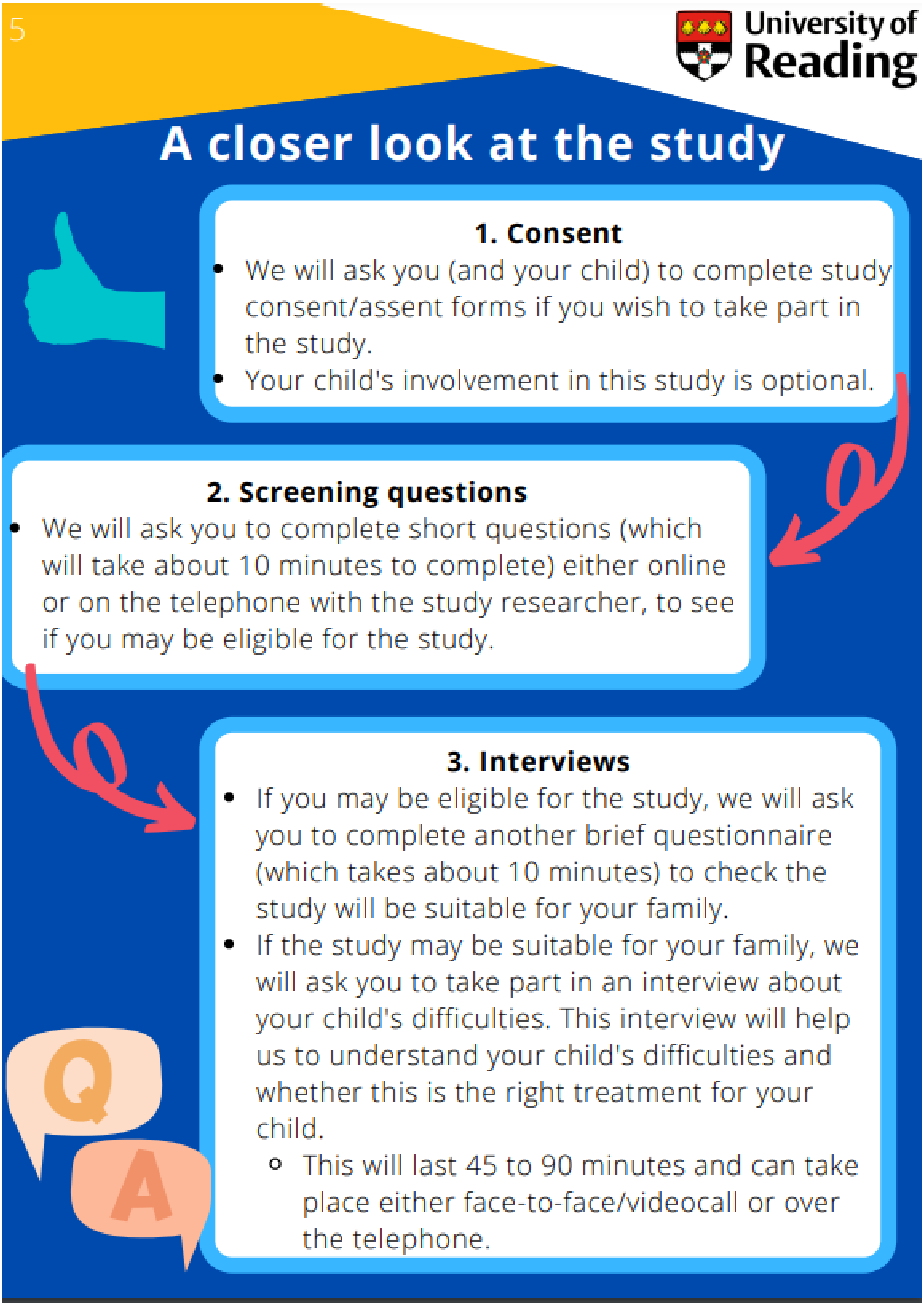
- This study involves a **therapist supporting parents/carers to learn techniques** that they can put in place at home to **help their child** to overcome OCD.

What will you be asked to do?

- We will ask you to complete **screening questions** to see if you may be eligible for the study.
- If you may be eligible for the study, we will then ask you to take part in some **interviews** to see if your child has OCD and some other common difficulties.
- Eligible parents/carers will complete **weekly questionnaires** to monitor your child's symptoms before starting treatment.
- Parents/carers will then receive **individual treatment sessions with a therapist** on behalf of their child. We will ask you to carry on completing the weekly questionnaires throughout the treatment.
- We will ask you to **repeat the interviews** soon after finishing treatment and one-month later to see whether there have been improvements in your child's OCD and any other difficulties.
- You will be invited to attend an **optional feedback interview** to tell us how you found the treatment programme.

What will my child be asked to do?

- Your child will be **invited to attend part of the interviews with you** to help us to understand their experiences of OCD. **It is helpful if your child joins these interviews but they do not have to do so for you to take part in the study.**
- We will ask your child to **complete some activities with you** between treatment sessions.



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A closer look at the study

1. Consent

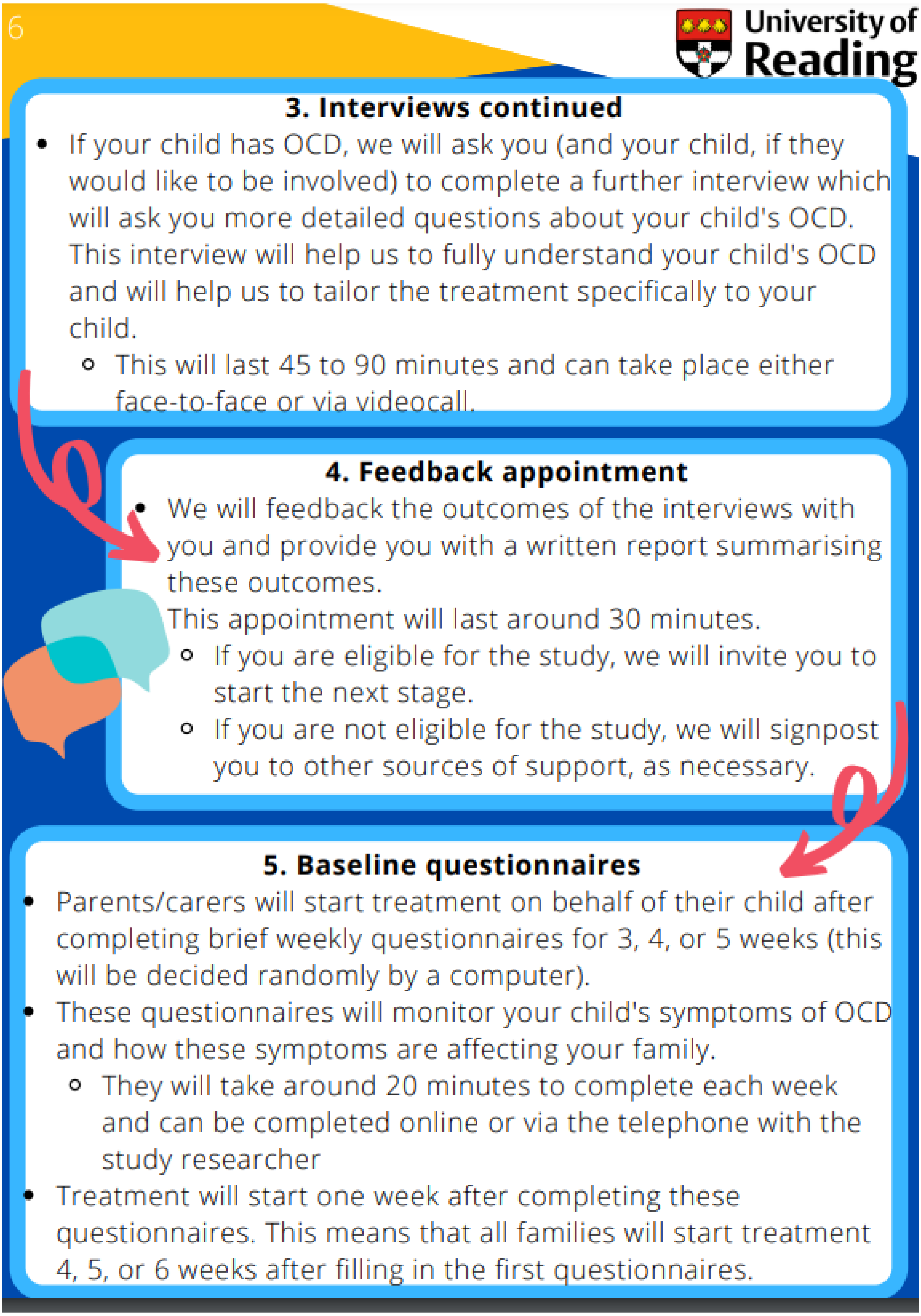
- We will ask you (and your child) to complete study consent/assent forms if you wish to take part in the study.
- Your child's involvement in this study is optional.

2. Screening questions

- We will ask you to complete short questions (which will take about 10 minutes to complete) either online or on the telephone with the study researcher, to see if you may be eligible for the study.

3. Interviews

- If you may be eligible for the study, we will ask you to complete another brief questionnaire (which takes about 10 minutes) to check the study will be suitable for your family.
- If the study may be suitable for your family, we will ask you to take part in an interview about your child's difficulties. This interview will help us to understand your child's difficulties and whether this is the right treatment for your child.
    - This will last 45 to 90 minutes and can take place either face-to-face/videocall or over the telephone.



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3. Interviews continued

- If your child has OCD, we will ask you (and your child, if they would like to be involved) to complete a further interview which will ask you more detailed questions about your child's OCD. This interview will help us to fully understand your child's OCD and will help us to tailor the treatment specifically to your child.
    - This will last 45 to 90 minutes and can take place either face-to-face or via videocall.

4. Feedback appointment

- We will feedback the outcomes of the interviews with you and provide you with a written report summarising these outcomes.

This appointment will last around 30 minutes.

- If you are eligible for the study, we will invite you to start the next stage.
- If you are not eligible for the study, we will signpost you to other sources of support, as necessary.

5. Baseline questionnaires

- Parents/carers will start treatment on behalf of their child after completing brief weekly questionnaires for 3, 4, or 5 weeks (this will be decided randomly by a computer).
- These questionnaires will monitor your child's symptoms of OCD and how these symptoms are affecting your family.
    - They will take around 20 minutes to complete each week and can be completed online or via the telephone with the study researcher
- Treatment will start one week after completing these questionnaires. This means that all families will start treatment 4, 5, or 6 weeks after filling in the first questionnaires.

6. Treatment

- Parents/carers will receive 6 to 8 individual treatment sessions with a Psychological Wellbeing Practitioner on behalf of their child.
    - There will be 4 face-to-face/videocall sessions lasting around 1 hour.
    - There will be 2 to 4 telephone sessions lasting around 20 minutes.
- There is more information about what the treatment involves on page 8 and 9.
- We will ask you to carry on completing questionnaires during the treatment so that we can monitor your child's OCD symptoms and how these symptoms impact your family.
- We will ask you to complete a short feedback questionnaire at the end of the treatment, to tell us how you found the treatment

7. Follow-up interviews

- We will ask you to complete a shortened version of the initial interviews soon after finishing treatment, and the full versions of the initial interviews one-month later, to see whether the treatment has led to improvements in your child's OCD symptoms and any other difficulties.
    - The shortened interviews will take approximately 30 to 40 minutes (in total) to complete.
    - All interviews can take place face-to-face/videocall or via telephone.
- Your child will be invited to attend the relevant parts of these interviews if they wish to take part.
- We will ask you to complete the same questionnaires that you completed during the treatment at the one-month follow-up interview.

8. Feedback appointment

- We will feedback the outcomes of the interviews and treatment with you and provide you with a written report summarising these outcomes.
- This appointment will last around 30 minutes.
- We will not be able to provide any further treatment within the study at this point. If your child may benefit from further support, we will signpost you to relevant sources of support, as necessary.

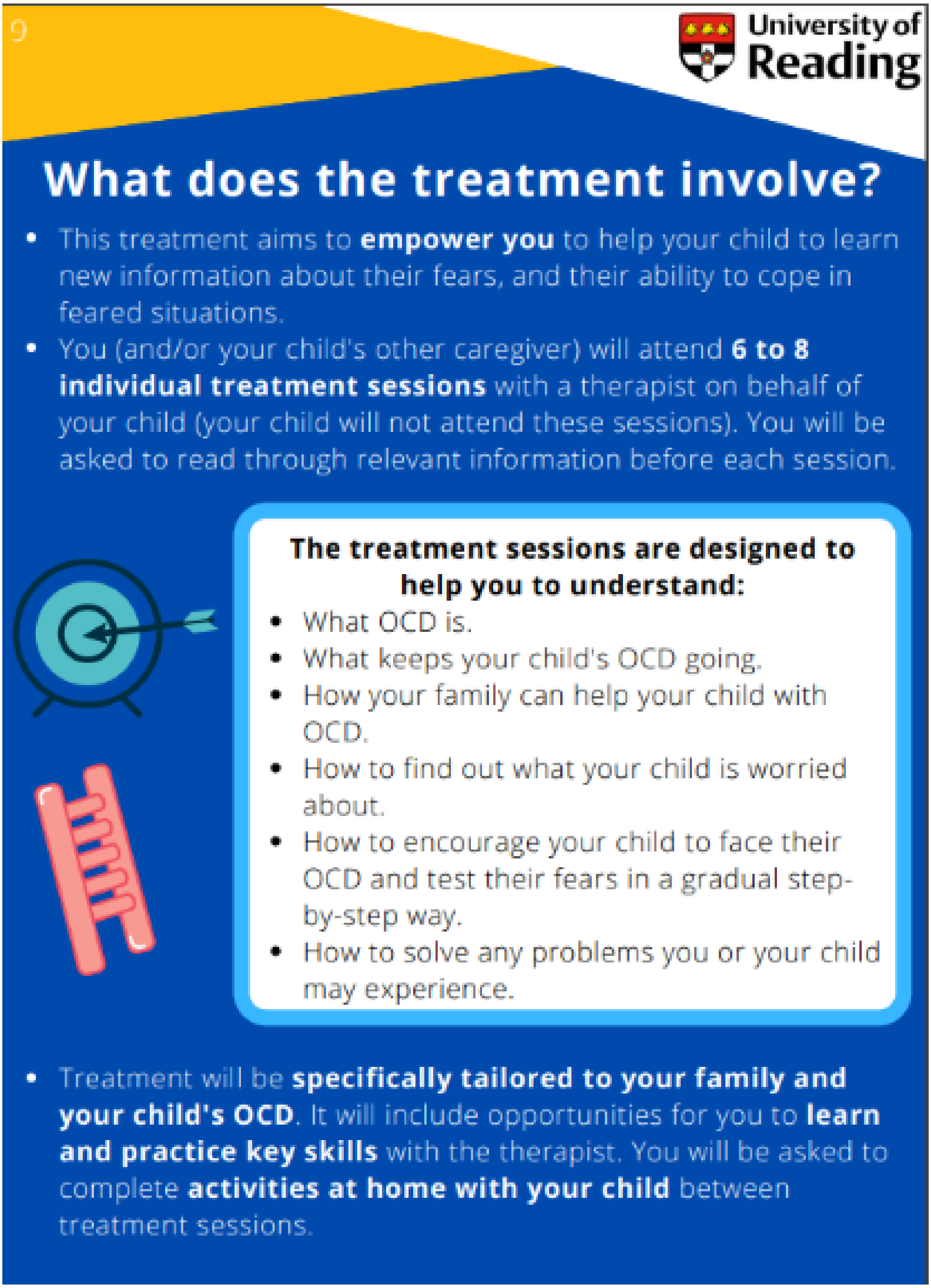
9. Optional feedback interview

- We will invite you to take part in an optional feedback interview which will ask you about your experiences of receiving this treatment.
    - The interview will be face-to-face/videocall or over the telephone and will last around 45 minutes.

What does the treatment involve?

- The recommended treatment for children with OCD is **Cognitive Behavioural Therapy (CBT)** including Exposure and Response Prevention (ERP).
- This is where children face their obsessions, whilst trying to not do their compulsions, in a gradual way.

- CBT including ERP is **recommended** by the National Institute of Health and Care Excellence, who are an independent organisation who review all of the research evidence and recommend treatments based on this.
- The treatment you will receive is in line with these guidelines.



What does the treatment involve?

- This treatment aims to **empower you** to help your child to learn new information about their fears, and their ability to cope in feared situations.
- You (and/or your child's other caregiver) will attend **6 to 8 individual treatment sessions** with a therapist on behalf of your child (your child will not attend these sessions). You will be asked to read through relevant information before each session.

The treatment sessions are designed to help you to understand:

- What OCD is.
- What keeps your child's OCD going.
- How your family can help your child with OCD.
- How to find out what your child is worried about.
- How to encourage your child to face their OCD and test their fears in a gradual step-by-step way.
- How to solve any problems you or your child may experience.

- Treatment will be **specifically tailored to your family and your child's OCD**. It will include opportunities for you to **learn and practice key skills** with the therapist. You will be asked to complete **activities at home with your child** between treatment sessions.

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Who will be delivering the treatment?

Psychological Wellbeing Practitioner

The treatment will be delivered by Chloe Chessell (who is a Psychological Wellbeing Practitioner) and has experience of delivering CBT based treatment to parents of preadolescent children with anxiety disorders and CBT based workshops to parents of children and adolescents with OCD.

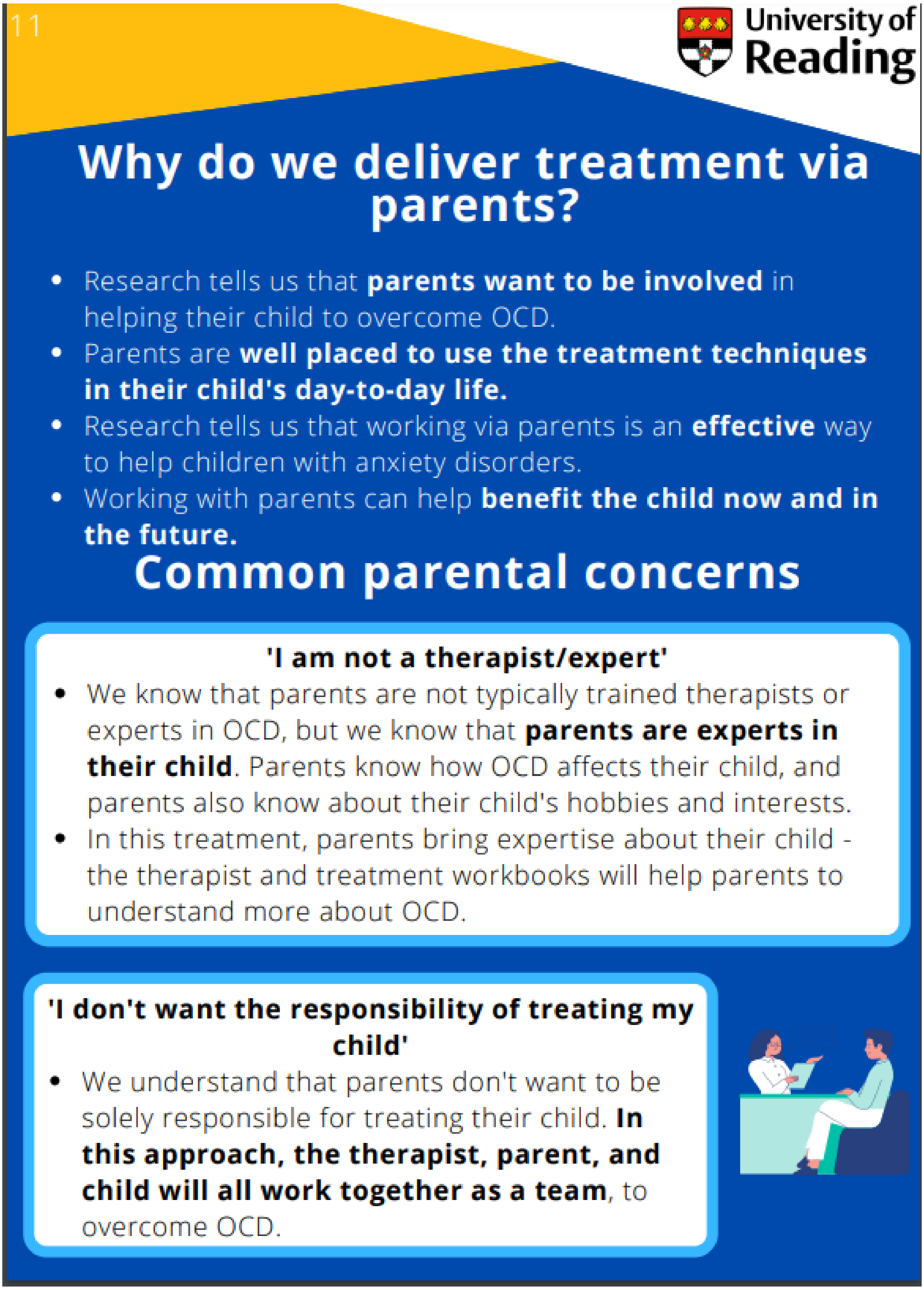
Treatment Supervisors

Dr Brynjar Halldorsson is a Clinical Psychologist at the University of Oxford who has expertise in CBT treatment for adults and children with OCD.

Professor Cathy Creswell is a Clinical Psychologist at the University of Oxford who has expertise in therapist guided, parent-led CBT treatments for preadolescent children with anxiety disorders.

Dr Sasha Walters is a Principal Clinical Psychologist at Oxford Health NHS Foundation Trust who has expertise in CBT treatment for children and adolescents with OCD.

Dr Alice Farrington is a Principal Clinical Psychologist at Berkshire Healthcare NHS Foundation Trust who has expertise in CBT treatment for adults and children with OCD.



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Why do we deliver treatment via parents?

- Research tells us that **parents want to be involved** in helping their child to overcome OCD.
- Parents are **well placed to use the treatment techniques in their child's day-to-day life.**
- Research tells us that working via parents is an **effective** way to help children with anxiety disorders.
- Working with parents can help **benefit the child now and in the future.**

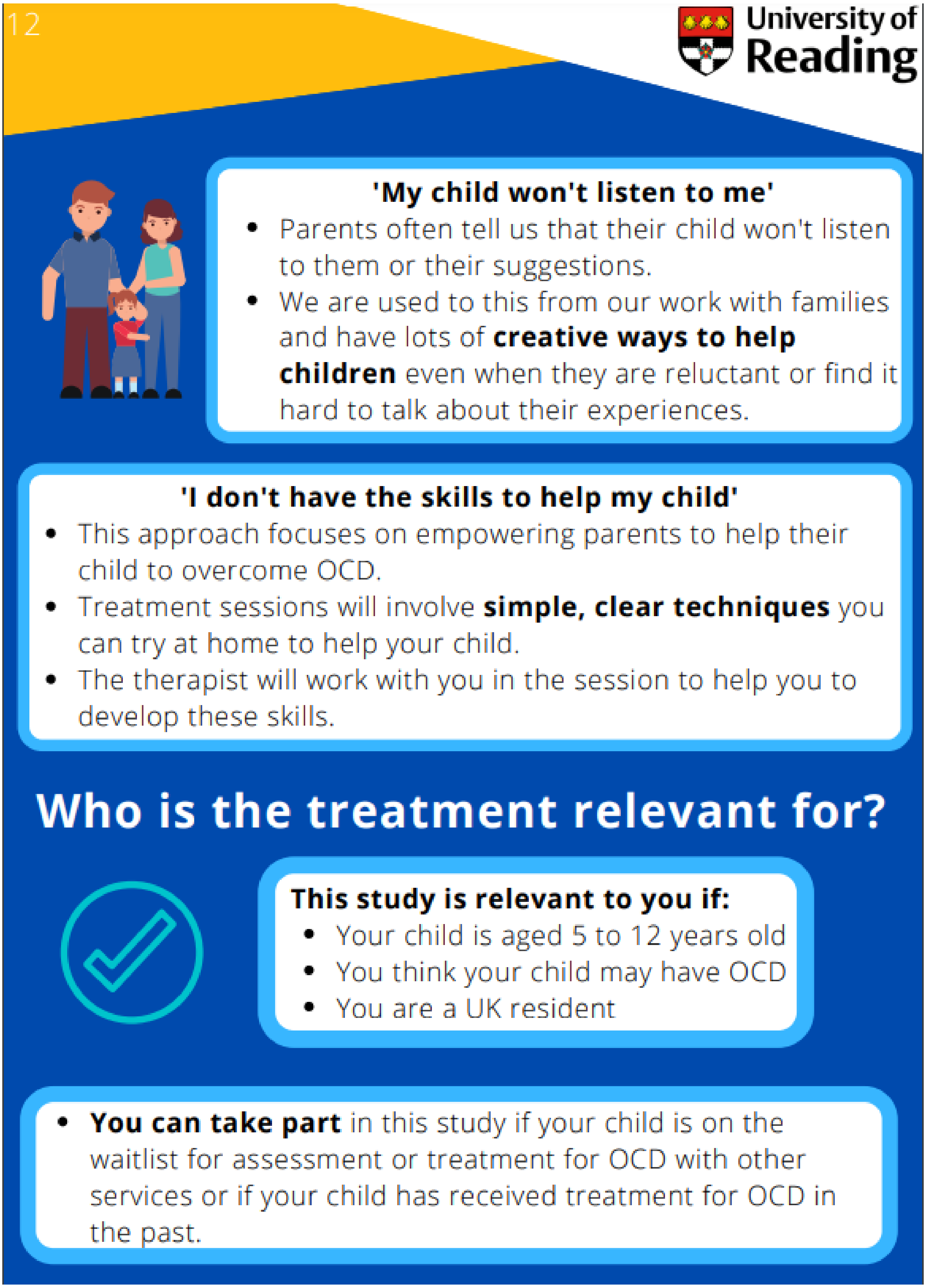
Common parental concerns

'I am not a therapist/expert'

- We know that parents are not typically trained therapists or experts in OCD, but we know that **parents are experts in their child**. Parents know how OCD affects their child, and parents also know about their child's hobbies and interests.
- In this treatment, parents bring expertise about their child - the therapist and treatment workbooks will help parents to understand more about OCD.

'I don't want the responsibility of treating my child'

- We understand that parents don't want to be solely responsible for treating their child. **In this approach, the therapist, parent, and child will all work together as a team**, to overcome OCD.



'My child won't listen to me'

- Parents often tell us that their child won't listen to them or their suggestions.
- We are used to this from our work with families and have lots of **creative ways to help children** even when they are reluctant or find it hard to talk about their experiences.

'I don't have the skills to help my child'

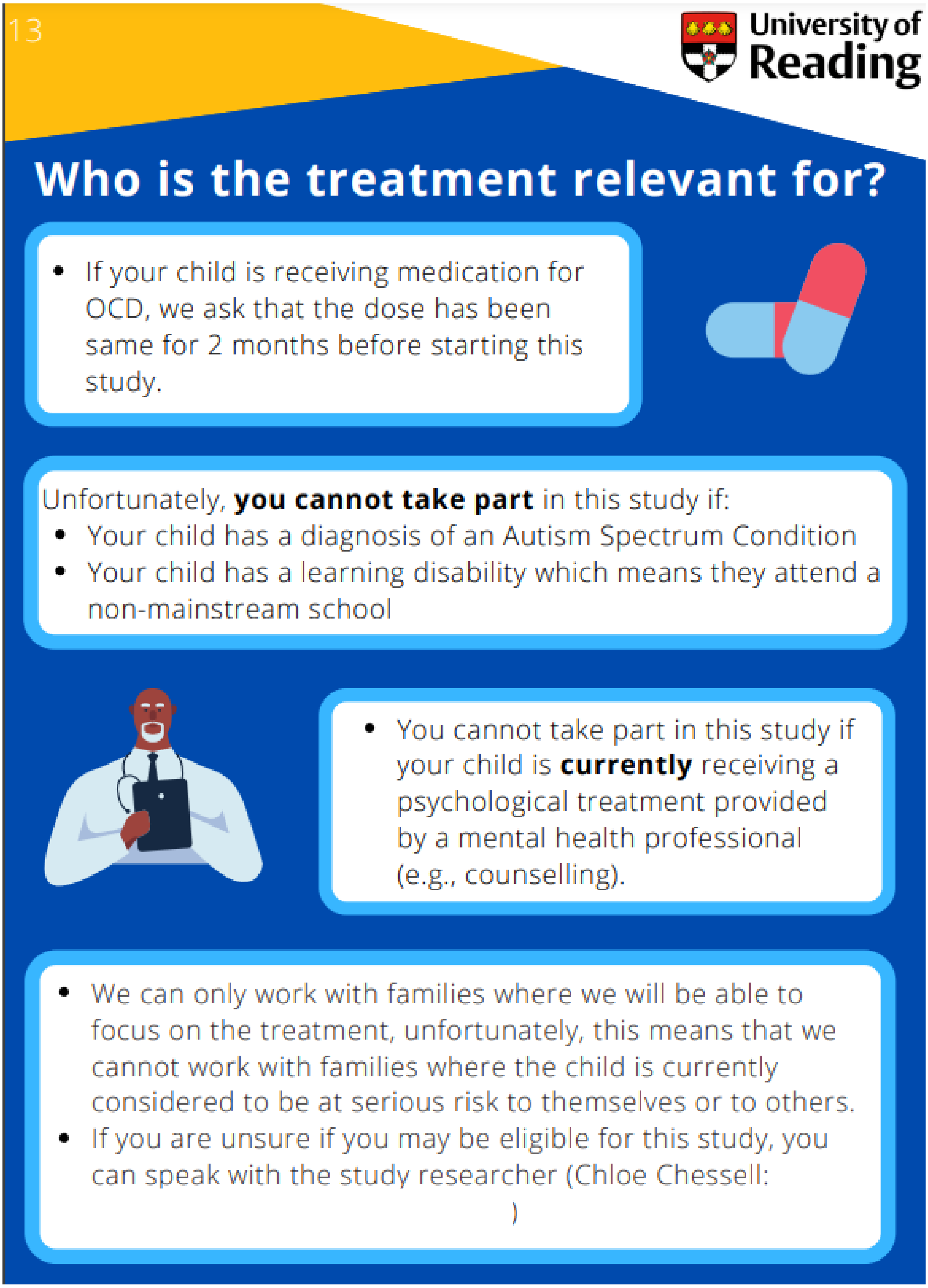
- This approach focuses on empowering parents to help their child to overcome OCD.
- Treatment sessions will involve **simple, clear techniques** you can try at home to help your child.
- The therapist will work with you in the session to help you to develop these skills.

Who is the treatment relevant for?

This study is relevant to you if:

- Your child is aged 5 to 12 years old
- You think your child may have OCD
- You are a UK resident

- **You can take part** in this study if your child is on the waitlist for assessment or treatment for OCD with other services or if your child has received treatment for OCD in the past.



13

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Who is the treatment relevant for?

- If your child is receiving medication for OCD, we ask that the dose has been same for 2 months before starting this study.

Unfortunately, **you cannot take part** in this study if:
- Your child has a diagnosis of an Autism Spectrum Condition
- Your child has a learning disability which means they attend a non-mainstream school

- You cannot take part in this study if your child is **currently** receiving a psychological treatment provided by a mental health professional (e.g., counselling).

- We can only work with families where we will be able to focus on the treatment, unfortunately, this means that we cannot work with families where the child is currently considered to be at serious risk to themselves or to others.
- If you are unsure if you may be eligible for this study, you can speak with the study researcher (Chloe Chessell:

)

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Important Information

Does my family have to take part?
You and your child do not have to take part. Deciding whether to not to take part will not affect your child's future treatment in anyway.

You can still take part in this study if you are on the waitlist for other treatment (e.g., with your local child and adolescent mental health services). Taking part in this study will not affect your place on the waitlist for other treatments.

- You and your child have the **right to withdraw** from the assessments, treatment, and optional feedback interview **at any time**. If you do withdraw, you can also choose to withdraw some or all of your information from the study, but if you wish to do this, you must tell us before the end of the study.
- When we write up our research, we will include some **quotes** from the feedback questionnaire, so that people know what parents' views of the treatment were. We will anonymise this information so that your family cannot be identified.

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What are the advantages of taking part?

- We have good reason to think that families who receive this treatment will **benefit**. This treatment is based on an existing therapist guided, parent-led treatment for children with anxiety disorders. Research shows us that around **75% of children with anxiety disorders** whose parents/carers received this treatment no longer met criteria for their main anxiety difficulty 6 months after treatment.
- We are able to provide **timely access to treatment**. All parents/carers will begin treatment 4, 5 or 6 weeks after completing the first baseline questionnaire.

What are the disadvantages of taking part?

- You will be asked to complete **interviews** before, soon after, and one month after completing the treatment so that we can see whether the treatment has helped your child. You will also be asked to complete weekly baseline and treatment **questionnaires.**
- In total, we anticipate that families will be involved in the study over the course of 4 to 5 months.

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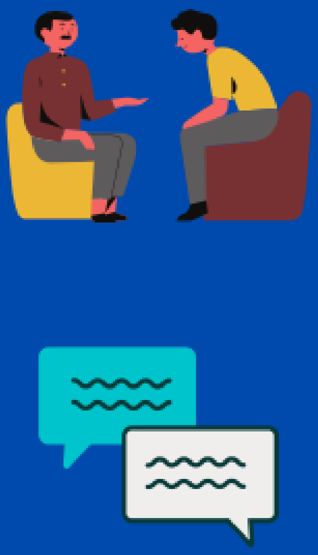
What are the disadvantages of taking part?

- Some questions will involve discussing thoughts and feelings that **may be upsetting**.
  - The questions we will ask you are often used in mental health services, and **we work with families** to make sure the questions are acceptable.
- Some children may find treatment upsetting, as we will encourage children to face their fears.
  - We will work with you to make sure your child is facing their fears in a **gradual way**, so they can build confidence in their ability to overcome OCD.
  - We try to make **treatment fun and rewarding** by encouraging you to incorporate your child's interests.



What if I need further support when the study finishes?

- We will not be able to provide further treatment after you finish the treatment.
- We will discuss the outcomes of the treatment and interviews with you, to see if you would like further support for you child. We will be able to signpost you to further sources of support, if necessary.
- If your child is on the waitlist for support with child and adolescent mental health services, with your permission, we can share a report of the treatment you received as part of this study with them.

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Will I get paid for my time?

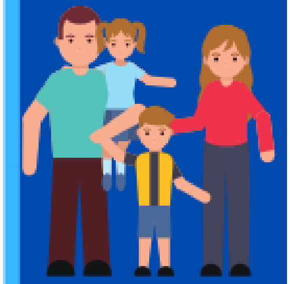
- You will be given a **£20 voucher** to thank you for your time completing the interviews which will take place one month after finishing treatment.
- You will be given a **further £20 voucher** if you decide to take part in the optional feedback interview about your experiences of the treatment, to thank you for your time.

Who is organising and funding the study?

- This study is sponsored by the University of Reading and is funded by the Economic and Social Research Council.
- The project is organised by researchers and clinicians at the University of Reading, University of Oxford and Berkshire Healthcare NHS Foundation Trust.
- This study is being conducted towards a PhD qualification.

Have patients and the public been involved in designing the study?

- This treatment has been **developed from interviews with parents** of preadolescent children with OCD, where we asked parents about their experiences of parenting a child with OCD and their views about parent involvement in treatment.
- This information has been used to ensure the treatment is **suitable and acceptable** for families.



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Who has checked this study?

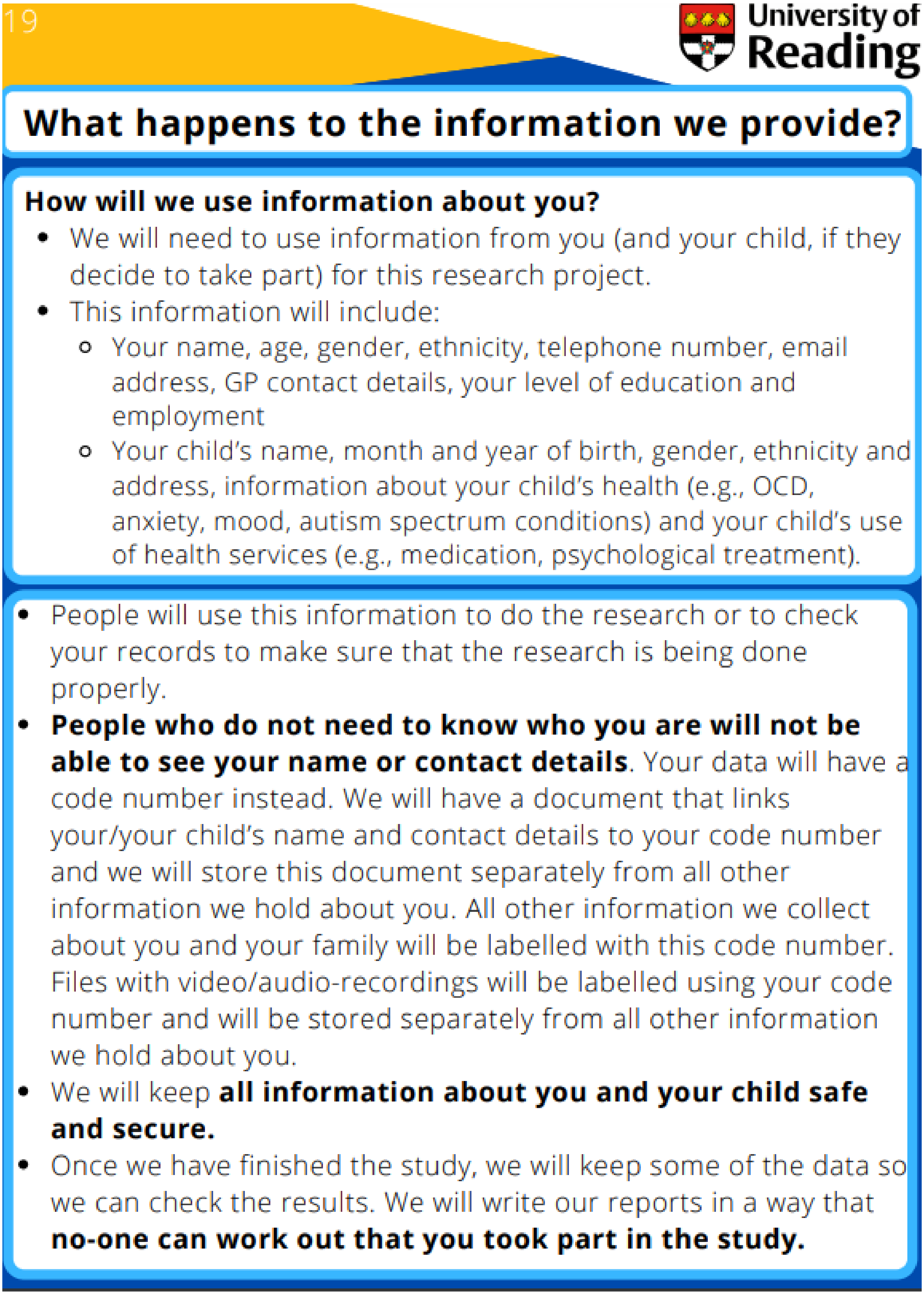
- This study has been checked by the West Midlands South Birmingham NHS Research Ethics Committee and the University of Reading Ethics Committee and has been given a favourable ethical opinion for conduct.

What if there is a problem?

- We do not expect anything bad to happen to you or your child by taking part in this research.
- In the unlikely event that it does, the University of Reading has insurance in case you suffer any harm as a direct consequence of taking part in this study.
- If you would like to make a formal compliant about any part of this study, please contact:
    - Professor Kate Harvey (k.n.harvey@reading.ac.uk) or
    - Professor Carmel Houston-Price, Head of the School of Psychology and Clinical Language Sciences, University of Reading, Harry Pitt Building, RG6 6BZ. Telephone 0118 987 8523 or email c.houston-price@reading.ac.uk.

What if I have a question or concern?

- If you have a question about the study, please contact the study researcher - Chloe Chessell ( )
- If you have a concern about the study, please contact the Chief Investigator - Professor Kate Harvey (k.n.harvey@reading.ac.uk)



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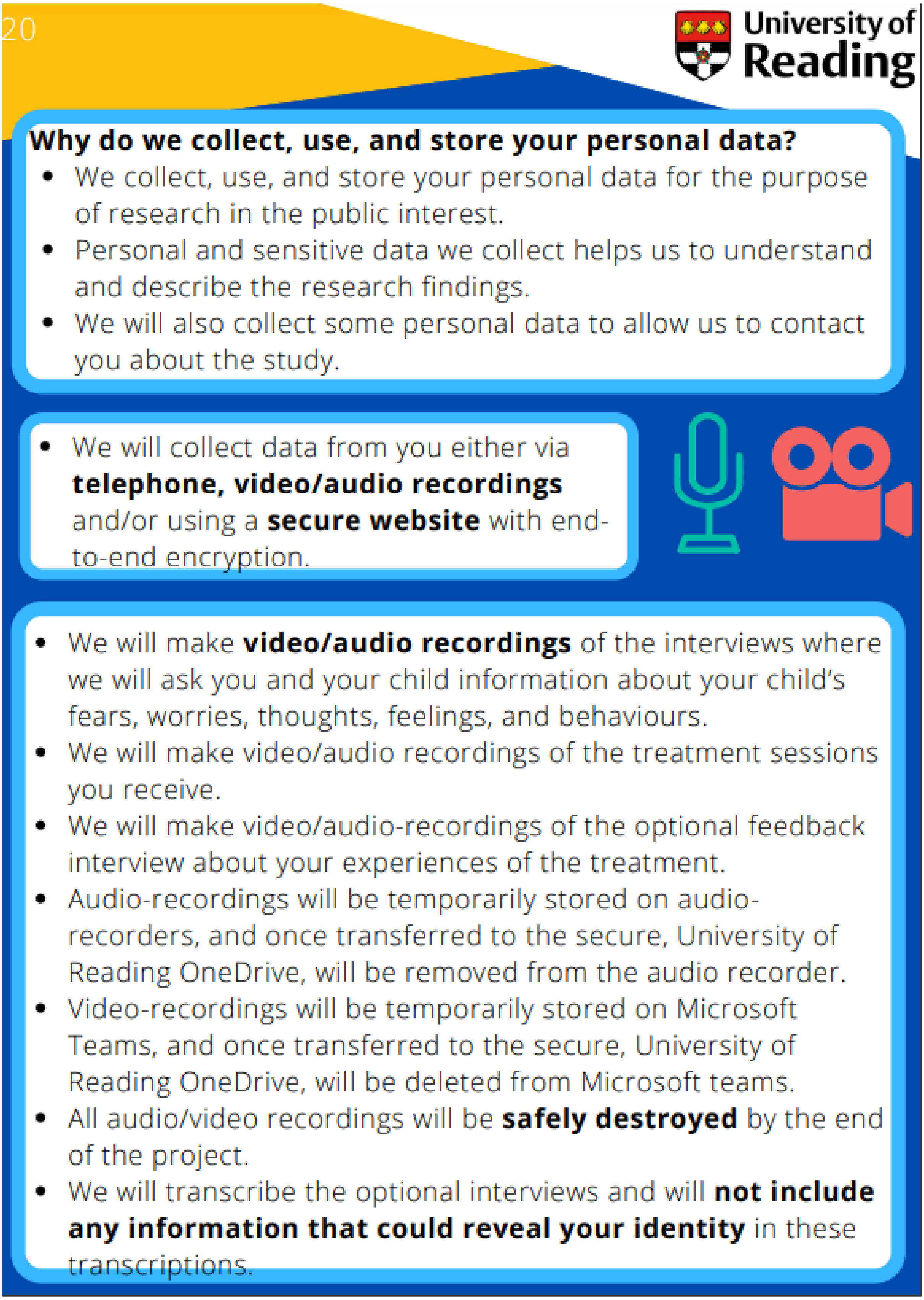
What happens to the information we provide?

How will we use information about you?

- We will need to use information from you (and your child, if they decide to take part) for this research project.
- This information will include:
    - Your name, age, gender, ethnicity, telephone number, email address, GP contact details, your level of education and employment
    - Your child's name, month and year of birth, gender, ethnicity and address, information about your child's health (e.g., OCD, anxiety, mood, autism spectrum conditions) and your child's use of health services (e.g., medication, psychological treatment).

- People will use this information to do the research or to check your records to make sure that the research is being done properly.
- **People who do not need to know who you are will not be able to see your name or contact details**. Your data will have a code number instead. We will have a document that links your/your child's name and contact details to your code number and we will store this document separately from all other information we hold about you. All other information we collect about you and your family will be labelled with this code number. Files with video/audio-recordings will be labelled using your code number and will be stored separately from all other information we hold about you.
- We will keep **all information about you and your child safe and secure.**
- Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that **no-one can work out that you took part in the study.**



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Why do we collect, use, and store your personal data?

- We collect, use, and store your personal data for the purpose of research in the public interest.
- Personal and sensitive data we collect helps us to understand and describe the research findings.
- We will also collect some personal data to allow us to contact you about the study.

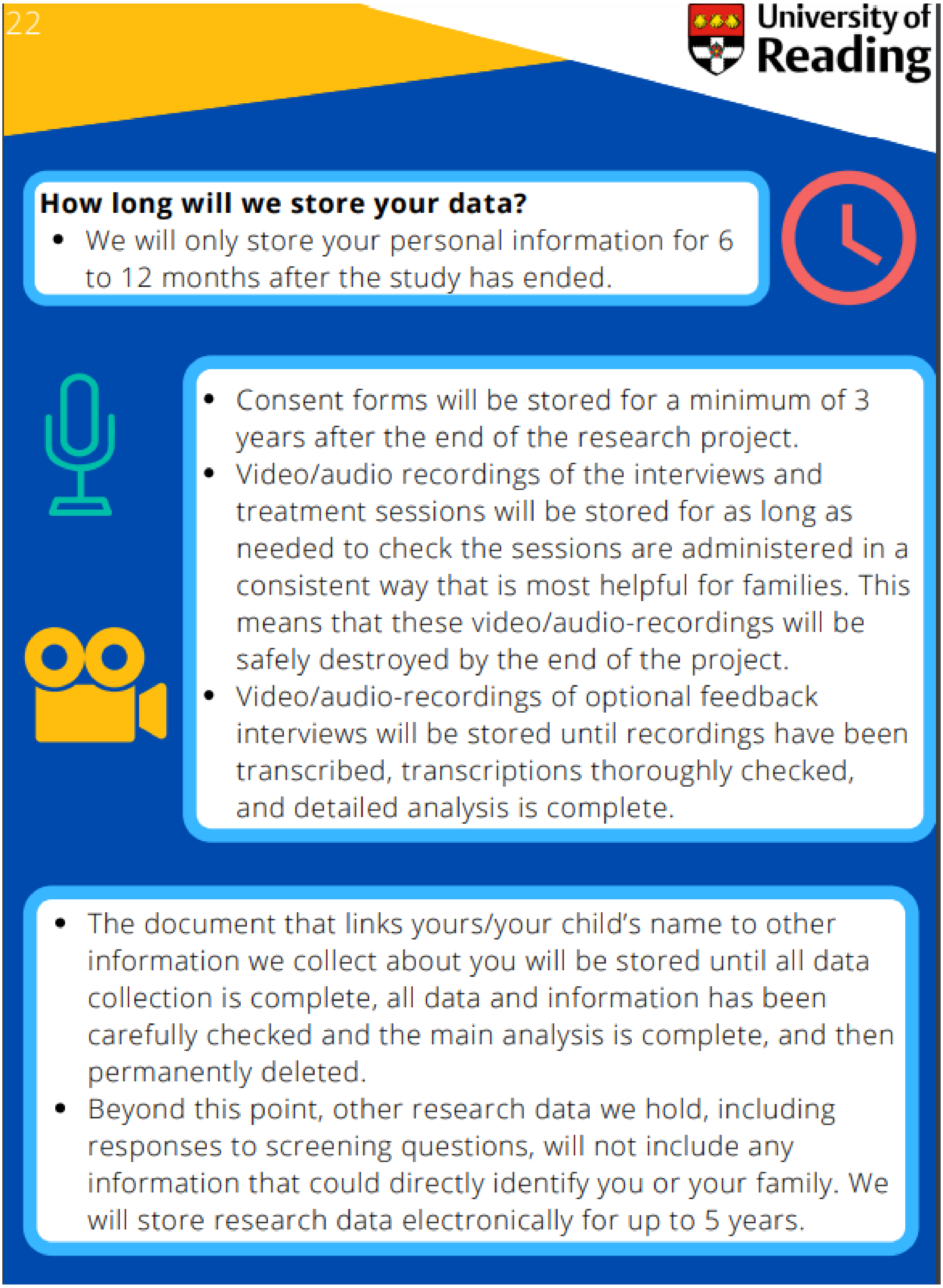
- We will collect data from you either via **telephone, video/audio recordings** and/or using a **secure website** with end-to-end encryption.

- We will make **video/audio recordings** of the interviews where we will ask you and your child information about your child's fears, worries, thoughts, feelings, and behaviours.
- We will make video/audio recordings of the treatment sessions you receive.
- We will make video/audio-recordings of the optional feedback interview about your experiences of the treatment.
- Audio-recordings will be temporarily stored on audio-recorders, and once transferred to the secure, University of Reading OneDrive, will be removed from the audio recorder.
- Video-recordings will be temporarily stored on Microsoft Teams, and once transferred to the secure, University of Reading OneDrive, will be deleted from Microsoft teams.
- All audio/video recordings will be **safely destroyed** by the end of the project.
- We will transcribe the optional interviews and will **not include any information that could reveal your identity** in these transcriptions.

- We will inform **your GP** that you and your child are taking part in this study. We will send your GP copies of the reports we will send to you, following the initial and follow-up interviews.
- If your child is on the waitlist for support with child and adolescent mental health services, with your permission, we can also share these reports with them.

- We will share necessary personal information we collect from you with the **study supervisors** at the University of Oxford, Oxford Healthcare NHS Foundation Trust and Berkshire Healthcare NHS Foundation Trust for supervision only. This information will be shared using a **secure link** which can only be opened by the intended person.
- We will not share what you or your child tells us to anyone outside of the research team unless we believe that your child or someone else may be at risk of serious harm.
    - If this happened, we may need to tell someone outside of the research team (e.g., GP, local safeguarding team and/or other relevant healthcare professionals), and we would always try to talk to you about this first.

- Any data or findings from the research that is published will not identify you or your child. We may use **direct quotes** from the feedback questionnaire and optional feedback interview in publications, but this will not include any information that could identify you or your family.



How long will we store your data?

- We will only store your personal information for 6 to 12 months after the study has ended.

- Consent forms will be stored for a minimum of 3 years after the end of the research project.
- Video/audio recordings of the interviews and treatment sessions will be stored for as long as needed to check the sessions are administered in a consistent way that is most helpful for families. This means that these video/audio-recordings will be safely destroyed by the end of the project.
- Video/audio-recordings of optional feedback interviews will be stored until recordings have been transcribed, transcriptions thoroughly checked, and detailed analysis is complete.

- The document that links yours/your child's name to other information we collect about you will be stored until all data collection is complete, all data and information has been carefully checked and the main analysis is complete, and then permanently deleted.
- Beyond this point, other research data we hold, including responses to screening questions, will not include any information that could directly identify you or your family. We will store research data electronically for up to 5 years.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

Who is responsibility for protecting your personal information?

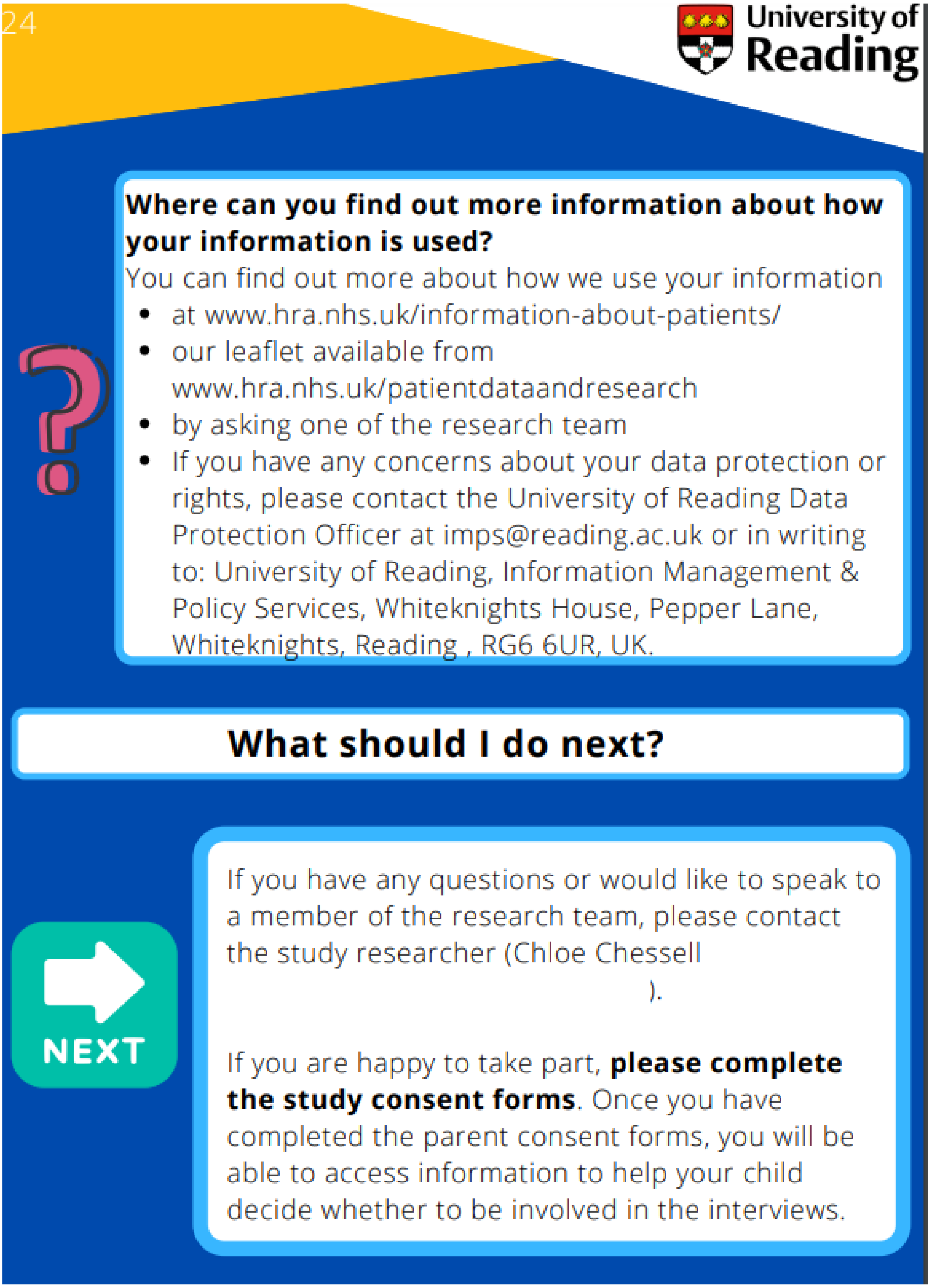
The University of Reading is responsible for protecting your personal data (the ‘Data Controller’).

What are your rights under data protection law?

You have certain rights under data protection law which are:

- Withdraw your consent, for example if you opted in to be added to a participant register.
- Access your personal data or ask for a copy.
- Rectify inaccuracies in personal data that we hold about you
- Be forgotten, that is your details to be removed from systems that we use to process your personal data.
- Restrict uses of your data.
- Object to uses of your data, for example retention after you have withdrawn from a study.

Some restrictions apply to the above rights where data is collected and used for research purposes. You can find out more about your rights on the website of the Information Commissioners Office (ICO) at https://ico.org.uk. You also have a right to complain the ICO if you are unhappy with how your data has been handled. Please contact the University Data Protection Officer in the first instance.



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Where can you find out more information about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- If you have any concerns about your data protection or rights, please contact the University of Reading Data Protection Officer at imps@reading.ac.uk or in writing to: University of Reading, Information Management & Policy Services, Whiteknights House, Pepper Lane, Whiteknights, Reading , RG6 6UR, UK.

What should I do next?

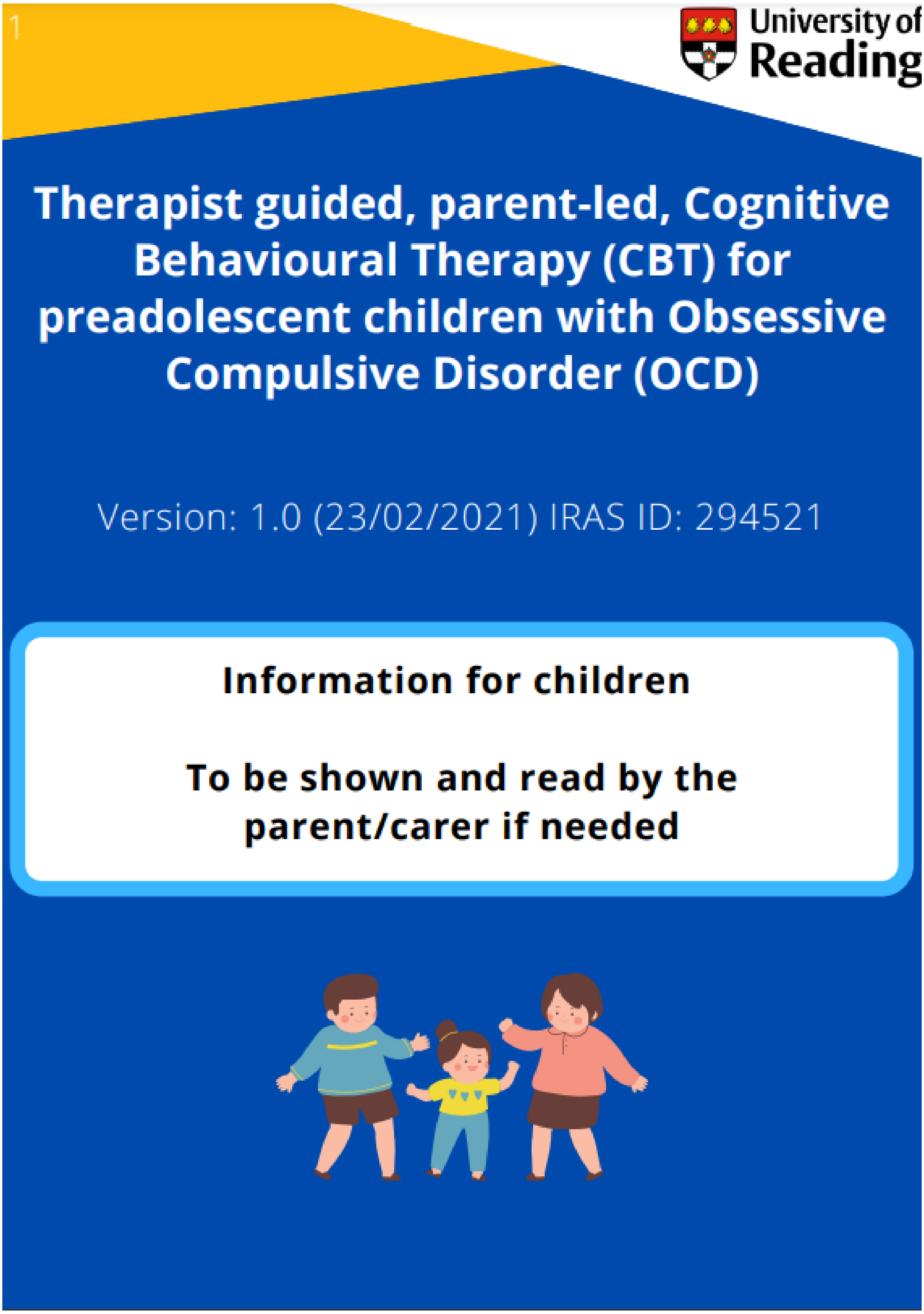
NEXT

If you have any questions or would like to speak to a member of the research team, please contact the study researcher (Chloe Chessell

).

If you are happy to take part, **please complete the study consent forms**. Once you have completed the parent consent forms, you will be able to access information to help your child decide whether to be involved in the interviews.

Information sheet for children – treatment study (Paper 3)



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Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD)

Version: 1.0 (23/02/2021) IRAS ID: 294521

Information for children

To be shown and read by the parent/carer if needed

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What is this all about?

We are doing research to **help children** who are having problems with **worries** or **habits.**

You might have worries that **pop up** in your head even though **you don't want them to be there**. These worries might go round and round in your head and be **upsetting**. You might have worries about:

- Being dirty
- Something bad happening to you or your family
- Things needing to be even or symmetrical
- Causing harm to yourself or others
- Needing to tell or confess information

Habits are **things you might have to do**, sometimes over and over again, to try and **make the worries go away** or to stop something bad from happening. Common habits are:

- Having to wash parts of your body a lot
- Checking things at home like doors or taps
- Counting to certain numbers in your head
- Asking mum and dad if things will be okay
- Having to do things until it feels right
- Having to order things in a certain way

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What is research?

- Research is how we try to **find out the answers to important questions!**
- This research is all about helping children with worries and habits.

What will happen in this research?

- If you would like to take part, we will ask you and your parents to answer some **questions about your worries and habits** with a researcher.
- If we think the study will help you, **your parents will get help** from a researcher, **to help you with your worries and habits**.
- Your parents will be asked to do **some activities with you** at home.
- We will then ask you and your parents to answer the **same questions about your worries and habits** with a researcher to see if there have been any changes.

Do I have to take part?

- **No.** It is up to you if you would like to answer the questions about your worries and habits.
- If you do not want to take part, your parents can answer the questions about your worries and habits.
- You can decide to stop taking part at any time.

What are the good things about taking part?

- Your parents will be better able to understand your difficulties and support you.
- We hope to help you to reduce your worries and habits so that you can do more of the things you enjoy!

Are there any bad things about taking part?

- You might find the questions about your worries or habits upsetting.
- You might find the activities to do with your parents a bit tricky.
- **But,** we work with lots of children who have similar difficulties to you. We have lots of ways to make the questions and activities fun.

What if I have questions?

- You can ask your parents any questions you may have. Your parents can contact us and we will let them know the answers to your questions

NEXT

What happens now?

- If you would like to take part, you can fill out a form to tell us.
- If you do not want to take part, you do not need to do anything.

Information sheet for parents – qualitative interview (Paper 3)

University of Reading

Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD): Feedback Interviews.

Parent/Carer Information Sheet
Version: 2.0 (29/03/2021) IRAS ID: 294521

If you would like to speak to a member of the research team, or request paper copies of this information please contact a member of the research team below:

Chloe Chessell is the main contact for this study.

Please email: [redacted]

You can also contact one of the study supervisors:

Professor Cathy Creswell
[redacted]

Dr Alice Farrington

Professor Kate Harvey
k.n.harvey@reading.ac.uk

Dr Sasha Walters

Dr Brynjar Halldorsson
[redacted]

Overview: What is this all about?

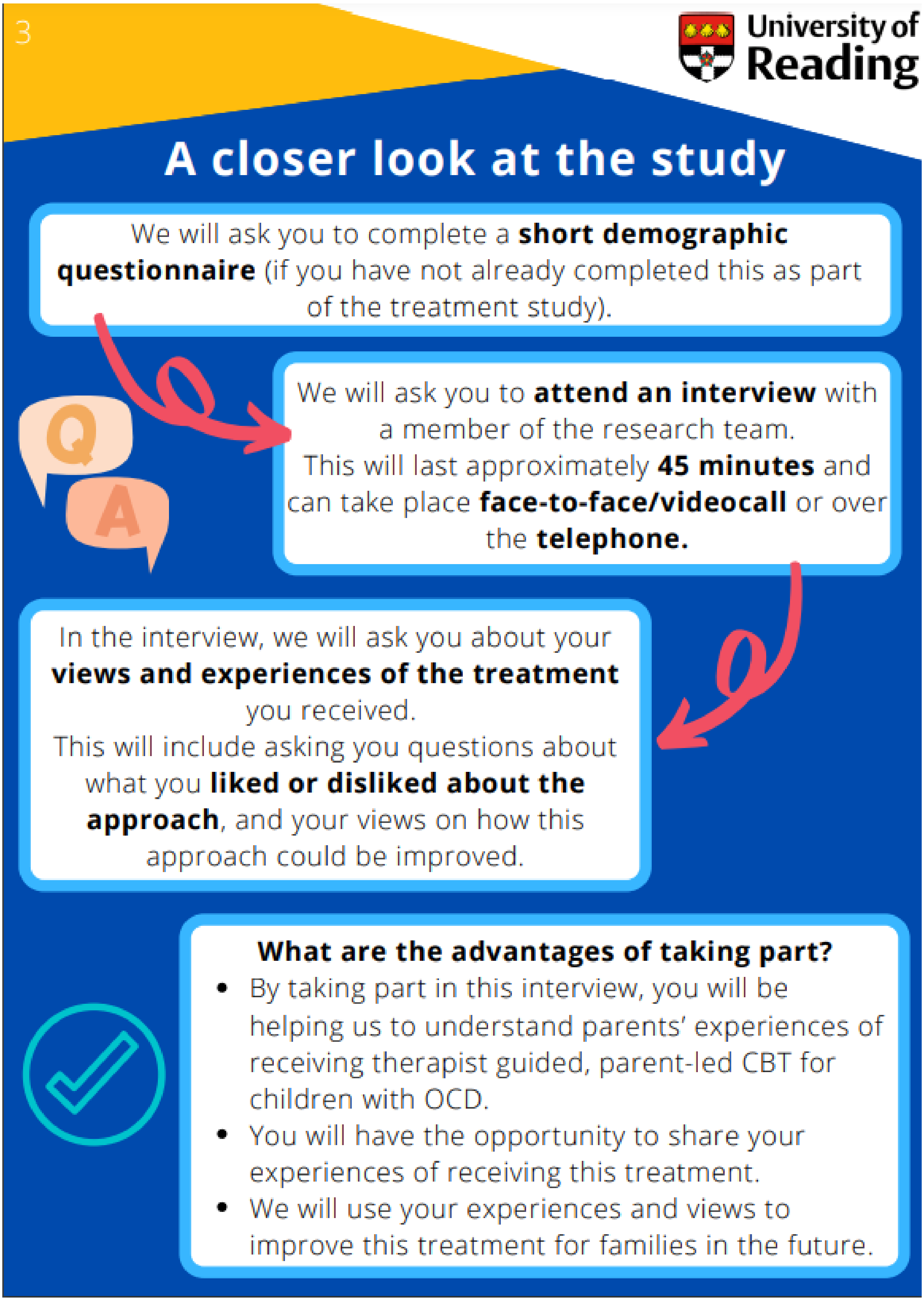
We are asking parents who have taken part in the therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) treatment to take part in an interview so that we can find out about parents' experiences of receiving this treatment.

We would like to invite you to take part.
We will provide you with some information that we hope will help you to decide whether you would like to take part.

A brief overview

- We want to **understand parents' experiences** of receiving therapist guided, parent-led CBT for preadolescent children with OCD.
- You have been asked to take part as you and/or your child's other caregiver have recently received this treatment for your child.
- We will ask you to **attend an interview**, where we will ask you about your experiences of receiving this treatment. We expect that this interview will take **approximately 45 minutes.**

- In this research study we will use information from you. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.
- Everyone involved in this study will **keep your data safe and secure.** We will also follow all privacy rules. At the end of the study we will save some of the data in case we need to check it.
- We will make sure no-one can work out who you are from the reports we write. **The information pack tells you more about this.**



University of Reading

A closer look at the study

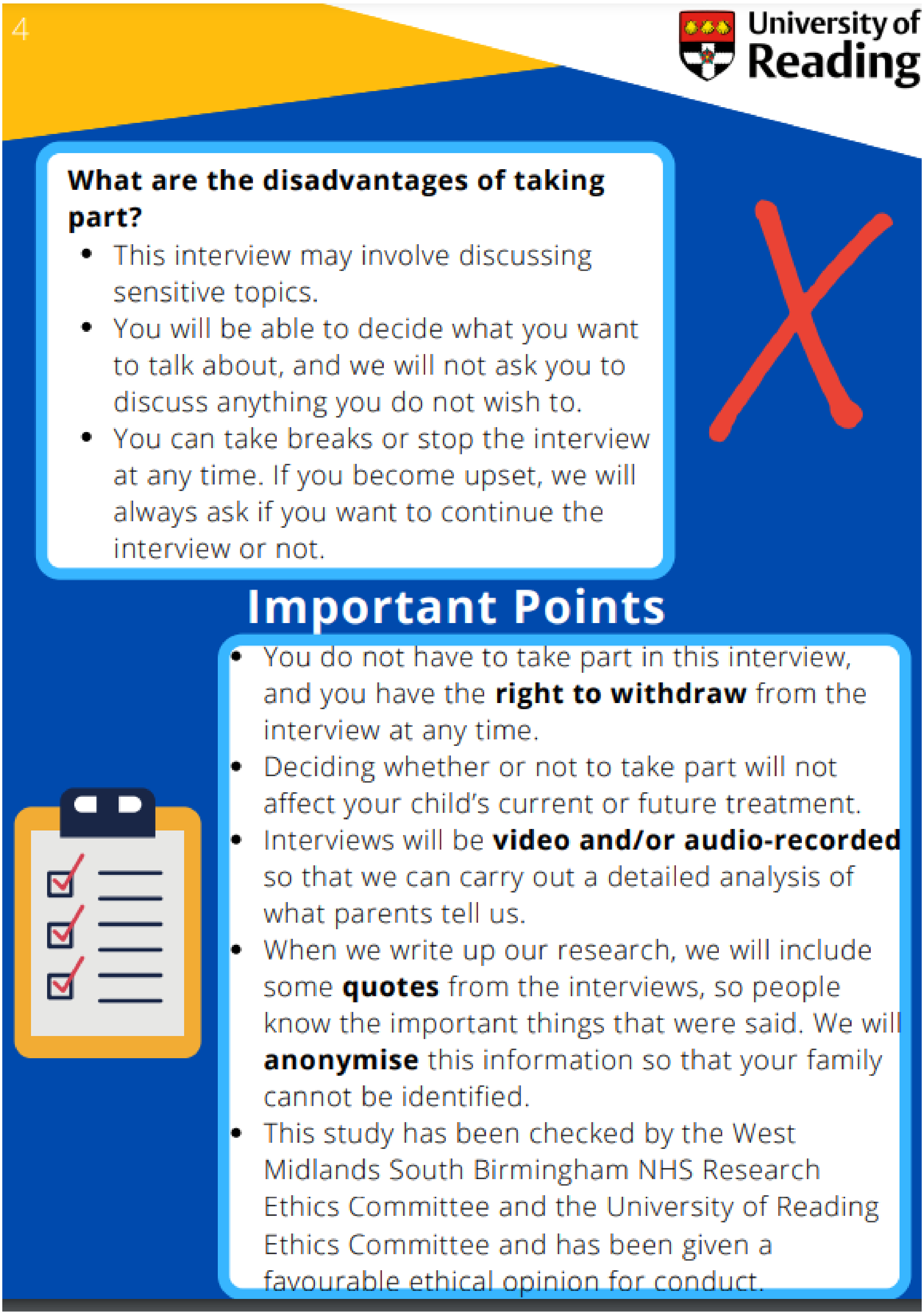
We will ask you to complete a **short demographic questionnaire** (if you have not already completed this as part of the treatment study).

We will ask you to **attend an interview** with a member of the research team.
This will last approximately **45 minutes** and can take place **face-to-face/videocall** or over the **telephone.**

In the interview, we will ask you about your **views and experiences of the treatment** you received.
This will include asking you questions about what you **liked or disliked about the approach**, and your views on how this approach could be improved.

What are the advantages of taking part?

- By taking part in this interview, you will be helping us to understand parents' experiences of receiving therapist guided, parent-led CBT for children with OCD.
- You will have the opportunity to share your experiences of receiving this treatment.
- We will use your experiences and views to improve this treatment for families in the future.



What are the disadvantages of taking part?

- This interview may involve discussing sensitive topics.
- You will be able to decide what you want to talk about, and we will not ask you to discuss anything you do not wish to.
- You can take breaks or stop the interview at any time. If you become upset, we will always ask if you want to continue the interview or not.

Important Points

- You do not have to take part in this interview, and you have the **right to withdraw** from the interview at any time.
- Deciding whether or not to take part will not affect your child's current or future treatment.
- Interviews will be **video and/or audio-recorded** so that we can carry out a detailed analysis of what parents tell us.
- When we write up our research, we will include some **quotes** from the interviews, so people know the important things that were said. We will **anonymise** this information so that your family cannot be identified.
- This study has been checked by the West Midlands South Birmingham NHS Research Ethics Committee and the University of Reading Ethics Committee and has been given a favourable ethical opinion for conduct.

Will I get paid for my time?

- You will be given a **£20 voucher** to thank you for your time completing the interview.

Who is organising and funding the study?

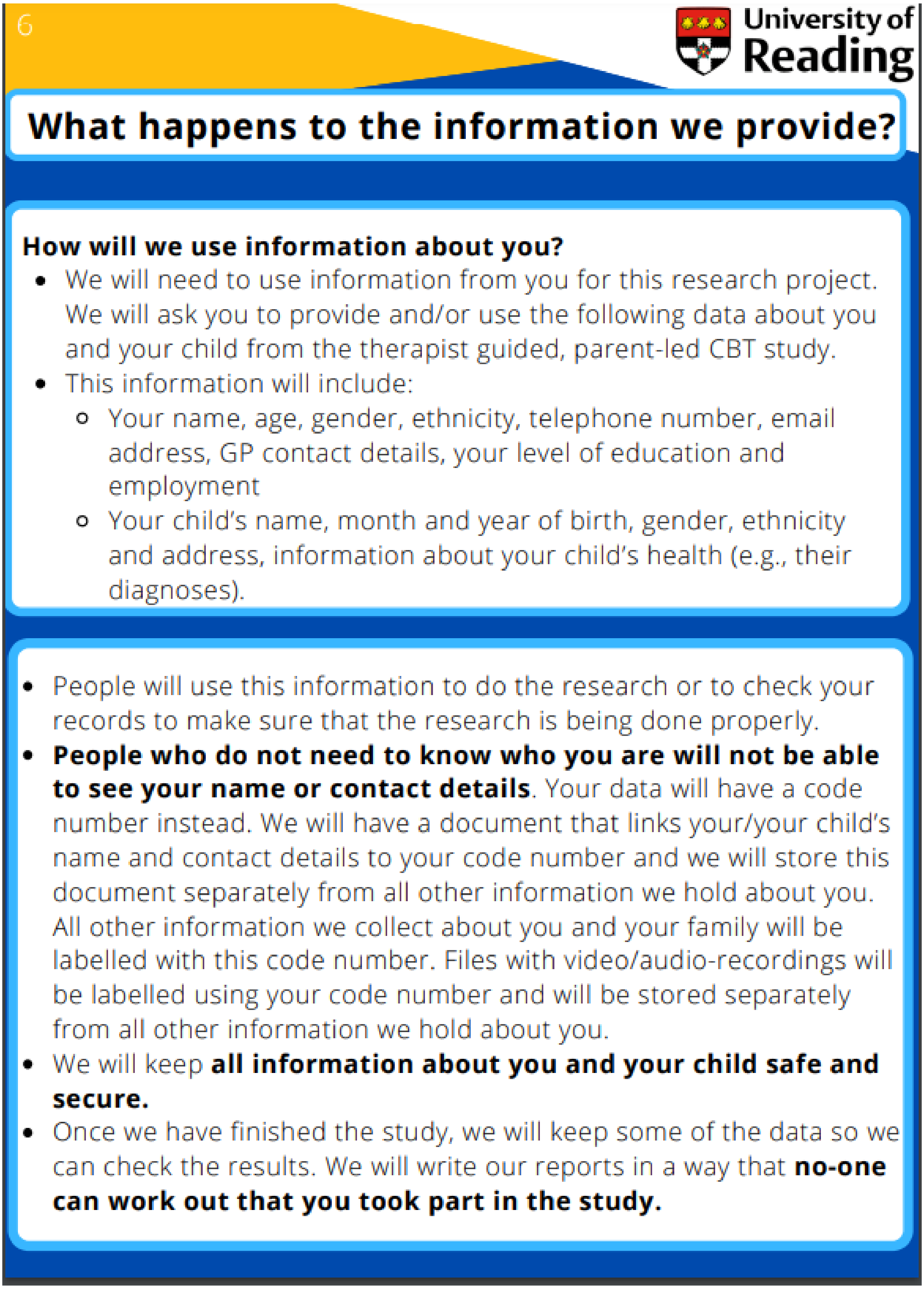
- This study is sponsored by the University of Reading and is funded by the Economic and Social Research Council.
- The project is organised by researchers and clinicians at the University of Reading, University of Oxford and Berkshire Healthcare NHS Foundation Trust.
- This study is being conducted towards a PhD qualification.

Have patients and the public been involved in designing the study?

- We have checked the questions that we will ask you with other parents, to make sure they are suitable and acceptable to families.

What if there is a problem?

- We do not expect anything bad to happen to you or your child by taking part in this research. In the unlikely event that it does, the University of Reading has insurance in case you suffer any harm as a direct consequence of taking part in this study.
- If you would like to make a formal compliant about any part of this study, please contact:
  - Professor Kate Harvey (k.n.harvey@reading.ac.uk) or
  - Professor Carmel Houston-Price, Head of the School of Psychology and Clinical Language Sciences, University of Reading, Harry Pitt Building, RG6 6BZ. Telephone 0118 987 8523 or email c.houston-price@reading.ac.uk.



What happens to the information we provide?

How will we use information about you?

- We will need to use information from you for this research project. We will ask you to provide and/or use the following data about you and your child from the therapist guided, parent-led CBT study.
- This information will include:
    - Your name, age, gender, ethnicity, telephone number, email address, GP contact details, your level of education and employment
    - Your child's name, month and year of birth, gender, ethnicity and address, information about your child's health (e.g., their diagnoses).

- People will use this information to do the research or to check your records to make sure that the research is being done properly.
- **People who do not need to know who you are will not be able to see your name or contact details**. Your data will have a code number instead. We will have a document that links your/your child's name and contact details to your code number and we will store this document separately from all other information we hold about you. All other information we collect about you and your family will be labelled with this code number. Files with video/audio-recordings will be labelled using your code number and will be stored separately from all other information we hold about you.
- We will keep **all information about you and your child safe and secure.**
- Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that **no-one can work out that you took part in the study.**

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Why do we collect, use, and store your personal data?

- We collect, use, and store your personal data for the purpose of research in the public interest.
- Personal and sensitive data we collect helps us to understand and describe the research findings.
- We will also collect some personal data to allow us to contact you about the study.

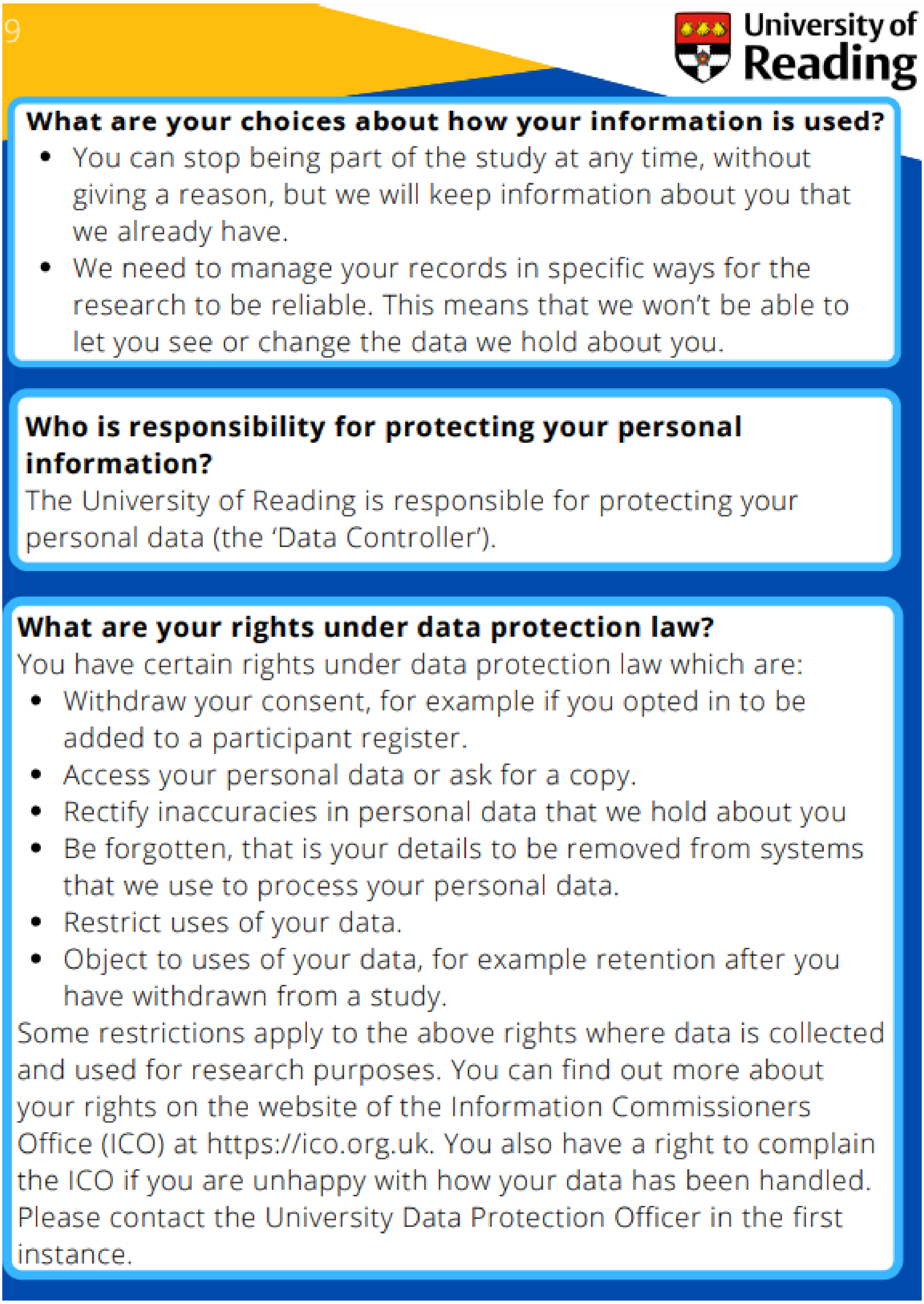
- We will collect data from you either via **telephone, video/audio recordings** and/or using a **secure website** with end-to-end encryption.

- We will video and/or audio-record the interviews.
- Audio recordings will be temporarily stored on audio-recorders, and once transferred to the secure, University of Reading OneDrive, will be removed from the audio-recorder.
- Video-recordings will be temporarily stored on Microsoft Teams, and once transferred to the secure, University of Reading OneDrive, will be deleted from Microsoft teams.
- All recordings will be safely destroyed at the end of the project.
- We will transcribe the interviews and will **not include any information that could reveal your identity** in these transcriptions.
- Any data or findings from the research that is published will not identify you or your child. We may use **direct quotes** from the interviews in publications, but this will not include any information that could identify you or your family.

- We will share necessary personal information we collect from you with the **study supervisors** at the University of Oxford, Oxford Healthcare NHS Foundation Trust and Berkshire Healthcare NHS Foundation Trust for supervision only. This information will be shared using a **secure link** which can only be opened by the intended person.
- We will not share what you or your child tells us to anyone outside of the research team unless we believe that your child or someone else may be at risk of serious harm.
    - If this happened, we may need to tell someone outside of the research team (e.g., GP, local safeguarding team and/or other relevant healthcare professionals), and we would always try to talk to you about this first.

How long will we store your data?

- We will only store your personal information for 6 to 12 months after the study has ended.
- Consent forms will be stored for a minimum of 3 years after the end of the research project.
- Video/audio-recordings of the interviews will be stored until recordings have been transcribed, transcriptions thoroughly checked, and detailed analysis is complete.
- The document that links yours/your child's name to other information we collect about you will be stored until all data collection is complete, all data and information has been carefully checked and the main analysis is complete, and then permanently deleted.
- Beyond this point, other research data we hold, including responses to screening questions, will not include any information that could directly identify you or your family. We will store research data electronically for up to 5 years.



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What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

Who is responsibility for protecting your personal information?

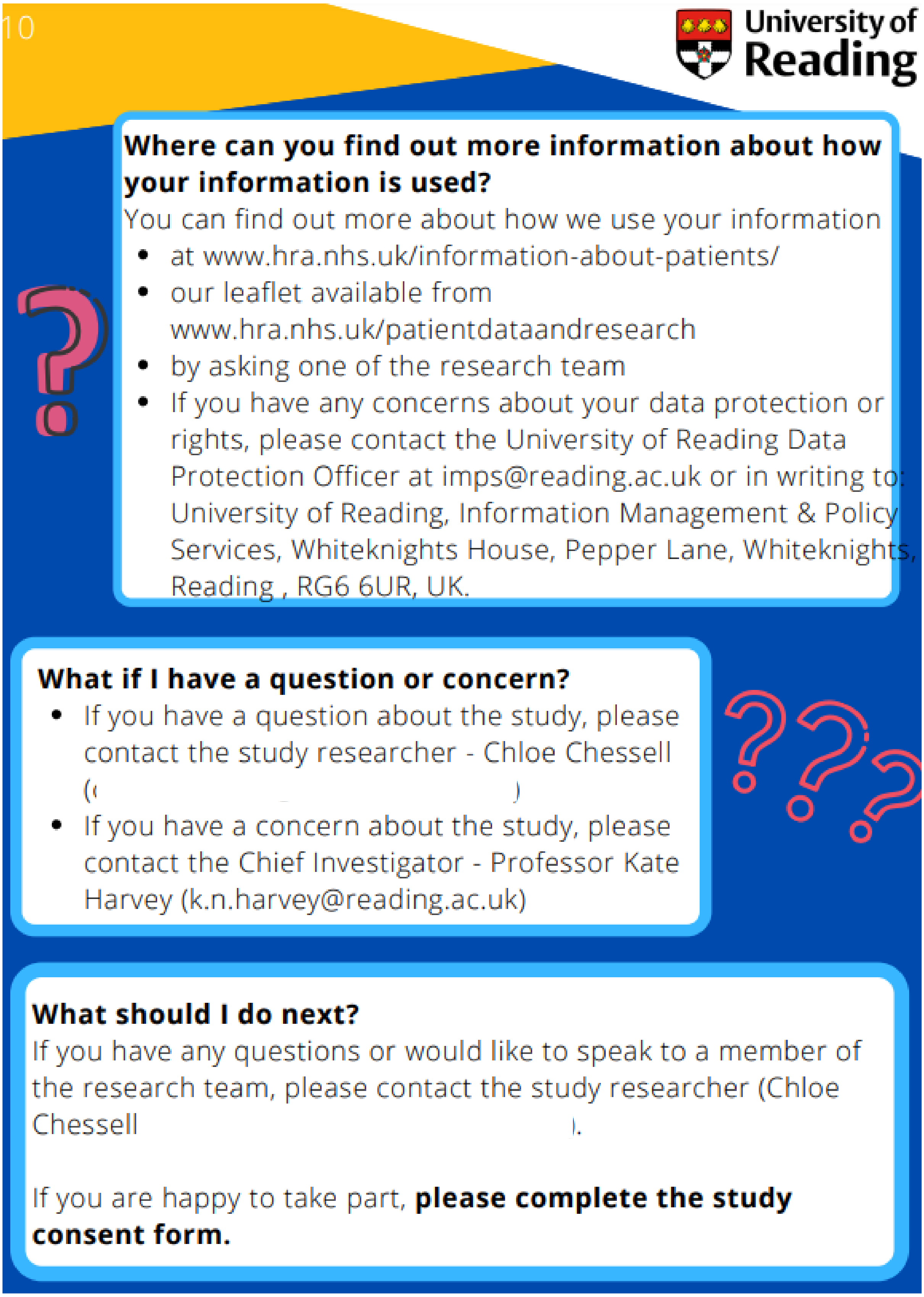
The University of Reading is responsible for protecting your personal data (the ‘Data Controller’).

What are your rights under data protection law?

You have certain rights under data protection law which are:

- Withdraw your consent, for example if you opted in to be added to a participant register.
- Access your personal data or ask for a copy.
- Rectify inaccuracies in personal data that we hold about you
- Be forgotten, that is your details to be removed from systems that we use to process your personal data.
- Restrict uses of your data.
- Object to uses of your data, for example retention after you have withdrawn from a study.

Some restrictions apply to the above rights where data is collected and used for research purposes. You can find out more about your rights on the website of the Information Commissioners Office (ICO) at https://ico.org.uk. You also have a right to complain the ICO if you are unhappy with how your data has been handled. Please contact the University Data Protection Officer in the first instance.



University of Reading

Where can you find out more information about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- If you have any concerns about your data protection or rights, please contact the University of Reading Data Protection Officer at imps@reading.ac.uk or in writing to: University of Reading, Information Management & Policy Services, Whiteknights House, Pepper Lane, Whiteknights, Reading , RG6 6UR, UK.

What if I have a question or concern?

- If you have a question about the study, please contact the study researcher - Chloe Chessell ()
- If you have a concern about the study, please contact the Chief Investigator - Professor Kate Harvey (k.n.harvey@reading.ac.uk)

What should I do next?

If you have any questions or would like to speak to a member of the research team, please contact the study researcher (Chloe Chessell).

If you are happy to take part, **please complete the study consent form.**

Appendix 3: Consent and Assent Forms

Consent to be contacted by the research team (Paper 2)

Parent consent form (Paper 2)

Consent to be contacted by the research team (Paper 3)

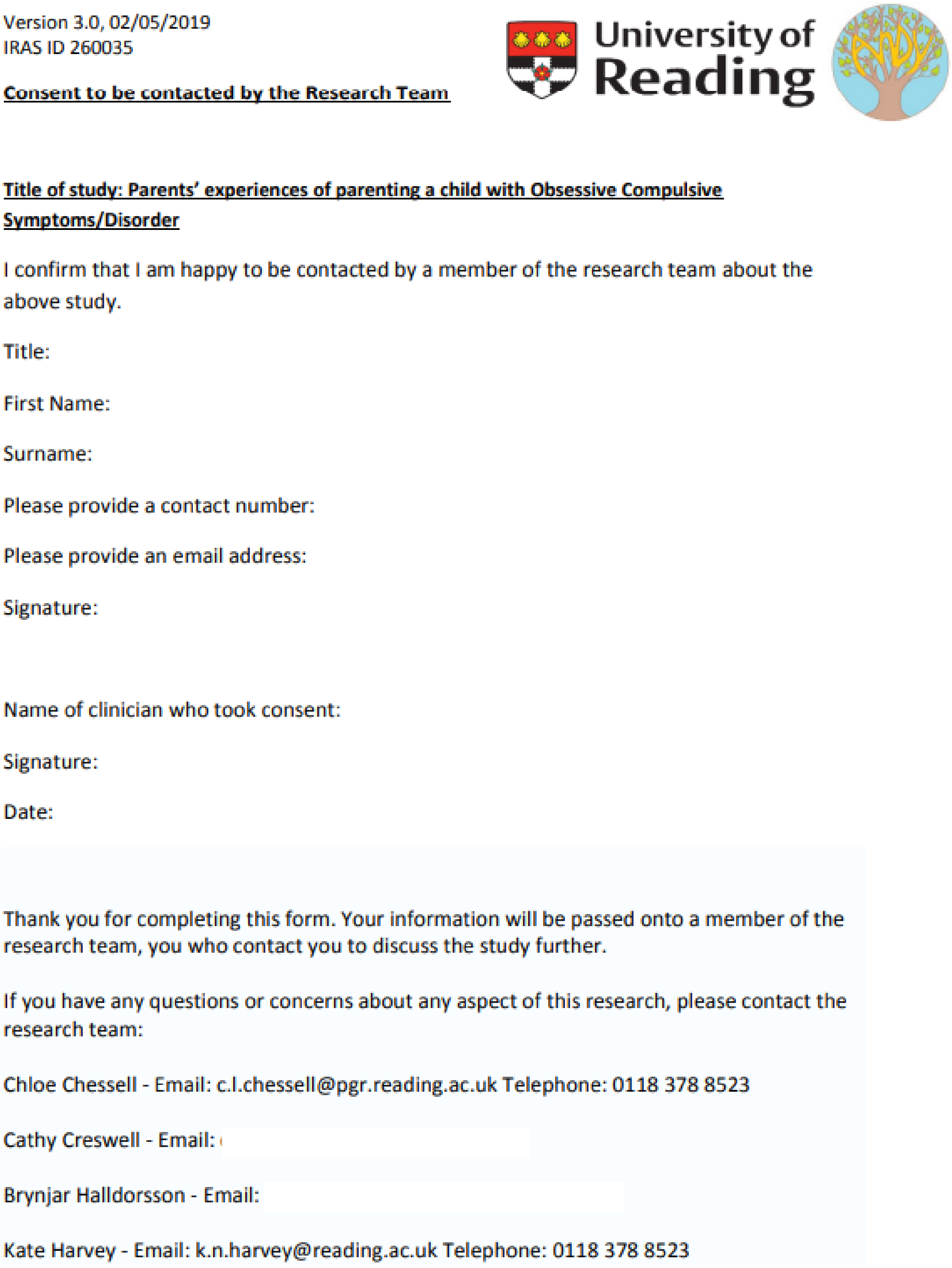
Parent consent form – treatment study (Paper 3)

Parent consent for child participation form – treatment study (Paper 3)

Child assent form – treatment study (Paper 3)

Parent consent form – optional qualitative interview (Paper 3)

Consent to be contacted by the research team (Paper 2)



Version 3.0, 02/05/2019
IRAS ID 260035

Consent to be contacted by the Research Team

Title of study: Parents' experiences of parenting a child with Obsessive Compulsive Symptoms/Disorder

I confirm that I am happy to be contacted by a member of the research team about the above study.

Title:

First Name:

Surname:

Please provide a contact number:

Please provide an email address:

Signature:

Name of clinician who took consent:

Signature:

Date:

Thank you for completing this form. Your information will be passed onto a member of the research team, you who contact you to discuss the study further.

If you have any questions or concerns about any aspect of this research, please contact the research team:

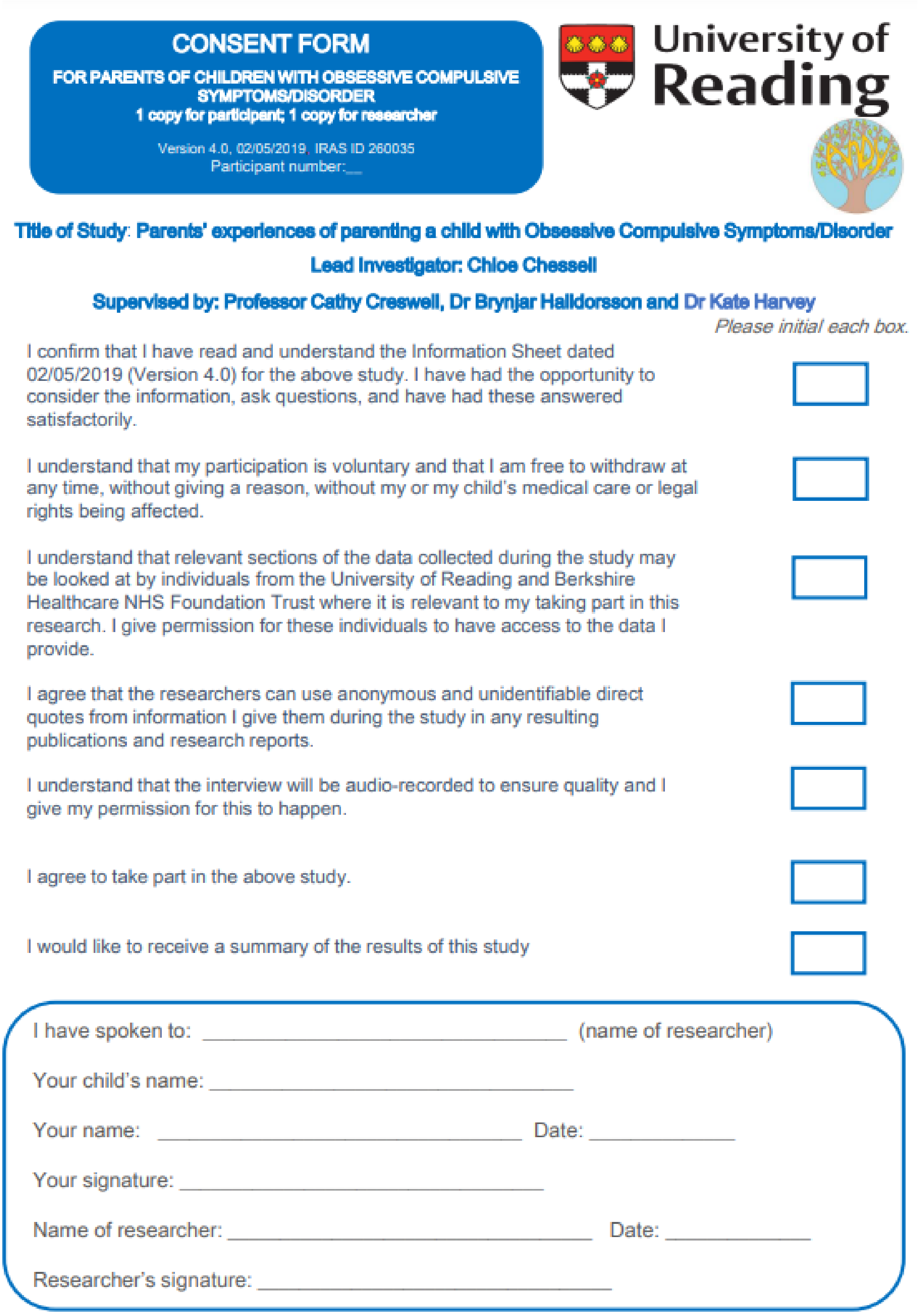
Chloe Chessell - Email: c.l.chessell@pgr.reading.ac.uk Telephone: 0118 378 8523

Cathy Creswell - Email: [redacted]

Brynjar Halldorsson - Email: [redacted]

Kate Harvey - Email: k.n.harvey@reading.ac.uk Telephone: 0118 378 8523

Parent consent form (Paper 2)



CONSENT FORM

FOR PARENTS OF CHILDREN WITH OBSESSIVE COMPULSIVE SYMPTOMS/DISORDER

1 copy for participant; 1 copy for researcher

Version 4.0, 02/05/2019, IRAS ID 260035
Participant number:__

University of Reading

Title of Study: Parents' experiences of parenting a child with Obsessive Compulsive Symptoms/Disorder

Lead Investigator: Chloe Chessell

Supervised by: Professor Cathy Creswell, Dr Brynjar Halldorsson and Dr Kate Harvey

Please initial each box.

I confirm that I have read and understand the Information Sheet dated 02/05/2019 (Version 4.0) for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my or my child's medical care or legal rights being affected.	☐
I understand that relevant sections of the data collected during the study may be looked at by individuals from the University of Reading and Berkshire Healthcare NHS Foundation Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data I provide.	☐
I agree that the researchers can use anonymous and unidentifiable direct quotes from information I give them during the study in any resulting publications and research reports.	☐
I understand that the interview will be audio-recorded to ensure quality and I give my permission for this to happen.	☐
I agree to take part in the above study.	☐
I would like to receive a summary of the results of this study	☐

I have spoken to: ________________________________ (name of researcher)

Your child's name: ________________________________

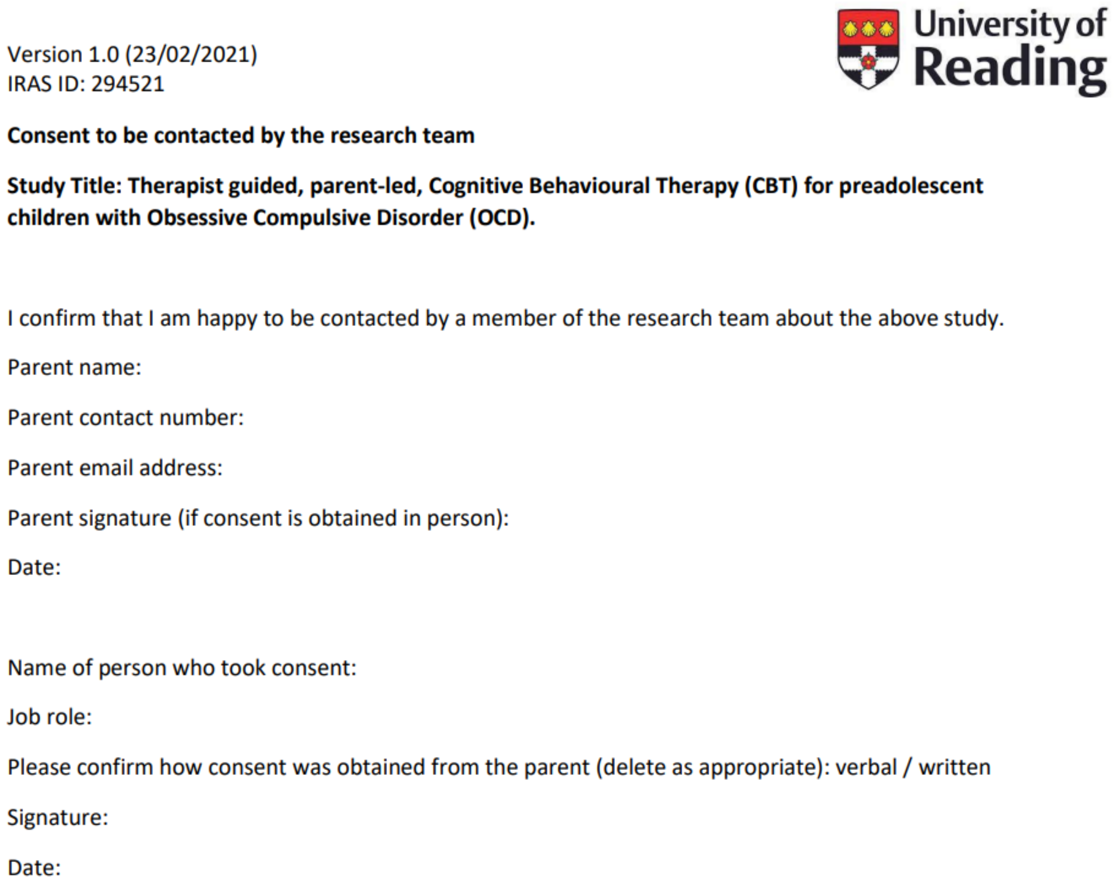
Your name: ________________________________ Date: _____________

Your signature: ________________________________

Name of researcher: ________________________________ Date: _____________

Researcher's signature: ________________________________

Consent to be contacted by the research team (Paper 3)



Version 1.0 (23/02/2021)
IRAS ID: 294521

University of Reading

Consent to be contacted by the research team

Study Title: Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD).

I confirm that I am happy to be contacted by a member of the research team about the above study.

Parent name:

Parent contact number:

Parent email address:

Parent signature (if consent is obtained in person):

Date:

Name of person who took consent:

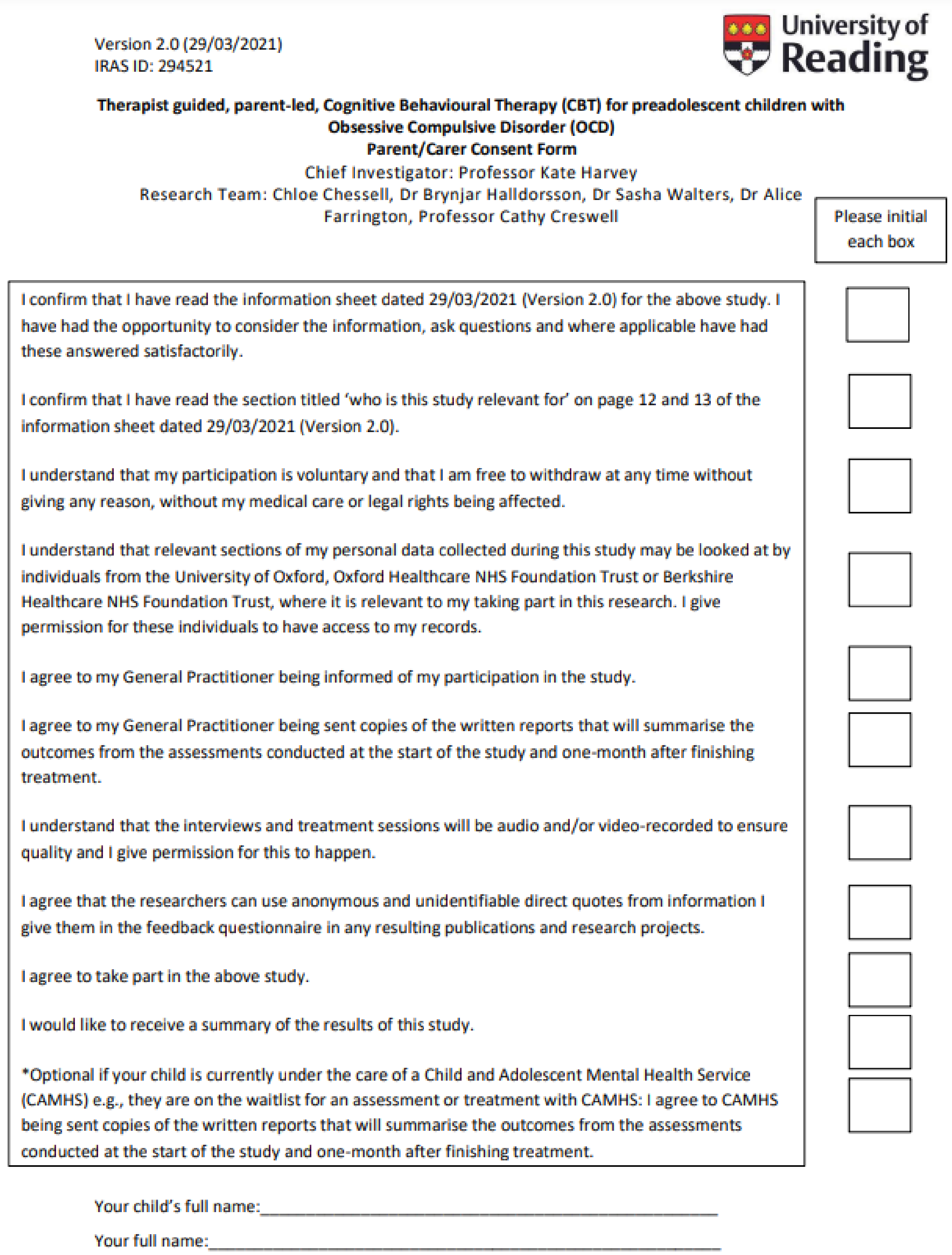
Job role:

Please confirm how consent was obtained from the parent (delete as appropriate): verbal / written

Signature:

Date:

Parent consent form – treatment study (Paper 3)



Version 2.0 (29/03/2021)
IRAS ID: 294521

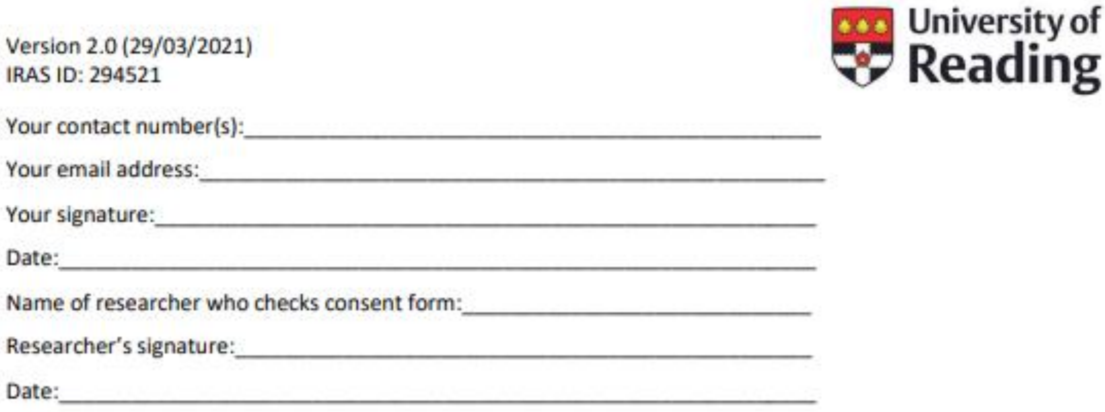
University of Reading

Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD)
Parent/Carer Consent Form
Chief Investigator: Professor Kate Harvey
Research Team: Chloe Chessell, Dr Brynjar Halldorsson, Dr Sasha Walters, Dr Alice Farrington, Professor Cathy Creswell

	Please initial each box
I confirm that I have read the information sheet dated 29/03/2021 (Version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and where applicable have had these answered satisfactorily.	☐
I confirm that I have read the section titled 'who is this study relevant for' on page 12 and 13 of the information sheet dated 29/03/2021 (Version 2.0).	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
I understand that relevant sections of my personal data collected during this study may be looked at by individuals from the University of Oxford, Oxford Healthcare NHS Foundation Trust or Berkshire Healthcare NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐
I agree to my General Practitioner being informed of my participation in the study.	☐
I agree to my General Practitioner being sent copies of the written reports that will summarise the outcomes from the assessments conducted at the start of the study and one-month after finishing treatment.	☐
I understand that the interviews and treatment sessions will be audio and/or video-recorded to ensure quality and I give permission for this to happen.	☐
I agree that the researchers can use anonymous and unidentifiable direct quotes from information I give them in the feedback questionnaire in any resulting publications and research projects.	☐
I agree to take part in the above study.	☐
I would like to receive a summary of the results of this study.	☐
*Optional if your child is currently under the care of a Child and Adolescent Mental Health Service (CAMHS) e.g., they are on the waitlist for an assessment or treatment with CAMHS: I agree to CAMHS being sent copies of the written reports that will summarise the outcomes from the assessments conducted at the start of the study and one-month after finishing treatment.	☐

Your child's full name:____________________________________

Your full name:____



Version 2.0 (29/03/2021)
IRAS ID: 294521

University of Reading

Your contact number(s):______________________________

Your email address:______________________________

Your signature:______________________________

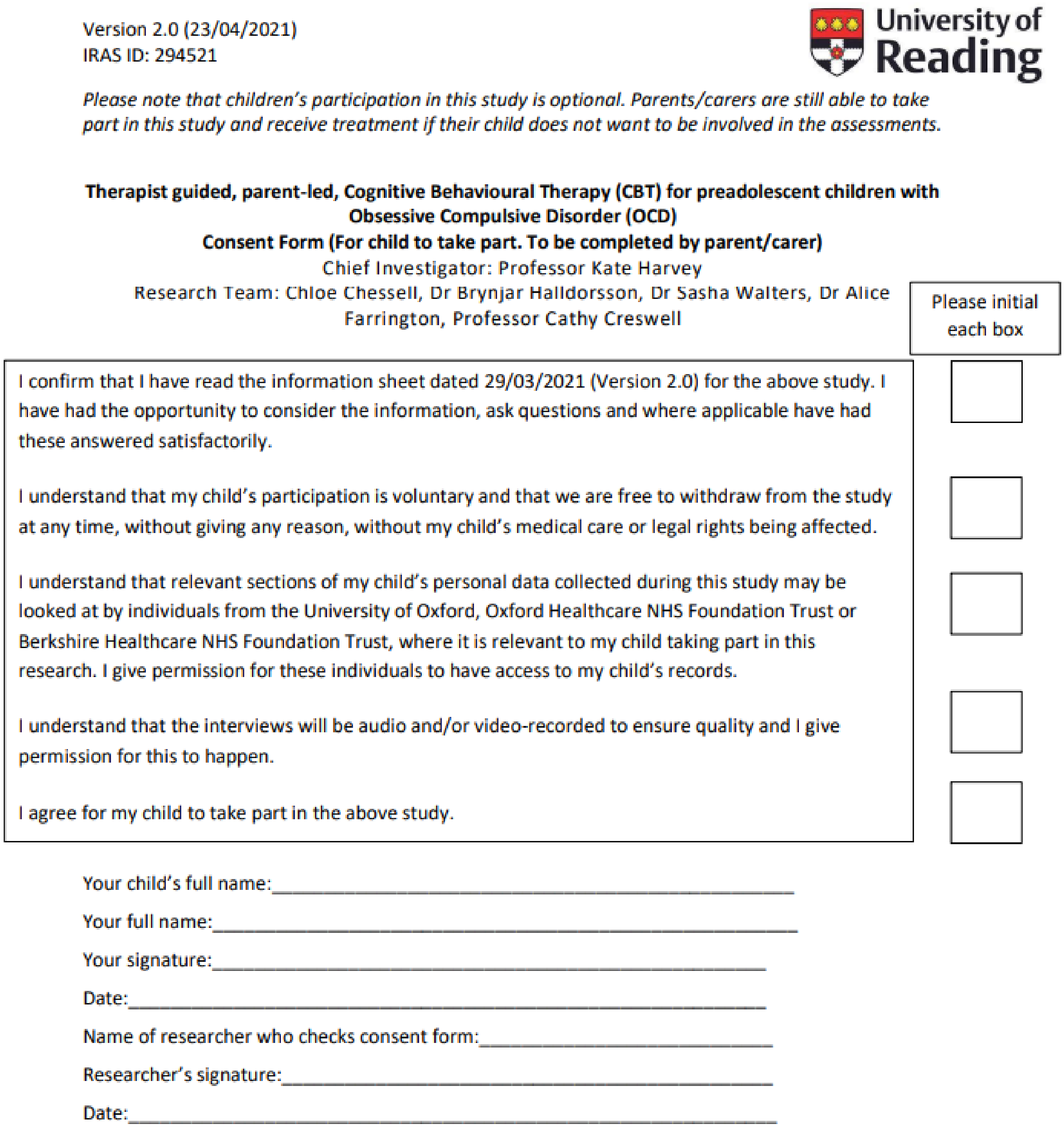
Date:______________________________

Name of researcher who checks consent form:______________________________

Researcher's signature:______________________________

Date:______________________________

Parent consent for child participation form – treatment study (Paper 3)



Version 2.0 (23/04/2021)
IRAS ID: 294521

University of Reading

Please note that children's participation in this study is optional. Parents/carers are still able to take part in this study and receive treatment if their child does not want to be involved in the assessments.

Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD)

Consent Form (For child to take part. To be completed by parent/carer)

Chief Investigator: Professor Kate Harvey

Research Team: Chloe Chessell, Dr Brynjar Halldorsson, Dr Sasha Walters, Dr Alice Farrington, Professor Cathy Creswell

	Please initial each box
I confirm that I have read the information sheet dated 29/03/2021 (Version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and where applicable have had these answered satisfactorily.	☐
I understand that my child's participation is voluntary and that we are free to withdraw from the study at any time, without giving any reason, without my child's medical care or legal rights being affected.	☐
I understand that relevant sections of my child's personal data collected during this study may be looked at by individuals from the University of Oxford, Oxford Healthcare NHS Foundation Trust or Berkshire Healthcare NHS Foundation Trust, where it is relevant to my child taking part in this research. I give permission for these individuals to have access to my child's records.	☐
I understand that the interviews will be audio and/or video-recorded to ensure quality and I give permission for this to happen.	☐
I agree for my child to take part in the above study.	☐

Your child's full name:____

Your full name:____

Your signature:____

Date:____

Name of researcher who checks consent form:_____________________

Researcher's signature:_____________________________________

Date:____

Child assent form – treatment study (Paper 3)

Version 1.0 (23/02/2021)
IRAS ID: 294521

University of Reading

Please note that children's participation in this study is optional. Parents/carers are still able to take part in this study and receive treatment if their child does not want to be involved in the assessments.

Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD)

Assent Form (To be completed by the child)

Chief Investigator: Professor Kate Harvey

Research Team: Chloe Chessell, Dr Brynjar Halldorsson, Dr Sasha Walters, Dr Alice Farrington, Professor Cathy Creswell

Please circle your answer

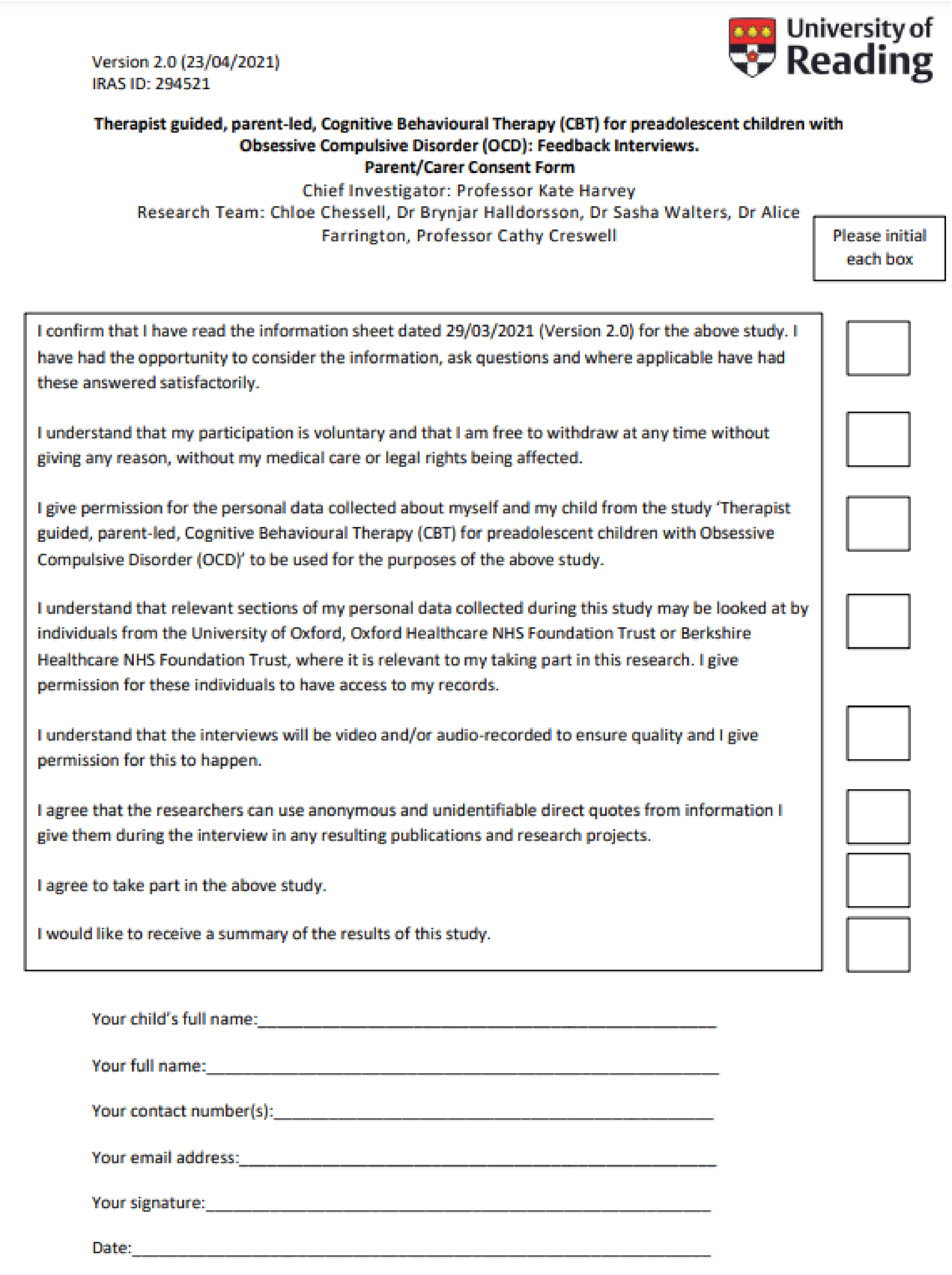
Have you read (or had read to you) the information about this research?	(Yes/No)
Has someone explained the research to you?	(Yes/No)
Have you asked any questions you want to?	(Yes/No/No questions)
Did you understand the answers?	(Yes/No/No questions)
Do you understand it's ok to stop taking part at any time?	(Yes/No)
Are you happy to take part?	(Yes/No)

Your first name:____

Your surname:____

Date:____

Parent consent form – optional qualitative interview (Paper 3)



Version 2.0 (23/04/2021)
IRAS ID: 294521

University of Reading

Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD): Feedback Interviews.
Parent/Carer Consent Form
Chief Investigator: Professor Kate Harvey
Research Team: Chloe Chessell, Dr Brynjar Halldorsson, Dr Sasha Walters, Dr Alice Farrington, Professor Cathy Creswell

	Please initial each box
I confirm that I have read the information sheet dated 29/03/2021 (Version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and where applicable have had these answered satisfactorily.	☐
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
I give permission for the personal data collected about myself and my child from the study 'Therapist guided, parent-led, Cognitive Behavioural Therapy (CBT) for preadolescent children with Obsessive Compulsive Disorder (OCD)' to be used for the purposes of the above study.	☐
I understand that relevant sections of my personal data collected during this study may be looked at by individuals from the University of Oxford, Oxford Healthcare NHS Foundation Trust or Berkshire Healthcare NHS Foundation Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	☐
I understand that the interviews will be video and/or audio-recorded to ensure quality and I give permission for this to happen.	☐
I agree that the researchers can use anonymous and unidentifiable direct quotes from information I give them during the interview in any resulting publications and research projects.	☐
I agree to take part in the above study.	☐
I would like to receive a summary of the results of this study.	☐

Your child's full name:____

Your full name:____

Your contact number(s):____

Your email address:____

Your signature:____

Date:____

Name of researcher who checks consent form:______________________________

Researcher's signature:____

Date:____

Appendix 4: Study Materials

Demographic and screening questionnaire (Paper 2)

Factsheet for parents (Paper 2)

Topic guide (Paper 2)

Demographic and screening questionnaire (Paper 3)

Adapted Family Accommodation Scale – Parent Report (Paper 3)

Items assessing parental knowledge and confidence to help their child to overcome OCD (Paper 3)

Items assessing whether children have learned new information about their fears and their ability to cope in feared situations (Paper 3)

Topic guide (Paper 3)

Treatment acceptability questionnaire (Paper 3)

Demographic and screening questionnaire (Paper 2)

Version 3.0, 18/06/19, IRAS ID 260035

Screening questions

About you and your child

Your child's age:	
Your child's gender:	
Your age:	
Your gender:	
Relationship to child:	
Caregiver status: Primary caregiver/ Secondary caregiver/ Shared caregiver/Other	
Parent relationship status: Single, never married/ Married (first time) / Remarried/ Divorced/separated/ Living with partner/ Widowed/ Not Applicable	
Parent education: School completion/ Further education (e.g. college, vocational courses)/ Higher education (undergraduate degree)/ Postgraduate qualification	
Parent employment status: Unemployed/ Employed full-time/Employed Part-time/ Retired	
If employed, please state occupation	

Ethnicity

Please enter the relevant code from the table below for your child and for you.

Your child's ethnicity	
Your ethnicity	

White	**Code**	**Black or Black British**	**Code**
British	A	African	M
Irish	B	Caribbean	N
Any other White Background	C	Any other Black background	P
Mixed		**Other Ethnic groups**	
White and Black Caribbean	D	Chinese	R
White and Black African	E	Any other Ethnic group	S
White and Asian	F	**Not Stated**	
Any other mixed background	G	I do not wish to state their ethnicity	Z
Asian or Asian British			
Indian	H		
Pakistani	J		
Bangladeshi	K		
Any other Asian background	L		

About you and your child

Please answer all of the questions below:

1. Is your child suspected to have OCD?	Yes / No
2. Does your child currently have a diagnosis of OCD?	Yes / No
3. Has your child previously had a diagnosis of OCD?	Yes / No
4. Have you sought treatment for your child's OCD at any point?	Yes / No
5. Is your child currently on the waitlist for treatment for OCD?	Yes / No
6. Is your child currently receiving treatment for OCD?	Yes / No
7. Has your child previously received treatment for OCD?	Yes / No
8. Does your child have a confirmed diagnosis of an Autism Spectrum Disorder (ASD)?	Yes / No
9. Does your child attend a specialist school (i.e. non-mainstream school) due to having a significant learning disability?	Yes / No
10. Does your child have a diagnosis of any other mental health conditions? (e.g. Attention Deficit Hyperactivity Disorder (ADHD), Generalised Anxiety Disorder etc.)	Yes / No If YES, please provide details: ______________________________ ______________________________ ______________________________
11. Do **you** have an intellectual impairment which would interfere with your ability to take part in an interview?	Yes / No
12. Are **you** a UK-resident?	Yes / No

Below are four sections. Please answer all of the questions in each section which is applicable to your child.
If a section is not applicable to your child, please leave the section blank.

SECTION 1. Please answer these questions if your child has a **current diagnosis of OCD**, or has **previously had a diagnosis of OCD**.	
1. How old was your child when they were diagnosed with OCD?	Years Old
2. Who diagnosed your child with OCD?	General Practitioner (GP) Mental Health Professional (e.g. CAHMS) Other (please state)________________

SECTION 2. Please answer these questions if your child is **currently on the waitlist for treatment** for OCD

1. What treatment is your child waiting to receive?

Service provider (e.g. CAMHS)____

Type of treatment (e.g. CBT, counselling, EMDR, play therapy, medication etc.)________________________________

SECTION 3. Please answer these questions if your child is **currently receiving treatment** for OCD.

1. What treatment is your child currently receiving?

Service provider (e.g. CAMHS)____

Type of treatment (e.g. CBT, counselling, EMDR, play therapy, medication etc.)________________________________

SECTION 4. Please answer these questions if your child has **previously received treatment** for OCD.

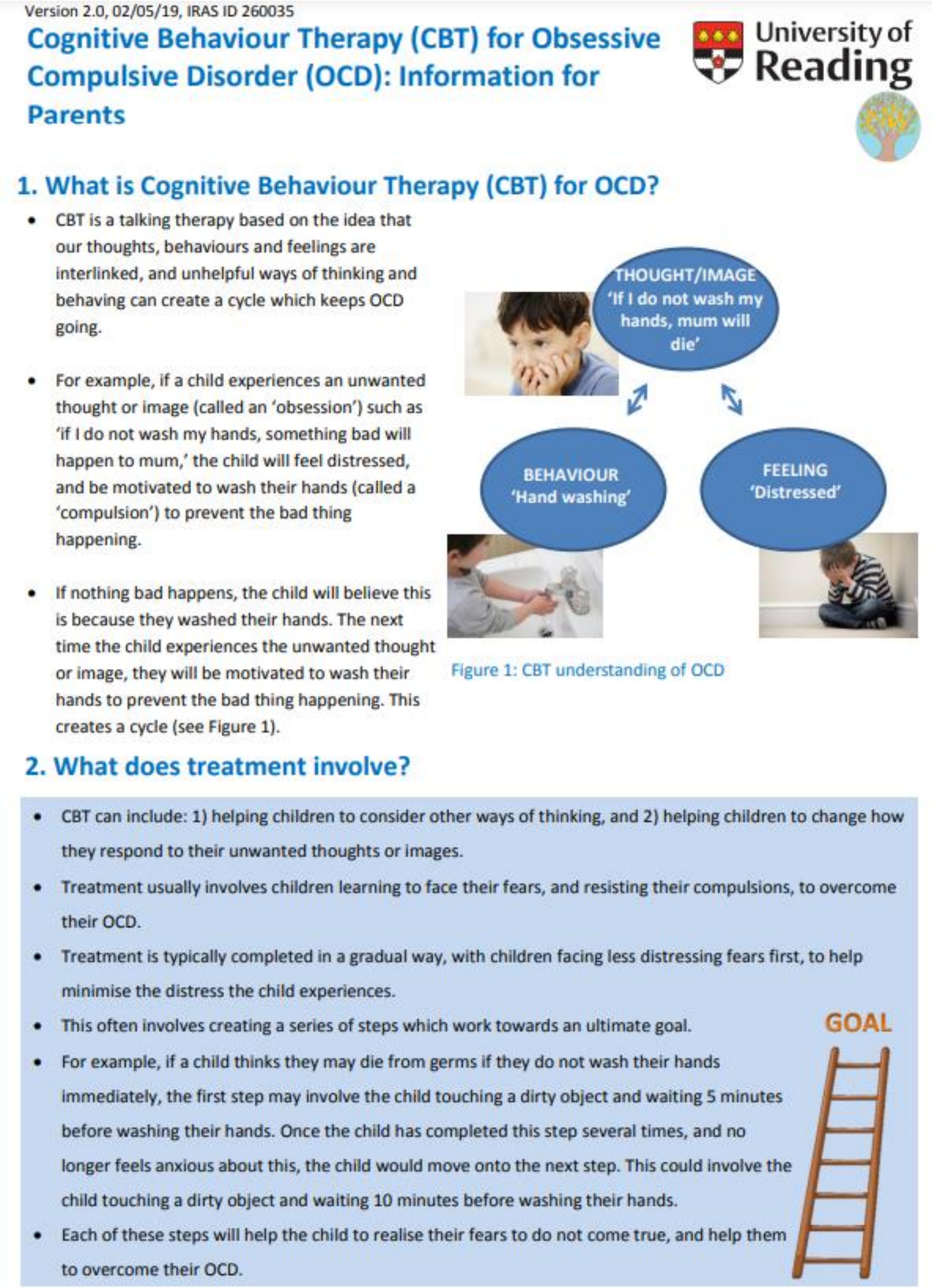
1. What treatment did your child receive?

Service provider (e.g. CAMHS)____

Type of treatment (e.g. CBT, counselling, EMDR, play therapy, medication etc.)________________________________

2. How old was your child when they received this treatment?	Years Old

Factsheet for parents (Paper 2)



Version 2.0, 02/05/19, IRAS ID 260035

Cognitive Behaviour Therapy (CBT) for Obsessive Compulsive Disorder (OCD): Information for Parents

1. What is Cognitive Behaviour Therapy (CBT) for OCD?

- CBT is a talking therapy based on the idea that our thoughts, behaviours and feelings are interlinked, and unhelpful ways of thinking and behaving can create a cycle which keeps OCD going.
- For example, if a child experiences an unwanted thought or image (called an 'obsession') such as 'if I do not wash my hands, something bad will happen to mum,' the child will feel distressed, and be motivated to wash their hands (called a 'compulsion') to prevent the bad thing happening.
- If nothing bad happens, the child will believe this is because they washed their hands. The next time the child experiences the unwanted thought or image, they will be motivated to wash their hands to prevent the bad thing happening. This creates a cycle (see Figure 1).

Figure 1: CBT understanding of OCD

2. What does treatment involve?

- CBT can include: 1) helping children to consider other ways of thinking, and 2) helping children to change how they respond to their unwanted thoughts or images.
- Treatment usually involves children learning to face their fears, and resisting their compulsions, to overcome their OCD.
- Treatment is typically completed in a gradual way, with children facing less distressing fears first, to help minimise the distress the child experiences.
- This often involves creating a series of steps which work towards an ultimate goal.
- For example, if a child thinks they may die from germs if they do not wash their hands immediately, the first step may involve the child touching a dirty object and waiting 5 minutes before washing their hands. Once the child has completed this step several times, and no longer feels anxious about this, the child would move onto the next step. This could involve the child touching a dirty object and waiting 10 minutes before washing their hands.
- Each of these steps will help the child to realise their fears to do not come true, and help them to overcome their OCD.

3. How can parents be involved in CBT for children with OCD?

Listed below are four different ways parents can be involved in treatment. The differences between each option are highlighted in purple. During your interview, you will be asked to discuss your views on each of these options. Please note - the number and length of treatment sessions can vary depending on the treatment provider, and the child's progress in treatment.

1. Child sessions with no parent involvement

- Children receive treatment sessions with a therapist, delivered face-to-face at a mental health service.
- On average, 14 individual treatment sessions might be offered, but the number of treatment sessions may range between 12 and 20. Each session is approximately 1 hour long.
- Parents do not attend the treatment session with their child.

2. Child sessions with limited parent involvement

- Children receive treatment sessions with a therapist, delivered face-to-face at a mental health service.
- On average, 14 individual treatment sessions might be offered, but the number of treatment sessions may range between 12 and 20. Each session is approximately 1 hour long.
- Parents would attend the beginning and/or the end of their child's treatment session, to give feedback to the therapist and to hear what their child has been asked to do between treatment sessions.

3. Child and Parent treatment sessions

- Children receive treatment sessions with a therapist, delivered face-to-face at a mental health service.
- On average, 14 individual treatment sessions with the child might be offered, but the number of treatment sessions may range between 12 and 20. Each session is approximately 1 hour long.
- Parents receive additional parent sessions with a therapist to receive information on what OCD is; how the family can influence OCD; and to encourage parents to help children to keep working on overcoming their OCD at home.

4. Therapist guided, parent delivered treatment sessions

- Parents receive treatment sessions with a therapist, delivered using a combination of face-to-face, telephone and/or internet appointments.
- The therapist does not work directly with the child after the initial assessment.
- On average, between 8 and 12 individual treatment sessions with the parent might be offered, each lasting between 20 minutes and 1 hour long.
- Parents are provided with a treatment workbook, outlining how they can help their child to overcome OCD, for their use within and between treatment sessions. Therapists guide parents to apply these techniques with their child.

If you have any questions or concerns, please contact Chloe Louise Chessell, PhD Student, University of Reading: c.l.chessell@pgr.reading.ac.uk

Topic guide (Paper 2)

Topic Guide

1. Introduction

Establish the purpose of the interview and the limits of confidentiality.

2. Contextual information

Review the information from the screening questions and identify further contextual information as necessary.

Possible prompts:

- OCD diagnosis
- Type of treatment
- Frequency and duration of treatment
- Parent involvement
- Success of treatment
- OCD presentation

3. Parents' experiences of parenting a child with OCD

Discuss parents' experiences of parenting a child with OCD

Possible questions:

- How does your child's OCD affect daily life? (e.g. school, work, home, family)
- What are the challenges of having a child with OCD?
- Are there any positives of having a child with OCD?
- What aspects of your child's OCD do you find harder or easier to manage?
- What do you wish you knew about how to manage your child's OCD?
- Have you tried anything to manage your child's OCD? What have you tried?
- What could be given to help you to manage [whilst you are on the waitlist]?
- What can we learn from parents who are able to help their child?

4. Parents' views towards different levels of parent involvement in treatment. Review information on CBT for OCD and how parents could be involved.

Discuss each level of parent involvement with the parent.

Possible questions:

- How do you think you and your family would get on with this approach?
- How do you think your child would respond to this approach?
- What do you think the benefits of the approach would be?
- What do you think the challenges of the approach would be?
- Do you have any ideas how these challenges could be overcome in treatment?

- What does a child get from a therapist that they would not get from a parent? Can this be overcome? Why does a child need to be seen by a therapist?

5. Parents' preferred level of parent involvement

Discuss parents' preferred level of involvement in helping their child.

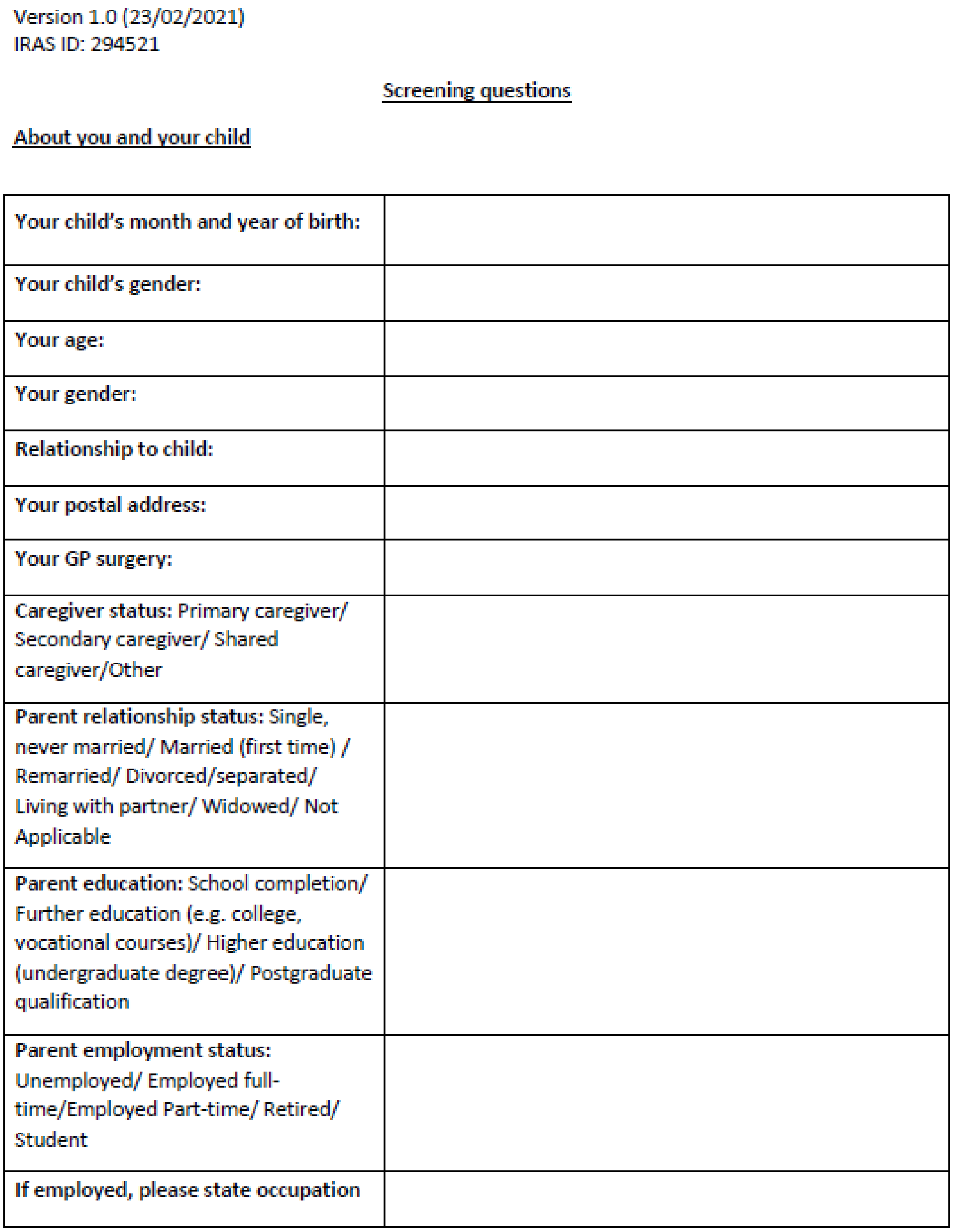
Possible questions:

- What are your reasons for your preferred level of parent involvement?
- Do you think any of these treatment approaches would be more or less helpful when concerns had first arisen and when concerns had been more longstanding?
- Would you be prepared to help your child with treatment techniques or strategies at home?
- What support or guidance would you like or need to help you to implement treatment techniques or strategies at home?
- How would you find managing your child's distress during treatment? What would make a difference to this? How can we empower you to help your child?
- What support would you like to receive as a parent?
- Are there any skills or knowledge you would like to gain (or wish you had gained) to support your child?

6. Summarise the interview

Probe whether there is anything else the parent wishes to add to the information discussed. Ask parents if they wish to receive a summary of the research findings. Thank the parent for their time.

Demographic and screening questionnaire (Paper 3)



Version 1.0 (23/02/2021)
IRAS ID: 294521

Screening questions

About you and your child

Your child's month and year of birth:	
Your child's gender:	
Your age:	
Your gender:	
Relationship to child:	
Your postal address:	
Your GP surgery:	
Caregiver status: Primary caregiver/ Secondary caregiver/ Shared caregiver/Other	
Parent relationship status: Single, never married/ Married (first time) / Remarried/ Divorced/separated/ Living with partner/ Widowed/ Not Applicable	
Parent education: School completion/ Further education (e.g. college, vocational courses)/ Higher education (undergraduate degree)/ Postgraduate qualification	
Parent employment status: Unemployed/ Employed full-time/Employed Part-time/ Retired/ Student	
If employed, please state occupation	

Ethnicity

Please enter the relevant code from the table below for your child and for you.

Your child's ethnicity	
Your ethnicity	

White	**Code**	**Black or Black British**	**Code**
British	A	African	M
Irish	B	Caribbean	N
Any other White Background	C	Any other Black background	P
Mixed		**Other Ethnic groups**	
White and Black Caribbean	D	Chinese	R
White and Black African	E	Any other Ethnic group	S
White and Asian	F	**Not Stated**	
Any other mixed background	G	I do not wish to state their ethnicity	Z
Asian or Asian British			
Indian	H		
Pakistani	J		
Bangladeshi	K		
Any other Asian background	L		

About your child's difficulties

The following questions will help us to understand if your child may have OCD.

OCD stands for Obsessive Compulsive Disorder. Children who have OCD often experience unwanted thoughts, images or urges, known as obsessions. Obsessions are often repetitive and cause children high levels of distress or anxiety. Common obsessions include fears about:

- Being dirty or contaminated
- Harm coming to oneself or others
- Unwanted sexual thoughts
- Things needing to be even or symmetrical
- Needing to tell or confess information

Compulsions are things that children do, to try and reduce the distress they feel from their obsession, or to prevent something bad from happening. Common compulsions include:

- Washing
- Checking
- Counting
- Arranging
- Trying to cancel out bad thoughts
- Asking for reassurance

OCD often causes interference in a child's life.

1. Does your child experience repetitive thoughts or images that don't seem to make sense?	Yes/ No
2. Does your child find it hard to control or stop these thoughts?	Yes/ No
3.Does your child ever feel anxious or uncomfortable if they cannot do the same thing over and over again in a special order or manner (e.g., washing their hands over and over again?)	Yes/ No
4.Does this get in the way of their life (e.g., by causing problems with friendships, at home or at school?)	Yes/ No
5.Has this stopped your child from doing things that they want to do?	Yes/ No

About you and your child

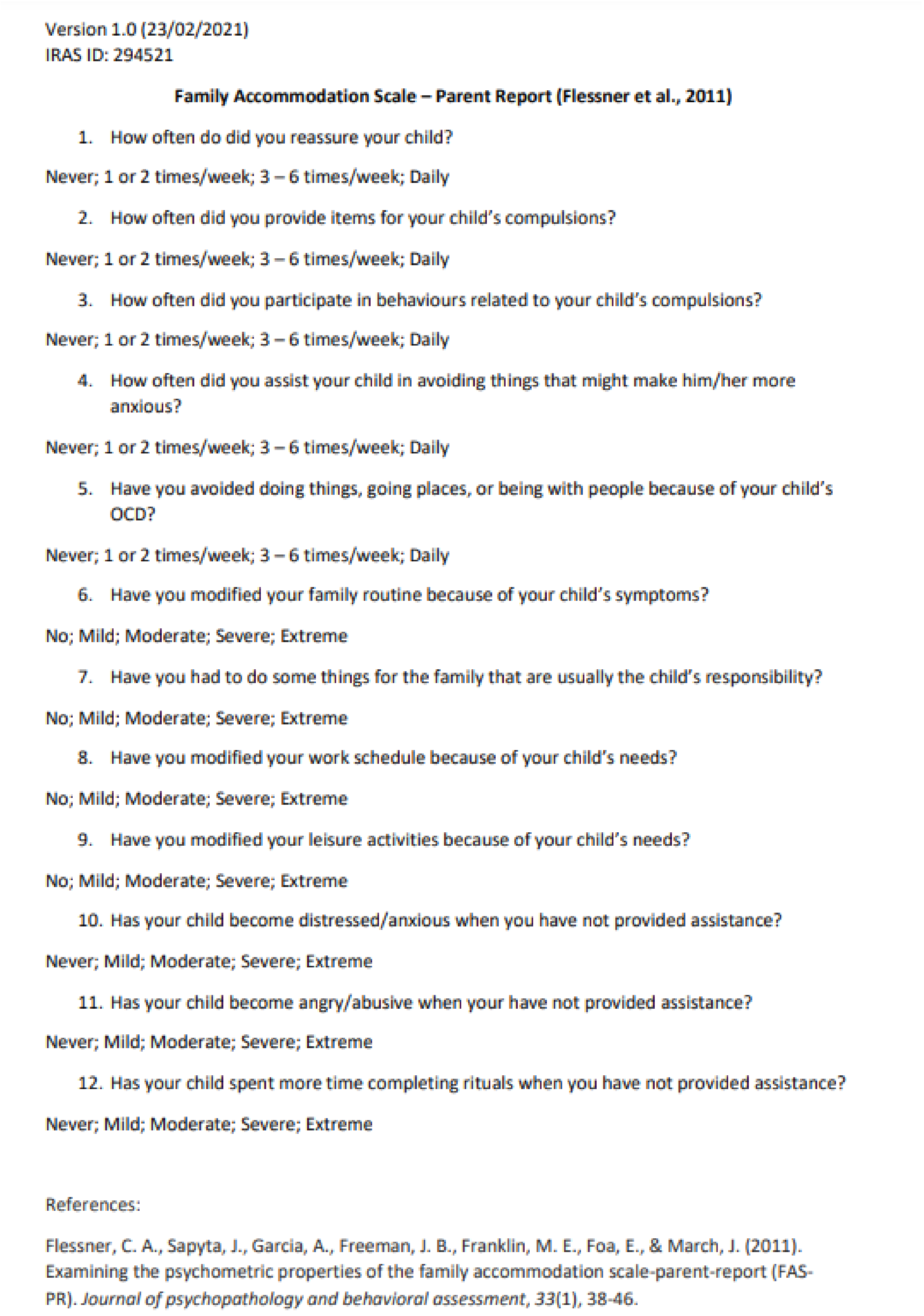
Please answer the following questions about you and your child.

1. Is your child a UK resident?	Yes / No
2. Are you a UK resident?	Yes / No
3. Does your child have a diagnosis of OCD?	Yes / No
3a. If yes, please specify: (i) How old your child was when they were diagnosed with OCD	

(ii) Who diagnosed your child with OCD (e.g., CAMHS, private treatment providers)	
4. Is your child currently receiving any psychological treatment for OCD (e.g., cognitive behavioural therapy, counselling etc.)?	Yes/No
4a. If yes, please specify: (i) What treatment your child is currently receiving (e.g., CBT, counselling etc.) (ii) The length and duration of the treatment (e.g., if your child is receiving CBT or counselling, how many sessions has your child received and over what time period?) (iii) When you are due to finish this treatment (if known) (iv) Where is your child receiving treatment (e.g., CAMHS, private treatment provider)	
5. Is your child currently prescribed any medication for mental health difficulties? (e.g., sertraline, fluoxetine)	Yes / No
5a. If yes, please specify: (i) What medication your child has been prescribed (ii) How long your child has been taking this medication at the current dosage	Yes / No
6. Is your child currently on the waitlist for treatment for OCD?	Yes / No
6a. If yes, please specify: (i) What treatment is your child waiting to receive (e.g., CBT, counselling, medication, not known etc.) (ii) Where is your child waiting for treatment (e.g., CAMHS, private treatment provider etc.)	
7. Has your child previously received treatment for OCD? (e.g., psychological treatment, medication)	Yes / No
7a. If yes, please specify: (i) What treatment your child received (e.g., cognitive behavioural therapy, medication etc.) (ii) The length and duration of the treatment (e.g., if your child received CBT, how many sessions	Yes / No

did your child receive and over what time period? If your child received medication, what medication were they prescribed and for how long?) (iii) How old was your child when they received this treatment? (iv) Where did your child receive treatment (e.g., CAMHS, private treatment provider)	
8. Does your child have a confirmed diagnosis of an Autism Spectrum Condition (ASC)?	Yes / No
9. Is your child on the waitlist for an assessment for a possible Autism Spectrum Condition (ASC)?	Yes / No
10. Does your child attend a specialist school (i.e., non-mainstream school) due to having a significant learning disability?	Yes/ No
11. Does your child have a diagnosis of any other mental health difficulties (e.g., Attention Deficit Hyperactivity Disorder, Tic Disorder etc.)	Yes / No
12. Do you have a significant intellectual impairment which would interfere with your ability to engage in treatment for your child?	Yes/ No

Adapted Family Accommodation Scale – Parent Report (Paper 3)



Version 1.0 (23/02/2021)
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Family Accommodation Scale – Parent Report (Flessner et al., 2011)

1. How often do did you reassure your child?

Never; 1 or 2 times/week; 3 – 6 times/week; Daily

2. How often did you provide items for your child's compulsions?

Never; 1 or 2 times/week; 3 – 6 times/week; Daily

3. How often did you participate in behaviours related to your child's compulsions?

Never; 1 or 2 times/week; 3 – 6 times/week; Daily

4. How often did you assist your child in avoiding things that might make him/her more anxious?

Never; 1 or 2 times/week; 3 – 6 times/week; Daily

5. Have you avoided doing things, going places, or being with people because of your child's OCD?

Never; 1 or 2 times/week; 3 – 6 times/week; Daily

6. Have you modified your family routine because of your child's symptoms?

No; Mild; Moderate; Severe; Extreme

7. Have you had to do some things for the family that are usually the child's responsibility?

No; Mild; Moderate; Severe; Extreme

8. Have you modified your work schedule because of your child's needs?

No; Mild; Moderate; Severe; Extreme

9. Have you modified your leisure activities because of your child's needs?

No; Mild; Moderate; Severe; Extreme

10. Has your child become distressed/anxious when you have not provided assistance?

Never; Mild; Moderate; Severe; Extreme

11. Has your child become angry/abusive when your have not provided assistance?

Never; Mild; Moderate; Severe; Extreme

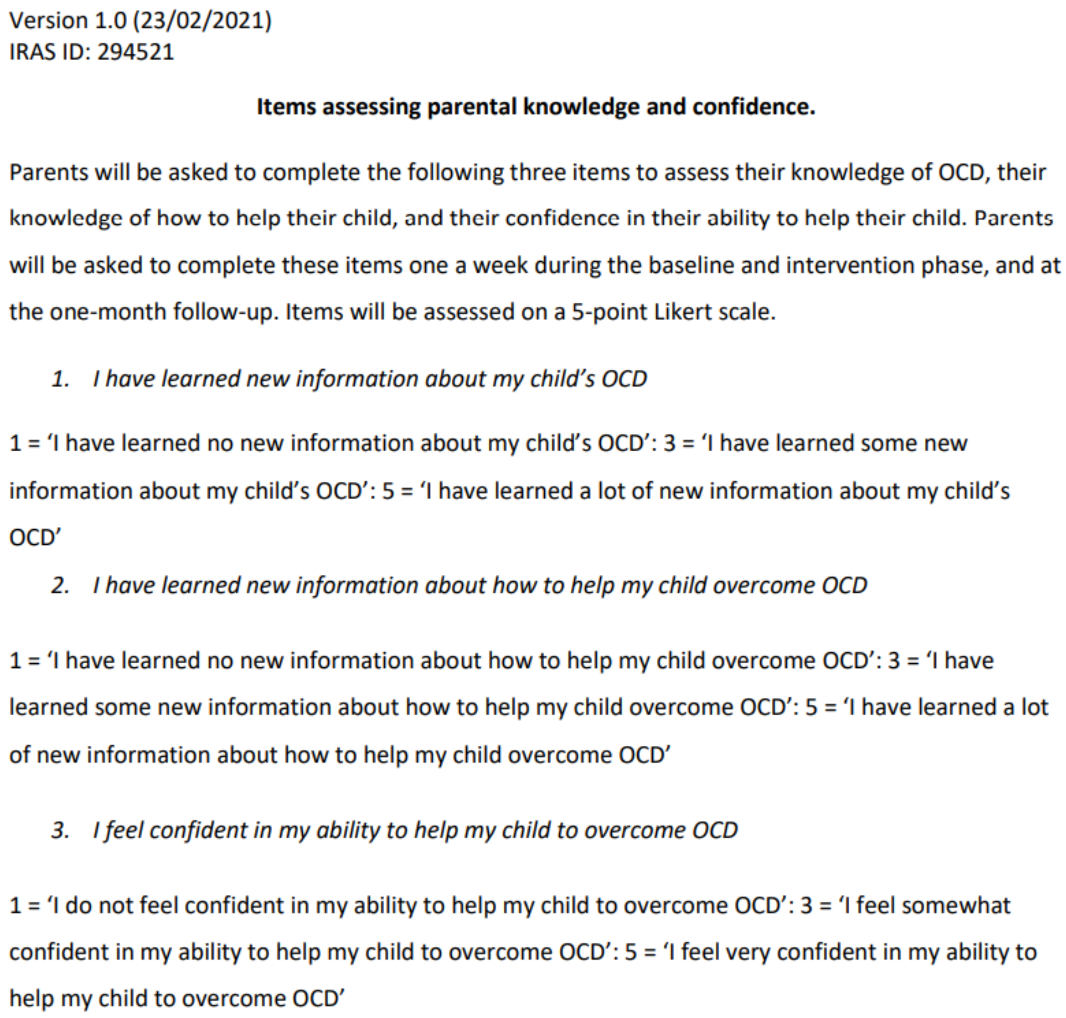
12. Has your child spent more time completing rituals when you have not provided assistance?

Never; Mild; Moderate; Severe; Extreme

References:

Flessner, C. A., Sapyta, J., Garcia, A., Freeman, J. B., Franklin, M. E., Foa, E., & March, J. (2011). Examining the psychometric properties of the family accommodation scale-parent-report (FAS-PR). *Journal of psychopathology and behavioral assessment*, *33*(1), 38-46.

Items assessing parental knowledge and confidence to help their child to overcome OCD (Paper 3)



Version 1.0 (23/02/2021)
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Items assessing parental knowledge and confidence.

Parents will be asked to complete the following three items to assess their knowledge of OCD, their knowledge of how to help their child, and their confidence in their ability to help their child. Parents will be asked to complete these items one a week during the baseline and intervention phase, and at the one-month follow-up. Items will be assessed on a 5-point Likert scale.

1. *I have learned new information about my child's OCD*

1 = 'I have learned no new information about my child's OCD': 3 = 'I have learned some new information about my child's OCD': 5 = 'I have learned a lot of new information about my child's OCD'

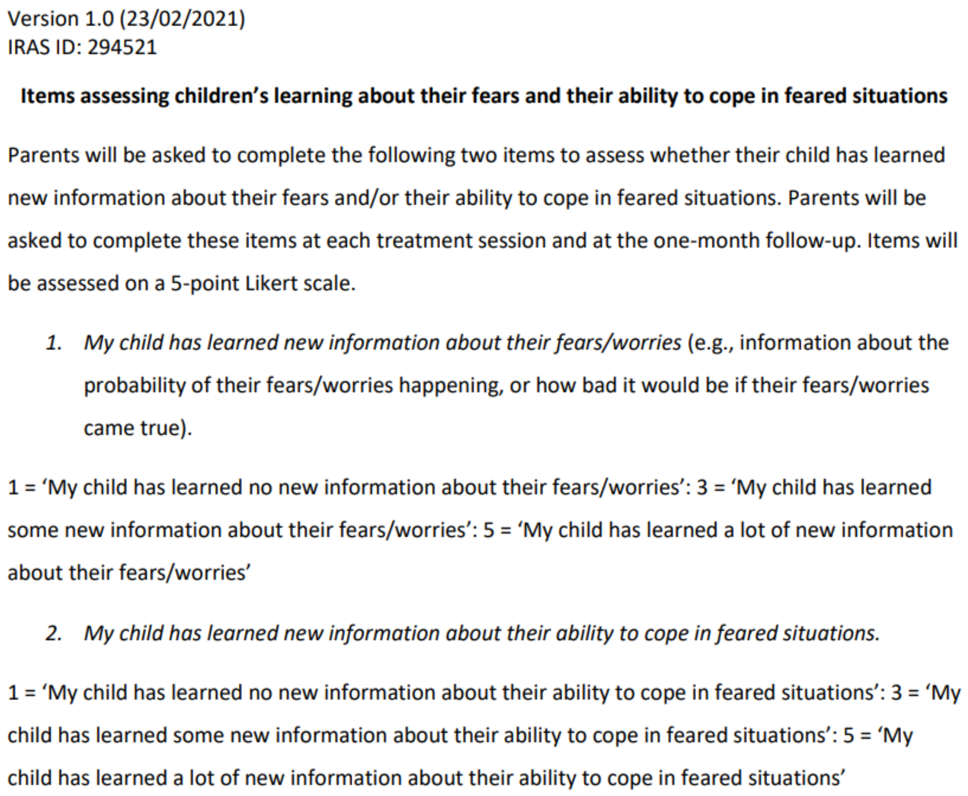
2. *I have learned new information about how to help my child overcome OCD*

1 = 'I have learned no new information about how to help my child overcome OCD': 3 = 'I have learned some new information about how to help my child overcome OCD': 5 = 'I have learned a lot of new information about how to help my child overcome OCD'

3. *I feel confident in my ability to help my child to overcome OCD*

1 = 'I do not feel confident in my ability to help my child to overcome OCD': 3 = 'I feel somewhat confident in my ability to help my child to overcome OCD': 5 = 'I feel very confident in my ability to help my child to overcome OCD'

Items assessing whether children have learned new information about their fears and their ability to cope in feared situations (Paper 3)



Version 1.0 (23/02/2021)
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Items assessing children's learning about their fears and their ability to cope in feared situations

Parents will be asked to complete the following two items to assess whether their child has learned new information about their fears and/or their ability to cope in feared situations. Parents will be asked to complete these items at each treatment session and at the one-month follow-up. Items will be assessed on a 5-point Likert scale.

1. *My child has learned new information about their fears/worries* (e.g., information about the probability of their fears/worries happening, or how bad it would be if their fears/worries came true).

1 = 'My child has learned no new information about their fears/worries': 3 = 'My child has learned some new information about their fears/worries': 5 = 'My child has learned a lot of new information about their fears/worries'

2. *My child has learned new information about their ability to cope in feared situations.*

1 = 'My child has learned no new information about their ability to cope in feared situations': 3 = 'My child has learned some new information about their ability to cope in feared situations': 5 = 'My child has learned a lot of new information about their ability to cope in feared situations'

Topic guide (Paper 3)

Qualitative Interview – Indicative Topic Guide

Aim: To explore parents' experiences of the treatment (with a particular focus on the acceptability of the treatment)

1. Introduction

Establish the purpose of the interview and the limits of confidentiality

2. Contextual information

Review with the relevant contextual information with the parent

Possible information to review:

- Age of child
- Diagnoses
- Number of treatment sessions received
- Who attended the treatment sessions

3. Explore the parents' initial views of the treatment approach (e.g., when they first read the participant information sheet or first spoke to the study researcher).

Possible questions:

- What were your initial views of this treatment?
- What were your initial thoughts on the possible benefits of this approach?
- What were your initial thoughts on the possible challenges of this approach?
- How did you think your child might respond to this approach?
- What information did you found particularly helpful/unhelpful or would have liked at this stage?

4. Explore the parents' experiences of receiving this treatment

Possible questions:

- Can you tell me about your experiences of receiving the treatment?
- What were the benefits of this approach?
    - Probe for benefits for the parent, child, family
- What challenges did you experiences in this approach?
    - Probe for challenges for the parent, child, family
- What was your experience of implementing the treatment techniques at home?
    - Probe for any techniques the parent found easier or harder to implement
    - Probe how parents found this alongside other responsibility e.g., work, other children
- Can you talk me through a time when you tried to implement the techniques at home with your child?
    - Probe for what was easier/hard about this/how they found engaging their child
- How did your child respond to this approach?

    - Probe for child engagement, things that the child liked/disliked, things that the child found harder/easier
- Did you involve any other family members in the treatment (e.g., other caregivers)? What was your experience of this?
    - Probe for benefits and challenges of involving others in treatment
- How did you find the level of parent involvement? Would you have preferred a different arrangement?
    - Probe for why

5. **Explore parents' experiences of the mode, content, and structure of the treatment sessions**

*Possible questions (for this section, particularly probe for **<u>why</u>** parents liked/disliked the following):*

- How did you find the face-to-face/videocall and telephone appointments?
    - Probe for what the parent liked/disliked about these modes of delivery
- How did you find the number and length of the sessions?
    - Probe for why parent liked/disliked number and length of sessions.
    - Did the sessions help the parent to feel confident to deliver the treatment techniques? Probe their answer to understand why.
- How did you find the content of the treatment?
    - Probe for what parents liked/disliked, how the parent found the amount of information covered in the treatment sessions, the pacing of information, whether the parent felt there were enough opportunities to develop skills/build confidence in the techniques in the session. Follow-up on their answers.
- How did you find completing the questionnaires?
    - Probe for whether these felt relevant to the family and/or useful for the treatment
- What were your views of the reading materials and handouts?
    - Probe for what the parent liked/disliked about these. Does the parent have any suggestions of things they would have found helpful/preferred to receive?

6. **Explore parents' broader views of the approach**

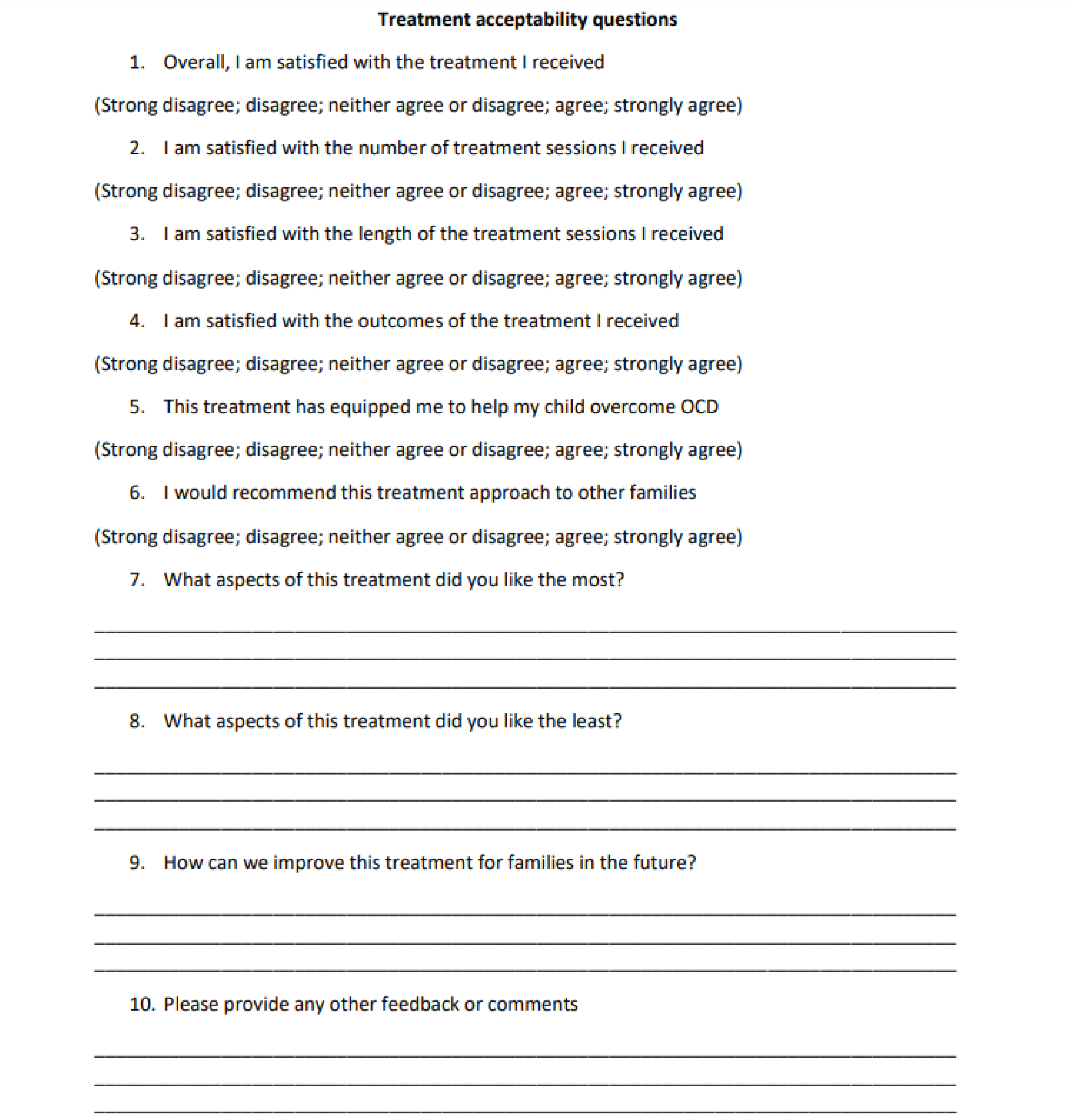
Possible questions:

- What would you say to other parents who were considering this approach? What advice would you give other parents?
    - Probe for greater depth in responses
- Would you recommend this approach to other parents?
    - Probe for reason why/why not
- What would you change about this approach?
- Was the treatment helpful? What difference has the treatment made?
- How have you found continuing to implement the techniques now the sessions have ended?

7. **Summarise the interview**

Probe whether there is anything else the parent wishes to add to the information discussed. Thank the parent for their time.

Treatment acceptability questionnaire (Paper 3)



Treatment acceptability questions

1. Overall, I am satisfied with the treatment I received

(Strong disagree; disagree; neither agree or disagree; agree; strongly agree)

2. I am satisfied with the number of treatment sessions I received

(Strong disagree; disagree; neither agree or disagree; agree; strongly agree)

3. I am satisfied with the length of the treatment sessions I received

(Strong disagree; disagree; neither agree or disagree; agree; strongly agree)

4. I am satisfied with the outcomes of the treatment I received

(Strong disagree; disagree; neither agree or disagree; agree; strongly agree)

5. This treatment has equipped me to help my child overcome OCD

(Strong disagree; disagree; neither agree or disagree; agree; strongly agree)

6. I would recommend this treatment approach to other families

(Strong disagree; disagree; neither agree or disagree; agree; strongly agree)

7. What aspects of this treatment did you like the most?

____
____
____

8. What aspects of this treatment did you like the least?

____
____
____

9. How can we improve this treatment for families in the future?

____
____
____

10. Please provide any other feedback or comments

____
____
____