Understanding parents' experiences of seeking and accessing professional support for anxiety disorders in pre-adolescent children

Submitted thesis for: Doctor of Philosophy

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Declaration

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

Tessa Reardon

January 2018

Contribution to papers

Tessa Reardon was the lead researcher for all research reported in the papers included in this thesis. She planned the research with support from her supervisors, gained the necessary ethics approval, conducted and supervised participant recruitment, data collection and data entry. She conducted all analyses included in the papers, wrote the first draft of each paper, and submitted the papers for publication. Her specific contribution to each paper, together with contributions from co-authors, is detailed below.

Paper 1: Systematic Review

Tessa Reardon (TR) led planning for the review, including designing the research questions, search strategy, inclusion/exclusion criteria, templates for screening and data extraction. Co-authors (CC, KH, DOB) contributed to planning the review through regular team meeting and providing feedback on study documents. TR ran the literature search, assessed all abstracts/full texts for eligibility for inclusion, assessed the quality of studies, extracted data from included papers, and conducted the data synthesis. Co-authors (LB and MB) were second independent raters for abstract/full text screening and data extraction; and TR discussed and reached a consensus on discrepancies related to study inclusion with CC and KH. TR wrote the first draft of the manuscript, and revised the manuscript after receiving feedback from CC and KH.

Tessa Reardon's estimated percentage contribution: 85%

Paper 2: Qualitative Study

TR designed the study and prepared the ethics application, with support from co-authors (CC, KH, BY, DOB) through regular team meetings and feedback on study materials. TR led participant recruitment and data collection activities, including: recruiting schools and families, administering screening questionnaires and diagnostic interviews, entering data, and supervising undergraduate students to help recruit schools, administer screening questionnaires and enter data. TR met regularly with CC to discuss diagnostic interviews and reach a consensus on diagnostic outcomes. TR conducted all qualitative interviews, transcribed interviews, coded and analysed transcribed interview data. Co-authors (CC, KH, BY, DOB) contributed to the analysis process through regular team meetings where we discussed coding and the emerging themes. TR wrote the first draft of the manuscript, and revised the manuscript after receiving feedback from CC, KH and BY.

Tessa Reardon's estimated percentage contribution: 85%

Paper 3: Survey

TR designed the study, prepared the ethics application and planned statistical analyses, with support from co-authors (CC, KH). TR led participant recruitment, data collection, and data entry including: recruiting schools and families, administering screening questionnaires and diagnostic interviews, entering data, and supervising a team of undergraduate/postgraduate students and research assistants to help with recruitment, data collection and data entry. TR met regularly with CC and team assessors to discuss diagnostic interviews and reach a consensus on diagnostic outcomes. TR conducted all statistical analyses, wrote the first draft of the manuscript, and revised the manuscript after receiving feedback from CC and KH.

Tessa Reardon's estimated percentage contribution: 85%

Paper 4: Identification tool

TR designed the study and planned statistical analyses, with support from co-authors (CC, SS). TR led participant recruitment, data collection, and data entry for the community sample (as detailed in Paper 2), and co-authors (JH and AS) contributed this data collection. Data relating to clinical-referred sample was collected as part of two trials led by CC, and TR did not contribute to collecting this data. TR conducted all statistical analyses, wrote the first draft of the manuscript, and revised the manuscript after receiving feedback from CC and SS. Tessa Reardon's estimated percentage contribution: 85%

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Abstract

Anxiety disorders are among the most common mental health disorders experienced by children and young people, and are associated with significant negative outcomes for individuals and economic burden for broader society. Effective treatments for child anxiety disorders exist, and although there are a lack of current UK data on help-seeking and access to professional support for child anxiety disorders, previous studies have suggested that only a minority of young people with mental health disorders receive treatment. Identifying barriers to seeking and accessing professional support in the context of child anxiety disorders would inform targeted interventions designed to increase rates of treatment access.

This thesis adopts a mixed methods approach and aims to improve understanding of parents' experiences of seeking and accessing professional support for anxiety disorders in pre-adolescent children. Findings identify a substantial unmet need in relation to child anxiety disorders, with approximately one third of parents not seeking professional help, more than 60% of children not receiving any professional support, and less than 3% accessing evidence-based treatment. Barriers to seeking and accessing professional support for child anxiety disorders include barriers related to i) identifying anxiety difficulties in children; ii) help-seeking knowledge and attitudes towards professional support; and iii) availability of evidence-based treatment.

The findings have clear implications for ways to minimise barriers in each of these areas and improve access to professional support for child anxiety disorders. The thesis provides preliminary evidence to support the potential for brief identification tools to improve accurate identification of anxiety disorders in children in community settings. Findings also highlight the need for i) interventions to promote public understanding of help-seeking, and positive attitudes towards professional support for child anxiety disorders; and ii) increased

provision of evidence-based treatment for child anxiety disorders in school and primary care settings.

Chapter 1: General Introduction

1.1 Childhood anxiety disorders

Anxiety disorders are the most common mental health disorders experienced across the lifespan, with an estimated lifetime prevalence rate of 28.8% (Kessler, Chiu, Demler, & Walters, 2005). These disorders typically first emerge during childhood or adolescence (Gregory et al., 2007; Kim-Cohen et al., 2003), and have a median age of onset of 11 years (Kessler et al., 2005). Among children and adolescents, anxiety disorders are also the most prevalent mental health disorders, with a worldwide prevalence rate of 6.5% (Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015); and among pre-adolescent children estimated prevalence rates range from 2.2%-12.3% (Costello, Egger, Copeland, Erkanli, & Angold, 2011; Green, McGinnity, Meltzer, Ford, & Goodman, 2005; Lawrence et al., 2015).

Anxiety disorders are characterised by excessive fear, worry or anxiety, together with associated distress or functional impairment (American Psychiatric Association, 2013). The most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) classifies the following disorders as anxiety disorders: separation anxiety disorder, social anxiety disorder, selective mutism, generalised anxiety disorder, specific phobias, panic disorder and agoraphobia. In a departure from the DSM-IV-TR (American Psychiatric Association, 2000), obsessive compulsive disorder, post-traumatic stress disorder and acute distress disorder are no longer classified as anxiety disorders. The core features of anxiety disorders are the same in children as in adults, although there are some differences in the diagnostic criteria (e.g. a minimum of one physical symptom is required for diagnosing generalised anxiety disorder in children compared to three in adults). Prevalence rates and average age of onset vary for individual anxiety disorders, with evidence that separation anxiety disorder and specific phobias are the most prevalent anxiety disorders among pre-adolescent children (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003; Green et al., 2005; Lawrence et al., 2015). Anxiety disorders in children commonly co-occur with other anxiety disorders, and also with depression and behavioural disorders (Costello et al., 2003; Ford, Goodman, & Meltzer, 2003; Lawrence et al., 2015).

Anxiety disorders in young people have a negative impact on family life, peer relationships, school functioning, and social activities (Essau, Conradt, & Petermann, 2000; Ezpeleta, Keeler, Erkanli, Costello, & Angold, 2001; Mychailyszyn, Mendez, & Kendall, 2010; Strauss, Frame, & Forehand, 1987). Children with anxiety disorders also show higher rates of school absence and poorer general health than children without mental health disorders (Green et al., 2005; Lawrence et al., 2015). Moreover, childhood anxiety disorders are associated with significant negative outcomes later in life. As well as placing an individual at heightened risk for continued or re-occurring anxiety disorders, childhood anxiety is associated with subsequent depression, suicidality, and substance use (Boden, Fergusson, & Horwood, 2007; Kim-Cohen et al., 2003; Woodward & Fergusson, 2001); and adverse academic, health and social functioning in adulthood (Copeland, Angold, Shanahan, & Costello, 2014; Essau, Lewinsohn, Olaya, & Seeley, 2014). Anxiety disorders are therefore also associated with considerable societal burden, with estimated total costs in England of £8.9 billion, expected to rise to £14.2 billion by 2026, largely accounted for by lost employment costs (McCrone, Dhanasiri, Patel, Knapp, & Lawton-Smith, 2008).

1.2 Child anxiety treatment and treatment access

The most well-evaluated treatment for child anxiety disorders is cognitive behavioural therapy (CBT), with good evidence to support its effectiveness (James, James, Cowdrey, Soler, & Choke, 2013; Reynolds, Wilson, Austin, & Hooper, 2012; Warwick et al., 2017), and long-term benefits (Puleo, Conner, Benjamin, & Kendall, 2011; Wolk, Kendall, & Beidas, 2015). However, poor rates of access to treatment for mental health problems in children and adolescence are widely reported (Green et al., 2005; Lawrence et al., 2015; Merikangas et al., 2011). Moreover, studies report lower rates of treatment access for anxiety and internalising disorders in young people, compared to externalising disorders (Brown, Green, Desai, Weitzman, & Rosenthal, 2014; Chavira, Stein, Bailey, & Stein, 2004; Merikangas et al., 2011). Indeed, long delays in help-seeking for anxiety disorders are reported across the lifespan, with the longest delays associated with anxiety disorders that first emerge during childhood (Wang et al., 2005).

Although studies consistently report that only a minority of children with anxiety disorders receive treatment, estimated rates of treatment access do vary across studies, partly depending on how ‘treatment access’ or ‘service use’ are defined. The most recent UK national survey of child and adolescent mental health was in 2004 and reported 24% of parents of 5-16 year olds with emotional disorders had contacted or been referred to a specialist mental health service (Green et al., 2005). A similar national survey in the USA reported 32% of 5-15 years with an anxiety disorder had ‘been to see someone in a hospital, clinic or at their office’ about their anxiety (Merikangas et al., 2011). Higher rates of service use among children with anxiety disorders are reported in the corresponding Australian youth mental health survey (53.6%), but this includes receiving support from a range of health and school services (Lawrence et al., 2015). Indeed, in the UK survey 64% of parents of children with emotional disorders reported contacting a professional for help or advice, and most commonly this was a teacher (47%) (Green et al., 2005), indicating that more families in the UK seek help from a professional than the reported 24% who reach a specialist mental health services. Follow-up data from the previous 1999 UK national survey reported that the vast majority of parents who had contact with teachers about their child’s mental health, described discussing their child’s difficulties with a teacher, but a minority (15.5%) also reported that their child received additional mental health support at school (Ford, Hamilton, Goodman, & Meltzer, 2005). However, there are a lack of up-to-date data on how many families affected by pre-adolescent anxiety disorders in the UK seek help from a professional, and how many then go on to receive treatment or support to help manage and overcome these difficulties with anxiety, either from specialist mental health services, school or elsewhere. Moreover, data available on rates of treatment access tell us little about the type of treatment or support families receive so we do not know how many children with anxiety disorders access evidence-based treatment (i.e. CBT).

1.3 Understanding treatment access

The disparity between the number of children affected by mental health problems, and the number who access treatment has prompted calls for the need to improve access to child mental health services (Children and Young People’s Mental Health Taskforce, 2015; Department of Health and Department of Education, 2017; NHS England, 2016). These government reports highlight the importance of early recognition and access to effective early intervention for young people with mental health difficulties. The development of evidence-based interventions designed to improve rates of treatment access, however, relies on an understanding of the reasons for the unmet need in relation to child mental health. Identifying barriers to treatment access can help identify key areas to target in order to improve access. Outlined below are several key areas of research that provide insight into potential barriers to accessing treatment for mental health problems in general for children.

1.3.1 Factors associated with treatment access

Studies have explored factors associated with mental health service use among children and adolescents, and this research helps illustrate who accesses treatment, and who does not (Wichstrøm, Belsky, Jozefiak, Sourander, & Berg-Nielsen, 2014). Indeed, there is evidence that it is not only a child's level of 'need' or severity of mental health difficulties that predicts whether or not a child accesses treatment (Costello & Janiszewski, 1990). The association between various demographic variables, including ethnicity, socio-economic status, and a child's age and gender, and mental health service use has been examined. There is some evidence that being white increases the likelihood of use of services in the USA (Kataoka, Zhang, & Wells, 2002; Zimmerman, 2005), although this has not been replicated in UK samples (Ford, Hamilton, Meltzer, & Goodman, 2008; Gronholm et al., 2015). Most studies indicate a parent's level of education and employment, and family income are not significant predictors of service use (Ryan, Jorm, Toumbourou, & Lubman, 2015); although insurance coverage in the USA is associated with use of mental health services (Angold et al., 2002; Brown et al., 2014; Zwaanswijk, Verhaak, Bensing, van der Ende, & Verhulst, 2003). Some studies report that living in urban areas increases the likelihood of service use (Cohen & Hesselbart, 1993), and regional differences are reported in the UK, with higher rates of mental health service use in the south of England compared to the north of England (Ford et al., 2008). Studies often fail to report a significant age or gender effect in use of child mental health services, although there is some evidence that a larger proportion of adolescents with mental health problems may use services than younger children (Kataoka et al., 2002; Lawrence et al., 2015); and among pre-adolescent children, boys may be more likely to use services than girls (Kataoka et al., 2002; Zimmerman, 2005).

Various other child and family characteristics have also been linked to service use for mental health problems in children. Children with more severe mental health difficulties are more likely to use mental health services, than those with less severe difficulties (Ford et al., 2008), and prior mental health service use also predicts current service use in children (Gronholm et al., 2015). However, parental perceptions of a child's difficulties also play an important role. Parents who consider their child's symptoms or behaviour to be a problem, and think their child's difficulties have a negative impact on family life are more likely to access services for their child than parents who do not perceive a problem or negative impact on family life (Sayal, Goodman, & Ford, 2006; Teagle, 2002). In keeping with the literature surrounding the key role of perceived need for professional help in adult mental health service use (Mojtabai, Olfson, & Mechanic, 2002), parental perceptions of their child's need for professional help is associated with a child's mental health service use (Ryan et al., 2015). Some studies have also examined the role of parents' own experience of mental health difficulties, use of mental health services, and attitudes towards mental health services in relation to a child's use of mental health services. Indeed, studies report both parental mental health difficulties and parental prior use of mental health services increase the likelihood that a child accesses mental health services (Godoy, Mian, Eisenhower, & Carter, 2014; Ryan et al., 2015; Turner & Liew, 2010). Similarly, parents' intended stigmatising or discriminatory behaviour towards people with mental health problems is negatively associated with a child's mental health service use (Gronholm et al., 2015); and there is some evidence that positive attitudes towards mental health services among parents predicts mental health service use in children (McKay, Pennington, Lynn, & McCadam, 2001).

Existing literature examining factors associated with use of services for mental health problems in children illustrate the key role parents play in accessing mental health treatment for children, and help identify families who may be more or less likely to experience barriers to accessing support. These studies however tend to address mental health service use among young people across a wide age range, and it is possible that the role of parental characteristics, such as parental perceptions, experiences and attitudes, is different among younger children than adolescents (Ryan et al., 2015). Studies have also tended to focus on specialist mental health service use, so we know less about factors associated with use of school-based or primary care services (Ryan et al., 2015). Indeed, many children with mental health problems who receive support use multiple types of services (Farmer, Burns, Phillips, Angold, & Costello, 2003), and there is some evidence that parent and family predictors of service use may vary across different types of services (Ford et al., 2008; Gronholm et al., 2015). For example, Gronholm et al (2015) found that parents' stigmatising attitudes towards people with mental health problems was negatively associated with child mental health service use in school settings, but parental stigma was only associated with child mental health services use in health settings if parents had not used mental health services themselves.

1.3.2 Factors associated with anxiety treatment access

Very few studies have specifically addressed factors associated with service use in the context of child anxiety disorders. Indeed, given the lower reported rates of service use among children with anxiety disorders in comparison with children with other mental health disorders, it is possible additional or different factors may influence who accesses support for child anxiety disorders and who does not. Chavira, et al. (2004) examined access to counselling among a sample of 8-17 year olds with anxiety disorders recruited through primary care setting in the USA. In this study, older children (13-17 year olds), and white children were more likely to receive counselling than younger children and non-white children. Essau (2005) found the presence of a non-anxiety comorbid disorder and a past suicide attempt were predictors of receiving support from mental health services in a community sample of adolescents with anxiety disorders in Germany. Information about parental psychopathology was obtained from adolescents in this study, and adolescent reported parental anxiety and parental depression were also associated with mental health service use among adolescents. In contrast, the presence of a comorbid non-anxiety disorder did not predict referral to a mental health centre in a sample of 8-13 year olds with an anxiety disorder in the Netherlands (Jongerden, Simon, Bodden, Dirksen, & Bögels, 2015). Notably, Jongerden, et, al. (2015) found that interference associated with a child’s anxiety was associated with service use, but in this study parent self-reported anxiety symptoms was negatively associated with child mental health service use. The authors speculated that it is possible that parental anxiety could inhibit parents from attending a mental health clinic with their child, or may make them less likely to seek help for similar symptoms in their child. Studies to date, however, have not examined factors associated with accessing treatment or professional support among children with anxiety disorders in the UK; and findings are likely vary across contexts and mental health systems. Moreover, given that children receive support from a range of services for mental health problems (Farmer et al., 2003; Ford et al., 2005), it is important to consider services beyond specialist mental health services, but there is a lack of evidence surrounding the factors associated with access to other types of support (e.g. in school or primary care settings) in the context of child anxiety disorder.

1.3.3 Help-seeking models

Examining factors associated with service use helps illustrate who accesses treatment, but in isolation it tells us little about the processes involved in treatment access or how and why families may be more or less likely to seek help and/or go on to receive support. Several models of help-seeking for youth mental health problems have been developed that conceptualise help-seeking as a process and help illustrate potential barriers families can face at distinct stages in the help-seeking process (Costello, Pescosolido, Angold, & Burns, 1998; Logan & King, 2001; Sayal, 2006; Srebnik, Cauce, & Baydar, 1996; Stiffman, Pescosolido,

& Cabassa, 2004). These help-seeking models use core components from adult help-seeking and health behaviour models, in particular Anderson and Newman's (1973) behavioural model of health service use, Fischer, Weiner & Abramowitz's (1983) five-stage model of help-seeking, and Prochaska, Redding & Evers's (1997) stages of change model. Drawing on these adult models, Logan and King (2001) proposed a model parental help-seeking for mental health problems in adolescents that emphasises the key role parents play in the help-seeking process. The model suggests parental help-seeking involves a series of six stages: gaining awareness of an adolescent's distress, recognising the severity and nature of the problem, considering help-seeking options, developing an intention to seek help, making an attempt to seek help, and obtaining services. Logan and King (2001) refer to the first three stages as a 'contemplation' phase, and the latter three as an 'action phase', and suggest various 'predisposing' and 'enabling/inhibiting' factors influence each of the contemplation and action stages. By focusing specifically on the role of parents, Logan and King's model helps illustrate potential barriers parents may experience at unique stages in the help-seeking process. This model, however, focuses on seeking and obtaining support from specialist mental health services, and does not consider factors that may influence seeking and/or obtaining other types of support (e.g. in school or primary care setting). Alternative models of help-seeking for youth mental health problems also incorporate different potential 'pathways' or routes to obtaining child mental health support from a range of types of services (Costello et al., 1998; Stiffman et al., 2004). Similar to Logan and King's model, these network or pathway models identify the key 'gatekeeper' role for parents in initiating access to support, but they also emphasise the key role professionals (e.g. teachers and GPs) play in determining whether a child subsequently obtains support from services or not (Stiffman et al., 2004).

These help-seeking models have provided a framework for empirical studies that explore factors associated with isolated stages in the help-seeking process. For example, studies of parental recognition indicate that symptom severity, impact on family life and parent psychopathology are each associated with parental recognition of a child's difficulties (Angold et al., 1998; Teagle, 2002). Interestingly, lower rates of parental recognition are also reported for anxiety disorders compared to behavioural disorders and depression (Teagle, 2002); and fewer parents of children with anxiety disorders perceive a need for professional help than parents of children with conduct disorders or depression (Johnson, Lawrence, Sawyer, & Zubrick, 2017). Studies exploring factors associated with help-seeking intentions have tended to focus on adolescents' help-seeking intentions, rather than parents', although there is evidence that stigmatising attitudes towards mental health are negatively associated with help-seeking intentions among both young people and parents (Dempster, Davis, Faye Jones, Keating, & Wildman, 2015; Dempster, Wildman, & Keating, 2013; Yap, Reavley, & Jorm, 2013; Yap, Wright, & Jorm, 2011). A relatively small number of studies draw a clear distinction between speaking to a professional (i.e. seeking professional help), and actual receipt of support or treatment, but there is evidence that when parents seek professional help, they frequently speak to or seek help from a range of professionals (Reid et al., 2011; Shanley, Reid, & Evans, 2008), and a larger proportion of families seek help from professionals than receive specialist mental health services (McCue Horwitz, Gary, Briggs-Gowan, & Carter, 2003; Zwaaswijk, Van der Ende, Verhaak, Bensing, & Verhulst, 2005). Notably, McCue et., al. (2003) found a wider range of child and parent characteristics were associated with seeking professional help for mental health problems in young children, than predicted actual use of services, illustrating the importance of distinguishing between seeking help, and receiving support to help overcome a child's difficulties. Studies have also explored later stages in the help-seeking process, such as GP recognition of a child's mental health difficulties and referrals to specialist mental health services. Indeed, low rates of recognition within primary care is cited as a barrier to accessing specialist child mental health services (Sayal & Taylor, 2004; Sayal, 2006); and parents expressing concerns and requesting a referral are associated with increased rates of GP recognition (Sayal, 2006; Sayal, Taylor, Beecham, & Byrne, 2002). Access to specialist mental health services typically requires a referral from a professional; and there is evidence that pre-adolescent children are most commonly referred to specialist mental health services by teachers, whereas GPs are the most frequent source of referral for adolescents (Zwaanswijk, Van Der Ende, Verhaak, Bensing, & Verhulst, 2007; Zwaaswijk et al., 2005). Together this evidence illustrates the range of potential barriers families may face throughout the mental health help-seeking process, from initially recognising a child's difficulties through to obtaining support from professionals to help overcome these difficulties. However, we know relatively little about what these barriers are in the context of child anxiety difficulties.

1.3.4 Perceived barriers to treatment access

Understanding the views and experiences of those who play a key role in seeking and accessing treatment for children is also necessary to identify the important areas to target in order to improve access. Indeed, studies examining factors associated with service use or treatment access, or factors associated with individual components of the process involved in accessing treatment do not consider the views of those involved in the help-seeking process or provide insight into what they perceive to be the key barriers. Previous systematic reviews have synthesised findings from studies addressing young people's perceptions of barriers and facilitators to seeking mental health support (Gulliver, Griffiths, & Christensen, 2010), and primary care practitioners' perceptions of barriers to managing child mental health difficulties (O'Brien, Harvey, Howse, Reardon, & Creswell, 2016). However, studies addressing parent perceptions of barriers/facilitators have not yet been systematically reviewed. Indeed, given the key role parents play in seeking and accessing help for children, it is particularly important to consider their views on the barriers they experience. Moreover, only one study to date has addressed parent perceptions of barriers to treatment access specifically in the context of child anxiety disorders (Salloum, Johnco, Lewin, McBride, & Storch, 2016). This study examined parent reported barriers to treatment access in a sample of parents of children who were receiving treatment for anxiety disorders. Notably, the most frequently reported barriers related to not knowing where to seek help, but as these families had all reached a specialist service it does not provide insight into the barriers experienced by families who do not seek and/or access treatment.

1.4 Summary and aims of the thesis

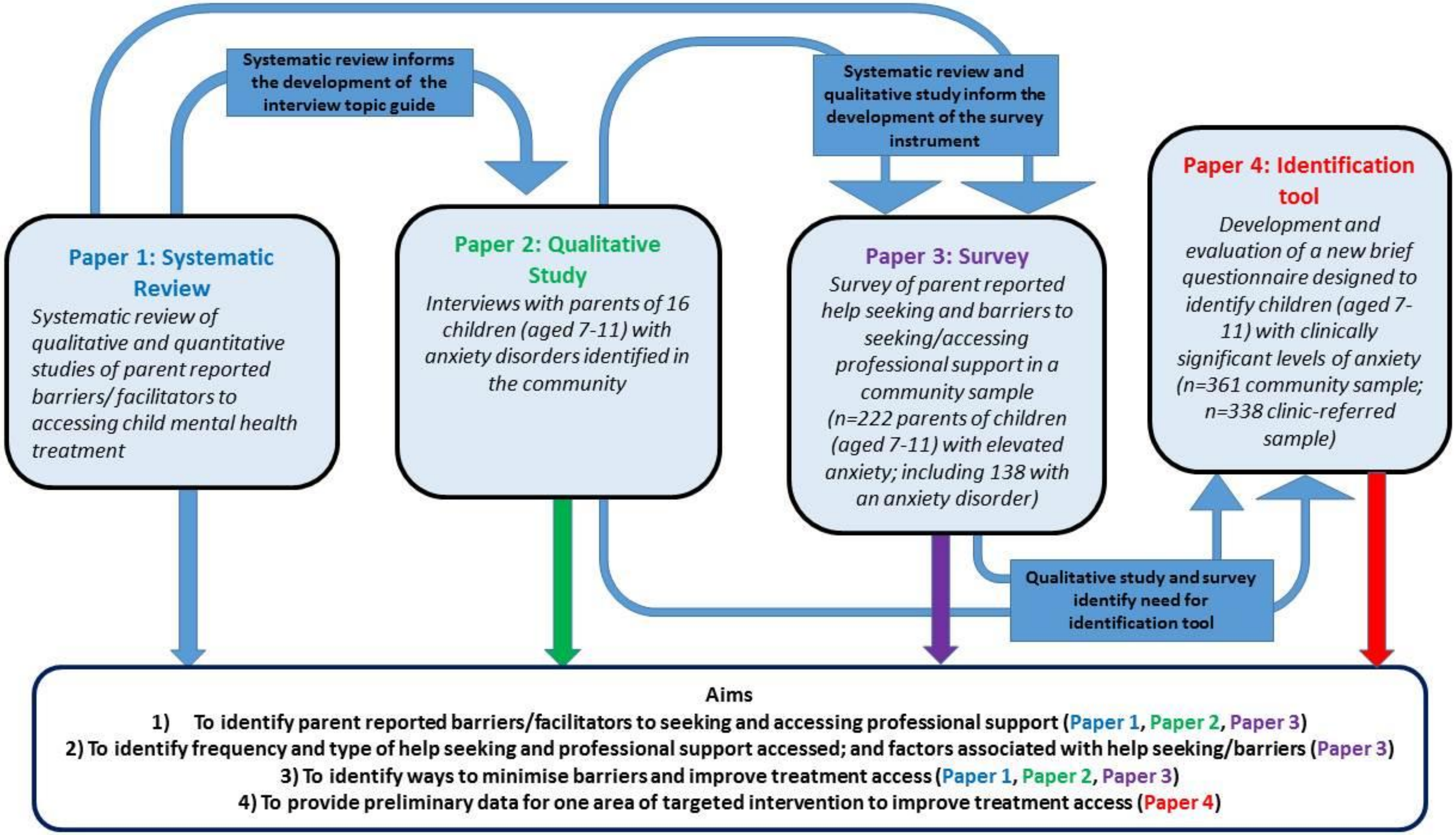
Childhood anxiety disorders are common and are associated with significant negative outcome for individuals and families, and substantial economic burden. Effective treatments for anxiety disorders in children exist, but the majority of children affected by mental health problems do not receive treatment. Reported rates of treatment access are lower for anxiety disorders than other mental health disorders in children and adolescents; but there are a lack of current data on the proportion of pre-adolescent children with anxiety disorders in the UK who access treatment or support for their difficulties, and little is known about the type of treatment or professional support they receive. This unmet need in relation to childhood anxiety disorders highlights the need for improved access to treatment for these children. Identifying barriers to accessing treatment for child anxiety and, in turn, ways to minimise these barriers, would inform targeted interventions aimed at ensuring more children affected by anxiety receive treatment. A range of child and parent characteristics are associated with use of child mental health services, but the process of accessing treatment for children incorporates a number of distinct components and it is therefore important to consider barriers and/or facilitators families face throughout this help-seeking process. Relatively little is known about help-seeking in the context of child anxiety, or the factors that influence whether families seek help or not; and given the lower rates of treatment access for anxiety disorders compared to other mental health disorders, there may be key determinants of help-seeking that are specific to child anxiety. Moreover, as parents play a key role in seeking and accessing treatment for pre-adolescent children, it is important to establish their own views on factors that help or hinder the help-seeking process.

This thesis aims to gain an improved understanding of seeking and accessing professional support for anxiety disorders in pre-adolescent children, including identifying: i) parent reported barriers and facilitators to seeking and accessing professional support; ii) rates and types of parent reported help-seeking and professional support accessed, and factors associated with seeking professional help; and iii) ways to minimise barriers and improve access to professional support for anxiety disorders in children. For the purpose of this thesis, seeking professional help or support refers to asking or contacting a professional for help or advice; and accessing professional support refers to receiving help or support from professionals to help manage or overcome a child’s anxiety difficulties, including support provided by teachers, GPs or other non-mental health professionals, as well as support or treatment provided by specialist mental health services or professionals.

1.5 Thesis outline

The thesis consists of four papers, and the specific aims of each paper are outlined below. A mixed-methods approach was used, and qualitative and quantitative methods were i) used sequentially, including using qualitative data to inform the design of a survey instrument, and ii) embedded within the overall design to contribute complementary data to address related aims (Creswell, Klassen, Clark, & Smith, 2011; Palinkas, Horwitz, Chamberlain, Hurlburt, & Landsverk, 2011). Figure 1 provides an overview of the thesis, and illustrates how each paper contributes to the overall thesis aims, and how Paper 1 (systematic review) and Paper 2 (qualitative study) informed the design of Paper 3 (survey), and how Paper 2 and Paper 3 informed the development of Paper 4 (identification tool).

Figure 1. Thesis overview



1.5.1 Paper 1 (Systematic Review): What do parents perceive are the barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents? A systematic review of qualitative and quantitative studies

As outlined above, parents play a key role in seeking and accessing child mental health treatment, and therefore it is important to establish their views on the factors that help or hinder this process. Given that parental help-seeking for anxiety disorders in children has received little attention, Paper 1 systematically reviewed studies from the broader literature examining parent perceptions of barriers and/or facilitators to seeking and accessing treatment for mental health problems for children and adolescents. This paper aimed to synthesise findings from qualitative and quantitative studies that reported parent perceptions of barriers and/or facilitators, and included studies that addressed specific mental health disorders, and those addressing emotional and/or behavioural problems more broadly; and included studies that considered seeking and/or obtaining professional help, either through specialist mental health services or primary care or school settings.

1.5.2 Paper 2 (Qualitative Study): Barriers and facilitators to parents seeking and accessing professional support for anxiety disorders in children: qualitative interview study

Paper 1 illustrated that many studies addressing parent reported barriers to seeking and accessing support for mental health problems in children have focused on populations who have already successfully reached services. Therefore our understanding of the experiences of families who do not reach specialist services is limited. Furthermore, Paper 1 confirmed the lack of prior studies examining parent experiences of seeking and accessing treatment in the context of child anxiety disorders. Paper 2 set out to address these gaps in the current literature and aimed to: i) identify barriers and facilitators to seeking and accessing professional support for anxiety disorders among parents of children with an anxiety disorder identified in the community; and ii) identify ways to minimise barriers to seeking and accessing professional support. Given the limited existing evidence surrounding help-seeking for anxiety difficulties in pre-adolescent children, an inductive qualitative approach was used to provide a rich and detailed insight into the barriers/facilitators experienced by these families. Qualitative interviews were conducted with parents of 16 children aged 7-11 with anxiety disorders, identified through screening in primary schools in England. Interviews were topic-guided, and findings from Paper 1 were used to develop the topic guide.

1.5.3 Paper 3 (Survey): Seeking and accessing professional support for child anxiety in a community sample

As outlined above, we know little about how many parents of children with anxiety disorders seek and access professional support, who does or does not seek professional help for child anxiety, or the type of support families receive. Paper 2 illustrated the range of barriers parents face throughout the help-seeking process in the context of child anxiety disorders, and some of the reported barriers appeared to be specific to child anxiety. Paper 3 aimed to further explore and provide quantitative data on help-seeking within a community sample of parents of children with elevated anxiety symptoms, and within a subsample where the child met diagnostic criteria for an anxiety disorder. Findings from Paper 2, together with Paper 1 were used to develop a questionnaire instrument designed to collect quantitative data on help-seeking for anxiety difficulties in children, and parent reported barriers/facilitators to seeking and accessing professional support. Specifically, Paper 3 aimed to establish the frequency and type of i) parental help-seeking, ii) professional support families receive; and iii) parental reported barriers and facilitators to seeking and accessing professional support for their child's anxiety. The paper also set out to explore iv) the child and parent characteristics associated with seeking professional support and parent reported barriers, and v) differences in parent reported barriers among those who have and those who have not sought professional support.

1.5.4 Paper 4 (Identification tool): Identifying children with anxiety disorders using brief versions of the Spence Children's Anxiety Scale for children, parents, and teachers.

Paper 4 explores and provides preliminary evidence for one area of targeted intervention to minimise barriers identified in Papers 2 and 3. Paper 2 and Paper 3 illustrated that difficulty identifying anxiety in children poses a key barrier to professional help-seeking. In particular, Paper 2 and Paper 3 indicate that parents face difficulties differentiating between developmentally appropriate fears, worries and anxieties, and clinically significant levels of anxiety, and parents report that GPs and teachers also experience difficulties recognising anxiety problems in children. Paper 4 therefore set out to develop a new tool designed to improve identification of children who are experiencing clinically significant levels of anxiety. Questionnaire measures designed to assess symptoms of anxiety disorders in children exist, but these questionnaires are long (typically approximately 40 items), making them time consuming to complete and impractical for use in community setting such as in GP appointments or school settings. Paper 4 aimed to develop a brief questionnaire for parents, children and teachers designed to assess symptoms of child anxiety disorders among 7-11 year olds, and i) to evaluate the reliability and validity of the brief questionnaire in a community and clinic-referred sample of children; ii) to establish the capacity of the brief questionnaire to discriminate between a community and clinic-referred sample of clinically anxious children, and iii) to identify the optimal combination of reporters and cut-off scores on the brief questionnaire for accurate identification of children with elevated anxiety symptoms for whom further clinical investigation is warranted.

1.5.5 Funding and contributions to the thesis

The research presented in this thesis was funded by a National Institute for Health Research (NIHR) Research Professorship awarded to Professor Cathy Creswell (CC); and Tessa Reardon (TR) was funded by a University of Reading PhD studentship. TR came to the University of Reading in September 2014, with a background in youth mental health research, and a particular interest in anxiety disorders in children and research focused on improving the lives of families affected by child anxiety disorders. This PhD provided TR with the opportunity to gain expertise in a range of research methods and experience planning and co-ordinating large-scale research studies. The initial outline for the systematic review (Paper 1), the qualitative study (Paper 2), and the survey (Paper 3) were developed by CC as part of her NIHR Research Professorship application; and TR led the detailed planning for each of these studies, and developed and planned the identification tool study (Paper 4). TR prepared the ethics applications, gained the necessary ethics approvals, and co-ordinated all participant recruitment and data collection activities, including recruiting schools and families, administering screening questionnaires and diagnostic interviews, and entering/checking data. TR supervised a team of undergraduate and postgraduate students and research staff who helped her with these recruitment and data collection activities. The only data collection that TR was not involved in was the data relating to the clinic-referred sample reported in Paper 4; this data was collected as part of two randomised controlled trial led by CC, and supported by the Medical Research Council. TR conducted all qualitative interviews, transcribed, and coded interview data reported in Paper 2; and planned and conducted all qualitative and quantitative analyses reported across all of the papers.

1.5.6 Ethical considerations

Studies reported in Papers 2 and 3, and data collected from the community sample reported in Paper 4 were all approved by the University of Reading Research Ethics Committee (UREC). These studies raised some key ethical issues. Parents, children and teachers were asked sensitive questions about the children's thoughts, feelings and behaviour; and parents were asked sensitive questions about their own mental health, and their views and their family's experiences of seeking professional help for mental health difficulties. It was possible that these areas of questioning could cause distress to parents and children. To help minimise any potential distress, participants were informed about the nature of the study before participating and told they could withdraw at any time, without giving a reason. Accessible and age appropriate information leaflets/letters were developed for children, parents and schools, with input from the Anxiety and Depression in Young People (AnDY) Research Advisors Group (see Appendix 5). Children (and teachers) were only asked to participate if the parent provided consent, and children were asked to provide assent before completing questionnaires. If a parent or child did become upset during an interview or while completing a questionnaire, the researcher always reminded the participant they could take a break, and/or stop taking part. All participants were provided with information about accessing professional help and provided with the study team's contact details.

In Papers 2 and 3, where responses on initial screening questionnaires indicated a child may have difficulties with anxiety, the parent was invited to take part in a follow-up study that included a more detailed diagnostic assessment. Some of these parents were not previously aware that their child was having problems with anxiety, and in some cases the scores on the questionnaires were misleading and the child was not experiencing difficulties with anxiety. The information leaflet sent to parents at the initial screening stage, together with the follow-up invitation letter both emphasised the potential for misleading results from the questionnaires, and the importance of a more detailed assessment to establish whether the child was experiencing genuine difficulties, or not. It was also anticipated that the diagnostic assessment would identify some children with an anxiety disorder who were not accessing appropriate professional support. After the diagnostic assessment, all families were provided with detailed information about accessing professional support, including a printed list of resources and services, tailored for the individual family's needs. Where appropriate, the researcher also discussed with the parent the possibility of seeking help through their GP, school and/or other local services. All families were also provided with a report of the diagnostic assessment which they were able to use to facilitate referrals, if appropriate. All researchers involved in the research were subject to disclosure and barring checks, received approval for working with children, and received ongoing clinical supervision from Professor Cathy Creswell.

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Chapter 2: Paper 1

What do parents perceive are the barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents? A systematic review of qualitative and quantitative studies

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REVIEW

What do parents perceive are the barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents? A systematic review of qualitative and quantitative studies

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Abstract A minority of children and adolescents with mental health problems access treatment. The reasons for poor rates of treatment access are not well understood. As parents are a key gatekeeper to treatment access, it is important to establish parents' views of barriers/facilitators to accessing treatment. The aims of this study are to synthesise findings from qualitative and quantitative studies that report parents' perceptions of barriers/facilitators to accessing treatment for mental health problems in children/adolescents. A systematic review and narrative synthesis were conducted. Forty-four studies were included in the review and were assessed in detail. Parental perceived barriers/facilitators relating to (1) systemic/structural issues; (2) views and attitudes towards services and treatment; (3) knowledge and understanding of mental health problems and the help-seeking process; and (4) family circumstances were identified. Findings highlight avenues for improving access to child mental health services, including increased provision that is free to service users and flexible to their needs, with opportunities to develop trusting, supportive relationships with professionals. Furthermore, interventions are required to improve parents' identification of mental health problems, reduce stigma for parents, and increase awareness of how to access services.

Keywords Mental health · Children · Adolescents · Treatment access · Barriers

Introduction

Mental health disorders are common among children and adolescents, with an estimated prevalence rate of 13.4% [1]. Youth is a time of heightened risk for mental health disorders, with half of all lifetime mental health disorders emerging before the age of 14 years [2]. Moreover, the negative impact of poor mental health early in life extends into adulthood, predicting poor academic outcomes [3], increasing the risk of subsequent mental health problems [4] and high rates of mental health service use [5], reducing life satisfaction [6], and creating a heavy economic burden for society [7].

In recent decades, there has been a rapid growth in the development of evidence-based treatments for mental health disorders in childhood and adolescence; and the lasting benefits of intervening early are well established [8, 9]. However, poor rates of treatment access have been repeatedly reported, and national surveys in the UK, Australia, and USA have estimated that only 25–56% of children and adolescents with mental health disorders access specialist mental health services [10–12], with particularly low rates of access for internalising compared with externalising problems [10, 12].

In an effort to explain the unmet need in relation to childhood mental health disorders, studies have often focused on identifying predictors of service use. Family and child characteristics, including ethnicity, family socioeconomic, and insurance status, living in an urban or rural area, and severity of the child's problems have all been implicated in determining the likelihood of service utilization. Overall

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studies suggest that being Caucasian [13, 14], having insurance coverage (in the USA) [15, 16], living in an urban area [17], and having a child with more severe mental health problems [12] increases the likelihood of a family accessing treatment. While these studies shed some light on who accesses treatment, they tell us little about the reasons for discrepancies in service use or the processes underlying accessing treatment.

An alternative approach draws on models of help-seeking behaviour to conceptualise different stages and processes involved in accessing treatment for mental health problems in children and adolescents [16, 18, 19]. Specifically, factors have been explored that underlie the distinct stages of (1) parental recognition of difficulties, (2) the decision or intention to seek help, and (3) contact with services. Studies of parental recognition suggest that parents who perceive that a problem exists and think that the problem has a negative impact on family life are more likely to seek help and access mental health services for their children than those who do not recognise a problem or its negative impact [20, 21]. Parental attitudes surrounding mental health and mental health services have been shown to influence help-seeking decisions—in particular, beliefs that mental health problems are caused by child's personality or relational issues [22], negative perceptions of mental health services [18], and perceived stigma associated with mental health problems [23, 24] have all been associated with reduced help-seeking behaviour. Similarly, 'logistical' factors (such as transport access and flexibility of appointment system) have been shown to influence the likelihood of a family having contact with services [25, 26]; and a parent sharing concerns about a child's mental health with a primary care practitioner has also been shown to improve access to mental health services [27, 28].

Together these studies highlight the key 'gatekeeper' or 'gateway provider' [29], role parents can play in treatment access for mental health problems for children and adolescents, and point towards numerous potential barriers parents may face in the process of seeking and obtaining help. However, to improve access to treatment, it is important to establish parents' own views on the factors that may help and hinder access. Indeed, studies focusing on ongoing treatment engagement (i.e., continuing treatment after initial access) have identified key factors that parents perceive to be barriers to treatment attendance [30, 31], and thereby highlight areas to target to improve treatment retention. Therefore, similarly, identifying what parents perceive to be the barriers and facilitators to the initial access to treatment would highlight areas to target to improve rates of access.

A recent systematic review synthesised findings across studies that reported young people's perceptions of barriers and facilitators to accessing mental health treatment [32]. However, given that children and adolescents are rarely able to seek and access help alone, it is equally important to establish parents' corresponding views; a review of parents' perceptions of barriers and facilitators to treatment access has not been conducted to date. The purpose of this study is to systematically review studies that report parents' perceptions of barriers and/or facilitators to accessing treatment for mental health problems in children and adolescents. The review synthesises findings across both quantitative and qualitative studies, incorporating studies that focus on specific mental health disorders, as well as those considering emotional and/or behavioural problems more broadly. The review focuses on access to psychological treatments (rather than medication), and is concerned with the processes of both seeking and obtaining help through specialist mental health services, as well as primary care and school settings.

Method

A systematic literature review was conducted following PRISMA guidelines [33].

Literature search

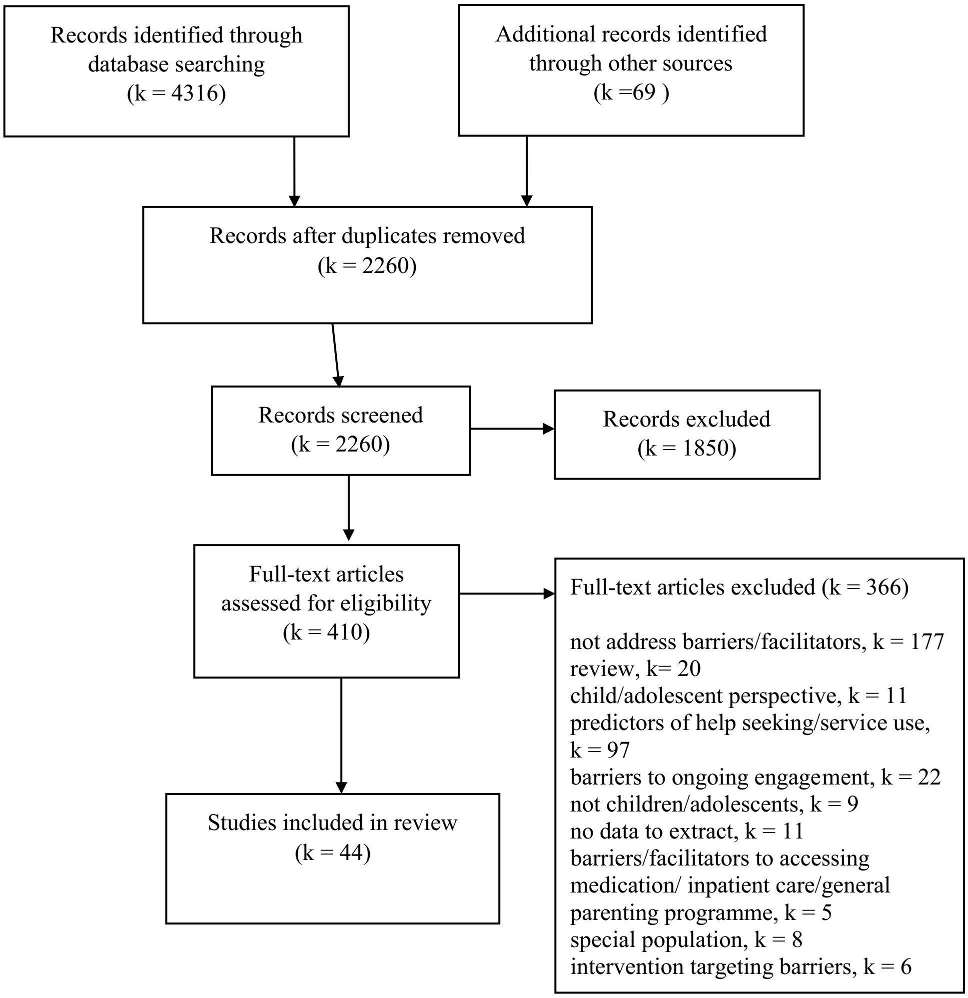
Four electronic databases were searched in October 2014. The NHS Evidence Healthcare Database was used to run a combined search of Medline, PsychInfo, and Embase; and the Web of Science Core Collection was searched separately. With reference to relevant literature and previous reviews, search terms to reflect the following four key concepts were generated: barriers/facilitators; help-seeking; mental health; and parents/children/adolescents. Search terms within each of these four categories were combined using 'AND' to search titles/abstracts. Searches were limited to articles published in English (see Electronic supplementary material 1 for details of search strategy).

Additional hand searching methods were also employed. The reference lists of relevant articles in the field identified through the database search were scanned for additional studies. Citations of relevant articles were then searched to help identify more recent studies not yet included in the electronic databases.

Study eligibility

Inclusion and exclusion criteria were drafted and then refined after piloting using a small sample of papers (see Electronic supplementary material 2 for details of full criteria). A study was selected for inclusion if:

Fig. 1 PRISMA flowchart



1. parents/caregivers of children/adolescents were participants. Studies were excluded if the mean age of the children/adolescents was over 18 years or the sample included adults over 21 years;
2. parents'/caregivers' perceived barriers/facilitators to accessing treatment for mental health problems in children or adolescents were reported. Studies that only reported barriers/facilitators perceived by children/adolescents were not included;
3. the study was published in English in a peer-reviewed journal. Reviews were excluded.

Studies reporting quantitative or qualitative data (or both) were included. There was no requirement relating to the nature of the mental health problem; studies focusing on either a specific mental health disorder (e.g., depression, ADHD) or behaviour and/or emotional problems more generally were included. However, studies that only reported factors associated with or predictors of help-seeking or service use were not included. Similarly, studies reporting outcomes of an intervention targeted at overcoming one or more barriers to help-seeking were not included. As the focus of the review was barriers and facilitators to accessing psychological treatments within the general population, studies focusing on access within a special population (e.g., children/adolescents with intellectual disability and children/adolescents with mental health problems in the context of a specific physical health condition); and studies specifically addressing access to medication or inpatient psychiatric care (as these would rarely be the first-line treatments), or parenting programmes not specifically targeting mental health problems in children/adolescents were not included.

Study selection

Details of the study selection process are provided in the flowchart in Fig. 1. The combined electronic database search retrieved 4316 records, leaving 2191 records after duplicates were removed. Hand searching identified additional 69 potentially eligible papers. Two independent reviewers (TR and MB/LS) then screened the 2260 titles and abstracts and excluded studies using the criteria detailed above. Agreement between reviewers was good (85% agreement). If either reviewer selected the study for potential inclusion, the full paper was sourced. Two reviewers (TR and MB/LS) then independently assessed the 410 full papers for inclusion, and if the study failed to meet inclusion criteria, the primary reason for exclusion was recorded. In cases of disagreement in inclusion/exclusion judgement, the paper was passed to a third independent reviewer (CC) and a final decision was agreed. In total, 44 studies met criteria for inclusion in the review.

Data extraction

Two standard data extraction forms were developed: one for studies reporting quantitative data and a second for studies reporting qualitative data. The extraction forms were drafted and then refined after the initial piloting by reviewers. Two reviewers (TR and MB or LS) then independently extracted data for each included study, using the corresponding extraction form (or in the case of mixed method studies, using both forms). Any discrepancies in extraction were discussed between the two reviewers, and if there were differences in interpretation, a third reviewer (CC) was consulted and a consensus agreed.

The following information was extracted for each included study: (1) methodology used (quantitative, qualitative, or mixed methods); (2) country of study; (3) study setting (e.g., mental health clinic, school); (4) parent/caregiver characteristics (number and percentage of mothers); (5) child/adolescent characteristics (age range, mental health status, mental health service use, type of mental health problem, or disorder); and (6) whether the study targeted a particular ethnic group or urban/rural population. For studies that collected and analysed quantitative data, details relating to the measure of barriers/facilitators were also extracted (e.g., name of measure, number and format of items, content of items [e.g., subscales, broad areas covered], whether it is a published measure or developed for the study). Where studies reported qualitative data, the method used to collect data (e.g., focus groups, interviews) and areas of relevant questioning were recorded. Finally, information relating to parental perceived barriers/facilitators was extracted from the results section, including the name of each reported barrier and facilitator and associated evidence (e.g., number of participants who endorsed the barrier/facilitator, participant quotes).

Quality rating

The quality of included studies was assessed using modified versions of the two checklists developed by Kmet and colleagues [34]. One checklist was specifically designed for use with quantitative studies and the other for use with qualitative studies, thus allowing corresponding evaluations of different study designs; and studies that used mixed methods were assessed using both checklists. Items on the checklist for assessing the quality of quantitative studies that were not relevant to studies included in this review were removed (e.g., 'If interventional and random allocation was possible, was it described?'); and the wording of other items was tailored for the purpose of this review (e.g., 'Measure of barriers/facilitators well defined'). Items on the checklist for assessing the quality of qualitative studies were slightly modified to incorporate Dixon-Woods' [35] prompts for appraising qualitative research (e.g., 'Are the research questions suited to qualitative inquiry?'). Items on both checklists are rated on a three-point scale (yes = 2, partial = 1, and no = 0), with a maximum score of 20 on the quantitative checklist and 18 on the qualitative checklist. Items on each checklist that related to methods of data collection, data analyses, and conclusions drawn were judged specifically in relation to the part of the study that focused on parental perceived barriers/facilitators (see Electronic supplementary material 3 for modified versions of checklists). Based on the final score, studies were classified into three groups to reflect the overall spread of quality ratings across studies, including: low (quantitative: 0–12; qualitative: 0–11), medium (quantitative: 13–16; qualitative: 12–15), and high (quantitative: 17–20; qualitative: 16–18) quality.

Two reviewers (TR and MB/LS/KH) independently assessed the quality of each included study. Twenty studies were rated using the checklist for quantitative studies, twenty-two studies were assessed using the checklists for qualitative studies, and two studies that used both qualitative and quantitative methods were assessed using both checklists. The two reviewers discussed any discrepancies in ratings, and, if necessary, consulted a third reviewer (KH or CC) to reach a final decision.

Data synthesis

A narrative synthesis was conducted, drawing on the framework and techniques described in 'ERSC Guidance on Conducting Narrative Synthesis' [36]. Initially, preliminary syntheses of the quantitative data and the qualitative data were each conducted separately. Tabulated quantitative data were reorganised to group findings according to reported perceived barriers/facilitators, and then, a code was attached to each individual reported barrier/facilitator. Data were reorganised according to the initial codes, and then, an iterative process was adopted in which codes were refined, and grouped into overarching emerging barrier/facilitator themes. Tabulated qualitative data were then coded and organised into barrier/facilitator themes, following the same iterative process. The next step was to develop a 'common rubric' [36] to amalgamate quantitative and qualitative findings. This involved refining quantitative and qualitative codes, to develop a single-coding framework, that described and organised the barriers/facilitators identified across all studies.

To facilitate the process of comparing and contrasting findings across studies, and in particular to examine variation in the number of participants who endorsed particular barriers/facilitators, further 'transformation' [36] of quantitative data was performed. First, where applicable, responses on Likert response scales were converted into 'percentage endorsed' by summing positive responses (e.g., summing number of 'agree' and 'strongly agree' responses). Next, the 'percentage endorsed' for each barrier/facilitator was examined and categorised into three groups according to the relative overall spread of endorsement rates across studies ['small' (0–10%), 'medium' (10–30%), and 'large' (more than 30%)]. Graphical representations were then used to display the percentage of studies that reported individual barriers and facilitators, illustrating the percentage of quantitative studies in which the barrier/facilitator was reported by at least a 'medium' percentage of participants, as well as the percentage of qualitative studies that reported corresponding barriers/facilitators. Similarities and differences in study findings, and the relationship between individual barriers/facilitators, and barrier/facilitator themes, were further explored using data extracted in relation to study characteristics (e.g., study setting, sample characteristics, and mental health service use).

Finally, to assess the robustness of the data synthesis, a sensitivity analysis was performed in which findings from studies assessed to be of 'low' quality were removed, and the remaining data were re-examined to determine if the codes, key themes, and conclusions remained unchanged.

One reviewer (TR) conducted the data synthesis, with regular discussion with team members (CC, KH, and DO'B) to agree interpretation of data and formulation of codes and themes.

Results

Description of included studies

In total, 44 studies were included in the review, with 20 studies providing quantitative data, 22 providing qualitative data, and two providing both quantitative and qualitative data. Details related to the study characteristics are provided in Tables 1 and 2.

The studies varied widely on a number of characteristics, including country (with the largest number from the USA); age range (with variable age range, and some focusing on younger/older age groups); demographic profile (with some urban or rural populations, and some studies of immigrant groups or particular ethnic/racial groups); method of recruitment and study settings (with samples recruited through various community settings or through mental health service providers); mental health status of participants (with samples of parents of children with mental health problems/diagnosis or without mental health problems); nature of mental health problem (with some studies focused on mental health problems, in general, and others focused on specific mental health problems); and extent of mental health service use (with samples of current/previous service users or referrals, those with a history of help-seeking/prior receipt of a mental health diagnosis, non-service users, a minority of service users/varying levels of service use, or service use was not reported).

Studies providing quantitative data tended to measure parental perceived barriers using a questionnaire that asked participants to either endorse the presence or absence of barriers from a list or rate barriers on a 3–5 point Likert response scale. Some quantitative studies, however, asked more open questions about the reasons for not seeking help or difficulties associated with seeking help/attending services/accessing services. Only two quantitative studies provided data relating to perceived facilitators of accessing mental health services [37, 38]. The amount of relevant quantitative data reported across studies ranged from data relating to responses to a single question [39, 40] or particular questionnaire subscales [23], through studies reporting a breakdown of responses to a large number of questionnaire items [26, 38, 41].

Qualitative data relating to perceived barriers and facilitators tended to be collected using interviews and/or focus groups, with a minority using written questionnaires. All qualitative studies provided data relating to perceived barriers, and 13 provided data relating to perceived facilitators. Like quantitative studies, the amount of relevant data provided by qualitative studies varied considerably, with perceived barriers/facilitators to treatment access only forming a very small part of some studies [42, 43], and the primary focus of others [44, 45].

Quality ratings

As shown in Tables 1 and 2, quality ratings of quantitative studies ranged widely from 8 to 19 (out of a possible 20); and corresponding ratings of qualitative studies similarly ranged from 7 to 18 (out of a possible 18). Research questions, study design, participant selection, and sample size were mostly assessed positively for quantitative studies; whereas methods of data collection, analyses, and reporting of findings specifically in relation to perceived barriers/facilitators were areas of weakness across lower quality

Table 1 Study characteristics of quantitative studies

Study	N	Age range	Country	% mothers ethnicity urban/rural	Study setting	Mental health status	Mental health service use	Measure of perceived barriers/facilitators	Quality rating (0–20)
Berger-Jenkins (2012) [64]	70	5–17	USA	Hispanic (57.1%) African American (34.3%)	primary care and mental health clinic waiting room	ADHD diagnosis (self reported/chart review)	No current treatment	5 items yes/no response; system-related barriers (responses to other items not included)	18 (high)
Bussing (2003) [47]	91	5–11	USA	African American (50%)	schools	ADHD diagnosis (screening; diagnostic assessment)	No treatment (previous 12 months)	20 items yes/no response; system-related barriers; stigma; perceived need; financial; negative expectations	19 (high)
Cheng (2013) [39]	67	5–17	UK	Chinese (100%)	Chinese language schools	7% borderline/abnormal range (SDQ)		1 item; reasons not seek professional help	12 (low)
Dempster (2013) [23]	102	5–8	USA	Mothers (95%) Rural	Primary care (appointment check in)	8.8% above clinical cut-off (PSC)		Obstacles to Engagement Scale 14 items four-point response scale; barriers to attending parenting class for child behaviour problems personal/family stressors; trust/relevance intervention; intervention demands; time/scheduling demands	19 (high)
Eapen (2004) [40]	205 (out of 325)	United Arab Emirates		Community			Not sought help	1 item; reasons not seek specialist help	8 (low)

Table 1 continued

Study	N	Age range	Country	% mothers ethnicity urban/rural	Study setting	Mental health status	Mental health service use	Measure of perceived barriers/facilitators	Quality rating (0–20)
Girio-Herrera (2013) [50]	306	5	USA	Caucasian (94.4%) Rural	Elementary schools	'At risk' (above cut-off on BASC-2)	11% receiving professional help	Barriers to Participation Scale (modified) 44 items five-point response scale; relevance; demands/issues; relationship; stress/obstacles	18 (high)
Gould (2009) [76]	17	13–19	USA		High school	'At risk' (above cut-off SIQ, or endorse relevant SIQ and BDI items)	Not follow through with referral and seek treatment	Help-seeking utilization questionnaire 18 items; reasons for non-use of services: shame; self-efficacy and structure	18 (high)
Harrison (2004) [72]	66		USA	African American (79%) Hispanic (12%) Urban	Referred to mental health clinic	Clinically significant mental health need (CPRS)	Not attend first appointment at mental health clinic	CASA; reasons for non-attendance at mental health clinic: concrete obstacles; receptivity to services; attitudes towards professional helpers; previous experience with services	15 (medium)
Harwood (2009) [37]	110	3–6	USA	Caucasian (63%) African American (20%)	Paediatric primary care waiting rooms	34% above cut-off on ECBI (disruptive behaviour)	24% never received mental health service 62% only read information	Survey of parental attitudes (some relevant items) five-point response scale; barriers and facilitators to obtaining recommended services	16 (medium)

Table 1 continued

Study	N	Age range	Country	% mothers ethnicity urban/rural	Study setting	Mental health status	Mental health service use	Measure of perceived barriers/ facilitators	Quality rating (0–20)
Hickson (1983) [70]	149		USA	Mothers (100%)	Paediatric primary care waiting room	Report psychosocial concern	Not communicated psychosocial concern with paediatrician	Part of interview reasons for not communicating psycho-social concerns with paediatrician	8 (low)
Ho and Chung (1996) [77]	74	0–15	Hong Kong		Consecutive referrals to psychiatric clinic	Range of psychiatric diagnoses	Referred to psychiatric clinic; no prior access	Part of interview difficulties encountered in help-seeking process	12 (low)
Larson (2013) [38]	55	2–17	USA	African American (98%)	Referrals within a paediatric clinic to a mental health clinic	Range of mental health problems	64% followed-up with referral; 36% not attend initial evaluation/not schedule first appointment	23 items; perceptions of mental health treatment and potential barriers to seeking mental health care	18 (high)
McKay (2002) [62]	159		USA	African American (81%) Latino (11%) Urban	Consecutive referrals to mental health clinic	Disruptive behaviour problems	Referred to mental health clinic; 45% prior treatment	Adapted CASA barriers to services use	11 (low)
Meredith (2009) [49]	329	13–17	USA	Hispanic (45.8%) Black (33.9%) White (16.7%)	Primary care waiting room	Depression diagnosis ($n = 162$) [49] matched sample with no depression diagnosis ($n = 167$) [49] (diagnostic interview)		Part of interview 6 items five point response scale; imagine need or want care 6 months in future, rate following barriers: cost; what others think; difficulty making appointment; personal responsibilities; no good care available; not want to	19 (high)

Table 1 continued

Study	N	Age range	Country	% mothers ethnicity urban/rural	Study setting	Mental health status	Mental health service use	Measure of perceived barriers/facilitators	Quality rating (0–20)
Mukolo (2011) [51]	175	4–17	USA	African American (100%) urban (33%)	Medicaid enrolment data (subsample)	Mean score above clinical cut-off (CBCL-internalising and externalising scales)	Mental health service use previous 6 months	14 items yes/no response; rate if items made it difficult to obtain services or prevented their child getting services in previous 6 months location/time; provider/payer; family perception barriers	19 (high)
Murry (2011) [46]	163	13+	USA	Mothers (100%) African American (100%) Rural	Longitudinal study (wave 8) random sample of African American families from school lists	23% clinical/borderline range (CBCL)	10% reported seeing someone for child's emotional/behaviour problem	Mothers' Perceptions About Help Seeking three-point response scale; mother's/child's lack of willingness; cultural/general mistrust service providers; lack of social support; stigma	17 (high)
Owens (2002) [26]	116		USA	African American (81.9%)	School-based early intervention study (grade 1) follow-up across control and intervention groups (grade 7)	Reported need for mental health service 71.3% no diagnosis; 16.5% conduct disorder; 12.2% other diagnosis (DISC-IV)	35.6% accessed mental health services (one year previously)	15 items; reasons not accessed care: structural; perceptions about mental health problems; perceptions about mental health service	19 (high)
Pavuluri (1996) [53]	34	30–60 months	New Zealand		Preschools subsample who reported barrier/s to help-seeking		Reported need for mental health service	16 items; reasons for not seeking help when help was needed	15 (medium)

Table 1 continued

Study	N	Age range	Country	% mothers ethnicity urban/rural	Study setting	Mental health status	Mental health service use	Measure of perceived barriers/facilitators	Quality rating (0–20)
Sawyer (2004) [52]	286	4–17	Australia		National survey diagnostic interview	ADHD diagnosis (diagnostic interview)	Reported not attending services in previous 6 months	Part of service use survey reason for not attending services	11 (low)
Sayal (2015) [41]	162	10	UK		Part school-based intervention trial	High risk for ADHD (screening at age 5)	Specialist service use in previous 5 years ($n = 81$) [41] matched sample with no specialist service use in previous 5 years ($n = 81$) [41]	Part of Children Services Interview aspects of service provision perceived as presenting a barrier to service use (educational and health) availability of information about where to seek help; attitudes and communication of professionals; practical issues (e.g., cost, getting to appointments, confidentiality); what other people would think	17 (high)
Shivram (2009) [59]	420	5–16	UK		National survey	Conduct disorder diagnosis (DAWBA)	25.2% specialist child mental health service use	15 items; reasons that prevented service access (previous 12 months) when concerned	17 (high)

Table 1 continued

Study	N	Age range	Country	% mothers ethnicity urban/rural	Study setting	Mental health status	Mental health service use	Measure of perceived barriers/facilitators	Quality rating (0–20)
Thurston (2008) [48]	194	2–17	USA	African American (51.5%) Caucasian (48.5%)	Community (responders to flyers and adverts)		19.4% past service use	Barriers to Treatment Utilization Likert response scale structural barriers (accessibility, availability); attitudinal barriers (acceptability, accountability)	14 (medium)

n number of parents/caregivers, *age range* age range of children/adolescents, *SDQ* Strengths and Difficulties Questionnaire, *PSC* Pediatric Symptom Checklist, *BASC-2* Behaviour Assessment System for Children Second Edition, *SIQ* Suicidal Ideation Questionnaire, *BDI* Beck Depression Inventory, *CPRS* Conners Parent Rating Scale, *ECPI* ECPI Intensity Scale, *CASA* Child and Adolescent Services Assessment; *CBCL* Child Behaviour Checklist, *DISC-IV* diagnostic Interview Schedule for Children Version 4, *DAWBA* Development and Well-Being Assessment

studies. Evidence of robust development and evaluation of the measure of barriers/facilitators among the target population was lacking across all quantitative studies.

Similarly, research questions, study context, and overall study design were mostly well described and appropriate across qualitative studies, but the barrier/facilitator data collection methods and data analysis were often not clearly described among lower quality studies, and the credibility of the findings among these studies was often limited.

Quantitative and qualitative data synthesis

As illustrated in Fig. 2, perceived barriers and facilitators relating to four inter-related themes emerged: (1) systemic and structural issues associated with the mental health system; (2) views and attitudes towards services and treatment; (3) knowledge and understanding of mental health problems and the help-seeking process; and (4) family circumstances. Perceived barriers/facilitators within each theme are summarised below[1] and outlined in detail in Electronic supplementary material 4.

Systemic-structural barriers and facilitators

Figure 3 illustrates the range of barriers and facilitators relating to systemic-structural aspects of mental health services that were reported across quantitative and qualitative studies.

The cost of mental health services was reported to be a barrier by more than 10% of participants across almost half of quantitative studies [26, 37, 46–53]; and among a smaller number of qualitative studies [54–58]. With a few exceptions, these studies were all conducted in USA and participants were typically not mental health service users. Other financial barriers identified in fewer quantitative and qualitative studies included a lack of insurance coverage (in USA studies) and indirect costs (e.g., loss of wages and travel costs).

Various logistical-type barriers and facilitators were identified. Quantitative studies often asked participants to rate 'inconvenient (appointment) times' as a possible barrier, although typically, only a small minority of participants rated this as a barrier [38, 41, 53, 59]. Qualitative studies also identified the cumbersome administrative system [56] and various aspects of the appointment system [44, 45, 57, 61] as perceived barriers/facilitators. Both

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[1] Two quantitative studies reported data relating to perceived barriers/facilitators for two sub-samples (a sample of service users and non-service users [41]; and a sample with depression and without depression [49])—and these sub-samples were treated separately in the following analyses

Table 2 Study characteristics of qualitative studies

Study	N	Age range	Country	% mothers ethnicity rural/urban	Study setting	Mental health status	Mental health service use	Method of data collection (relating to perceived barriers/facilitators)	Quality rating score (0–18)
Boulter and Rickwood (2013) [44]	15	<18	Australia	Mothers (93%)	Local mental health services, parent support groups, community mental health education group		Previous help seeking for mental health problems	Semi structured interview; address type of help sought, help-seeking process and decision to seek help	18 (high)
Boydell (2006) [60]	30	3–17	Canada	Mothers (80%) Rural	Community meetings; two rural areas	Previous emotional/behavioural disorder diagnosis		Indepth interview; address issues related to access to mental health care, including barriers and facilitators	14 (medium)
Bradby (2007) [63]	(a) 35 (b) 7 (c) 6	a. b. 6–14 c. 5–13	UK	South Asian (100%) Urban	(a) Community sample, various sources (b) Current/recent specialist mental health service users (c) professionals (GPs, health visitors, schools) identified families where child would benefit from specialist mental health service	(a) (b, c) range of mental health problems	(a) (b) Current/recent mental health specialist service users (c) 'Potential' service users (not yet received referral)	(a) Community focus groups; vignettes describing an adolescent with depression, behavioural problems, and psychotic symptoms; address suggested advice helpful services (b, c) semi-structured interviews; address experiences with services, expectations, suggested improvements	15 (medium)

Table 2 continued

Study	N	Age range	Country	% mothers ethnicity rural/urban	Study setting	Mental health status	Mental health service use	Method of data collection (relating to perceived barriers/facilitators)	Quality rating score (0–18)
Brown (2014) [73]	20	3–4	USA	Black (75%) Mothers (90%) Urban	Primary care centre	Parental concerns about emotion/behaviour problems	Prior referral to behavioural health services (70%); followed through with referral (45%)	Interviews; questions related to experiences of discussing problem behaviour with primary care doctor, thoughts and feelings related to referral and decision to follow through or not with referral	18 (high)
Bussing (2012) [43]	161	14–19	USA	African American (28%); white (72%)	Longitudinal study; school screening	High risk ADHD (75%; elevated ADHD ratings/previous diagnosis) low risk ADHD (25%)	previous ADHD treatment (58%)	Open ended question on written survey; undesirable aspects of treatment	16 (high)
Chapman (2014) [56]	16	12–18	USA	Latino (100%)	Part larger state-wide study immigrant youth and their parents			Interviews; scenarios covering range symptoms (depression, PTSD, behavioural disorders); questions relating to views about these behaviour difficulties and help seeking	15 (medium)
Cohen (2012) [61]	24	<19	USA	Mothers (92%) Spanish speakers (67%)	Part of evaluation of child health insurance program		Previous mental health service use	Focus groups and interviews; questions relating to decision to seek care, response from professionals, impressions, and experiences of services	10 (low)

Table 2 continued

Study	N	Age range	Country	% mothers ethnicity rural/urban	Study setting	Mental health status	Mental health service use	Method of data collection (relating to perceived barriers/facilitators)	Quality rating score (0–18)
Crawford and Simonoff (2003) [65]	30	6–17	UK	Mothers (70%) White (70%) Black (23%) Asian (7%) Urban	School for emotionally and behaviourally disturbed Random subsample from larger study	Emotional/behavioural disorder problems (and special educational needs)		Focus groups; questions relating to previous experience with a range of services (including child and adolescent mental health services), barriers to accessing services and areas for improvement	18 (high)
dosReis (2010) [42]	48	6–18	USA	Mothers (75%) Urban	Primary care clinics; developmental and behavioural pediatric clinics; specialty mental health outpatient clinic	ADHD diagnosis	Within one month of diagnosis; on medication or still deciding treatment	Semi-structured interview; address understanding of child's problems and diagnosis, perceptions and expectations of treatment	18 (high)
Flink (2013) [69]	41	10–20	The Nether-lands	Mothers (100%) Dutch (26.8%), Moroccan (31.7%) Turkish (41.5%)	Migrant organisations, mosques and schools		7% reported mental health care past year	Focus groups;questions based on vignette describing internalising problems in adolescent girl and stages of help seeking (including barriers and facilitators)	15 (medium)

Table 2 continued

Study	N	Age range	Country	% mothers ethnicity rural/urban	Study setting	Mental health status	Mental health service use	Method of data collection (relating to perceived barriers/facilitators)	Quality rating score (0–18)
Gerdes (2014) [75]	73	5–12	USA	Latino (100%) Urban	Parishioners at local Catholic churches			Written response to open ended questions included in the 'Problem Recognition Questionnaire for ADHD', including possible barriers to seeking help, and ways to overcome barriers	17 (high)
Goncalves (2012) [54]	6	12–17	Portugal	None born in Portugal	Schools in areas with high number of immigrants; immigrant organisations			Two focus groups; address access to mental health care for migrant and ethnic minority families, including concepts of mental health, barriers/facilitators to help seeking and service access	12 (medium)
Guzder (2013) [68]	20	7–12	Canada	Immigrant (50%); native born (50%)	Psychiatric hospital patients	Externalising disorders (CBCL)	Psychiatric day hospital (100%)	Semi-structured interview; address help-seeking process, and experiences with services or support	10 (low)
Klasen and Goodman (2000) [66]	29		UK		Specialist services; support groups; community services	Hyperactivity diagnosis/waiting to see specialist	Accessed specialist service/waiting to access	Semi-structured interviews; views of hyperactivity, perception of GP views, treatment options, sources of information	18 (high)

Table 2 continued

Study	N	Age range	Country	% mothers ethnicity rural/urban	Study setting	Mental health status	Mental health service use	Method of data collection (relating to perceived barriers/facilitators)	Quality rating score (0–18)
Lindsey (2013) [58]	11		USA	African American (100%) Urban	Two elementary/middle schools			Focus groups; address help seeking, school and community mental health services, barriers and facilitators to help seeking	17 (high)
Meredith (2009) [49]	16	13–17	USA	Hispanic/black/White	Purposive subsample from larger sample recruited through primary care waiting room, followed by diagnostic assessment	Depression diagnosis	Previous treatment (approximately 50%)	Semi-structured interview; include questions about barriers to care	10 (low)
Messent and Murrell (2003) [78]	7		UK	Mothers (57%) Bangladeshi (100%) Urban	Child and adolescent mental health service users with positive view of service		Current or recent mental health service users	Two meetings; views about low rate of referral to specialist mental health services among Bangladeshi families	7 (low)
Murry (2011) [46b]	21	13+	USA	Mothers (100%) African American (100%) Rural	Subsample from follow-up in longitudinal study	Borderline/clinical range on CBCL subscale	25% reported seeing someone for child's emotional/behaviour problem	Semi-structured interview; address identification of child problems, beliefs about illness, formal and informal support systems, experiences with behavioural health systems, and community resources	18 (high)

Table 2 continued

Study	N	Age range	Country	% mothers ethnicity rural/urban	Study setting	Mental health status	Mental health service use	Method of data collection (relating to perceived barriers/facilitators)	Quality rating score (0–18)
Pailler (2009) [55]	59	12–18	USA	Mothers (65%) African American (70%)	Emergency department in hospital			Semi-structured interview; address views relating to depression screening in emergency departments, acceptability of depression screening, and barriers/facilitators to following through with referral	18 (high)
Pullman (2010) [56]	8	4–17	USA	Mothers (75%) White (88%) Rural	Referred to service for severe emotional problems	Severe emotional problems	Referred to specialist service (100%); attended service (50%)	Semi-structured interview; experience of referral and service, and associated benefits and challenges	18 (high)
Sayal (2010) [45]	34	2–15	UK	Black or ethnic minority (52%) Urban	Community based organisations; schools; GPs parents with concerns about child's mental health	SDQ abnormal range (86%)	Previous mental health service user (9%)	Focus groups; address barriers and facilitators to accessing care	18 (high)
Semanksy (2004) [67]	68		USA		Two states with comprehensive state child and adolescent mental health services	Serious emotional disturbance		Focus groups; address experiences of seeking treatment	12 (medium)

Table 2 continued

Study	N	Age range	Country	% mothers ethnicity rural/urban	Study setting	Mental health status	Mental health service use	Method of data collection (relating to perceived barriers/facilitators)	Quality rating score (0–18)
Stein (2003) [71]	UK	Mothers (100%) Pakistani (50%) White (50%) Urban	Urban health centre 79 participants complete questionnaire, subsample respond to open-ended questions					Open-ended questions as part of questionnaire related to help-seeking intentions, advantages and disadvantages of attending services, improvements to services	8 (low)
Thompson (2013) [74]	32	13–19	USA	Mothers (100%) African American Urban	Purposive subsample from larger longitudinal study of mother–child dyads from area of high poverty/high rates child protection service use		Reported mental health service use (100%)	Semi-structured interview; address experiences, expectations and intentions to use mental health services	18 (high)

n number of parents/caregivers, *age range* age range of children/adolescents, *CBCL* Child Behaviour Checklist, *SDQ* Strengths and Difficulties Questionnaire

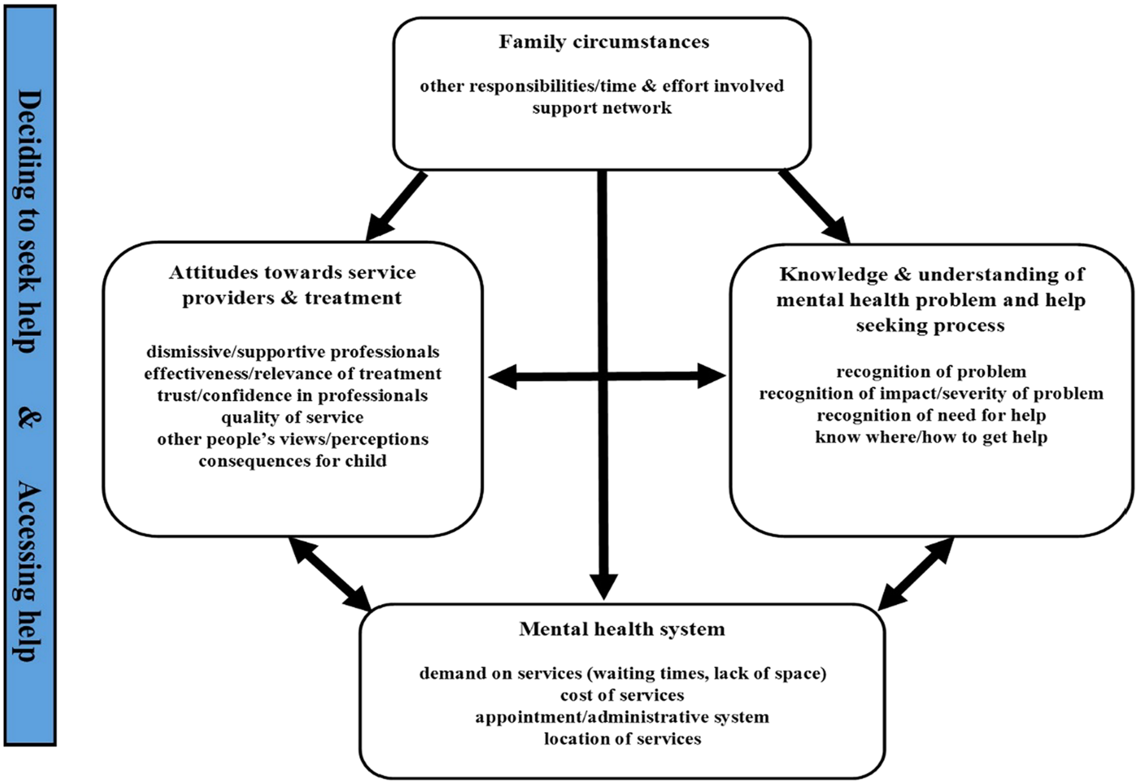

Fig. 2 Perceived barrier/facilitator themes

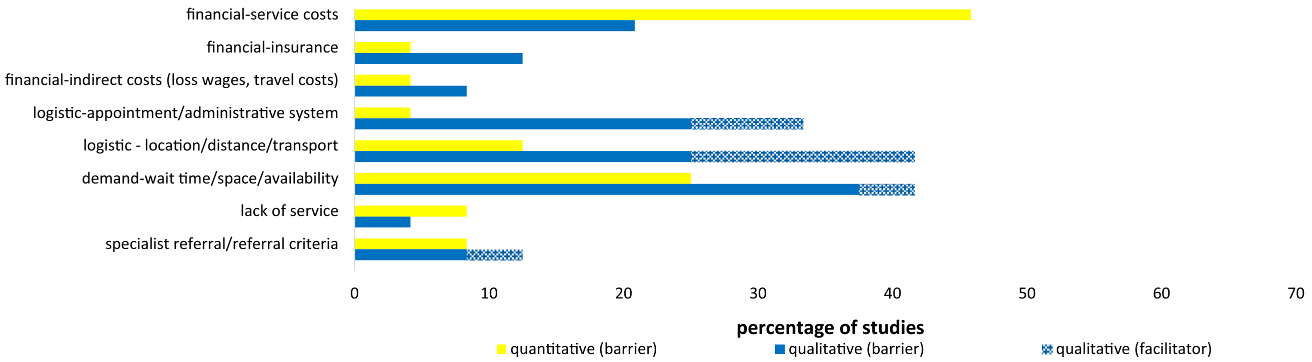

Fig. 3 Perceived systemic-structural barriers and facilitators: Percentage of quantitative* and qualitative** studies to report each barrier/facilitator. *Percentage of quantitative studies = Percentage of 24 included samples where a 'medium' (10-30) or 'large' (>30) percentage of participants endorsed the barrier/facilitator. **Percentage of qualitative studies = Percentage of 24 included studies that reported the barrier/facilitator

quantitative and qualitative studies highlighted the location of service providers and the availability of transport as logistical barriers for some families; and the potential benefit of providing logistical support for families was also noted in qualitative studies.

The demands on services, and in particular, the wait to access services were a recurring systemic-structural barrier reported across quantitative [41, 49, 51, 52, 64] and qualitative [44, 55, 60, 61, 65–69] studies from different countries, particularly among samples of service users. Studies also identified a complete lack of specialist services and referral criteria as perceived barriers/facilitators.

Attitudes towards service providers and psychological treatment

Figure 4 illustrates the wide range of views and attitudes relating to professionals, different elements of service

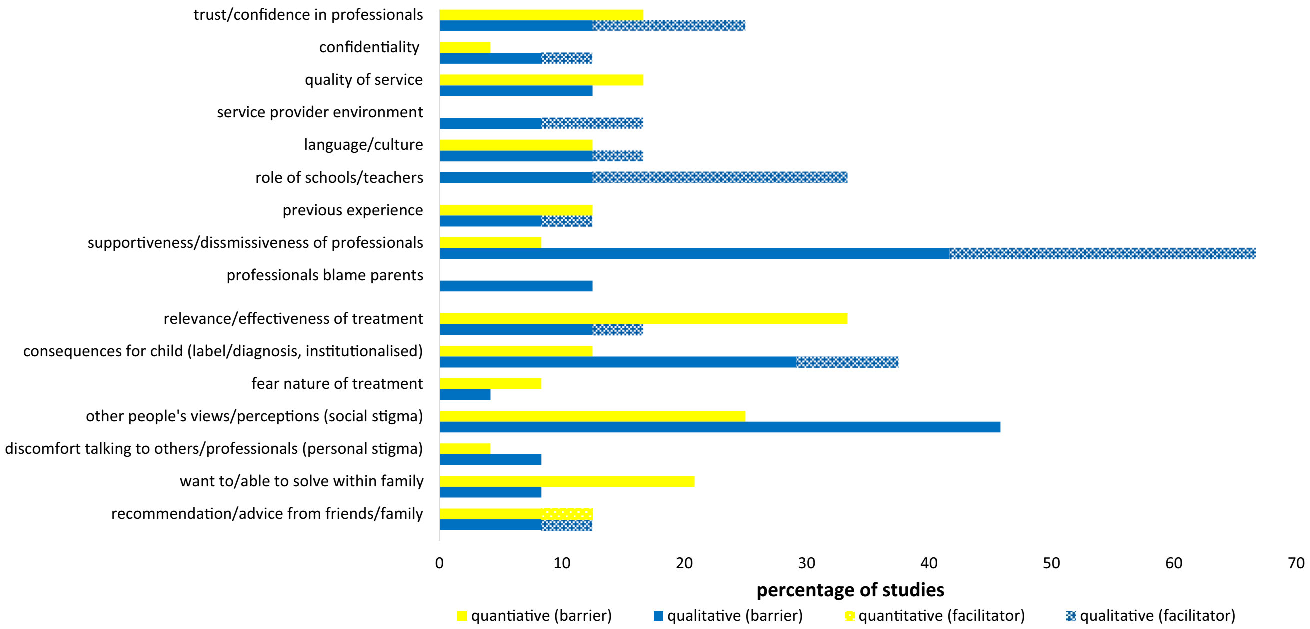

Fig. 4 Perceived barriers and facilitators related to attitudes towards service providers and psychological treatment: Percentage of quantitative* and qualitative** studies to report each barrier/facilitator. *Percentage of quantitative studies = Percentage of 24 included samples where a 'medium' (10-30) or 'large' (>30) percentage of participants endorsed the barrier/facilitator. **Percentage of qualitative studies = Percentage of 24 included studies that reported the barrier/facilitator

providers, and the consequences of seeking and receiving psychological treatment that were identified as barriers/facilitators across studies.

Trust and confidence in professionals and the existence/absence of a trusting relationship with professionals were reported as a barrier/facilitator in both quantitative [26, 38, 46, 70] and qualitative studies [45, 55, 60, 63, 66, 71]. Concerns surrounding confidentiality of discussions with professionals, broader perceptions of the nature, and quality of services, and the previous experience with services were also identified as perceived barriers/facilitators among quantitative and qualitative studies. A perceived language or cultural barrier/facilitator was specifically reported among samples of minority populations; and the service provider environment and specific views towards teachers/schools emerged as potential barriers/facilitators in qualitative studies.

The attitudinal barrier reported by parents in the largest number of (predominantly qualitative) studies was the feeling of not being listened to or dismissed by professionals. A sense of parents feeling dismissed emerged among 10 (42%) qualitative studies [42, 45, 46, 60, 61, 66, 67, 69, 73, 75]; and several qualitative studies [45, 61, 66] also reported that parents felt 'blamed' by professionals. On the other hand, a quarter of qualitative studies [45, 46, 55, 58, 61, 75] reported that perceiving that health professionals listen to voiced concerns encouraged parental help-seeking.

Various beliefs surrounding the consequences of help-seeking, for example, the relevance/effectiveness of treatment, the potential consequences for the child, and fears associated with the treatment itself were all identified among some studies as posing barriers/facilitators to help seeking. The most commonly reported barrier related to concerns surrounding the consequences of help seeking, however, was the barrier posed by the perceived negative attitudes among other people. The 'stigma' associated with mental health problems or attending mental health services was reported as a barrier in studies from different countries and cultures, including 11 (46%) qualitative studies [45, 54, 55, 57, 58, 60, 61, 63, 69, 71, 75], and among at least 10% of participants in six (25%) quantitative studies [40, 41, 46, 47, 49]. More 'personal stigma' or negative self-evaluation among parents, and discomfort talking about a child's difficulties; a desire to solve problems within the family; and the role of advice from family/friends, were also all highlighted as deterring or encouraging help seeking in several quantitative and qualitative studies.

Knowledge and understanding of mental health problems and the help-seeking process

Figure 5 illustrates that the barriers and facilitators reported across studies relating to awareness and understanding of both child mental health problems and the process of seeking professional help for these problems.

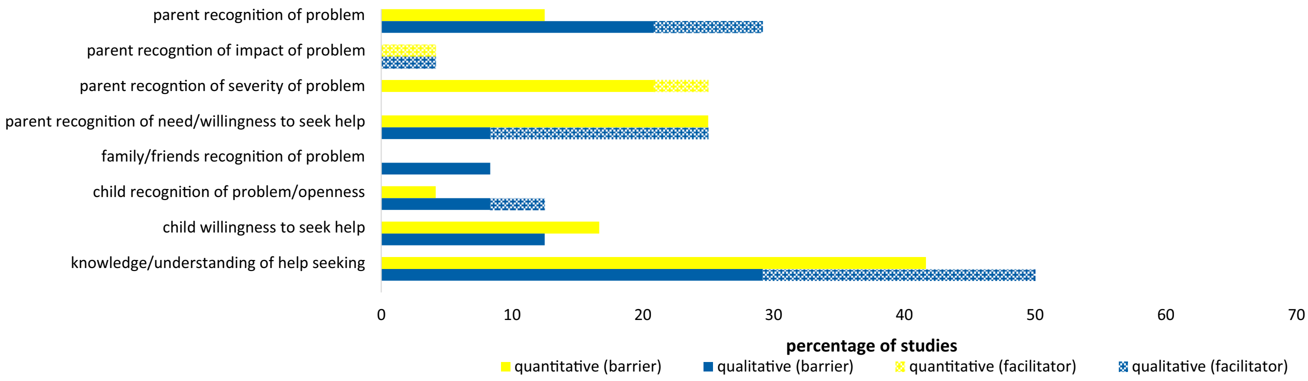

Fig. 5 Perceived barriers and facilitators related to knowledge and understanding of a child's mental health problem and the help-seeking process: Percentage of quantitative* and qualitative** studies to report each barrier/facilitator. *Percentage of quantitative studies = Percentage of 24 included samples where a 'medium' (10–30) or 'large' (>30) percentage of participants endorsed the barrier/facilitator. **Percentage of qualitative studies = Percentage of 24 included studies that reported the barrier/facilitator

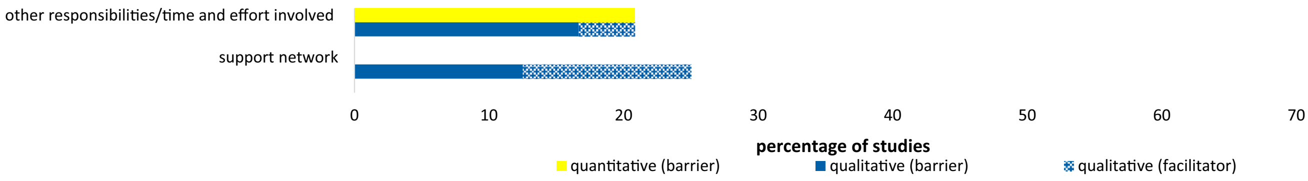

Fig. 6 Perceived barriers and facilitators related to a family's circumstances: Percentage of quantitative* and qualitative** studies to report each barrier/facilitator. *Percentage of quantitative studies = Percentage of 24 included samples where a 'medium' (10–30) or 'large' (>30) percentage of participants endorsed the barrier/facilitator. **Percentage of qualitative studies = Percentage of 24 included studies that reported the barrier/facilitator

Parental recognition of (1) the existence of a child's mental health problem, (2) the severity of the problem, and (3) the associated impact was each reported as perceived barriers/facilitators to help seeking among a number of studies. Similarly, between 12 and 26% of parents reported not wanting/not needing help across a quarter of quantitative samples [38, 49, 50, 70, 76], and recognition of the need for help or parental willingness to seek help was similarly cited as barriers/facilitators to help seeking in a number of qualitative studies [44, 58, 74, 75, 78]. A lack of family recognition, the presence/absence of recognition by the child themselves, and a child's own reluctance to seek help were also reported as helping/hindering help seeking in some studies.

Among 10 (42%) quantitative samples [26, 41, 47, 51–53, 59, 70, 77], at least 14% (and up to 75%) of participants reported a lack of knowledge about where or how to get help as a barrier. This lack of knowledge about where to go to ask for help and how to go about getting help was corroborated in a number of qualitative studies [45, 56, 60, 78]. Qualitative studies [45, 46, 55, 58, 61, 63, 69, 71, 73] also highlighted that wider parental understanding of the mental health system also acted as a barrier/facilitator to help seeking.

Family circumstances

As displayed in Fig. 6, other barriers/facilitators reported in studies related to additional specific aspects of family circumstances, including other responsibilities and commitments, and the time commitment involved in help seeking; and the family's support network.

Robustness of data synthesis

Studies assessed to be of low quality (six quantitative studies and five qualitative studies) were removed, and barrier/facilitator codes and themes were re-examined. This sensitivity analysis showed that the overall synthesis remained unchanged when limited to higher quality studies only.

Discussion

This review synthesised findings from 44 studies addressing parental perceptions of barriers/facilitators to seeking and accessing help for mental health problems in children and adolescents. Perceived barriers/facilitators related to four key themes emerged across studies (displayed in Fig. 2).

In relation to systemic-structural issues surrounding the mental health system, the demand on services emerged as a perceived barrier internationally, reported in studies conducted in the UK, USA, Australia, and Canada. Importantly, waiting times and difficulty getting a referral were most commonly reported as barriers among samples of service users, suggesting that it is after some experience of waiting to access services (or experiencing difficulty accessing services) that these issues often become most pertinent to families. In contrast, the barrier posed by the cost of services (or associated insurance issues) was most frequently reported among community samples in USA, suggesting the 'threat' of paying fees to access services can actually deter families from attempting to seek help at all. Other indirect costs associated with service use, such as loss of wages and travel costs, were less commonly reported as barriers within and across studies, but, nevertheless, highlight how certain family circumstances (e.g., living in a rural area) may increase the likelihood that aspects of the mental health system present a barrier to access. Equally, findings indicated that some parents perceive logistical aspects of mental health systems (such as the appointment/administrative system and the location of services) as both barriers and facilitators to seeking and accessing help—but the wide variation in the frequency with which these issues were reported across studies highlights how both variations in mental health systems (e.g., presence/absence of flexible appointment systems/convenient services) and variation in family circumstances (e.g., access to transport and time available to attend appointments) may influence the likelihood that parents perceive such issues as barriers.

A range of views and attitudes towards services and treatment emerged as perceived barriers/facilitators, and notably, these views and attitudes often appeared to be shaped by the previous experience with the mental health system (or contact with services/professionals more generally). In particular, feeling not listened to or dismissed/blamed by professionals was frequently reported as a barrier to seeking and accessing help across qualitative studies; and equally, the perceived benefit of 'supportive' professionals was also evident. Similarly, trust and confidence in professionals, views surrounding the quality of services, and views relating to specific professionals (e.g., teachers, GPs) were all identified as presenting barriers/facilitators to both seeking and accessing help across diverse samples. Other attitudinal barriers/facilitators related to the consequences of treatment also emerged, including beliefs surrounding the effectiveness or relevance of treatment, fears surrounding the negative consequences of treatment, and fears associated with treatment itself. However, more notable was the frequency with which parents across studies reported the detrimental impact of perceived negative attitudes of others (as well as personal discomfort surrounding mental health) on help seeking.

Knowledge surrounding both mental health problems and the help seeking process emerged as perceived barriers and facilitators across a wide range studies. The large number of studies—and the large number of participants within some studies—that reported barriers related to not knowing where or how to seek help was particularly salient. Interestingly, among studies that addressed recognition of a child's mental health problem, relatively large numbers of parents reported perceived difficulties identifying a problem (or a child's lack of recognition) as a barrier to seeking help, and similarly, parents' perception of the importance of recognition of the severity and impact of a problem was also clear in some studies.

Perceived barriers/facilitators relating specifically to family circumstances, such as other commitments or responsibilities and a family's support network, were less commonly directly addressed in studies than other types of barriers/facilitators. Nevertheless, these issues were raised in qualitative studies, and reported by a sizeable minority of participants in several quantitative studies, thus highlighting the role family circumstances can play. Moreover, the potential impact of other aspects of a family's circumstances (e.g., prior contact with mental health services, living in a rural area, access to transport, language spoken) on the experience of other types of barriers was also clearly illustrated.

Implications

This review highlights several key areas of potential intervention to minimise barriers to help seeking to improve rates of treatment access for mental health problems in children. In relation to mental health systems, it is evident that ensuring service provision is sufficient, and available free of charge would remove key barriers to seeking and accessing professional help. Minimising the 'cumbersome' nature of mental health systems and offering flexible services would also make seeking help easier for many families (e.g., providing drop-in services in local community settings, such as schools and primary care facilities). Moreover, the potential benefit of ensuring professionals working within the mental health system (primary care, schools and specialist services) have the opportunity and skills to develop trusting relationships with families, adopt a supportive approach, and communicate well with other professionals was equally evident.

In addition to improvements to mental health systems, the potential benefit of targeted approaches to improving public knowledge and understanding of childhood mental health difficulties and the help-seeking process was also illustrated. Equipping parents with knowledge and tools to help them identify mental health problems in children, as well as specifically targeting stigmatising attitudes towards parents and the culture of parental 'blame' would help to overcome key barriers to help seeking. Moreover, raising awareness and understanding of the professional help that is available and the process involved in seeking help for childhood mental health problems could help provide families with the necessary knowledge about where and how to seek help, as well as foster positive attitudes towards the potential benefits of psychological treatment.

Strengths and limitations

By focusing on parents' own perspective surrounding the help-seeking process, this review importantly extends what is known from research specifically addressing the predictors of service use. Notably, the wide range of perceived barriers/facilitators identified here illustrates the plethora of factors at play in determining the likelihood that a family will access services. Findings from quantitative studies shed light on the number of parents who perceive particular barriers at different stages of the help–seeking process; and qualitative studies provided further detail on the specific nature of barriers and corresponding facilitators, as well as identifying additional issues that were not addressed in questionnaire studies. Variation in findings across studies helped illustrate who may and may not experience particular barriers/facilitators and the relationship between barriers/facilitators across the key themes.

Studies included in the review varied widely in terms of design and primary purpose, the amount of data relevant to the review, participant populations, and measures of barriers/facilitators. While similarities and differences across study characteristics were explored, due to the wide variability in sample characteristics, it was not possible to carry out more detailed sub-group analyses examining factors associated with perceived barriers/facilitators, e.g., the age of the child/adolescent, study setting, child/adolescent mental health status, or the type of mental health problem. Although removing the poorest quality studies from the analysis did not impact on the overall findings, it is also important to acknowledge the wide variation in quality of studies included in the synthesis. The lack of well-evaluated measures of perceived parental barriers/facilitators specifically in relation to help seeking for childhood mental health problems presented a limitation across quantitative studies. Indeed, the fact that barriers/facilitators were reported in qualitative studies that were not addressed in the questionnaires illustrates limitations with existing questionnaire measures. Moreover, a large number of both qualitative and quantitative studies focused on parents of children who had accessed services, and therefore, the review was limited in the extent that it was able to address barriers among families who have not reached services. It is also important to note that the systematic search used to identify studies for inclusion in this review was conducted in October 2014, and therefore, any relevant studies published since this data were not included in the review.

The available literature highlights the need for improvements to child mental health services and interventions to raise public awareness and understanding of childhood mental health difficulties and how to access available services. However, further investigation into parents' perceptions of barriers and facilitators to seeking and accessing treatment for mental health problems in children and adolescents is needed. Specifically, findings from qualitative studies should inform the development of questionnaire measures to ensure all relevant barriers/facilitators which are captured and can be quantified. For example, qualitative studies have highlighted the need to address parents' perceptions of the dismissiveness/supportiveness of professionals in barrier/facilitator measures—an area frequently neglected in quantitative studies to date. Studies also need to focus on community populations to develop a fuller understanding of varying factors that help and hinder parents at all stages of the help-seeking process. Closer examination of variation in the perceived barriers/facilitators among parents of children of different ages and across different mental health disorders is also necessary to inform more tailored approaches to improve access to treatment.

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Supplementary Material

What do parents perceive are the barriers and facilitators to accessing psychological treatment for mental health problems in children and adolescents? A systematic review of qualitative and quantitative studies

European Child & Adolescent Psychiatry

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Supplementary Material 1

Search PsychInfo, Embase & Medline using NHS Evidence Healthcare Database

Search: Title / Abstract

Limits: English, Article

Search terms: Group 1 AND Group 2 AND Group 3 AND Group 4

Group 1	Group 2	Group 3	Group 4
Barrier*	Help-seeking	Mental*	Child*
Hurdle	help seeking	disorder*	Adolescen*
Obstruct*	helpseek*	Psychopathology	Youth
Obstacle	‘Seek* help’	‘Emotional problems’	Parent*
Promot*	‘Care seeking’	‘Emotional distress’	Caregiver*
Facilitat*	‘seek* care’	‘Behavio* problems’	Carer*
Encourage*	‘access treatment’	Internali*	Teen*
Support*	‘access service’	Anxi*	Mother*
Cause*	‘seek* treatment’	Affect*	Father*
Predict*	‘Service* use’	Depress*	Maternal
‘Unmet need’	‘Service* utilisation’	Suicid*	Paternal
Hinder	‘Service* utilization’	Externali*	
Willingness	‘treatment participation’	ADHD	
Enable*	‘treatment engagement’	‘self harm’	
		Psychosis	
		Oppositional	
		Conduct	

Supplementary Material 2

Inclusion and exclusion criteria

Inclusion criteria:

1. Study reported parents'/ caregivers' perceived barriers or facilitators to accessing psychological treatment for mental health problems in children or adolescents

2. Study addressed mental health problems; emotional and/or behavioural problems; or a specific mental health disorder

3. Study participants were parents/caregivers (i.e. primary carers) of children/adolescents

Exclusion criteria:

1. Study did not report barriers or facilitators to accessing treatment for mental health problems in children/adolescents

2. Study was a review.

3. Study was not published in English in a peer-reviewed journal.

4. Study only reported child/adolescent perceived barriers or facilitators to accessing treatment for mental health problems

5. Study only reported factors associated with or predictors of parent or child/adolescent help seeking behaviour / service use / help seeking intentions

6. Study only reported findings from an intervention designed to address one or more barrier to help-seeking

7. Study only reported perceived barriers/facilitators to accessing ongoing to treatment, not initial access to treatment

8. Study only reported perceived barriers/facilitators to accessing treatment for autism spectrum disorder or developmental disabilities

9. Participants in the study were not parents/caregivers of children or adolescents.
    (excluded if the mean age of the children/adolescents was >18 years or if the sample included adults >21 years)

10. Study did not report any qualitative or quantitative data that could be extracted.

11. Study only reported perceived barriers/facilitators to accessing medication or inpatient psychiatric care

12. Participants in the study represented a special population (ie, children/adolescents with an intellectual or developmental disability, young offenders, children/adolescents with mental health problems in the context of a specific physical health condition, looked after children)

13. Study only reported perceived barriers/facilitators to accessing parenting support not specifically targeted at mental health problems in children

Supplementary Material 3

Quality Rating Checklists

1. Quantitative studies quality rating checklist

	Yes = 2	Partial = 1	No = 0
Question / objective sufficiently described			
Study design evident and appropriate			
Method of participant selection described and Appropriate			
Sample size appropriate			
Participant characteristics sufficiently described			
Measure of barriers/facilitators well defined			
Measure robust			
Analyses described/justified and appropriate			
Results reported in sufficient detail			
Conclusions support results			

Modified version of Kmet et al's Standard Quality Assessment Criteria [33]

2. Qualitative studies quality rating checklist

	Yes = 2	Partial = 1	No = 0
Question/objective sufficiently described			
Are the research question/s suited to qualitative inquiry			
Study design well described and appropriate			
Context of study clear			
Sampling strategy described, appropriate and justified			
Data collection methods systematic, clearly described and appropriate for research question			
Data analysis systematic, clearly described and appropriate for research question			
Use of verification procedures to establish credibility			
Are the claims/conclusion credible?			

Modified version of Kmet et al's Standard Quality Assessment Criteria [33], incorporating Dixon-Woods'[34] *prompts*

Supplementary Material 4

Quantitative and qualitative data synthesis: Detail relating to the perceived barriers/facilitators within each theme

Systemic-structural barriers and facilitators

Figure 3 illustrates the range of barriers and facilitators relating to systemic-structural aspects of mental health services that were reported across quantitative and qualitative studies.

Financial factors

Questions relating to financial barriers were frequently incorporated into questionnaires, and the cost of mental health services was viewed to be a barrier by more than 10% of participants across almost half of samples (and more than 25% of participants in a quarter of samples). All but two of these studies were conducted in the USA [26, 37, 46, 47, 48, 49, 50, 51], with the remaining two from Australia [52] and New Zealand [53]. With the exception of one sample of mental health service users [51], participants who frequently rated the cost of services as a barrier were recruited in the community, and were typically not mental health service users. The cost of services was reported as a perceived barrier in a smaller number of qualitative studies, but similarly, with the exception of a study of immigrants in Portugal [54], other qualitative studies were from the USA [55-58] and were mostly with those who had not accessed services.

In addition to the direct cost of services, other financial barriers identified in a small number of quantitative and qualitative studies included a lack of insurance coverage and indirect costs (e.g. loss of wages, travel costs). All four studies that specifically identified insurance issues as barriers were USA studies [37, 49, 55, 56]. Loss of wages was only rated as a barrier by a small number of participants in several samples [38, 41, 59], and was not rated as a barrier by more than 10% in any sample [41]. Participants in both qualitative studies that referred specifically to costs associated with travel, noted the barrier in relation to living in a rural area [56, 60].

Logistical factors

As well as financial barriers, various logistical-type barriers and facilitators were identified in studies. Quantitative studies often asked participants to rate ‘inconvenient (appointment) times’ as a possible barrier, however, with the exception of one sample [51], only a small minority of participants in other samples (less than 8%) [38, 41, 53, 59], rated this as a barrier. Qualitative studies, on the other hand, pointed towards several wider – but related - issues that presented hurdles to treatment access. As well as appointment times (e.g. ‘their hours aren’t very flexible’ [57], pp. 8), qualitative studies also identified the cumbersome administrative system [56], the need to make multiple telephone calls to access specialist services [61], and the system for making appointments and length of appointments with primary care doctors as barriers [45]. Equally, authors of qualitative studies also noted that parents identified ‘flexible services’ [44], being able to make appointments easily and being given time to discuss concerns about their child’s mental health [45] as potential facilitators.

Both quantitative and qualitative studies also highlighted the location of service providers and the availability of transport as logistical-barriers for some families. The number of participants in quantitative studies who rated lack of transport and the location of services as a barrier varied greatly from more than 40% of participants [62] through to only 1% [59]. Both distance to services, and lack of transport were also identified in qualitative studies as barriers for some parents; and were not restricted to studies of rural populations [49, 55].

The potential benefit of providing logistical support for families to help them access services was also noted by participants in qualitative studies, (e.g. '…arrange transportation for them…Help them get where they need to go…' [55] pp. 725). In one qualitative study one participant also noted the potential benefit to anonymity of using distant service providers: 'the location provides us with some confidentiality' [63] (pp. 2422).

Demands on services, availability of services and referral criteria

Another recurring systemic-structural barrier reported across quantitative and qualitative studies related to demands on services, and in particular, the wait to access services. Although the number of participants who rated waiting times as a barrier varied across quantitative studies, almost half of a sample of UK service-users [41], more than a third of a USA sample of parents of children with a ADHD diagnosis [64]; and at least 10% of participants in four other samples considered waiting times to be a barrier [49, 51, 52]. Waiting times were similarly cited as a barrier in qualitative studies across different countries, including the UK [65, 66], the USA [61, 67], and Canada [60, 68]. Notably, waiting for appointments most frequently emerged as a barrier among samples of service users, and the quantitative studies in which only a small number of participants endorsed waiting times as a barrier, involved samples of non-service users (or predominantly non-service users) [26, 41, 59]. Several qualitative studies highlighted that parents perceived the limited number of specialists as the cause for long waiting times [60, 66, 67]. Indeed, one study noted that parents perceived GPs and social workers to be relatively 'available' in comparison with psychologists or psychiatrists ('I always say even if you don't know anything you will always be able to find a GP' [69] pp. 296). However, as well as limited service provision, a complete lack of specialist services was also perceived as a barrier by participants in one qualitative study [68] and a few quantitative studies [40, 41] – again, including more than 40% of a sample of UK service users [41].

Related to the high demand on services, a few quantitative and qualitative studies also specifically identified referral criteria and difficulties families face being referred to specialist services as perceived barriers. Again, difficulty with referral was most frequently endorsed as a barrier by a UK sample of service users [41]. The rigid intake criteria and the required severity of the problem were cited in qualitative studies as reasons for making it difficult to access help from specialists [44, 60]. Equally, one qualitative study highlighted that the referral criteria only posed a barrier in some situations, and in 'crisis' situations 'jumping the queue' occurs – and so if a child's problem meets service criteria, this will facilitate access [60].

Attitudes towards service providers and psychological treatment

Figure 4 illustrates the wide range of views and attitudes relating to professionals, different elements of service providers, and the consequences of seeking and receiving psychological treatment that were identified as barriers/facilitators across studies.

Trust and confidence in professionals

Trust and confidence in professionals, and the existence – or absence of – a trusting relationship with professionals was reported as a barrier/facilitator in both quantitative and qualitative studies. Among the four (17%) samples asked to rate 'a lack of trust' or 'a lack of confidence' in professionals, at least 10% of participants endorsed the item as a barrier [26, 38, 46, 70]; and importantly it was given both as a reason for not seeking help [46, 70], and as a reason for not following through with a referral [38]. Similar views were echoed in several qualitative studies [63, 66, 71]; but while Klasen et al [66] cited that ‘parents felt GPs were often badly informed’; a more specific belief that services and professionals would be ‘discriminatory’ was reported in studies of ethnic minority populations in the UK [63, 71]. On the other hand, Pailler et al [55] reported that a belief in professionals’ ‘expertise’ was perceived as a facilitator among some parents. Similarly, two other qualitative studies highlighted the potential benefits of having a good and trusting relationship with health professionals. Boydell et al [60] cited familiarity and the ‘long-established relationships’ with service providers in rural communities as facilitators; while Sayal et al [45] specifically highlighted the positive influence a good relationship with a primary care doctor can have on help seeking: ‘I’m lucky in that I’ve got a very good family doctor . . . I would feel personally fairly happy to go with my son to him because I’ve got the trust in my GP – maybe I’m just fortunate perhaps’ (pp. 481).

Confidentiality

A concern surrounding the confidentiality of discussions with professionals was also identified as a barrier by participants in a small number of quantitative and qualitative studies. However, while 15% of a sample of service users reported worries about confidentiality as a barrier [41]; fewer participants in (predominantly) non-service user samples endorsed the same barrier [41, 59]. Nevertheless, similar concerns that professionals ‘cannot keep a secret’ [63] (pp. 2417) and the fact that in rural communities ‘everybody knows when mental health service is sought for a child’[60] (pp. 184) were cited as deterrents to seeking help in two qualitative studies; interestingly, professionals maintaining confidentiality was also reported by parents in one study as important for adolescents themselves as well as parents [69].

Quality of services and service provider environment

In addition to views focusing on professionals, and relationships with professionals, quantitative and qualitative studies also identified the role of broader perceptions surrounding the nature and the quality of services available. The absence of good quality of care was endorsed as a barrier among 12-19% of participants in several samples [41, 49], and more specifically, poor communication between professionals providing services [41] and a lack of communication between service providers and families [72] were endorsed as barriers by almost half of two samples. However, quality of care and communication between service providers were far less frequently reported as barriers in two other samples of non-service users [41, 59]. Qualitative studies identified as barriers both a general dissatisfaction with services (e.g. ‘didn't give us anything that was terribly helpful’ [44] pp.137), and frustration with being passed from one service to another [45]. The service provider environment was also reported in qualitative studies to either encourage or discourage families from attending services, with the ‘clinic environment’ cited as a barrier by participants in one study [71], and the need to attend specialist services outside a primary care setting cited as a barrier in another study (‘I don’t trust just leaping into another physician or leaping into another office that we have no history with’ [73] pp. 417). Similarly, a ‘comfortable’ physical environment and seeking help in a ‘welcoming environment’ were identified as facilitators in two qualitative studies [46, 71].

Language/cultural factors

Another negative perception of service providers reported as a barrier among a few samples was a perceived language or cultural barrier. More than a quarter of a sample of Chinese parents living in the UK cited a language barrier as deterrent to help seeking [39], and 13% of a predominantly Hispanic sample in the USA [64]. Similarly, over 30% of Murry et al's [46] sample rated white professionals as not understanding the problems of African Americans. Qualitative studies of minority populations reported parallel findings, with Spanish speakers in the USA citing language as a barrier both in relation to communicating with professionals and to understanding the mental health system [61]; and immigrants in Portugal [54] and Pakistani parents in the UK [71] also referred to language difficulties as a barrier. Additionally, Stein et al [71] noted that parents also referred to 'language facility' and an awareness of 'religious knowledge and appreciation' among staff as a potential facilitators.

Role of schools/teachers

As well as views relating to health care professionals and services, specific views and attitudes towards teachers and the role of schools also emerged from qualitative studies as posing potential barriers and facilitators in the help seeking process. A perception that teachers lack expertise and training in mental health was reported as a barrier in three (13%) qualitative studies [58, 61, 68], but on the other hand, the role teachers can play in identifying difficulties [46, 58, 69] providing mental health information [61] and helping to facilitate subsequent help seeking [54] were also reported.

Previous experience

The role prior experience with service providers can play in shaping these pertinent attitudes and views was evident across findings that highlighted the importance of these attitudes. Several quantitative and qualitative studies also specifically identified 'previous experience' as either a barrier or facilitator to future help seeking. Negative experiences associated with previous attempts to seek help or previous service use were rated as a barriers by 11-18% of participants in three samples [41, 53, 59], and fewer than 10% in a further two samples [26, 41]. Similarly, previous negative experience was identified as a reason for giving up seeking help [45] and shaping future expectations and help seeking behaviour [58]; but equally a positive help seeking experience among another family member was cited as a reason for subsequent help seeking for a child in another qualitative study [74].

Supportiveness/dismissiveness of professionals

The attitudinal barrier reported by parents in the largest number of studies was the feeling of not being listened to or dismissed by professionals. Interestingly, only a relatively small number of quantitative studies asked participants to rate not being listen to by professionals as a barrier, however, when posed with this exact question, more than half of a sample of UK service users rated it as a barrier [41], whereas very few non-service users in the same study rated it in this way [41]. Similarly, Hickson et al [70] reported that 10% and 16% of participants respectively reported doctor ‘unwillingness’ and appearing ‘too busy’ as reasons for not sharing a psychosocial concern with a paediatrician. However, a stronger sense of parents feeling dismissed emerged among 10 (42%) qualitative studies [42, 45, 46, 60, 61, 66, 67, 69, 73, 75] (e.g. ‘I’m trying to tell them now that children don’t normally bite themselves and pull their own hair out. My daughter’s doing this and no one will listen’ [67] pp. 24; ‘You see no one understands, no one believes you. It's like smashing your head against a brick wall’ [66] pp. 200). Boydell et al [60] reported parents feeling their expertise as caregivers was ‘ignored and undervalued’, and Sayal et al [45] similarly reported that parents felt GPs and health visitors did not take them seriously (e.g. ‘I’ve spoken to him on about five occasions. It’s always been brushed under the carpet.’[45] pp. 480). Studies also referred to parents’ frustration when doctors attributed their child’s behaviour to a ‘phase’ [46] or suggested behaviours were normal and age-appropriate behaviours [73]. However, in contrast, a quarter of qualitative studies [45, 46, 55, 58, 61, 75] reported that perceiving that health professionals are understanding and empathetic, and that they listen to voiced concerns encouraged parental help seeking. For example, a parent in one study reported a positive experience when ‘They [mental health professional] are interested in what’s going on, you know, and ask questions of the child or the parent. And, suggesting things and wait for a response from either one of them’ [58] (pp. 115). Cohen et al [61] also emphasised the importance of primary care physicians ‘validating’ parent concerns, and Sayal et al [45] similarly described that parents reported cases where GPs sympathised and gave families time as positively impacting help seeking.

Professionals blaming parents

Three (13%) qualitative studies also reported that parents felt ‘blamed’ by professionals, particularly when parents shared concerns about their child, professionals focused on their parenting or the parent’s own mental health. For example, Klasen et al [66] reported that parents described situations where GPs attempted to reassure them or give parenting advice, and that they felt criticised by this and were discouraged from seeking help in the future. Similarly, a parent in Sayal et al’s [45] study reported being described as an ‘over-anxious parent’ by her GP, and this caused her to avoid returning to the GP again.

Relevance/effectiveness of treatment

As well as perceptions and views surrounding available services and associated professionals, beliefs related to the consequences of seeking and receiving psychological treatment were also identified across many studies as posing barriers and facilitators to help seeking. Parental beliefs surrounding the relevance and usefulness of treatment were addressed in a number of quantitative studies, including a perception that no-one could help with their child’s difficulty, an assumption that their child’s problem would improve without treatment and that treatment would not be beneficial. Almost 80% of participants who identified at least one barrier to help seeking in Pavuluri's et al [53] study, endorsed the barrier that the 'problem would get better by itself', and approximately one third of the same sample reported 'no-one could help' and 'seeking help was not appropriate because of the child's age' as barriers. Almost half of Sayal et al's [41] sample of service users rated the 'perception no-one could help with their child's problem' as a barrier, although fewer (16%) of the non-service users reported the same barrier [41]. Similarly, concerns that treatment may not help and doubts about the usefulness of treatment were reported as barriers by 10-25% in three further studies [40, 59, 62]. A related belief that a child's problem would get better without treatment was rated as a barrier to seeking help by 36% of a community sample with a child with ADHD [47], and was rated as a barrier to following through with a referral by 30% in school-based suicide screening study [76]. Other quantitative studies also reported that beliefs that treatment was not relevant or could not help were rated as barriers, but only by a small number of participants [23, 26, 38, 50, 51, 77]. The role of views surrounding the relevance and usefulness of treatment was also highlighted in the findings of several qualitative studies. Stein et al [71] reported that some parents believed treatment would not help or could be detrimental, and another study reported parents' specific concerns surrounding possible negative consequences of behavioural therapy, including creating conflict between a parent and child [43]. On the other hand, Lindsey et al's [58] findings highlighted that positive expectations surrounding treatment encouraged parents to seek help (e.g. 'if it's gonna be positive, if it's gonna work, I wouldn't have a problem with sending my child to [a therapist] to get the help' [58] pp. 112).

Negative consequences for a child

Related to views surrounding the effectiveness of treatment, was the belief that receiving treatment may have negative consequences for a child – and in several quantitative studies such a belief was reported as a deterrent to seeking help. In particular, concern that a child would be labelled and it would be left on their record was rated as a barrier by more than 20% of parents in both a USA and a UK sample of service users [41, 51], but by fewer participants in two non-service user samples [37, 41]. However, with the exception of one USA study where 34% of the sample identified a fear that the child would be taken away as barrier [48], fewer than 5% rated the same concern as a barrier in other quantitative studies [41, 53, 59]. Qualitative studies provided further evidence that fears surrounding possible stigmatisation for a child deters some parents from seeking help, with repeated reference to possible impact on a child's future, (e.g. 'many application forms ask if your child has ever received counseling' [43] pp. 98; 'You're labelled so therefore you stunt your own life, you can't get some jobs...' [74] pp. 8) Sayal et al [45] also highlighted that fear of a diagnosis was also reported by parents to stop them from seeking help, and equally a fear their child would be taken away was a barrier for others, while concern a child would be 'institutionalised' was reported in another sample [73]. Nevertheless, in two qualitative studies [45, 66], the potential positive impact of receiving a diagnosis was also identified, both in relation to helping a child to receive appropriate outside support and in motivating a parent to follow expert recommendations.

Fears surrounding the nature of treatment

As well as perceived negative consequences of receiving treatment, fears surrounding the treatment itself were also reported as barriers in a few studies. More than one third of those participants who reported a barrier to help seeking in Pavuluri et al's [53] sample endorsed 'afraid what treatment would be offered' as a barrier, and another quantitative study reported that 13% of participants endorsed a fear that seeking treatment would result in a child receiving medication [38]. A similar fear of ‘medicating’ a child was reported to deter some parents from seeking any help in a qualitative study [73].

Social and personal stigma

The most commonly reported barrier related to concerns surrounding the consequences of help seeking, was the barrier posed by the perceived negative attitudes among other people. The ‘stigma’ associated with mental health problems and attending mental health services, and worries about what other people would think were reported as barriers by participants in quantitative studies across various countries and cultures, including, among others, half of a USA sample [46a], more than a quarter of a United Arab Emirates sample [40], and 22% of a UK sample [41]. Nevertheless, it is notable that in a quarter of quantitative samples, concern about what others would think and other people’s attitude were rated as barriers by less than 7% of participants [26, 38, 41, 51, 53, 59]. Findings from qualitative studies elaborate on some of the specific concerns parents have about the perceptions of friends/family or others in the community and the impact of ‘courtesy stigma’ or stigma by association. Such concerns include a fear of being judged as a bad parent (e.g. ‘that they would say the problem starts with the parents’[75] pp. 508), fear of gossip (‘The fear of what people will say….if you tell one friend, she will just tell a couple more’ [63] pp. 2417) and feeling embarrassed or ashamed [45]. Indeed, as well as reported ‘social stigma’ or ‘courtesy stigma’ (i.e. concern about other people’s views of parents of children with mental health problems) several studies also identified more ‘personal stigma’ or negative self-evaluation as a barrier, and parents’ discomfort surrounding talking to others about their child’s mental health problems. Among quantitative studies that addressed parental discomfort surrounding discussing a child’s mental health problems, it tended to be only a small minority of participants who endorsed this as a barrier [37, 53, 70, 77], though 12% of participants who reported a barrier in Pavuluri et al's [53] study rated 'hating answering personal questions' as a barrier. Two qualitative studies also referred specifically to the view that talking to others about mental health problems was 'culturally inappropriate' and therefore prevented parents from seeking help [45, 71].

Solving problems within the family and advice from family/friends

Closely related to reports of social and personal stigma, were references to a desire to solve problems within the family, rather than seek outside help. Wanting to solve the problem alone or within the family was rated as a barrier by 17-42% across three quantitative studies [26, 48, 76]; and similarly feeling able/strong enough to manage the problem alone was rated as a barrier by more than half of those who reported barriers in Pavuluri et al's [53] study and by 20% in Sawyer et al's [52] study. Qualitative studies of ethnic minority groups in the UK again reported a similar view that mental health problems should be 'kept in the family' [63, 71]. Linked to both a reported desire to solve problems within the family, and concerns surrounding other people's views, was the reported role of recommendations and advice from family and friends – to either seek help, or to not seek help. Two (8%) quantitative studies reported that family not recommending or supporting help seeking was a barrier for 10-15% of participants [26, 38]; but conversely over half of participants in Harwood et al's [37] study reported 'someone telling them they needed help' as a facilitator. Similarly, both Lindsey et al [58] and Brown et al [73] reported that family members criticising parents for asking for help and recommending that they do not seek help presented barriers for some parents, but equally family members giving parents a 'push' to seek help was reported as a facilitator in another qualitative study [44].

Knowledge and understanding of mental health problems and the help seeking process

Figure 5 illustrates the barriers and facilitators reported across studies relating to awareness and understanding of both child mental health problems and the process of seeking professional help for these problems.

Parent recognition of the problem, and its impact and severity

Parental understanding (or lack of understanding) of their child's mental health problem was not typically included in quantitative studies; however, among studies that did include items relating to a lack of parent recognition of a child's mental health problem, relatively large numbers of participants did endorse this as a barrier. More than half of one sample reported that thinking their child did not have a problem was a barrier [76], 38% in another study endorsed 'reluctance' to recognise the problem as a barrier [40], and more than a quarter in another sample reported thinking their child's behaviour was appropriate for their age deterred help seeking [38]. Parental reluctance to acknowledge or 'denial' that a mental health problem exists was similarly reported in several qualitative studies as a perceived barrier [58, 73, 75]; and the 'invisible' nature of mental health problems making them difficult to detect was highlighted in another qualitative study [60]. Equally, parental recognition that a child's behaviour was not 'normal' was also reported as important in facilitating help seeking [44], but interestingly parental recognition in terms of a 'deficit' rather than 'madness' was also reported as important in one qualitative study [63]. As well as recognising that a mental health problem exists, recognising the impact of a mental health problem was also reported to facilitate help seeking in one qualitative [44] and another quantitative study [38]. Boulter and Rickwood [44] reported that recognising the impact on the family was a motivator to seek help, and almost 80% of participants in Larson et al's [38] sample reported that recognising the interference in school, friendships and family life, and an effect on a child's future and stress in their own life all facilitated help seeking. Similarly, a view that a child's problem was not severe enough for treatment was rated as a barrier by participants in a number of quantitative studies, ranging from as many as 52% of participants [76], to less than 10% [72, 77]. Moreover, more than 80% in another sample reported that viewing a problem as 'out of control' was a facilitator to help seeking [37].

Parent recognition of the need for professional help

Similarly, between 12 and 26% of parents reported not wanting or not needing help as a barrier across a quarter of quantitative samples [38, 49, 50, 70, 76]. Messent and Murrell [78] reported that a small number of parents were reluctant to acknowledge children had difficulties that needed outside help; and parents disagreeing with a referral was cited as a barrier in another qualitative study [75]. Conversely, being ready to receive help [75], being open to the prospect of getting help [74], recognising the importance of getting help [58], and recognising they are not able to manage a problem alone [44, 74], were all cited as facilitating parental help seeking in qualitative studies.

Family recognition and child recognition/willingness

In addition to parental recognition, (a lack of) family recognition along with absence of recognition by the child themselves, were also reported as barriers in several studies. Family members denying or 'normalising' the mental health problem was reported as a deterrent to help seeking in two qualitative studies [44, 73]. The child's lack of recognition of their own problem was only addressed in one quantitative study, but reported as barrier by almost 30% of participants [76]. Two qualitative studies highlighted a child's reluctance to talk openly about their difficulties as hindering parent recognition [58, 69]; but equally a 'trustful bond' between an adolescent and mother was reported as encouraging a young person to talk to a parent who could in turn seek help [69]. A child not wanting to attend a mental health clinic was included as possible response in several questionnaire studies, and reported as a barrier by between 10 and 22% of participants [26, 38, 51, 62]. Similarly, a child's 'resistance' to attend services or talk to professionals was reported as a barrier in two qualitative studies [54, 61], and the role of adolescents' own responsibility in initiating help seeking was reported in another [45].

Knowledge and understanding of help seeking

In comparison to knowledge and understanding of the mental health problem itself, barriers related to a lack of knowledge surrounding where and how to seek help were more frequently reported across quantitative and qualitative studies. Among 10 (42%) samples, at least 14% of participants reported a lack of knowledge about where or how to get help as a barrier, and as many as 75% of one sample endorsed this barrier [41], and more than 30% in a further four samples [41, 47, 53, 70]. This lack of knowledge about where to go to ask for help and how to go about getting help was corroborated in a number of qualitative studies [45, 56, 60, 78]. Qualitative studies also highlighted that a lack of understanding surrounding what to expect from services and treatment [58, 73], and a limited awareness of how the 'mental health system' works [69]; as well as doubts surrounding whether GPs are the appropriate person to ask for help [45], all acted as barriers to parental help seeking. Moreover, a number of qualitative studies also identified the potential benefit of providing parents with information about where to seek help and the referral process in order to facilitate help seeking [46, 55, 61, 63, 71].

Family circumstances

As displayed in Fig. 6, other barriers/facilitators reported in studies related to additional specific aspects of family circumstances, including other responsibilities and commitments, and the family's support network. A 'lack of time' was rated as a barrier by almost a third of the sample in one quantitative study [62], and 18% in another [53]; and similarly other responsibilities and being 'busy' were endorsed as barriers by 18-24% in a further three samples [49, 72]; although similar barriers were endorsed by fewer than 8% in another quantitative study [38]. Barriers related to child care were also reported by a small minority in two quantitative studies [37, 38]. Two further quantitative studies reported that a minority of parents reported barriers relating to work commitments, other family responsibilities and stressors, and the time involved in treatment [23, 50]. Other priorities and responsibilities, and the time commitment involved, were similarly cited as barriers to help seeking in several qualitative studies [49, 58, 75] (e.g. 'Maybe she's focusing on keeping a roof over her head than she actually is on the mental health of the child' [58], pp.115). Parents in one qualitative study also reported not getting services because they 'did not push hard enough' [60], highlighting the effort involved in accessing help – and similarly being 'demanding' was reported to facilitate accessing help [60]. Qualitative studies also pointed towards the role of a family's extended support network in both helping and hindering help seeking. While Lindsey et al [58] and Flink et al [69] reported that some parents relied on support from other church members and church leaders, in place of seeking professional help, feeling 'socially isolated' was cited as a barrier to help seeking in another study [57] and receiving informal social support helped some parents 'overcome barriers' [75] and learn about available services by 'word of mouth' [60].

Chapter 3: Paper 2

Barriers and facilitators to parents seeking and accessing professional support for anxiety disorders in children: qualitative interview study

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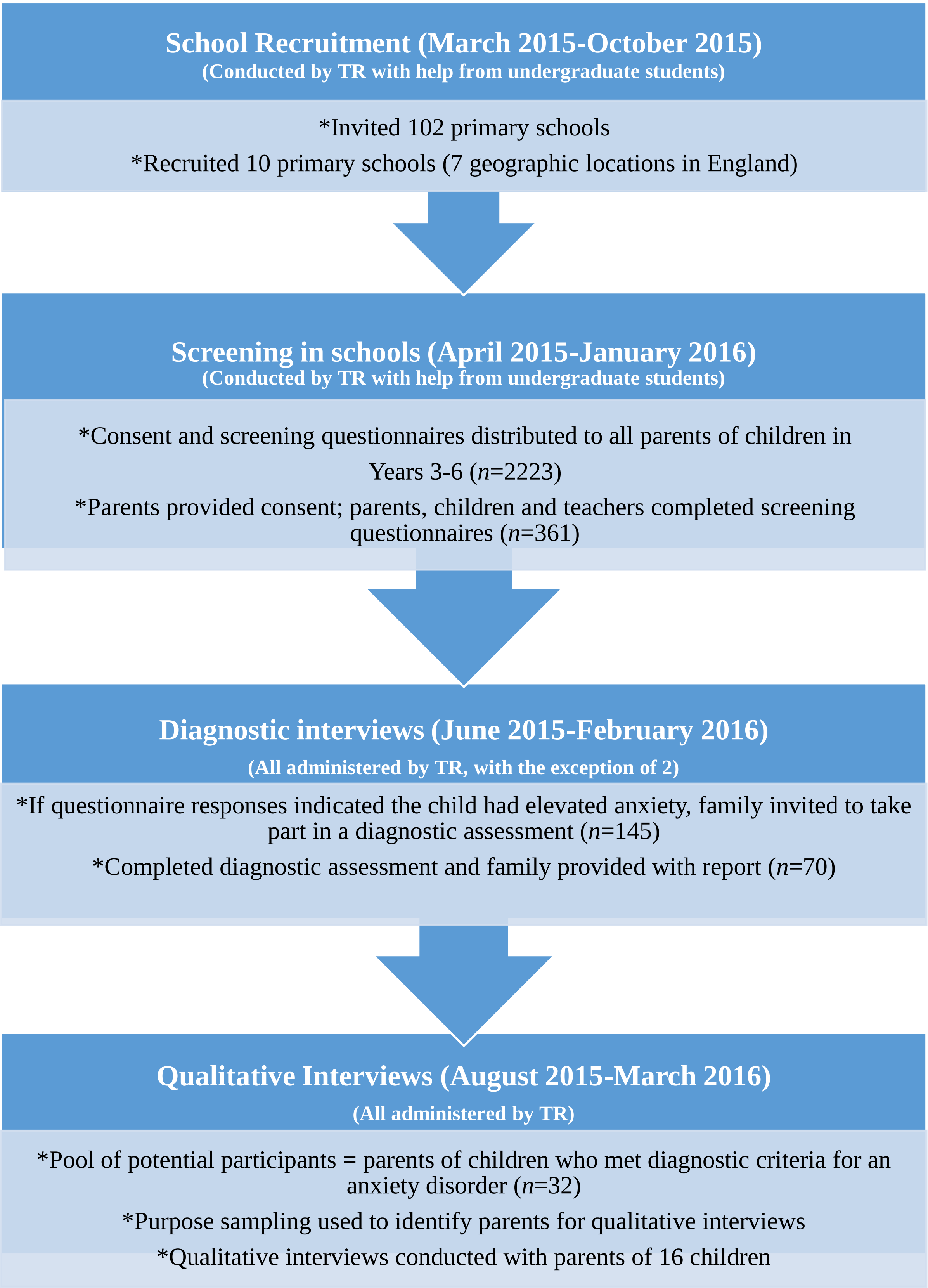
[*] Minor amendments have been made to the paper for the purpose of this thesis

3.1 Introduction to Paper 2

Paper 1 identified several key limitations associated existing studies that report parental barriers to seeking and accessing professional support for mental health problems in children and adolescents, including i) a focus on service user populations, and ii) a lack of studies examining parent experiences of seeking and accessing treatment in the context of child anxiety disorders. Paper 2 aimed to address these gaps in the current literature and to explore help-seeking among parents of pre-adolescent children with an anxiety disorder identified in the community. An inductive qualitative approach was used to provide detailed insight into the barriers and facilitators experienced by these families. Findings from Paper 1 were used to the develop an interview topic guide, and topic-guided qualitative interviews were conducted with parents of 16 children (aged 7-11) with an anxiety disorder identified through screening in primary schools. The study was approved by the University of Reading Research Ethics Committee (UREC) in March 2015. Full details of the study aims and study design are provided in Paper 2, and summary of the recruitment procedure is provided below in Figure 1.

Figure 1 Recruitment procedure for qualitative study reported in Paper 2



School Recruitment (March 2015-October 2015)
(Conducted by TR with help from undergraduate students)

*Invited 102 primary schools

*Recruited 10 primary schools (7 geographic locations in England)

Screening in schools (April 2015-January 2016)
(Conducted by TR with help from undergraduate students)

*Consent and screening questionnaires distributed to all parents of children in Years 3-6 (*n*=2223)

*Parents provided consent; parents, children and teachers completed screening questionnaires (*n*=361)

Diagnostic interviews (June 2015-February 2016)
(All administered by TR, with the exception of 2)

*If questionnaire responses indicated the child had elevated anxiety, family invited to take part in a diagnostic assessment (*n*=145)

*Completed diagnostic assessment and family provided with report (*n*=70)

Qualitative Interviews (August 2015-March 2016)
(All administered by TR)

*Pool of potential participants = parents of children who met diagnostic criteria for an anxiety disorder (*n*=32)

*Purpose sampling used to identify parents for qualitative interviews

*Qualitative interviews conducted with parents of 16 children

3.2 Paper 2: Barriers and facilitators to parents seeking and accessing professional support for anxiety disorders in children: qualitative interview study

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Abstract

Background

Anxiety disorders are among the most common mental health disorders experienced by children, but only a minority of these children access professional help. Understanding the difficulties parents face seeking support for child anxiety disorders could inform targeted interventions to improve treatment access.

Aims

To identify barriers and facilitators to seeking and accessing professional support for child anxiety disorders, and ways to minimise these barriers.

Methods

A qualitative interview study with parents of 16 children (aged 7-11 years) with anxiety disorders identified through screening in schools.

Results

Barriers and facilitators were identified in relation to four distinct stages in the help-seeking process: parents recognising the anxiety difficulty, parents recognising the need for professional support, parents contacting professionals, and families receiving professional support. Barriers and facilitators at each stage related to the child's difficulties, the role of the parent, and parent perceptions of professionals and services.

Conclusions

Findings illustrate the need i) for readily available tools to help parents and professionals identify clinically significant anxiety in children, ii) to ensure families and professionals can easily access guidance on the help-seeking process and available support, and iii) to ensure existing services offer sufficient provision for less severe difficulties that incorporates direct support for parents.

Key words: help-seeking; barriers; parents; children; anxiety disorders

Introduction

Anxiety disorders are among the most common mental health disorders experienced across the lifespan [1]; and are associated with significant negative outcomes for individuals [2, 3] and economic burden for society [4]. These typically first emerge during childhood, with a median age onset of 11 years [1] and affect approximately 6.5% of children and adolescents [5]. Effective treatments for child anxiety disorders exist (e.g. Cognitive Behaviour Therapy; CBT) [6] with clear evidence for the lasting benefits both in alleviating anxiety [7] [8] and reduced risk of other mental health difficulties [9, 10]. However, rates of access to treatment for childhood mental health difficulties are poor [11, 12] and approximately two-thirds of children with anxiety disorders do not access any professional help [13].

Poor rates of treatment access for childhood mental health problems in the UK have been linked to limited service provision [14]. The extent of service provision, however, is only part of the story and strategies to improve provision must take the broader picture in to account. Children with mental health problems typically depend on a parent or caregiver to seek help on their behalf. Studies focusing on parents' perceptions of seeking professional help for child mental health difficulties highlight a broad range of difficulties families can face seeking professional support, including structural issues associated with mental health services, as well as attitudinal barriers and a lack of knowledge surrounding mental health and the help-seeking process [15]. However, previous studies examining parental help seeking have tended to focus on populations of service users, and therefore the difficulties experienced by those who have not reached services are less well understood. Moreover, little is known about help-seeking for difficulties relating to child anxiety disorders specifically. Given the early onset, high prevalence and low rates of treatment access for anxiety difficulties (compared with, for example, behavioural difficulties [12]) it is important to establish the barriers to treatment faced by these families in particular. Indeed, among adults, anxiety disorders are associated with lower rates of recognition [16] and longer delays in receiving treatment [17] compared to other mental health disorders. This evidence that there are specific barriers to help-seeking for anxiety difficulties later in life raises questions about whether these barriers may also apply to children and young people. An improved understanding of the factors that help or make it harder for families to seek professional help specifically in the context of an anxiety disorder would inform targeted interventions to improve rates of treatment access.

This study aimed to i) identify barriers and facilitators to seeking and accessing support from professionals for anxiety disorders among parents of children with an anxiety disorder identified in the community; and ii) identify ways to overcome and minimise barriers to seeking and accessing professional support. Given the limited understanding of help-seeking for child anxiety problems, an inductive qualitative approach was used to provide a detailed insight into the barriers/facilitators described by these families.

Method

The study was approved by the University of Reading Research Ethics Committee (UREC 15/04), and participants provided informed consent.

Recruitment

The study aimed to recruit a community sample of parents of children with an anxiety disorder with a diverse range of experiences. As there is regional variation in available support for child mental health difficulties, and mental health support provided within schools is also likely to vary, we aimed to include families from a range of geographic locations and schools within England. A two-stage screening process was used. Firstly, during the period March to October 2015, 102 primary/junior schools from different geographic locations in England and with a varied demographic profile were invited to participate. Ten schools were recruited across seven geographic locations (Buckinghamshire, East Sussex, Hampshire, Middlesex, Northumberland, Surrey, Worcestershire), and included nine state schools (2.1% to 57.5% of children on the roll receiving free school meals) and one fee-paying school.

The screening process within recruited schools is detailed in Fig. 1. Within recruited schools, study information and consent/questionnaires were distributed to all parents with a child in years 3-6 (aged 7-11 years). Parents were asked to complete a questionnaire to assess their child’s anxiety symptoms (SCAS-P), and one or two researchers attended the school to administer corresponding questionnaires (SCAS-C and SCAS-T) with the children and class teachers of those children whose parent provided consent. In cases where the child scored above the designated cut-off[1] on either the SCAS-P, the SCAS-C, or the SCAS-T, the family was invited to take part in a follow-up diagnostic assessment (ADIS-IV-C/P). Following the diagnostic assessment, parents were sent a report summarising the assessment findings, which where applicable described the particular difficulties with anxiety that the child was experiencing. Parents of the children who met the DSM-5 criteria for a current anxiety disorder formed a pool of potential participants for the qualitative interviews. Schools and families were reimbursed for giving their time to participate in the study. Schools were given £5 for each set of complete parent/child/teacher questionnaires, and families were given a £20 gift voucher for taking part in the diagnostic assessment, and a further £20 gift voucher for taking part in the qualitative interview.

[*Insert Fig. 1 about here*]

Measures

Spence Children's Anxiety Scale – Child (SCAS-C/P)

The SCAS-C/P are child and parent report questionnaires and comprise 38 items addressing symptoms of DSM anxiety disorders (and 6 filler items in the child report version). Items are rated on a four-point scale (never=0; sometimes=1; often=2; always=3), and total scores reflect the sum of responses to the 38 anxiety items. The SCAS-C/P are widely used measures of child anxiety symptoms, with good evidence in support of their reliability and validity [18–21], and excellent internal consistency in the current sample (SCAS-C $\alpha = 0.95$; SCAS-P $\alpha = 0.91$).

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[1] Published cut-scores on the SCAS-C indicating 'elevated' anxiety symptoms (for girls and boys aged 8-11 years) were used (available on www.scaswebsite.com). Published cut-scores are not available for the SCAS-P or SCAS-T, therefore the following were used as cut-scores: SCAS-P mean total score+ 1 s.d in a normal sample as published on www.scaswebsite.com; SCAS-T mean total score+ 1 s.d in the current study.

Adapted Spence Children's Anxiety Scale – Teacher (SCAS-T)

The research team developed a teacher-report version of the SCAS-C/P. Eight items that appear on the SCAS-C/P were considered inappropriate for teachers (e.g. 'I would feel afraid of being at home on my own') and omitted. The wording of the remaining items was amended to reflect the reporter (e.g. 'I worry about things' was changed to 'Worries about things'). The SCAS-T comprised 30 items, with the same four-point response scale as the SCAS-C/P, and total scores reflect the sum of responses to all items. Internal consistency for the SCAS-T in the current sample was excellent ($\alpha = 0.90$).

Anxiety Disorders Interview Schedule-IV-Parent and Child Interview (ADIS-C/P)

The ADIS-C/P consists of structured parent and child interview schedules consistent with DSM-IV anxiety diagnoses and common comorbid diagnoses, and has strong psychometric properties [22]. Minor amendments were made to the interview schedules to enable diagnoses consistent with DSM5 diagnostic criteria. The child and parent interviews were administered independently, with diagnoses and Clinical Severity Ratings (CSRs) assigned independently for each interview. CSRs provide a measure of impairment, ranging from 0 (no impairment) to 8 (debilitating). As per the guidelines, a child met diagnostic criteria where the required symptoms were reported and a CSR from 4 to 8 was assigned. In cases where there were discrepancies between the child and parent report, the higher CSR was assigned as the overall CSR. Comorbid behavioural disorders were only assessed in the parent interview. With the exception of two interviews, all assessments were administered by one assessor (TR), and for the first 20 assessments, interviews were discussed with an experienced clinician (CC) and a consensus reached. Assessor reliability was checked at this stage (with a minimum kappa/ICC of 0.85 required), and subsequently one in six interviews were discussed and consensus reached. Overall inter-rater reliability within the assessment team was excellent (child report diagnoses, kappa = 0.95; CSR ICC = 0.97; parent report diagnoses, kappa = 0.98, CSR ICC = 0.96).

Participants

We used purposive sampling to ensure that those families invited to be interviewed (from the pool of 32 eligible families) varied in their experiences surrounding seeking help for their child. Invited families varied on the following characteristics, judged by the researchers to be relevant to their help-seeking experiences: i) child age and gender; ii) type and severity of child anxiety disorders, iii) prior help-seeking for the child's anxiety difficulties, iv) socio-economic status, and v) geographic location.

Parents of 20 children were identified. Interviews were conducted with 16 of them; at which point analyses indicated that theoretical saturation [23] had been reached, as new data ceased contributing to the development and refinement of new codes and concepts. Participant characteristics are provided in Table 1. Interviews were conducted with parents of 11 girls and five boys, aged 7 to 11 years (median age 8.9 years). Interviewees were typically mothers (14 families) but in two cases the father was also interviewed. The sample spanned socio-economic status; with nine families categorised as higher/professional and three received free school meals for their children. The sample was predominantly White British (*n* = 13), and three children were from other White backgrounds. Children had between one and three anxiety disorder diagnoses, including separation anxiety disorder (*n* = 3), social anxiety disorder (*n* = 5), generalised anxiety disorder (*n* = 10) and specific phobias (*n* = 7), with clinical severity ratings (CSRs) for primary disorders ranging from 4 to 6. Children had a non-anxiety comorbid disorder in one quarter of cases (depression, *n* = 1; attention deficit hyperactivity disorder, *n* = 2; oppositional defiant disorder, *n* = 1). There was variation in prior help-seeking reported across cases (sought help/advice from a professional, *n* = 9; not sought help/advice from a professional, *n* = 7).

[Insert Table 1 about here]

Procedure

Semi-structured topic-guided interviews were conducted with parents, with four interviews conducted face-to-face and 12 on the telephone. Interviews were conducted by a doctoral researcher (TR) and lasted from 33 to 79 minutes. Interviews were audio-recorded and explored parents' views and experiences of recognition and help-seeking for their children's anxiety difficulties. The topic guide explored parents' i) knowledge and beliefs surrounding child anxiety; ii) recognition of their child's anxiety difficulties; iii) knowledge and beliefs surrounding help-seeking; iv) beliefs and experiences of services; and v) suggestions for improvements to the help-seeking process; but it was used flexibly, allowing for variation in the order and wording of questions and ensuring participants had the opportunity to discuss issues that departed from the prepared areas of questioning. Interviews were transcribed verbatim, with all information that could identify participants removed, and participants' names replaced with pseudonyms.

Coding and analysis

Analysis of the transcribed interviews was guided by the six phases of a thematic analysis described by Braun and Clark [24]. The analysis was inductive in that codes and themes were data-driven, rather than according to a pre-existing theoretical framework and focussed on the specific research questions of the study, rather than attempting to encompass the entire content of the dataset. Codes were generated through an iterative process whereby as each new transcript was coded, earlier transcripts were revisited and codes were constantly reviewed and refined. Codes were gradually organised into candidate themes and sub-themes, paying particular attention to linkages and distinctions between key ideas and concepts, and commonalities and discrepancies within and across transcripts. The analysis was led by one researcher (TR) who met regularly with other research team members to discuss codes and candidate themes, and alternative interpretations of the data. Following team discussions, candidate themes and sub-themes were reviewed and refined to ensure the thematic structure provided a coherent and credible interpretation of the data that did not only reflect a single researcher's perspective.

Results

The findings are described in relation to the four main themes identified which correspond to key stages in the help-seeking process: i) parent recognises anxiety difficulty; ii) parent recognises the need for professional support; iii) parent contacts professionals for help or advice; and iv) family receives professional support to help manage and overcome a child's difficulties with anxiety. As illustrated in Fig. 2, a number of factors were identified that helped or hindered families at each stage, and influenced whether a family successfully progresses towards receiving treatment. Barriers and facilitators identified at each stage in the help-seeking process related to i) the child's difficulties, ii) the parent, and iii) parent perceptions of professionals and services; and parents also suggested ways to overcome barriers associated with each stage. Findings are described in detail (including direct quotations from the interviews) in Online Resource 1, and a summary is provided below.

[Insert Fig 2 about here]

1. Parent recognises anxiety difficulty

Parents faced difficulties in both identifying their child symptoms or behaviour as 'anxiety', and determining whether or not these symptoms or behaviour were a 'difficulty'. Parents more readily attributed some symptoms (e.g. clingy or nervous behaviour) to anxiety, than other symptoms (e.g. temper tantrums or anger outbursts); and found it easier to identify sudden or marked changes in a child's behaviour as problematic, compared to more gradual or fluctuating changes in behaviour. A perception that anxiety is a personality trait or a common childhood experience also deterred parents from considering their child’s anxiety as a problem.

Parents were clear that it was their responsibility to make judgements about the extent or severity of a child’s anxiety, but some lacked confidence in their ability to do this. They reported drawing on their own and others’ experience when forming judgements about whether their child’s anxiety was ‘normal’ or not; and this helped some identify their child’s anxiety difficulties, but deterred recognition for others. Interestingly, while parental anxiety helped some parents recognise similar difficulties in their child, others parents were concerned about being an oversensitive or overprotective parent and this hindered recognition. As well as parents having a key role in identifying a child’s anxiety difficulties, the parents also described the important role that professionals can also play either in validating (or failing to validate) parental concerns, or in raising (or failing to raise) concerns with parents.

2. Parent recognises the need for professional support

Perceptions surrounding the negative impact associated with a child’s anxiety prompted (or deterred) parents to recognise the need for professional support. The importance parents attached to their own role as the primary source of support for their child was evident, and parents varied in confidence in their ability to manage their child’s anxiety. Knowing that the support they could provide their child may be insufficient prompted some parents to recognise that additional input from a professional may be needed.

Some parents contemplated the possibility of help-seeking for some time before actually seeking help. The general busyness of life lengthened or hindered this process of contemplation, while for others, changes in circumstances or the nature of a child's difficulties elevated help-seeking from a possibility to a priority. Equally, similar to the role for professionals in helping parents identify a child's anxiety difficulties, some parents also identified a role for professionals in helping parents determine whether further support from professionals to address a child's anxiety was required or not.

Parents' views surrounding i) the potential benefit and appropriateness of anxiety treatment; ii) their child's willingness or reluctance to seek help; and iii) sharing concerns with others also each influenced their willingness to seek professional help for their child. Importantly, parent perceptions surrounding the stigma associated with anxiety and mental health were important determinants of their openness (or reluctance) to share concerns about their child, both informally and with professionals. Parents were concerned that other people would blame their parenting for their child's difficulties, and they were also concerned about the negative consequences for their child, if they talked to other people about their child's difficulties.

3. Parent contacts professionals

Parents reported lacking knowledge of how to seek help for their child, and were uncertain about who to contact for help and advice. Similar to earlier recognition stages, parents drew on their own and others' experiences to determine where and how to seek help. Parents varied in their views of whether GPs or teachers were the most appropriate point of initial contact, illustrating a key role for both. Parents also described anticipating how GPs and teachers would respond, and parents' perceptions of the anticipated response, and the family's relationship with these professionals, influenced their decision to contact (or not contact) a professional for help or advice. In particular, anticipating that professionals may dismiss their concerns or blame them as a parent deterred some parents from seeking help. Interestingly, some parents described a lack of available services and long waiting times for child mental health difficulties and commented that this had deterred them from making initial contact with a professional.

4. Family receives professional support

Parents who had sought help from professionals described difficulties meeting strict service criteria, and limited or lacking service provision as barriers to accessing support to help overcome their child's anxiety difficulties. Among families who had sought help, the key role that both parents and professionals could play in determining whether a family receives support or not was also apparent. In particular, parents described the importance of knowing how to communicate with professionals, and the need to make repeated contact with professionals and not give up; as well as the importance of the response from individual professionals.

Discussion

Barriers and facilitators associated with four distinct stages in the help-seeking process were identified from interviews with parents of 16 children with anxiety disorders. This study illustrates how challenging it can be for parents to identify and make judgements about the extent or severity or a child's anxiety. Notably, several recognition barriers were anxiety-specific, including the perception that anxiety is a personality trait or common childhood experience, and the role of parents' own experience (or lack of experience) of anxiety. Indeed, complexities surrounding the role of parental anxiety indicated here help account for discrepant findings across studies examining child mental health service use, with evidence indicating both the potential positive [25] and negative [26] impact of parental anxiety on child service use.

Recognition of the need for help is a key determinant of help-seeking for mental health difficulties in adults [27], and findings reported here illustrate the range of factors that influence whether or not a parent recognises and prioritises the need for professional help for their child's anxiety difficulties. We found that parents' views surrounding treatment and the stigma associated with anxiety difficulties can contribute to parental reluctance to seek help. This echoes findings across the broader literature surrounding mental health difficulties in children [15], and illustrations of the impact of stigma on parenting [30] and help seeking among adults with mental health difficulties [31]. Similarly, in relation to the subsequent stage of contact with professionals, the barrier posed by a lack of available information surrounding the help-seeking process, and the importance of the anticipated response from professionals are also reported elsewhere [15]. Importantly, structural barriers associated with services, including a lack of available services and high demands on services, appeared most influential following initial contact with professionals, and influenced whether a family accessed professional support or not.

Implications

This study identifies areas for intervention and ways to overcome key barriers to seeking and accessing professional support for child anxiety disorders (see Fig. 2). In relation to improving recognition of child anxiety disorders, findings highlight the importance of raising awareness about the presentation of anxiety difficulties in children. In particular, parents' experiences identify a need for readily available tools to help families, teachers and GPs to make judgements about when a child experiencing anxiety may benefit from professional support, and to differentiate between developmentally appropriate fears and worries, and clinically significant levels of anxiety. Indeed, GPs have similarly identified a lack of available tools to help identify anxiety difficulties in children [28]; and although questionnaire measures designed to identify anxiety symptoms in children exist (e.g. the SCAS), these tools are long and time consuming to complete, often making them impractical for use in school or primary care settings [29]. Furthermore, as reported elsewhere [15], the need to raise awareness of and ensure families can access guidance on the help-seeking process is also apparent. The findings indicate the particular need for efforts to reduce the stigma associated with child mental health difficulties and negative attitudes towards parents whose children experience difficulties. It is important that guidance is readily available to families, and professionals working with families (e.g. GPs and teachers) to ensure that they are aware of and understand: i) the professional points of contact and support available; ii) the benefits of professional support and early intervention for anxiety difficulties; iii) tools and strategies available to help support a child experiencing difficulties with anxiety. Efforts to promote public awareness of appropriately endorsed online resources could help to ensure improved access to such information and guidance. Indeed, evidence of the need for greater awareness of and access to guidance for professionals is consistent with findings that GPs themselves feel ill-equipped to manage child anxiety disorders [28].

Additionally, findings surrounding parents' experiences also highlight the importance of ensuring available services for child anxiety disorders include i) sufficient provision that incorporates early intervention for less severe difficulties; ii) direct support for parents to enable them to help their child manage and overcome their difficulties with anxiety; and iii) training and guidance for professionals (e.g. GPs and teachers) to equip them with the skills to communicate effectively with families. Indeed, these findings have clear implications for access to child and adolescent mental health services more broadly, and indicate important areas to target to improve access to these wider services.

Strengths and limitations

By identifying children in the community with anxiety disorders, this study explored the views and experiences of families who varied in their prior help-seeking, including those who had not sought or accessed professional help. This is a notable departure from much of the existing work examining help-seeking for child mental health difficulties in which families tend to be recruited through specialist support services, and comprise solely those who have successfully accessed professional help. The purposive sampling approach ensured that the sample had a varied socio-economic profile and included families from different schools and geographic regions in England. Moreover, parents' experiences surrounding seeking professional support is likely to change as a child gets older, and by focusing specifically on anxiety disorders among pre-adolescent children our findings provide insight into help-seeking among a population for whom parents play a particularly pertinent role. Furthermore, focusing on pre-adolescent children means that findings can be used to inform targeted interventions to improve access to professional support specifically among this population for whom rates of access are particularly poor.

Nevertheless, it is important to note that there was a likely participation bias in the study. Many families invited to take part in the initial screening stage of the study did not participate, and approximately 50% of those invited to take part in follow-up diagnostic assessments did not complete the assessment. Although parents who had concerns about a child’s anxiety were not specifically targeted, it is likely that these families were over represented in our sample. Other barriers (e.g. the parent did not speak English) are likely to have prevented some families from taking part, and the sample was predominantly White British. This means that the views and experiences among underserved families, including families from minority ethnic backgrounds, and parents who had not considered the possibility that their child may be experiencing anxiety, are unlikely to have been fully captured in this study. Similarly, many schools who were invited to take part in the study did not respond, and it is possible that schools with staff who had some awareness or understanding of anxiety difficulties in children were more likely to take part, and therefore the experiences of families from schools where staff have no awareness of child anxiety may not have been captured. Furthermore, the study’s capacity to identify children in the community with anxiety disorders was limited by the tools currently available. Although the SCAS is a widely used measure of anxiety symptoms in children, and three informant versions were used in this study, its capacity to identify children with clinically significant levels of anxiety has not been established. Therefore, the number of parents of children with anxiety disorders who were missed (i.e. the child scored below the cut-off score on the SCAS-P, SCAS-C and SCAS-T) is not known.

It is also important to acknowledge that other aspects of the methodology will also have shaped the data in this study. One researcher (TR) conducted the interviews, and led the analysis, and this researcher also administered screening questionnaires and diagnostic assessments with families in the recruitment phase. TR's knowledge of participating families prior to the qualitative interviews, and participants' awareness of TR's position as the study lead with expertise in anxiety assessments will also have influenced the interview data. During team meetings to discuss codes and emerging themes, the role of TR's prior contact with participants was reflected upon and alternative potential interpretations of the data were carefully considered. The fact that prior to the qualitative interview, families took part in an anxiety assessment for their child, and received a report summarising the difficulties their child was experiencing with anxieties will also have shaped the qualitative interview data. Indeed, as described earlier, for some parents, taking part in the study influenced their views surrounding seeking help for their child and some of the study findings.

This study importantly underlines the range of challenges families face throughout the help-seeking process from child anxiety disorders, and identifies key interventions needed to minimise these challenges and ensure more families seek help and go on to access professional support. Closer examination of the particular barriers to seeking help for childhood anxiety disorder among underserved populations is also necessary.

Tables

Table 1 Characteristics of participants

Child	
n	16
median age (range), years	8.9 (7.7-11.7)
female, *n* (%)	11 (68.8)
Parent[a]	
n	18
median age (range), years	43.5 (25-54)
mother, *n* (%)	16 (88.9)
SES	
Free school meals	
n (% of families)	3 (18.8)
Higher / professional[b]	
n (% of families)	9 (56.3)
Child's ethnicity	
White British	13 (81.3)
Other White background	3 (18.8)
ADIS Primary anxiety diagnosis *n* (%)	
Separation Anxiety Disorder	2 (12.5)
Social Anxiety Disorder	1 (6.3)
Generalised Anxiety Disorder	9 (56.3)
Specific Phobia	4 (25.0)
Primary anxiety diagnosis CSR *n* (%)	
CSR 4	10 (62.5)
CSR 5	4 (25.0)
CSR 6	2 (12.5)
Presence of anxiety and other disorders (based on ADIS) *n* (%)	
Separation Anxiety Disorder	3 (18.8)
Social Anxiety Disorder	5 (31.3)
Generalised Anxiety Disorder	10 (62.5)
Specific Phobia	7 (43.4)
Major Depressive Disorder	1 (6.3)
ADHD	2 (12.5)
ODD	1 (6.3)
Parent reported contact with GP and/or school staff for help or advice related to child's anxiety difficulties	9 (56.3)
Parent reported child had received referral to CAMHS (for anxiety or other difficulties)	6 (37.5)

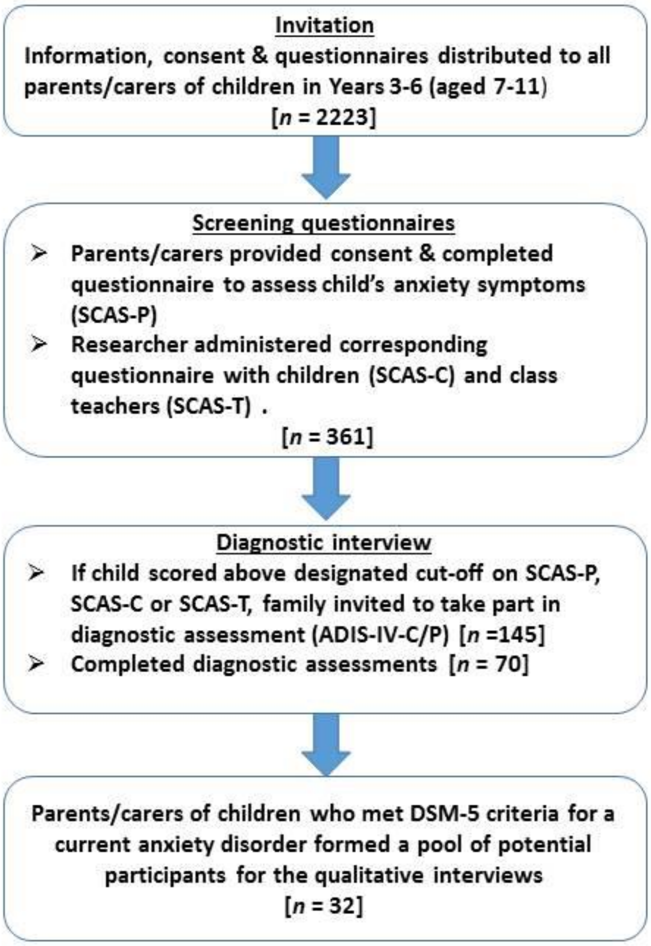
[a] Two interviews were conducted with child's two parents

[b] Higher / professional = managers, directors, senior officials, professional occupations, based on the Office for National Statistics Standard Occupation Classification

SES, socioeconomic status; ADIS, Anxiety Disorders Interview Schedule; CSR, Clinical Severity Rating; CAMHS, Child and Adolescent Mental Health Service

Figures

Fig. 1 Screening process within recruited schools to identify potential participants



SCAS-P = Spence Children's Anxiety Scale-Parent Version; SCAS-C = Spence Children's Anxiety Scale-Child Version; SCAS-T = Spence Children's Anxiety Scale-Teacher Version.

Fig. 2 Barriers and facilitators at four key stages of the help-seeking process

Conflict of interest

The authors declare that they have no conflict of interest.

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Online Resource 1

Results

1. Parent recognises anxiety difficulty

1.1 Nature of child anxiety symptoms

Both the development or course of a child's anxiety difficulties, and the type of symptoms a child displayed influenced whether parents i) attributed a child's behaviour or symptoms to 'anxiety' or not; and ii) perceived the anxiety to be a problem or not. Some parents described that their child had displayed anxieties from a very young age, and clearly labelled their child as anxious ('*she's always when she's gone into a new environment when she was younger she was very clingy she wouldn't let go she was crying she took a long time to settle in*' [1036]). Others described the anxiety developing over a period of time, and this gradual emergence of particular behaviours or symptoms hindered or delayed recognition for some parents ('*it happened gradually it didn't happen you know from one day to another suddenly it gradually I think creeped in you know'* [ID1091]). In contrast, some parents referred to more marked changes in their child's behaviour or specific events that either triggered their child's anxiety or marked a crisis point, and acted as recognition prompts:

> *'compare her to year 3 from when she was in year 4 was there was just two completely different children really'* [ID 1212]
>
> '*for us it was I suppose it was a bit easy because it went from nothing to everything because of her accident'* [ID 7]

For some parents the persistence of these 'new' behaviours led them to consider the behaviour as problematic ('*he has refused to* [leave home] *pretty much constantly since about April this year'* [ID 1131). Whereas other parents described that their child's anxiety fluctuated or anticipated that it would not continue, and therefore did not consider their anxiety as problematic:

> *'he's not doing that now erm I think it was sort of a period that he was going through I think and he seems to have settled down'* [ID 1020]
>
> *'I think that Michelle's going to come out of it'* [ID 3]

Parents who felt that their child had always been anxious often described them as shy or nervous or clingy in new situations; whereas parents who considered their child to be socially confident, felt the anxiety was less obvious and hard to identify ('*she er in some ways is a very chatty kind of you know quite a bubbly personality erm and not the kind of shy retreating child in in the back of the classroom'* [ID 53]). Parents also experienced difficulties distinguishing between anxiety and other comorbid difficulties (*'it's so tangled up in his other aggressive behaviours …from very young there were behaviours but I couldn't have said they were anxiety related*' [ID 1209]); and expressed uncertainty surrounding whether their child's behaviour problems or anger outbursts were indicators of anxiety or not:

> '*sometimes I think it does come down to just a temper tantrum rather than it being a real worry'* [ID 2011]).
>
> *'a withdrawn type of quiet insular sort of reaction which is what I would have expected from anxiety rather than the complete explosive* [behaviour]*'* [ID 7]

Several parents referred to physical symptoms as key signs of a child's difficulties ('*I think it was just stress and emotion he had eczema all over his foot which he'd never done before*' [ID 1205]). Other parents similarly identified the absence of physical symptoms or a child's limited capacity to understand and articulate their difficulties as obstacles to recognition ('*if you ask Chloe why why is she feeling worried she doesn't understand why she's feeling worried*' [ID 1212]). Changes in how a child expressed their anxiety as they got older helped some parents identify their child's difficulties ('*when she's distressed now she vocalises it'*

[ID 2]), and made it harder for others (‘*the anxiety is there but I think he er doesn’t outwardly manifest it as he did*’ [ID.1209]).

1.2 Parent view of anxiety

Several pertinent views surrounding the nature of anxiety and what it represents appeared to influence whether parents considered their child’s anxiety as a difficulty or not. It was apparent that some parents viewed anxiety as a personality trait or a fixed characteristic, and had not considered that anxiety was a problem that could be or needed to be addressed:

> ‘*you’ve always got in groups the loudest one the very you know extroverted one and the one that’s a bit more shy or a bit more in the background…there’s different types of people*’ [ID.3]
>
> *‘I hadn’t seen it as such a diagnosable erm issue maybe I thought it was you know either your child has these characteristics or they don’t’* [ID. 2009]

Parents who did not consider their child’s anxiety as problematic, also described anxiety as a common experience among children or as part of growing up:

> *‘as children develop they change…you know some things they do sort grow out of’* [ID 1020]
>
> *‘I suspect that it’s it’s quite common for the younger ones to er to er have this…. I see it as part of growing up er you know the shyness’* [ID 3]

On the other hand, some parents who had considered the possibility that their child’s anxiety may be a difficulty, also acknowledged that anxiety could be a type of emotional or mental health difficulty (‘*I think people have all sorts of different* [mental health] *problems you know and anxiety is one thing they might be you know…anxiety is really one of of many problems’* [ID 1091]).

1.3 Parent identification ability

A perception that it is a parent's role and responsibility to identify anxiety difficulties in children was evident across interviews. A number of parents' lacked confidence in their ability to make judgments about whether their child's anxiety was 'normal' or not ('*they're normal child childlike you know personality traits all children get nervous and anxious about things but is it too much or is it just you know regular*' [ID.1131]). Some parents who reported experiencing anxiety themselves felt this experience helped them to identify similar difficulties in their child ('*that's why I can also see erm Ella's anxieties I can kind of er have empathy for her because I I was there'* [ID1036]); but others were concerned that their own anxieties made them over sensitive or likely to over react to signs of anxiety in their child (*'maybe I think about it a bit sooner than perhaps other people might erm sometimes cos I think he might be a bit like me and also his dad's quite a nervous person so I think oh perhaps he's going to be like me or his dad'* [ID 1020]). Equally, one parent felt that their lack of personal experience with anxiety made it harder for them to notice their child's anxiety ('*because it didn't match either my experience or my husband's experience…we didn't have that comparison*' [ID 1091]).

Parents also described making comparisons with other children when forming judgements about their child's anxiety and, to varying degrees, referred to seeking advice from family, friends, other parents, colleagues and the internet to help them to make judgements about their child's anxiety. While this process of informal help-seeking helped some parents identify their child's difficulties, for others it acted as a deterrent to parental recognition (*'it just seems there's probably quite a few….it seems that each child is experiencing something of a similar nature if you like'* [ID 38]). Several parents reported that this study provided an opportunity to help them establish the extent or severity of their child's anxiety ('*it was* *certainly a couple of the questions you asked* [in the questionnaire] *that helped me to realise that actually you know there might be a problem here*' [ID 1036]; and parents who lacked confidence in their identification ability referred to the need for tools to help parents with this process (*'like a checklist for er parents to look at is your child doing this or is your child acting like this maybe that's the sign to worry'* [ID 1131]).

1.4 Professional identification

It was evident that some parents saw a role for professionals, as well as parents, in identifying anxiety difficulties in children, and one parent described the failure of a professional to raise concerns about their child as the reason for not considering the anxiety as a significant problem. Equally, a professional raising concerns with a parent, or a professional endorsing parental concerns, were key prompts to recognition for some parents ('*the turning point was when the school actually came to me and said we've noticed behaviour changes'* [ID.1051]).

2. Parent recognises the need for professional support

2.1 Perceptions of level of impairment

Recognition that a child's anxiety had a significant negative impact on the child's life ('*he got to the point where he didn't want to go to school*' [ID.1205]), or was distressing for the child ('*it starts to affect them or it's really it really erm it starts to be a burden and it builds up over time but then when it happens every night and it's really something that he's not happy with'* [ID 1091]) or caused significant interference in family life ('*it's soul destroying as a parent having a child like that I just it was making our lives miserable*' [ID.53]) were described as key indicators of the need for professional support. Equally, a judgement that a child's anxiety was not currently impacting on a child's life was cited as a reason for not seeking professional help ('*I don't think it's a serious issue I see it as erm er a small* *challenge she's she's shy I don't think it causes her disruption to any degree'* [ID 3]). Judgements surrounding the potential impact for the child in the future also influenced parents' perceptions of the current need for professional involvement ('*I really don't want to go into that situation* [puberty] *with the anxiety that we've got at the moment*' [ID 2]).

2.2 Support provided by the parent

Parents commonly considered it their role and responsibility to help their child to manage their anxiety, and this appeared to deter some parents from recognising the potential for professional involvement. Parents described providing support for their child, and referred to seeking advice from family, friends, colleagues and through online forums to identify strategies to use at home. Some parents also described drawing on their experience of managing their own anxiety as helping them to provide support for their child ('*I said to Peter about sort of when you sort get worried deep breaths and letting it out and counting to ten the things sort of I'd been told when I'd had panic attacks and things in the past*' [ID.1020]).

It was evident however that some parents lacked confidence in their ability to manage their child's anxiety or perceived their difficulty managing their child's anxiety as a weakness:

> *'because we're not very strong or we're still not really sure how to deal with it'* [ID.2009]
>
> *'because as a parent there's nothing worse than thinking I've done everything I can and I can't help my child'* [ID.1212]

and this prompted them to recognise the need to seek professional help. Notably parents highlighted that the professional support required included a need for support for parents to enable them to provide appropriate support for their child *(‘actually the parents should have help too to help the children I think in the first place’* [ID.1091]).

2.3 Parent considers and prioritises help-seeking

It was apparent that some parents went through a period of contemplation where they considered the possibility of seeking professional help (‘*I don’t know erm I’ve said loads of time maybe I should get him some help or some counselling*’ [ID.1131]). Several parents referred to the busyness of life as making it hard for families to devote time to seriously consider or prioritise help-seeking:

> *‘you just get get so caught up in the humdrum of just daily life…as a parent it’s really difficult to try and juggle and you know just set that time aside to kind of go right ok do you know what we’re going to sit down and we’re going to deal with it with this’* [ID.38].

Similarly, one parent specifically referred to a reduction in other family demands as providing an opportune time to ‘prioritise’ seeking professional help; and other parents identified the opportunity to take part in this study as a prompt to consider or ‘focus’ on help-seeking (‘*it was always just bubbling along and causing quite a bit of stress but never actually being looked at in the face….this project allowed* [that] *to happen*’ [ID 2009]). Equally, among parents who had sought professional help, a sense of desperation seemed to elevate help-seeking from a possibility to a priority (‘*until it’s screaming you in the face people don’t react and you wait til the worst possible moment to go shit we need to do something about this*’ [ID.1228]).

2.4 Parent willingness to seek help

Parents' views surrounding i) anxiety treatment; ii) their child's willingness to seek help; iii) and sharing concerns with other people each influenced their willingness to seek help from professionals for their child's anxiety. Parents varied in the extent to which they considered professional support or treatment for anxiety difficulties in children as appropriate or beneficial. Some parents described the potential benefit of professional support, either provided through school or by specialist therapists or psychologists; while others were more sceptical ('*it's really hard to make someone think differently about certain situations'* [ID1131]).

Some parents expressed concerns that talking to children about anxiety and mental health may trigger or heighten their anxiety or felt that this may have happened with their child ('*I think sewed a little seed for Sally in her brain erm … the more negatives you give kids the more they're gonna tap into it and and fuel the fire*' [ID.1228]). For some parents, either their own or others' experience of receiving professional support for mental health difficulties influenced their perceptions of the potential benefits for child anxiety:

> '*I'm not totally confident that any of it really helped, there was just something in me that suddenly went right I've had enough of being doing this to myself'* [ID.1020])
> '*they did go and get help and she's had all sorts of counselling and everything else and thankfully after a year later with all this help she's she's you know more or less back to how she was before*' [ID 2011]

Some parents emphasised the importance of a child's willingness and acceptance of the need for professional support; while others attached less importance to the child's view or their involvement in the decision making process ('*where she's involved obviously I'll discuss it with her and kind of help her prepare* [but] *I'm not going to discuss discuss all the things*'

[ID 1036]). Several parents expressed concerns that receiving support from professionals would be anxiety provoking for their child (*'to take her out which it probably will be during school hours to see this psychologist it it will give her a huge amount of anxiety'* [ID.2009]); and some speculated that their child's reluctance was linked to concerns surrounding what other people would think.

Parents varied in their overall openness or reluctance to share concerns about their child's anxiety with both family and friends, and with professionals. Interestingly, parent perceptions surrounding the stigma associated with anxiety and mental health seemed important determinants of their openness (or reluctance) to share concerns both informally and with professionals. Parents referred to common negative perceptions associated with anxiety and mental health and expressed concerns surrounding negative consequences for their child if they were to talk to other people about their child's difficulties:

> *'it is viewed as a weakness it's a bit liked depression you know it's a mental health issue and it doesn't matter how you dress it up or you know all the campaigns or whatever it will always be viewed as a weakness'* [ID.38]
>
> *'it'd be straight round the school within 30 seconds and she'll be she'll be you know outcast as the weirdo within the group'* [ID.1228]

Parents also expressed concerns surrounding other people blaming them as the parent:

> *'you don't talk about it sometimes because you think I can't deal with the negative feedback and you're going to start saying it's me'* [ID.2]
>
> *'it's not wanting to look like you're doing the wrong thing parenting wise'* [ID.1131]

They also described feeling a sense of failure or blaming themselves. This type of self-stigma deterred some parents from both talking to friends and family (*'it's not the kind of thing you want to talk about with your friends you know being honest with you…*[a] *sense of failure perhaps and that I don't know what to do with her*' [ID.7]) and from raising concerns with professionals ('*if it'd got that far then I'd done something wrong I may not have done but that would be the response I know what my response would be I would be upset concerned what have I done wrong'* [ID.3]).

Parents referred to the importance of raising public awareness and understanding of anxiety and mental health difficulties in children, and some also specifically identified the potential benefit of online resources to allow parents to seek information and advice in private ('*people would probably want to do it through the internet at home by themselves cos they at that stage because they wouldn't necessarily want to be broadcasting it'* [ID.7]).

2.5 Professional guidance

As well as highlighting a role for professionals in helping parents identify a child's difficulties, some parents also identified a role for professionals in helping parents determine whether their child needed support from professionals to help address their anxiety or not. Parents who did not feel their child needed professional support sometimes anticipated that this view would change if a professional recommended getting professional support ('*if somebody said to me I really do think your child suffers from either mild or whatever moderate anxiety and would benefit from some sort of help then I would be right ok where do I get it from then what do I do*' [ID.2011]).

3. Parent contacts professionals

3.1 Type of impairment

For some parents, the fact that their child's anxiety was not evident at school or impacting on their school work deterred them from seeking advice from teachers ('*she doesn't do that at school…so I suppose now I wouldn't tell teachers*' [ID 7]). In contrast, those parents who were in regular contact with teachers about other difficulties their child was facing (e.g. learning or behavioural) also sought advice from teachers about their child's anxiety.

3.2 Parent help-seeking knowledge

Many parents expressed a degree of uncertainty surrounding what professional support was available and who best to contact for help or advice ('*you see it's knowing where to look for the help who do you ask erm'* [ID.2011]). Several parents also emphasised that they felt there was not a clear first point of contact who could signpost families to the available sources of support. Similar to the earlier recognition stages, some parents described seeking advice about where and how to seek professional help from friends, family, other parents, and colleagues, and through using the internet. Parents' personal and professional experience also informed the extent of their help-seeking knowledge:

> *'I don't think I know a lot about it erm help that's available erm… you know I haven't br-schooled or brought up in England with the systems and everything that's available it could just be that I'm not aware of what's available out there just because I'm from another country'* [ID.1036]
>
> *'I worked closely with CAMHS* [Child and Adolescent Mental Health Services] *anyway through my work and I'd spoken to a colleague who worked for CAMHS'* [ID.1205]

Parents also described the importance of identifying appropriate sources of professional support, and some parents lacked confidence in their ability to make judgements about whether particular types of support were appropriate or not. Parents described using the internet as a source of information and the role of online resources, but several referred specifically to facing difficulties judging the credibility of online information:

> *'People say oh you can google it but you don't you need to know what you are googling don't you and what's going to be good you know'* [ID.2]
>
> *'I've started looking on the internet and stuff but it's there's so much you know crap really on there that you don't know where to trust or anything'* [ID.1131]

In a similar vein, a few parents highlighted the need for guidance for parents on the help-seeking process, and about the support and resources that are available:

> *'if there was kind of a map of how do you this…have something like that and go I've completed this whatever survey I've hit sixteen …and my kind of next port of call is to call you and see what help there is either within the GP surgery or externally where could I go where would you recommend I go'* [ID.38]

3.3 Perceived role and expected response from teachers and GPs

Some parents considered a GP to be an appropriate point of contact for parents concerned about their child's anxiety ('*I just assume that you have to go the doctor to try to get some help*' [ID.1020]); whereas others felt that it was not appropriate to seek advice from a GP for emotional difficulties ('*it's not really a medical thing is it…it's not something that you would go to the GP for I mean if your child has tummy ache and you know it's not not because of a physical thing it's more emotional thing'* [ID.1036]). Similar contrasting views were expressed in relation to a teacher's role as a point of contact for parents of children with anxiety difficulties:

> '[the school] *that would be sort of my natural way of looking for some some advice'* [ID.1091]
>
> *'she's a teacher she's there to teach…Yeah I'd see it as though I'm offloading my problems onto somebody that's not what they're there to listen to'* [ID.7]

As well as signposting families to external sources of professional support, some parents also referred to the school's role as a direct source of support to help a child manage their anxiety ('[the teacher] *giving them strategies to help them get through it*' [ID 2009]).

It was equally apparent that parent perceptions surrounding the anticipated response from GPs/teachers impacted on their decision to contact (or not) a professional for help or advice. Several parents expressed reservations about raising concerns with a teacher or GP because they felt their concerns would be dismissed ('*I would worry that I would be fobbed off* [by the GP] *with oh no you know she's fine and not necessarily taken seriously enough'* [ID 2011]). Others were also hesitant for fear that teachers or GPs may blame them as a parent ('*you're thinking do they think you know I should have done this or I should have done that erm'* [ID 1212]). The family's relationship with the GP and/or teacher, and whether the parent trusted the GP/teacher or not, also seemed to prompt/deter contact with these professionals. For example, the fact that teachers '*see your child everyday*' [ID 1205] and that school is a child's '*familiar environment*' [ID 1091] were given as reasons to seek help through school. Similarly, while some parents commented that their family did not regularly visit the GP, one parent described that the GP knew her daughter and her history; and was therefore an appropriate point of contact.

3.4 Perceived availability of professional support

Parent perceptions regarding the availability of professional support for children with anxiety difficulties also appeared to play a role in some parental decisions to contact (or not contact) professionals for help or advice. Some parents felt uncertain about whether any appropriate support was available or not, and several referred to anticipated long waiting lists to access support as a deterrent to contacting professionals for help or advice. In contrast, one parent felt confident professional support was available, and did not feel that doubt surrounding the availability of support had deterred them from seeking help.

4. Family receives professional support

4.1 Service criteria

Parents who had sought help described the importance of ‘ticking boxes’ and the need for a child’s difficulties to match strict specialist service requirements (‘*Joseph didn’t quite meet the criteria*’ [ID.1205]), and that less severe difficulties do not meet these criteria. Several parents referred to Child and Adolescent Mental Health Services (CAMHS) prioritising cases where there was a risk of self harm or suicide, and one parent attributed her daughter’s quick access to a CAMHS service to her ‘priority’ status. In relation to receiving support through school, parents described a similar need for difficulties to meet school criteria, with priority given to children with behavioural difficulties (‘*there were always children that were considered erm a bigger concern cos Jasmine’s behaviour wasn’t in disruptive in in school she didn’t affect anyone else*’ [ID 53])

4.2 Parent help-seeking skills

The need for parental perseverance, and the importance of not giving up and repeated contact with different professionals, was evident among those families who had received support from services. Equally, parental resilience in the face of dismissive attitudes among professionals also seemed crucial in some cases (‘*yes when everyone kept saying it’s your parenting I kind of thought why am I even bothering why am I following this if I’m not actually going to get anywhere’*[ID.1051]).

One parent also emphasised the importance of a parent’s communication skills and how parents communicate concerns with professionals (*‘there’s no point getting people’s backs up and going in all guns blazing you’ve got to kind of go nicely nicely and kind of get on side with people to try and get help and ask the right questions in the right way to receive the right response*’ [ID. 53]). This parent also felt that as a health professional she was taken more seriously by professionals. Parents who had contacted professionals also described the need for parents to demand or shout loudly for a referral from their GP. The potential benefit of parents preparing for discussions with professionals and gaining a good understanding of the available services was also clear *(‘before I went to see her I thought I need to be clear on what I’m asking her to help with’* [ID.2009]).

4.3 Professional response

Professionals were seen as having a key role in enabling or preventing a family from obtaining support to help with the child’s anxiety. Professional recognition of the child’s need for services was identified as a requirement for receiving professional support and as a means to access additional support (‘*it wasn’t until I got the diagnosis from CAMHS and I could say to them* [school] *look this is what they’ve said she’s got that they would take any notice really*’ [ID.1212]). Parents referred to the importance of the level of knowledge and skills among professionals, both in relation to identifying a child’s difficulties and in relation to an ability to disseminate information about available support and services, with several highlighting the need for training for school staff. The importance of communication skills among professionals was also evident, and parents identified the need for professionals to communicate well with both the child and the parent. Parents referred to professionals dismissing their concerns or feeling blamed by professionals (*'there's a lot of erm assumptions that it's to do with my parenting there seems to be a lot of oh well you know it's obviously you're not parenting her in the right way yeah there was a lot of offering of various parenting erm courses'* [ID.2]). One parent emphasised the importance of feeling listen to by professionals (*'If people actually listened to what I was saying rather than just trying to fob me off'* [ID.1051]), and another identified the key role of talking to the right individual, and someone who responds positively, in order to successfully access professional support.

4.4 Service provision

Parents who had sought help described a lack of available professional support, and high demands on available services as barriers to receiving treatment ('*the doctor said that there was a you know a waiting time anyway erm for for that sort of help erm'* [ID.1020]). Parents who had not sought help also anticipated that if they did seek help, a lack of available support would present a hurdle to obtaining support ('*my fear would be that you know your child needs help but then you know it all falls apart… there's nobody within a hundred mile radius that can help you with it for six months*' [ID.2011]). Among parents with a child who had been referred to CAMHS, the complex and lengthy referral system was also described as a significant hurdle to treatment access. Parents similarly experienced or anticipated limited provision of support within schools to help children with anxiety difficulties ('*I guess school can help support them but to be honest I don't think they've got the time or resources'* [ID.1020]). Some parents considered private services as a potential means to avoid waiting lists, but cited the cost of these services as a barrier. One parent however also felt that suitable private services were not '*readily available*' [ID.38].

Chapter 4: Paper 3

Seeking and accessing professional support for child anxiety in a community sample

Submitted for publication in *BMC Psychiatry* (11.03.2018)

Reardon, T., Harvey, K., & Creswell, C. (submitted manuscript) Seeking and accessing professional support for child anxiety in a community sample.[*]

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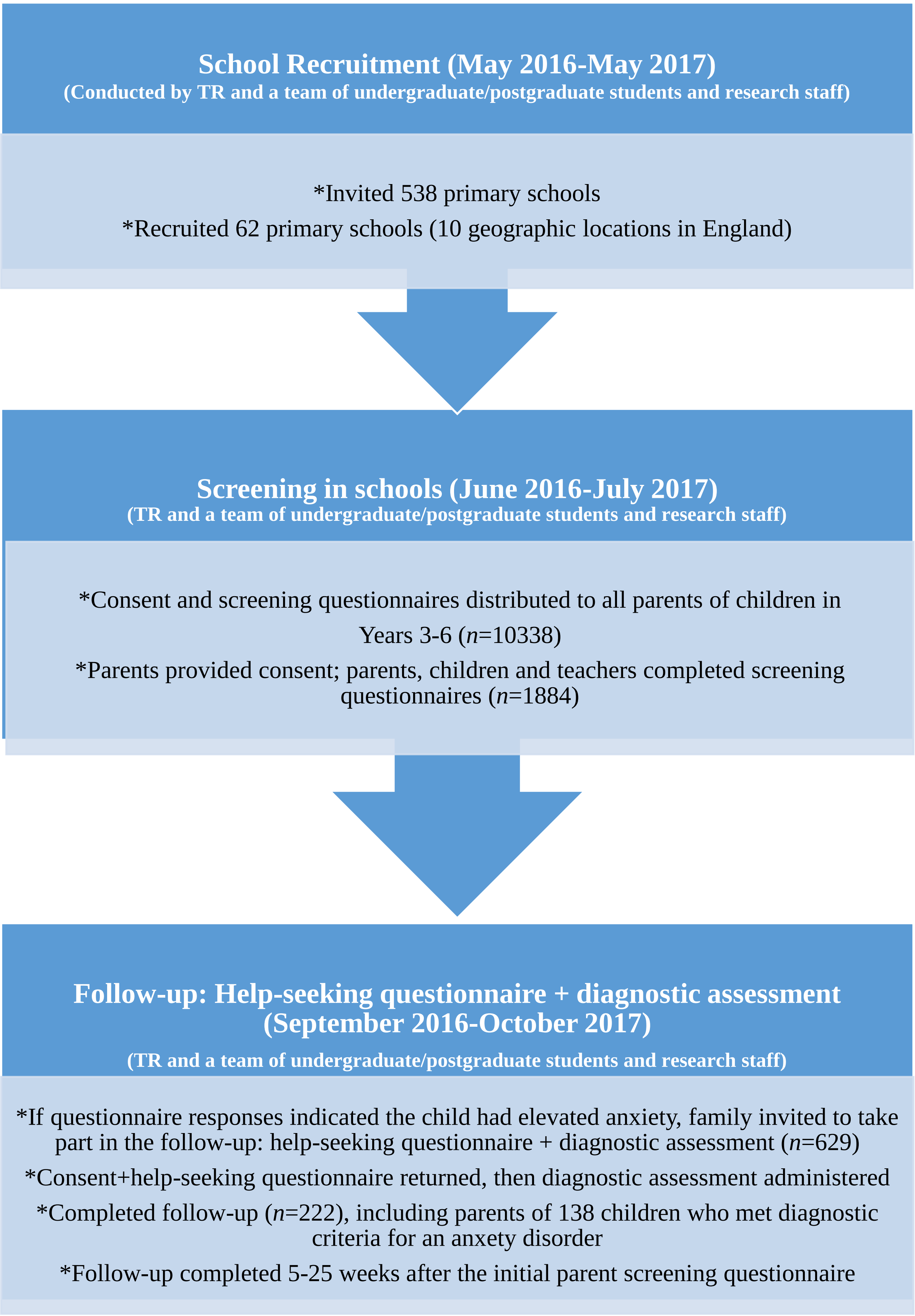
[*] Minor amendments have been made to the paper for the purpose of this thesis

4.1 Introduction to Paper 3

Paper 2 identified the range of barriers parents face i) recognising a child's anxiety difficulties, ii) recognising the need for professional support, iii) contacting professionals for help or advice, and iv) receiving support from professionals. Paper 2 also provided insight into the complexity of the help-seeking process in the context of child anxiety disorders, and the variation across families in the extent and type of help-seeking and support received. Paper 3 aimed to build on this qualitative work and provide quantitative data on i) rates and types of help seeking and professional support received for child anxiety disorders, ii) parent reported barriers/facilitators to seeking and accessing professional support; and iii) factors associated with help-seeking and parent reported barriers. Findings from Papers 2, together with Paper 1 were used to develop a new questionnaire instrument to collect quantitative data on help-seeking and parent reported barriers/facilitators. A questionnaire was used rather than an interview to collect this information to reduce demand on participants. Paper 1 identified limitations associated with existing measures of parent reported barriers/facilitators so developing a new questionnaire helped ensure we were able to capture all relevant barriers in the context of anxiety difficulties in pre-adolescent children. It also ensured areas of questioning related to help-seeking and access to support were relevant to this particular population. The study was approved by the University of Reading Research Ethics Committee (UREC) in May 2016. Full study details are provided in Paper 3, and summary of the recruitment procedure is provided below in Figure 1.

Figure 1 Recruitment procedure for survey study reported in Paper 3



School Recruitment (May 2016-May 2017)

(Conducted by TR and a team of undergraduate/postgraduate students and research staff)

*Invited 538 primary schools

*Recruited 62 primary schools (10 geographic locations in England)

Screening in schools (June 2016-July 2017)

(TR and a team of undergraduate/postgraduate students and research staff)

*Consent and screening questionnaires distributed to all parents of children in Years 3-6 (*n*=10338)

*Parents provided consent; parents, children and teachers completed screening questionnaires (*n*=1884)

Follow-up: Help-seeking questionnaire + diagnostic assessment (September 2016-October 2017)

(TR and a team of undergraduate/postgraduate students and research staff)

*If questionnaire responses indicated the child had elevated anxiety, family invited to take part in the follow-up: help-seeking questionnaire + diagnostic assessment (*n*=629)

*Consent+help-seeking questionnaire returned, then diagnostic assessment administered

*Completed follow-up (*n*=222), including parents of 138 children who met diagnostic criteria for an anxety disorder

*Follow-up completed 5-25 weeks after the initial parent screening questionnaire

4.2 Paper 3: Seeking and accessing professional support for child anxiety in a community sample

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Abstract

Background

There are a lack of current data on help-seeking, and barriers to seeking and accessing professional support for child anxiety disorders. This study aimed to provide current data on the frequency and type of i) parental help-seeking, ii) professional support received, and iii) parent reported barriers/facilitators in the context of child anxiety. We also set out to explore factors associated with help-seeking, and parent reported barriers among help-seekers and non help-seekers.

Methods

A survey of help-seeking in parents of 222 children (aged 7-11) with elevated anxiety symptoms identified through screening in schools, 138 children of whom met diagnostic criteria for an anxiety disorder.

Results

Almost two-thirds (64.5%) of parents of children with an anxiety disorder reported seeking help from a professional, and in 38.4% of cases parents reported that their child had received support from a professional to help manage and overcome their anxiety difficulties. Parents who had sought help most frequently reported contacting school staff for help or advice; and families who had received professional support reported a range of types of support, but <3% had received evidence-based treatment (CBT). Frequently reported parental barriers related to difficulties differentiating between developmentally appropriate and clinically significant anxiety, a lack of help-seeking knowledge, perceived negative consequences of help-seeking, and limited service provision. Parental perceived need for professional support for their child, parents' own contact with a mental health specialist and impairment related to home/family activities were each uniquely associated with help-seeking. Non-help seekers were more likely than help seekers to report barriers related to thinking a child’s anxiety may improve without professional support, and the absence of professional recognition.

Conclusions

Findings identify the need for i) tools for parents and primary school staff to help identify children who may benefit from professional support to overcome difficulties with anxiety difficulties; and ii) increased evidence-based provision for child anxiety disorders, including delivery within school settings and direct support for parents.

Keywords

Help-seeking; barriers; parents; children; anxiety disorders

Background

Anxiety disorders are the most prevalent mental health disorders experienced across the lifespan, with an average age of onset of 11 years [1]. Childhood anxiety disorders have a significant negative impact on educational, social and health functioning, and are associated with continued anxiety and other mental health disorders in adulthood [2], and substantial economic burden [3]. Cognitive behavioural therapy (CBT) is the most well evaluated treatment for anxiety disorders in children [4], with evidence for long term positive outcomes [5,6]. However, poor rates of access to treatment for mental health problems in children are widely reported [7-9]. Studies report lower rates of treatment access among children with anxiety disorders compared to children with behavioural disorders [8,10,11], although there are a lack of current UK data on the number of families who seek and access professional support for child anxiety disorders, and we know little about the type of support families receive.

The unmet need in relation to child mental health has prompted calls to improve access to effective early intervention [12]. Children typically rely on a parent or caregiver to seek help on their behalf so it is important that interventions designed to improve access to professional support for child mental health problems address barriers parents face throughout the help-seeking process [13]. Studies that explore factors associated with use of child mental health services help illustrate who does and who does not access treatment, and help identify potential barriers to accessing treatment. For example, if parents perceive a child’s difficulties to be problematic, and perceive a negative impact on family life, and need for professional help, a child is more likely to access mental health services than if parents do not recognise a child’s difficulties, associated impact or need for help [14]. Parents’ own experience of mental health problems and use of mental health services, and a child’s symptom severity are also associated with child mental health service use [15,16]. However, few studies have explored help-seeking specifically in the context of child anxiety disorders; given that reported rates of treatment access are lower for anxiety disorders compared to behavioural disorders, there may be barriers to help-seeking that are unique to anxiety difficulties. In order to identify key areas to target to improve treatment access, it is also pertinent to establish parents' own views on barriers/facilitators associated with seeking and accessing professional support in the context of child anxiety. Salloum, et al. [17] described parental perceptions of barriers to treatment access within a sample of parents of children who received treatment for anxiety, but given that so few families reach services, we also need to consider the experiences of parents who have not sought and/or accessed support for their child. Indeed, qualitative interviews we conducted with parents of children with anxiety disorders identified in the community illustrate the range of difficulties parents can face recognising a child's anxiety difficulties, identifying the need for support, contacting professionals for help or advice, and receiving support from professionals [18]. It is therefore important to establish barriers to both seeking help and obtaining support to help manage and overcome a child's anxiety difficulties. Establishing the extent to which parents report different types of barriers, and improving understanding of who experiences which types of barriers would help inform targeted interventions to both promote help-seeking and ensure more families receive appropriate support.

This study aimed to build on the qualitative findings to date [18] by providing quantitative data on help-seeking within a community sample of parents of children with elevated anxiety symptoms, and within a subsample where the child met diagnostic criteria for an anxiety disorder. Specifically we aimed to provide current data on the frequency and type of i) parental help-seeking, and ii) professional support families receive to help manage and overcome a child's anxiety difficulties. We also aimed to iii) provide quantitative data on the frequency and type of parental reported barriers and facilitators to seeking and accessing professional support for their child’s anxiety. Additionally, we set out to explore iv) the child and parent characteristics associated with seeking professional help and parent reported barriers, and v) differences in parent reported barriers among those who have and those who have not sought professional help.

Methods

Recruitment procedure

Participants were recruited through screening in primary/junior schools in England. In order to ensure the sample included participants from different geographic regions and captured a varied demographic profile, we identified a random sample of primary/junior schools in England to approach, stratified by the Department of Education’s 10 geographic regions and the number of children on the roll eligible for free school meals. Between May 2016 and May 2017 538 schools were invited to participate in the study, and 62 were recruited. Recruited schools were from across all 10 geographic regions (North-West, North-East, East Midlands, Yorkshire and the Humber, East Midlands, West Midlands, London [outer and inner], East of England, South East, and South West), with 22-731 pupils on the school roll, and a mean of 15.88% (SD 11.51) children eligible for free school meals[*]. Schools that were invited but did not participate usually did not respond to the invitation (476 schools; >90%), and where schools declined the invitation, the most frequently cited reason was a lack of available time. Invited schools that did not take part did not differ from recruited schools in terms number of pupils on the school roll or mean number of children eligible for free school meals.

Recruited schools distributed study information and anxiety screening questionnaires (Spence Children’s Anxiety Scale-Parent Version; SCAS-P) to all parents/caregivers of

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[*] 15.6% of children are eligible for free school meals in state funded nursery and primary schools in England (available on https://www.gov.uk/government/statistics/schools-pupils-and-their-characteristics)

children in year groups 3-6 (aged 7-11 years). Parents/caregivers (hereby referred to as parents) provided informed consent and completed the SCAS-P on paper or online. Researchers then visited the school to administer corresponding questionnaires with the children whose parents had provided consent, and their class teachers. In total, parents of 10338 children were invited to take part, 1884 provided consent, and 1881 parents, 1617 children and 1579 teachers completed screening questionnaires. In cases where screening questionnaire scores indicated the child had elevated anxiety symptoms,[a] the parent was invited to take part in a follow-up diagnostic assessment (Anxiety Disorder Interview Schedule-Parent Version; ADIS-P) and to complete follow-up questionnaire measures relating to their child's anxiety (Child Anxiety Impact Scale-Parent Version; CAIS-P), their views and experiences surrounding seeking professional help for their child's anxiety and their own mental health (Depression Anxiety Stress Scales; DASS-21) and mental health service use. Diagnostic assessments were administered by telephone, and follow-up questionnaires were posted to parents and returned in a pre-paid envelope. We invited parents of 639 children with elevated anxiety symptoms to take part in the follow-up, parents of 255 children agreed to take part, and parents of 222 children both completed the diagnostic assessment and returned the help-seeking questionnaire. Child anxiety symptoms (SCAS-P) were significantly higher among parents who took part in the follow-up, than those who were invited but did not participate (t [634] =3.74, p <0.001).

Participants

The sample included parents of 222 children aged 7-11 years with elevated anxiety symptoms, 138 children of whom met DSM-5 criteria for at least one anxiety disorder. Participant characteristics for the total sample and the subsample are provided in Table 1. Across the total sample the majority of parents who participated were female (*n*=206, 92.8%), with a mean age of 40.46 years (SD 5.92), and 99 (44.6%) completed higher education. Children had a mean age of 9.63 (SD 1.22), and 107 (48.2%) were female. Among children with an anxiety disorder, 58 (42.0%) children had 2 or more anxiety diagnoses, and the most common anxiety disorders were Generalised Anxiety Disorder (*n*=87, 63.0%), Social Anxiety Disorder (*n*=52, 37.7%), Specific Phobia (*n*=34, 24.6%) and Separation Anxiety Disorder (*n*=31, 22.5%). Non-anxiety comorbid disorders were Obsessive Compulsive Disorder (*n*=8, 5.8%), Attention Deficit and/or Hyperactivity Disorder (ADHD; *n*=17, 12.3%), and Oppositional Defiant Disorder (ODD; *n*=2, 1.4%); an additional 6 children who did not meet criteria for an anxiety disorder had behavioural disorders (ADHD, *n*=4; ODD, *n*=2).

Measures

Spence Children's Anxiety Scale – parent, child and teacher report versions (SCAS-P; SCAS-C-27; SCAS-T-20)

The Spence Children's Anxiety Scale is a widely used 38-item questionnaire measure designed to assess symptoms of DSM child anxiety disorders, with parent and child report versions [19,20]. To reduce administration time, the obsessive compulsive behaviours and physical injury fears subscales were not included in the child report questionnaire, on the basis of the DSM5 classification of anxiety disorders and item functioning analyses [21]. A corresponding teacher-report version of the SCAS that consists of 20 items derived from the SCAS-C/P (SCAS-T-20) [21] was also used. Evidence in support of the reliability and validity of the SCAS is widely reported [22-24], and internal consistency was excellent in the current sample (SCAS-P, $\alpha = 0.92$; SCAS-C-27, $\alpha = 0.92$; SCAS-T-20, $\alpha = 0.91$).

Anxiety Disorder Interview Schedule-Parent Version (ADIS-P)

The ADIS- P is a reliable and valid structured parent interview designed to assess a child's diagnostic status, including an assessment of DSM anxiety diagnoses and common comorbid disorders [25]. There is good-excellent agreement between diagnostic outcomes based on telephoned administered parent interviews, and independent child/parent interviews [26]. Indeed, among pre-adolescent children, child and parent ADIS interviews show moderate agreement, but final clinician awarded diagnoses more closely reflect parent report than child report [27]. Minor amendments were made to enable diagnoses consistent with DSM5 following personal communication with the authors. As per the guidelines, diagnoses and Clinical Severity Ratings (CSRs) 4-8 were assigned where the child met the diagnostic criteria, and the disorder with the highest CSR was assigned as the primary disorder. Assessments were administered by graduate and undergraduate psychology students, and for each assessor the first 20 assessments were discussed with an experienced diagnostician and consensus reached. After a minimum of 20 assessments, and once assessors obtained a minimum kappa/ICC of 0.85, then one in six subsequent interviews were discussed. Inter-rater reliability within the assessment team was excellent (diagnoses, kappa = 0.91, CSR ICC = 0.95).

Child Anxiety Impact Scale-Parent Version (CAIS-P)

The CAIS-P is a 27-item parent report questionnaire measure of the impact of a child's anxiety symptoms on their psychosocial functioning, with good psychometric properties [28,29]. Two items considered inappropriate for pre-adolescent children (going on a date, having a boyfriend/girlfriend) were omitted. Items are organised into three subscales to assess impairment in relation to school, social and home/family activities. Internal consistency for total and subscale scores in the current sample were good-excellent ($\alpha = 0.83$-0.92).

Help-seeking views and experiences questionnaire

This questionnaire measure was developed for this study and provided information on the following:

i) Parental help-seeking and professional support received for their child's anxiety difficulties

These questions were based on questions used in the *National survey of mental health in children and young people in Great Britain* [7]. Parents were asked i) if they had ever contacted a professional for help or advice about their child's difficulties with anxiety, and if so to indicate the professional/s they contacted; and ii) if their child had ever received support from a professional to help manage or overcome their child's difficulties with anxiety, and if so to indicate the type of support received and who provided the support. To assess informal help-seeking, parents were asked to indicate other people they had spoken to for help or advice about i) their child's anxiety, and ii) getting support from a professional to help with their child's anxiety.

ii) Parental perceived need for professional support for their child's anxiety

Parents were asked to rate the extent to which they felt i) their child may benefit from professional support, and ii) the parent may benefit from support from a professional to help their child manage/overcome their difficulties with anxiety.

iii) Parent perceived barriers and facilitators to seeking and accessing professional support for their child's anxiety difficulties

Parents rated the extent to which 44 items stopped/made it harder for them to seek/access professional support. Items were rated on a 4-point Likert scale (*not stopped/not made it harder* = 0 to *very much stopped/made it very much harder* = 3). In cases where the parent reported contacting a professional for help or advice, parents also rated the extent to which 30 items encouraged/made it easier for them to seek/access professional support for their child's difficulties with anxiety. Facilitator items were also rated on a 4-point scale (*not encouraged/not made it easier* = 0 to *very much encourage/made it very much easier* = 3). Barrier and facilitator items were developed based on findings from a systematic review of parental perceived barriers/facilitators to child mental health treatment [13] and qualitative interviews with parents of children with anxiety disorders [18]; and refined and finalised following consultation and piloting with members of a local research advisors group comprising of parents of children who have experienced mental health difficulties. Responses to all barrier/facilitator items were summed to produce total scores. Barriers and facilitators relate to four distinct stages in the help-seeking process identified in underpinning qualitative work (recognising a child's anxiety difficulties; recognising the need for professional support; contacting professionals; receiving support) [18], and items related to each stage were summed to produce four respective barrier/facilitator subscale scores. Internal consistency for barrier and facilitator total scores and subscale scores were good-excellent ($\alpha = 0.78\text{-}0.95$).

Depression Anxiety and Stress Scales (DASS-21)

The DASS-21 is a brief self-report questionnaire that was used to measure parents' symptoms of anxiety, depression and stress. It has demonstrated good reliability and validity in community populations [30,31] and internal reliability for total and subscale scores in this sample were good ($\alpha = 0.82\text{-}0.94$).

Parent mental health service use

Parents were asked if they had spoken to a professional about their own mental health using an item sourced from similar surveys [15,32]. Where applicable, parents also indicated the professional they had spoken to and rated the helpfulness of the support they received (*not at all helpful* = 0 to *extremely helpful* = 4).

Data analytic approach

Descriptive statistics

Parental help-seeking, support received, and parent reported barriers were examined within the total sample, and within the subsample where the child met criteria for an anxiety disorder. The number and proportion of parents who reported seeking professional help for their child's anxiety difficulties were calculated, together with the number/proportion who reported seeking help from school staff, General Practitioners (GPs), mental health specialists, and other non-professionals. Similarly, the number and proportion of parents who reported that their child received professional support were calculated, together with the type of support (CBT, counselling, parenting support, recommended strategies/resources) and professional who provided the support (teacher/school staff, GP, National Health Service [NHS] mental health specialist, private professional, other professional). In relation to parent reported barriers, the number/proportion who endorsed each barrier (and 95% CI), mean item score (and 95% CI) for each barrier, total barriers score, and four barrier subscale scores were examined. Among parents who reported seeking professional help for their child's anxiety, corresponding descriptive statistics were examined for parent reported facilitators.

Parental help-seeking

Characteristics associated with parental help-seeking were then examined. Bivariate analyses (independent *t*-test, X^2 test) were used to explore whether the following child/parent characteristics were associated with seeking professional help or not: demographic variables (child's age, child's gender, parent education, parent occupation), child's anxiety symptoms/associated impairment (SCAS-P and CAIS-P), parent perceived need for professional support for their child, parental mental health (DASS-21), and parental use of mental health services/rated helpfulness of mental health services. A logistic regression model was then used to examine the unique contribution of individual parent/child characteristics in identifying whether parents had sought professional help for the child's anxiety or not across the total sample. Parent/child characteristics that were significantly associated with seeking professional help in the bivariate analyses, together with presence/absence of a child anxiety disorder were entered into the logistic regression model using a block-enter method.[b]

Parent reported barriers

Bivariate analyses (Pearson's r, X^2 test) were also used to explore child/parent characteristics associated with parent reported barriers (total barrier scores and barrier subscale scores), and independent *t*-tests were used to examine differences in parent reported barriers between parents who had sought professional support and those who had not. A logistic regression model was used to further explore whether particular barriers were uniquely associated with seeking/not seeking help (i.e. to determine whether some barriers deter parents from contacting professionals, and others become relevant following contact with professionals). In order to explore particularly pertinent barriers, for each subscale the first and second rank ordered barriers (based on the proportion of parents who endorsed the item) were used as predictor variables, and whether the parent had sought help/not sought help as the outcome variable. Barrier scores for the first and second rank ordered barriers for each subscale were entered into the logistic regression model using a block-enter method in order to identify the unique contribution of individual barriers in identifying whether parents had sought help or not. To control for the presence/absence of an anxiety diagnosis and demographic variables that were significantly associated with parent reported barriers in bivariate analyses, these variables were also included in the model. Variance Inflation Factors (VIF) and tolerance statistics were examined for evidence of multicollinearity in regression models.[c]

Results

Frequency and type of help-seeking and support received

Parent reported help-seeking and support received to help with their child's anxiety difficulties are displayed in Table 2. Almost two-thirds (64.5%) of parents of children with an anxiety disorder reported contacting a professional for help or advice, and just over half (52.7%) of parents in the total sample reported contacting a professional. The majority of parents who sought help contacted school staff (58.7% of parents of a child with an anxiety disorder; 47.3% in the total sample), and a smaller proportion contacted a GP (37.7%/27.7% respectively), someone specialising in mental health (27.5%/21.0% respectively) or another professional (13.0%/9.9% respectively). Interestingly, almost all parents (>90%) across the whole sample reported some informal help-seeking and had spoken to someone for help or advice about their child's anxiety. Almost three-quarters (73.5%) of parents of children with anxiety disorders, and 60.4% across the total sample, also reported seeking informal advice specifically about getting professional support for their child.

In relation to receiving professional support, 38.4% of parents of children with an anxiety disorder (and 32.4% across the total sample) reported that their child had received some type of support from a professional to help manage or overcome anxiety difficulties. Families received a range of types of professional support, including child counselling (14.5% of children with anxiety disorders; 12.2% across the total sample), professionals recommending resources/strategies (15.2%/13.1% respectively), and parenting support (8.7%/6.8% respectively). Notably, only 2.3% of parents across the total sample reported that their child had received CBT. Parents most frequently reported receiving professional support from school staff (21.7% of parents of children with an anxiety disorder, 18.9% across the total sample), followed by NHS mental health specialists (15.2%/13.1% respectively).

Parent reported barriers

Parent reported barriers across the total sample, and among those where the child met criteria for an anxiety disorder are displayed in Table 3. Mean total barrier scores were 36.95 (SD 25.15) in the total sample, and 43.39 (SD 24.93) among parents of children with anxiety disorders.

Barriers to recognising a child's anxiety difficulties

The most frequently endorsed barriers to recognising a child's anxiety difficulties, were *my child's anxiety comes and goes in phases* (73.2% of parents of children with an anxiety disorder; 68.9% across the total sample) and *I'm not sure if my child's anxiety is normal* (69.6% of parents of children with an anxiety disorder; 63.5% across the total sample). Notably, less than a third (across both the total sample and those with a child with an anxiety disorder) endorsed *I don't know other people who have had anxiety difficulties* as a barrier.

Barriers to recognising the need for professional support

The most commonly endorsed barrier to recognising the need for professional support was *I don't want my child to think she/he has a problem* (68.8% of parents of children with anxiety disorders; 63.5% across the total sample). More than half of parents across the whole sample also rated *teachers or other professionals have never suggested my child would benefit from professional help*, *my child's anxiety may improve without professional help*, *I want us to* *manage my child's anxiety as a family*, and *I feel a sense of failure or blame as a parent* as barriers. Notably, only one-fifth of the sample endorsed *professionals can't help with anxiety difficulties in children* as a barrier.

Barriers to contacting professionals

I don't know what help is available for children with anxiety difficulties and *I don't know who to ask for help* were the most frequently endorsed barriers to contacting professionals (72.5%/64.5% respectively among parents of children with anxiety disorders; and 67.6%/55.0% respectively across the total sample).

Barriers to receiving professional support

In relation to accessing or obtaining professional support to help manage and overcome a child's difficulties, more than half of all parents rated *it is difficult to get a referral to a specialist service, there are long waiting times for specialist services, I can't afford to pay for private professional help*, and *it is a battle to access professional help* as barriers; and almost two-thirds (64.5%) of parents with anxiety disorders endorsed the barriers related to referral difficulties and waiting times.

Parent reported facilitators

Table 4 displays reported facilitators among those parents who had contacted a professional for help or advice about their child's anxiety. More than 80% of parents who had sought help rated *my child's anxiety got worse, my child's anxiety impacts on his/her life* and *I am desperate to get help for my child* as encouraging them or making it easier for them to seek professional help. The majority of help-seekers (>80%) also endorsed the facilitators *I trust the teachers at my child's school* and *Teachers at my child's school are understanding and* *supportive*. In relation to receiving professional support, parents most frequently endorsed facilitators related to parental effort (*I have not given up asking for help,* 61.5%; *I have pushed hard to get professional help for my child*, 51.3%).

Factors associated with parental help-seeking

Findings from bivariate analyses and a logistic regression examining factors associated with parental help-seeking are reported in Additional file 1 and 2 respectively. Parent reported child anxiety symptoms (SCAS-P), impact of child anxiety (CAIS-P total) and impairment related to home/family activities (CAIS-home), were each significantly higher among help-seekers than non-help seekers in both the total sample and the anxiety disorder subsample. Teacher reported child anxiety symptoms (SCAS-T-20), and parent reported impairment related to school/social activities were also significantly higher among help-seekers than non-help seekers across the total sample. Across the total sample and the anxiety disorder subsample, parental perceived need for support for their child, both in relation to direct support for their child and support for the parent to enable them to help their child, and parent self-reported mental health symptoms were each significantly higher among help-seekers than non-help seekers. Significantly more help-seekers than non-help seekers also reported contact with a mental health specialist for their own mental health, among the total sample and the anxiety disorder subsample. No significant differences were found between help-seekers and non-help seekers on demographic variables or parent ratings on the helpfulness of the professional support they received for their own mental health difficulties.

Parental perceived need for professional support for their child (Odds Ratio 4.23 [95% CI 2.08-8.83]), parents' own contact with a mental health specialist (Odds Ratio 2.63 [95% CI 1.33-5.19]), and impairment related to home/families activities (Odds Ratio 1.14 [95% CI 1.03-1.27]) were each uniquely associated with help-seeking for a child's anxiety difficulties. Notably, after controlling for other variables, parent perceived need for support for themselves to enable them to help their child was significantly associated with *not* seeking help for their child's anxiety difficulties (Odds Ratio 0.35 [95% CI 0.17-0.73]). Child anxiety symptoms (SCAS-P), presence of an anxiety diagnosis and parental mental health symptoms (DASS-21) were not uniquely associated with parental help-seeking.

Factors associated with parent reported barriers

As shown in Additional file 3, the same variables were significantly associated with total barrier scores in the total sample and the anxiety disorder subsample. Total barrier scores were significantly higher among parents with lower educational qualifications; and significantly higher among parents who reported contact with a mental health specialist for their own mental health compared to those who had not had contact with a mental health specialist. Child anxiety symptoms, (SCAS-P, SCAS-C-27), associated impairment (CAIS-P, CAIS-subscales), parental perceived need for support for their child, and parent mental health symptoms (DASS-21) were also each significantly correlated with total barrier scores.

Parent reported barriers associated with help-seeking

Differences between help-seekers and non-help seekers on total barrier and barrier subscale scores are displayed in Additional file 1, and similar patterns were observed across the total sample and the anxiety disorder subsample. Total barrier scores were significantly higher among parents who had sought help for their child's anxiety than those who had not sought help. Unsurprisingly, barriers related to contacting professionals and receiving support were also significantly higher among help-seekers than non-help seekers; however there were no significant differences between these two groups in reported barriers related to recognising a child's anxiety difficulties and recognising the need for professional support.

As shown in Additional file 4, individual barriers related to recognising a child's anxiety difficulty did not make a unique contribution in identifying help-seekers/non-help-seekers (*my child's anxiety comes and goes in phases*, *I'm not sure if my child's anxiety is normal*), and nor did barriers related to a lack of knowledge surrounding help-seeking (*I don't know who to ask for help, I don't know what help is available for children with anxiety difficulties*). Two barriers related to recognising the need for support however were negatively associated with seeking professional help (*my child's anxiety may improve without professional help*, Odds Ratio, 0.60 [95% CI 0.40-0.89]; *teachers or other professionals have never suggested my child would benefit from professional help*, Odds Ratio, 0.57 [95% CI 0.40-0.82]). In contrast, the parent reported barrier related to difficulty getting a referral to a specialist service was positively associated with seeking professional help (Odds Ratio, 2.36 [95% CI 1.28-4.35]). After controlling for these frequently endorsed barriers, the presence of an anxiety diagnosis was also associated with help-seeking (Odds Ratio 3.12 [95% CI 1.52-6.43]).

Discussion

Main findings

This study aimed to provide current and more detailed information on help-seeking for child anxiety difficulties than previously reported. Our findings illustrate a substantial unmet need in relation to child anxiety. We found that more than 60% of children with anxiety disorders had not received any professional support to help manage and overcome their difficulties with anxiety, and in about one third of cases parents had not sought help from a professional. Parents who had sought help, usually spoke to a member of school staff; and families who received professional support reported a range of support, but only a very small minority (<3%) reported that their child had received evidence-based treatment (CBT). Indeed, while there is evidence that 50-60% of pre-adolescent children recover from anxiety disorders without treatment over a 2-3 year period [2,33], even those children who recover without treatment are at an estimated 50% increased risk for poor functioning in adulthood [34].

Importantly, our findings show that factors other than a child's level of need are the most important determinants of seeking help for child anxiety difficulties. Consistent with the broader literature surrounding child mental health service use [14], we found that parents who perceived that their child may benefit from professional support were more likely to have sought help than those who did not perceive a need for help, but interestingly, after controlling for other child and parent factors, parents who had *not* sought help were more likely to perceive that they themselves may benefit from professional support than those who had sought help for their child. One possible interpretation of this finding is that many parents may feel they would benefit from some support, but this is not enough to prompt actual help-seeking behaviour; or it may relate to a belief that seeking professional help for a child's anxiety may facilitate access to direct support for a child rather than for a parent. In line with previous studies, our findings also indicate that parents' own mental health plays a role in help-seeking for child anxiety [14,15], but we found that it was parents' prior use of mental health services, not their mental health symptoms, that was uniquely associated with help-seeking for a child. We did not find evidence that parents' perceptions surrounding the helpfulness of their mental health support was associated with help-seeking for their child, but it is possible this a reflection of the limited variability in perceived helpfulness reported in this sample.

We also set out to establish parents' own views on barriers/facilitators to seeking and accessing support for child anxiety difficulties. Our findings support previous evidence that parental perceptions of a child's mental health difficulties are an important determinant of parental help-seeking [14], and this study illustrates particular difficulties parents commonly face identifying anxiety problems in children. The majority of parents of children with elevated anxiety, including those where the child met diagnostic criteria, reported barriers related to differentiating between developmentally appropriate and clinically significant anxiety in children. Our findings also highlight the key role primary school staff play in relation to parental help-seeking for child anxiety, with many parents citing a failure of teachers or other professionals to suggest a child needs help as a barrier, and the vast majority of help-seekers endorsing trustworthy and/or understanding teachers as facilitators. Parents also frequently experienced a range of other barriers that made them hesitant or reluctant to seek professional support. Interestingly, although negative views surrounding the effectiveness of mental health treatment is cited as a parent-reported barrier elsewhere [18], only a minority of parents in this study endorsed *professionals can't help with anxiety difficulties in children* as a barrier. Rather, concerns surrounding negative consequences for the child, specifically: not wanting their child to think they have a problem; a belief the anxiety may improve without professional help; a desire to manage the difficulties as a family; and feeling a sense of blame as a parent, more frequently deterred parents from seeking professional support. A lack of help-seeking knowledge is reported elsewhere as a barrier to parental help-seeking [18], and we similarly found that many parents considered a lack of knowledge about who to ask for help and what help is available as barriers in the context of child anxiety. Parents commonly reported barriers related to limited service provision, including long waiting times and referral difficulties; and the level of parental effort required to get help was also apparent, with parents not giving up and pushing hard to get help the most frequently reported facilitators related to accessing support.

The findings also indicate that particular barriers deter or prevent parents from seeking help from professionals; and additional barriers tend to become relevant after parents contact professionals, and make it hard for families to access support. It is therefore not surprising that help-seekers reported more barriers than non-help-seekers, and other variables associated with help-seeking were also associated with parent reported barriers (child’s symptoms and impairment, parental perceived need for help, parental mental health symptoms and mental health service use); indicating that barriers accumulate as a parent progresses through the help-seeking process. In particular, we found that parents who had sought help were more likely to report barriers related to limited service provision than those who had not sought help. Some recognition barriers were common across help-seekers and non-helpseekers, such as the transient nature of the child’s anxiety, and uncertainty about whether the anxiety is normal or not. However, parents who had not sought help were more likely to report the absence of professional recognition of the child’s need for help and a belief that a child’s anxiety may improve without professional help as barriers, suggesting these are particularly pertinent deterrents to help-seeking.

Strengths and limitations

This study focused on parental help-seeking specifically in the context of anxiety in pre-adolescent children, and by doing so identified areas to target to promote help-seeking and access to support within this population where anxiety disorders typically first emerge and the role of parents is paramount. By using standardised assessments to identify children in the community with elevated anxiety, and those who met diagnostic criteria, we were able to establish barriers experienced by families who do not seek professional help, and those who seek help but do not successfully access it. Moreover, we used findings from underpinning qualitative work to develop the questionnaire instrument to help ensure we captured barriers/facilitators relevant to parents of children with anxiety disorders in the community. Indeed, many of the barriers in this study were endorsed by a larger proportion of parents than observed in other studies [13], indicating that we did capture barriers/facilitators pertinent to parents who have and have not sought professional help.

We acknowledge this study has several limitations. We relied on parent report to collect information on help-seeking and support accessed by families and it is possible this may have resulted in either under or over estimating frequencies of help-seeking/support accessed. For example, a larger proportion of parents reported that their child had received counselling (14.5% of parents of children with an anxiety disorder) than CBT (2.2%), and it is possible that parents may not always have been aware of the difference between the two. It is also possible that there was participation bias in the study, both at the school and family level. Participation rates in the initial screening stage of the study were relatively low, with a response rate of 11.5% among schools and 18.2% among families. Schools with an awareness of anxiety difficulties in children may have been more likely to respond to the invitation and participate; and therefore we may not have captured the experiences of families in schools where there is the least support in place to facilitate help-seeking and access to anxiety support. Although we did not target parents of children with anxiety difficulties in the initial screening stage, it is possible that these families were more likely to participate, and the proportion of children screened who met diagnostic criteria and were included in the study was slightly higher than the estimated prevalence rates for child anxiety disorders (7.3% compared to 6.5%) [35]. Parents who had some concerns about their child's anxiety may also have been more likely to take part in the follow-up study, and as a result we may not have fully represented the experiences of families who have not considered that their child may be experiencing difficulties with anxiety. Indeed, although it was not possible to assess the level of parental concern among those who did not take part in the follow-up, parent-reported child anxiety symptoms (SCAS-P) were significantly lower among those who were invited but did not take part in the follow-up, than those who took part. Also, although schools with a varied demographic profile took part in the study, families with lower socio-economic status and from non-White backgrounds were under-represented within the sample, and therefore our findings may not reflect help-seeking experiences within these groups.

Implications

The study findings identify a number of key areas to target to promote both help-seeking and access to professional support for child anxiety. In relation to promoting parental help-seeking, this study confirmed the widespread need for readily accessible tools to help parents make judgements about when a child's anxiety warrants some concern, and may benefit from professional support [18]. Moreover, the findings further illustrate the need to improve public awareness and understanding of how to seek professional support and the type of professional support that is available for child anxiety. In particular this study highlights the importance of targeting negative attitudes and stigma surrounding seeking support for child anxiety, both in relation to parents seeking support for themselves to enable them to help their child and seeking direct support for children; and the need to be sensitive to the fact that parents without personal experience of using mental health services may be less likely to seek support for their child. This study also illustrates the particular importance of ensuring primary school staff are equipped with the skills and resources to enable them to recognise anxiety difficulties in children, as well as to provide guidance for families on tools, strategies and sources of support available. In relation to improving access to professional support, our findings also illustrate the need for i) increased provision for child anxiety, ii) efforts to ensure available support is evidence-based, and iii) services to offer support for parents to equip them with the skills to support their children. Given that families most commonly seek help and receive support through school, further work is needed to develop and evaluate targeted approaches to identify child anxiety problems and deliver evidence-based treatments within school settings.

Conclusions

This study provides current data on parental help-seeking for child anxiety in a community sample from across England. Findings identify a substantial unmet need in relation to this common child mental health problem. The majority of children had not received any professional support, only a tiny minority had received evidence-based treatment, and a sizeable minority of parents had not sought professional help for their child's anxiety. Our findings illustrate the range of barriers to both seeking, and accessing support for child anxiety difficulties, and importantly identify keys areas to target in order to improve access to evidence-based child anxiety treatment. In particular, the findings identify the need for readily available child anxiety identification tools, guidance for families and school staff on the help-seeking process, and increased evidence-based provision that incorporates direct support for parents and is available in school settings.

Additional files

Additional file 1	Factors associated with parental help-seeking: bivariate analyses
Additional file 2	Logistic regression examining contribution of child and parent characteristics in identifying help-seekers and non-help seekers (total sample)
Additional file 3	Factors associated with parent reported barriers (total barrier scores): bivariate analyses
Additional file 4	Individual barriers associated with parental help-seeking (total sample, *n*=222)

List of abbreviations

ADIS-P: Anxiety Disorder Interview Schedule-Parent Version; ADHD: Attention Deficit and/or Hyperactivity Disorder; CAIS-P: Child Anxiety Impact Scale-Parent Version; CSR: Clinical Severity Rating; CBT: Cognitive behavioural therapy; DASS-21: Depression Anxiety and Stress Scales-21; DSM-5: Diagnostic and Statistical Manual of Mental Disorders-5; GP: General Practitioner; Other Specified AD: Other Specified Anxiety Disorder; NHS: National Health Service; ODD: Oppositional Defiant Disorder; SCAS-P: Spence Children's Anxiety Scale-Parent Version; SCAS-C-27: Spence Children's Anxiety Scale-Child Version-27; SCAS-T-20: Spence Children's Anxiety Scale-Teacher Version-20.

Declarations

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Ethics approval and consent to participate

The study was approved by the University of Reading Research Ethics Committee (UREC 16/25). Participants provided informed consent to participate, and where applicable parents provided informed consent for their child to participate.

Consent for publication

Not applicable

Availability of data and material

The dataset used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

Author contributions

All authors contributed to the design of the study. TR collected data, analysed the data, and wrote drafts of the paper, with input from CC and KH. All authors read and approved the final manuscript.

Endnotes

[a] We used published cut-off scores on the SCAS-P and a subset of items on the teacher questionnaire (SCAS-T-8) to identify families to follow-up. Where a child scored above the cut-off on the SCAS-P and/or the SCAS-T-8, the family was invited to take part in the follow-up. Both measures display a good-acceptable level of accuracy in identifying children with anxiety disorders [21] [b] To ensure we had sufficient power for the logistic regression model, child/parent characteristics that were not significantly associated with seeking professional help in the bivariate analyses were not included in the logistic regression model. Reducing the number of predictor variables helped to improve the interpretability of the

logistic regression results, but it does mean that it was not possible to fully explore the role of all parent/child characteristics. Predictor variables were entered into the logistic regression model simultaneously (block-enter method) to capture whether individual variable/s were uniquely associated with help-seeking, after controlling for the influence of other variables that were also related to help-seeking. [c] There was no evidence of multicollinearity in the regression model examining the contribution of individual child/parent characteristics in identifying help-seekers/non help-seekers. Tolerance statistics for two barrier items (*It is difficult to get a referral to a specialist service, There are long waiting times for specialist services*) indicated possible multicollinearity in the regression model examining the contribution of individual barriers. This logistic regression was repeated including only one of these items (*It is difficult to get a referral to a specialist service*) and the results were consistent with the original model so only the original regression model is reported here.

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Tables

Table 1

Sample characteristics

	Anxiety disorder sample (*n*=138)	Total sample (*n*=222)
Child gender		
Female, *n* (%)	63 (45.7)	107 (48.2)
Child age		
Mean (SD)	9.79 (1.18)	9.63 (1.22)
Parent gender		
Female, *n* (%)	133 (96.4)	206 (92.8)
Parent age		
Mean (SD)	40.38 (5.49)	40.46 (5.92)
Parent ethnicity		
White British, *n* (%)	128 (92.8)	200 (91.2)
Family SES		
higher / professional, *n* (%)[a]	64 (46.4)	105 (47.3)
other employed, *n* (%)	66 (47.8)	102 (45.9)
unemployed, *n* (%)	5 (3.6)	9 (4.1)
Parent education		
School completion, *n* (%)	20 (14.5)	35 (15.8)
Further education, *n* (%)	62 (44.9)	85 (38.3)
Higher education / postgraduate, *n* (%)	53 (38.4)	99 (44.6)
SCAS-P (total score)		
Mean (SD)	39.37 (15.72)	33.99 (15.73)
SCAS-C-27 (total score)		
Mean (SD)	29.36 (14.73)	28.33 (14.31)
SCAS-T-20 (total score)		
Mean (SD)	12.04 (8.65)	11.94 (8.04)
CAIS-P		
Total score, Mean (SD)	26.26 (13.53)	21.46 (14.22)
School, Mean (SD)	11.86 (6.78)	10.06 (7.09)
Social, Mean (SD)	7.95 (5.53)	6.36 (5.54)
Home/family, Mean (SD)	6.44 (4.41)	5.05 (4.32)
Parent rated need for support for child's anxiety		
Child benefit from professional support		
Mean (SD)	3.00 (1.16)	2.73 (1.24)
n (%) somewhat/strongly agree	102 (73.9)	142 (64.0)
Parent benefit from support to help child		
Mean (SD)	3.01 (1.12)	2.78 (1.20)
n (%) somewhat/strongly agree	106 (76.8)	151 (68.3)
DASS-21		
Total score, Mean (SD)	15.60 (12.36)	13.90 (11.69)
Anxiety, Mean (SD)	3.32 (3.77)	2.77 (3.49)
Stress, Mean (SD)	7.85 (5.34)	7.13 (5.19)
Depression, Mean (SD)	4.42 (4.80)	4.00 (4.54)
Parent contact with professional about mental health problems	94 (68.1)	147 (66.2)
GP, *n* (%)	86 (62.3)	127 (58.0)
Therapist/counsellor, *n* (%)	63 (45.7)	94 (42.3)
Psychiatrist, *n* (%)	11 (8.0)	18 (8.2)
Parent rated professional support not helpful *n* (%)	10 (7.2)	12 (5.4)
Parent rated professional support very helpful/ extremely helpful *n* (%)	40 (29.0)	73 (32.9)
Primary anxiety diagnosis		

Separation anxiety disorder, *n* (%)	14 (10.2)	
Social anxiety disorder, *n* (%)	32 (23.4)	
Generalised anxiety disorder, *n* (%)	67 (48.9)	
Specific phobia, *n* (%)	15 (10.9)	
Selective Mutism, *n* (%)	1 (0.7)	
Other Specified AD, *n* (%)	8 (5.8)	
Primary anxiety disorder, CSR		
Mean (SD)	4.86 (0.82)	
Presence anxiety diagnosis.		
Separation anxiety disorder, *n* (%)	31 (22.5)	
Social anxiety disorder, *n* (%)	52 (37.7)	
Generalised anxiety disorder, *n* (%)	87 (63.0)	
Specific phobia, *n* (%)	34 (24.6)	
Selective Mutism, *n* (%)	1 (0.7)	
Other Specified AD, *n* (%)	9 (6.5)	
Presence of other diagnoses		
OCD, *n* (%)	8 (5.8)	
ADHD, *n* (%)	17 (12.3)	21 (9.5)
ODD, *n* (%)	2 (1.4)	4 (0.9)

Note

Other Specified AD = Other Specified Anxiety Disorder; CSR = Clinical Severity Rating; OCD = Obsessive Compulsive Disorder; ADHD = Attention Deficit and/or Hyperactivity Disorder; ODD = Oppositional Defiant Disorder

[a] 30.7% of those in employment in the UK classified as higher / professional (available from: https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/datasets/employmentbyoccupationemp04)

Table 2

Frequency and type of help seeking and support accessed

	Anxiety disorder sample (*n*=138)	Total sample (*n*=222)
Contacted a professional for help or advice, *n* (%)	89 (64.5)	117 (52.7)
Professional contacted		
GP / family doctor, *n* (%)	52 (37.7)	62 (27.9)
Teacher or support staff, *n* (%)	81 (58.7)	105 (47.3)
Someone specialising in child mental health, *n* (%)	38 (27.5)	48 (21.0)
School nurse, *n* (%)	1 (1.2)	5 (2.3)
Telephone helpline, *n* (%)	3 (2.2)	4 (1.8)
Other health/social care professional, *n* (%)	18 (13.0)	22 (9.9)
Informal help seeking about child's anxiety, *n* (%)	136 (98.6)	210 (94.6)
Spoken to/used:		
friends, *n* (%)	124 (89.9)	176 (79.3)
family, *n* (%)	127 (92.0)	199 (89.6)
other parents, *n* (%)	109 (79.0)	152 (68.5)
work colleagues, *n* (%)	69 (50.0)	96 (43.2)
internet, *n* (%)	99 (71.7)	134 (60.6)
online parent forums, *n* (%)	26 (18.8)	36 (16.5)
books, *n* (%)	44 (31.9)	64 (29.2)
Informal help seeking about seeking professional support for child, *n* (%)	101 (73.2)	134 (60.4)
friends, *n* (%)	60 (43.5)	79 (35.6)
family, *n* (%)	62 (44.9)	84 (37.8)
other parents, *n* (%)	41 (29.7)	56 (25.7)
work colleagues, *n* (%)	36 (26.1)	46 (21.4)
internet, *n* (%)	62 (44.9)	83 (37.4)
online parent forums, *n* (%)	14 (10.1)	20 (9.0)
Received help from a professional, *n* (%)	53 (38.4)	72 (32.4)
Type of help received		
CBT with child and/or parent, *n* (%)	3 (2.2)	5 (2.3)
Counselling for child, *n* (%)	20 (14.5)	27 (12.2)
Parenting support, *n* (%)	12 (8.7)	15 (6.8)
Professional recommended resources/strategies/books, *n* (%)	21 (15.2)	29 (13.1)
Other type of help, *n* (%)	21 (15.2)	27 (12.2)
Unspecified school support, *n* (%)	5 (3.6)	8 (3.6)
Nurture/emotional group at school, *n* (%)	3 (2.2)	5 (2.3)
Speech therapy, *n* (%)		1 (0.5)
Art/play/drama/alternative therapy, *n* (%)	6 (3.5)	
Medication, *n* (%)	2 (1.4)	
Unspecified support, *n* (%)	4 (2.9)	
Who provided help		
GP / family doctor, *n* (%)	5 (3.6)	8 (3.6)
Teacher or school staff, *n* (%)	30 (21.7)	42 (18.9)
NHS professional specialising in child mental health, *n* (%)	21 (15.2)	29 (13.1)
Private professional, *n* (%)	6 (4.3)	7 (3.2)
Charity, *n* (%)	9 (6.5)	10 (4.5)
School nurse, *n* (%)	1 (0.7)	2 (0.9)
School counsellor, *n* (%)	2 (1.4)	2 (0.9)
Paediatrician, *n* (%)	2 (1.4)	3 (1.4)
Occupational/speech therapist, *n* (%)	1 (0.7)	2 (0.9)

Table 3

Parent reported barriers to seeking and accessing professional support for child anxiety difficulties

	Anxiety disorder sample (*n*=138)		Total sample (*n*=222)	
	Mean (SD) 95% CI	*n* (%) endorsed 95% CI	Mean (SD) 95% CI	*n* (%) endorsed 95% CI
Recognising child's anxiety difficulty barriers (Total)	***8.33 (5.17) 7.45-9.23***		***7.41 (5.21) 6.71-8.12***	
My child has always been anxious	1.10 (1.06) 0.92-1.28	81 (58.7) 50.0-67.0	0.87 (1.00) 0.73-1.00	111 (50.0) 43.2-56.8
My child's anxiety comes and goes in phases[a]	1.55 (1.01) 1.36-1.74	**101 (73.2) [a] 65.0-80.4**	1.38 (1.08) 1.23-1.52	**153 (68.9)[a] 62.4-74.9**
I'm not sure if my child's anxiety is normal[a]	1.38 (1.10) 1.19-1.57	**96 (69.6) [a] 61.2-77.1**	1.20 (1.08) 1.05-1.34	**141 (63.5)[a] 56.8-69.9**
I think my child's anxiety is normal	0.78 (0.97) 0.61-0.95	62 (44.9) 36.5-53.6	0.82 (1.01) 0.68-0.95	101 (45.5) 38.8-52.3
I'm not sure if my child has anxiety difficulties or other difficulties	1.35 (1.14) 1.15-1.55	89 (64.5) 55.9-72.4	1.23 (1.51) 1.07-1.39	134 (60.4) 53.6-66.8
My child has other difficulties that are more serious than anxiety	0.73 (1.01) 0.56-0.90	55 (39.9) 31.6-48.5	0.63 (0.97) 0.50-0.76	77 (34.7) 28.4-41.3
My child doesn't understand that she/he has anxiety difficulties	0.98 (1.09) 0.79-1.16	73 (52.9) 44.2-61.4	0.82 (1.04) 0.68-0.96	104 (46.9) 40.1-53.6
I don't know other people who have had anxiety difficulties	0.49 (0.86) 0.34-0.64	40 (29.0) 21.6-37.3	0.49 (0.87) 0.37-0.61	65 (29.3) 23.4-35.7
Recognising the need for professional support barriers (Total)	***12.47 (8.35) 11.03-13.90***		***10.88 (8.17) 9.79-11.98***	
Teachers or other professionals have never suggested my child would benefit from professional help[b]	1.25 (1.21) 1.05-1.46	**81 (58.9)[b] 50.0-67.0**	1.11 (1.18) 0.95-1.27	**120 (54.1) [b] 47.3-60.3**
Talking to my child about her/his anxiety may make the problem worse	1.01 (1.04) 0.83-1.19	74 (53.6) 44.9-62.1	0.88 (1.01) 0.74-1.01	110 (49.6) 42.8-56.3
I don't want my child to think she/he has a problem[b]	1.36 (1.10) 1.18-1.55	**95 (68.8)[b] 60.4-76.4**	1.22 (1.10) 1.07-1.37	**141 (63.5)[b] 56.8-69.9**
Family life is busy or we have lots of other things going on in the family	0.89 (1.08) 0.70-1.07	64 (46.4) 37.9-55.1	0.82 (1.03) 0.68-0.96	100 (45.1) 38.4-51.8
Professionals can't help with anxiety difficulties in children	0.34 (0.71) 0.22-0.46	30 (21.7) 15.2-29.6	0.28 (0.65) 0.20-0.37	42 (18.9) 14.0-24.7
My child's anxiety may improve without professional help	0.99 (1.05) 0.81-1.17	77 (55.8) 47.1-64.2	0.95 (1.02) 0.81-1.09	**120 (54.1)[b]47.3-60.7**
I want us to manage my child's anxiety as a family	0.95 (1.05) 0.77-1.13	72 (52.2) 43.5-60.5	0.92 (1.03) 0.78-1.06	116 (52.3) 45.5-59.0
I feel a sense of failure or blame as a parent	1.15 (1.14) 0.96-1.35	78 (56.5) 47.8-64.9	0.98 (1.11) 0.83-1.13	111 (50.0) 43.2-56.8
People I know may blame me or judge me or think I am a bad parent	0.85 (1.10) 0.66-1.04	58 (42.0) 33.7-50.7	0.66 (0.99) 0.52-0.79	80 (36.0) 29.7-42.7
People see anxiety or mental health difficulties as a weakness	0.98 (1.14) 0.79-1.18	66 (47.8) 39.3-56.5	0.83 (1.07) 0.69-0.97	96 (43.2) 36.6-50.0
I don't want my child to be labelled	1.08 (1.18) 0.88-1.28	73 (52.9) 44.2-61.4	0.98 (1.15) 0.82-1.13	109 (49.1) 42.3-55.9
I don't want other people to know about my child's difficulties	0.59 (0.91) 0.43-0.74	48 (34.8) 26.9-43.4	0.48 (0.83) 0.37-0.59	68 (30.6) 24.6-37.1
My child is worried about what other children will think about her/him getting help	1.05 (1.18) 0.84-1.25	69 (50.0) 41.4-58.6	0.86 (1.12) 0.71-1.01	95 (42.8) 36.2-49.6
Contacting professionals barriers (Total)	***11.05 (7.80) 9.70-12.39***		***8.95 (7.66) 7.92-9.98***	
I don't know who to ask for help[c]	1.32 (1.29) 1.12-1.51	**89 (64.5)[c] 55.9-72.9**	1.12 (1.15) 0.96-1.27	**122 (55.0)[c] 48.2-61.6**
I don't know what help is available for children with anxiety difficulties[c]	1.53 (1.09) 1.34-1.71	**100 (72.5)[c] 64.2-79.7**	1.36 (1.13) 1.21-1.51	**150 (67.6)[c] 61.0-73.6**
I don't trust information I've read online about professional help for	0.64 (0.88) 0.49-0.79	54 (39.1) 30.9-47.8	0.51 (0.81) 0.40-0.62	73 (32.9) 26.7-39.5

anxiety difficulties in children				
I don't know if GPs can provide advice on anxiety difficulties	0.85 (1.07) 0.66-1.03	61 (44.2) 35.8-52.1	0.67 (0.99) 0.54-0.80	82 (36.9) 30.6-43.7
I don't know if teachers can provide advice on anxiety difficulties	1.02 (1.05) 0.83-1.20	79 (57.3) 48.6-65.6	0.84 (1.02) 0.70-0.97	105 (47.3) 40.6-54.1
I am afraid if I talk to a professional it will raise concerns about my parenting	0.62 (0.90) 0.46-0.77	54 (39.1) 30.9-47.8	0.46 (0.81) 0.35-0.57	68 (30.6) 24.6-37.1
Professionals won't listen to me or won't take me seriously	0.86 (1.07) 0.68-1.05	63 (45.7) 37.2-54.3	0.66 (0.97) 0.53-0.79	83 (37.4) 31.0-44.1
Professionals will blame me	0.58 (0.95) 0.42-0.74	43 (31.2) 23.6-39.6	0.43 (0.83) 0.32-0.54	56 (25.2) 19.7-31.5
Teachers don't know much about anxiety difficulties in children	1.01 (1.08) 0.83-1.20	76 (55.1) 46.4-63.5	0.81 (1.02) 0.68-0.95	102 (46.0) 39.3-52.7
My GP doesn't know me and/or my child	1.03 (1.23) 0.82-1.24	63 (45.7) 37.2-54.3	0.84 (1.15) 0.69-0.99	88 (39.6) 33.2-46.4
GPs don't know much about anxiety difficulties in children	0.76 (1.00) 0.58-0.93	57 (41.3) 33.0-50.0	0.61 (0.92) 0.49-0.73	79 (35.6) 29.3-42.3
It is difficult to make an appointment at my GP surgery	1.09 (1.18) 0.89-1.29	61 (44.2) 35.8-52.9	0.94 (1.12) 0.79-1.08	105 (47.3) 40.6-54.1
Receiving professional support barriers (Total)	***12.24 (9.30) 10.62-13.84***		***10.15 (9.01) 8.92-11.37***	
Professionals have dismissed my concerns about my child in the past	1.01 (1.20) 0.80-1.21	64 (46.4) 37.9-55.1	0.78 (1.14) 0.63-0.93	79 (35.6) 29.3-42.3
Professionals don't think my child needs professional help	0.64 (0.94) 0.47-0.80	50 (36.2) 28.2-44.8	0.53 (.88) 0.41-0.65	68 (30.6) 24.6-37.1
Professionals only offer parenting courses	0.59 (1.02) 0.41-0.77	38 (27.5) 20.3-35.8	0.46 (.92) 0.33-0.58	50 (22.5) 17.2-28.6
There isn't any professional help available for children with anxiety difficulties	0.57 (0.91) 0.41-0.72	43 (31.2) 23.6-39.6	0.47 (.83) 0.35-0.58	62 (27.9) 22.1-34.3
It is a battle to access professional help	1.35 (1.24) 1.13-1.56	81 (58.7) 50.0-67.0	1.08 (1.20) 0.92-1.25	111 (50.0) 43.2-56.8
It is difficult to get a referral to a specialist service[d]	1.49 (1.23) 1.28-1.70	**89 (64.5|) 55.9-72.4[d]**	1.18 (1.21) 1.02-1.34	**120 (54.1) [d] 47.3-60.7**
There are long waiting times for specialist services[d]	1.57 (1.27) 1.35-1.79	**89 (64.5) 55.9-72.4[d]**	1.27 (1.27) 1.10-1.45	**121 (54.5) [d] 47.7-61.2**
I can't afford to pay for private professional help	1.44 (1.34) 1.21-1.67	79 (57.3) 48.6-65.6	1.27 (1.32) 1.09-1.45	116 (52.3) 45.5-59.0
My child's behaviour is not disruptive at school	0.93 (1.17) 0.73-1.12	62 (44.9) 36.5-53.6	0.85 (1.14) 0.70-1.01	94 (42.3) 35.8-49.1
My child's school does not prioritise mental health	0.69 (1.04) 0.51-0.87	50 (36.2) 28.2-44.8	0.58 (.95) 0.45-0.70	71 (32.0) 25.9-38.6
My child's school has limited resources	0.92 (1.07) 0.74-1.10	68 (49.3) 40.7-57.9	0.80 (1.04) 0.66-0.94	97 (35.6) 37.1-50.5
Total barriers	***43.39 (24.93) 39.13-47.65***		***36.95 (25.15) 33.59-40.31***	

a First and second rank ordered *Recognising child's anxiety difficulty* barriers based on % endorsed
b First and second rank ordered *Recognising the need for professional support* barriers based on % endorsed
c First and second rank ordered *Contacting professionals* barriers based on % endorsed
d First and second rank ordered *Receiving support* barriers based on % endorsed

Table 4

Parent reporters facilitators among parents who reported seeking help (*n*=117)

	Mean (SD) 95% CI	*n* (%) endorsed 95% CI
Recognising child's anxiety difficulty facilitators (Total)	***7.78 (3.80) 7.07-8.49***	
My child's anxiety got worse [a]	2.18 (0.97) 2.00-2.36	**104 (88.9)** [a] **81.7-93.9**
My child's anxiety difficulties are serious [a]	1.64 (1.05) 1.44-1.83	**92 (78.6)** [a] **70.1-85.7**
My friends/family think that my child has anxiety difficulties	1.58 (1.17) 1.36-1.80	84 (71.8) 62.7-79.7
Something happened to trigger or cause my child's anxiety difficulties	1.20 (1.22) 0.98-1.43	65 (55.6) 46.1-64.7
A professional told me my child may have anxiety difficulties	1.17 (1.28) 0.93-1.41	58 (49.6) 40.2-59.0
Recognising the need for professional support facilitators (Total)	***8.87 (5.02) 7.93-9.80***	
My friends/family think my child may benefit from professional help	1.54 (1.21) 1.31-1.77	79 (67.5) 58.2-75.9
My child wants professional help	1.01 (1.18) 0.79-1.23	55 (47.0) 37.7-56.5
I am desperate to get help for my child [b]	1.77 (1.13) 1.56-1.98	**94 (80.3)** [b] **72.0-87.1**
I cannot manage my child's anxiety without professional help or support	1.38 (1.12) 1.17-1.58	81 (69.2) 60.0-77.4
My child's anxiety impacts on his/her life [b]	2.25 (.88) 2.08-2.41	**106 (90.6)** [b] **83.8-95.2**
A professional advised me to seek help for my child	0.91 (1.18) 0.69-1.13)	50 (42.7) 36.6-52.6
Contacting professionals facilitators (Total)	***13.27 (6.31) 12.09-14.44***	
I know how to talk to professionals	1.37 (1.15) 1.16-1.59	80 (68.4) 59.1-76.7
Professional listen to me	1.12 (1.02) 0.93-1.30	75 (64.1) 54.7-72.8
My GP is understanding and supportive	0.73 (0.99) 0.54-0.91	49 (41.9) 32.8-51.4
Teachers at my child's school are understanding and supportive [c]	1.73 (1.06) 1.53-1.92	**96 (82.1)** [c] **73.9-88.5**
I trust my GP	1.04 (1.07) 0.85-1.24	67 (57.3) 47.8-66.4
I trust the teachers at my child's school [c]	1.81 (1.04) 1.61-2.00	**98 (83.8)** [c] **75.8-89.9**
Teachers at my child's school know my child	1.85 (1.11) 1.64-2.06	94 (80.3) 72.0-87.1
There is a clear point of contact at my child's school	1.80 (1.23) 1.57-2.02	86 (73.5) 64.5-81.2
I have read online about the help that is available for children with anxiety difficulties	0.88 (1.14) 0.66-1.09	48 (41.0) 32.0-50.5
I know other parents who have spoken to professionals	0.91 (1.13) 0.70-1.12	53 (45.3) 36.1-34.8

about their child's anxiety or other mental health difficulties		
Receiving professional support facilitators (Total)	***7.97 (6.74) 6.71-9.23***	
I paid a private professional for an assessment or support for my child's anxiety.	0.35 (0.91) 0.17-0.52	12 (10.3) 5.4-17.2
I have pushed hard to get professional help for my child[d]	1.11 (1.22) 0.88-1.33	**60 (51.3)[d] 41.9-60.6**
I have not given up asking for help[d]	1.40 (1.27) 1.17-1.64	**72 (61.5) [d] 52.1-70.4**
I have contacted different professionals to try to get help for my child	1.01 (1.15) 0.79-1.22	58 (49.6) 40.2-59.0
My child meets the required criteria to access specialist services	0.80 (1.21) 0.57-1.03	39 (33.3) 24.9-42.6
My GP referred my child to a specialist service	0.73 (1.17) 0.51-0.94	36 (30.8) 22.6-40.0
My child's school helped with a referral to a specialist service	1.00 (1.25) 0.77-1.23	50 (42.7) 33.6-53.2
My child has received professional help for another mental health or physical health difficulty	0.65 (1.12) 0.45-0.86	32 (27.4) 19.5-36.4
My child has received support through school for an academic/learning related difficulty	0.97 (1.21) 0.75-1.20	50 (42.7) 33.6-52.2
Total facilitators	***37.92 (18.01) 34.55-41.27***	

a First and second rank ordered *Recognising child's anxiety difficulty* facilitators based on % endorsed
b First and second rank ordered *Recognising the need for professional support* facilitators based on % endorsed
c First and second rank ordered *Contacting professionals* facilitators based on % endorsed
d First and second rank ordered *Receiving support* facilitators based on % endorsed

Additional file 1

Factors associated with parental help seeking: bivariate analyses

	Anxiety disorder sample (*n*=138)			Total sample (*n*=222)		
	Help-seekers (*n*=89)	Non-help seekers (*n*=49)	Group difference	Help-seekers (*n*=117)	Non-help seekers (*n*=105)	Group difference
Child gender						
Female, *n* (%)	40 (44.9)	23 (46.9)	$X^2 = 0.05$, $p = 0.82$	50 (42.7)	57 (54.3)	$X^2 = 2.96$, $p = 0.09$
Child age						
mean (SD)	9.86 (1.15)	9.66 (1.23)	$t(134) = 0.97$, $p = 0.33$	9.75 (1.19)	9.48 (1.23)	$X^2 =1.63$, $p = 0.11$
Family SES						
higher / professional, *n* (%)	41 (47.1)	23 (47.9)	$X^2 = 0.01$, $p = 0.93$	56 (49.1)	49 (48.0)	$X^2 = 0.03$, $p = 0.87$
Parent education						
Higher education, *n* (%)	31 (34.8)	22 (44.9)	$X^2 = 1.72$, $p = 0.19$	49 (41.9)	50 (47.1)	$X^2 = 0.88$, $p = .35$
SCAS-P (total score)						
Mean (SD)	41.89 (17.01)	34.80 (11.92)	**$t(136) = 2.59$, $p = 0.01$, $d = 0.48$**	38.64 (16.48)	28.80 (13.10)	**$t(220) = 4.89$, $p < 0.001$, $d = 0.66$**
SCAS-C-27 (total score)						
Mean (SD)	31.05 (15.20)	26.38 (13.53)	$t(114) = 1.66$, $p = 0.10$	30.02 (14.70)	26.57 (13.48)	$t(186) = 1.66$, $p = 0.10$
SCAS-T-20 (total score)						
Mean (SD)	12.97 (8.68)	10.18 (8.41)	$t(115) = 1.66$, $p = 0.10$	13.46 (8.56)	10.18 (7.03)	**$t(196) = 2.92$, $p = 0.004$, $d = 0.42$**
CAIS-P						
Total score, Mean (SD)	28.25 (14.25)	22.73 (11.47)	**$t(134) = 2.32$, $p = 0.02$, $d = 0.43$**	26.20 (14.76)	16.28 (11.62)	**$t(218) = 5.51$, $p < 0.001$, $d = 0.75$**
School, Mean (SD)	12.51 (7.08)	10.63 (6.07)	$t(130) = 1.53$, $p = 0.13$	12.04 (7.23)	7.83 (6.26)	**$t(213) = 4.53$, $p < 0.001$, $d = 0.62$**
Social, Mean (SD)	8.22 (6.04)	7.46 (4.50)	$t(132) = 0.76$, $p = 0.45$	7.54 (6.18)	5.07 (4.01)	**$t(215) = 3.35$, $p = 0.001$, $d = 0.47$**
Home/family, Mean (SD)	7.47 (4.38)	4.57 (3.87)	**$t(136) = 3.88$, $p < 0.001$, $d = 0.70$**	6.59 (4.46)	3.34 (3.47)	**$t(215) = 6.00$, $p < 0.001$, $d = 0.81$**
Perceived need for professional help (child)						
Mean (SD)	3.25 (1.16)	2.55 (1.02)	**$t(136) = 3.51$, $p = 0.001$, $d = 0.64$**	3.17 (1.14)	2.23 (1.18)	**$t(220) = 6.05$, $p < 0.001$, $d = 0.81$**
Perceived need for professional help (parent)						
Mean (SD)	3.16 (1.12)	2.73 (1.08)	**$t(136) = 2.16$, $p = 0.03$, $d = 0.39$**	3.08 (1.11)	2.46 (1.23)	**$t(219) = 3.96$, $p < 0.001$, $d = 0.53$**
DASS-21						
Total score, Mean (SD)	17.16 (13.41)	12.81 (9.75)	**$t(134) = 1.99$, $p = 0.05$, $d = 0.37$**	15.63 (12.62)	11.99 (10.29)	**$t(217) = 2.32$, $p = 0.02$, $d = 0.32$**
Anxiety, Mean (SD)	3.60 (4.15)	2.82 (2.95)	$t(134) = 1.16$, $p = 0.25$	3.04 (3.83)	2.46 (3.07)	$t(217) = 1.23$, $p = 0.22$
Stress, Mean (SD)	8.40 (5.64)	6.88 (4.65)	$t(134) = 1.61$, $p = 0.11$	7.91 (5.53)	6.26 (4.66)	**$t(217) = 2.38$, $p = 0.02$, $d = 0.32$**

Depression, Mean (SD)	5.17 (5.27)	3.06 (3.47)	**$t(133) = 2.49, p = 0.01, d = 0.47$**	4.68 (4.97)	3.24 (3.89)	**$t(216) = 2.36, p = 0.02, d = 0.32$**
Parent contact with professional about mental health problems, *n*(%)	66 (75.0)	28 (57.1)	**$X^2 = 4.04, p = 0.04$**	83 (70.9)	64 (61.0)	$X^2 = 2.19, p = 0.14$
GP *n* (%)	61 (68.6)	25 (51.0)	**$X^2 = 3.97, p = 0.05$**	75 (64.1)	52 (49.5)	**$X^2 = 4.50, p = 0.03$**
MH Specialist, *n* (%)	52 (58.4)	16 (32.7)	**$X^2 = 8.24, p = 0.004$**	65 (55.6)	35 (33.3)	**$X^2 = 10.70, p = 0.001$**
Parent rated professional support not helpful[a], *n* (%)	7 (7.9)	3 (6.1)	$X^2 = 0.14, p = 0.71$	7 (6.0)	5 (4.8)	$X^2 = 0.16, p = 0.69$
Parent rated professional support very helpful/ extremely helpful[b], *n* (%)	29 (32.6)	11 (22.4)	$X^2 = 0.58, p = 0.21$	42 (35.9)	31 (29.5)	$X^2 = 1.02, p = 0.31$
Total barriers	47.02 (25.66)	36.43 (22.10)	**$t(132) = 2.38, p = 0.02, d = 0.44$**	43.74 (25.55)	29.24 (22.42)	**$t(216) = 4.28, p < 0.001, d = 0.60$**
Recognising child's anxiety difficulties barriers	8.31 (5.47)	8.39 (4.61)	$t(131) = 0.09, p = 0.93$	8.04 (5.43)	6.70 (4.88)	$t(213) = 1.88, p = 0.06$
Recognising the need for professional support barriers	12.74 (5.58)	11.96 (7.97)	$t(131) = 0.51, p = 0.61$	11.85 (8.38)	9.80 (7.82)	$t(214) = 1.85, p = 0.07$
Contacting professionals barriers	12.11 (8.04)	8.93 (6.94)	**$t(129) = 2.24, p = 0.03, d = 0.42$**	10.95 (7.97)	6.66 (6.62)	**$t(213) = 4.25, p < 0.001, d = 0.59$**
Receiving support barriers	14.55 (9.09)	7.66 (8.00)	**$t(132) = 4.26, p < 0.001, d = 0.80$**	13.43 (8.84)	6.32 (7.61)	**$t(208) = 6.20, p < 0.001, d = 0.86$**

Note. SES=socio-economic status; MH Specialist = mental health specialist

[a] Comparison group = Parents who had not received professional support themselves + those who had received support and rated it as slightly helpful/moderately helpful/very helpful/extremely helpful. [b] Comparison group = Parents who had not received professional support themselves+those who had received support and rated it as not helpful/slightly helpful/moderately helpful

Additional file 2

Logistic regression examining contribution of child and parent characteristics in identifying help-seekers and non-help seekers (total sample)

	b (Wald statistic)	Adjusted Odds Ratio (95% CI)	R^2	Model
SCAS-P	0.18 (1.69), $p = 0.19$	1.01 (0.99-1.05)	0.30 (Cox & Snell)	$X^2(7) =$
CAIS-P-Home/family	**0.14 (6.74), $p = 0.009$**	**1.14 (1.03-1.27)**	0.39 (Nagelkerke)	75.29
DASS-21-Total	0.001 (0.003), $p = 0.96$	1.00 (0.97-1.03)		
Parent contact with mental health specialist	**0.97 (7.77), $p = 0.005$**	**2.63 (1.33-5.19)**		
Perceived need for professional help (child)	**1.44 (15.76), $p < 0.001$**	**4.23 (2.08-8.63)**		
Perceived need for professional help (parent)	**-1.04 (7.90), $p = 0.005$**	**0.35 (0.17-0.73)**		
Anxiety diagnosis	0.46 (1.56), $p = 0.21$	1.59 (0.77-3.29)		

Additional file 3

Factors associated with parent reported barriers (total barrier scores): bivariate analyses

	Anxiety disorder sample (n=138)	Total sample (n=222)
Child gender		
Female, Mean (SD)	43.20 (26.06)	35.30 (25.34)
Male, Mean (SD)	43.45 (24.13)	38.49 (24.99)
	$t(132) = 0.08$, $p = 0.94$	$t(216) = 0.93$, $p = 0.35$
Child age	$r = -0.04$, $p = 0.62$	r = 0-.00, $p = 0.93$
Family SES		
higher / professional, Mean (SD)	40.38 (22.88)	38.44 (25.05)
other, Mean (SD)	43.91 (24.81)	34.23 (23.48)
	$t(129) = 0.85$, $p = 0.40$	$t(210) = 1.26$, $p = 0.21$
Parent education		
Higher education, Mean (SD)	36.44 (19.69)	31.86 (21.07)
School/further education, Mean (SD)	46.83 (26.63)	40.29 (27.06)
	$t(129) = 2.41$, $p = 0.02$	**$t(213) = 2.51$, $p = 0.01$**
SCAS-P (total score)	**$r = 0.21$, $p = 0.02$**	**$r = 0.36$, $p < 0.001$**
SCAS-C-27 (total score)	**$r = 0.19$, $p = 0.05$**	**$r = 0.20$, $p = 0.007$**
SCAS-T-20 (total score)	$r = 0.10$, $p = 0.30$	$r = 0.02$, $p = 0.78$
CAIS-P		
Total score	**$r = 0.32$, $p < 0.001$**	**$r = 0.47$, $p < 0.001$**
School	**$r = 0.31$, $p < 0.001$**	**$r = 0.45$, $p < 0.001$**
Social	**$r = 0.18$, $p = 0.04$**	**$r = 0.33$, $p < 0.001$**
Home/family	**$r = 0.30$, $p < 0.001$**	**$r = 0.40$, $p < 0.001$**
Perceived need for professional help (child)	$r = 0.14$, $p = 0.10$	**$r = 0.27$, $p < 0.001$**
Perceived need for professional help (parent)	**$r = 0.18$, $p = 0.04$**	**$r = 0.29$, $p < 0.001$**
DASS-21 (total score)	**$r = 0.49$, $p < 0.001$**	**$r = 0.40$, $p < 0.001$**
Parent contact with mental health specialist		
No contact	37.58 (23.40)	31.89 (23.51)
Contact	48.79 (25.16)	42.92 (25.61)
	$t(130) = 2.65$, $p = 0.009$	**$t(213) = 3.29$, $p = 0.01$**

Note. SES=socio-economic status

Additional file 4

Individual barriers associated with parental help seeking (total sample, *n*=222)

	b (Wald statistic)	Adjusted Odds Ratio (95% CI)	R^2	Model
Parent education	0.14 (0.14), *p* = 0.70	1.15 (0.56-2.35)	0.30 (Cox & Snell) 0.40 (Nagelkerke)	$X^2(11)$ = 70.62
Anxiety diagnosis	**1.14 (9.56), *p* = 0.02**	**3.12 (1.52-6.43)**		
My child's anxiety comes and goes in phases	0.23 (1.27), *p* = 0.26	1.25 (0.85-1.85)		
I'm not sure if my child's anxiety is normal	0.27 (1.72), *p* = 0.19	1.31 (0.88-1.94)		
I don't want my child to think she/he has a problem	0.04 (0.05), *p* = 0.83	1.04 (0.72-1.52)		
My child's anxiety may improve without professional help	**-0.52 (6.45), *p* = 0.01**	**0.60 (0.40-0.89)**		
Teachers or other professionals have never suggested my child would benefit from professional help	**-0.56 (9.32), *p*= 0.02**	**0.57 (0.40-0.82)**		
I don't know who to ask for help	-0.29 (1.15), *p* = 0.28	0.75 (0.44-1.27)		
I don't know what help is available for children with anxiety difficulties	0.25 (0.83), *p* = 0.36	1.29 (0.75-2.23)		
It is difficult to get a referral to a specialist service	**0.86 (7.58), *p* = 0.06**	**2.36 (1.28-4.35)**		
There are long waiting times for specialist services	0.14 (0.24), *p* = 0.63	1.14 (0.67-1.97)		

Chapter 5: Paper 4

Identifying children with anxiety disorders using brief versions of the Spence Children's Anxiety Scale for children, parents, and teachers.

Accepted for publication in *Psychological Assessment* (26.12.2017)

Reardon, T., Spence, S., Hesse, J., Shakir, A., & Creswell, C. (in press) Identifying children with anxiety disorders using brief versions of the Spence Children's Anxiety Scale for children, parents, and teachers. *Psychological Assessment*[*]

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[*] Minor amendments have been made to the paper for the purpose of this thesis

5.1 Introduction to Paper 4

Papers 2 and 3 illustrated that difficulties identifying anxiety in children presents a key barrier to professional help-seeking, and identified a need for a tool to help parents and professionals identify anxiety difficulties in children. Paper 4 therefore set out to develop new brief questionnaires for parents, children and teachers designed to improve identification of children who are experiencing difficulties with anxiety, and in turn improve access to appropriate professional support.

Paper 4 includes the community sample (*n*=361) recruited as part of the screening phase of the qualitative study reported in Paper 2, and a clinic-referred sample (*n*=338) recruited as part of two randomised controlled trials (RCTs) conducted within the Berkshire Child Anxiety Clinic (BCAC). 175 children in the clinic-referred sample participated in an RCT comparing Child Cognitive Behavioural Therapy (CCBT) alone, with CCBT supplemented by either CBT to target maternal anxiety or an intervention to target mother-child interactions (Creswell et al., 2015); and 163 children participated in an RCT comparing two guided parent-delivered CBT groups to a wait-list control (Thirlwall et al., 2013). Data used in Paper 4 was collected as part of the initial assessment conducted prior to randomisation and treatment group allocation in each RCT. Recruitment procedure and sample details for the community sample and clinic-referred sample are provided in Paper 4, and further details relating to the recruitment procedure used in the two RCTs are provided below.

5.1.1 RCT examining treatment for child anxiety disorders in the context of maternal anxiety (Creswell et al., 2015)

Participants were referrals to the BCAC and were recruited between June 2008 and May 2011. Families were assessed for eligbility for the trial if i) there was a supected child anxiety disorder, ii) the child was aged 7-12 years, and iii) the child did not have a significant physical or intellectual impairment. The study was described to potential participants orally and in writing, and informed consent was obtained from mothers, and assent from children. Baseline assessments included diagnostic assessments with the children and their mothers to determine whether or not both the child and their mother met diagnostic criteria for an anxiety disorder. As part of the baseline assessment, questionnaire measures were also adminsitered with children and their mothers; and questionnaire measures were posted to the child's class teacher. Recruited participants were 211 children aged 7-12 with an anxiety disorder, and their mother who also had an anxiety disorder. Inclusion criteria for the clinic-referred sample in Paper 4 required that the child was aged 7-11 at the trial baseline assessment (*n*=175).

5.1.2 RCT examing treatment for child anxiety disorders via guided-parent delivered CBT (Thirlwall et al., 2013)

Participants were referrals to the BCAC and were recruited from April 2008 to December 2010. All children aged 7-12 referred to the BCAC, and their primary carer were assessed to establish suitability for the trial and to collect baseline measures. Children and their primary caregiver attended baseline assessment appointments, including a diagnostic assessment with the child and the parent, and questionnaire measures. Questionnaire measures were also posted to the child's class teacher. In total 194 children (aged 7-12) with an anxiety disorder, whose primary carer did not have a current anxiety disorder were recruited into the trial. Inclusion criteria for the clinci-referred sample in Paper 4 required that the child was aged 7-11 at baseline assessment (*n*=163).

5.1.3 References

Creswell, C., Cruddace, S., Gerry, S., Gitau, R., McIntosh, E., Mollison, J., … Cooper, P. J. (2015). Treatment of childhood anxiety disorder in the context of maternal anxiety disorder: a randomised controlled trial and economic analysis. *Health Technology Assessment*, *19*(38). https://doi.org/10.3310/hta19380

Thirlwall, K., Cooper, P. J., Karalus, J., Voysey, M., Willetts, L., & Creswell, C. (2013). Treatment of child anxiety disorders via guided parent-delivered cognitive-behavioural therapy: Randomised controlled trial. *British Journal of Psychiatry*, *203*(6), 436–444. https://doi.org/http://dx.doi.org/10.1192/bjp.bp.113.126698

5.2 Paper 4: Identifying children with anxiety disorders using brief versions of the Spence Children's Anxiety Scale for children, parents, and teachers.

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Abstract

Anxiety disorders are among the most prevalent mental health disorders experienced by children, and are associated with significant negative outcomes. Only a minority of affected children, however, access professional help, and a failure to identify children with anxiety disorders presents a key barrier to treatment access. Existing child anxiety questionnaire measures are long and time consuming to complete, limiting their potential for widespread use as identification tools in community settings. We developed a brief questionnaire for parents, children and teachers using items from the Spence Children's Anxiety Scale (SCAS); and evaluated the new measure's psychometric properties, capacity to discriminate between a community (n=361) and clinic-referred sample (n=338) of children aged 7-11, and identified optimal cut-off scores for accurate identification of pre-adolescent children experiencing clinically significant levels of anxiety. The findings provided support for the reliability and validity of 8-item versions of the SCAS, with the brief questionnaire scores displaying comparable internal consistency, agreement among reporters, and convergent/divergent validity to the full-length SCAS scores. The brief SCAS scores also discriminated between the community and clinic-referred samples, and identified children in the clinic-referred sample with a moderate-good level of accuracy, and acceptable sensitivity and specificity. Combining reporters improved sensitivity, but at the expense of specificity; and findings suggested parent report should be prioritised. This new brief questionnaire has potential for use in community settings as a tool to improve identification of children who are experiencing clinically significant levels of anxiety and warrant further assessment and potential support.

Word count: 245

Key words: anxiety; child; identification; brief measure

Public Significance Statement

We developed and evaluated brief versions of the Spence Children's Anxiety Scale for parents, children and teachers. Results provide support for the potential application of this new brief questionnaire in community settings to improve identification of children with anxiety disorders.

Identifying children with anxiety disorders using brief versions of the Spence Children's Anxiety Scale for children, parents, and teachers

Anxiety disorders are the most common mental health disorders experienced by children and young people (Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015), with half of all lifetime anxiety disorders emerging by age 11 (Kessler, Chiu, Demler, & Walters, 2005). Anxiety disorders during childhood are associated with impaired academic, financial, social and health functioning; and place an individual at increased risk for continued or recurring anxiety and other mental health disorders later in life (Copeland, Angold, Shanahan & Costello, 2014; Essau, Lewinsohn, Olaya, & Seeley, 2014). The high prevalence and significant negative outcomes associated with child anxiety disorders, coupled with the associated economic burden for society (Fineberg et al., 2013), highlight the importance of effective early intervention. However, while effective child anxiety treatments exist (James, James, Cowdrey, Soler, & Choke, 2013), only a minority of children affected by anxiety disorders access treatment (Chavira, Stein, Bailey, & Stein, 2004; Merikangas et al., 2011).

In order for a child to access anxiety treatment, they need to be identified as experiencing a clinically significant anxiety problem; and recent reviews of barriers to child mental health treatment illustrate the difficulties that both parents (Reardon et al., 2017) and primary care practitioners (O'Brien, Harvey, Howse, Reardon, & Creswell, 2016) face identifying mental health difficulties in children. In particular, parents report that difficulties recognising a child's mental health problem, and difficulties recognising the severity and impact of a problem are barriers to help-seeking (Reardon, et al.,2017); and primary care practitioners report that a lack of confidence in identification, time restrictions, and a lack of tools and resources hinders recognition of child mental health problems (O'Brien, et al., 2016). The availability of accurate identification tools could help overcome these barriers and improve identification of children with anxiety disorders in community settings.

A number of questionnaires designed to assess anxiety in children exist, typically consisting of corresponding child and parent report questionnaires (e.g. Spence Children's Anxiety Scale, SCAS; Revised Depression and Anxiety Scale, RCADS [a derivative of the SCAS]; Screen for Child Anxiety Related Disorders, SCARED; Multidimensional Anxiety Scale for Children, MASC 2). As a potential tool for identifying children with clinically significant levels of anxiety, the SCAS, has the following strengths: i) it was designed specifically to assess symptoms of DSM-IV anxiety disorders in children, ii) it was developed within a community (rather than clinical) population, and iii) it is available free of charge. Indeed, both the child and parent report versions of the SCAS (SCAS-C/P) have been well evaluated in community and clinical samples of children and young people with evidence to support their internal consistency, test-retest reliability, convergent and divergent validity, and capacity to discriminate between children with anxiety disorders versus community samples (e.g. Arendt, Hougaard, & Thastum, 2014; DeSousa et al., 2014; Nauta et al., 2004; Orgilés, Fernández-Martínez, Guillén-Riquelme, Espada, & Essau, 2016; Spence, Barrett, & Turner, 2003; Whiteside & Brown, 2008). A few studies have also examined the capacity of the SCAS-C/P and their subscales to identify specific anxiety diagnoses (Brown-Jacobsen, Wallace, & Whiteside, 2011; Whiteside, Gryczkowski, Biggs, Fagen, & Owusu, 2012), and to discriminate between those with anxiety versus non-anxiety psychiatric diagnoses (Olofsdotter, Sonnby, Vadlin, Furmark, & Nilsson, 2015). However, data relating to optimal cut-off scores on the SCAS-C/P that maximise sensitivity (correct classification of children with anxiety disorders) and specificity (correct classification children without anxiety disorders) among pre-adolescent children are not currently available. Furthermore, the SCAS-C/P consists of 38-items and as such is time consuming to complete, limiting its potential for widespread application as a tool for identifying children with clinically significant levels of anxiety in community settings. Validated brief questionnaires designed to identify anxiety and depressive disorders in adults are widely used in primary care settings (GAD-7; Spitzer, Kroenke, Williams, & Löwe, 2006; PHQ-9; Kroenke, Spitzer, & Williams, 2001), but corresponding, well-evaluated, brief questionnaires to assess anxiety in children are yet to be developed despite their clear utility in both primary care and school settings. Shorter versions of the RCADS have been developed (including a 20-item anxiety scale (Muris, Meesters, & Schouten, 2002) and 15-item anxiety scale (Ebesutani et al., 2012), but these are not as brief as the adult equivalents and may be too long for routine use in, for example, primary care settings where time constraints are a particular concern (Klinkman, 1997; O'Brien et al., 2016). Primary care appointments are short, typically lasting less than 10 minutes (Hobbs, et al, 2016), making questionnaire length and completion time key determinants of the acceptability of identification tools (Kroenke, Monahan, & Kean, 2015; Mitchell & Coyne, 2007). Indeed, brevity has been prioritised in the development of adult mental health screening tools, with a focus on minimising the number of items required for accurate identification (Spitzer, et al., 2006) and ensuring completion time of less than 5 minutes (Mitchell & Coyne, 2007), with typically fewer than 10 items (Kroenke, Monahan, & Kean, 2015). Moreover, there is evidence to support the potential role of teachers in identifying mental health problems in children, and the benefit of adopting a multiple informant approach to child mental health screening, particularly where difficulties may be context-dependent (De Los Reyes, et al., 2015; Goodman, Ford, Simmons, Gatward & Meltzer, 2000). The evidence base surrounding teacher-report questionnaires designed to assess symptoms of anxiety disorders in children is however limited. There have been promising findings from an initial evaluation of a 16-item teacher questionnaire that includes some SCAS items together with new items (Lyneham, Street, Abbott, & Rapee, 2008). However, similar to primary care settings, questionnaire length and completion time are key determinants of the acceptability of mental health screening questionnaires in school settings

(Levitt, Saka, Romanelli, & Hoagwood, 2007), indicating the need to prioritise brevity and minimise the number of items in teacher-report questionnaires. A brief teacher-report questionnaire (with <10 items), including data relating to optimal cut-off scores to identify children with clinically significant levels of anxiety in children, is not currently available.

The aims of this study were to develop a brief questionnaire (child, parent and teacher versions) designed to assess symptoms of DSM child anxiety disorders using items from the SCAS-C/P among 7 – 11 year olds; and i) to evaluate the reliability and validity of the brief SCAS scores (child, parent, teacher versions) in a community and clinic-referred sample of children; ii) to establish the capacity of the brief SCAS scores (child, parent, teacher versions) to discriminate between a community and clinic-referred sample of clinically anxious children, including the relative contribution of each reporter and the optimal combination of reporters; and iii) to identify optimal cut-off scores on the brief SCAS (child, parent, teacher versions) for accurate identification of children with elevated anxiety symptoms for whom further clinical investigation is warranted.

Method

Participants

Participants included a community sample and a clinic-referred sample of children, and their parent/carer and class teacher. Characteristics of each sample are detailed in Table 1.

The community sample were recruited as part of a wider study of parental perceived barriers and facilitators to seeking and accessing professional help for anxiety disorders in children (see Reardon, Harvey, Young, O'Brien, & Creswell, [under review], for full study details). The study was approved by the University of Reading Research Ethics Committee (UREC 15/04). As displayed in Table 1, this sample consisted of 361 children (192 female, 169 male) recruited from 10 primary/junior schools in England. Children were aged 7-11 years (mean age 9.50, standard deviation [SD] 1.09), and 46.5% were from families classed as ‘higher/ professional’. Details of the number of parents, children and teachers who completed the SCAS adequately (>75% items complete) are provided in Table 1.

The clinic-referred sample consisted of 338 children (170 female, 168 male) with a primary anxiety disorder recruited as part of two randomised controlled trials (RCT) conducted within the Berkshire Child Anxiety Clinic (BCAC). The trials were approved by the NHS Research Ethics Committee (07/H0505/157 and 07/H0505/156) and the University of Reading Research Ethics Committee. All 338 children were referrals to the BACA, and 175 participated in an RCT comparing Child Cognitive Behavioural Therapy (CCBT) alone, with CCBT supplemented by either CBT to target maternal anxiety or an intervention to target mother-child interactions (Creswell et al., 2015); and 163 participated in an RCT comparing two guided parent-delivered CBT groups to a wait-list control (Thirlwall et al., 2013). Full details of the recruitment procedure for these trials are reported elsewhere (Creswell, et al., 2015; Thirwall, et al., 2013). Inclusion criteria for this sample required that children were aged 7-11 years at the time of the pre-treatment assessment. The clinic-referred sample had a mean age of 9.70 years (SD 1.36), and 57.7% were from families classed as ‘higher/ professional’. Diagnostic profiles for the clinic-referred sample and details of the number of parents, children and teachers who completed the SCAS adequately (>75% items complete) are provided in Table 1.

Differences between the demographic profiles of the two samples were examined. There was no significant difference between the samples on gender (X^2 = .71, p = .40). The community and clinic-referred samples did differ significantly on child age (mean age 9.50 and 9.70 years respectively; $t[674] = 2.11$, p =.04) and socio-economic status (frequencies higher/ professional; $X^2 = 10.79$, $p = .001$, $d = .27$), however in the case of age this reflected a negligible effect size (d =.16).[1]

[Insert Table 1 about here]

Procedure

Community sample.

Primary and junior schools from different geographic locations in England were approached and invited to take part in the study. Recruited schools distributed study materials to all parents/carers of children in UK school years 3 to 6 (aged 7-11 years); and parents/carers were asked to provide consent for their child to participate in the study, and to complete questionnaire measures (Spence Children's Anxiety Scale-Parent Version; SCAS-P; Strengths and Difficulties Questionnaire-Parent; SDQ-P). Consent was obtained from 361 (16.2%) of the 2223 parents/carers invited to take part in the study. Corresponding questionnaires (Spence Children's Anxiety Scale-Child Version; SCAS-C; Strengths and Difficulties Questionnaires-Child; SDQ-C) were administered by a member of the research team with the children during a visit to the school; and class teachers were asked to complete corresponding questionnaires about the children whose parent provided consent (Spence Children's Anxiety Scale-Teacher Version; SCAS-T; Strengths and Difficulties Questionnaire-Teacher; SDQ-T).

Clinic-referred sample.

Children in both trials were assessed prior to randomisation and treatment group allocation, and these data were used in the current study. As part of this assessment, parents

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[1] Differences on SCAS-P/C/T total scores among those classed as 'higher/professional' compared with other socio-economic groups, and among 7-8 year olds compared with 9-11 year olds were examined. No significant differences on SCAS total scores were found among those classed as 'higher/professional' compared with other socio-economic groups. No significant age effects were found on SCAS-P/T total scores, although significant age effects were found on the SCAS-C within the community sample, with total scores significantly higher among 7-8 year olds than 9-11 years ($t[301] = 3.59$, $p<.001$, $d = .42$), with the highest mean scores among 8 year olds. Given the narrow age range of participants included in this study, however, subsequent analyses were not conducted separately for different age groups. With the aim of developing a brief measure, together with optimal cut-off scores for use in primary care and school settings, it would be impractical to provide gender differentiated cut-off scores for very narrow age bands.

and children completed the ADIS-IV-C/P and the SCAS-C/P and SDQ-C/P, and teachers were asked to complete the SCAS-T and SDQ-T.

Measures

Spence Children’s Anxiety Scale (SCAS-C, SCAS-P, SCAS-T).

The SCAS is a 38-item questionnaire designed to assess a child’s anxiety symptoms, and includes corresponding child (SCAS-C; Spence, 1997, 1998) and parent report (SCAS-P; Nauta et al., 2004) versions. Items address symptoms of DSM-IV anxiety disorders, including separation anxiety, generalised anxiety, social phobia, obsessive compulsive behaviours, panic and agoraphobia, and physical injuries fears. Items are rated on a four point scale (0-3; never-always) and total scores reflect the sum of responses to the 38 items. SCAS-C/P total scores were calculated if >75% of items were complete, and in cases with missing data, the average total score using completed items was calculated. The reliability and validity of the SCAS-C/P scores have been reported in community and clinical samples (Arendt et al., 2014; Nauta et al., 2004; Whiteside & Brown, 2008).

A teacher report version of the SCAS (SCAS-T) was developed by the research team, and includes 30 items from the SCAS rated on the same four point rating scale. Items were reworded to account for the change in reporter and eight SCAS-C/P items relating to symptoms that teachers would not be able to observe were omitted (e.g. items relating to sleep, animal fears). No new items were added. SCAS-T total scores reflect the sum of responses to the 30 items, and were calculated if >75% of items were complete, and in cases with missing data, the average across completed items was used.

Strengths and Difficulties Questionnaires (SDQ-C; SDQ-P/T).

The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) provides a broad-based measure of a child’s emotional and behavioural difficulties. The child (SDQ-C) and parent/teacher (SDQ-P/T) report versions include corresponding items addressing a child’s emotional symptoms (5 items), peer relationship problems (5 items), conduct problems (5 items) and hyperactivity/inattention (5 items), with strong evidence in support of its psychometric properties both in community (Goodman, et al., 2000) and clinic-referred samples (Goodman, Renfrew, & Mullick, 2000). In this study the SDQ-emotional problems scale, internalising problems scale (emotional + peer relationship problems), conduct problems scale, and externalising problems scale (conduct+ hyperactivity/inattention) were used to examine the convergent and divergent validity of scores on the new brief anxiety measure (Goodman, Lamping, & Ploubidis, 2010). The internal consistency for the SDQ scale scores were acceptable-good in the current samples (SDQ-emotional problems scale, child α = .76 , parent α = .84, teacher α = .85; SDQ-internalising problems scale, child α = .76, parent α = .82, teacher α = .82; SDQ-conduct problems scale, child α = .60, parent α = .65, teacher α = .70; SDQ-externalising problems scale, child α = .74, parent α = .82, teacher α = .85).

Anxiety Disorders Interview Schedule-Child and Parent Interviews (ADIS-C/P).

The ADIS-C/P was administered with the clinic-referred sample to assess the child’s diagnostic status, including the assessment of DSM-IV anxiety, mood and externalising disorders. The reliability and validity of the ADIS has been widely reported (Silverman, Saavedra, & Pina, 2001). As per the standard guidelines, overall diagnoses and Clinical Severity Ratings (CSRs) (4-8) were assigned if the child met diagnostic criteria based on either the child or parent report, and the higher of the two CSRs was assigned. The disorder with the highest CSR was assigned as the primary disorder. Assessors were psychology graduates in both trials, and all assessments were discussed with a consensus team for at least the first 20 interviews for each assessor, at which stage the assessor’s reliability was checked (minimum kappa = .85). After this point, at least one in six interviews were discussed with a consensus team; and overall reliability within the assessment team in both trials was excellent (child-report diagnosis: kappa = 0.98; CSR: ICC = 0.98-0.99; parent-report diagnosis: kappa = 0.98; CSR: ICC = 0.97-0.99).

Data analytic approach

Development of brief versions of the SCAS.

The following procedure was used to develop a brief version of the SCAS (parent, child and teacher report versions). 1) The functioning of SCAS-P/C/T items was examined in the two samples combined, including item-differential functioning (Univariate Logistic Regression; SCAS item score = independent variable, sample=dependent variable) and item-total correlations (Pearson's *r* correlation coefficient). Additionally, as the SCAS-T is a new measure, response rates for each item were examined and items with a very high proportion (> 97%) of 'never' responses in the community sample (suggesting the item is not appropriate for teachers) were not considered for inclusion in the brief questionnaire. 2) Alternative potential versions of brief parent/child/teacher questionnaires (including varying combinations of 6-10 items) were developed, prioritising items that showed significant prediction of community/clinic-referred sample membership (Odds Ratio >2.00), with at least moderate item-total correlation (*r* >.50). Content of items was also considered in order to: i) minimise overlap between items, ii) include items that address symptoms of a range of types of anxiety disorders (excluding the obsessive compulsive items to reflect the change in the DSM5 classification of anxiety disorders), and iii) where possible to maximise the number of common items across the parent/child/teacher questionnaire. 3) ROC (Receiver Operating Characteristics) analyses were used to compare the capacity of alternative potential versions of parent/child/teacher brief questionnaires to identify children with anxiety disorders (i.e. the clinic-referred sample). The Area Under the Curve (AUC) statistic was examined, and as per previous studies examining the AUC statistic associated with anxiety screening tools (van Gastel & Ferdinand, 2008; Villabø, Gere, Torgersen, March, & Kendall, 2012), AUC = .70

was taken as the minimum threshold to indicate that the measure was moderately accurate at identifying children in the clinic-referred sample. The sensitivity and specificity values for alternative cut-off scores were also examined. Given the purpose of the measure is to identify children with anxiety disorders, sensitivity was prioritised, with the optimal cut-off score reflecting sensitivity values >.80 and specificity >.70. In cases where it was not possible to achieve sensitivity/specificity values of .80/.70 respectively, cut-off scores with lower sensitivity/specificity values (>.60) were considered (where possible selecting cut-off values with sensitivity >.70). Findings from the ROC analyses for the brief parent/child/teacher SCAS with the optimal capacity to identify children with anxiety disorders are reported below.

Evaluation of the brief questionnaires.

Total scores on the optimal brief versions of the parent/child/teacher SCAS were calculated using the same procedure to deal with missing data as detailed above for the full length SCAS (total scores reflect the sum of responses to all included items). The following psychometric properties of scores on the optimal brief versions of the parent/child/teacher SCAS were examined in each sample and compared with scores on the full length SCAS-P/C/T: i) internal consistency (Cronbach alpha coefficients); ii) agreement between reporters (Pearson's *r* correlation coefficients); iii) convergent and divergent validity (Pearson's *r* correlation coefficient between full/brief SCAS scores and SDQ internalising/emotional/externalising/conduct scale scores). The capacity of the optimal brief parent/child/teacher SCAS scores to discriminate between children in the clinic-referred sample and children in the community sample was examined for the total sample, and for gender groups using i) independent sample *t*-tests (and cohen's *d*), and ii) ROC analyses (as detailed above, examining both the AUC and the sensitivity/specificity values associated with optimal cut-off scores on the parent/child/teacher brief SCAS). In order to compare the functioning of the brief SCAS with the full-length SCAS, the capacity of the full-length SCAS to discriminate between the two samples was also analysed. A series of Logistic Regressions were used to examine the contribution of each reporter (parent, child, teacher), to determine if using multiple informants improves the capacity of the brief SCAS scores to identify children in the clinic-referred sample. Using optimal cut-off scores identified in the ROC analyses, the sensitivity and specificity values associated with each combination of reporters (parent+child, parent+teacher, teacher+child, parent+child+teacher) were examined. For each combination of reporters, the sensitivity value reflected the proportion of children in the clinic-referred sample who scored above the optimal cut-off score based one at least one of reporter; and specificity value reflected the proportion of children in the community sample who scored below the optimal cut-off for each reporter. Gender differences on total scores on the brief (and full length SCAS) within each sample (independent samples *t*-tests) were also examined.

As the sample sizes were large (>330 in each sample), a conservative p-value ($p<.01$) was used to indicate a statistical significance. All analyses were conducted using IBM SPSS (Version 21).

Results

Development of brief parent/child/teacher SCAS

Rank ordered item-total correlations for SCAS-P items in the two samples combined, together with item differential functioning statistics are detailed in Table 2. Items selected for the brief parent questionnaire (SCAS-P-8) are also displayed in Table 2, with item-total correlations ranging from .56-.70, and all items were significant predictors of sample ($p<.001$), with higher scores among the clinic-referred sample (Odds Ratio, 1.94-6.87). As Obsessive Compulsive Disorder is no longer classed as an anxiety disorders within DSM5, two items addressing obsessive compulsive behaviours (item 17 and 36), with strong item-total correlations were not considered for inclusion in the brief measure. The selected items addressed generalised anxiety (3 items), social anxiety (2 items), separation anxiety (2 items), and panic/agoraphobia (1 item).

[Insert Table 2 about here]

Table 3 details the SCAS-C rank ordered item-total correlations, and associated differential functioning statistics associated with each item, together with items selected for the brief child questionnaire (SCAS-C-8). The predictive values associated with SCAS-C item scores were notably smaller than for SCAS-P items. Item-total correlations for SCAS-C-8 items ranged from .52-.68, and selected items significantly predicted the sample (p<.001), with higher item scores among the clinic-referred sample (Odds Ratio, 1.39-2.00). As for the SCAS-P-8, items addressing obsessive compulsive behaviour were not considered for inclusion in SCAS-C-8 (item 41 and 19). The two social anxiety items from the SCAS-P-8 (item 9 and item 29) were not selected for inclusion in the SCAS-C-8 as neither were significant predictors of community/clinic-referred sample, and including these items reduced the overall capacity of the brief child questionnaires to discriminate between the two groups. Item 22 ('I worry something bad will happen to me') and item 32 ('all of a sudden I feel really scared for no reason at all') from the SCAS-P-8 were also less strongly associated with the clinic-referred sample based on child-report (Odds Ratio, 1.29 and 1.31 respectively) than alternative SCAS-C items, and were therefore also not selected for inclusion in the SCAS-C-8. Final selected SCAS-C-8 items address generalised anxiety (2 items), separation anxiety (4 items), and panic/agoraphobia (2 items), and 4 of these items appear on the SCAS-P-8.

[Insert Table 3 about here]

Table 4 displays the rank ordered item-total correlations, and associated item functioning for 20 items included in the SCAS-T. Ten SCAS-T items were not considered for inclusion in the brief measure because they were associated with very low response rates

(7 items; >97% ‘never’ response in the community sample) or addressed obsessive compulsive behaviour (3 items). Items selected for the SCAS-T-8 are identified in Table 4, with item-total correlations ranging from .56-.75, and all items were significant predictors of sample (p<.001), with higher scores among the clinic-referred sample (Odds Ratio, 1.89-5.35). Three SCAS-T-8 items appear on both the SCAS-P-8 and SCAS-C-8 (item 1, item 6, item 12), and a further 3 items appear on the SCAS-P-8 (item 7. item, 16, item 22). The social anxiety item addressing worries about school (‘worries that he/she will do badly at school’) had the second highest item-total correlation (.74) among SCAS-T items and, with its focus on school, appears particularly relevant to teachers so was selected to replace ‘worries what others think’ from the SCAS-P-8. Item 15 (‘suddenly starts to tremble or shake’) from the SCAS-C-8 was also selected for the brief teacher questionnaires as scores on this item were more strongly associated with sample than the SCAS-P-8/SCAS-C-8 item ‘feels afraid’ (Odds Ratio, 3.67 compared to 1.58). Selected SCAS-T-8 items address generalised anxiety (2 items), social anxiety (2 items), separation anxiety (2 items), and panic/agoraphobia (2 item).

[Insert Table 4 about here]

Evaluation of SCAS-P-8, SCAS-C-8 and SCAS-T-8

Internal consistency.

Internal consistency for the brief and full SCAS within each sample are provided in Online Supplement 1. Cronbach alpha coefficients for the brief questionnaires ranged from .80-.84 in the community sample, and .73-.85 in the clinic-referred sample, indicating items have an acceptable-good level of internal consistency.

Agreement between reporters.

Agreement between reporters within each sample are provided in Online Supplement 2, indicating similar levels of agreement on the brief SCAS as the full SCAS. For the brief questionnaires, parent-child agreement was the highest (community sample, *r* = .40, *p*<.001; clinic-referred sample, *r* = .34, *p*<.001) and teacher-child agreement the lowest (community sample, *r* = .25, *p*<.001, clinic-referred sample, *r* = .05, *p* = .46).

Convergent and divergent validity.

Convergent and divergent validity indices for the brief and full SCAS scores within each sample are provided in Online Supplement 3. Similar patterns were observed for the brief SCAS scores as for the full SCAS scores, with significantly higher correlations between the brief parent/child/teacher SCAS scores and the SDQ-emotional problems scale scores (*r* = .62-.76) and the SDQ-internalising scale scores (*r* = .58-.70), than between the brief parent/child/teacher SCAS scores and the SDQ-conduct problems scale scores (*r* = .08-.32) and SDQ-externalising problems scale scores (*r* = .10-.34) (*z* = 4.91-9.16, *p* < .0001).

Discriminating between community sample and clinic-referred sample.

Sample differences on questionnaires.

As displayed in Table 5, mean SCAS-P-8 scores were significantly higher in the clinic-referred sample than the community sample (*t* [671] = 19.51, *p*<.001), with a large effect size (*d* = 1.49). This finding was replicated among gender differentiated groups (*d* = 1.50-1.51), and similar sample differences were observed for the full SCAS-P scores (*d* = 1.39-1.54).

As displayed in Table 5, Mean SCAS-C-8 scores were also significantly higher in the clinic-referred sample than the community sample (*t* [647] = 8.73, *p*<.001), with a medium effect size (total sample, *d* = 0.69; boys, *d* = 0.77; girls, *d* = 0.67). Sample differences for the full child SCAS scores represented small-medium effect sizes (total sample, *d* = 0.41; boys, *d* = 0.51; girls; *d* = 0.38).

Sample differences on the teacher questionnaires are also displayed in Table 5. Mean SCAS-T-8 scores were significantly higher in the clinic-referred sample than the community sample (*t* [568] = 12.43, *p*<.001), with a large effect size (*d* = 1.01). This finding was replicated among gender differentiated groups (boys, *d* = 0.93; girls, *d* = 1.10), and similar sample differences were observed for the SCAS-T-20 scores (*d* = 0.86-1.01).

[Insert Table 5 about here]

ROC analyses.

As displayed in Table 6, the SCAS-P-8 was able to accurately identify children in the clinic-referred sample with an AUC of .86; and using an optimal cut-off score of 7.5, achieved .85 sensitivity and .75 specificity overall (with sensitivity/specificity values of .81/.79 for boys; and .89/.71 for girls). Corresponding sensitivity/specificity values for optimal cut-off scores on the full SCAS-P were 82/.78 (boys, .83/.80; girls, .82/.77).

The SCAS-C-8 also achieved an AUC >.70, both in the total sample and the gender differentiated groups (boys, .74; girls, .70). ROC analyses examining the SCAS-C-8 in the total sample indicated that the optimal cut-off score was 6.5, achieving a sensitivity value of .67, and specificity of .64 (it was not possible to achieve sensitivity >.70, with specificity >.60 for the total sample). The ROC analyses among the gender differentiated groups, however, indicated that the optimal cut-off scores among boys was 5.5, and among girls was 7.5, with respective sensitivity/specificity values of .73/.70, and .64/.63. The full child SCAS failed to achieve an AUC >.70 in the total sample or among gender differentiated groups, and the optimal cut-off scores on full child SCAS achieved similar sensitivity to the SCAS-C-8 (boys, .71; girls, .61), but with lower specificity (boys, .61; girls, .55).

The SCAS-T-8 achieved an AUC of .76, and the optimal cut-off score of 4.5 in the total sample was associated with a sensitivity value of .70, and specificity of .73. Analyses among gender differentiated groups indicated the optimal cut-off score on the SCAS-T-8 among boys was 3.5 (sensitivity/specificity, .74/.64), and among girls was 4.5

(sensitivity/specificity, .73/.69). Optimal cut-off scores on the SCAS-T-20 achieved sensitivity/specificity values of .71/.71 among boys, and .74/.64 among girls.

[Insert Table 6 about here]

Using multiple reporters and the contribution of each reporter.

Findings from the series of Logistic Regressions using different combinations of the SCAS-P-8, SCAS-C-8 and SCAS-T-8 scores to predict whether the child was in the community or clinic-referred sample are displayed in Table 7. Among the models including two reporters, using parent report (SCAS-P-8) and teacher report (SCAS-T-8) explained the most variance (Nagelkerk, .54, Cox & Snell, .40); and scores on both the SCAS-P-8 and SCAS-T-8 were uniquely associated with sample (Odds Ratio, 1.40 [1.31-1.49] and 1.18 [1.11-1.26], respectively). Replacing the teacher report (SCAS-T-8) with the child report (SCAS-C-8) only slightly reduced the total amount of variance explained (Nagelkerk, .47, Cox & Snell, .35), although in this parent+child model, the SCAS-C-8 score was not significantly associated with the sample. Using teacher report (SCAS-T-8) and child report (SCAS-C-8) explained the least variance of all of the models (Nagelkerk, .33, Cox & Snell, .24), but both the SCAS-T-8 score and SCAS-C-8 score made small significant contributions (Odds Ratio, 1.28 [1.21-1.35] and 1.12 [1.07-1.16] respectively). In the model including all three reporters, higher scores on the SCAS-P-8 best predicted whether participants were in the community or clinic-referred sample (Odds Ratio, 1.39 [1.29-1.48]), and the SCAS-T-8 score also made a significant unique contribution (Odds Ratio, 1.17 [1.09-1.25]), but the SCAS-C-8 did not (Odds Ratio, 1.02 [.97-1.08]).

[Insert Table 7 about here]

As displayed in Online Supplement 4, the brief SCAS scores accurately identified >89% of children in the clinic-referred sample when multiple reporters were used, with the highest sensitivity achieved when all three brief questionnaires are combined (.97), and lowest when teacher and child report are combined (.89). The brief SCAS specificity was reduced when multiple reporters were combined; ranging from .54 (parent+teacher and parent+child) to .42 (parent+teacher+child) based on the optimal cut-off points identified in Table 6.

Gender differences.

Gender means for the brief and full length SCAS scores are displayed in Online Supplement 5. Significant gender effects were found for the SCAS-C-8, with significantly higher scores among girls than boys both in the community sample ($t[322] = 3.78$, $p<.001$, $d = .42$) and clinic-referred sample ($t[323] = 2.90$, $p<.001$, $d = .32$); and this same pattern was observed on the full length SCAS-C. No significant gender differences were found on either the SCAS-P-8 scores or SCAS-T-8 scores; although scores on the full length SCAS-P were significantly higher among girls than boys within the community sample ($t[355] = 2.91$, $p<.001$, $d = .31$).

Discussion

In this study we developed a brief questionnaire (parent, child and teacher report versions) designed to assess symptoms of DSM5 anxiety disorders. Each version of the brief questionnaire (SCAS-P-8, SCAS-T-8, SCAS-C-8) includes 8 SCAS items. Item functioning and the content of items were considered to select items for inclusion in the brief questionnaire. Item functioning varied across reporters, and in order to maximise performance of each version of the questionnaire, the selected items varied across reporters (with 3 common items across the SCAS-P-8, SCAS-T-8, and SCAS-C-8). Each version of the brief questionnaire includes items that address generalised anxiety, separation anxiety and panic/agoraphobia; and the SCAS-P-8 and SCAS-T-8 also includes items that address social anxiety.

The findings provide support for the reliability and validity of the SCAS-P-8, SCAS-C-8, and SCAS-T-8 scores in a community and clinical sample of children with anxiety disorders. In line with previous studies of the full length SCAS (Arendt et al., 2014; Nauta et al., 2004; Spence, 1998; Whiteside & Brown, 2008), the brief questionnaire scores displayed acceptable to good internal consistency in both samples, although not as strong as the full-length SCAS scores. Similar levels of agreement among reporters were observed for the brief SCAS scores as the full-length SCAS scores, with highest agreement between parent and child and lowest between teacher and child. In relation to convergent and divergent validity, the brief questionnaire also displayed similar patterns to the full-length SCAS, with the SCAS-P-8, SCAS-C-8, and SCAS-T-8 scores each significantly correlated with the SDQ-internalising and emotional problems scale scores, and weakly correlated with SDQ-externalising and conduct problems scale scores.

The findings also illustrated the capacity of the SCAS-P-8, SCAS-C-8 and SCAS-T-8 scores to discriminate between the clinic-referred sample and the community sample. As previously reported for the full length SCAS (Arendt et al., 2014; Nauta et al., 2004; Spence, 1998; Whiteside & Brown, 2008), scores on each version of the brief questionnaire were significantly higher among the clinic-referred sample than the community sample. ROC analyses also indicated that the SCAS-P-8, SCAS-C-8 and SCAS-T scores were each able to identify children in the clinic-referred sample with at least a moderate level of accuracy (AUC > .70) with an acceptable level of sensitivity and specificity. The SCAS-P-8 score identified children in the clinic-referred sample with a good level of accuracy (AUC = .86), and the optimal cut-off score of 7.5, achieved sensitivity/specificity values > .80/.70 respectively (.85/.75 for the total sample; .81/.79 for boys; and .89/.71 for girls). Optimal cut-off scores on the SCAS-C-8 (5.5 for boys; 7.5 for girls) achieved sensitivity/specificity values >. 70 among boys (.73/.70), and >.60 among girls (.64/.63); and optimal cut-off scores on the SCAS-T-8 (3.5 for boys; 4.5 for girls) achieved sensitivity/specificity values > .70/.60 respectively (.74/.64 for boys; .73/.69 for girls). SCAS-C-8 total scores were significantly higher among girls than boys, thus accounting for gender differentiated optimal cut-off scores; although interestingly, there were not significant difference between boys and girls on the SCAS-T-8 (or SCAS-P-8), despite the gender differentiated optimal cut-off scores on the brief teacher questionnaire.

Encouragingly, the ROC analyses also indicted that the SCAS-P-8 and SCAS-T-8 scores were able to identify children in the clinic-referred sample with a similar level of accuracy as the full length SCAS scores, suggesting reducing the SCAS-P/T to 8 items does not reduce its capacity to discriminate clinically anxious children from children in the community. Furthermore, the SCAS-C-8 score displayed a higher level of accuracy than the full-length SCAS score which did not achieve an AUC > .70 in the total sample or among gender groups. The optimal cut-off scores on the full length SCAS-C were also associated with lower specificity values (.55- .61) than the SCAS-C-8, thus illustrating the advantage of using a sub-set of optimally functioning SCAS-C items. Interestingly, the capacity of the individual SCAS-C items to discriminate between the community and clinic-referred sample was notably lower than that for the SCAS-P items and the SCAS-T items; and this was particularly marked for social anxiety items, suggesting that it may be difficult for pre-adolescent children to differentiate between developmentally appropriate and clinically significant levels of social anxiety.

Findings indicated some benefit to adopting a multi-informant approach, suggesting that a combined parent plus teacher score provides the optimal combination for the detection of children with an anxiety disorder of reporters, although parent report should be prioritised above either child or teacher. Interestingly, previous studies examining the use of child and parent report to identify particular anxiety disorders among clinical samples suggest each reporter does provide unique information (Villabø, et al,. 2012; Wei, et al, 2014), but that there may be variation in the capacity of each reporter to identify particular types of anxiety disorders, and with different patterns among children versus adolescents (Wei, et al, 2014). Indeed, while our findings suggest parent report should be prioritised above child (or teacher) report to identify pre-adolescent children with clinically significant levels of anxiety, this may not extend to older children and adolescents, or to situations where the aim is to identify particular anxiety disorders within a clinical population. Moreover, the stronger capacity for the parent report questionnaire to identify children in the clinic-referred sample than either the child or teacher report questionnaire may, however, at least in part reflect a dominant influence of parent report in the diagnostic assessment. Diagnostic outcomes derived from the ADIS among pre-adolescent children show higher levels of agreement with parent report than child report (Evans, Thirlwall, Cooper, & Creswell, 2016; Grills & Ollendick, 2003), and therefore it may not be surprising that the parent report questionnaire score is the best predictor of sample in this study. Using multiple reporters improved the capacity of the brief questionnaire to correctly identify children in the clinic-referred sample (increased sensitivity), but this advantage would need to be weighed up against the reduced specificity associated with using multiple reporters unless alternative cut-off points are used to optimize specificity and sensitivity when multiple informants are used.

Implications

This new brief anxiety questionnaire has potential for use in schools and primary care settings as a tool to improve identification of children who are experiencing high levels of anxiety and for whom a clinical diagnostic assessment may be warranted. With only 8 items, the questionnaire is very quick to administer, providing a more time efficient alternative to existing questionnaires (e.g. the 38-item SCAS, the 47-item RCADS, the adapted 15 item and 20 item RCADS anxiety scales). Moreover, the availability of parent, child and teacher report versions maximises potential application across situations where only one particular reporter may be available (e.g. teachers in schools), and where multiple reporters may be available (e.g. parents and children in a primary care settings). The GAD-7 is widely used in primary care settings to aid identification of anxiety disorders in adults, and is recommended as an initial screening tool where an anxiety disorder is suspected to determine if further assessment is required (National Institute for Clinical Excellence, 2011). This new brief questionnaire provides an equivalent tool for use with children, parents and teachers, to aid identification of potential cases of clinically significant levels of anxiety, and to help determine if further assessment and support is needed.

Limitations

It is important to note several limitations associated with this study. The study examined the capacity of the new brief questionnaire scores to discriminate between a community sample and a clinic-referred sample of children who met criteria for an anxiety disorder. Diagnostic assessments, however, were not administered with the community sample, and given the prevalence rates of anxiety disorders, it can be assumed that the community sample also included some children who would have met criteria for an anxiety disorder. This would have reduced the capacity of the brief questionnaire scores to discriminate between the two samples. Future research should examine the capacity of the measure to discriminate between clinically anxious and non-anxious children where this status has been established through a diagnostic interview. It is also likely that there was a degree of participation bias in the community sample given that parents were informed that the wider study was also examining barriers to accessing anxiety treatment, and the response rate was relatively low (16.2%), thus those who were concerned about their child’s anxiety may have been more likely to take part in the study. As a result, the community sample may have included more anxious children than the general population. In fact, among boys the mean score on the full

SCAS-C (26.12) and full SCAS-P (16.23) were similar to published norms (26.65 and 16.0 respectively; available at www.scaswebsite.com), but among girls the mean scores (SCAS-C, 36.18; SCAS-P, 20.13) were higher than reported elsewhere (34.02 and 15.9 respectively; available at www.scaswebsite.com), indicating that the community sample may have included more anxious girls than the general population. Thus, again the results from the present study may have underestimated the capacity of the brief questionnaire scores to discriminate between children with and without anxiety disorders.

It is also important to acknowledge that the proportion of teachers who completed SCAS questionnaires in the clinic-referred sample (63%) was relatively low compared with the proportion of teachers in the community sample (94%), and the proportion of parents and children in both samples (>89%). It is likely that the lower return rate among teachers in the clinic-referred sample is due to methodological differences in questionnaire administration across reporters and samples. In the clinic-referred sample, teacher questionnaires were administered by post, whereas children and parents completed questionnaires as part of face-to-face assessment sessions; and the community sample were recruited through schools as part of a wider study that involved researchers visiting schools to administer questionnaires. It will be important for future studies to consider methods that maximise teacher response rates among samples recruited in clinical settings.

This study also examined a number of other reliability and validity indices (internal consistency, agreement among reporters, convergent/divergent validity), but it will be important for future evaluations of the new brief questionnaire to examine its test-retest reliability. The Strengths and Difficulties Questionnaire (SDQ) scales were used to examine the convergent/divergent validity of the brief SCAS scores, but it is important to note that the psychometric properties of the child-report version of the SDQ have not been previously evaluated in children younger than 11 years old. Moreover, we developed and evaluated the new questionnaire in a single study in which participants completed the full version of the SCAS. Thus, further research is now needed to evaluate the new measure in an independent sample that completes the abbreviated form the SCAS.

It is also important to note that this new brief questionnaire is designed to identify children with an anxiety disorder, but it does not include a sufficient number of items addressing any particular anxiety disorder to provide detailed information about specific anxiety disorders. As such this measure should be considered an initial tool to identify children who have elevated symptoms of anxiety, and for whom a more in-depth assessment is needed. This issue also applies to full-length anxiety questionnaires for children and youth. McLeod, Jensen-Doss, Wheat, & Becker (2013) cautioned against using anxiety rating scales, both general and multi-dimensional, as stand-alone diagnostic instruments, but noted their value in screening to identify children who warrant further assessment. Also, although the items address a range of types of anxiety, no items specifically address selective mutism or specific phobias, and the SCAS-C-8 items do not ask about social anxiety as these items did not discriminate between the clinical and non-clinical groups (although 64% of the clinical sample had social anxiety disorder). It is also noteworthy that the SCAS-P-8 does not include items that ask about physical symptoms, and the SCAS-C-8 and SCAS-T-8 both only include one such item (suddenly starts to tremble or shake), indicating that items relating to other non-physical symptoms may be better able to identify children with clinically significant levels of anxiety. Given the capacity of the brief questionnaire scores to discriminate between children in a clinic-referred sample (who had a range of different types of anxiety disorders) and a community sample, it is likely that the items relate to symptoms that are common across anxiety disorders (e.g. general worry, feeling afraid, trouble going to school); however, the capacity of the new brief questionnaire scores to identify particular anxiety disorders is not yet known. Future research is needed to establish whether the brief questionnaire scores have greater capacity to detect some anxiety disorders (e.g. Generalised Anxiety Disorder), than others (e.g. Social Anxiety Disorder). Similarly, this study did not examine the capacity of the brief SCAS scores to discriminate between children with anxiety disorders and those with non-anxiety psychiatric diagnoses. The GAD-7 has reduced specificity within psychiatric samples compared to its ability to discriminate between adults with anxiety disorders and non-clinical groups (Beard & Björgvinsson, 2014; Kertz, Bigda-Peyton, & Bjorgvinsson, 2014); and it will be important for future research to examine the sensitivity/specificity associated with optimal cut-off scores on the brief SCAS in mental health service use settings.

This study provides support for this multi-informant 8-item questionnaire as a tool to identify children with anxiety disorders, together with data relating to optimal cut-off scores. Further research is needed to evaluate the ability of the brief questionnaire to identify specific anxiety disorders; and to evaluate its capacity to discriminate between children with and without any anxiety disorders in community settings in which diagnostic assessments confirm both the presence and the absence of anxiety disorders. This study focuses on identifying anxiety disorders in pre-adolescent children, and a corresponding brief questionnaire for adolescents should be developed and evaluated. It will also be important for future evaluations to examine the capacity of the brief questionnaire to be sensitive to changes in symptoms and functioning over time in response to treatment, and to discriminate between children with anxiety disorders and other non-anxiety psychiatric disorders.

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Table 1

Sample characteristics

	Community sample (n = 361)	Clinic-referred sample (n = 338)
Gender		
Female, *n* (%)	192 (53.2%)[b]	170 (50.3%)
Age		
mean (SD)	9.50 (1.09)[c]	9.70 (1.36)
7-8 year olds	126 (34.9%)	99 (29.3%)
9-11 year olds	212 (58.7%)	239 (70.7%)
SES		
higher/professional[a]	168 (46.5%)[d]	195 (57.7%)[e]
other employed	133 (36.8%)	93 (27.5%)
unemployed	22 (6.1%)	12 (3.6%)
Ethnicity		
White British, *n* (%)	277 (76.7%)[f]	287 (84.9%)[g]
SCAS-P (total score), *n (%)*[h]	359 (99.4%)	312 (92.3%)
SCAS-P-8 (total score), *n (%)*[h]	360 (99.7%)	313 (92.6%)
SCAS-C (total score), *n (%*[h]	322 (89.2%)	323(95.6%)
SCAS-C-8 (total score), *n (%)*[h]	324 (89.8%)	325 (96.1%)
SCAS-T (total score), *n (%)*[h]	340 (94.2%)	214 (63.3%)
SCAS-T-20 (total score), *n (%)*[h]	340 (94.2%)	227 (67.2%)
SCAS-T-8 (total score), *n (%)* [h]	340 (94.2%)	230 (68.0%)
Primary anxiety diagnosis. *n* (%)		
Separation anxiety disorder		91 (26.9%)
Social anxiety disorder		64 (18.9%)
Generalised anxiety disorder		99 (29.3%)
Specific phobia		59 (17.6%)
Panic disorder with Agoraphobia		3 (0.9%)
Panic disorder without Agoraphobia		3 (0.9%)
Agoraphobia without Panic disorder		9 (2.7%)
Selective Mutism		1 (0.3%)
Anxiety NOS		9 (2.7%)
Primary anxiety disorder, CSR mean (SD)		5.59 (0.79)
Presence anxiety diagnosis. *n* (%)		
Separation anxiety disorder		199 (58.9%)
Social anxiety disorder		213 (63.0%)
Generalised anxiety disorder		215 (63.6%)
Specific phobia		152 (45.0%)
Panic disorder with Agoraphobia		3 (0.9%)
Panic disorder without Agoraphobia		7 (2.1%)
Agoraphobia without Panic disorder		17 (5.0%)
Selective Mutism		1 (0.3%)
Anxiety NOS		12 (3.6%)
Presence of other diagnoses, *n* (%)		
OCD		9 (2.7%)
Major Depressive Disorder or Dysthymia		42 (12.4%)
ADHD		51 (15.1%)
ODD		62 (18.3%)
SDQ scales, mean (SD)		
SDQ-P-Emotional problems	2.59 (2.58)	6.40 (2.74)
SDQ-P-Conduct problems	1.82 (1.94)	2.37 (1.84)
SDQ-P-Internalising problems	4.29 (3.76)	9.02 (3.86)
SDQ-P-Externalising problems	5.90 (4.35)	6.92 (3.86)
SDQ-C-Emotional problems	3.80 (2.72)	5.49 (2.43)

SDQ-C-Conduct problems	2.70 (2.06)	2.88 (1.88)
SDQ-C-Internalising problems	6.79 (4.12)	8.64 (3.68)
SDQ-C-Externalising problems	7.01 (3.82)	7.43 (3.68)
SDQ-T-Emotional problems	1.70 (1.99)	4.08 (2.94)
SDQ-T-Conduct problems	1.04 (1.66)	.93 (1.53)
SDQ-T-Internalising problems	3.20 (3.21)	5.80 (4.15)
SDQ-T-Externalising problems	4.30 (4.14)	3.88 (3.70)

Note. SES = socioeconomic status; CSR = Clinical Severity Rating; Anxiety NOS = Anxiety Disorder Not Otherwise Stated; OCD = Obsessive compulsive disorder; PTSD = Post traumatic stress disorder; ADHD = Attention Deficit Hyperactivity Disorder; ODD = Oppositional Defiant Disorder

[a] higher / professional = managers, directors, senior officials, professional occupations

Missing data: [b] *n* = 2 (0.6%); [c] *n* = 23 (6.4%); [d] *n* = 38 (10.5%); [e] *n* = 38 (11.2%); [f] *n* = 22 (6.1%); [g] *n* = 10 (3.0%)

[h] *n* (%) with >75% of items complete

Table 2

SCAS-P rank ordered item-total correlations and item differential functioning

Item	Abbreviated SCAS-P item	Sub-scale	Item-total correla-tion^{a}	Estim-ated coeff-icient	Wald statistic	Odds Ratio (95% CI)
17	can't get bad or silly thoughts out of head	OC	.72**	1.25	131.19**	3.49 (2.81-4.32)
__20^{b}__	__worries something bad happen to him/her__	__GA__	__.70**__	__1.10__	__93.98**__	__3.01 (2.41-3.76)__
__4 ^{b}__	__feeling afraid__	__GA__	__.70**__	__1.53__	__132.55**__	__4.62 (3.56-5.99)__
36	bothered by bad or silly thoughts	OC	.69**	1.02	92.70**	2.77 (2.25-3.41)
33	worries will suddenly get scared feeling	P/A	.66**	1.38	94.59**	3.98 (3.01-5.26)
__28^{b}__	__all of a sudden feels really scared for no reason__	__P/A__	__.66**__	__1.56__	__92.44**__	__4.75 (3.46-6.53)__
__8 ^{b}__	__worries about being away from us__	__SEP__	__.66**__	__1.09__	__120.97**__	__2.96 (2.44-3.60)__
11	worries something awful happen to family	SEP	.65**	.85	85.62**	2.34 (1.95-2.80)
__26 ^{b}__	__worries what others think of him/her__	__SOC__	__.62**__	__.70__	__57.83**__	__2.01 (1.68-2.40)__
__15 ^{b}__	__trouble going to school in mornings__	__SEP__	__.61**__	__1.20__	__108.23**__	__3.32 (2.65-4.17)__
18	complains heart beating really fast	GA	.61**	.92	54.82**	2.50 (1.96-3.18)
22	feels shaky	GA	.61**	1.25	74.97**	3.48 (2.62-4.61)
3	funny feeling in stomach	GA	.61**	.88	105.50**	2.42 (2.04-2.86)
38	scared if stay away from home overnight	SEP	.61**	1.10	105.37**	2.99 (2.42-3.68)
6	scared when has to take a test	SOC	.60**	.62	53.38**	1.86 (1.58-2.20)
__9 ^{b}__	__afraid will make fool of self__	__SOC__	__.57**__	__.66__	__53.21**__	__1.94 (1.62-2.32)__
10	worries will do badly at school	SOC	.57**	.65	57.04**	1.92 (1.62-2.28)
__1 ^{b}__	__worries about things__	__GA__	__.56**__	__1.93__	__168.36**__	__6.87 (5.14-9.20)__
12	suddenly can't breathe	P/A	.55**	1.00	40.84**	2.71 (2.00-3.68)
19	suddenly starts tremble or shake	P/A	.54**	1.32	36.13**	3.73 (2.43-5.72)
14	scared if has to sleep on own	SEP	.54**	1.02	104.81**	2.77 (2.28-3.36)
30	suddenly becomes dizzy or faint	P/A	.54**	1.26	43.22**	3.52 (2.42-5.12)
24	special thoughts stop bad things happening	OC	.54**	.92	25.84**	2.50 (1.76-3.56)
32	heart suddenly starting to beat too quickly	P/A	.53**	.94	35.62**	2.57 (1.88-3.50)
7	afraid when has to use public toilets	SOC	.53**	.93	59.01**	2.53 (2.00-3.20)
31	afraid when has to talk in front of class	SOC	.52**	.59	44.70**	1.80 (1.52-2.14)
2	scared of the dark	PHY	.51**	.70	75.43**	2.00 (1.71-2.35)
21	scared of going to doctor or dentist	PHY	.51**	.65	44.39**	1.92 (1.58-2.32)
5	afraid of being on own at home	SEP	.51**	.68	83.76**	1.97 (1.70-2.28)
37	has to do certain things in just right way	OC	.47**	.64	16.97**	1.89 (1.40-2.55)
13	has to keep checking has done things right	OC	.47**	.70	29.21**	2.01 (1.56-2.58)
27	afraid of being in crowded place	P/A	.47**	.59	24.80**	1.81 (1.43-2.28)
25	scared if has to travel in car, bus or train	P/A	.43**	.97	32.25**	2.63 (1.88-3.67)
35	has to do same things over and over	OC	.41**	.51	13.89**	1.67 (1.27-2.18)
34	afraid of being in small closed places	P/A	.41**	.65	26.27**	1.92 (1.50-2.46)
29	scared of insects or spiders	PHY	.33**	.21	6.55*	1.23 (1.05-1.44)

23	scared of heights	PHY	$.33^{**}$	.07	.64	1.07 (.91-1.27)
16	scared of dogs	PHY	$.23^{**}$	.34	16.98**	1.41 (1.20-1.66)

Note. CI = Confidence Interval; OC = obsessive-compulsive; GA = generalised anxiety; P/A = panic and agoraphobia; SOC = social phobia; SEP = separation anxiety; PHY = physical injuries fear.

[a] Use combined community sample and clinic-referred sample.

[b] Proposed SCAS-P-8 items

** = *p*<.001

* = *p*<.01

Table 3

SCAS-C rank ordered item-total correlations and item differential functioning

Item	Abbreviated SCAS-C item	Subscale	Item-total correlation[a]	Estimated coefficient	Wald statistic	Odds Ratio (95% CI)
22	worry something bad will happen to me	GA	.72**	.26	9.97*	1.29 (1.10-1.51)
37[b]	**worry will suddenly get scared feeling**	**P/A**	**.68****	**.54**	**32.03****	**1.72 (1.42-2.07)**
32	all of a sudden feel really scared for no reason	P/A	.67**	.27	8.47*	1.31 (1.09-1.57)
41	bad or silly pictures or thoughts in mind	OC	.67**	.18	5.81	1.20 (1.04-1.40)
29	worry what other people think of me	SOC	.65**	.07	.88	1.08 (.92-1.25)
24	feel shaky	GA	.65**	.18	4.26	1.19 (1.00-1.41)
12	worry something awful happen to family	SEP	.64**	.12	2.73	1.13 (.98-1.31)
36	heart suddenly starts to beat too quickly	P/A	.63**	.13	1.95	1.14 (.95-1.38)
9	afraid will make fool self	SOC	.62**	.09	1.17	1.09 (.93-1.28)
4[b]	**feel afraid**	**GA**	**.62****	**.66**	**34.60****	**1.94 (1.55-2.41)**
20	heart beats really fast	GA	.62**	.00	.00	1.00 (.87-1.16)
8[b]	**worry about being away from my parents**	**SEP**	**.62****	**.40**	**26.16****	**1.49 (1.28-1.73)**
1[b]	**worry about things**	**GA**	**.62****	**.69**	**39.44****	**2.00 (1.61-2.48)**
19	can’t get bad or silly thoughts out of head	OC	.61**	.28	13.23**	1.33 (1.14-1.54)
21[b]	**suddenly start to tremble or shake**	**P/A**	**.59****	**.33**	**11.67****	**1.39 (1.15-1.69)**
16[b]	**trouble going to school in the mornings**	**SEP**	**.57****	**.45**	**24.43****	**1.57 (1.31-1.87)**
39	afraid small closed places	P/A	.57**	.11	2.24	1.12 (.97-1.30)
13	suddenly feel as if can’t breathe	P/A	.56**	.21	5.28	1.23 (1.03-1.47)
30	afraid of being in crowded places	P/A	.56**	.17	3.77	1.18 (1.00-1.40)
35	afraid if have to talk in front of class	SOC	.56**	.25	10.30**	1.28 (1.10-1.49)
42	have to do some things in just right way	OC	.56**	.06	0.50	1.06 (.91-1.24)
10	worry will do badly at schoolwork	SOC	.53**	.23	7.01*	1.26 (1.06-1.48)
6	feel scared when have to take a test	SOC	.53**	.19	6.02	1.21 (1.04-1.41)
34	suddenly become dizzy or faint	P/A	.52**	.08	.54	1.08 (.88-1.32)
44[b]	**scared if had to stay away overnight**	**SEP**	**.52****	**.43**	**29.59****	**1.53 (1.31-1.79)**
15[b]	**feel scared if have to sleep on own**	**SEP**	**.52****	**.56**	**40.39****	**1.76 (1.48-2.09)**
5	afraid to be at home alone	SEP	.52**	.35	25.53**	1.42 (1.24-1.62)
3	funny feeling in stomach	GA	.52**	.28	12.76**	1.32 (1.14-1.55)
27	special thoughts stop bad things happening	OC	.50**	.17	5.03	1.19 (1.02-1.38)
7	feel afraid to use public bathrooms	SOC	.49**	.21	5.63	1.23 (1.04-1.46)
14	keep checking that done things right	OC	.47**	.04	.25	1.04 (.89-1.21)
28	scared if have to travel in car bus or train	P/A	.46**	.29	6.73*	1.34 (1.07-1.66)
23	scared of going to doctors or dentist	PHY	.45**	.24	7.95*	1.27 (1.08-1.50)
2	scared of the dark	PHY	.43**	.26	13.24**	1.30 (1.23-1.50)
25	scared of high places or lifts	PHY	.39**	.17	4.84	1.18 (1.02-1.37)
40	have to do some things over and over	OC	.38**	.02	.07	1.02 (.88-1.18)
33	scared of insects and spiders	PHY	.35**	.03	.20	1.03 (.90-1.19)
18	scared of dogs	PHY	.20**	.19	4.93	1.21 (1.02-1.43)

Note. CI = Confidence Interval; OC = obsessive-compulsive; GA = generalised anxiety; P/A = panic and agoraphobia; SOC = social phobia; SEP = separation anxiety; PHY = physical injuries fear.

[a] Use combined community sample and clinic-referred sample.

[b] Proposed SCAS-C-8 items

** = p<.001

* = p<.01

Table 4

SCAS-T rank ordered item-total correlations and item differential functioning

Item	Abbreviated SCAS-T item[a]	SCAS-P/C subscale	Item-total correlation[b]	Estimated coefficient	Wald statistic	Odds Ratio (95% CI)
16[c]	**worries something bad will happen to him/her**	**GA**	**.75****	**1.30**	**60.31****	**3.66 (2.64-5.07)**
8[c]	**worries that he/she will do badly at school**	**SOC**	**.74****	**.69**	**37.96****	**2.00 (1.60-2.49)**
1[c]	**worries about things**	**GA**	**.74****	**.92**	**58.97****	**2.51 (1.99-3.18)**
4	scared when takes test	SOC	.73**	.71	41.32**	2.03 (1.64-2.52)
17	feels shaky when has a problem	GA	.72**	1.32	57.19**	3.76 (2.67-5.30)
22[c]	**all of sudden feels scared for no reason**	**P/A**	**.71****	**1.21**	**36.56****	**3.35 (2.26-4.95)**
7[c]	**afraid make fool self**	**SOC**	**.70****	**.64**	**31.59****	**1.89 (1.51-2.35)**
6[c]	**worries about being away from parents**	**SEP**	**.70****	**1.00**	**60.58****	**2.73 (2.12-3.51)**
12[c]	**trouble going to school in mornings**	**SEP**	**.69****	**1.68**	**90.65****	**5.35 (3.79-7.56)**
26	worries will suddenly get a scared feeling	P/A	.67**	1.19	30.05**	3.27 (2.14-5.00)
20	worries what others think	SOC	.67**	.68	38.10**	1.98 (1.59-2.45)
9	worries something awful will happen to family	SEP	.66**	1.02	54.09**	2.77 (2.11-3.64)
3	feeling afraid	GA	.65**	.46	11.64*	1.58 (1.21-2.05)
24	afraid when has to talk in front of class	SOC	.63**	.42	14.70**	1.53 (1.23-1.89)
21	afraid of crowded places	P/A	.59**	.73	16.09**	2.08 (1.45-2.97)
15[c]	**suddenly starts to tremble or shake**	**P/A**	**.56****	**1.30**	**22.26****	**3.67 (2.14-6.30)**
2	tummy aches	GA	.55**	.48	15.40**	1.62 (1.27-2.06)
14	complains heart beating really fast	GA	.47**	1.08	16.02**	2.94 (1.74-5.00)
23	suddenly becomes dizzy or faint	P/A	.44**	.81	9.93**	2.25 (1.35-3.73)
10	suddenly can't breathe	P/A	.40**	.88	12.70**	2.40 (1.48-3.99)

Note. CI = Confidence Interval; GA = generalised anxiety; P/A = panic and agoraphobia; SOC = social phobia; SEP = separation anxiety;

[a] Item functioning reported for 20 SCAS-T items considered for inclusion in brief questionnaire

[b] Use combined community sample and clinic-referred sample.

[c] Proposed SCAS-T-8 items

** = *p*<.001

* = *p*<.01

Table 5

Differences between community sample and clinic-referred sample on brief SCAS and full-length SCAS (parent, child, teacher report)

	Parent report			Child report			Teacher report		
	Community Mean (SD)	Clinic-referred Mean (SD)	*t* test (Cohen's *d*)	Community Mean (SD)	Clinic-referred Mean (SD)	*t* test (Cohen's *d*)	Community Mean (SD)	Clinic-referred Mean (SD)	*t* test (Cohen's *d*)
Total sample									
Brief SCAS	5.68 (3.68)	11.86 (4.53)	*t*(671)= 19.51** (*d* = 1.49)	5.97 (4.70)	9.18 (4.67)	*t*(647) = 8.73** (*d* = 0.69)	3.39 (2.92)	7.34 (4.67)	*t*(568) = 12.43** (*d* = 1.01)
SCAS (full)	18.28 (12.73)	39.45 (16.31)	*t*(669)= 18.85** (*d* = 1.45)	31.68 (21.02)	39.76 (18.47)	*t*(643) = 5.19** (*d* = 0 .41)	6.84 (6.17)	14.61 (10.05)	*t*(565) = 11.40** (*d* = 0.93)
Boys									
Brief SCAS	5.33 (3.35)	11.36 (4.58)	*t*(317)= 13.47** (*d* = 1.50)	4.90 (4.47)	8.44 (4.70)	t(305) = 6.74** (*d* = 0.77)	3.19 (2.98)	6.67 (4.38)	*t*(261) = 7.69** (*d* = 0.93)
SCAS (full)	16.23 (10.85)	37.93 (16.64)	*t*(317)= 13.90** (*d* = 1.54)	26.12 (20.43)	35.93 (17.85)	*t*(303) = 4.48** (*d* = 0.51)	6.19 (6.20)	13.12 (9.53)	*t*(262) = 7.16** (*d* = 0.86)
Girls									
Brief SCAS	6.03 (3.91)	12.33 (4.43)	*t*(350)= 14.17** (*d* = 1.51)	6.84 (4.71)	9.93 (4.53)	*t*(340) = 6.15** (*d* = 0.67)	3.56 (2.86)	7.92 (4.85)	*t*(305) = 9.89** (*d* = 1.10)
SCAS (full)	20.13 (13.97)	40.90 (15.90)	*t*(348)= 13.00** (*d* = 1.39)	36.18 (20.45)	43.57 (18.33)	*t*(338) = 3.49** (*d* = 0.38)	7.39 (6.11)	15.96 (10.34)	*t*(301) = 9.06** (*d* = 1.01)

Note. Brief SCAS = SCAS-P-8/SCAS-C-8/SCAS-T-8. SCAS (full) = SCAS-P/SCAS-C/SCAS-T-20.
** = *p*<.001

Table 6

Receiver Operating Characteristics for parent, teacher and child questionnaires

		Brief SCAS	SCAS (full)
Parent report	Total sample		
	n (positive; negative)	313; 360	312; 359
	AUC	.86	.86
	Optimal cut score	7.5	24.5
	Sensitivity	.85	.82
	Specificity	.75	.78
	Boys		
	n (positive; negative)	153; 166	153; 166
	AUC	.86	.88
	Optimal cut score	7.5	23.5
	Sensitivity	.81	.83
	Specificity	.79	.80
	Girls		
	n (positive; negative)	160; 192	159; 191
	AUC	.86	.85
	Optimal cut score	7.5	26.5
	Sensitivity	.89	.82
	Specificity	.71	.77
Child report	Total sample		
	n (positive; negative)	325; 324	323; 322
	AUC	.71	.63
	Optimal Cut score	6.5	32.50*
	Sensitivity	.67	.61
	Specificity	.64	.58
	Boys		
	n (positive; negative)	162; 145	161;144
	AUC	.74	.68
	Optimal cut score	5.5.	24.5
	Sensitivity	.73	.71
	Specificity	.70	.61
	Girls		
	n (positive; negative)	163; 179	162; 178
	AUC	.70	.62
	Optimal cut score	7.5	36.5*
	Sensitivity	.64	.61
	Specificity	.63	.55
Teacher report	Total		
	n (positive; negative)	230; 340	227; 340
	AUC	.76	.75
	Optimal cut score	4.5	8.5
	Sensitivity	.70	.71
	Specificity	.73	.68
	Boys		
	n (positive; negative)	107; 156	108; 156
	AUC	.76	.75
	Optimal cut score	3.5	7.5
	Sensitivity	.74	.71
	Specificity	.64	.71
	Girls		
	n (positive; negative)	123; 184	119; 184
	AUC	.77	.76
	Optimal cut score	4.5	8.5
	Sensitivity	.73	.74
	Specificity	.69	.64

Note. Brief SCAS = SCAS-P-8/SCAS-C-8/SCAS-T-8. SCAS (full) = SCAS-P/SCAS-C/SCAS-T-20.

*Not possible to achieve .60/.60 sensitivity/specificity balance

Table 7

Logistic regressions examining the contribution of each reporter using the brief SCAS

	b (Wald statistic)	Odds Ratio (95% CI)	R^2	Model
Parent+teacher model				
Constant	-4.23 (153.39**)			
SCAS-P-8 (total score)	.34 (103.44**)	1.40 (1.31-1.49)	.40 (Cox&Snell)	$X^2(2)$ =
SCAS-T-8 (total score)	.17 (24.63**)	1.18 (1.11-1.26)	.54 (Nagelkerk)	278.07**
Parent+child model				
Constant	-3.19 (135.60**)			
SCAS-P-8 (total score)	.34 (128.97**)	1.40 (1.32-1.48)	.35 (Cox&Snell)	$X^2(2)$ =
SCAS-C-8 (total score)	.03 (2.20, *p* = .14)	1.03 (.99-1.08)	.47 (Nagelkerk)	273.23**
Teacher+child model				
Constant	-2.44 (106.49**)			
SCAS-T-8 (total score)	.25 (69.72**)	1.28 (1.21-1.35)	.24 (Cox&Snell)	$X^2(2)$ =
SCAS-C-8 (total score)	.11 (25.75**)	1.12 (1.07-1.16)	.33 (Nagelkerk)	148.63**
Parent+child+teacher model				
Constant	-4.24 (136.26**)			
SCAS-P-8 (total score)	.33 (85.76**)	1.39 (1.29-1.48)		
SCAS-C-8 (total score)	.02 (.71, *p* = .40)	1.02 (.97-1.08)	.40 (Cox&Snell)	$X^2(3)$ =
SCAS-T-8 (total score)	.16 (21.28**)	1.17 (1.09-1.25)	.54 (Nagelkerk)	261.40**

Note. CI=Confidence Interval
**$p<.001$
*$p<.01$

Online Supplements

Online Supplement 1

Internal consistency (Cronbach's alpha) for brief and full versions of the SCAS in the two samples

	Community sample	Clinic-referred sample
SCAS-P-8	.82	.73
SCAS-P	.91	.89
SCAS-C-8	.84	.77
SCAS-C	.95	.91
SCAS-T-8	.80	.85
SCAS-T-20	.89	.92

Online Supplement 2

Agreement between reporters (Pearson's *r*) on the brief and full versions of the SCAS in the two samples

	Community sample	Clinic-referred sample
Parent-Child		
SCAS-P 8-SCAS-C-8	.40**	.34**
SCAS-P-SCAS-C	.42**	.34**
Parent-Teacher		
SCAS-P-8-SCAS-T-8	.32**	.28**
SCAS-P-SCAS-T-20	.29**	.21*
Teacher-Child		
SCAS-T-8 SCAS-C-8	.25**	.05, p = .46
SCAS-T-20-SCAS-C	.21**	.06, p =.39

**p<.001
*p<.01

Online Supplement 3

Convergent and Divergent validity indices for the brief and full SCAS

		Community sample	Clinic-referred sample
	Parent report		
Convergent validity	SCAS-P-8– SDQ-P-emotion	.76**	.62**
	SCAS-P-8 SDQ-P-internalising	.70**	.58**
	SCAS-P-SDQ-P-emotion	.76**	.59**
	SCAS-P -SDQ-P internalising	.70**	.53**
Divergent validity	SCAS-P-8 -SDQ-conduct	.32**	.14*
	SCAS-P-8 -SDQ-P-externalising	.34**	.10, *p* = .07
	SCAS-P - SDQ-P-conduct	33**	.20**
	SCAS-P - SDQ-P-externalising	34**	.15*
	Child report		
Convergent Validity	SCAS-C-8– SDQ-C-emotion	.73**	.65**
	SCAS-C-8- SDQ-C-internalising	.68**	.62**
	SCAS-C- SDQ-C-emotion	.81**	.72**
	SCAS-C- SDQ-C-internalising	.75**	.69**
Divergent validity	SCAS-C-8- SDQ-C-conduct	.24**	.27**
	SCAS-C-8-SDQ-C-externalising	.33**	.31**
	SCAS-C-SDQ-C-conduct	.31**	.29**
	SCAS-C - SDQ-C-externalising	.40**	.34**
	Teacher report		
Convergent Validity	SCAS-T-8–SDQ-emotion	.74**	.73**
	SCAS-T-8- SDQ-T-internalising	.64**	.65**
	SCAS-T-20– SDQ-T-emotion	.76**	.75**
	SCAS-T-20- SDQ-T-internalising	.65**	.68**
Divergent validity	SCAS-T-8-SDQ-T-conduct	.26**	.08, *p* = .22
	SCAS-T-8 -SDQ-T-externalising	.21**	.11, *p* = .10
	SCAS-T-20-SDQ-T conduct	.26**	.09, *p* = .18
	SCAS-T-20-SDQ-T externalising	.22**	.12, *p* = .08

SDQ-P/C/T-emotion = SDQ-P/T/C- emotional problems scale; SDQ-P/C/T-internalising = SDQ-P/T/C-internalising problems scale; SDQ-P/C/T-conduct = SDQ-P/T/C-conduct problems scale; SDQ-P/T/C-externalising = SDQ-P/C/T-externalising problems scale
**p<.001
*p<.01

Online Supplement 4

Sensitivity and specificity when using multiple informant versions of the brief SCAS

	Sensitivity	Specificity
SCAS-P-8 + SCAS-T-8 (parent+teacher)	.93	.54
SCAS-P-8+ SCAS-C-8 (parent+child)	.95	.54
SCAS-P-T+ SCAS-C- (teacher+child)	.89	.48
SCAS-P-8+SCAS-T-8+SCAS-C-8 (parent+teacher+child)	.97	.42

Note.

Sensitivity/specificity values calculated using optimal cut-off scores for boys/girls identified in Table 6: SCAS-P-8, 7.5 (boys & girls); SCAS-C-8, 5.5 (boys), 7.5 (girls); SCAS-T-8, 3.5 (boys), 4.5 (girls).

n = 518 (i.e. participants with SCAS-P-8, SCAS-T-8, and SCAS-C-8 data available)

Online Supplement 5

Gender differences on the brief and full length SCAS

	Community sample			Clinic-referred sample		
	Boys Mean (SD)	Girls Mean (SD)	*t* test (Cohen's *d*)	Boys Mean (SD)	Girls Mean (SD)	*t* test (Cohen's *d*)
SCAS-P-8	5.33 (3.35)	6.03 (3.91)	*t*(356) = 1.79, *p* = .07	11.36 (4.58)	12.33(4.43)	*t*(311) = 1.91, *p* = .06
SCAS-P	16.23 (10.85)	20.13 (13.99)	*t*(355) = 2.91** (*d* = 0.31)	37.93 (16.64)	40.90 (15.90)	*t*(310) = 1.61, *p* = .11
SCAS-C-8	4.90 (4.47)	6.84 (4.71)	*t*(322) = 3.78** (*d* = 0.42)	8.44 (4.70)	9.93 (4.53)	*t*(323) = 2.90* (*d* = 0.32)
SCAS-C	26.12 (20.43)	36.18 (20.45)	*t*(320) = 4.39** (*d* = 0.49)	35.93 (17.85)	43.57 (18.33)	*t*(321) = 3.79** (*d* = 0.42)
SCAS-T-8	3.19 (2.98)	3.56 (2.86)	*t*(338) = 1.18, *p* = .24	6.67 (4.38)	7.92 (4.85)	*t*(228) = 2.03, *p* = .04
SCAS-T-20	6.19 (6.20)	7.39 (6.11)	*t*(338) = 1.80 *p* = .07	13.12 (9.53)	15.96 (10.34)	*t*(225) = 2.14, *p* = .03

**p<.001
*p<.01

5.3: Paper 4: Supplementary exploratory analyses

5.3.1 Introduction

Paper 4 examined the capacity of the brief SCAS to discriminate between a community sample (*n*=361) and a clinic-referred sample of children with an anxiety disorder (*n*=338). As noted in Paper 4, it will be important for future research to examine the capacity of the brief SCAS to discriminate between children with and without an anxiety disorder where this status is established through a diagnostic assessment. Moreover, given that this new questionnaire is designed for use within community settings, it will be particularly pertinent to establish the capacity of the brief questionnaire to discriminate between children with and without clinically significant levels of anxiety from within a community sample.

The community sample included in Paper 4 were recruited as part of the screening phase of the qualitative study reported in Paper 2. As described in Paper 2, the diagnostic status of a subsample (*n*=70) were assessed, and 32 children met diagnostic criteria for an anxiety disorder. These analyses aimed to explore differences on brief SCAS scores among those children in the community sample known to have an anxiety disorder (*n*=32), and the clinic-referred sample (*n*=338).

5.3.2 Method and Results

Differences between those in the community sample with an anxiety diagnosis (*n*=32) and the clinic-referred sample with an anxiety diagnosis (*n*=338) on the brief SCAS total scores (parent, child, teacher report) were examined using independent *t*-tests, and cohen's *d*. As displayed in Table 1, mean SCAS-P-8 scores were significantly higher in the clinic-referred sample than those with an anxiety diagnosis in the community sample (*t* [343] = 2.46, *p* = .01), with a small effect size (*d* = .43). No significant differences between the samples were found on the SCAS-C-8 or the SCAS-T-8.

Table 1

Differences between children in the community sample with an anxiety disorder diagnosis and the clinic-referred sample on brief SCAS scores (parent, child, teacher report)

	Children in the community sample with an anxiety diagnosis (*n* = 32)	Clinic-referred sample (*n* = 338)	*t* test (Cohen's *d*)
SCAS-P-8	9.81 (3.93)	11.86 (4.53)	*t* (343) = -2.46, *p* = .01, (*d* = .43)
SCAS-C-8	9.39 (5.74)	9.18 (4.67)	*t* (354) = .23, *p* = .82
SCAS-T-8	6.00 (3.29)	7.34 (4.67)	*t* (258) = -1.52, *p* = .13

5.3.3 Discussion

These findings suggest that scores on the parent-report brief SCAS may be higher among children with anxiety disorders who are clinically referred, than children with anxiety disorders in the community. No evidence of similar differences were found on the child- or teacher-report brief SCAS. These analyses were intended to be exploratory, and given the small community sample (*n*=32), the findings should be treated with caution. Nevertheless, is plausible that the children in the clinic-referred sample had more severe anxiety symptoms than clinically anxious children in the community, and this difference in symptom severity could account for differences on the SCAS-P-8 scores. Indeed, it is possible that the SCAS-P-8 has a stronger capacity to detect differences in the severity of anxiety symptoms than either the SCAS-C-8 or SCAS-T-8. However, the fact that clinically anxious children in the community may typically have less severe symptoms than those referred to a clinic highlights the need to further evaluate the brief

SCAS within community settings. Indeed, it is possible that the optimal cut-off on the brief SCAS to identify children in a clinic-referred sample, may differ from the optimal cut-off for screening purposes in the community. It will therefore be particularly important for future research to establish the optimal cut-off on the brief SCAS (parent, child, teacher) for accurate identification of children with elevated anxiety within a community sample.

Chapter 6: General Discussion

This thesis aimed to improve understanding of parents' experiences of seeking and accessing professional support for anxiety disorders in pre-adolescent children. Specifically, the thesis set out to establish: i) parent reported barriers and facilitators to seeking and accessing professional support; ii) rates and types of parent reported help-seeking and professional support accessed, and factors associated with seeking professional help; and iii) ways to minimise barriers and improve access to professional support for anxiety disorders in children. The main findings from each paper are outlined below, followed by a synthesis of the findings in relation to key barriers and associated implications for improving access to professional support for childhood anxiety disorders. Finally, implications for future research are considered, together with wider implications for approaches to improving access to professional support for child and adolescent mental health problems more broadly.

6.1 Overview of findings from each paper

6.1.1 Paper 1: Systematic Review

This paper systematically reviewed qualitative and quantitative studies from the broader child and adolescent mental health literature that reported parent perceptions of barriers/facilitators to accessing treatment. Parent perceived barriers/facilitators were identified in relation to four related areas: i) systemic/structural issues; ii) views and attitudes towards mental health services and treatment; iii) knowledge and understanding of mental health problems and seeking help; and iv) family circumstances. Demands on services and costs associated with services were the most commonly reported structural barriers; although importantly the former was more frequently reported in studies of service user populations, and the latter was largely restricted to USA studies. The review illustrated the range of attitudinal barriers/facilitators, with perceptions surrounding the perceived supportiveness/dismissiveness of professionals, and the negative consequences associated with treatment most frequently reported across studies. Parent reported barriers related to not knowing where or how to seek help were also prevalent across and within studies; and, although most studies did not directly assess parent perceptions of barriers related to recognition of a child's difficulties, among those that did, a relatively large proportion of parents endorsed these barriers. Studies did not tend to directly address barriers related to family circumstances either, although barriers related to other commitments/responsibilities and a family's social network were reported in a minority of studies. The review also illustrated the role of family circumstances in relation to the experience of other barriers (e.g. the influence of past contact with services on attitudes towards services).

Paper 1's findings have clear implications for ways to minimise barriers to accessing professional support for child and adolescent mental health problems. In particular, ensuring service provision is sufficient to meet demand and free at the point of use would address key structural barriers. But, importantly, Paper 1 also illustrated the need to minimise parental attitudinal and knowledge related barriers by, for example, improving understanding of mental health difficulties and the help-seeking process, and targeting negative attitudes associated with seeking child mental health support.

The findings from Paper 1 illustrated several important shortcomings associated with existing research, namely: i) the focus on service user populations means that our understanding of barriers experienced by families who do not reach services is limited; ii) the failure to differentiate between help-seeking for adolescents and younger children, and different types of mental health problems means that implications for targeted approaches to improving treatment access within particular populations are limited; and iii) the lack of established tools for assessing parent perceived barriers, particularly among non-service user populations, means that studies may not have captured all relevant parent perceived barriers.

6.1.2 Paper 2: Qualitative Study

In light of the limitations with the existing literature, the study presented in Paper 2 aimed to specifically explore help-seeking and barriers/facilitators among parents of pre-adolescent children with anxiety disorders identified in the community. This study adopted a qualitative approach in order to provide in-depth insight into parents' help-seeking experiences, and the barriers associated with seeking and accessing support in the context of child anxiety. Findings from Paper 1 were used to identify relevant areas for qualitative investigation and semi-structured interviews were conducted with parents of 16 children (aged 7-11) with anxiety disorders.

Barriers and facilitators were identified in relation to four stages in the help-seeking process: i) recognising a child's anxiety difficulties, ii) recognising the need for professional support, iii) contacting professionals for help or advice, and iv) receiving support from professionals to help manage and overcome a child's anxiety difficulties. In particular, findings identified recognition barriers/facilitators that appear to be specific to anxiety, including a perception that anxiety is a common childhood experience or personality trait, identifying particular behaviours/symptoms as anxiety, and the potential role of parental anxiety in both enabling and hindering access to support. Findings also indicated that a range of factors influenced whether parents recognised a need for professional support or not. This study confirmed that the detrimental impact of stigma associated with seeking mental health support described in Paper 1 is equally applicable to seeking support for child anxiety problems. Paper 2 also identified that parents' confidence in their own ability to manage their child's anxiety, and guidance from professionals, can influence parents' recognition of the need for support and help-seeking decisions. A lack of knowledge about where and how to seek help identified in Paper 1, was also evident in this study; and importantly findings suggested that structural barriers associated with service provision were more relevant among parents who had tried to seek help or support for their child, than those who had not.

Paper 2 identified ways to minimise barriers to seeking and accessing professional support, including: i) appropriate tools to help parents, teachers and GPs identify significant anxiety difficulties in children; ii) accessible guidance and resources for families and professionals on the help-seeking process and types of support available; and iii) sufficient service provision that incorporates support for parents to enable to them to support their children.

6.1.3 Paper 3: Survey

As previously outlined, there are a lack of current data on rates and types of help seeking and professional support obtained for anxiety disorders in children, and Paper 3 set out to provide this quantitative data. This study also aimed to provide quantitative data on parent reported barriers/facilitators to seeking and accessing professional support for child anxiety, factors associated with seeking/not seeking child anxiety support, and differences in parent reported barriers among those who have and have not sought professional help. Findings from Paper 1 and Paper 2 were used to develop a questionnaire to collect information on help-seeking and barriers/facilitators among parents of children (aged 7-11) with elevated anxiety, and a subsample where the child met diagnostic criteria for an anxiety disorder, identified through screening in primary/junior schools across England.

Findings illustrated that the majority of children with anxiety disorders do not receive professional support to help with their anxiety; and a sizeable minority of families do not contact professionals for help or advice. Families who received professional support, received a range of different types of support, but it was rarely evidence-based. A parental perception that their child may benefit from professional support, and use of specialist mental health services for their own mental health difficulties were both associated with seeking professional help for their child's anxiety. In contrast, a parent perceived need for support for themselves to enable them to help their child was associated with reduced likelihood of seeking help for their child's anxiety. Parents frequently reported a range of barriers to both asking for help or advice, and barriers to receiving professional support. Barriers associated with differentiating between 'normal' and clinically significant anxiety, uncertainty surrounding the need for professional support, a lack of knowledge about who to contact for help and the professional support available, and barriers related to limited service provision were all common. Barriers associated with limited service provision were more frequent among parents who had sought help for their child than those who had not; and the absence of professional recognition of a child's anxiety difficulties and a belief that a child's anxiety may improve without professional input were more common among non-help seekers than help-seekers.

The findings from Paper 3 confirm the need to minimise barriers to both seeking and accessing professional support for child anxiety, and in particular illustrated the widespread need for: i) available tools to assist parents and professionals to accurately identify anxiety difficulties in children, in school and primary care settings; ii) efforts to raise awareness of the help-seeking process and available support for both parents and children; and iii) increased provision of evidence-based child anxiety treatment that includes providing support for parents, delivered in both school and primary care settings.

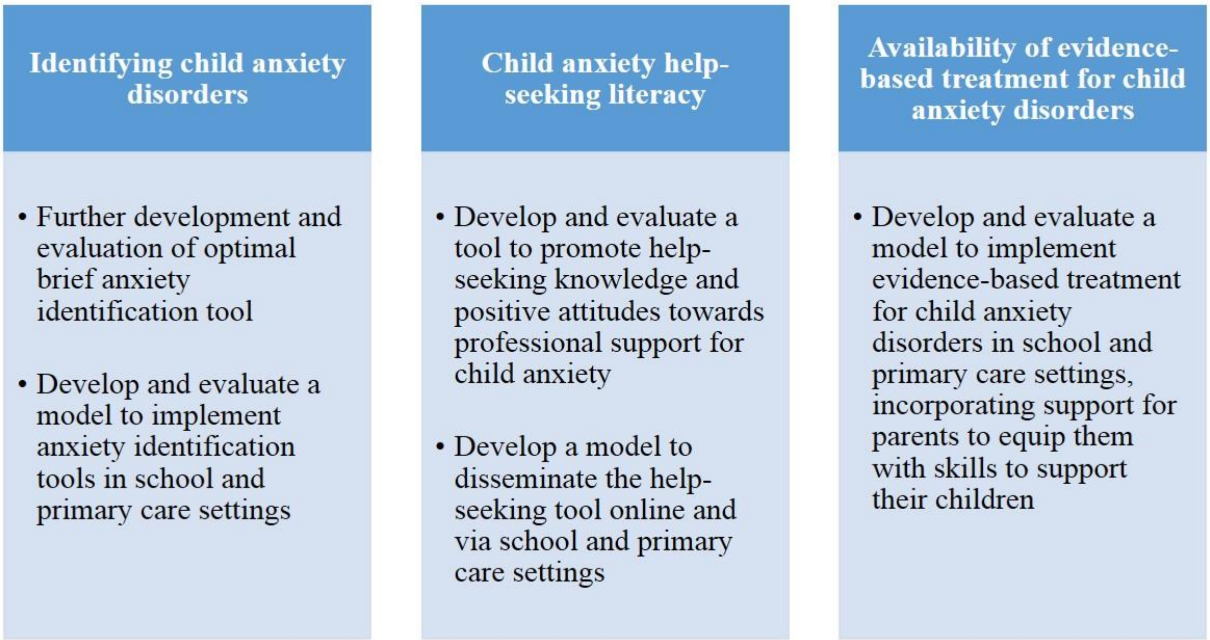
6.1.4. Paper 4: Identification tool

Papers 2 and 3 identified a need for appropriate tools to help parents, school staff and GPs to identify anxiety difficulties in children and to make judgements about when a child may benefit from additional support. Paper 4 aimed to develop and evaluate brief questionnaires (parent, teacher, and child versions) designed to identify symptoms of anxiety disorders in children aged 7-11 years, using items from the Spence Children's Anxiety Scale (SCAS). The findings provided support for the reliability and validity of the 8-item questionnaires, with the brief questionnaires demonstrating similar psychometric properties to the full length SCAS. The 8-item questionnaires discriminated between a community and clinic-referred sample of children with anxiety disorders, and were able to identify children in the clinic-referred sample with at least a moderate level of accuracy, and acceptable sensitivity and specificity. The parent report questionnaire was the most accurate of the three; and findings indicated that parent+teacher report was the optimal combination of reporters. Paper 4 illustrated that this brief identification tool has potential to address recognition barriers reported in Papers 2 and 3, and to facilitate the identification of pre-adolescent children with clinically significant levels of anxiety.

6.2. Synthesis of study findings and implications for future research

Findings across the papers highlight key barriers and associated implications for minimising these barriers and improving access to professional support for child anxiety disorders in three main areas, as described in detail below and considered in relation to relevant literature and implications for future research. Figure 1 provides a summary of the implications for future research to address the key barriers identified in this thesis.

Figure 1. Implications for future research to minimise barriers and improve treatment access for child anxiety disorders



Identifying child anxiety disorders

- Further development and evaluation of optimal brief anxiety identification tool
- Develop and evaluate a model to implement anxiety identification tools in school and primary care settings

Child anxiety help-seeking literacy

- Develop and evaluate a tool to promote help-seeking knowledge and positive attitudes towards professional support for child anxiety
- Develop a model to disseminate the help-seeking tool online and via school and primary care settings

Availability of evidence-based treatment for child anxiety disorders

- Develop and evaluate a model to implement evidence-based treatment for child anxiety disorders in school and primary care settings, incorporating support for parents to equip them with skills to support their children

6.2.1 Identifying child anxiety disorders

Paper 2 illustrated the range of difficulties parents can face identifying anxiety in children, and Paper 3 confirmed that such difficulties are commonplace. These findings are consistent with evidence that parents' perceptions surrounding the existence of children's difficulties are associated with use of mental health services (Sayal, Goodman, & Ford, 2006; Teagle, 2002); and illustrate how recognition barriers can deter parents from contacting professionals for help. Similarly, in line with findings that parent perceived impairment associated with a child's symptoms predicts child mental health service use (Ryan, Jorm, Toumbourou, & Lubman, 2015), parent reported impairment associated with child anxiety, and particularly impairment associated with family/home activities, was associated with seeking help for a child anxiety disorders in Paper 3. The vast majority of help-seekers in Paper 3 also endorsed the impact on a child's life as a reason for their help-seeking. However, notably, Paper 1 indicated that studies have not typically directly assessed a lack of parental recognition of a child's mental health problems or associated impact as *perceived* barriers, but, it is clear that parents do conceptualise lacking or limited parental recognition as a help-seeking barrier, at least in the context of child anxiety.

The finding that parents face particular difficulties differentiating between 'normal' and 'problematic' anxiety is consistent with the poor recognition associated with anxiety disorders among adults (Coles & Coleman, 2010; Coles, Schubert, Heimberg, & Weiss, 2014). Notably, Coles and Coleman (2010) reported that adults rarely attribute social anxiety disorders and generalised anxiety disorders to mental illness, rather the former is usually attributed to environmental factors or personal weakness; and the latter is most commonly attributed to stress. Qualitative findings from Paper 2 similarly indicate that parental views about the cause of a child's anxiety contribute to uncertainty surrounding whether the anxiety is 'normal' or not. In particular, viewing anxiety as part of a child's personality deterred parents from considering it as 'problematic' (e.g. '*I hadn't seen it as such a diagnosable erm issue maybe I thought it was you know either your child has these characteristics or they don't'* [ID 2009]). Further, the view that anxiety is a common childhood experience that emerged in Paper 2 illustrated an additional complexity surrounding differentiating 'normal' from clinically significant anxiety specifically in children (e.g. '*I suspect that it's it's quite common for the younger ones to er to er have this…. I see it as part of growing up er you know the shyness'* [ID 3]*)*. The transient nature of a child's anxiety was another frequently reported barrier in Paper 3, and qualitative findings from Paper 2 illustrated how parents' perceptions of the ongoing or fluctuating nature of a child's anxiety can influence whether they consider it as 'normal' or not. Indeed, Paper 2 showed how parents sometimes attributed phases of anxiety to things going on in a child's life, and this deterred them seeking professional help (e.g. '*he's not doing that now erm I think it was sort of a period that he was going through I think and he seems to have settled down'* [ID 1020]*)*. In contrast, marked changes in a child's behaviour or where particular behaviours or symptoms persisted made it easier for parents to recognise the anxiety as problematic (e.g. '*he has refused to* [leave home] *pretty much constantly since about April this year'* [ID 1131]). Moreover, it is also evident from Paper 3 that parents frequently face difficulties differentiating between anxiety and other types of difficulties. Qualitative findings in Paper 2 suggest that this may partly due to uncertainty among parents surrounding whether behaviours such as temper tantrums or anger outbursts are anxiety symptoms or not (e.g. '*a withdrawn type of quiet insular sort of reaction which is what I would have expected from anxiety rather than the complete explosive behaviour*' [ID 7]).

Together the findings from Papers 2 and 3 illustrate the potential benefit of ensuring tools are available to help parents overcome these difficulties identifying anxiety difficulties in their children. Moreover, Papers 2 and 3 also illustrate the important role professionals play in influencing parental recognition of a child's anxiety difficulties. The failure of teachers or other professionals to suggest a child needs help was negatively associated with seeking help in Paper 3. Indeed, it was clear from Paper 2 how parents look to school staff and GPs to endorse, validate or raise concerns about a child's anxiety (e.g. '*if somebody said to me I really do think your child suffers from either mild or whatever moderate anxiety and would benefit from some sort of help then I would be right ok where do I get it from then what do I do'* [ID 2011]*).* These findings are consistent with previous reports that parents often do not directly raise concerns about a child's mental health with GPs (Sayal & Taylor, 2004), and illustrate the importance of ensuring teachers and GPs have the skills and tools to accurately identify anxiety difficulties in children. As outlined in Paper 4, available questionnaire tools for assessing child anxiety symptoms are long and time consuming to complete, making them impractical for use in GP appointments. GPs themselves also report a lack of suitable tools to help them identify anxiety in children (O'Brien, Harvey, Young, Reardon, & Creswell, 2017). Findings from Paper 4 provide evidence to support the potential for the use of brief questionnaire tools in school and primary care settings to help improve the identification of anxiety disorders. Moreover, although child report is frequently used in child mental health screening in school settings for pragmatic reasons, findings from Paper 4 importantly indicate that parent report should be prioritised over child report to maximise accurate identification of anxiety difficulties in pre-adolescent children.

6.2.2 Implications for future research to promote identification of child anxiety disorders

This thesis illustrates the need to address barriers to recognising anxiety difficulties in children, and provides preliminary evidence for the potential use of brief questionnaires to help address these recognition barriers. However, as outlined in Paper 4, further development and evaluation of the brief tool is now needed to ensure the optimal identification tool is available. In particular, future studies need to evaluate the brief tool's capacity to discriminate between children with and without anxiety disorders within the general community, where both groups are established through a diagnostic assessment. Moreover, given that impairment associated with a child's anxiety is a key characteristic of a clinical diagnosis, coupled with the fact that impact associated with a child's anxiety is a key determinant of professional help-seeking, future studies should explore the potential benefit of incorporating questions related to impairment in the brief questionnaire tool. Indeed, including questions assessing the impact associated with mental health difficulties improves the capacity of a broad measure of emotional and behaviour problems to detect mental health disorders (Goodman, 1999).

Future research also needs to explore the potential implementation of anxiety identification tools in school and primary care settings. Indeed, such research clearly aligns with the role described for schools and GPs in improving early identification of mental health problems in children and adolescents outlined in recent government reports (Children and Young People's Mental Health Taskforce, 2015; Department of Health & Department for Education, 2017). The availability of appropriate tools is only one element of planning and implementing mental health screening in schools (Weist, Rubin, Moore, Adelsheim, & Wrobel, 2007). In particular, it is essential that school staff have appropriate training and resources to implement mental health screening, and appropriate support is available following identification of difficulties (Levitt, Saka, Hunter Romanelli, & Hoagwood, 2007; Weist et al., 2007). Moreover, given that obtaining parent report is particularly important for accurate identification of child anxiety disorders, research efforts will need to consider how best to maximise parent engagement in school based anxiety screening. Indeed, the relatively low participation rates in the screening stages in Papers 2 and 3 highlight the challenges associated with seeking parental consent for child anxiety screening.

Further research needs to establish the benefits, or any potential harms, associated with screening for anxiety difficulties in children, and to explore ways to maximise benefits and minimise potential harms. Indeed, a study of school-based screening for attention deficit and hyperactivity in 4-5 year olds found that screening was associated with higher rates of inattention/hyperactivity at a 5 year follow-up, compared to no intervention or screening plus an educational intervention for teachers (Sayal et al., 2010). In this study the names of children identified with high symptoms were provided to schools, not directly to parents, and it will be particularly important to explore how best to provide direct feedback to parents in the context of child anxiety screening. Sayal et al's study of inattention/hyperactivity screening also found that among children with high symptoms at baseline, screening combined with an educational intervention for teachers had a negative impact on children's reading and mathematics at a 2 year follow up (Tymms & Merrell, 2006). It will therefore be necessary to determine how best to combine screening with an evidence-based intervention for child anxiety disorders in school settings. For example, and as discussed further below, a more targeted approach may be needed that involves working directly with families where a child is identified with high levels of anxiety, rather than taking a universal approach with teachers.

The potential benefit of assessing child anxiety in primary care settings is reported elsewhere (Ramsawh, Chavira, & Stein, 2010), but there is a lack of research addressing how best to implement child anxiety assessment or screening in primary care settings (Blossom & Roberts, 2017). Future research needs to explore GPs' views about how such child anxiety identification tools can feasibly be implemented in primary care settings. This research would benefit from adopting a 'co-design' approach (Larkin, Boden, & Newton, 2015), whereby by researchers work collaboratively with GPs, GP practice managers and families to develop a model for implementing child anxiety screening in primary care. Indeed, research examining the use of brief tools in primary care to identify depression in adults suggests that GPs are often sceptical about using questionnaire results (Dowrick et al., 2009), and it will be necessary to ascertain GPs' views and use of results from brief child anxiety screening tools.

6.2.3 Child anxiety help-seeking literacy

Papers 1, 2 and 3 each identified key barriers related to a lack of knowledge about seeking professional help. Not knowing who to ask for help or what professional support is available for child anxiety difficulties were among the most frequently reported parent barriers in Paper 3; and Paper 1 indicated that similar barriers apply to seeking mental health support for children more broadly. Moreover, qualitative findings from Paper 2 illustrated why parents can face particular uncertainty about whether it is appropriate to contact GPs and/or school staff for help or advice about anxiety difficulties in children. For example, parents who did not view anxiety as a ‘medical’ problem were unsure about whether anxiety problems were within a GP’s remint or not (e.g. ‘*it’s not really a medical thing is it…it’s not something that you would go to the GP for I mean if your child has tummy ache and you know it’s not not because of a physical thing it’s more emotional thing’* [ID 1036]). Similarly, parents who described their child’s anxiety as not visible at school felt it may not be appropriate to seek help from teachers (e.g.’ *she doesn’t do that at school…so I suppose now I wouldn’t tell teachers’* [ID 7]). Indeed, the finding in Paper 3 that parents’ contact with a mental health professional for their own mental health difficulties increased the likelihood of seeking professional support for their child could in part be attributable to the associated increased knowledge or ‘literacy’ surrounding mental health help-seeking. Certainly qualitative findings in Paper 2 showed how parents’ own personal and professional experience influenced their help-seeking knowledge.

Deficits in ‘mental health literacy’, or knowledge and beliefs about mental health difficulties and professional support for mental health difficulties are widely reported among adults and adolescents (Jorm, 2000; Kelly, Jorm, & Wright, 2007). Findings from this thesis importantly illustrate the pertinence of knowledge and beliefs about help-seeking to parents. Furthermore, unlike help-seeking literacy in the context of adults or adolescents seeking help for themselves, findings from Papers 2 and 3 highlight the importance of parents’ knowledge and beliefs about their role as a source of support in the context of child anxiety disorders. It was evident from Paper 3 that parents often prefer to manage their child’s anxiety difficulties themselves, and Paper 2 showed how this may partly be because parents see it as their role or responsibility (e.g. ‘*it’s more you know it’s part of his life part of our life we need to we need to support him here first and take it take it as a family basically*’ [ID 1091]). Moreover, Paper 3 showed that many parents feel they would benefit from support to enable them to help their child, but the fact that this was not associated with help-seeking may in part be attributed to a belief or assumption that help-seeking would only facilitate direct support for the child. Together these findings illustrate the importance of raising awareness of the help-seeking process, including identifying i) points of contact for parents; ii) self-help strategies and resources for families; and iii) sources of professional support for parents, as well as direct support for children. Moreover, the finding that so many parents in Paper 3 reported speaking to others in their social network about help-seeking highlights the potential benefit of ensuring families and the wider public are aware of and understand the help-seeking process. Similarly, the clear role for both primary school staff and GPs as points of contact that was evident across the papers, indicates a need to promote similar help-seeking literacy among professionals working with families.

Findings from across the papers illustrated the detrimental impact a range of negative beliefs and attitudes towards seeking professional support can have on parental help-seeking. It will therefore be important that efforts to promote knowledge about child anxiety help seeking also address pertinent negative attitudes towards professional help-seeking. In particular, findings from Papers 2 and 3 highlight the need to target the stigma associated with seeking professional support for anxiety disorders in children. The detrimental impact of mental health stigma on adult help-seeking is widely reported (Corrigan, Druss, & Perlick, 2014). There is also some evidence that interventions targeting stigma are effective in reducing ‘personal stigma’, or adults’ own negative attitudes towards people with mental health problems (Griffiths, Carron-Arthur, Parsons, & Reid, 2014). However, ‘perceived stigma’ (beliefs about other people’s negative attitudes towards individuals with mental health problems) and ‘self stigma’ (an individual’s negative attitudes towards their own mental health problems) have received less attention in the adult literature (Griffiths et al., 2014). Furthermore, very few studies have directly assessed negative attitudes towards people with anxiety disorders. One study that assessed negative attitudes towards generalised anxiety disorders among adolescents, however, notably reported a high level of both personal and perceived stigma (Calear et al., 2017). Importantly, findings from this thesis illustrate that parental concerns about other people's negative perceptions of i) children with anxiety disorders, and ii) parents of children with anxiety disorders deter parents from seeking help. Indeed, Paper 2 highlighted how parents' concerns about other people's negative attitudes towards them as parents included concerns that professionals may blame them (e.g. '*you're thinking do they think you know I should have done this or I should have done that erm*' [ID 1212]). In addition to perceived negative attitudes among others, Paper 3 also showed that parental concerns about 'self stigma' among children (i.e. a concern that their child will think they have a problem); as well as parents' own 'self stigma' (i.e. parents' own sense of blame or failure) were common barriers to help-seeking. Moreover, Paper 2 highlighted how parents who lacked confidence in their ability to support their child perceived this as a weakness in themselves (e.g. '*because as a parent there's nothing worse than thinking I've done everything I can and I can't help my child'* [ID 1212]). Indeed, this sense of failure or perceived weakness as a parent may also partly explained why the need for parental support was negatively associated with help-seeking in Paper 3. It will therefore be particularly important that efforts to promote child anxiety help-seeking literacy addresses negative attitudes towards both parents and children.

6.2.4 Implications for future research to promote child anxiety help-seeking literacy

Further research now needs to explore the development and evaluation of tools to promote help-seeking knowledge and positive attitudes towards professional help-seeking for anxiety difficulties in children. Interventions designed to promote 'mental health literacy', and interventions to address stigma within the wider community and specifically within schools exist (Henderson, Evans-Lacko, & Thornicroft, 2013; Kauer, Mangan, & Sanci, 2014;

Wei, Hayden, Kutcher, Zygmunt, & McGrath, 2013). However, there is currently little evidence relating to the impact of such interventions on help-seeking behaviour or use of professional support for mental health difficulties (Kauer, Buhagiar, Blake, Cotton, & Sanci, 2017; Kauer et al., 2014). Indeed, Kauer et al., (2017) described the need to develop a theory-informed, evidence-based intervention designed to promote mental health help-seeking among adolescents, and to evaluate outcomes in relation to changes in help-seeking behaviour. Griffiths, Walker, & Batterham (2017) similarly developed an online intervention specifically designed to promote help-seeking for social anxiety in adults. This online intervention incorporates information about social anxiety disorders, information and activities designed to counter negative attitudes towards individuals with social anxiety disorders, and help-seeking guidance. Encouragingly, the intervention was associated with improved attitudes towards help-seeking and increased perceived need for professional support among adults with elevated social anxiety symptoms. Findings from this thesis could be used to develop a similar help-seeking tool tailored specifically for parents of children experiencing anxiety difficulties.

The potential opportunity to improve accessibility of interventions designed to promote help-seeking among young people and adults through internet delivery is reported elsewhere (Griffiths, 2013), and findings from Papers 2 and 3 indicate that many parents use the internet to seek information about child anxiety. However, further research is needed to explore how best to use the internet and other approaches to disseminate information about professional help-seeking for child anxiety difficulties to parents. Indeed, mass media has been used effectively to promote behavioural parent training interventions such as the Triple P Parenting Programme (Sanders, Calam, Durand, Liversidge, & Carmont, 2008); and there are similar calls for ‘direct consumer marketing’ to promote public understanding of evidence-based anxiety treatments for adults (Gallo, Comer, & Barlow, 2013). Findings from this thesis suggest a similar approach is warranted to promote public understanding of treatment for child anxiety disorders.

6.2.5 Availability of evidence-based treatment for child anxiety disorders

In line with recent reports of the unmet need in relation to child mental health (Children and Young People's Mental Health Taskforce, 2015; Department of Health & Department for Education, 2017; NHS England, 2016), Paper 3 specifically identified the substantial gap between the number of parents who seek help from professionals and those who go on to receive evidence-based treatment for child anxiety disorders. Indeed, Papers 2 and 3 illustrate that after seeking professional help for anxiety in children, parents experience a range of barriers that make it hard for them to actually access services, including referral difficulties and long waiting lists. Notably, in Paper 3 only a handful of families accessed an evidence-based treatment for child anxiety disorders. These findings clearly illustrate the need to ensure sufficient provision is available for children with anxiety disorders, and to ensure families are offered professional support that is evidence-based. Indeed, while it is estimated that 50-60% of pre-adolescent children with anxiety disorders recover over a 2-3 year period without treatment (Copeland, Angold, Shanahan, & Costello, 2014; Ford, MacDIarmid, Russell, Racey, & Goodman, 2017), arguably this is a long time to wait for recovery. Moreover, even if children do recover without treatment from anxiety disorders early in life, they are still at an estimated 50% increased risk of poor functioning in adulthood (Costello & Maughan, 2015)

As outlined above, the findings from Papers 2 and 3 indicate the potential benefit of providing direct support for parents, both to satisfy the parental perceived need for support and to help address concerns about there being negative consequences for a child associated with receiving direct support from professionals. Moreover, the variation in parents' attitudes towards seeking support from teachers and GPs illustrated in Paper 2 highlights the importance of ensuring anxiety treatment is available via both primary care and school settings. Increasing the visibility of evidence-based mental health treatments within school and primary care settings can also help promote awareness of and target stigma associated with mental health support (Dempster, Davis, Faye Jones, Keating, & Wildman, 2015). This approach could therefore also help address knowledge and attitudinal barriers to anxiety help-seeking outlined above.

6.2.6 Implications for future research to increase the availability of evidence-based treatment for child anxiety disorders

Evidence of the substantial unmet need in relation to child anxiety disorders, together with the highlighted potential role for schools and primary care settings indicate that further research is needed to explore how best to implement evidence-based anxiety treatment for children in these settings. Indeed, this research would clearly align with plans to deliver CBT in school settings for children experiencing anxiety outlined in the recent government Green paper (Department of Health & Department for Education, 2017). The research could be guided by the discipline of ‘Implementation Science’ which aims to address the gap between research and clinical practice, and provides frameworks to inform research examining how and why evidence-based treatments are/are not implemented, and to evaluate implementation outcomes (Nilsen, 2015). This thesis provides important ‘pre-implementation’ work, and it will now be particularly important to establish teacher views on the feasibility of and barriers to delivery of evidence-based anxiety treatment within schools (Reinke, Stormont, Herman, Puri, & Goel, 2011). It will also be necessary to identify conditions that are needed for successful implementation in schools, such as leadership and administrative support (Langley, Nadeem, Kataoka, Stein, & Jaycox, 2010). To date studies that have evaluated CBT anxiety interventions in school settings have adopted a universal approach, but outcomes are limited for those with clinically significant anxiety at baseline (Stallard et al., 2014). It will therefore be particularly important for future research to establish outcomes for children with anxiety disorders if a more targeted approach is adopted. Similarly, although primary care has been identified as an appropriate place to deliver child anxiety treatment (Rozenman & Piacentini, 2016), very few studies to date have evaluated the delivery of child anxiety treatment within primary care settings. In a recent systematic review, Blossom & Roberts (2017) identified only three USA studies that evaluated child anxiety interventions delivered in primary care settings, although encouragingly each reported promising findings in relation to acceptability and feasibility. However, it will be important to evaluate the delivery of child anxiety interventions in primary care settings in the UK, and establish primary care staff views on the feasibility of such interventions in a UK context. Furthermore, efforts to increase the availability of child anxiety treatment would clearly need to consider efficiency and cost effectiveness. Various brief versions of traditional CBT for child anxiety have been developed, including a brief 5 hour parent-led CBT programme, with good evidence to support its effectiveness and cost-effectiveness (Creswell et al., 2017; Thirlwall et al., 2013). Future research would benefit from examining how such brief treatments could best be delivered within school and primary care settings.

6.2.7 Broader implications for improving access to child and adolescent mental health treatment

Findings from this thesis illustrate the importance of identifying and addressing a complex range of barriers to accessing child mental health support. In particular, findings across the papers provide support for theoretical approaches that conceptualise parental help-seeking as a process that consists of a number of distinct stages (Logan & King, 2001), with particular barriers associated with each of these stages. Consequently, while efforts to increase service provision are needed, findings from this thesis indicate that it is also important to consider barriers to making initial contact with professionals which are unlikely to be fully addressed by only ensuring treatments are available. Moreover, by focusing on a narrow age range and a specific mental health disorder, this thesis was able to identify pertinent barriers for a particular population. Adopting the same approach for older/younger children in the context of other specific mental health disorders would be similarly beneficial. For example, the role of school staff as a point of contact for parents, and parents' views surrounding their role as a source of support for their children, are likely to be different in secondary schools and among older children and adolescents. Furthermore, the fact that some barriers reported in qualitative studies in Paper 1, such as the dismissiveness of professionals, were often not captured in existing questionnaire measures highlights the need for further development and improvement to tools assessing perceived barriers to accessing youth mental health treatment.

6.3 Limitations

Limitations associated with each of the studies included in this thesis are outlined in Papers 1-4. However, it is also necessary to acknowledge some further limitations, and those that are relevant to the broader conclusions. The systematic literature search used to identify studies for inclusion in Paper 1 was conducted in October 2014, and because of the volume of work involved in conducting the review, there was an 18-month delay before submission to the journal, and a further delay before publication. Given the complexity of the narrative synthesis used in the review, it was not feasible to update the search and incorporate findings from any additional relevant studies prior to submission. Indeed, as detailed in Paper 3, it is important to note that one relevant study that reported parental perceptions of barriers to treatment access within a sample of parents of children who received treatment for anxiety was published in 2016 (Salloum, et al., 2016). Consistent with the systematic review's findings, not knowing where to seek help and uncertainty surrounding whether a child's anxiety reflected a genuine problem or not were the most frequently reported parental barriers in this recent study (Salloum, et al. 2016). The systematic review was also limited to studies published in English, and peer reviewed articles. As such, findings from studies of parent perceived barriers/facilitators reported in other languages, and reported in alternative publications (e.g. charity and government reports) were not captured in Paper 1.

A strength of Papers 2 and 3 is that standardised assessments were used to assess the child's diagnostic status, including an assessment of DSM anxiety diagnoses and common comorbid diagnoses. Diagnoses of comorbid behavioural disorders, however, were based solely on parent-report, and as such can only be seen as a guide for disorders that conventionally incorporate observations and/or teacher assessment (e.g. Attention Deficit and/or Hyperactivity Disorder, Conduct Disorder). There were some also limitations associated with the teacher report version of the SCAS (SCAS-T) that was used in the screening stages in Papers 2 and 3, and to develop a new brief questionnaire in Paper 4. The SCAS-T is an adapted version of the published SCAS-P/C, and had not been tested or piloted prior to the studies reported in this thesis. The studies recruited participants throughout the academic year so teachers will have known the children for varying lengths of time, and this may have limited some teachers' abilities to complete the questionnaires. In Papers 2 and 3 (and the community sample in Paper 4), class teachers completed the SCAS-T for all participating children, and it is possible that completing multiple questionnaires influenced teacher responses. Future studies evaluating the SCAS-T (full and brief versions) would benefit from exploring the impact of clustering on teacher responses, particularly given that anxiety identification or screening programmes in schools would involve teachers completing multiple questionnaires.

Participation rates at each stage of the recruitment process used in Papers 2 and 3 was relatively low; approximately one in ten schools who were contacted took part, and only 16.2-18.5% of parents invited to take part in the initial questionnaire screening stage in each study provided consent. It is likely that there was participation bias in both studies where schools with an interest or awareness of anxiety problems in children, and parents with some concern about their child's anxiety were more likely to take part than schools or parents without this awareness or concern. As a result, findings from both of these papers may not have captured help-seeking experiences among harder to reach schools and families for whom potential barriers to seeking and accessing professional support may have been greater and/or different. Indeed, it is likely that some families will have experienced barriers to taking part in the studies, including limited English language/literacy, that are likely to pose similar barriers to professional help-seeking for child anxiety. It is therefore possible that there are additional barriers to professional help-seeking for child anxiety that were not identified in this thesis.

The measure of parental perceived barriers/facilitators used in Paper 3 was also a new questionnaire, developed for the purpose of collecting discrete information for this research, and as result its psychometric properties are not yet fully established. As reported in Paper 3, internal consistency for barrier and facilitator total and subscale scores were good, but further evaluation of relevant psychometrics in future larger samples is needed (e.g. factor analysis to examine the subscale structure and to identify any redundant items). Additionally, it is important to acknowledge that information on help-seeking and receipt of professional support in Paper 3 was based on parent report, and it was not possible to verify this with, for example, medical/school records.

6.4 Conclusions

Anxiety disorders are among the most common mental health disorders experienced by children, and are associated with significant negative outcomes for families and economic burden for society. Evidence-based treatments for child anxiety disorders exist, and although there are a lack of current data on rates of help-seeking and treatment access in the context of child anxiety, only a minority of children with mental health problems access treatment. This thesis demonstrates a substantial unmet need in relation to anxiety disorders in pre-adolescent children, and reveals that a sizeable minority of parents do not seek professional help, the majority of families do not successfully obtain support to address a child’s anxiety disorder, and very few receive evidence-based treatment. Findings across Papers 1, 2 and 3 identify a complex array of barriers to seeking and accessing professional support for anxiety disorders in pre-adolescent children, including barriers associated with: i) identifying anxiety disorders in children; ii) child anxiety help-seeking literacy, including knowledge of the help-seeking process and attitudes towards professional support for child anxiety; and iii) the availability of evidence-based treatment for child anxiety disorders.

The thesis findings have clear implications for potential ways to minimise barriers in these three areas, and further research needed in order to improve access to evidence-based child anxiety treatment. Firstly, in relation to identifying child anxiety difficulties, the thesis provides preliminary evidence to support the potential for brief identification tools to promote accurate identification of anxiety disorders in children. Further development and evaluation of these brief tools is now needed; together with efforts to promote their implementation in school and primary care settings. Secondly, the findings illustrate the need to improve public knowledge and understanding of child anxiety help-seeking, and awareness of the benefits of professional support; and indicate the need for further research to develop and disseminate tools designed to promote child anxiety help-seeking literacy. Lastly, the thesis illustrates the need to increase provision for families affected by child anxiety disorders, and to ensure professional support is evidence based; and highlights the importance of future research designed to promote the delivery of evidence based anxiety treatments within school and primary care settings.   Together these findings underline the importance of ensuring efforts to improve access to child and adolescent mental health problems target key barriers to initial help-seeking, as well as ensuring sufficient evidence-based provision across service providers.

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Chapter 7 Appendices

Appendix 1: Ethics committee approval letters

University of Reading

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

Academic and Governance Services

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Professor Catharine Creswell
Professor of Developmental Clinical
Psychology
School of Psychology and Clinical
Language Sciences
University of Reading
RG6 6AL

12 March 2015

Dear Cathy

UREC 15/04: I-CAT: Improving access to Child Anxiety Treatment. *Favourable opinion*

Thank you for the response (email dated 8 February 2015, from Tessa Reardon and including attachments, refers) addressing the issues raised by the UREC Sub-committee at its January meeting. Thank you also for the further minor amendments to the project, requested in the same email. On the basis of your response and the revised documentation, 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: Dr John Wright (Chair); Professor Laurie Butler (Head of School); Tessa Reardon

University of Reading

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

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Professor Cathy Creswell
School of Psychology and Clinical Language
Sciences
University of Reading
RG6 6AL

25 May 2016

-

Dear Cathy

UREC 16/25: Improving access to child anxiety treatment (I-CAT): A national survey. *Confirmation – condition met*

Thank you for the information (email dated 25 May 2016 from Tessa Reardon and including attachments refers). On the basis of these documents I can confirm that the Condition set in my Favourable Opinion letter of 10 May has been met and the Favourable Opinion is confirmed.

Yours sincerely

Dr M J Proven
Coordinator for Quality Assurance in Research (UREC Secretary)
cc: Dr John Wright (Chair); Professor Laurie Butler (Head of School); Tessa Reardon (PhD student)

University of Reading

Coordinator for Quality Assurance in Research
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Professor Cathy Creswell
School of Psychology and Clinical Language
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University of Reading
RG6 6AL

25 May 2016

Dear Cathy

UREC 16/25: N-CAT: National survey of Child Anxiety and Treatment access. *Amendment – Favourable opinion*

Thank you for your application (email dated 25 May 2016, from Tessa Reardon and including attachments refers) requesting and detailing amendments to the above project (*change of study title; minor revision to information leaflet; inclusion of demographic question in Phase 1 parent questionnaire; revision of parental consent form; removal of items from SCAS-T and SCAS-C questionnaires*). I can confirm that the UREC Chair has reviewed that request and is happy for the project to continue

Yours sincerely

Dr M J Proven
Coordinator for Quality Assurance in Research (UREC Secretary)
cc: Dr John Wright (Chair); Professor Laurie Butler (Head of School); Tessa Reardon (PhD student)

University of Reading

Director of Quality Support
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Professor P.J.Cooper
School of Psychology and Clinical Language Sciences

24 January 2008

Dear Professor Cooper

Research Ethics Committee
Project 07/48: Treatment of Child Anxiety Disorder in the Context of Maternal Anxiety: A Randomised Controlled Trial

Project 07/49: Guided Self-help Treatment of Child Anxiety Disorder: A Randomised Controlled Trial

Project 07/50: Treatment of Child Anxiety: Predictors and Outcomes of Treatment

Thank you for your letter of 18 January 2008 regarding the above project, providing appropriately revised information. As indicated in my letter of 14 January 2008, the Chair is happy for the project to proceed.

Yours sincerely

D.A.Stannard
Director of Quality Support

cc Professor E.J.Cooke, School of Law
Dr J.A.Ellis, School of Psychology and Clinical Language Sciences
Ms V.Williams, School of Health and Social Care

SL38 Progress report reminder
Version 4.0, April 2009

NHS
National Research Ethics Service
Berkshire Research Ethics Committee
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London Road
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Tel: 0118 918 0550 / 0551
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26 November 2009

Professor Peter Cooper
Professor of Psychopathology
University of Reading
School of Psychology
University of Reading
Reading, Berkshire
RG6 6AL

Dear Professor Cooper

Full title of study: **Guided Self-help Treatment of Child Anxiety Disorder: A Randomised Controlled Trial**
REC reference number: **07/H0505/157**

The REC gave a favourable ethical opinion to this study on 16 November 2007.

It is a condition of approval by the Research Ethics Committee that the Chief Investigator should submit a progress report for the study 12 months after the date on which the favourable opinion was given, and then annually thereafter. To date, the Committee has not yet received the annual progress report for the study, which was due on 16 November 2009. It would be appreciated if you could complete and submit the report by no later than 26 December 2009.

Guidance on progress reports and a copy of the standard NRES progress report form is available at http://www.nres.npsa.nhs.uk/applications/after-ethical-review/progress-reports/

There is also guidance on declaring the end of the study at
http://www.nres.npsa.nhs.uk/applications/after-ethical-review/endofproject/
If the study has finished please just send a copy of the end of study: you do not need to send in a progress report aswell.

Failure to submit progress reports may lead to a suspension of the favourable ethical opinion for the study.

REC reference number: 07/H0505/157 **Please quote this number on all correspondence**

Yours sincerely

Ms Lavenda Lee
Assistant Co-ordinator
Email: scsha.berksrec@nhs.net

Copy to: Dr Mike Proven, University of Reading

N:\Letters\07 REC Numbers\07.H0505.151 - 160\07.H0505.157 - SL38 - Remind pro report - 26.11.09.doc

NHS
National Research Ethics Service
Berkshire Research Ethics Committee
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13 November 2007

Professor Peter Cooper
Professor of Psychopathology
University of Reading
School of Psychology
University of Reading
Reading, Berkshire
RG6 6AL

Dear Professor Cooper

Full title of study: **Treatment of Child Anxiety Disorder in the Context of Maternal Anxiety: A Randomised Controlled Trial**
REC reference number: **07/H0505/156**

Thank you for your letter of 05 November 2007, responding to the Committee's 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.

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.

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Application		14 August 2007
Investigator CV		08 August 2007
Protocol	1	01 August 2007
Covering Letter		08 August 2007
Summary/Synopsis	1	01 August 2007

Letter from Sponsor		14 August 2007
Interview Schedules/Topic Guides	1	01 August 2007
Questionnaire: Social Communication questionnaire for Children (SCQ): Parent report	1.2	29 August 2007
Questionnaire: Spence Children's Anxiety Scale (Parent Report)	1.2	29 August 2007
Questionnaire: Spence Children's Anxiety Scale	1.2	29 August 2007
Questionnaire: Teacher report: Child adjustment to school	1.2	29 August 2007
Questionnaire: Spence Children's Anxiety Scale (Teacher Report)	1.2	29 August 2007
Questionnaire: Mattick-Social Phobia Scale	1.2	29 August 2007
Questionnaire: Penn-State Worry	1.2	29 August 2007
Questionnaire: Depression, Anxiety, Stress Scales (DASS21T)	1.2	29 August 2007
Questionnaire: Child Anxiety Impact Scale (CAIS-C)	1.2	29 August 2007
Questionnaire: Child Anxiety Impact Scale (CAIS-P)	1.2	29 August 2007
Questionnaire: Mattick-Social Interaction Assessment Scale	1.2	01 January 1900
GP/Consultant Information Sheets	1.2	29 October 2007
Participant Information Sheet: Parent/Guardian	1.2	29 October 2007
Participant Information Sheet: Children	1.2	29 October 2007
Participant Consent Form	1.2	29 October 2007
Response to Request for Further Information		05 November 2007
Teacher report form (6-18)	1.2	29 August 2007
Assent form for children	1.2	29 October 2007
Cover letter to child's teacher	1.2	29 October 2007
Referee's reports		06 October 2006
Letter from funder		23 May 2007
Statement re: Insurance		14 August 2007

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from http://www.rdforum.nhs.uk/rdform.htm.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

Here you will find links to the following

a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.

b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nationalres.org.uk .

07/H0505/156	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Professor Nigel Wellman
Chair

Email: scsha.berksrec@nhs.net

Enclosures: Standard approval conditions
Site approval form

Copy to: Dr Mike Proven, University of Reading

Appendix 2: Information leaflets/letters for schools, parents and children

University of Reading

Principal Investigator: Professor Cathy Creswell
Email: c.creswell@reading.ac.uk
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Researchers: Tessa Reardon; Jordan Hesse;
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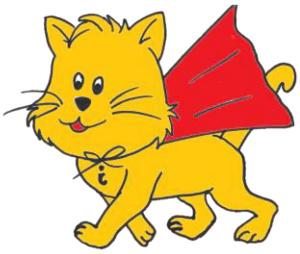


Dear {headteacher/nominated contact's name},

I-CAT: Improving access to Child Anxiety Treatment

We are writing to ask if you and your school may be interested in working with our team of researchers at the University of Reading on a research project designed to help improve access to treatment for children with anxiety disorders. Further information about the research project is provided below, including the nature of your involvement and benefits for your school, should you choose to participate. We will contact you by telephone in due course to discuss the research project further with you, but if in the mean time you have any questions or would like any further information, please feel free to contact us by phone xxxxx or email (t.c.reardon@pgr.reading.ac.uk).

Background

Anxiety disorders are one of the most common mental health disorders experienced by children; affecting approximately one child in every classroom in the UK. As well as impacting on a child's social and academic functioning, if left untreated, anxiety can continue into adolescence and is associated with other serious mental health problems. Although effective treatments for anxiety in children do exist, less than one third of children with an anxiety disorder actually access professional help. This project has two stages, both with the overarching aim of improving access to treatment for children with anxiety disorders.

Stage 1

One reason a child may not access treatment is that the anxiety that they are experiencing has not been identified. Questionnaires designed to help identify anxiety in children have been developed for parents and children to complete, but not for teachers. Teachers can offer unique insight into a child's emotional wellbeing, and collecting information from teachers, parents and children may help provide the most complete picture of children's anxiety levels. This project will collect information on anxiety in children from teachers, parents and children; and we aim to use the results to develop a brief questionnaire specifically to help teachers to identify anxiety disorders in children.

Stage 2

Identifying anxiety in a child is the first step towards accessing treatment. However, once a problem has been identified, there are other obstacles that may stand in the way of a child receiving professional help. Some previous research has examined barriers experienced by families to accessing treatment for mental health problems, but these studies have not focused specifically on anxiety disorders. This project aims to identify factors that may help or hinder families accessing professional help for anxiety disorders.

What will be involved for your school?

Stage 1

1. We will ask you to distribute the attached information leaflet about the first stage of our research project to all parents of children in year 3 to year 6. We can provide this information electronically for you to include as a link in a newsletter. Or, if you prefer, we can also provide paper copies of the leaflet and questionnaires for you to distribute to parents. For the first stage of the project **we are keen to recruit as many families as possible, whether they are having difficulties with anxiety or not.**

2. Parents who choose to participate will be asked to complete two questionnaires. One parent or both parents can each complete the questionnaires independently. Parents can complete these questionnaires online via a secure website (https://www.smartsurvey.co.uk/s/ICATstudy/). If you choose to distribute paper copies of the questionnaires for parents to complete, we will provide these as well as sealable envelopes so that they can return them to school. We would ask for you to keep the returned questionnaires secure until we collect them.

3. We will liaise with you or a nominated staff member to arrange a convenient time to come in to your school. At the agreed time, one or two researchers will visit and ask children whose parents have provided consent to complete two questionnaires. This should take approximately 20 minutes and arrangements will be made to minimise any inconvenience caused to children or teachers.

4. During our visit to your school we will also ask class teachers to complete questionnaires relating to participating children. This should take up to 5 minutes per child and can be done online via a secure website or on paper copies. We would be happy to provide support in the classroom if it would help teachers find time to complete the measures.

5. We will also need to collect some demographic information relating to the children involved (eg ethnicity, whether the child is eligible for free school meals, whether the child has a statement for special educational needs). We would appreciate it if you could advise us on which staff member will be best to approach regarding this information.

Stage 2

1. We will use information provided in the questionnaires completed by children, parents and teachers to help identify children who may be experiencing problems with anxiety. However, the questionnaires are not always accurate so we will contact the parents of children where responses from teacher, parent or child report suggest the child may be

having difficulties and invite them to take part in the second stage of the study, including a more detailed assessment of their child's anxiety.

2. Parents and children who agree to take part in this second stage will each be asked a standard set of questions relating to the child's anxiety. These interviews will be conducted by a member of the researcher team at a location convenient to the family (eg at the University of Reading, at the family home, community centre).

3. Responses to these standard questions will be used to assess if the child has an anxiety disorder. We will then contact parents of children with an anxiety disorder to invite them to take part in another interview. In this interview, parents will be asked about their experience of accessing (or not accessing) treatment for their child's anxiety. This interview will typically last up to 45 minutes and will take place at a location convenient for the parent or by telephone.

What are the benefits for your school?

- After the research project has been completed, we can provide your school and parents with a report of the findings.
- Children within your school who are experiencing problems with anxiety will receive an assessment and information about accessing professional help. A report of the assessment can be used to facilitate referrals if appropriate.
- As a way of saying thank you, we will provide a certificate of participation for each class involved and **£5 to the school for each complete set of returned questionnaires** (parent, child, teacher questionnaires).
- If there is sufficient interest within your school, we will also be happy to visit your school again to provide teachers or parents with further information, for example, through a workshop about anxiety in children and approaches to building resilience in children.

Other important information

The project has been reviewed by the University of Reading Research Ethics Committee, and this committee has given this study a favourable opinion for conduct. All researchers involved in the project have been through the enhanced Disclosure and Barring Service checking process and received approval by the School of Psychology and Clinical Language Sciences for working with children. This research project will form part of a doctoral thesis and two undergraduate dissertations and your school will be acknowledged in each of these and any associated publications in academic journals or conference presentations.

We very much hope that you will be interested in working together with us on this research project. We will be in touch again soon, but if in the mean time you have any questions please do feel free to contact us.

Yours sincerely,

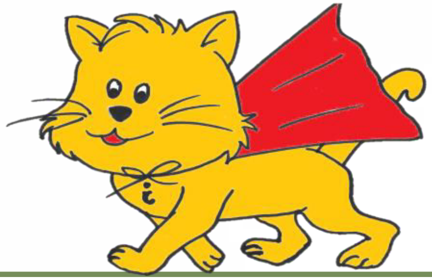
Tessa Reardon

Postgraduate researcher

Email: t.c.reardon@pgr.reading.ac.uk; Tel: xxxxxx

This project is funded by a National Institute for Health Research
Research Professorship awarded to Cathy Creswell

NHS
National Institute for
Health Research



★ Get involved ★

We are looking for families with children in year 3 to year 6 who might be willing to help us with our research.

We are keen to work with a broad range of families, including children who are confident, those who are anxious and those in between.

Your child's school has offered support for our study by forwarding this leaflet to all parents with children in these year groups.

As a way of saying thank you, we will provide your school with £5 for each complete set of returned questionnaires (parent, child, teacher).

NHS
National Institute for Health Research

The University of Reading Ethics Committee has given this study a favourable opinion for conduct.

Contact details

Principal Investigator: Professor Cathy Creswell
Email: c.creswell@reading.ac.uk
Tel: 0118 378 6798

Researchers: Tessa Reardon, Jordan Hesse, Alia Shakir, Magda Baranowska, Lydia Smith
Email: t.c.reardon@pgr.reading.ac.uk
Tel: 0118 378 5438

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This project is funded by a National Institute for Health Research Research Professorship awarded to Cathy Creswell

I – CAT

Improving access to Child Anxiety Treatment

- On average one child in every UK classroom is experiencing anxiety, fears or worries that significantly affects their day-to-day life.
- At the moment, only one-third of these children are receiving professional help. We want to help ensure more children who are experiencing anxiety receive the help they need.
- Parents, teachers and children can all play an important role in helping to identify whether a child is having problems with anxiety or not. We hope to use the results from this study to develop a short questionnaire to help teachers identify children who may need help with their anxiety.
- We also want to find out more about the experiences of parents of children who are experiencing anxiety. This will help us to identify challenges families face accessing professional help.

University of Reading

What are we asking you to do?

1. Complete the short questionnaires attached to this leaflet and return them to the designated teacher at your child's school. It should only take 10 minutes. If you prefer, you can complete the questionnaires online https://www.smartsurvey.co.uk/s/ICATstudy/ One parent or both parents can each complete the questionnaires independently.

2. We will then ask your child and your child's teacher to complete similar questionnaires at school. We will also collect some information from your child's school records.

3. If responses on questionnaires from you, your child or your child's teacher suggest your child **may** be having difficulties with anxiety we will get in touch with you and invite you to take part in a follow-up study. *Responses to the initial questionnaires can be influenced by how children feel on the day and may not reflect a problem* so if we do contact you, we will offer a more detailed assessment of your child's anxiety.

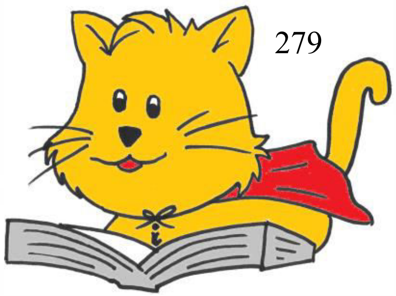
Things you need to know

- We would like you to understand why the research is being done and what is involved before you decide if you would like to take part.
- Taking part is voluntary - you do not have to take part if you do not want to
- You can withdraw from the study at any time without giving us a reason.
- All the investigators in the study have been subject to disclosure and barring checks and been approved by the school to work with children.

Your information will be kept confidential

✧ We will not share information collected with anyone, but we will get in touch with you if we think your child may be having difficulties with anxiety to offer a more detailed assessment. The only time that we would share information without agreement is if we believe that someone is at serious risk of harm, and in this case we would raise it with you or school personnel first.

✧Completed questionnaires will be stored under an anonymous ID number and will be kept securely in locked cabinets or on the secure University server. Consent forms will be stored in locked cabinets or on the secure University server for 5 years. Questionnaires completed online use an encryption enabled website.



Who will see the results?

The results will form part of Tessa Reardon's PhD and part of Jordan Hesse and Alia Shakir's undergraduate dissertations. This may include publications in scientific journals and presentations to other researchers and professionals.

None of the data included in publications or presentations will be identifiable to you or your child.

If you would like a report of what we find, just let us know.

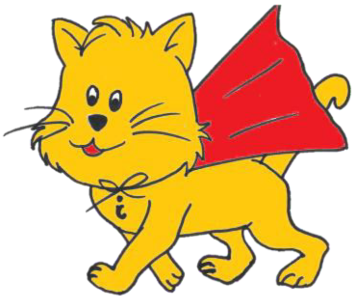
The questionnaires will ask you about your child's fears, worries and behaviour. If this raises any concerns there are people you can talk to for advice and support:

- Your GP
- The Principal Investigator (Professor Cathy Creswell) can provide appropriate contacts
- National organisations such as the Samaritans (08457 90 90 90)

This information is provided to all families.

Principal Investigator: Professor Cathy Creswell
Address: School of Psychology & Clinical Language Science,
University of Reading, Reading, RG6 7BE
Email: c.creswell@reading.ac.uk
Tel: 0118 378 6798

Researchers: Tessa Reardon; Jordan Hesse; Alia Shakir;
Magda Baranowska; Lydia Smith
Email: t.c.reardon@pgr.reading.ac.uk
Tel: xxxxxxxxxx



I-CAT Improving access to Child Anxiety Treatment

Dear {parent/s name]

As you know, you and your child {child's name} recently took part in a research study looking at anxiety, fears and worries in children. You, {child's name}, and {child's name}'s teacher each completed some questionnaires about {child's name} fears, worries and behaviour.

Some information provided in these questionnaires suggests that {child's name} **may** experience worries, fears or anxiety that could get in the way of him/her being able to do things in life.

Responses to the initial questionnaires can be influenced by various things, including how children felt on the day, and may not reflect a problem.

To get a clearer idea of which children are experiencing difficulties we are inviting all parents of children who have higher scores on one of the questionnaires to take part in a follow-up assessment.

Some further information about the follow-up study and what will be involved in taking part is provided below, but if you have any questions, please feel free to contact us by phone (xxxxx) or email (t.c.reardon@pgr.reading.ac.uk).

Follow-up study

Many children who are experiencing problems with worries, fear or anxiety do not receive professional help. We are hoping to find out more about the experiences of families affected by anxiety and any difficulties they may face getting help or support. In order to identify children who are experiencing anxiety, fears or worries that are significantly affecting their day-to-day life, we are inviting families to take part in a detailed assessment of their child's anxiety. The assessment will help us establish whether the child is experiencing genuine difficulties.

We will then invite parents of children who are experiencing significant problems with anxiety to take part in an interview. These interviews will help us to better understand the challenges families can face accessing professional help.

What are we asking you to do?

We are inviting you and your child to take part in a detailed assessment. If you agree to take part, researchers will ask you and your child a standard set of questions relating to anxiety your child may be experiencing. We would like to do this assessment face-to-face. It will last approximately one hour. The researchers can come to your home to do the interviews, you can come to us, or we can meet you in another location (e.g. community centre). In order to be sure that all our assessments are carried out in the same way, with your permission, we will make audio recordings of the assessment sessions.

Afterwards, we will give you a report of the assessment. If we think your child may be experiencing any serious problems with anxiety, we will talk to you about the possibility of receiving some professional help and will provide information on useful resources and sources of support. If appropriate, the report we give you can be used to help with referrals to support services.

We may then also invite you to take part in an interview. This interview will typically last up to 45 minutes and can take place over the phone, or we can come to you in your home or you can come to us. In this interview, we will discuss your experiences related to your child's anxiety, fears and worries and accessing professional help. With your permission, we will make an audio recording of this interview so that we can carry out a detailed examination of your responses. Following the interview, we will send you a brief summary of what has been said, along with our contact details so that you can get in touch if you would like to discuss things further.

The research team

The lead researcher for this study is Tessa Reardon, a PhD student at the University of Reading. This research forms part of her PhD and it is being supervised by Professor Cathy Creswell, Clinical Psychologist, at the School of Psychology and Clinical Language Studies at the University of Reading.

Why have we been invited?

You have been invited to take part because some of the information provided in the questionnaires in the first part of this research study suggests your child may be experiencing problems with anxiety. However, it is important that we emphasise that responses to the initial questionnaires can be influenced by various things, including how children felt on the day, and may not reflect a problem.

Do we have to take part?

No, it is up to you and your child to decide. If you do want to join in then you'll be asked to sign a consent form, a copy of which you can keep with this information letter. Even if you do consent to join the study, both you and your child will be free to withdraw at any point *without giving us a reason*.

Will our information be kept confidential?

All information collected will be kept strictly confidential. The only time that we would share information without agreement is if we believe that someone is at serious risk of harm, and in this case we would raise it with you first. All information (including audio recordings) will be stored under an anonymous ID number and will be kept securely in locked cabinets or on the secure University server. Consent forms will be stored in locked cabinets or on the secure University server for 5 years.

Who will see the results?

The results will form part of Tessa Reardon's PhD. This may include publications in scientific journals and presentations to other researchers and professionals. None of the data presented will identify you or your child. If you would like a report of what we find just let us know.

What if my child is experiencing emotional difficulties and I want some advice or support?

If we think that your child might be experiencing any serious emotional difficulties, we will talk to you about the possibility of receiving help through your GP and your local support services. There are also other people you can talk to for advice and support, including national organisations such as the Samaritans (08457 90 90 90; or local branch: 0118 926 6333).

Expenses

If you wish to complete the interviews away from your home we will reimburse your travel expenses. We will also provide you with £20 to compensate you for your time when you have completed the assessments.

Has this research study been approved by an ethics committee?

Yes, this study has been reviewed and been given a favourable opinion by the University of Reading Ethics Committee. Everyone working on this study been subject to disclosure and barring checks and has been approved to work with children.

If you have any questions or want to know more you can ask us any time.

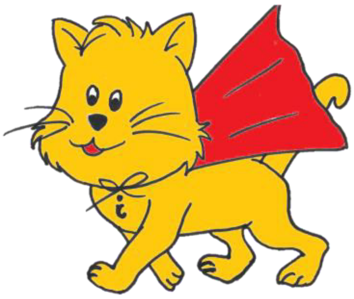
Thank you very much for reading about our research. We will be in touch soon to see if you will be interested in taking part in this follow-up study, but if in the mean time you have any questions please do feel free to contact us.

Your sincerely,

Tessa Reardon
Postgraduate researcher
Email: t.c.reardon@pgr.reading.ac.uk
Tel: xxxxxx

This project is funded by a National Institute for Health Research
Research Professorship awarded to Cathy Creswell

I-CAT Improving access to Child Anxiety Treatment



University of Reading

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Do children who worry or feel scared get the help they need?

What is research? Why is this research being done?

Research is a way we try to find out the answers to questions. We want to learn about how children feel so we can make sure that if children need help they can get it.

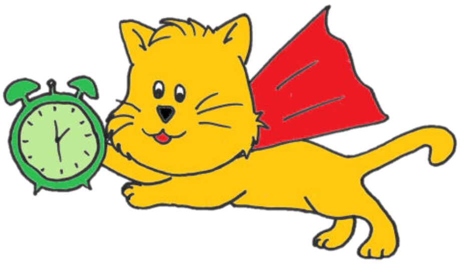
Why have I been asked to take part?

You have been asked to join in because your school has agreed for us to ask you and your parent/carer(s) to take part in this study. Your parent/carer has said it is okay for us to ask you to join in.

Do I have to take part?

No, it is up to you to choose if you want to join in.

What happens if I take part in the research?



We would ask you to answer some questions when you are at school.

The questions will ask you about how you are feeling and about any worries you may have. The questions will take up to 20 minutes to answer. We will also speak to your parent/carer and your teacher.

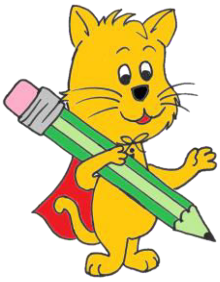
Who will know I am taking part in this research?

We won't tell anyone else that we are asking you some questions, but you can tell other people about it if you want to!

Everything you tell us is treated like a secret, so we won't share what you tell us with anyone else.

The only time we would not be able to keep a secret is if you told us that you or someone else was in real danger. Then, we would speak to you before speaking to an adult - like one of the grownups that looks after you or your family doctor.

What happens if I feel upset?



If you feel upset when answering the questions then you can tell us about this. You can always take a break from answering the questions, talk to your teacher, or just stop taking part. It is completely up to you.

Will joining in help me?

We cannot promise that the study will help you, but we hope what you tell us will teach us about how to make sure other children who worry or feel scared get the help they may need.

Did anyone check the research is OK to do?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is OK to do. Your project has been checked by the Reading University Ethics Committee. Everyone working with us is allowed to work with children.

What if I don't want to do the research anymore?

If you don't want to answer any more questions, just tell your teacher or parent or tell us. It is OK to change your mind at any time.

What if I have more questions?

You can ask us any questions you might have and you can telephone or email us any time – we will be happy to talk to you.

Thank you very much for reading about our research.

Cathy Creswell
School of Psychology & Clinical Language Science, University of Reading, Reading, RG6 7BE
Telephone number: 0118 378 6798. Email: c.creswell@reading.ac.uk

Research team: Tessa Reardon; Jordan Hesse; Alia Shakir, Alia Shakir, Magda Baranowska, Lydia Smith
Telephone number: 0118 3785438 Email: t.c.reardon@pgr.reading.ac.uk

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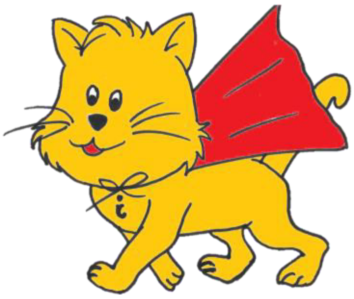
NHS
National Institute for Health Research

I-CAT Improving access to Child Anxiety Treatment



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Do children who worry or feel scared get the help they need?

What is research? Why is this research being done?

Research is a way we try to find out the answers to questions. We want to learn about how children feel so we can make sure that if children need help they can get it.

Why have I been asked to take part?

You have been asked to join in because we want to find out if you are feeling more scared or worried than other children your age. Your parent/carer has said it is okay for us to ask you to join in.

Do I have to take part?

No, it is up to you to choose if you want to join in.

What happens if I take part in the research?

We would ask you to answer some questions about how you feel and about any worries you may have.

The questions will take up to an hour to answer. We will also speak to your parent/carer.

Who will know I am taking part in this research?

We won't tell anyone else that we are asking you some questions, but you can tell other people about it if you want to!

Everything you tell us is treated like a secret, so we won't share what you tell us with anyone else.

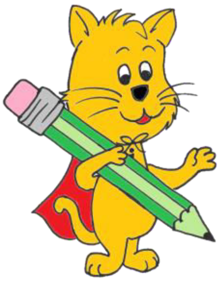
The only time we would not be able to keep a secret is if you told us that you or someone else was in real danger. Then, we would speak to you before speaking to an adult - like one of the grownups that looks after you or your family doctor.

What happens if I feel upset?

If you feel upset when answering the questions then you can tell us about this. You can always take a break from answering the questions, talk to your parent/carer or just stop taking part. It is completely up to you.

Will joining in help me?

We cannot promise that the study will help you, but we hope what you tell us will teach us about how to make sure you or children who worry or feel scared get the help they may need.



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What if I don’t want to do the research anymore?

If you don‘t want to answer any more questions, just tell your teacher or parent or tell us. It is OK to change your mind at any time.

What if I have more questions?

You can ask us any questions you might have and you can telephone or email us any time – we will be happy to talk to you.

Thank you very much for reading about our research.

Cathy Creswell
School of Psychology & Clinical Language Science, University of Reading, Reading, RG6 7BE
Telephone number: 0118 378 6798. Email: c.creswell@reading.ac.uk

Research team: Tessa Reardon; Jordan Hesse; Alia Shakir, Alia Shakir, Magda Baranowska, Lydia Smith
Telephone number: xxxxxxxxxxx Email: t.c.reardon@pgr.reading.ac.uk

This project is funded by a National Institute for Health Research Research Professorship awarded to Cathy Creswell

NHS
National Institute for Health Research

University of Reading

Principal Investigator: Professor Cathy Creswell
Email: c.creswell@reading.ac.uk
Tel: 0118 378 6798
Lead Researcher: Tessa Reardon
Email: t.c.reardon@pgr.reading.ac.uk
Tel: 07811479928

AnDY Research Clinic
School of Psychology & Clinical
Language Sciences
University of Reading
Earley Gate, Whiteknights Road
Reading , RG6 6AL

Date

Contact name
School Name

Dear {headteacher/nominated contact's name},

N-CAT: National survey of Child Anxiety and Treatment access

We are writing to ask if you and your school may be interested in working with our team of researchers at the University of Reading on a large scale research project designed to help improve access to treatment for children with anxiety disorders. This project is funded by the National Institute of Health Research. We are hoping to work with many schools from across England on this research project. Further information about the research is provided below, including the nature of your involvement and benefits for your school, should you choose to participate. We will contact you by telephone in due course to discuss the research project further with you, but if in the mean time you have any questions or would like any further information, please feel free to contact us by phone (07811479928) or email (t.c.reardon@pgr.reading.ac.uk).

Background

Anxiety disorders are one of the most common mental health disorders experienced by children; affecting approximately two children in every classroom in the UK. As well as impacting on a child's social and academic functioning, if left untreated, anxiety can continue into adolescence and is associated with other serious mental health problems. Although effective treatments for anxiety in children do exist, less than one third of children with an anxiety disorder actually access professional help. This project has two phases, both with the overarching aim of improving access to treatment for children with anxiety disorders.

Phase 1

One reason a child may not access treatment is that the anxiety that they are experiencing has not been identified. Questionnaires designed to help identify anxiety in children have been developed for parents and children to complete, but we want to make sure that these questionnaires include the best questions to pick up more serious anxiety problems. Also, we know that teachers can offer unique insight into a child's emotional wellbeing, and collecting information from parents, teachers and children may help provide the most complete picture of children's anxiety levels. This project will collect information on anxiety in children from a large number of parents, teachers and children; and we aim to use the results to develop brief questionnaires specifically to help parents and teachers to identify anxiety disorders in children.

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Phase 2

Identifying anxiety in a child is the first step towards accessing treatment. However, once a problem has been identified, there are other obstacles that can stand in the way of a child receiving professional help. This project aims to recruit a large number of families from across England to identify the factors that help and hinder parents to seek help and access treatment for childhood anxiety difficulties.

What will be involved for your school?

Phase 1

1. We will ask you to distribute the attached information leaflet about the first phase of our research project to **all parents** of children in year 3 to year 6. We can provide this information electronically for you to include as a link in a newsletter. Or, if you prefer, we can also provide paper copies of the leaflet and questionnaires for you to distribute to parents. For the first phase of the project **we are really keen to recruit a wide range of families – including those with children who are anxious, those with children who are not anxious, and those in between.**

2. Parents who choose to participate will be asked to complete questionnaires about their child's anxiety and behaviour, and answer some demographic questions. One parent or both parents can each complete the questionnaires independently. Parents can complete these questionnaires online via a secure encryption enabled website (https://reading.onlinesurveys.ac.uk/n-cat_parent_questionnaires). If you choose to distribute paper copies of the questionnaires for parents to complete, we will provide these as well as sealable envelopes so that they can return them to school. We would ask for you to keep the returned questionnaires secure until we collect them.

3. We will liaise with you or a nominated staff member to arrange a convenient time to come in to your school. At the agreed time, one or two researchers will visit and ask children whose parents have provided consent to complete two questionnaires. This should take approximately 20 minutes and arrangements will be made to minimise any inconvenience caused to children or teachers.

4. During our visit to your school we will also ask class teachers to complete questionnaires relating to participating children. This should take 5-10 minutes per child and can be done online via a secure website or on paper copies. We would be happy to provide support in the classroom if it would help teachers find time to complete the questionnaires.

5. We will also need to collect some demographic information relating to the children involved (e.g. ethnicity, whether the child is eligible for free school meals, whether the child has any special educational needs). We would appreciate it if you could advise us on which staff member will be best to approach regarding this information.

.

Phase 2

1. We will use information provided in the questionnaires completed by children, parents and teachers to help identify children who may be experiencing problems with anxiety. However, the questionnaires are not always accurate so we will contact the parents of children where responses from teacher, parent or child report suggest the child may be having difficulties and invite them to take part in the second phase of the study, including a more detailed assessment of their child's anxiety. **At this stage we will ask you to send a letter to all parents of children in year 3 to year 6 just to remind them that the research team will be getting in touch with some families to invite them to take part in the next phase of the study.**

2. Parents who agree to take part in this second phase of the study will be asked a standard set of questions relating to the child's anxiety. These interviews will be conducted by telephone.

3. Parents who take part in the second phase of the study will also be asked to complete a questionnaire about their views and experiences of seeking help and accessing treatment.

What are the benefits for your school?

- You will be contributing to a large research study along with many other schools from all across England. After the research project has been completed, we can provide your school and parents with a report of the findings. The report will show how your school compares to other schools from across the country on responses given on the anxiety questionnaires.
- Children within your school who are experiencing problems with anxiety will receive an assessment and information about accessing professional help. A report of the assessment can be used to facilitate referrals if appropriate.
- As a way of saying thank you, we will provide a certificate of participation for your school and **£1 to the school for each complete set of returned questionnaires** (parent, child, teacher questionnaires). Your school will also be entered into a **Prize Draw and a prize of £100** will be given to one participating school.

Other important information

The project has been reviewed by the University of Reading Research Ethics Committee, and this committee has given this study a favourable ethical opinion for conduct. All researchers involved in the project have been through the enhanced Disclosure and Barring Service checking process and received approval by the School of Psychology and Clinical Language Sciences for working with children. This research project will form part of a doctoral thesis and your school will be acknowledged in this and any associated publications in academic journals or conference presentations.

We very much hope that you will be interested in working together with us on this research project. We will be in touch again soon, but if in the mean time you have any questions please do feel free to contact us.

Yours sincerely,

Tessa Reardon

Doctoral researcher

Email: t.c.reardon@pgr.reading.ac.uk Tel: 07811479928

This project is funded by a National Institute for Health Research
Research Professorship awarded to Cathy Creswell

NHS
National Institute for
Health Research

N– CAT

National survey of Child Anxiety and Treatment access

- Anxieties, fears and worries are part of growing up. But approximately two children in every classroom experience anxiety that significantly affects their day-to-day life. For these children, anxiety can impact on their life at school, at home or with friends.
- At the moment, only one-third of these children receive professional help. We want to help ensure more children who experience difficulties with anxiety receive the help they need.

What is the purpose of this National survey?

- **We want to develop tools for parents and teachers to help them decide if a child may need help to overcome problems with anxiety.** To help us develop these tools, we need to collect information from a broad range of families from schools across the country, **including children who are anxious and those who are not.**
- **We also want to find out more about the views and experiences of parents of children who are experiencing difficulties with anxiety.** We will invite some families to take part in a follow-up study to help us to identify challenges families face accessing professional help and ways to overcome these.

This study has been reviewed by The University of Reading Research Ethics Committee and it has been given a favourable ethical opinion for conduct.

Contact details

Principal Investigator: Professor Cathy Creswell
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Lead Researcher: Tessa Reardon
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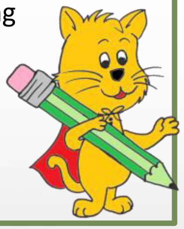

This project is funded by a
National Institute for Health Research
Research Professorship awarded to
Cathy Creswell

NHS
National Institute for Health Research

N– CAT

National survey of Child Anxiety and Treatment access

Your child's school is taking part in a national research study and has forwarded this leaflet to all families with children in year 3 – year 6.

We are looking for families with children in these year groups who might be willing to help us with our research.

We are keen for as many families as possible to be involved, including those with children who are confident, those who are anxious, and those in between.

And to say thank you we will..

- Provide your school with £1 for each complete set of returned questionnaires (parent, child, teacher).
- Enter your school into a prize draw, with a prize of £100 given to the school picked out of the hat!
- Provide your school with a report to show how your school compares with other schools across the country on anxiety questionnaire responses.
- If responses on the questionnaires suggest your child may be experiencing difficulties with anxiety, we will contact you directly to offer a more detailed assessment.

What are we asking you to do?

1. Complete the short questionnaires attached to this leaflet and return them to the designated teacher at your child's school. It should only take 10 minutes. If you prefer, you can complete the questionnaires online (https://reading.onlinesurveys.ac.uk/n-cat_parent_questionnaires). One parent or both parents can each complete the questionnaires independently.

2. We will then ask your child and your child's teacher to complete questionnaires that ask similar questions at school. We will also collect some information from your child's school records.

What will happen next?

- **We will invite some families to take part in a follow-up study.**

If responses on the questionnaires suggest your child **may** be having difficulties with anxiety, we will get in touch to invite you to take part in the follow-up. *Responses to the initial questionnaires can be influenced by how children feel on the day and may not reflect a problem* so if we do contact you, we will offer a more detailed assessment of your child's anxiety.

- **We will provide all families who choose to take part in the follow-up with a report of the assessment and information about accessing professional help.**

Your information will be kept confidential

✧ We will not share information collected about your child with your child's school or anyone else, but we will get in touch with you if we think your child may be having difficulties with anxiety to offer a more detailed assessment. You can share this information with your child's school, if you want to.

✧ The only time that we would share information without agreement is if we believe that someone is at serious risk of harm, and in this case we would raise it with you or school personnel first.

✧Completed questionnaires will be stored under an anonymous ID number and will be kept securely in locked cabinets or on the secure University server. Consent forms will be stored in locked cabinets or on the secure University server for 5 years. Questionnaires completed online use an encryption enabled website.

Who will see the results?

The results will form part of Tessa Reardon's PhD. This may include publications in scientific journals and presentations to other researchers and professionals.

None of the data included in reports, publications or presentations will be identifiable to you or your child.

We will send your school a report of what we find – if you would like a report too, just let us know.

Things you need to know

- We would like you to understand why the research is being done and what is involved before you decide if you would like to take part.
- Taking part is voluntary - you do not have to take part if you do not want to
- You can withdraw from the study at any time without giving us a reason.
- All the investigators in the study are researchers from the University of Reading who have experience of working with children and families, and have been subject to disclosure and barring checks and been approved to work with children.

The questionnaires will ask you about your child's fears, worries and behaviour. If this raises any concerns there are people you can talk to for advice and support:

- Your GP
- The Principal Investigator (Professor Cathy Creswell) can provide appropriate contacts
- National organisations such as Young Minds (http://www.youngminds.org.uk/; Parent helpline: **0808 802 5544**)

This information is provided to all families.

Principal Investigator: Professor Cathy Creswell
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N-CAT (National survey of Child Anxiety and Treatment access) – Follow-up Study

Dear {parent/s name}

As you know, you and your child {child's name} recently took part in a research study looking at anxiety, fears and worries in children. You, {child's name}, and {child's name}'s teacher each completed some questionnaires about {child's name} fears, worries and behaviour.

Some information provided in these questionnaires suggests that {child's name} **may** experience worries, fears or anxiety that could get in the way of {him/her} being able to do things in life.

Responses to the initial questionnaires can be influenced by various things, including how children felt on the day, and may not reflect a problem.

To get a clearer idea of which children are experiencing difficulties we are inviting all parents of children who have higher scores on one of the questionnaires to take part in a follow-up assessment.

Some further information about the follow-up study and what will be involved in taking part is provided below, but if you have any questions, please feel free to contact us by phone (07811479928) or email (t.c.reardon@pgr.reading.ac.uk).

Follow-up study

Many children who experience problems with worries, fear or anxiety do not receive professional help. We are hoping to find out more about the experiences of families affected by anxiety and any difficulties they may face getting help or support. In order to identify children who are experiencing anxiety, fears or worries that are significantly affecting their day-to-day life, we are inviting families to take part in a detailed assessment of their child's anxiety. The assessment will help us establish whether the child is experiencing genuine difficulties.

As well as the assessment, we will also ask you to complete a questionnaire about your views and experiences surrounding seeking and accessing professional help for your child. We are hoping to use responses to this questionnaire to identify ways that we can make it easier for families to get professional help if they need it. Some parents have told us that experiencing (or not experiencing) feelings of anxiety or depression themselves can influence their decision to seek professional help for their child. Some questions in the help seeking in questionnaire will therefore also ask you about your own experiences of feelings of stress, anxiety and depression – you will be able to choose whether or not you answer these questions.

What are we asking you to do?

We are inviting you to take part in a detailed assessment of your child's anxiety. If you agree to take part, researchers will ask you a standard set of questions relating to anxiety your child may be experiencing. We would like to do this by telephone where possible and it will last approximately one hour. In order to be sure that all our assessments are carried out in the same way, with your permission, we will make audio recordings of the assessment sessions.

Afterwards, we will give you a report of the assessment. If we think your child may be experiencing any serious problems with anxiety, we will talk to you about the possibility of receiving some professional help and will provide information on useful resources and sources of support. If appropriate, the report we give you can be used to help with referrals to support services.

We will also ask you to complete a questionnaire about your views and experiences surrounding seeking and accessing professional help for anxiety difficulties in children. This help seeking questionnaire will also include some questions about your own experience of feelings of stress, anxiety and depression. We will send you a copy of the questionnaire to complete prior to the telephone assessment and you can choose to complete it online (using an encryption enabled website) or on a paper copy. This questionnaire will take about 20 minutes to complete.

The research team

The lead researcher for this study is Tessa Reardon, a PhD student at the University of Reading. This research forms part of her PhD and it is being supervised by Professor Cathy Creswell, Clinical Psychologist, at the School of Psychology and Clinical Language Studies at the University of Reading.

Why have we been invited?

You have been invited to take part because some of the information provided in the questionnaires in the first part of this research study suggests your child may be experiencing problems with anxiety. However, it is important that we emphasise that responses to the initial questionnaires can be influenced by various things, including how children felt on the day, and may not reflect a problem.

Do I have to take part?

No, it is up to you. If you do want to join in then you'll be asked to sign a consent form, a copy of which you can keep with this information letter. Even if you do consent to join the study, you will be free to withdraw at any point *without giving us a reason*.

Will our information be kept confidential?

All information collected will be kept strictly confidential. The only time that we would share information without agreement is if we believe that someone is at serious risk of harm, and in this case we would raise it with you first. All information (including audio recordings) will be stored under an anonymous ID number and will be kept securely in locked cabinets or on the secure University server. Consent forms will be stored in locked cabinets or on the secure University server for 5 years.

Who will see the results?

The results will form part of Tessa Reardon's PhD. This may include publications in scientific journals and presentations to other researchers and professionals. None of the data presented will identify you or your child. If you would like a report of what we find just let us know.

What if my child is experiencing emotional difficulties and I want some advice or support?

If we think that your child might be experiencing any serious emotional difficulties, we will talk to you about the possibility of receiving help through your GP and your local support services. There are also other people you can talk to for advice and support, including national organisations such as the Young Minds (http://www.youngminds.org.uk/; Parent helpline: 0808 802 5544).

Prize draw

All families who take part in this follow-up study will be entered into a Prize draw to thank you for your time, with a prize of £100 available for two families.

Has this research study been approved by an ethics committee?

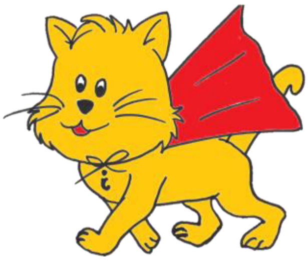
Yes, this study has been reviewed the University of Reading Research Ethics Committee and been given a favourable ethical opinion for conduct. Everyone working on this study been subject to disclosure and barring checks and has been approved to work with children.

If you have any questions or want to know more you can ask us any time.

Thank you very much for reading about our research. We will be in touch soon to see if you will be interested in taking part in this follow-up study, but if in the mean time you have any questions please do feel free to contact us.

Yours sincerely,

Tessa Reardon
Doctoral researcher
Email: t.c.reardon@pgr.reading.ac.uk
Tel: 07811479928



University of Reading

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Do children who worry or feel scared get the help they need?

What is research? Why is this research being done?

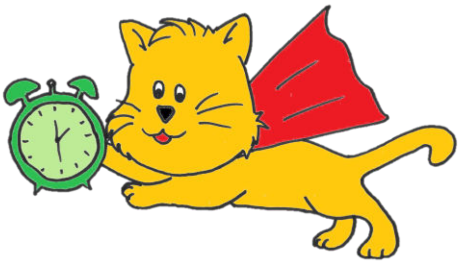
Research is a way we try to find out the answers to questions. We want to learn about how children feel so we can make sure that children can get help if they need it.

Why have I been asked to take part?

You have been asked to join in because your school has agreed for us to ask you and your parent/carer(s) to take part in this study. Your parent/carer has said it is okay for us to ask you to join in.

Do I have to take part?

No, it is up to you to choose if you want to join in.



What happens if I take part in the research?

We would ask you to answer some questions when you are at school.

The questions will ask you about how you are feeling and about any worries you may have. The questions will take up to 20 minutes to answer. Your parent/carer has answered similar questions and we will also speak to your teacher.

Who will know I am taking part in this research?

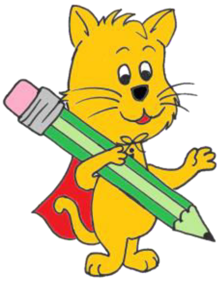
We won't tell anyone else that we are asking you some questions, but you can tell other people about it if you want to!

We won't share what you tell us with anyone else.

The only time we would have to talk to someone about what you told us is if you said that you or someone else was in real danger. Then, we would speak to you before speaking to an adult - like your parent or your teacher or your doctor.

What happens if I feel upset?

If you feel upset when answering the questions then you can tell us about this. You can always take a break from answering the questions, talk to your teacher, or just stop taking part. It is completely up to you.



Will joining in help me?

We cannot promise that the study will help you, but we hope what you tell us will teach us about how to make sure other children who worry or feel scared get the help they may need.

Did anyone check the research is OK to do?

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure that the research is OK to do. This project has been checked by the Reading University Research Ethics Committee. Everyone working with us is allowed to work with children.

What if I don't want to do the research anymore?

If you don't want to answer any more questions, just tell your teacher or parent or tell us. It is OK to change your mind at any time.

What if I have more questions?

You can ask us any questions you might have and you can telephone or email us any time – we will be happy to talk to you.

Thank you very much for reading about our research.

Cathy Creswell
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Lead Researcher: Tessa Reardon
Telephone number: 07811479928 Email: t.c.reardon@pgr.reading.ac.uk

Berkshire Research Ethics reference number: 07/H0505/156- 157-176
University of Reading Ethics reference number: 07/48-49-50
Version 1.5 (6.2.08)

Berkshire Healthcare NHS
NHS Foundation Trust

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Trials Secretary: Brendan Lawrence; b.lawrence@reading.ac.uk
Research Director: Professor Peter Cooper (Tel: 0118 378 6617); p.j.cooper@reading.ac.uk

INFORMATION SHEET FOR PARENT/GUARDIAN

Study of the Treatment of Anxiety in Children

You and your child are being invited to take part in a research study we are doing in Berkshire Healthcare NHS Foundation Trust and the University of Reading. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Do discuss this matter with others if you wish.

There is a standard talking treatment for anxious children (called 'cognitive behaviour therapy'). Studies have shown that this treatment is very helpful to lots of children. However this treatment is often not readily available within the health service as it is costly and involves highly trained staff. We have developed a brief form of this treatment that parents can use with their children, with the support of a psychologist. This 'guided self-help' approach to treatment has been found to be very helpful for a range of other types of difficulties that children experience.

Over a period of 30 months we are inviting all parents, who are not themselves anxious, who bring their children for help with anxiety and their children to participate in our study. It is entirely up to you and your child to decide whether to take part or not. If you do decide to participate, you will be given this Information Sheet (and your child will also be given one) and you will be asked to sign a consent form (a copy of which you will be given to keep). We will inform your GP that you are helping us, and we will keep in touch with your GP about your child's progress in the normal way. If you are happy, we would also like to contact your child's teacher to request information about how your child is getting on at school at the beginning and end of the study. A copy of the letter and questionnaires we would send to your child's teacher if you agree is attached. You will be free to withdraw from the study at any time without having to give any reason. If you or your child decide not to participate, or you or your child decide to participate and then have a change of mind, this will not affect the standard of care your child will receive.

The study involves both assessment and treatment.

1 Assessment

The study involves our team making a detailed enquiry of how you are and how your child is (especially as regards problems with anxiety) before treatment begins, at the end of the course of treatment, and then six months after treatment ends. These enquiries will involve your completing some questionnaires and you and your child being asked a standard set of questions. The responses you and your child give will be treated as entirely confidential. In fact, they will be coded and entered into a computer file with anonymity completely preserved (there will be no names in the file).

2. Treatment

Two thirds of the families in the study will be offered treatment immediately. The other third will be placed on a waiting list for three months and then receive treatment if it is still needed (as studies have shown that some children recover without treatment). All children in the study will receive treatment within a shorter time period than is typically the case in local and national child and adolescent mental health services. To make sure that the groups receiving the treatment immediately or after a short wait are comparable to begin with, who goes in each group is decided randomly.

The treatment involves parent(s) meeting with a Psychologist face-to-face and having telephone appointments. Half of the parents will have 8 appointments, (four face-to-face and four telephone appointments). The other half will have four appointments (two face-to-face and two over the telephone). To make sure that the groups receiving four or eight appointments are comparable to begin with, who goes in each group is decided randomly. Parents will also be provided with a book entitled 'Overcoming your child's fears and worries'. The psychologist will help you to use the book to help your child to learn to manage his/her anxiety problems.

If the assessments show that your child has not experienced a clear reduction in anxiety following treatment, we will offer you and your child further treatment within our clinic; or if other problems emerge we will discuss this with your local child and adolescent mental health team.

In order for us to be sure that all the different forms of treatment are being delivered by the study therapists in the same way, we ask mothers and children if we can make tape recordings of the therapy sessions. Also, to understand exactly how your child reacts to stress, and your own response to this, on two occasions we will ask if we can make a short video-tape and record your own and your child's heart rate whilst we do this. Specific permission will be sought to make these recordings. The audio and video tapes will be heard and seen only by members of the research team; and they will be destroyed at the end of the research study.

Medication

One of the requirements of this trial is that participants (parents and children) must either not be prescribed medication aimed at changing their mood or behaviour (e.g. anti-depressant medication or Ritalin) or this must have been prescribed at a stable dose for at least one month prior to joining the trial, with agreement to maintain that dose throughout the study. If medication does need to be changed whilst you are taking part, you would have to withdraw from the study (however we would not withdraw treatment). If you have any concerns regarding this requirement please do not hesitate to discuss this with us and/or your general practitioner.

To summarise, if you and your child decide to take part in this study, you will be helped to work with your child to manage his/her anxiety problems. This will either begin immediately or after a three-month wait. We will ask you and your child standard questions to find out how you both are before treatment begins and on two subsequent occasions. All information collected in this study is treated as confidential and nothing will be divulged to any other party (the exception being, if we learn that you or your child is at risk of harm). Our intention is to publish the results of this study in a medical journal. When we do this, no personal information will be given and the findings will be reported as anonymous summary statistics. If we quote anything that has been said by participants in the study, these will be anonymous and will not be traceable to a particular individual. If you would like a report of the findings of our study, we will be happy to provide it.

We anticipate that the children and parents who participate in this study will benefit considerably. However, there will be a review assessment of each mother and child at the final assessment, and if further treatment is judged to be necessary, we will ensure that this is provided.

This study was given a favourable ethical opinion for conduct by both the University of Reading Research Ethics Committee and the Berkshire Research Ethics Committee. Everyone working on this study has been through the formal Criminal Records Bureau Disclosure process and has been approved by the School of Psychology of the University of Reading to work with children.

Berkshire Research Ethics reference number: 07/H0505/156- 157-176
University of Reading Ethics reference number: 07/48-49-50
Version 1.5 (6.2.08)

If you have any questions or concerns about this study, now or at any time in the future, please do ask one of us.

Yours sincerely

Lucy Willetts Clinical Director	Dr Sue Cruddace Trial Manager	Professor Peter Cooper Research Director

Berkshire Research Ethics reference number: 07/H0505/156- 157-176
University of Reading Ethics reference number: 07/48-49-50.
Version 1.5 (12.8.08)
ISRCTN19762288

Berkshire Healthcare NHS
NHS Foundation Trust

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Trials Secretary: Jackie Barton; j.m.barton@reading.ac.uk
Research Director: Professor Peter Cooper (Tel: 0118 378 6617); p.j.cooper@reading.ac.uk

INFORMATION SHEET FOR PARENT/GUARDIAN

Study of the Treatment of Anxiety in Children

You and your child are being invited to take part in a research study we are doing, funded jointly by the Medical Research Council and the Berkshire Healthcare NHS Foundation Trust. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Do discuss this matter with others if you wish.

There is a standard talking treatment for anxious children (called 'cognitive behaviour therapy'). Studies have shown that this treatment is very helpful to lots of children. However, some children do not benefit as much as we would like. One group who do not always do as well as we would wish is children whose mothers also have problems with anxiety. In our clinic we have been trying out various ways of helping these children. We now want to do a study to test whether the outcome for children who receive the standard treatment is actually improved by the additional help we offer.

Over a period of 30 months we are inviting all mothers who bring their children for help with anxiety, who themselves are also anxious, and their children, to participate in our study. You are being invited because you have told us that you have some problems with anxiety. It is entirely up to you and your child to decide whether to take part or not. If you do decide to participate, you will be given this Information Sheet (and your child will also be given one) and you will be asked to sign a consent form (a copy of which you will be given to keep). We will inform your GP that you are helping us, and we will keep in touch with your GP about your child's progress in the normal way. If you are happy, we would also like to contact your child's teacher to request information about how your child is getting on at school at the beginning and end of the study. A copy of the letter and questionnaires we would send to your child's teacher if you agree is attached. You will be free to withdraw from the study at any time without having to give any reason. If you or your child decide not to participate, or you or your child decide to participate and then have a change of mind, this will not affect the standard of care your child will receive.

The study involves both assessment and treatment.

1 Assessment

The study involves our team making a detailed enquiry of how you are and how your child is (especially as regards problems with anxiety) before treatment begins, mid-way through the treatment, at the end of the course of treatment, and then six and twelve months later. These enquiries will involve your completing some questionnaires and you and your child being asked a standard set of questions. The responses you and your child give will be treated as entirely confidential. In fact, they will be coded and entered into a computer file with anonymity completely preserved (there will be no names in the file).

2. Treatment

As noted above, all the children who take part in the study receive the standard treatment we routinely offer all children in our clinic. This involves eight weekly 50 minute sessions in which the child is seen by a clinical psychologist. In our current study, as part of our effort to help children more, before we begin treatment with the children, mothers receive help with their own difficulties **over an eight week period**. Then, during the phase when the children receive the usual treatment, there are an extra four to eight therapy sessions involving guidance on issues of family health or on child **management**. To ensure that the groups receiving the different forms of additional help are comparable to begin with, which families receive which of these extra treatments is decided randomly.

In order for us to be sure that all the different forms of treatment are being delivered by the study therapists in the same way, we ask mothers and children if we can make tape recordings of the therapy sessions. Also, to understand exactly how your child reacts to stress, and your own response to this, on two occasions we will ask if we can make a short video-tape and record your own and your child's heart rate whilst we do this. Specific permission will be sought to make these recordings. The audio and video tapes will be heard and seen only by members of the research team; and they will be destroyed at the end of the research study.

Medication

One of the requirements of this trial is that participants (mothers and children) must either not be prescribed medication aimed at changing their mood or behaviour (e.g. anti-depressant medication or Ritalin) or this must have been prescribed at a stable dose for at least one month prior to joining the trial, with agreement to maintain that dose throughout the study. If medication does need to be changed whilst you are taking part, you would have to withdraw from the study (however we would not withdraw treatment). If you have any concerns regarding this requirement please do not hesitate to discuss this with us and/or your general practitioner.

To summarise, if you and your child decide to take part in this study, you will be given help with your own difficulties, your child will then receive the usual treatment for his/her anxiety, and finally there will be extra sessions during which you and your child will be seen together. We will ask you and your child standard questions to find out how you both are before treatment begins and on four subsequent occasions. All information collected in this study is treated as confidential and nothing will be divulged to any other party (the exception being, if we learn that you or your child is at risk of harm). Our intention is to publish the results of this study in a medical journal. When we do this, no personal information will be given and the findings will be reported as anonymous summary statistics. If we quote anything that has been said by participants in the study, these will be anonymous and will not be traceable to a particular individual. If you would like a report of the findings of our study, we will be happy to provide it.

We anticipate that the children and mothers who participate in this study will benefit considerably. However, there will be a review assessment of each mother and child at the final assessment, and if further treatment is judged to be necessary, we will ensure that this is provided.

This study was given a favourable ethical opinion for conduct by both the University of Reading Research Ethics Committee and the Berkshire Research Ethics Committee. Everyone working on this study has been through the formal Criminal Records Bureau Disclosure process and has been approved by the School of Psychology of the University of Reading to work with children.

If you have any questions or concerns about this study, now or at any time in the future, please do ask one of us.

Yours sincerely,

Dr Lucy Willetts
Clinical Director

Dr Rachel Gitau
Trials Manager

Professor Peter Cooper
Research Director

Berkshire Research Ethics reference number: 07/H0505/156- 157-176
University of Reading Ethics reference number: 07/48-49-50
Version 1.3 (24.11.07)

Berkshire Healthcare NHS
NHS Foundation Trust

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Study Assessors: Sarah Cook; s.e.cook@reading.ac.uk. Amy Corcoran; a.corcoran@reading.ac.uk. Jenny Crosby; j.crosby@reading.ac.uk. Ray Percy; r.s.percy@reading.ac.uk. Rebecca O'Grady; r.r.ogrady@reading.ac.uk .
Trials Secretary: Brendan Lawrence; b.lawrence@reading.ac.uk
Research Director: Professor Peter Cooper (Tel: 0118 378 6617); p.j.cooper@reading.ac.uk

INFORMATION SHEET FOR CHILDREN

Overcoming your Child's Fears and Worries

You have come to our clinic for help with some problems you have been having. At this clinic we help children with these problems and we are going to do everything we can to help you.

As well as giving you some help, we are inviting you and your mum or dad to take part in a study we are doing. This study is to help us find better ways of helping children. In the study we will do two things. First, we will be working with your mum or dad to help them to help you with your anxiety problems. We will either do this now or there will be a short wait before this starts.

Second, we will ask the children and their mums or dads lots of questions about how they are feeling. We ask these questions before treatment begins, and then again every few months. We also would like to tape record the treatment sessions (so that we can check that all the children are receiving the same sort of help) and make some video-tapes of you and your mum or dad doing some different activities together. If you don't mind we will also use a small machine which can tell us how much your heart is beating when you do these tasks.

We would like you to help us by taking part in our study. You do not have to do this. If you and your mum or dad don't want to take part, you will still receive the usual help that we give children. Also, if you do take part and then change your mind, this won't matter at all. You won't have to give us a reason, and we will still help you with your problems.

Everything you tell us in the clinic and anything you tell us as part of our study is treated as a secret; nobody other than us will ever know what you have told us. If we use anything you have said when we are telling people about our study, we will make sure nobody can tell who has said it. (The only time we would not be able to keep a secret is if you told us that you or someone else was at risk of real danger. In this situation we would have to speak to another adult - like your mum or your family doctor).

Berkshire Child Anxiety Clinic
University of Reading

Berkshire Research Ethics reference number: 07/H0505/156- 157-176
University of Reading Ethics reference number: 07/48-49-50
Version 1.3 (24.11.07)

Before any research is allowed to happen, it has to be checked by a group of people called an Ethics Committee. They make sure that the research is OK to do. This study has been checked by the Reading University Committee and the Berkshire NHS Committee, and they were happy for it to go ahead.

If you have any questions about our study, either now or later, please do ask us. You have a right to know everything and we will be happy to tell you everything.

Yours sincerely,

Dr Lucy Willetts	Dr Sue Cruddace	Professor Peter Cooper
Clinical Director	Trial Manager	Research Director

Study Centre Address:
School of Psychology, University of Reading , Whiteknights, PO Box 238, Reading RG6 6AL
Clinical Research Team:
Clinical Director: Dr Lucy Willetts (Tel: 0118 378 6297); lucy.willetts@berkshire.nhs.uk
Clinical Research Fellow: Dr Cathy Creswell; Email: c.creswell@rdg.ac.uk
Trials Manager: Dr Rachel Gitau (Tel: 0118 378 4682); r.gitau@rdg.ac.uk
Clinical/counselling Psychologists: (Tel: 0118 378 8926); Dr Monika Parkinson; m.b.parkinson@reading.ac.uk. Dr Katie Adolphus; k.adolphus@reading.ac.uk. Mrs Sally Greenfield; s.a.m.greenfield@rdg.ac.uk .
Study Assessors: Sarah Cook; s.e.cook@rdg.ac.uk. Amy Corcoran; a.corcoran@rdg.ac.uk. Jenny Crosby; j.crosby@rdg.ac.uk. Ray Percy; r.s.percy@rdg.ac.uk. Sarah Shaw; sxs07ses@reading.ac.uk.
Trials Secretary: Jackie Barton; j.m.barton@rdg.ac.uk
Research Director: Professor Peter Cooper (Tel: 0118 378 6617); p.j.cooper@rdg.ac.uk

INFORMATION SHEET FOR CHILDREN

You have come to our clinic for help with some problems you have been having. At this clinic we help children with these problems and we are going to do everything we can to help you.

As well as giving you some help, we are inviting you and your mum to take part in a study we are doing. This study is to help us find better ways of helping children.

The study involves two things. First, it involves us giving a bit more help than we usually do. For example, as well as seeing children on their own, we will also sometimes be seeing children with their mums.

Second, it involves us asking the children and their mums lots of questions about how they are feeling. We ask these questions before treatment begins, and then again every few months. We also would like to tape record the treatment sessions (so that we can check that all the children are getting the same sort of help) and make some video-tapes of you and your mum doing some different activities together. If you don't mind we will also use a small machine which can tell us how much your heart is beating when you do these tasks.

We would like you to help us by taking part in our study. You do not have to do this. If you and your mum don't want to take part, you will still receive the usual help that we give children. Also, if you do take part and then change your mind, this won't matter at all: you won't have to give us a reason, and we will still help you with your problems.

Everything you tell us in the clinic and anything you tell us as part of our study is treated as a secret; nobody other than us will ever know what you have told us. If we use anything you have said when we are telling people about our study, we will make sure nobody can tell who has said it.

(The only time we would not be able to keep a secret is if you told us that you or someone else was at risk of real danger. In this situation we would have to speak to another adult - like your mum or your family doctor).

Before any research is allowed to happen, it has to be checked by a group of people called an Ethics Committee. They make sure that the research is OK to do. This study has been checked by the Reading University Committee and the Berkshire NHS Committee. They were both happy for it to go ahead.

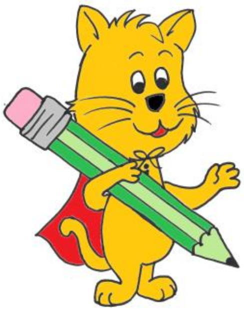
If you have any questions about our study, either now or later, please do ask us.

You have a right to know everything and we will be happy to tell you everything.

Yours sincerely,

Dr Lucy Willetts	Dr Rachel Gitau	Professor Peter Cooper
Clinical Director	Trials Manager	Research Director

Appendix 3: Consent forms for parents and assent forms for children



University of Reading

School of Psychology and Clinical Language Sciences
University of Reading
Earley Gate
Whiteknights Road
Reading
RG6 6AL

Parent's Consent Form

Research Study: I-CAT (Improving access to Child Anxiety Treatment)

Your Child's Full Name ________________________

	Please tick box to show agreement.
1. I confirm that I have read and understand the information leaflet for the above study. I have had the opportunity to consider the information, ask questions and (if applicable) have had these answered satisfactorily.	
2. I understand that my and my child's participation is voluntary and that we are free to withdraw at any time, without giving a reason.	
3. I agree to my child's teacher being contacted to provide information.	
4. I agree to researchers contacting me if responses given on questionnaires completed by me, my child or my child's teacher suggest my child may be experiencing problems with fears, worries or anxiety. I understand these questionnaires are not always accurate so we will be offered a more detailed assessment of my child's anxiety.	
5. I understand that the project has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion of conduct.	
6. I agree to take part in this study.	

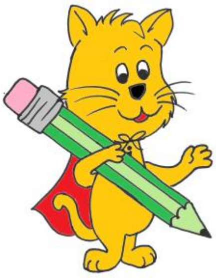
School name____________________________ **Year group**___________________

Your Full Name ____________________________**Relationship to Child:**_______________________

Address:________________________ ____

Email:______________________ **Telephone:**____

Signed __________________________________**Date** ___________________________________



University of Reading
School of Psychology and Clinical Language Sciences
University of Reading
Earley Gate
Whiteknights Road
Reading
RG6 6AL

Parent's Consent Form

I-CAT (Improving access to Child Anxiety Treatment) – Follow-up Study

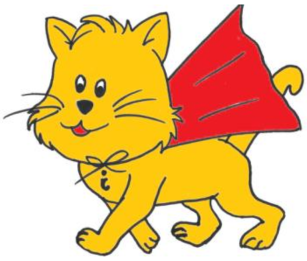
	Please tick box to show agreement.
1. I confirm that I have read and understand the information for the above study. I have had the opportunity to consider the information, ask questions and (if applicable) have had these answered satisfactorily.	
2. I understand that my and my child's participation is voluntary and that we are free to withdraw at any time, without giving a reason.	
3. I understand that the project has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion of conduct.	
4. I agree to take part in this study.	

Your Child's Name: ______________________________

Your Name _______________________________________

Signed ____

Date ____



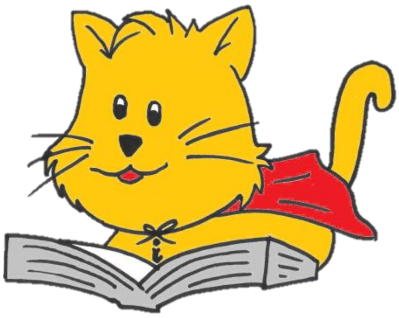
.

Parent Consent form for audio recordings

In order to be sure that all the assessments are carried out by researchers in the same way, we ask parents and children if we can make audio recordings of the assessment sessions.

Although audio recording is a helpful part of our research work, we also want to make it clear that everyone has the right to refuse permission for audio recording. We will not record unless we have your permission. Even if you agree to recordings being made, you have the right at any time to ask that all the recordings, or a particular one, or one piece of the recording be erased.

All audio recordings are treated as confidential material. All staff will undertake to safeguard audio recordings at all times and when not in use they will be locked away in a secure cabinet. Audio recordings will be heard and seen only by members of the research team.



Please tick as appropriate:

I give permission for audio recording of parental and child assessment sessions	YES ☐ NO ☐

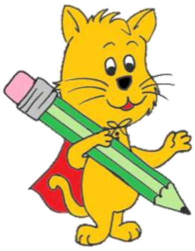
Name of Child: ________________________________

Name of Parent: ________________________________

Parent signature: ______________________________ Date: _____________________

Name of person taking consent: _____________________________

Signature: ___________________________________ Date: _____________________



University of Reading
School of Psychology and Clinical Language Sciences
University of Reading
Earley Gate
Whiteknights Road
Reading
RG6 6AL

Parent's Consent Form

I-CAT (Improving access to Child Anxiety Treatment) – Follow-up Study

	Please tick box to show agreement.
1. I confirm that I have read and understand the information for the above study. I have had the opportunity to consider the information, ask questions and (if applicable) have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.	
3. I understand that the project has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion of conduct.	
4. I agree to take part in this study.	

Your Child's Name: ____________________________

Your Name: ____________________________________

Signed: ____

Date: ____

This project is funded by a National Institute for Health Research Research Professorship awarded to Cathy Creswell

NHS
National Institute for Health Research

University of Reading

Parent Consent form for audio recordings

In order to carry out a detailed examination of the interview, we ask parents if we can make an audio recording of the interview.

Although audio recording is a helpful part of our research work, we also want to make it clear that everyone has the right to refuse permission for audio recording. We will not record unless we have your permission. Even if you agree to recordings being made, you have the right at any time to ask that all the recordings, or a particular one, or one piece of the recording be erased.

All audio recordings are treated as confidential material. All staff will undertake to safeguard audio recordings at all times and when not in use they will be locked away in a secure cabinet. Audio recordings will be heard and seen only by members of the research team.

Parent Consent form for audio recordings

Please tick as appropriate:

I give permission for audio recording of the interview	YES ☐ NO ☐

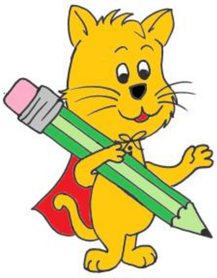
Name of Child: ____________________________________

Name of Parent: ____________________________________

Parent signature: ________________________________ Date: __________________
_

Name of person taking consent: ________________________________

Signature: ____________________________________ Date: ______________________



University of Reading
School of Psychology and Clinical Language Sciences
University of Reading
Earley Gate
Whiteknights Road
Reading
RG6 6AL

Children’s Assent Form

I-CAT (Improving access to Child Anxiety Treatment)

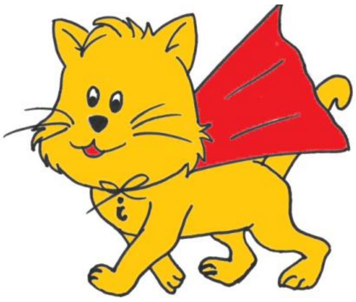
Please **Circle** all you agree with:

Example: Are you sitting in a classroom?	[✓ Yes] / No
Has somebody explained this project to you?	Yes / No
Do you understand what this project is about?	Yes / No
Have you asked all the questions you want?	Yes / No
If you had any questions, have they been answered in a way you understand?	Yes / No
Do you understand it’s OK to stop taking part at any time?	Yes / No
Are you happy to take part?	Yes / No
If any answers are ‘no’ or you **don’t** want to take part, **don’t** sign your name!	Yes/ No

If you **do** want to take part, please write your name and todays date.

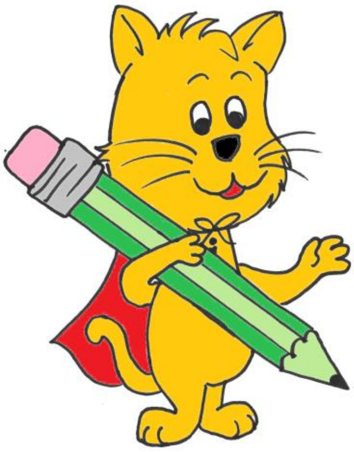
Your Name ____________________________

Date __________________________________



This project is funded by a National Institute for Health Research Research Professorship awarded to Cathy Creswell

NHS
National Institute for Health Research



School of Psychology and Clinical Language Sciences
University of Reading
Earley Gate
Whiteknights Road
Reading
RG6 6AL

Child's Assent Form

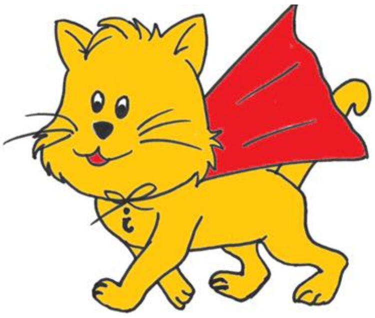
Research Study: I-CAT (Improving access to Childhood Anxiety Treatment)

Please Circle all you agree with:

Has somebody explained this project to you?	Yes / No
Do you understand what this project is about?	Yes / No
Have you asked all the questions you want?	Yes / No
If you had any questions, have they been answered in a way you understand?	Yes / No
Do you understand it's OK to stop taking part at any time?	Yes / No
Are you happy to take part?	Yes / No

If any answers are 'no' or you **don't** want to take part, **don't** sign your name!

If you **do** want to take part, please write your name and todays date.



Your Name: ____________________________________

Date: ____

This project is funded by a National Institute for Health Research Research Professorship awarded to Cathy Creswell

University of Reading

Child assent form for tape recordings

In our research, we ask children and their parent/carer if we can tape record the assessment session. This is so that we can check that everyone is getting asked the same type of questions.

Tape recordings are a helpful part of our research but you do not have to agree to be recorded. We will not record if you do not want us to. Even if you agree now to recordings being made, you can still change your mind later on and this won't matter at all: you won't have to give us a reason.

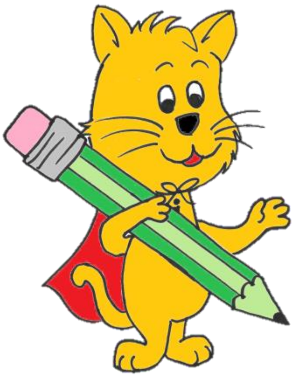
All tape recordings will only be listened to by the people who are in the research team. When the recordings are not being used, they will be kept locked away in a drawer.

University of Reading

Child Assent form for tape recordings

Please tick:

	I give permission for my assessment sessions to be tape recorded	YES ☐ NO ☐



Your Name: ______________________________

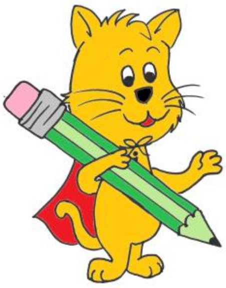
Date: ___________

Name of Parent: ______________________________

Parent signature: _________________________ Date: ____________________

Name of person taking consent: ___________________________

Signature: ________________________________ Date: ____________________



University of Reading
AnDY Research Clinic
School of Psychology and Clinical Language Sciences
University of Reading
Earley Gate, Whiteknights Road
Reading, RG6 6AL

Parent's Consent Form

Research Study: N-CAT (National survey of Child Anxiety and Treatment access)

	Please **initial** each box to show agreement.
1. I confirm that I have read and understand the information leaflet for the above study. I have had the opportunity to consider the information, ask questions and (if applicable) have had these answered satisfactorily.	
2. I understand that my and my child's participation is voluntary and that we are free to withdraw at any time, without giving a reason.	
3. I agree to my child's teacher being contacted to provide information.	
4. I agree to researchers contacting me if responses given on questionnaires completed by me, my child or my child's teacher suggest my child may be experiencing problems with fears, worries or anxiety. I understand these questionnaires are not always accurate so we will be offered a more detailed assessment of my child's anxiety.	
5. I understand that the project has been reviewed by the University of Reading Research Ethics Committee and has been given a favourable ethical opinion for conduct.	
6. I agree to take part in this study.	

Your Child's name ____

Your Child's school____

Your child's year group______________

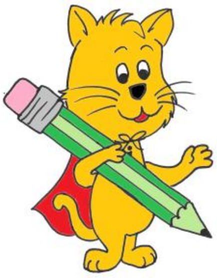
Your Name ________________________________**Relationship to Child:**_________________________

Address:__________________________ ____

Email:________________________ **Telephone:**_________________________________

Signed _____________________________________

Date _____________________________________



University of Reading
AnDY Research Clinic
School of Psychology and Clinical Language Sciences
University of Reading
Earley Gate
Whiteknights Road
Reading
RG6 6AL

Parent's Consent Form

N-CAT (National survey of Child Anxiety and Treatment access) – Follow-up Study

	Please **initial** each box to show agreement.
1. I confirm that I have read and understand the information for the above study. I have had the opportunity to consider the information, ask questions and (if applicable) have had these answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.	
3. I understand that the project has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion of conduct.	
4. I agree to take part in this follow-up study.	
5. I agree to the possibility of researchers contacting me in the future to invite me to take part in another research study.	

Your Child's Name: ____________________________

Your Child's School: _____________________________

Your Name ____________________________________

Your relationship to child___________________________

Signed ____

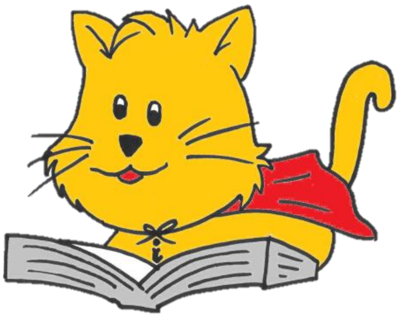
Date ____

Parent Consent form for audio recordings

In order to be sure that all the assessments are carried out by researchers in the same way, we ask parents and children if we can make audio recordings of the assessment sessions.

Although audio recording is a helpful part of our research work, we also want to make it clear that everyone has the right to refuse permission for audio recording. We will not record unless we have your permission. Even if you agree to recordings being made, you have the right at any time to ask that all the recordings, or a particular one, or one piece of the recording be erased.

All audio recordings are treated as confidential material. All staff will undertake to safeguard audio recordings at all times and when not in use they will be locked away in a secure cabinet. Audio recordings will be heard and seen only by members of the research team.



Parent Consent form for audio recordings

Please tick as appropriate:

I give permission for audio recording of parent assessment session	YES ☐ NO ☐

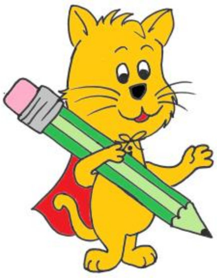
Name of Child: ____________________________________

Name of Parent: ____________________________________

Parent signature: _________________________________ Date: _______________________

Name of person taking consent: ________________________________

Signature: _______________________________________ Date: _______________________



University of Reading
AnDY Research Clinic
School of Psychology and Clinical Language Sciences
University of Reading
Earley Gate
Whiteknights Road
Reading
RG6 6AL

Children's Assent Form

N-CAT (National survey of Child Anxiety and Treatment access)

Please Circle all you agree with:

Example: Are you sitting in a classroom?	[✓ Yes] / No
Has somebody explained this project to you?	Yes / No
Do you understand what this project is about?	Yes / No
Do you understand it's OK to stop taking part at any time?	Yes / No

If you had any questions:

Have you asked all the questions you want?	Yes / No
Have they been answered in a way you understand?	Yes / No

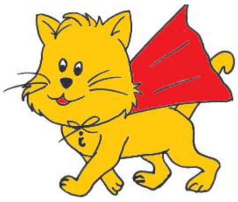
Are you happy to take part?	Yes / No

If any answers are 'no' or you **don't** want to take part, **don't** sign your name!

If you **do** want to take part, please write your name and today's date.

Your Name ________________________________

Date ______________________________________



Berkshire Research Ethics reference number: 07/H0505/156- 157-176
University of Reading Ethics reference number: 07/48-49-50
Version 1.6 (12.08.08)

Berkshire Healthcare NHS
NHS Foundation Trust

Study Centre Address:
School of Psychology, University of Reading , Whiteknights, PO Box 238 , Reading RG6 6AL

Clinical Research Team:

Clinical Director: Dr Lucy Willetts (Tel: 0118 378 6297); l.e.willetts@reading.ac.uk
Trials Manager: Dr Rachel Gitau (Tel: 0118 378 4682); r.gitau@reading.ac.uk
Study Assessors: Sarah Cook; s.e.cook@reading.ac.uk. Amy Corcoran; a.corcoran@reading.ac.uk. Jenny Crosby; j.crosby@reading.ac.uk. Ray Percy; r.s.percy@reading.ac.uk. Sarah Shaw; sxs07ses@reading.ac.uk.
Trials Secretary: Brendan Lawrence; b.lawrence@reading.ac.uk
Research Director: Professor Peter Cooper (Tel: 0118 378 6617); p.j.cooper@reading.ac.uk

Patient identification number for this trial:

PARENT CONSENT FORM

Overcoming your Child's Fears and Worries

	Please initial box to show agreement.
1. I confirm that I have read and understand the information sheet dated 6.2.08 (version 1.5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my and my child's participation is voluntary and that we are free to withdraw at any time, without giving a reason, without my medical care or legal rights being affected.	
3. I understand that any relevant section of our medical notes and data collected during the study, may be looked at by responsible individuals from The University of Reading or the NHS Trust, where it is relevant to our taking part in this research. I give permission for these individuals to have access to my records.	
4. I agree to our GP(s) being informed of this study	
5. I agree to my child's teacher being informed of their participation in this treatment study, and being contacted to provide information.	
6. I agree to audio and video-recordings being made during the course of the study. I understand that the audio and video tapes will be heard and seen only by members of the research team; and they will be destroyed at the end of the research study.	
7. I agree to anonymised quotations being used in research reports.	
8. I agree to take part in this study.	

Berkshire Research Ethics reference number: 07/H0505/156- 157-176
University of Reading Ethics reference number: 07/48-49-50
Version 1.6 (12.08.08)

Name of child: ____________________

Name of parent/guardian: ____________________

Parent/guardian signature: ____________________

Date: ____________________

Name of person taking consent: ____________________

Date: ____________________

Signature: ____________________

When completed, 1 for parent; 1 for researcher site file; 1 (original) in medical notes

Berkshire Research Ethics reference number: 07/H0505/156- 157-176
University of Reading Ethics reference number: 07/48-49-50
Version 1.6 (12.08.08)

Berkshire Healthcare NHS
NHS Foundation Trust

Study Centre Address:
School of Psychology, University of Reading , Whiteknights, PO Box 238 , Reading RG6 6AL

Clinical Research Team:

Clinical Director: Dr Lucy Willetts (Tel: 0118 378 6297); l.e.willetts@reading.ac.uk
Trials Manager: Dr Rachel Gitau (Tel: 0118 378 4682); r.gitau@reading.ac.uk
Study Assessors: Sarah Cook; s.e.cook@reading.ac.uk. Amy Corcoran; a.corcoran@reading.ac.uk. Jenny Crosby; j.crosby@reading.ac.uk. Ray Percy; r.s.percy@reading.ac.uk. Sarah Shaw; sxs07ses@reading.ac.uk.
Trials Secretary: Jackie Barton; j.m.barton@reading.ac.uk
Research Director: Professor Peter Cooper (Tel: 0118 378 6617); p.j.cooper@reading.ac.uk

Patient identification number for this trial:

PARENT CONSENT FORM

Overcoming your Child's Fears and Worries

	Please initial box to show agreement.
1. I confirm that I have read and understand the information sheet dated 6.2.08 (version 1.5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that my and my child's participation is voluntary and that we are free to withdraw at any time, without giving a reason, without my medical care or legal rights being affected.	
3. I understand that any relevant section of our medical notes and data collected during the study, may be looked at by responsible individuals from The University of Reading or the NHS Trust, where it is relevant to our taking part in this research. I give permission for these individuals to have access to my records.	
4. I agree to our GP(s) being informed of this study	
5. I agree to my child's teacher being informed of their participation in this treatment study, and being contacted to provide information.	
6. I agree to audio and video-recordings being made during the course of the study. I understand that the audio and video tapes will be heard and seen only by members of the research team; and they will be destroyed at the end of the research study.	
7. I agree to anonymised quotations being used in research reports.	
8. I agree to take part in this study.	

Berkshire Child Anxiety Clinic
University of Reading

Berkshire Research Ethics reference number: 07/H0505/156- 157-176
University of Reading Ethics reference number: 07/48-49-50
Version 1.6 (12.08.08)

Name of child: ____________________

Name of parent/guardian: ____________________

Parent/guardian signature: ____________________

Date: ____________________

Name of person taking consent: ____________________

Date: ____________________

Signature: ____________________

When completed, 1 for parent; 1 for researcher site file; 1 (original) in medical notes

Berkshire Research Ethics reference number: 07/H0505/156- 157-176
University of Reading Ethics reference number: 07/48-49-50
Version 1.3 (24.11.07)

Berkshire Healthcare NHS
NHS Foundation Trust

School of Psychology
University of Reading
Whiteknights
PO Box 238
Reading RG6 6AL
UK

CONSENT FORM FOR CHILDREN

(To be completed by the child and his/her guardian)

Overcoming your Child's Fears and Worries

Please circle all you agree with:

Have you read (or had read to you) the information about this project?	YES/ NO
Has somebody else explained this project to you?	YES/ NO
Do you understand what this project is about?	YES/ NO
Have you asked all the questions you want?	YES/ NO
Have you had your questions answered in a way you understand?	YES/ NO
Do you understand it's OK to stop taking part at any time?	YES/ NO
Are you happy to take part?	YES/ NO

If any answers are 'no' or you **don't** want to take part, **don't** sign your name!

If you **do** want to take part, please write your name and today's date
Your name ______________________
Date ______________________

Your parent or guardian must write his/her name here too if s/he is happy for you to do the project
Print name ______________________
Sign ______________________
Date ______________________

The person who explained this project to you needs to sign too:
Print name ______________________
Sign ______________________
Date ______________________

Berkshire Child Anxiety Clinic
University of Reading

Berkshire Research Ethics reference number: 07/H0505/156- 157-176
University of Reading Ethics reference number: 07/48-49-50
Version 1.3 (24.11.07)

Berkshire Healthcare NHS
NHS Foundation Trust

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CONSENT FORM FOR CHILDREN

(To be completed by the child and his/her guardian)

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Sign ______________________
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Sign ______________________
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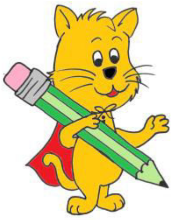
Berkshire Child Anxiety Clinic
University of Reading

Appendix 4: Study materials (questionnaire measures and interview topic guide)

Participant Number:
Date:



University of Reading

SCAS-P: Parent Report on Child

Instructions: Below is a list of items that describe children. For each item please circle the response that best describes your child. Please answer all the items.

1. My child worries about things	Never	Sometimes	Often	Always
2. My child is scared of the dark	Never	Sometimes	Often	Always
3. When my child has a problem, s(he) complains of having a funny feeling in his / her stomach	Never	Sometimes	Often	Always
4. My child complains of feeling afraid	Never	Sometimes	Often	Always
5. My child would feel afraid of being on his/her own at home	Never	Sometimes	Often	Always
6. My child is scared when s(he) has to take a test	Never	Sometimes	Often	Always
7. My child is afraid when (s)he has to use public toilets or bathrooms	Never	Sometimes	Often	Always
8. My child worries about being away from us / me	Never	Sometimes	Often	Always
9. My child feels afraid that (s)he will make a fool of him/herself in front of people	Never	Sometimes	Often	Always
10. My child worries that (s)he will do badly at school	Never	Sometimes	Often	Always
11. My child worries that something awful will happen to someone in our family	Never	Sometimes	Often	Always
12. My child complains of suddenly feeling as if (s)he can't breathe when there is no reason for this	Never	Sometimes	Often	Always
13. My child has to keep checking that (s)he has done things right (like the switch is off, or the door is locked).	Never	Sometimes	Often	Always
14. My child is scared if (s)he has to sleep on his/her own	Never	Sometimes	Often	Always
15. My child has trouble going to school in the mornings because (s)he feels nervous or afraid	Never	Sometimes	Often	Always
16. My child is scared of dogs	Never	Sometimes	Often	Always
17. My child can't seem to get bad or silly thoughts out of his / her head	Never	Sometimes	Often	Always
18. When my child has a problem, s(he) complains of his/her heart beating really fast	Never	Sometimes	Often	Always
19. My child suddenly starts to tremble or shake when there is no reason for this	Never	Sometimes	Often	Always
20. My child worries that something bad will happen to him/her	Never	Sometimes	Often	Always
21. My child is scared of going to the doctor or dentist	Never	Sometimes	Often	Always
22. When my child has a problem, (s)he feels shaky	Never	Sometimes	Often	Always
23. My child is scared of heights (eg. being at the top of a cliff)	Never	Sometimes	Often	Always

Participant Number:
Date:

24. My child has to think special thoughts (like numbers or words) to stop bad things from happening	Never	Sometimes	Often	Always
25. My child feels scared if (s)he has to travel in the car, or on a bus or train	Never	Sometimes	Often	Always
26. My child worries what other people think of him/her	Never	Sometimes	Often	Always
27. My child is afraid of being in crowded places (like shopping centres, the cinema, buses, busy playgrounds)	Never	Sometimes	Often	Always
28. All of a sudden my child feels really scared for no reason at all	Never	Sometimes	Often	Always
29. My child is scared of insects or spiders	Never	Sometimes	Often	Always
30. My child complains of suddenly becoming dizzy or faint when there is no reason for this	Never	Sometimes	Often	Always
31. My child feels afraid when (s)he has to talk in front of the class	Never	Sometimes	Often	Always
32. My child complains of his / her heart suddenly starting to beat too quickly for no reason	Never	Sometimes	Often	Always
33. My child worries that (s)he will suddenly get a scared feeling when there is nothing to be afraid of	Never	Sometimes	Often	Always
34. My child is afraid of being in small closed places, like tunnels or small rooms	Never	Sometimes	Often	Always
35. My child has to do some things over and over again (like washing his / her hands cleaning or putting things in a certain order)	Never	Sometimes	Often	Always
36. My child gets bothered by bad or silly thoughts or pictures in his/her head	Never	Sometimes	Often	Always
37. My child has to do certain things in just the right way to stop bad things from happening	Never	Sometimes	Often	Always
38. My child would feel scared if (s)he had to stay away from home overnight	Never	Sometimes	Often	Always
39. Is there anything else that your child is really afraid of?	YES		NO	
Please write down what it is, and fill out how often (s)he is afraid of this thing:				
	Never	Sometimes	Often	Always
	Never	Sometimes	Often	Always
	Never	Sometimes	Often	Always
	Never	Sometimes	Often	Always

This project is funded by a National Institute for Health Research Research Professorship awarded to Cathy Creswell

NHS
National Institute for
Health Research

Participant number:
Date:

University of Reading

SDQ-P: Parent Report on Child

Instructions: For each item, please mark the box for **Not True, Somewhat True** or **Certainly True**. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft!

Please give your answers on the basis of **your child's behaviour over the last 6 months** or **this school year.**	**Not True**	**Somewhat True**	**Certainly True**
1. Considerate of other people's feelings	○	○	○
2. Restless, overactive, cannot stay still for long	○	○	○
3. Often complains of headaches, stomach-aches or sickness	○	○	○
4. Shares readily with other children (treats, toys, pencils etc)	○	○	○
5. Often has temper tantrums or hot tempers	○	○	○
6. Rather solitary, tends to play alone	○	○	○
7. Generally obedient, usually does what adults request	○	○	○
8. Many worries, often seems worried	○	○	○
9. Helpful if someone is hurt, upset or feeling ill	○	○	○
10. Constantly fidgeting or squirming	○	○	○
11. Has at least one good friend	○	○	○
12. Often fights with other children or bullies them	○	○	○
13. Often unhappy, down-hearted or tearful	○	○	○
14. Generally liked by other children	○	○	○
15. Easily distracted, concentration wanders	○	○	○
16. Nervous or clingy in new situations, easily loses confidence	○	○	○
17. Kind to younger children	○	○	○

Participant number:
Date:

Please give your answers on the basis of **your child's behaviour over the last 6 months** or **this school year.**	**Not True**	**Somewhat True**	**Certainly True**
18. Often lies or cheats	○	○	○
19. Picked on or bullied by other children	○	○	○
20. Often volunteers to help others (parents, teachers, other children)	○	○	○
21. Thinks things out before acting	○	○	○
22. Steals from home, school or elsewhere	○	○	○
23. Gets on better with adults than with other children	○	○	○
24. Many fears, easily scared	○	○	○
25. Sees tasks through to the end, good attention span	○	○	○

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Research Professorship awarded to Cathy Creswell

NHS
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Health Research

Participant Number:
Date:

University of Reading

SCAS-C: Child Self-Report

Instructions: Please put a circle around the word that shows how often each of these things happen to you. There are no right or wrong answers.

1. I worry about things	Never	Sometimes	Often	Always
2. I am scared of the dark	Never	Sometimes	Often	Always
3. When I have a problem, I get a funny feeling in my stomach	Never	Sometimes	Often	Always
4. I feel afraid	Never	Sometimes	Often	Always
5. I would feel afraid of being on my own at home	Never	Sometimes	Often	Always
6. I feel scared when I have to take a test	Never	Sometimes	Often	Always
7. I feel afraid if I have to use public toilets or bathrooms	Never	Sometimes	Often	Always
8. I worry about being away from my parents	Never	Sometimes	Often	Always
9. I feel afraid that I will make a fool of myself in front of people	Never	Sometimes	Often	Always
10. I worry that I will do badly at my school work	Never	Sometimes	Often	Always
11. I am popular amongst other kids my own age	Never	Sometimes	Often	Always
12. I worry that something awful will happen to someone in my family	Never	Sometimes	Often	Always
13. I suddenly feel as if I can’t breathe when there is no reason for this	Never	Sometimes	Often	Always
14. I have to keep checking that I have done things right (like the switch is off, or the door is locked)	Never	Sometimes	Often	Always
15. I feel scared if I have to sleep on my own	Never	Sometimes	Often	Always
16. I have trouble going to school in the mornings because I feel nervous or afraid	Never	Sometimes	Often	Always
17. I am good at sports	Never	Sometimes	Often	Always
18. I am scared of dogs	Never	Sometimes	Often	Always
19. I can’t seem to get bad or silly thoughts out of my head	Never	Sometimes	Often	Always
20. When I have a problem, my heart beats really fast	Never	Sometimes	Often	Always
21. I suddenly start to tremble or shake when there is no reason for this	Never	Sometimes	Often	Always
22. I worry that something bad will happen to me	Never	Sometimes	Often	Always
23. I am scared of going to the doctors or dentists	Never	Sometimes	Often	Always
24. When I have a problem, I feel shaky	Never	Sometimes	Often	Always
25. I am scared of being in high places or lifts (elevators)	Never	Sometimes	Often	Always
26. I am a good person	Never	Sometimes	Often	Always

Participant Number:
Date:

27. I have to think of special thoughts to stop bad things from happening (like numbers or words)	Never	Sometimes	Often	Always
28. I feel scared if I have to travel in the car, or on a bus or a train	Never	Sometimes	Often	Always
29. I worry what other people think of me	Never	Sometimes	Often	Always
30. I am afraid of being in crowded places (like shopping centres, the cinema, buses, busy playgrounds)	Never	Sometimes	Often	Always
31. I feel happy	Never	Sometimes	Often	Always
32. All of a sudden I feel really scared for no reason at all	Never	Sometimes	Often	Always
33. I am scared of insects or spiders	Never	Sometimes	Often	Always
34. I suddenly become dizzy or faint when there is no reason for this	Never	Sometimes	Often	Always
35. I feel afraid if I have to talk in front of my class	Never	Sometimes	Often	Always
36. My heart suddenly starts to beat too quickly for no reason	Never	Sometimes	Often	Always
37. I worry that I will suddenly get a scared feeling when there is nothing to be afraid of	Never	Sometimes	Often	Always
38. I like myself	Never	Sometimes	Often	Always
39. I am afraid of being in small closed places, like tunnels or small rooms	Never	Sometimes	Often	Always
40. I have to do some things over and over again (like washing my hands, cleaning or putting things in a certain order)	Never	Sometimes	Often	Always
41. I get bothered by bad or silly thoughts or pictures in my mind	Never	Sometimes	Often	Always
42. I have to do some things in just the right way to stop bad things happening	Never	Sometimes	Often	Always
43. I am proud of my school work	Never	Sometimes	Often	Always
44. I would feel scared if I had to stay away from home overnight	Never	Sometimes	Often	Always
45. Is there something else that you are really afraid of?	Yes		No	
Please write down what it is				
How often are you afraid of this thing?	Never	Sometimes	Often	Always

This project is funded by a National Institute for Health Research Research Professorship awarded to Cathy Creswell

NHS
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Participant number:
Date:

University of Reading

SDQ-C: Child Self-Report

Instructions: For each item, please colour in the circle for **Not True, Somewhat True or Certainly True**. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft.

Please give your answers on the basis of **how things have been for you over the last 6 months.**	**Not True**	**Somewhat True**	**Certainly True**
1. I try to be nice to other people. I care about their feelings	○	○	○
2. I am restless. I cannot stay still for long	○	○	○
3. I get a lot of headaches, stomach aches or sickness	○	○	○
4. I usually share with others (food, toys, pencils etc.)	○	○	○
5. I get very angry and often lose my temper	○	○	○
6. I am usually on my own. I generally play alone or keep to myself	○	○	○
7. I usually do as I am told	○	○	○
8. I worry a lot	○	○	○
9. I am helpful if someone is hurt, upset or feeling sick	○	○	○
10. I am constantly fidgeting or squirming	○	○	○
11. I have one good friend or more	○	○	○
12. I fight a lot. I can make other people do what I want	○	○	○
13. I am often unhappy, downhearted or tearful	○	○	○
14. Other people my age generally like me	○	○	○
15. I am easily distracted, I find it difficult to concentrate	○	○	○
16. I am nervous in new situations. I easily lose confidence	○	○	○
17. I am kind to younger children	○	○	○
18. I am often accused of lying or cheating	○	○	○

Participant number:
Date:

Please give your answers on the basis of **how things have been for you over the last 6 months.**		**Not True**	**Somewhat True**	**Certainly True**
19.	Other children or young people pick on me or bully me	○	○	○
20.	I often volunteer to help others (parents, teachers, children)	○	○	○
21.	I think before I do things	○	○	○
22.	I take things that are not mine from home, school or elsewhere	○	○	○
23.	I get on better with adults than with people my own age	○	○	○
24.	I have many fears, I am easily scared	○	○	○
25.	I finish the work I am doing. My attention is good	○	○	○

Robert Goodman, 2005

This project is funded by a National Institute for Health Research Research Professorship awarded to Cathy Creswell

NHS
National Institute for Health Research

Participant number:
Date:

University of Reading

SCAS-T: Teacher Report

Instructions: Below is a list of items that describe children. For each item please circle the response that best describes the child. Please answer all the items, even if some do not seem to apply to this child.

1. Worries about things	Never	Sometimes	Often	Always
2. Complains of tummy aches	Never	Sometimes	Often	Always
3. Complains of feeling afraid	Never	Sometimes	Often	Always
4. Is scared when has to take a test	Never	Sometimes	Often	Always
5. Is afraid when (s)he has to use school toilets or bathrooms	Never	Sometimes	Often	Always
6. Worries about being away from parent(s)	Never	Sometimes	Often	Always
7. Feels afraid that (s)he will make a fool of him/herself in front of people	Never	Sometimes	Often	Always
8. Worries that (s)he will do badly at school	Never	Sometimes	Often	Always
9. Worries that something awful will happen to someone in his/her family	Never	Sometimes	Often	Always
10. Complains of suddenly feeling as if (s)he can't breathe when there is no reason for this	Never	Sometimes	Often	Always
11. Has to keep checking that (s)he has done things right (like the switch is off, or the door is locked)	Never	Sometimes	Often	Always
12. Has trouble going to school in the mornings because (s)he feels nervous or afraid	Never	Sometimes	Often	Always
13. Can't seem to get bad or silly thoughts out of his / her head	Never	Sometimes	Often	Always
14. Complains of his/her heart beating really fast when(s)he has a problem,	Never	Sometimes	Often	Always
15. Suddenly starts to tremble or shake when there is no reason for this	Never	Sometimes	Often	Always
16. Worries that something bad will happen to him/her	Never	Sometimes	Often	Always
17. Feels shaky when s/he has a problem	Never	Sometimes	Often	Always
18. Has to think special thoughts (like numbers or words) to stop bad things from happening	Never	Sometimes	Often	Always
19. Feels scared if (s)he has to travel in school transport	Never	Sometimes	Often	Always
20. Worries what other people think of him/her	Never	Sometimes	Often	Always
21. Is afraid of being in crowded places (like school halls, busy playgrounds)	Never	Sometimes	Often	Always
22. All of a sudden feels really scared for no reason at all	Never	Sometimes	Often	Always
23. Complains of suddenly becoming dizzy or faint when there is no reason for this	Never	Sometimes	Often	Always
24. Feels afraid when (s)he has to talk in front of the class	Never	Sometimes	Often	Always

Participant number:
Date:

25. Complains of his / her heart suddenly starting to beat too quickly for no reason	Never	Sometimes	Often	Always
26. Worries that (s)he will suddenly get a scared feeling when there is nothing to be afraid of	Never	Sometimes	Often	Always
27. Is afraid of being in small closed places, like tunnels or small rooms	Never	Sometimes	Often	Always
28. Has to do some things over and over again like washing his / her hands, cleaning or putting things in a certain order	Never	Sometimes	Often	Always
29. Gets bothered by bad or silly thoughts or pictures in his/her head	Never	Sometimes	Often	Always
30. Has to do certain things in just the right way to stop bad things from happening	Never	Sometimes	Often	Always
31. Is afraid of asking questions in class	Never	Sometimes	Often	Always
32. Speaks only when someone asks a question of them	Never	Sometimes	Often	Always
33. Does not volunteer answers or comment during class	Never	Sometimes	Often	Always
34. Is afraid of making mistakes	Never	Sometimes	Often	Always
35. Hates being the centre of attention	Never	Sometimes	Often	Always
36. Hesitates in starting tasks or asks whether they understood the task before starting	Never	Sometimes	Often	Always
37. Seems very shy	Never	Sometimes	Often	Always
38. Complains of headaches, stomach aches or feeling sick	Never	Sometimes	Often	Always
39. Hesitates to speak when in group situations	Never	Sometimes	Often	Always
40. Appears nervous when approached by other children or adults	Never	Sometimes	Often	Always
41. Is there anything else that this child is really afraid of?	YES		NO	
Please write down what it is, and fill out how often (s)he is afraid of this thing:				
	Never	Sometimes	Often	Always
	Never	Sometimes	Often	Always
	Never	Sometimes	Often	Always

Based on 2000 Susan H. Spence &
'School Anxiety Scale' Centre for Emotional Health, Macquarie University, Sydney

This project is funded by a National Institute for Health Research Research Professorship awarded to Cathy Creswell

Participant number:
Date:

University of Reading

SDQ-T: Teacher Report

Instructions: For each item, please mark the box for **Not True**, **Somewhat True** or **Certainly True**. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft!

Please give your answers on the basis of the child's behaviour **over the last six months or this school year**.	**Not True**	**Somewhat True**	**Certainly True**
1. Considerate of other people's feelings			
2. Restless, overactive, cannot stay still for long			
3. Often complains of headaches, stomach-aches or sickness			
4. Shares readily with other children (treats, toys, pencils etc)			
5. Often has temper tantrums or hot tempers			
6. Rather solitary, tends to play alone			
7. Generally obedient, usually does what adults request			
8. Many worries; often seems worried			
9. Helpful if someone is hurt, upset or feeling ill			
10. Constantly fidgeting or squirming			
11. Has at least one good friend			
12. Often fights with other children or bullies them			
13. Often unhappy, down-hearted or tearful			
14. Generally liked by other children			
15. Easily distracted, concentration wanders			
16. Nervous or clingy in new situations, easily loses confidence			
17. Kind to younger children			
18. Often lies or cheats			
19. Picked on or bullied by other children			
20. Often volunteers to help others (parents, teachers, other children)			
21. Thinks things out before acting			
22. Steals from home, school or elsewhere			
23. Gets on better with adults than with other children			
24. Many fears, easily scared			
25. Sees tasks through to the end, good attention span			

Participant number:
Date:

SCAS-P: Parent Report on Child

Instructions: Below is a list of items that describe children. For each item please circle the response that best describes your child. Please answer all the items.

1. My child worries about things	Never	Sometimes	Often	Always
2. My child is scared of the dark	Never	Sometimes	Often	Always
3. When my child has a problem, s(he) complains of having a funny feeling in his/her stomach	Never	Sometimes	Often	Always
4. My child complains of feeling afraid	Never	Sometimes	Often	Always
5. My child would feel afraid of being on his/her own at home	Never	Sometimes	Often	Always
6. My child is scared when s(he) has to take a test	Never	Sometimes	Often	Always
7. My child is afraid when (s)he has to use public toilets or bathrooms	Never	Sometimes	Often	Always
8. My child worries about being away from us/me	Never	Sometimes	Often	Always
9. My child feels afraid that (s)he will make a fool of him/herself in front of people	Never	Sometimes	Often	Always
10. My child worries that (s)he will do badly at school	Never	Sometimes	Often	Always
11. My child worries that something awful will happen to someone in our family	Never	Sometimes	Often	Always
12. My child complains of suddenly feeling as if (s)he can't breathe when there is no reason for this	Never	Sometimes	Often	Always
13. My child has to keep checking that (s)he has done things right (like the switch is off, or the door is locked).	Never	Sometimes	Often	Always
14. My child is scared if (s)he has to sleep on his/her own	Never	Sometimes	Often	Always
15. My child has trouble going to school in the mornings because (s)he feels nervous or afraid	Never	Sometimes	Often	Always
16. My child is scared of dogs	Never	Sometimes	Often	Always
17. My child can't seem to get bad or silly thoughts out of his/her head	Never	Sometimes	Often	Always
18. When my child has a problem, s(he) complains of his/her heart beating really fast	Never	Sometimes	Often	Always
19. My child suddenly starts to tremble or shake when there is no reason for this	Never	Sometimes	Often	Always
20. My child worries that something bad will happen to him/her	Never	Sometimes	Often	Always
21. My child is scared of going to the doctor or dentist	Never	Sometimes	Often	Always
22. When my child has a problem, (s)he feels shaky	Never	Sometimes	Often	Always
23. My child is scared of heights (eg. being at the top of a cliff)	Never	Sometimes	Often	Always

24. My child has to think special thoughts (like numbers or words) to stop bad things from happening	Never	Sometimes	Often	Always
25. My child feels scared if (s)he has to travel in the car, or on a bus or train	Never	Sometimes	Often	Always
26. My child worries what other people think of him/her	Never	Sometimes	Often	Always
27. My child is afraid of being in crowded places (like shopping centres, the cinema, buses, busy playgrounds)	Never	Sometimes	Often	Always
28. All of a sudden my child feels really scared for no reason at all	Never	Sometimes	Often	Always
29. My child is scared of insects or spiders	Never	Sometimes	Often	Always
30. My child complains of suddenly becoming dizzy or faint when there is no reason for this	Never	Sometimes	Often	Always
31. My child feels afraid when (s)he has to talk in front of the class	Never	Sometimes	Often	Always
32. My child complains of his/her heart suddenly starting to beat too quickly for no reason	Never	Sometimes	Often	Always
33. My child worries that (s)he will suddenly get a scared feeling when there is nothing to be afraid of	Never	Sometimes	Often	Always
34. My child is afraid of being in small closed places, like tunnels or small rooms	Never	Sometimes	Often	Always
35. My child has to do some things over and over again (like washing his/her hands cleaning or putting things in a certain order)	Never	Sometimes	Often	Always
36. My child gets bothered by bad or silly thoughts or pictures in his/her head	Never	Sometimes	Often	Always
37. My child has to do certain things in just the right way to stop bad things from happening	Never	Sometimes	Often	Always
38. My child would feel scared if (s)he had to stay away from home overnight	Never	Sometimes	Often	Always
39. Is there anything else that your child is really afraid of?	YES		NO	
Please write down what it is, and fill out how often (s)he is afraid of this thing:				
	Never	Sometimes	Often	Always
	Never	Sometimes	Often	Always
	Never	Sometimes	Often	Always
	Never	Sometimes	Often	Always

2000 Susan H. Spence

Participant number:
Date:

SDQ-P: Parent Report on Child

University of Reading

Instructions: For each item, please mark the box for **Not True, Somewhat True** or **Certainly True**. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft!

Please give your answers on the basis of **your child's behaviour over the last 6 months** or **this school year.**	**Not True**	**Somewhat True**	**Certainly True**
1. Considerate of other people's feelings	○	○	○
2. Restless, overactive, cannot stay still for long	○	○	○
3. Often complains of headaches, stomach-aches or sickness	○	○	○
4. Shares readily with other children (treats, toys, pencils etc)	○	○	○
5. Often has temper tantrums or hot tempers	○	○	○
6. Rather solitary, tends to play alone	○	○	○
7. Generally obedient, usually does what adults request	○	○	○
8. Many worries, often seems worried	○	○	○
9. Helpful if someone is hurt, upset or feeling ill	○	○	○
10. Constantly fidgeting or squirming	○	○	○
11. Has at least one good friend	○	○	○
12. Often fights with other children or bullies them	○	○	○
13. Often unhappy, down-hearted or tearful	○	○	○
14. Generally liked by other children	○	○	○
15. Easily distracted, concentration wanders	○	○	○
16. Nervous or clingy in new situations, easily loses confidence	○	○	○
17. Kind to younger children	○	○	○
18. Often lies or cheats	○	○	○
19. Picked on or bullied by other children	○	○	○
20. Often volunteers to help others (parents, teachers, other children)	○	○	○
21. Thinks things out before acting	○	○	○
22. Steals from home, school or elsewhere	○	○	○
23. Gets on better with adults than with other children	○	○	○
24. Many fears, easily scared	○	○	○
25. Sees tasks through to the end, good attention span	○	○	○

Robert Goodman, 2005

Participant Number:
Date:

SCAS-C: Child Self-Report

Instructions: Please put a circle around the word that shows how often each of these things happen to you. There are no right or wrong answers.

1. I worry about things	Never	Sometimes	Often	Always
2. When I have a problem, I get a funny feeling in my stomach	Never	Sometimes	Often	Always
3. I feel afraid	Never	Sometimes	Often	Always
4. I would feel afraid of being on my own at home	Never	Sometimes	Often	Always
5. I feel scared when I have to take a test	Never	Sometimes	Often	Always
6. I feel afraid if I have to use public toilets or bathrooms	Never	Sometimes	Often	Always
7. I worry about being away from my parents	Never	Sometimes	Often	Always
8. I feel afraid that I will make a fool of myself in front of people	Never	Sometimes	Often	Always
9. I worry that I will do badly at my school work	Never	Sometimes	Often	Always
10. I am popular amongst other kids my own age	Never	Sometimes	Often	Always
11. I worry that something awful will happen to someone in my family	Never	Sometimes	Often	Always
12. I suddenly feel as if I can’t breathe when there is no reason for this	Never	Sometimes	Often	Always
13. I feel scared if I have to sleep on my own	Never	Sometimes	Often	Always
14. I have trouble going to school in the mornings because I feel nervous or afraid	Never	Sometimes	Often	Always
15. I am good at sports	Never	Sometimes	Often	Always
16. When I have a problem, my heart beats really fast	Never	Sometimes	Often	Always
17. I suddenly start to tremble or shake when there is no reason for this	Never	Sometimes	Often	Always
18. I worry that something bad will happen to me	Never	Sometimes	Often	Always
19. When I have a problem, I feel shaky	Never	Sometimes	Often	Always
20. I am a good person	Never	Sometimes	Often	Always
21. I feel scared if I have to travel in the car, or on a bus or a train	Never	Sometimes	Often	Always
22. I worry what other people think of me	Never	Sometimes	Often	Always
23. I am afraid of being in crowded places (like shopping centres, the cinema, buses, busy playgrounds)	Never	Sometimes	Often	Always
24. I feel happy	Never	Sometimes	Often	Always
25. All of a sudden I feel really scared for no reason at all	Never	Sometimes	Often	Always

Participant Number:
Date:

26. I suddenly become dizzy or faint when there is no reason for this	Never	Sometimes	Often	Always
27. I feel afraid if I have to talk in front of my class	Never	Sometimes	Often	Always
28. My heart suddenly starts to beat too quickly for no reason	Never	Sometimes	Often	Always
29. I worry that I will suddenly get a scared feeling when there is nothing to be afraid of	Never	Sometimes	Often	Always
30. I like myself	Never	Sometimes	Often	Always
31. I am afraid of being in small closed places, like tunnels or small rooms	Never	Sometimes	Often	Always
32. I am proud of my school work	Never	Sometimes	Often	Always
33. I would feel scared if I had to stay away from home overnight	Never	Sometimes	Often	Always

Participant Number:
Date:

SDQ-C: Child Self-Report

Instructions: For each item, please colour in the circle for **Not True, Somewhat True or Certainly True**. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft!

Please give your answers on the basis of **how things have been for you over the last 6 months.**	**Not True**	**Somewhat True**	**Certainly True**
1. I try to be nice to other people. I care about their feelings	○	○	○
2. I am restless. I cannot stay still for long	○	○	○
3. I get a lot of headaches, stomach aches or sickness	○	○	○
4. I usually share with others (food, toys, pencils etc.)	○	○	○
5. I get very angry and often lose my temper	○	○	○
6. I am usually on my own. I generally play alone or keep to myself	○	○	○
7. I usually do as I am told	○	○	○
8. I worry a lot	○	○	○
9. I am helpful if someone is hurt, upset or feeling sick	○	○	○
10. I am constantly fidgeting or squirming	○	○	○
11. I have one good friend or more	○	○	○
12. I fight a lot. I can make other people do what I want	○	○	○
13. I am often unhappy, downhearted or tearful	○	○	○
14. Other people my age generally like me	○	○	○
15. I am easily distracted, I find it difficult to concentrate	○	○	○
16. I am nervous in new situations. I easily lose confidence	○	○	○
17. I am kind to younger children	○	○	○
18. I am often accused of lying or cheating	○	○	○
19. Other children or young people pick on me or bully me	○	○	○
20. I often volunteer to help others (parents, teachers, children)	○	○	○
21. I think before I do things	○	○	○
22. I take things that are not mine from home, school or elsewhere	○	○	○
23. I get on better with adults than with people my own age	○	○	○
24. I have many fears, I am easily scared	○	○	○
25. I finish the work I am doing. My attention is good	○	○	○

Robert Goodman, 2005

Teacher number
Participant number
Date

SCAS-T: Teacher Report

Instructions: Below is a list of items that describe children. For each item please circle the response that best describes the child. Please try to answer all the items, even if some do not seem to apply to this child.

1. Worries about things	Never	Sometimes	Often	Always
2. Complains of tummy aches	Never	Sometimes	Often	Always
3. Complains of feeling afraid	Never	Sometimes	Often	Always
4. Is scared when has to take a test	Never	Sometimes	Often	Always
5. Worries about being away from parent(s)	Never	Sometimes	Often	Always
6. Feels afraid that (s)he will make a fool of him/herself in front of people	Never	Sometimes	Often	Always
7. Worries that (s)he will do badly at school	Never	Sometimes	Often	Always
8. Worries that something awful will happen to someone in his/her family	Never	Sometimes	Often	Always
9. Complains of suddenly feeling as if (s)he can't breathe when there is no reason for this	Never	Sometimes	Often	Always
10. Has trouble going to school in the mornings because (s)he feels nervous or afraid	Never	Sometimes	Often	Always
11. Complains of his/her heart beating really fast when(s)he has a problem	Never	Sometimes	Often	Always
12. Suddenly starts to tremble or shake when there is no reason for this	Never	Sometimes	Often	Always
13. Worries that something bad will happen to him/her	Never	Sometimes	Often	Always
14. Feels shaky when s/he has a problem	Never	Sometimes	Often	Always
15. Worries what other people think of him/her	Never	Sometimes	Often	Always
16. Is afraid of being in crowded places (like school halls, busy playgrounds)	Never	Sometimes	Often	Always
17. All of a sudden feels really scared for no reason at all	Never	Sometimes	Often	Always
18. Complains of suddenly becoming dizzy or faint when there is no reason for this	Never	Sometimes	Often	Always
19. Feels afraid when (s)he has to talk in front of the class	Never	Sometimes	Often	Always
20. Worries that (s)he will suddenly get a scared feeling when there is nothing to be afraid of	Never	Sometimes	Often	Always
21. Is there anything else that this child is really afraid of?	YES		NO	
Please write down what it is, and fill out how often (s)he is afraid of this thing:				
	Never	Sometimes	Often	Always
	Never	Sometimes	Often	Always
	Never	Sometimes	Often	Always

Based on 2000 Susan H. Spence

Participant Number:
Date:

SDQ-T: Teacher Report

Instructions: For each item, please mark the box for **Not True**, **Somewhat True** or **Certainly True**. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft!

Please give your answers on the basis of the child's behaviour **over the last six months or this school year**.	**Not True**	**Somewhat True**	**Certainly True**
1. Considerate of other people's feelings	○	○	○
2. Restless, overactive, cannot stay still for long	○	○	○
3. Often complains of headaches, stomach-aches or sickness	○	○	○
4. Shares readily with other children (treats, toys, pencils etc)	○	○	○
5. Often has temper tantrums or hot tempers	○	○	○
6. Rather solitary, tends to play alone	○	○	○
7. Generally obedient, usually does what adults request	○	○	○
8. Many worries, often seems worried	○	○	○
9. Helpful if someone is hurt, upset or feeling ill	○	○	○
10. Constantly fidgeting or squirming	○	○	○
11. Has at least one good friend	○	○	○
12. Often fights with other children or bullies them	○	○	○
13. Often unhappy, down-hearted or tearful	○	○	○
14. Generally liked by other children	○	○	○
15. Easily distracted, concentration wanders	○	○	○
16. Nervous or clingy in new situations, easily loses confidence	○	○	○
17. Kind to younger children	○	○	○
18. Often lies or cheats	○	○	○
19. Picked on or bullied by other children	○	○	○
20. Often volunteers to help others (parents, teachers, other children)	○	○	○
21. Thinks things out before acting	○	○	○
22. Steals from home, school or elsewhere	○	○	○
23. Gets on better with adults than with other children	○	○	○
24. Many fears, easily scared	○	○	○
25. Sees tasks through to the end, good attention span	○	○	○

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N-CAT: National survey of Child Anxiety and Treatment access

Help seeking views and experiences questionnaire

Contact: Tessa Reardon. Email: t.c.reardon@pgr.reading.ac.uk Tel: 07811479928

This project is funded by a National Institute for Health Research Research Professorship awarded to Cathy Creswell

NHS
National Institute for Health Research

Participant number
Date

Section 1: About your child's anxiety

1.1. Please rate the following about your child based on how he/she has been in the **past 6 months**:

	Strongly disagree	**Somewhat disagree**	**Neutral**	**Somewhat agree**	**Strongly agree**
1. My child has been experiencing difficulties with anxiety.					
2. My child would benefit from support from a professional to manage and overcome their difficulties with anxiety.					
3. I would benefit from support from a professional to help my child manage and overcome his/her anxiety difficulties.					

1.2 Please rate how much anxiety (feeling nervous and afraid) has caused problems for your child in the following areas **over the past month**. If the question does not apply mark ***Not at all***.

In the **past month**, how much trouble has your child had doing the following because of his/her anxiety?	**Not at All** **0**	**Just a Little** **1**	**Pretty Much** **2**	**Very Much** **3**
School Activities				
1. Getting to school on time in the morning	○	○	○	○
2. Giving oral reports or reading out loud	○	○	○	○
3. Writing in class	○	○	○	○
4. Taking tests or exams	○	○	○	○
5. Completing work in class	○	○	○	○
6. Doing homework	○	○	○	○
7. Getting good marks	○	○	○	○
8. Doing fun things during break or free time	○	○	○	○
9. Concentrating on his/her work	○	○	○	○
10. Eating lunch with other kids	○	○	○	○

In the **past month**, how much trouble has your child had doing the following because of his/her anxiety?	**Not at All**	**Just a Little**	**Pretty Much**	**Very Much**

Participant number
Date

	0	1	2	3
Social Activities				
11. Making new friends	○	○	○	○
12. Leaving the house	○	○	○	○
13. Talking on the phone	○	○	○	○
14. Being with a group of strangers	○	○	○	○
15. Going to a friend's house during the day	○	○	○	○
16. Spending a night at a friend's house	○	○	○	○
17. Going to a sports event	○	○	○	○
18. Going shopping or trying on clothes	○	○	○	○
19. Eating in public	○	○	○	○
Home/Family Activities				
20. Getting ready for bed at night	○	○	○	○
21. Sleeping at night	○	○	○	○
22. Getting along with his/her brothers or sisters	○	○	○	○
23. Getting along with his/her parents	○	○	○	○
24. Visiting relatives	○	○	○	○
25. Having relatives visit	○	○	○	○
Please list any other areas where your child's anxiety is causing a problem for your child				
26.	○	○	○	○
27.	○	○	○	○
Global Items				
28. Overall, how much is anxiety causing problems for your child at **school**?	○	○	○	○
29. Overall, how much is anxiety causing problems for your child **socially**, that is with friends?	○	○	○	○
30. Overall, how much is anxiety preventing your child from **going places** with friends or relatives?	○	○	○	○
31. Overall, how much is anxiety causing problems for your child with your **family and at home**?	○	○	○	○

Participant number
Date

Section 2: Help seeking for your child's anxiety

We would first like to find out about whether you have **contacted** a professional for help or advice about your child's difficulties with anxiety.

After contacting a professional for help or advice, sometimes families can face difficulties actually **receiving** help or support from a professional to manage or overcome a child's difficulties with anxiety.

If you have contacted a professional for help or advice about your child's difficulties with anxiety, we would also like to find out about whether you or your child has actually **received** help or support from a professional.

2.1 a) Have you ever **contacted** a professional for help or advice about your child's difficulties with anxiety?

Yes ☐ No ☐

If No, go straight to question 2.3

b) **If yes**, please indicate **who** you have contacted for help or advice about your child's difficulties with anxiety and **when** you contacted them (**tick all that apply**):

	Contacted in the past 6 months	**Contacted more than 6 months ago**
GP / family doctor		
Teacher at my child's school (including Head teacher, Class teacher or Special Educational Needs Co-ordinator)		
Support staff at my child's school (e.g. learning support assistant)		
Health visitor		
Social worker		
Someone specialising in child mental health (e.g. clinical psychologist, psychological therapist, counsellor)		
A telephone helpline		
Other (please specify)		

2.2 a) Have you or your child ever actually **received** help or support from a professional to manage or overcome your child's difficulties with anxiety?

Yes ☐ No ☐

If No, go to question 2.3

b) **If yes**, please indicate **what type** of help or support you received and **when** you received the help or support (**tick all that apply**):

	In the past 6 months	**More than 6 months ago**
Cognitive Behaviour Therapy (CBT) with my child		
Cognitive Behaviour Therapy (CBT) with you to help you help your child		
Counselling for your child		
Parenting support for you		
A professional recommended resources/strategies/books		
Don't know what help or support we received		
Other professional help or support received (please give details)		

c) **If yes**, please indicate **who** provided the help or support you received (**tick all that apply**)

Participant number
Date

GP / family doctor	
Teacher or school staff	
NHS professional specialising in child mental health (clinical psychologist, psychological therapist, counsellor)	
Private professional	
Other professional (please give details)	

Participant number
Date

We would also like to find out about other people you may have spoken to for:
(a) help or advice about your child’s anxiety
(b) advice about getting help from a professional to manage or overcome your child’s difficulties with anxiety

2.3 a) Please tick **yes** or **no** for each of the following:

	Yes	**No**
I have spoken to friends about my child’s anxiety		
I have spoken to family members about my child’s anxiety		
I have spoken to other parents I know about my child’s anxiety		
I have spoken to work colleagues about my child’s anxiety		
I have used the internet to find out more about anxiety difficulties in children		
I have used online parent forums for information and advice about my child’s anxiety		
I have used books to find out more about anxiety difficulties in children		
Other people or resources not mentioned above (please specify)		

b) Please tick **yes or no** for each of the following:

	Yes	**No**
I have spoken to friends for advice about getting help from a professional for my child’s difficulties with anxiety		
I have spoken to family members for advice about getting help from a professional for my child’s difficulties with anxiety		
I have spoken to other parents I know for advice about getting help from a professional for my child’s difficulties with anxiety		
I have spoken to work colleagues for advice about getting help from a professional for my child’s difficulties with anxiety		
I have used the internet to find out more about professional help that is available for anxiety difficulties in children		
I have used online parent forums for advice and information about professional help that is available for anxiety difficulties in children		
Other people or resources not mentioned above (please specify)		

Participant number
Date

Sometimes families face difficulties seeking professional help for a child's difficulties with anxiety.

We would like to find out if anything has **stopped you** or **made it harder** for you to seek professional help for your child's anxiety.

This may include difficulties you have faced initially contacting a professional, and/or difficulties actually receiving help or support from a professional.

2.4 Please rate how much each statement has **stopped** you or made it **harder** for you to seek professional help for your child's anxiety.

If the statement **does not apply** to you or your child select ***not stopped me / not made it harder at all.***

not stopped me / not made it harder at all → ***very much stopped me / made it very much harder***

My child has always been anxious	0	1	2	3
My child's anxiety comes and goes in phases	0	1	2	3
I'm not sure if my child's anxiety is normal	0	1	2	3
I think my child's anxiety is normal	0	1	2	3
I'm not sure if my child has anxiety difficulties or other difficulties	0	1	2	3
My child has other difficulties that are more serious than anxiety	0	1	2	3
My child doesn't understand that she/he has anxiety difficulties	0	1	2	3
I don't know other people who have had anxiety difficulties	0	1	2	3
I don't know who to ask for help	0	1	2	3
I don't know what help is available for children with anxiety difficulties	0	1	2	3
I don't trust information I've read online about professional help for anxiety difficulties in children	0	1	2	3
Professionals have dismissed my concerns about my child in the past	0	1	2	3
Teachers or other professionals have never suggested my child would benefit from professional help	0	1	2	3
Talking to my child about her/his anxiety may make the problem worse	0	1	2	3
I don't want my child to think she/he has a problem	0	1	2	3
Family life is busy or we have lots of other things going on in the family	0	1	2	3
Professionals can't help with anxiety difficulties in children	0	1	2	3
My child's anxiety may improve without professional help	0	1	2	3
I want us to manage my child's anxiety as a family	0	1	2	3
I feel a sense of failure or blame as a parent	0	1	2	3
People I know may blame me or judge me or think I am a bad parent	0	1	2	3
People see anxiety or mental health difficulties as a weakness	0	1	2	3
I don't want my child to be labelled	0	1	2	3
I don't want other people to know about my child's difficulties	0	1	2	3

not stopped → ***very much***

Participant number
Date

	me / not made it harder at all			***stopped me / made it very much harder***
My child is worried about what other children will think about her/him getting help	0	1	2	3
Professionals won't listen to me or won't take me seriously	0	1	2	3
Professionals will blame me	0	1	2	3
I am afraid if I talk to a professional it will raise concerns about my parenting	0	1	2	3
My child's behaviour is not disruptive at school	0	1	2	3
Teachers don't know much about anxiety difficulties in children	0	1	2	3
I don't know if teachers can provide advice on anxiety difficulties	0	1	2	3
My child's school does not prioritise mental health	0	1	2	3
My child's school has limited resources	0	1	2	3
GPs don't know much about anxiety difficulties in children	0	1	2	3
My GP doesn't know me and/or my child	0	1	2	3
I don't know if GPs can provide advice on anxiety difficulties	0	1	2	3
It is difficult to make an appointment at my GP surgery	0	1	2	3
Professionals don't think my child needs professional help	0	1	2	3
Professionals only offer parenting courses	0	1	2	3
There isn't any professional help available for children with anxiety difficulties	0	1	2	3
It is a battle to access professional help	0	1	2	3
It is difficult to get a referral to a specialist service	0	1	2	3
There are long waiting times for specialist services	0	1	2	3
I can't afford to pay for private professional help	0	1	2	3
*Please add anything else that has **stopped you** or **made it harder** for you to seek professional help:*	0	1	2	3

Participant number
Date

We would also like to find out whether anything has **encouraged** you or made it **easier** for you to seek professional help for your child's anxiety.

This may include things that encouraged you or made it easier for you to contact professionals, and/or easier for you to actually receive help or support from a professional.

2.5 Please rate how much each statement has **encouraged** you or made it **easier** for you to seek professional help for your child's anxiety.

If the statement **does not apply** to you or your child select ***not encouraged me / not made it easier at all.***

	not encouraged me / not made it easier at all			***very much encouraged me / made it very much easier***
My child's anxiety got worse	0	1	2	3
My child's anxiety difficulties are serious	0	1	2	3
My child's anxiety impacts on his/her life	0	1	2	3
Something happened to trigger or cause my child's anxiety difficulties	0	1	2	3
I know how to talk to professionals	0	1	2	3
Professional listen to me	0	1	2	3
I know other parents who have spoken to professionals about their child's anxiety or other mental health difficulties	0	1	2	3
My friends/family think that my child has anxiety difficulties	0	1	2	3
My friends/family think my child may benefit from professional help	0	1	2	3
My child wants professional help	0	1	2	3
I am desperate to get help for my child	0	1	2	3
I cannot manage my child's anxiety without professional help or support	0	1	2	3
My GP is understanding and supportive	0	1	2	3
Teachers at my child's school are understanding and supportive	0	1	2	3
I trust my GP	0	1	2	3
My GP referred my child to a specialist service	0	1	2	3
I trust the teachers at my child's school	0	1	2	3
Teachers at my child's school know my child	0	1	2	3
There is a clear point of contact at my child's school	0	1	2	3
My child's school helped with a referral to a specialist service	0	1	2	3
A professional told me my child may have anxiety difficulties	0	1	2	3
A professional advised me to seek help for my child	0	1	2	3
I have read online about the help that is available for children with anxiety difficulties	0	1	2	3
My child has received professional help for another mental health or physical health difficulty	0	1	2	3

not ***very much***

	encouraged me / not made it easier at all			***encouraged me / made it very much easier***
My child has received support through school for an academic/learning related difficulty	0	1	2	3
I paid a private professional for an assessment or support for my child's anxiety.	0	1	2	3
I have pushed hard to get professional help for my child	0	1	2	3
I have not given up asking for help	0	1	2	3
I have contacted different professionals to try to get help for my child	0	1	2	3
My child meets the required criteria to access specialist services	0	1	2	3
Please add anything else that has ***encouraged*** *you or made it* ***easier*** *for you to seek professional help:*	0	1	2	3

We would also like to find out about what you think would **encourage** you or make it **easier** for you to seek professional help for your child's anxiety in the **future**.

2.6 Please rate how much each statement would **encourage** you or make it **easier** for you to seek professional help for your child's anxiety in the **future**.

	not encourage me / not make it easier at all	→		***very much encourage me / make it very much easier***
If my child's school distributed information about anxiety difficulties in children	0	1	2	3
If my child's school distributed information about how to access professional help for anxiety difficulties in children	0	1	2	3
If my child completed a questionnaire at school which showed she/he may be experiencing anxiety difficulties	0	1	2	3
If I completed a questionnaire (via school) which showed my child may be experiencing anxiety difficulties	0	1	2	3
If there was more professional help available for children with anxiety difficulties	0	1	2	3
Please add anything else that would make it easier for you to seek professional help in the future:	0	1	2	3

Section 3: Online resources

Participant number
Date

We would like to find out a bit about your use of computers and the internet and your views and experiences of online/app resources and computer-based therapies.

In this context, we define these as:

Online/app resources are information and advice about child anxiety obtained via the internet or apps.

Computer-based therapies are psychological treatments delivered via computer technology (e.g. over the internet), with or without the support of a therapist

3.1 a) Please select which of the following technologies you have regular access to (**tick all that apply**)

Personal computer / laptop	
Internet	
Smartphone	
Tablet	
None of the above	

b) Please rate how confident you feel using the following technologies.

	Not at all confident	***Not confident***	***Somewhat confident***	***Confident***	***Very confident***
Personal computer / laptop					
Internet					
Smartphone					
Tablet					

c) Please rate how much you like using these technologies in general (**please tick one**)

Strongly dislike	***Dislike***	***Neutral***	***Like***	***Strongly like***

Participant number
Date

3.2. a) Are you aware of any online/apps resources or computer-based therapies for parents concerned about their child's anxiety?

Yes ☐ No ☐

If No, go straight to 3.2e

<u>If yes:</u>
b) please state which ones:

____

c) have you used these?

	Not used because not relevant to me	***Not used but is relevant to me***	***Yes used once or twice***	***Yes used often***
Online/apps resources				
Computer-based therapies				

d) if you have used these, how helpful did you find these online/app resources or computer-based therapies?

	Not at all helpful	***Slightly helpful***	***Moderately helpful***	***Very helpful***	***Extremely helpful***
Online/apps resources					
Computer-based therapies					

<u>If no:</u>
e) if you were aware of online/app resources or computer-based therapies, how likely would you be to use them if you were concerned about your child's anxiety?

	Not at all likely	***Slightly likely***	***Moderately likely***	***Very likely***	***Completely likely***
Online/apps resources					
Computer-based therapies					

3.3. How important would it be for an online/app resource or computer-based therapy for childhood anxiety to have been tested and shown to be effective in order for you to use it?

	Not at all important	***Slightly important***	***Moderately important***	***Very important***	***Extremely important***
Online/apps resources					
Computer-based therapies					

3.4 How important would it be for an online/app resource or computer-based therapy for childhood anxiety to have been approved for use by the NHS in order for you to use it?

	Not at all important	***Slightly important***	***Moderately important***	***Very important***	***Extremely important***
Online/apps resources					
Computer-based therapies					

> *Remember computer-based therapies are psychological treatments delivered via computer technology (e.g. over the internet), with or without the support of a therapist.*

3.5 Do you think computer-based therapies for parents of children with anxiety difficulties should be:

	Definitely no	***No***	***Maybe/ Neutral***	***Yes***	***Definitely yes***
Freely available on the internet					
Available for use in schools					
Available in GP surgeries					
Available in mental health clinics					
Available without professional support					
Only available with professional support					

3.6 How much do you believe computer-based therapies for parents can help children experiencing anxiety difficulties (**please tick one**):

Not at all helpful	***Slightly helpful***	***Moderately helpful***	***Very helpful***	***Extremely helpful***

3.7 How problematic do you consider the following factors to be in relation to computer-based therapies for parents?

	Not at all problematic	***Slightly problematic***	***Somewhat problematic***	***Moderately problematic***	***Extremely problematic***
Engaging the parent					
Completing the treatment					
Appropriateness of tasks					
Having additional explanations					
Time					
Privacy and security of information					
Computer access					
Technological problems					
Having contact with a therapist					
Meets my family's individual needs					

3.8 How beneficial do you consider the following factors to be in relation to computer-based therapies for parents?

	Not at all beneficial	***Slightly beneficial***	***Somewhat beneficial***	***Moderately beneficial***	***Extremely beneficial***
Engaging					
Reduced stigma					
Earlier access to treatment (avoid waitlist)					
More interactive than a self-help book					
Use at any time					
Used at home					
Can monitor my child's progress					
Easily accessible					

Section 4: More about you

Participant number
Date

Some parents have told us that their own experience (or lack of experience) of feelings of stress, anxiety and depression has influenced how they view their child's anxiety and deciding to seek help for their child's anxiety. The following questions will ask about your own experiences of stress, anxiety and depression but if you would rather not answer these questions, please leave this section blank.

4.1. Please read the following statements and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 = Did not apply to me at all
1 = Applied to me to some degree, or some of the time
2 = Applied to me to a considerable degree, or a good part of time
3 = Applied to me very much, or most of the time

1. I found it hard to wind down	0	1	2	3
2. I was aware of dryness of my mouth	0	1	2	3
3. I couldn't seem to experience any positive feeling at all	0	1	2	3
4. I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5. I found it difficult to work up the initiative to do things	0	1	2	3
6. I tended to over-react to situations	0	1	2	3
7. I experienced trembling (eg, in the hands)	0	1	2	3
8. I felt that I was using a lot of nervous energy	0	1	2	3
9. I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10. I felt that I had nothing to look forward to	0	1	2	3
11. I found myself getting agitated	0	1	2	3
12. I found it difficult to relax	0	1	2	3
13. I felt down-hearted and blue	0	1	2	3
14. I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15. I felt I was close to panic	0	1	2	3
16. I was unable to become enthusiastic about anything	0	1	2	3
17. I felt I wasn't worth much as a person	0	1	2	3
18. I felt that I was rather touchy	0	1	2	3
19. I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20. I felt scared without any good reason	0	1	2	3
21. I felt that life was meaningless	0	1	2	3

Participant number
Date

4.2.

The following question asks about your experience of speaking to a professional about **your own** anxiety, depression or other mental/emotional difficulties.

a) Have you ever spoken to a professional either in person or by telephone about being anxious or depressed or another mental, nervous or emotional problem? (e.g. a GP/ family doctor, a psychological therapist/counsellor)

Yes ☐ No ☐

b) **If yes**, please indicate the type of professional you have spoken to (**Tick all that apply**)

GP / family doctor	
psychological therapist / counsellor	
psychiatrist	
Other (please specify)	

c) **If yes**, please rate how helpful you found your experience of speaking to a professional about being anxious or depressed or another mental, nervous or emotional problem. (**Please tick one**)

Not at all helpful	
Slightly helpful	
Moderately helpful	
Very helpful	
Extremely helpful	

Interview topic guide

Knowledge / beliefs about anxiety in children

- Can you tell me what you know about anxiety problems in children?
  (Probe for understanding of anxiety disorders in children)

    - *Probe:* How may a child experiencing problems with anxiety behave? What difficulties may they have?
    - *Probe:* Have you ever known another child (or adult) who has had problems with anxiety?

Parental recognition

- The questionnaires and assessment asked you about any anxieties, fears or worries your child is experiencing. Can you tell me about your answers?
    - *Probe:* Do you think your child is experiencing problems with anxiety?
    - *Probe*: Can you tell me about when you first thought your child may be experiencing problems with anxiety?
    - *Probe:* Did you or someone else notice any change in your child?
    - *Probe:* Was their anxiety affecting their life at home / at school / friendships / other activities?
    - *Probe:* Was there any affect on your family? How about you?
    - *Probe:* Did you talk to another adult about it?

Knowledge / views about / experience of help seeking

- Do you think children should have any help with anxiety?
    - *Probe:* Where do you think this should come from? (eg family, friends, school, health professionals, church, alternative therapies, osteopath, reflexology, aromatherapy, or other sources?)

- Has your child had any help or support with their anxiety?
  (Probes for reasons for help seeking and any steps taken to seek help)
    - *Probe:* What made you decide to seek help?
    - *Probe:* What type of help/support?
    - *Probe:* Where did you go / who did you first speak to? (eg GP, teacher)
    - *Probe:* Did both you and your child agree about the need for support?
    - *Probe:* Did you and your child agree about the type of support?

- Have you ever tried to get any support to help with your child's anxiety? What happened?
  (Probe for (failed) attempts to seek help / outcome of steps taken)
    - *Probe:* Have you faced any difficulties getting help for your child?
    - *Probe:* Is there anything that made it harder?

- Is there anything that made the process of getting help easier for your family? *(Probe for factors that facilitated help seeking and accessing professional help)*

If no attempt has been made to access professional/clinical help:

- How much do you know about the help or support that is available for children who are experiencing problems with anxiety? *(Probe for knowledge/views about sources of professional/clinical help)*
    - *Probe:* Where can you go to ask for help? / Who can you speak to about getting help?

- What do you think are some of the difficulties/challenges a family may face getting support for their child? *(Probe for perceptions about accessing help and personal reasons for not seeking help / failing to access professional help)*
    - *Probe:* Did anything make it difficult for you / stop you from trying to seek help?
    - *Probe:* Were you concerned getting help could make the problem worse? (eg labelling, stigma)
    - *Probe:* Did anything make it difficult for your child to get professional help?
    - *Probe:* What do you think may prevent a family from getting professional help?

- What do think may help a family get professional help/support?

<u>Knowledge / experience of support services</u>

If accessed services:

- Can you tell me about yours and your child's experience with getting help for your child's difficulties?
    - *Probe:* What did you think about the services your family received?
    - *Probe:* What was the outcome? Did it help your child/ you/your family?
    - *Probe:* Would you recommend to a friend that they sort help? Help of this kind?

If not accessed services:

- Have you had any experience with any kind of support services for children having problems with anxiety? *(Probe for any personal experience / perceptions about CAMHS/GPs)*

Suggested improvements

- What improvements could be made to make it easier for families get help or support if their child is having problems with anxiety?

- What type of support do you think should be available for children with anxiety disorders?
  (Probe for perceived 'ideal' service - the steps that would be involved in accessing help / where and who families would go to access help / nature of services and help offered)

Appendix 5: Patient Public Involvement (PPI) input

PPI meeting notes 23.4.2016

Attended: Tessa Reardon, Sarah Harrison, 3 parents

Parent comment/suggestion	Action
• Parents may be concerned about a child's problem being highlighted – if assessment shows child is having difficulties, parents may be concerned could change teacher's view of the child / have negative impact on child at school. • School emphasise results will not influence how child is treated at school • Emphasise that questionnaire results will not be shared with school and that parents are in control of this decision	• Add text to leaflet to clarify we will not share child's questionnaire scores with school and parents can decide to share this information if they want to • Encourage school to send letter endorsing/supporting study – possibly include detail about how they will use findings?
• Send consent initially to parent, option to do questionnaires after child/teacher • Or perhaps make teacher/child questionnaires available to parents – so can see questions being asked - or make clear questions are same for teacher and child as parent	• It is important that parents complete questionnaires (as findings from study 1 indicate parent questionnaires are more accurate than child/teacher) so we will need parents to complete questionnaire first to maximise parent responses. • Add text to leaflet to clarify that questions in teacher/child questionnaire are same as parent questionnaires
• School send letter of support – emphasise everyone is taking part and schools actively supports. Parents trust school's opinion	• Amend text in info leaflet to emphasise that the school is taking part and inviting all families in year 3-6 to take part • Encourage schools to send letter of support encouraging as many families as possible to take part
• Parents may be reluctant take part – some won't want to know if there's a problem, may assume child is just in a phase, may not want to think their child is different • Parents feel a failure if their child is having difficulties – need to get over this before they take part. Parents feel anxiety reflects back on them as a parent	• This is difficult to address here but highlights need for work on developing tools to help parent identify when a child's anxiety may benefit from professional help / work to reduce parental blame
• May seem odd to go looking for a problem • Frame as finding anxiety levels in schools at the moment in this age group – make seem more normal. Study will mostly will identify that a child is not experiencing difficulties (rather than identifying a problem). Depersonalise eg will help the class/school, rather than focus on picking out individual	• Need to keep reference to 'anxiety' so that we don't mislead parents • Amend intro blurb to acknowledge that anxiety is part of childhood but sometimes it impacts on a child's life. • Amend text/title to emphasise that it is a national survey of anxiety across all children in year 3-6

children. Eg is your school/child happy? And 'trying to make children happier' rather than searching for a problem. A national survey to check all is ok.	• Amend text to frame study purpose as developing tools to help parents/teachers to decide if a child may benefit from help to overcome anxiety difficulties – rather than about identifying/looking for anxiety difficulties
• Emphasise positive effects of taking part • Front page simplified – include benefits eg national study, benchmarking for schools, allow comparison with other schools. Less anxiety = better outcomes in education, so need to help reduce/early intervention. Provide more detailed info later in leaflet	• Amend text on front of leaflet (2 pages) so simplified and presented in bullets. • Include clear benefit section on front page ('and to say thank you we will'…). Add detail about report for school. • Amend background blurb. Add egs of impact (including school) • More text heavy pages inside leaflet.
• What is the research for? – need to clarify. Purpose not clear. Clarify two stages of study	• Amend text in background/purpose section. Add 'purpose' heading, with two clear bullets stating aims of each stage of the study. •
• What is going to happen if anxiety is identified? What support will be provided? Need benefits not just finding info. Eg help provided in school – parents may not know about help available in school. Highlight parents can share assessment report with school/gp.	• Add 'what will happen next' header. Add detail that families taking part in the follow up will be provided with a report/resources. • Add to stage 2 invite letter that families can share report with schools as well as GP • Support in schools will vary hugely so difficult to include in info leaflet/letter – but we can encourage parents to share report with school at stage 2 (and let schools know we will do this)
• Link to online survey is good.	
• Research team attend school assemblies / PTA / governor mtgs	• To offer to attend PTA and governor meetings and/or give assemblies at school
• Parent literacy levels, language/cultural barriers eg not want acknowledge difficulties	
• Replace 'work with families' to 'hear from'	• Removed 'work with' families
• Make it clear qualified people doing school visits	• Add text stating investigators are researchers from UoR with experience of working with children and families

PPI meeting notes 16.7.2016

Attended: 2 parents; Tessa Reardon

Feedback comment	**Action taken**
Help seeking questionnaire – barriers/facilitators question, long list but will be able to answer quickly	
Help seeking questionnaire – offer opportunity for both parents to complete separately	-to make clear when talk to parents one or both can take part in phase 1 and phase 2
Help seeking questionnaire – may be simpler to use a numbered rating scale, and only label the extremes (eg not stopped me = 0, very much stopped me = 3/4) – stop parents having to keep referring back to scale descriptions. Could include n/a option.	-to consider using numbered rating scale in this way