Awareness of ADHD in primary care

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Abstract

Despite ADHD impacting around 5% of children in the UK, GPs are ill-equipped to deal with this disorder. Over half of children with ADHD will continue experiencing symptoms into adulthood, and untreated and undiagnosed ADHD can strongly impact individuals throughout their lifetime. It is therefore vital that individuals access treatment and diagnosis at an early stage. The diagnosis pathway for ADHD is very complex. Specialist services in secondary care are responsible for ADHD diagnosis, most often following a referral from the patient's GP. Without such referral, access to diagnosis and, in turn, access to care is often impossible. GPs' accurate understanding and awareness of ADHD is therefore primordial. Studies investigating GPs' awareness of ADHD have found that GPs are ill-equipped to deal with individuals with ADHD, demonstrating a lack of knowledge and training, the presence of stigmas and misconceptions and a lack of clarity about their role. These barriers impact GPs' ability to recognise ADHD in their patients and therefore referring to specialist services for assessment and treatment.

To address some of these issues, these doctoral studies aim to raise GPs' awareness and knowledge of ADHD through a targeted online training resource. In the first instance, this thesis sought to investigate the gaps and barriers in GPs' understanding of ADHD. These findings facilitated the development of an online psycho-education programme tailored for GPs. The second aim was to evaluate the efficiency and usability of this programme.

This thesis included three phases using mixed-methodologies:

- A systematic review and qualitative interviews with GP trainees, GPs, patients and healthcare professionals were conducted to investigates barriers in GPs' understanding of ADHD.

- These findings informed the development of a 45-minute online psycho-education programme. This programme was co-produced with GPs, and a usability study was conducted to assess the accessibility of the programme.

- A pilot Randomised Control Trial (RCT) and interviews were then conducted with GPs to assess the program's efficiency. A brief evaluation of long-term impacts and implementation was also conducted.

The development of an online intervention was informed by evidence from a literature review, and Chapter one provides an overview of GPs' role and pathway to care in the UK. Through a systematic review, the first study explores the barriers and facilitators of GPs' understanding of ADHD. To further investigate the gaps in GPs' understanding, the second study explores interviews with key stakeholders in the ADHD in primary care - patients, secondary care professionals, GP trainees and GPs. Findings from the first two studies were inputted into the development of the online resource for GPs. The usability of this co-produced resource was assessed through a usability and feasibility study. This led to the final and primary study, which explores an online psycho-education resource's efficiency through a pilot RCT. Preliminary findings on long-term implementation and impact of the research were also collated.

This thesis demonstrates the many gaps in primary care understanding of ADHD and evaluates the use of a psycho-educational programme in addressing these gaps. The contribution of the studies and the implication of the findings are discussed. Considerations over the development process, the impact on primary care and implications for future research are also presented.

GPs’ knowledge of ADHD was improved by developing an online psycho-education programme resulting in increased understanding of the pathways to care and reduced stigma. Lack of identification and recognition of ADHD in GPs can be remediated by GPs completing a short 45-minute online course, in turn improving patients’ access to care.

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Publications and Presentations

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- McGlashan H., Blanchard C., Sycamore N., French B. & Holmes N. (2017). Improvement in children's fine motor skills following a computerized typing intervention. *Human Movement Science, 56,* 29-36.
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- French, B., Sayal, K., & Daley, D. (2019). Barriers and facilitators to understanding of ADHD in primary care: a mixed-method systematic review. *European Child & Adolescent Psychiatry*, *28*(8), 1037-1064.
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- French, B., Hall, C., Vallejos, E. P., Sayal, K., & Daley, D. (2020). Evaluation of a web-based ADHD awareness training in primary care: Pilot randomized controlled trial with nested interviews*. JMIR Medical Education, 6*(2), e19871.

Presentations and awards

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- Development and evaluation of an online intervention. Oral presentation, IMH research day, May 2021.
- ADHD pathway to care, the role of primary care. Oral presentation, CANDAL seminar, June 2021.
- Development and evaluation of an online intervention. Poster presentation, RCGP annual conference, October 2021.

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List of Abbreviations

ADHD - Attention Deficit Hyperactivity Disorder

CAMHS - Child and Adolescent Mental Health Services

CCG – Clinical Commissioning Group

CPD - Continuing Professional Development

GPs – General Practitioners

HELM - Health E-Learning and Media

JBI - Joanna Briggs Institute

MRC – Medical Research Council

NICE - National Collaborating Centre for Mental Health (UK)

NHS – National Health Service

PCPs – Primary Care Practitioners

RCT – Randomised Control Trial

RCGP – Royal College of GPs

RLO – Reusable Learning Objectives

SES - Socioeconomic status

Key individuals

BF – lead researcher

DD – main supervisor

KS – second supervisor

EPV – third supervisor

CS – consulting GP with an ADHD diagnosis

AG – consultant psychiatrist in adult ADHD services

KG – specialist nurse in CAMHS

VP – GP at the RCGP with a specialist research interest in ADHD

Chapter 1 Introduction- ADHD and its relevance in primary care

1.1 Chapter summary

This chapter establishes the context of these doctoral studies and the rationale for conducting this research. Attention deficit hyperactivity disorder (ADHD) is a common neurodevelopmental disorder that affects many children and adults. Its symptoms and impairments strongly affect individuals in day-to-day life. Untreated and undiagnosed ADHD has been shown to have substantial impacts on adults and children, such as a higher rate of divorce, school dropout, drug addiction, or loss of jobs. The pathway to care for ADHD in the UK is very complex. GPs often act as gatekeepers to referral services where diagnosis and treatment can be sought. Therefore, they must have a strong understanding of this condition to identify it in their patients. Research has shown that GPs have inadequate training, knowledge, and understanding of ADHD. This thesis will follow the MRC guidelines for complex intervention to develop a tailored psycho-education resource on ADHD for GPs and will be evaluated and developed through a mixed-methods approach.

1.2 What is ADHD?

ADHD is a neuro-developmental disorder characterised by difficulties in hyperactivity, impulsivity, and inattention (NICE, 2013), leading to considerable functional impairments (Lebowitz, 2016; Moldavsky & Sayal, 2013). The DSM-5 guidelines (American Psychiatric Association, 2013) state that five criteria have to be met to receive an ADHD diagnosis:

- Five (for adults) / six (for children) or more symptoms of inattention and/or symptoms of hyperactivity/impulsivity must have persisted for over six months to a degree that is inconsistent with the developmental level and negatively impacts social and academic/occupational activities.
- Several symptoms were present before the age of 12.
- Several symptoms must be present in two or more settings (e.g., at home, school, or work, with friends, or relatives).
- There is clear evidence that the symptoms interfere with or reduce the quality of social, academic, or occupational functioning.
- Symptoms do not occur exclusively during the course of schizophrenia or another psychotic disorder and can not be better explained by another mental disorder (e.g., mood disorder, anxiety disorder, dissociative disorder, personality disorder, substance intoxication, or withdrawal).

1.2.1 Symptoms and functional impairments

The three core ADHD symptoms categories encompass 18 symptoms that can be experienced by individuals with ADHD (NICE, 2013). For instance, inattention symptoms can include difficulties in organising tasks, forgetfulness, or easy distraction by external stimuli. Hyperactivity and impulsivity symptoms may include talking excessively, difficulties in waiting turns and being fidgety.

Aside from impairments experienced with the main three symptoms, ADHD impacts many other critical cognitive functions. These include impairments with executive functions such as memory (Alderson et al., 2013), delay aversion (Sonuga-Barke et al., 2010), or inhibition (Wodka et al., 2007). ADHD can also impact emotional functioning. Difficulties with emotion regulation is a common impairment of ADHD (Bunford et al., 2015), which has been associated with long-term effects on life events such as difficulties with relationships or school dropout (Barkley & Fischer, 2010). These have substantial impacts on many aspects of individuals' daily lives. For instance, academic achievement is strongly influenced by ADHD. ADHD has been associated with academic underachievement in childhood (Barry et al., 2002), long-term school exclusions (Barbaresi et al., 2007) and reduced likelihood of achieving higher education qualifications (Fried et al., 2016). These risks worsen when ADHD is undiagnosed or untreated but can be significantly ameliorated by effective classroom management and supportive teachers (DuPaul et al., 2011) and by medication. Finally, these functional impairments also strongly impact social and peer relationships. Behaviours associated with ADHD often results in children and adults being less likely to make and sustain friendships (Canu & Carlson, 2007; Hoza, 2007), higher rates of divorce in adulthood (Robin & Payson, 2002) and greater social difficulties and exclusion in childhood and adulthood (Adamou et al., 2013; Shea & Wiener, 2003; Young & Gudjonsson, 2006).

1.2.2 Prevalence and comorbidities

ADHD impacts approximately 3-5% of children (National Collaborating Centre for Mental Health-UK, 2018). Although symptoms can decline with age, around 60% of children will carry on experiencing symptoms and impairments into adulthood (Simon et al., 2009). In the UK, according to The National Institute for Health and Care Excellence (NICE) guidelines, 3-5% of children and 2% of adults in the population should be eligible for an ADHD diagnosis; however, in 2010, a clinically diagnosed prevalence of only 0.506 % was estimated for children and 0.016 % in adults (Holden et al., 2013). These figures suggest that ADHD may be underdiagnosed in the UK.

Many disorders (such as autism spectrum disorder, dyspraxia, or bipolar disorder - Milberger et al., 1995) have overlapping symptoms with ADHD, which might complicate its diagnosis through shared genetic variance (Willcutt et al., 2010) or diagnostic overshadowing (Hendriksen et al., 2015). Additionally, ADHD often co-occurs with many other psychiatric conditions. A community prevalence study (Jensen & Steinhausen, 2015) found that the most frequent comorbid disorders with ADHD in their sample were: disorders of conduct (16.5 %), specific developmental disorders of language, learning and motor development (15.4 %), autism spectrum disorders (12.4 %), and intellectual disability (7.9 %). Children with Tourette Syndrome are also very likely to have ADHD symptoms (60% - Swain et al., 2007). Mood and anxiety disorders such as depression, bipolar disorder, or generalised anxiety disorder are also commonly observed in children and adults with ADHD (Sobanski, 2006; Wilens et al., 2002). Finally, ADHD is often associated with substance abuse in adolescence and adulthood (Wilens et al., 2002).

1.2.3 Aetiology

Many studies have investigated the aetiology of ADHD; however, the exact cause of ADHD is still unknown. Interactions between established environmental and biological risk factors have been considered.

Biological factors

Many studies have investigated the biological causes of ADHD. While a definite model is still to be determined, significant advances have been made in determining ADHD’s neurobiology. Neuroimaging studies have established that ADHD patients have: structural difference - a smaller volume of grey and white matter (Batty et al., 2010; Pavuluri et al., 2009) and prefrontal cortex (Ellison-Wright et al., 2008), functional difference - significant activation reductions in various frontal regions of the brain including the anterior cingulate, dorsolateral prefrontal, inferior prefrontal cortices and cerebellum (Wang et al., 2013), abnormal activation in the default mode network (Fair et al., 2010) and chemical imbalance in levels of dopamine and noradrenaline (Economidou et al., 2012). Genetic studies have produced strong evidence that about 70 to 80% of the variation among children in hyperactivity and inattention appears to be related to genetic variation, and heritability estimates from twin studies range from 0.6 to 0.9 (Doyle et al., 2005; Zhou et al., 2008). While molecular genetic studies of ADHD are often inconclusive and yield conflicting results, it is uncontested that ADHD has substantial genetic variation, showing a relationship with dopamine genes (DRD4 and DRD5 - Kebir et al., 2009).

Environmental factors

Many environmental risk factors have also been associated with ADHD. Parental smoking in pregnancy, for instance, has often been cited as an environmental risk factor (Langley et al., 2012); however, the evidence is limited and often confounded. Diet and nutritional intake have also been widely investigated in relation to ADHD risk factors. While some studies have linked nutritional intake and nutritional deficiency with the severity of ADHD symptoms (Arnold et al., 2005; Konofal et al., 2004), there is no substantial evidence to date to link diet and nutritional intake as a cause of ADHD (Pelsser et al., 2017; Thapar et al., 2013). Parenting has also often been cited as a risk factor. Some studies have established that adverse parenting practices are often observed in families with ADHD children (Johnston & Mash, 2001); however, it is difficult to establish whether these practices are a result of having a child with ADHD and challenging behaviours or a cause. Finally, low birth weight and preterm birth have also been linked to ADHD. Children born preterm are up to four times more likely to be diagnosed with ADHD (Johnson et al., 2010).

More recently, studies have focused on the interaction of biological and environmental factors (Nigg et al., 2010; Palladino et al., 2019), demonstrating that the interplay between these factors - rather than these factors alone - is of utmost significance.

1.2.4 Treatment

Treatments for ADHD include both pharmacological and non-pharmacological treatments. The most successful form of ADHD treatment has been shown to be a combination of medication and behavioural treatments (Tarver et al., 2014).

Pharmacological treatment

Pharmacological treatments for ADHD include stimulant and non-stimulant medications. Both work on specific neurological pathways that are impaired in the ADHD brain. Medication has shown short-term improvement in ADHD symptoms and is often recommended in initialising treatment for ADHD (NICE, 2018). However, the prescription of medication is complex as getting the right medication and dosage can take time, and effects vary widely between individuals. Adverse side effects can be common with ADHD medication. While these can be impairing, they can be tolerable if desired outcomes are evident (Cortese et al., 2013; Giovane et al., 2019).

Non-pharmacological treatment

Several non-pharmacological treatments are also available. Behavioural parenting interventions are the first line of recommended treatment for some children with ADHD (NICE, 2018) and have been shown to successfully reduce ADHD symptoms (Fabiano et al., 2009). Classroom-based behaviour intervention and child psychological therapy have also demonstrated to improve related children’s outcome (Chronis et al., 2006); however, the evidence for the positive effects of these interventions is still limited and need to be investigated further (Sonuga-Barke et al., 2013). For adults, pharmacological treatments tend to be the first-line treatment option; however, psycho-education is essential as a stepping stone for patients to understand their new diagnosis (Weiss, 2004). Multiple forms of therapy have shown to be effective in managing ADHD symptoms and functioning, such as cognitive-behaviour therapy (CBT) (Safren et al., 2017), group psycho-education and organization training (Stevenson et al., 2002), and dialectical behaviour therapy (DBT (Bramham et al., 2009). Similar to children's therapy, evidence needs to be interpreted with caution and a combination of pharmacological and non-pharmacological is often recommended (Tarver et al., 2014).

1.3 The challenge of ADHD in primary care

ADHD is the most frequent referral to Child and Adolescent Mental Health Services (CAMHS – Sayal, Goodman, & Ford, 2006). Yet, the rate of diagnosis in the UK is approximately 1% (Taylor, 2017), widely different from the estimated prevalence. ADHD is underdiagnosed and under-treated in the UK (Prasad et al., 2018; Sayal et al., 2018). Reports suggest that only 0.73% of children and 0.06% of adults currently receive ADHD medication in the UK (McCarthy et al., 2012). Even when patients have received a diagnosis, medication use varies widely across European countries (Bachmann et al., 2017), with medication use in the UK being relatively low. A greater understanding of the reasons behind these discrepancies is required (Wright et al., 2015).

Different factors have been identified concerning the difficulties in accessing care, for example, parents' lack of recognition and lack of help-seeking (Sayal et al., 2006), the complexity of the ADHD care pathway or GPs' lack of recognition (Sayal et al., 2002, 2006; Wright et al., 2015).

Although many factors influence service utilisation, the first port of call tends to be GPs who act as gatekeepers to care in the UK. To receive an ADHD assessment and diagnosis, children are referred to a psychiatrist or paediatrician usually through their GPs (National Institutes of Health Consensus Development Conference Report, 2000). Once a diagnosis has been made, GPs are then often involved in supporting the management of children with ADHD and in liaising with parents and specialists. It is, therefore, primordial that GPs have a comprehensive understanding of ADHD.

1.3.1 ADHD pathway to care

The pathway to care for ADHD is complex and varies widely across countries and regions (Sayal et al., 2018). In the UK, difficulties with accessing care pathways are primarily due to the wide variation of service provisions across localities. Services are different from one area to another, and commissioning priorities for ADHD also vary across the country.

Guidelines on ADHD management, assessment and care have been developed to standardise ADHD care. The NICE guidelines were updated in May 2018 to give an up-to-date account of ADHD management in the UK. European guidelines were also developed to further ADHD understanding and standard care across Europe (Kooij et al., 2019). These guidelines aim to guide healthcare professionals on healthcare standards and clarify the different steps in ADHD care from first identification to management and incorporate a multidisciplinary approach including schools, parents, GPs and other healthcare professionals (such as paediatricians, psychologists etc.). However, the timeframe and process between these different steps are somewhat unclear. The pathway to ADHD care can be summarised in four main steps: recognition, identification and referral, diagnosis and management.

- *Recognition.* Guidance on recognition firstly acknowledges an awareness of the groups of individuals that may have an increased prevalence of ADHD (such as individuals with a first-degree family member with ADHD, individuals known to the criminal justice system etc.). Acknowledging that certain groups (such as girls and adults) are widely under-recognised is also essential.
- *Identification and referral.* Identification and referral guidelines for ADHD discuss many aspects to be considered. While GPs are often responsible for referral to secondary care for diagnosis, referrals may involve other professionals (e.g., school staff) as care pathways vary locally. When identified in primary care, it is vital to determine the severity of the problems, how they impact the young person and their parents, and how they are expressed in different domains and settings. GPs should not make an initial diagnosis or initiate medication. Adults presenting with symptoms of ADHD in primary care should be referred for assessment in secondary care. For adults who have not received a diagnosis in childhood, there should be evidence of typical manifestations of ADHD having begun in childhood, have persisted throughout life and are not explained by other psychiatric diagnoses.
- *Diagnosis.* A diagnosis of ADHD should only be made by a qualified secondary healthcare professional with training and expertise in diagnosing ADHD. It should not be made solely based on rating scales or observational data. Symptoms should meet the diagnostic criteria in DSM-5 or ICD-10, cause at least moderate impairment (social, educational, or psychological) and occur in two or more important settings. Assessment of the person's needs, physical health, coexisting conditions, social, familial and educational, or occupational circumstances is also recommended. ADHD should be considered in all age groups, and symptom criteria should be adjusted for age-appropriate behavioural development.
- *Planning treatment.* Continuity of care for individuals with ADHD is of utmost importance. A comprehensive, holistic shared treatment plan that addresses all

> needs (educational, behavioural, or psychological) should be developed and checked by healthcare providers. Regular discussion on treatment plans should be held, and reassurance that decisions around treatments can be revisited. Before starting any treatment (pharmacological and non-pharmacological) for ADHD, the benefits and drawbacks of treatments and individual preferences and concerns should be discussed. It is also essential to address the importance of adherence to treatment and the benefits of a healthy lifestyle.

While these NICE guidelines aim to inform and influence the different steps in accessing care for ADHD, little is known about how well they are implemented into local clinical practice. Research studies have tried to evaluate the standard practices in clinical care for ADHD with little evidence on how these practices vary locally. A report conducted in Scotland (Healthcare improvement Scotland report, 2012) showed that significant variations between practices were observed. To this date, no published review or report has been conducted in assessing the pathways to care in other areas of the UK.

The main difficulty with published guidelines is the complex implementation in day-to-day practice. As services vary locally and are commissioned differently across the UK, it is difficult to make specific recommendations that fit all localities. For instance, the referral and diagnosis process involves referral to services that may or may not be available in different localities, especially for adult services. Adult services are patchy and poorly commissioned in the UK, with many localities having no secondary care services to refer to at all (Coghill, 2017; Price et al., 2020). In a recent Freedom of Information report conducted across English Clinical Commissioning Groups (CCG), only 35% of CCGs could provide specific information on commissioned ADHD services for those over 18. The average waiting time for adult services was 104 weeks (the longest waiting time was 201 weeks), and only 11 out of 195 CCGs were able to provide a figure for the total amount of budget spent annually on commissioned ADHD services (Takeda, 2019). Primary care professionals also often feel inadequately equipped to manage or recognise adult ADHD (Alder et al., 2009). Matheson et al. (2013) interviewed adults on their experiences of service provision. They found significant challenges in accessing services and a general struggle in securing a diagnosis, reflecting a wide gap between guidelines and current practice. Another review (Ginsberg, Beusterien, Amos, Jousselin, & Asherson, 2014) confirmed a lack of adult services across Europe and highlighted the limited experience and knowledge of healthcare professionals on adult ADHD. These factors create comprehensive difficulties for adults seeking diagnosis and impact young people transitioning from children to adult services. A scoping review (Swift, Sayal, & Hollis, 2014) established many issues with transitional care, including a lack of appropriate adult care services. This review and more recent studies on transitional services

(Janssens et al., 2020; Newlove-Delgado et al., 2018) also establishes that policy and guidelines recommendations are not often implemented into practice. NICE guidelines recommend that continued review of treatment should be shared between services (specialists' services and primary care). However, with a significant lack of adult services and untrained primary care professionals in initiating or changing existing pharmacological treatments (Marcer et al., 2008), this poses an issue on who is then responsible for treatment management.

If services are not available, have long waiting lists or have minimal resources, this also directly impacts the referral or diagnostic process. For instance, it creates longer waiting times to receive access to care. Long waiting times in accessing services and diagnostic delays are often reported once the referral process has been initiated (Fridman et al., 2017; Purper-Ouakil et al., 2007). A European review established that the UK had the longest waiting times, with the mean time from the first GP visit to receiving a diagnosis of 18.3 months (Fridman et al., 2017). Lack of services has also been shown to halt the referral process (Marcer et al., 2008), leaving patients without access to care.

The complexity of ADHD pathways impacts both patients and healthcare professionals. Fridman et al. (2017) demonstrated that many caregivers (35%) reported high levels of difficulty in obtaining an ADHD diagnosis, and over half identified lack of sufficient resources and gaps in support from healthcare providers as primary barriers to accessing care. Similarly, Kovshoff et al. (2012) explored clinicians' perception of ADHD pathways and found that they perceived the assessment and diagnosis decision-making processes to be inherently complex, requiring a great deal of time and experience.

In summary, the pathway to care for ADHD is convoluted in the UK and involves a series of steps from initial recognition to management. Guidelines have been developed to facilitate healthcare professionals' decision-making through this process and ameliorate the quality of care. However, many barriers impact the application of these guidelines into practice, which in turn impact the quality of care received by individuals with ADHD. These barriers reflect the complexity of a multiple-level approach and encompass factors triggered by individuals (e.g., lack of recognition in parents), healthcare professionals (e.g., lack of experience and negative connotations with ADHD) and wider commissioned services (e.g., lack of adult services or resources). These barriers significantly impact both the quality of care for individuals with ADHD and delivery from healthcare professionals.

1.3.2 The role and complexities of primary care in ADHD care

While referrers' eligibility can vary across different service providers and localities, in the majority of cases, GPs act as gatekeepers. After identification, GPs will refer patients on to secondary care services - Paediatric or CAMHS for children or Adult Mental Health Services - where individuals can gain an assessment, diagnosis and access to treatment if required. GPs are also often responsible for handling prescriptions of medication once treatment has been initiated. This process, however, depends on the different service providers and if a shared-care agreement is in place between secondary and primary care services. Therefore, GPs have two primary roles in the ADHD care pathway:

- Identification of ADHD in their patients and referral to specialist services where diagnosis and assessments are conducted.
- Treatment monitoring once it has been initiated in secondary care (if shared-care agreement in place).

GPs are not responsible for diagnosing ADHD and initialising treatment.

The complexity of ADHD in primary care

Many complexities arise from GPs being able to correctly refer and identify ADHD. First and foremost, GPs are under intense pressure with unprecedented workloads (Croxson et al., 2017; Riley et al., 2018) and only have ten-minute consultations to see their patients. It is challenging to identify such a complex disorder in such a short time. As the identification process implies understanding the patient's behaviour in different settings and over a period of time, it often requires more of their time. It is, therefore, a demanding process that cannot be routinely conducted during a standard ten-minute appointment.

Secondly, age and gender discrimination can be observed in the identifications of ADHD in general practice (Bruchmüller et al., 2012; Ramtekkar et al., 2010). One of the aspects of ADHD that is most complex in accessing care is found in adult ADHD. While some studies suggest a significant difference between adults and children with ADHD, little support has been found for theories advocating late-onset ADHD (Sibley et al., 2018). Adults presenting to their GPs might have developed other complex issues (such as depression or anxiety) due to untreated ADHD in childhood, making it very difficult for GPs to unpick (Newcorn et al., 2007). Adult ADHD can also be somewhat controversial; stigmas around ADHD in adulthood are still strongly present (Godfrey et al., 2020), and beliefs over the continuation of the disorder into adulthood mixed (McGough & Barkley, 2004). Unfortunately, these stigmas are also present in GPs (Gavin & McNicholas, 2018; Salt et al., 2005) and will impact access to care for these patients. Similarly, studies have shown that some healthcare providers still believe that ADHD only presents in boys (Gardner et al., 2002; Kwasman et al., 2004). Gender bias is strongly prominent, and girls tend to be identified less than boys (Bruchmüller et al., 2012; Eryılmaz & Üstündağ-Budak, 2019). However, girls tend to show more inattentive traits than boys, who tend to show more hyperactivity traits (Gaub & Carlson, 1997), which makes it more complex to identify in a brief GP consultation.

Finally, in the earliest stages of recognition and identification in the care pathway, a few barriers to individuals accessing care in primary care have been identified. Sayal, Goodman and Ford (2006) highlighted that one of the obstacles in accessing care for ADHD was the limited presentation of these problems to primary care. Parental recognition of issues and perceived burden to healthcare services were the principal associations with lesser contact with services. A study conducted with GPs on the pathways to care in the UK (Sayal et al., 2002) observed that GPs' non-recognition of ADHD significantly impacted individuals' ability to access care. GPs may hold negative feelings towards ADHD and see the ADHD label as a negative diagnostic label (Sayal et al., 2015), and many GPs report low levels of confidence in the recognition and management of ADHD (Salmon & Kirby, 2007). Moreover, Hinshaw et al. (2011) highlighted significant cultural and historical differences between countries and regions in the belief of ADHD as a valid disorder, demonstrating a substantial variance in attitudes and knowledge. Lack of awareness and identification both in GPs and in parents is a significant hurdle in accessing care. While referral to clinical services mostly comes from GPs, it is also widely dependant on parents' awareness and the pressure they place on their GPs.

The risk associated with untreated ADHD, and what do GPs know about ADHD?

GPs hold a gatekeeping role in accessing ADHD care, and their understanding and awareness of the disorder are of utmost importance in facilitating patients' access to a diagnosis and treatment. Issues experienced by people with ADHD in childhood can lead to considerable cognitive and behavioural impairment (Lebowitz, 2016; Moldavsky & Sayal, 2013), impacting social behaviour, schoolwork and family life (Danckaerts et al., 2010; Taylor & Sonuga-Barke, 2009). Most specifically, unmanaged and untreated ADHD results in long-term impairments in many domains (Shaw et al., 2012). In adulthood, these issues are associated with higher criminal behaviour rates, loss of work, addiction, suicidality and failed relationships (Bernfort, Nordfeldt, & Persson, 2008). While evidence-based treatments have been shown to help manage ADHD symptoms (Cortese et al., 2013), untreated ADHD can have substantial economic and social burdens (Vibert, 2018). There is, therefore, a strong need for early detection and diagnosis and gaining timely access to care is of great importance.

Previous research has demonstrated that accessing care can be influenced by the knowledge and attitudes of health professionals (Klasen & Goodman, 2000), with limited GP recognition being a key barrier (Sayal et al., 2015; Sayal et al., 2002; Sayal, Goodman, et al., 2006). In many countries, very few GPs have received formal training on ADHD (Ball, 2001). When asked about their experience of ADHD in clinics, British GPs were not confident in recognising and managing ADHD, with lack of education about the disorder being a key component of their lack of confidence (Salmon and Kirby, 2007). Therefore limited recognition in primary care could be due to the lack of accurate knowledge and understanding of the disorder, scepticism, misconceptions (Angermeyer & Dietrich, 2006; Throckmorton, 2000) and many stigmas still associated with ADHD (Asherson et al., 2012; Bussing et al., 2003).

1.4 Project Methodology

Due to the mixed-methodology used in the current thesis and fitting with the approach of the MRC framework, a pragmatic approach was adopted. This approach encompasses an epistemological position that allows for qualitative and quantitative methods to be commensurable. Primarily focused on the research question, a pragmatic approach adopts a needs-based approach to inquiry (O'Cathain et al., 2007), combining multiple positions within the scope of a single project. This approach recognises that the use of multiple methods has some limitations but can also be complementary. The use of mixed methods facilitated a multiple-angle argument, combining qualitative and quantitative to provide more evidence and different "pictures" of the issue presented in the thesis. A pragmatic approach landed itself well to the population of focus; GPs are a complex and heterogeneous population to work with (with limited times, availability and resources), and it was essential to adopt an approach that best fitted their needs.

The pathway to care for ADHD is complex and involves multiple stakeholders whom each have a crucial role in patients receiving appropriate care. GPs are at the root of this pathway. Without their ability to understand and identify the disorder, it is difficult and often impossible for patients to access other services. As lack of knowledge and understanding seems to be a key barrier in GPs' abilities to identify and manage ADHD, the development and evaluation of a psycho-education tool are proposed. A tailored educational resource can address issues around knowledge, misconceptions and lack of training. Ensuring that this resource is adequate and accessible for GPs is also essential. These doctoral studies propose developing and evaluating a co-produced, tailored psycho-education resource for GPs in understanding ADHD.

1.4.1 Medical Research Council framework

To develop and evaluate this resource, guidance on developing efficient intervention was sought. Multiple sources of guidance have been published on developing complex interventions, and upon looking at the published evidence, this thesis follows a framework conceptualised by the UK Medical Research Council (MRC). This influential framework on developing and evaluating complex interventions provides “guidance on the development, evaluation and implementation of complex interventions to improve health” in randomised control trials (RCT) (Craig et al., 2008). Complex interventions are “built up from a number of components, which may act both independently and interdependently”, such as interventions directed at health professionals’ behaviour (Campbell et al., 2007). Furthermore, the MRC developed a specific framework for developing and evaluating RCTs for complex health interventions (MRC, 2000). RCTs are widely accepted as a reliable and rigorous method to assess the efficacy of complex interventions. The MRC framework proposes four phases:

- Development: Identifying the evidence base and theory. Modelling process and outcomes
- Feasibility/piloting: Testing procedures, estimating recruitment and retention and determining sample size
- Evaluation: Assessing efficacy and cost-efficacy and understanding change processes.
- Implementation: Dissemination, long-term follow-up surveillance and monitoring.

These phases were slightly adapted for RCT methodology and are presented in Figure 1.

1.4.2 Project outline

Following the proposed MRC framework presented above, this thesis assesses the development and feasibility of a complex intervention - a psycho-educational online resource on ADHD for GPs through multiple studies.

The first study (Chapter 2) assessed the theory underpinning the proposal for developing an intervention and included a systematic literature review on the understanding of ADHD in GPs.

Phase 1 - The second study (chapter 3) evaluated the experiences of ADHD in primary care from the perspective of multiple stakeholders through semi-structured interviews.

Phase 2 – A complex co-development process, including extensive peer review and a small usability study (Chapter 4).

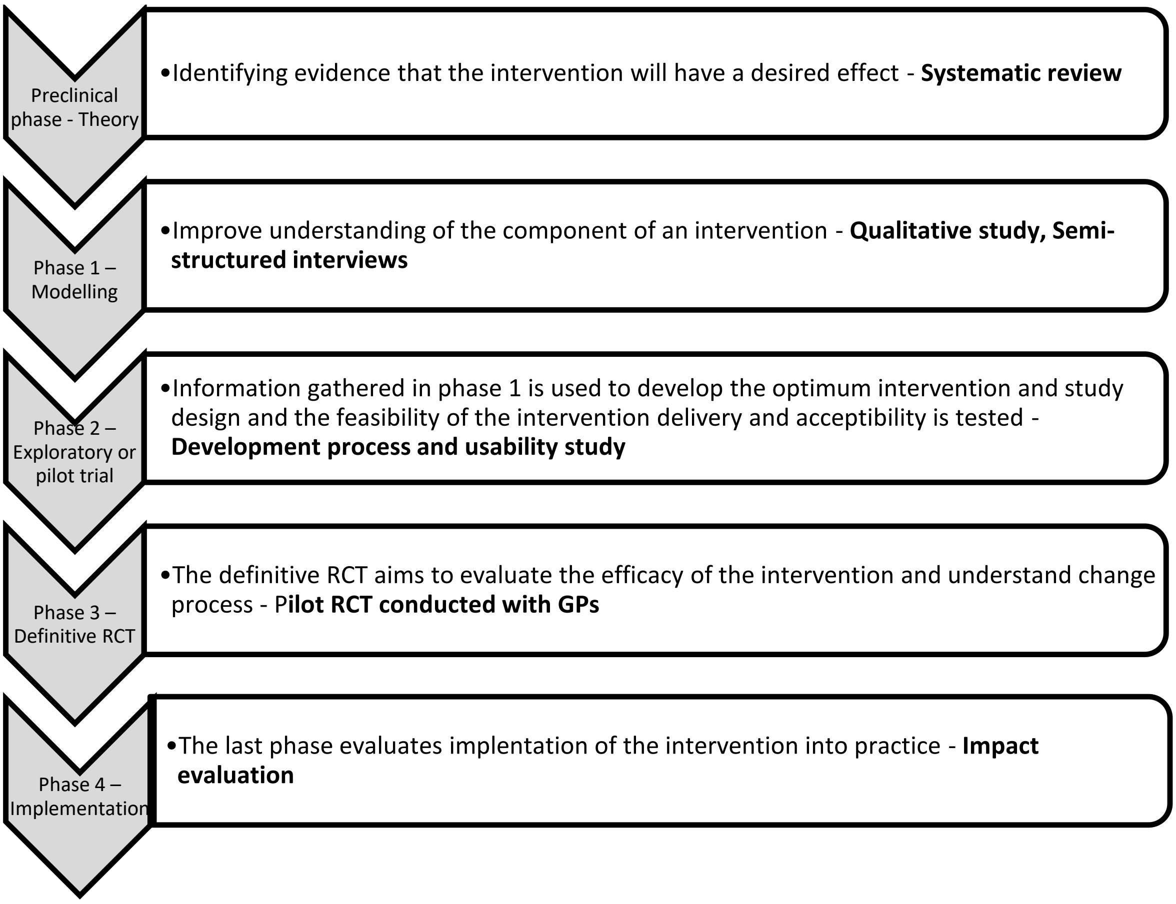
Phase 3 - The RCT (Chapter 5) was conducted with GPs to evaluate the intervention's efficacy.

Phase 4 - Due to the nature and the restricted time limit of the thesis, this phase was not fully implemented; however, a small evaluation of medium-term use and impacts was conducted (Chapter 6).

Figure 1 highlights (in bold) how each study aimed to answer each phase of the development process.

Figure 1

Key Phases of the MRC Framework for Design and Evaluation of Complex Interventions



While this thesis follows this influential MRC framework, it was also important to understand the multiple steps involved in following the development step (phases 1 and 2) of this framework and the practical implications of developing a complex intervention in healthcare. This step is only briefly outlined in the original MRC guidance, and further guidance (Framework of actions for intervention development - O'Cathain et al., 2019) has been published to gain a more comprehensive overview of the specific tasks to be undertaken. These tasks are highlighted in Table 1.

Table 1

Framework of Actions for Intervention Development Based on O'Cathain et al. (2019)

Action	Consider the relevance and importance of the following	Implemented development strategy
Plan the development process	• Identify the problem and refine the understanding of it throughout the process • Assess the problem's priority • Consider aspects that are amenable to change • Determine the time needed • Obtain sufficient resources • Involve stakeholders during the planning process • Produce a detailed protocol	• Conducted a systematic review and interviews • Understand the gaps in why there is a lack of recognition in ADHD and what can be addressed • Keep up to date with other research on the topic • Develop a GANTT chart for four years • Seek further funding for the online platform • GP group to review and take part in workshops • Timeline of tasks
Involve stakeholders, including those who will deliver, use and benefit from the intervention	• Work closely with relevant stakeholders • Develop a plan to integrate PPI • Identify the best way of working with each stakeholder • Use creative activities to work with stakeholders	• Co-production of the intervention with GPs • Inclusion of GPs with ADHD expertise and a GP with ADHD, remotely and in a way that fits them • Storyboarding workshops with groups of GPs
Bring together a team and establish decision-making processes	• Include within the development team individuals with relevant expertise • It may be hard to make final decisions, so dedicate specific team members to make these decisions.	• The development team included academic experts, GPs, patients and other healthcare professionals with ADHD expertise • Specific topics of the programme were reviewed by the most suitable experts.
Review published research evidence	• Review published research evidence before starting to develop the intervention and throughout the development process	• A systematic review was conducted, and continuous updates on new publications on the topic were sought.
Draw on existing theories	• Identify an existing theory or framework of theories to inform the intervention at the start of the process • If relevant, draw on more than one theory or framework	• Following the MRC framework for complex interventions.
Articulate programme theory	• Develop a programme theory • These aspects can be represented by a logic model • Test and refine the programme theory throughout the development process	• Programme theory and logic models were developed • Change from the initial project to the final one occurred throughout the project
Undertake primary data collection	• Use a wide range of research methods throughout	• Qualitative research to understand the context in which the intervention will operate, quantitative to measure changes in intermediate outcomes

Pay attention to future implementation of the intervention in the real world	• Understand facilitators and barriers to reaching the relevant population, future use of the intervention, 'scale up' and sustainability	• Evaluation of the recruitment process for RCT, working with clinical research networks and assessing sustainability and interaction through long-term impact.
Design and refine the intervention	• Generate ideas with stakeholders • Refine and optimise early versions of the prototype using a series of iteration on how acceptable, feasible and engaging the intervention is. Repeat the process until uncertainties are resolved • Check that the proposed mechanisms of action are supported by early testing	• Feedback and reviews were sought from stakeholders at three different time points, and changes were made until we reached an acceptable and usable model. • A usability study and pilot RCT support the efficacy of the proposed mechanisms of action.

1.5 Overall aims

ADHD is underdiagnosed in the UK (Taylor, 2017); this is an important issue as early interventions have been shown to greatly minimise the long-term risks associated with ADHD (Sonuga-Barke et al., 2011). The diagnosis pathway for ADHD is very complex and gives rise to many opportunities where patients can fall through the gaps (long waiting lists, lack of services, miscommunication between services etc.). However, primordially, the care pathway almost always starts with the GPs. GPs are gatekeepers in accessing further services and care, and therefore, any difficulties experienced in primary care will halt progress in successfully gaining a diagnosis and receiving treatment. Previous studies have established that GPs lack knowledge of ADHD, receive very little training and often hold misconceptions about this disorder (Tatlow-Golden et al., 2016; Wright et al., 2015).

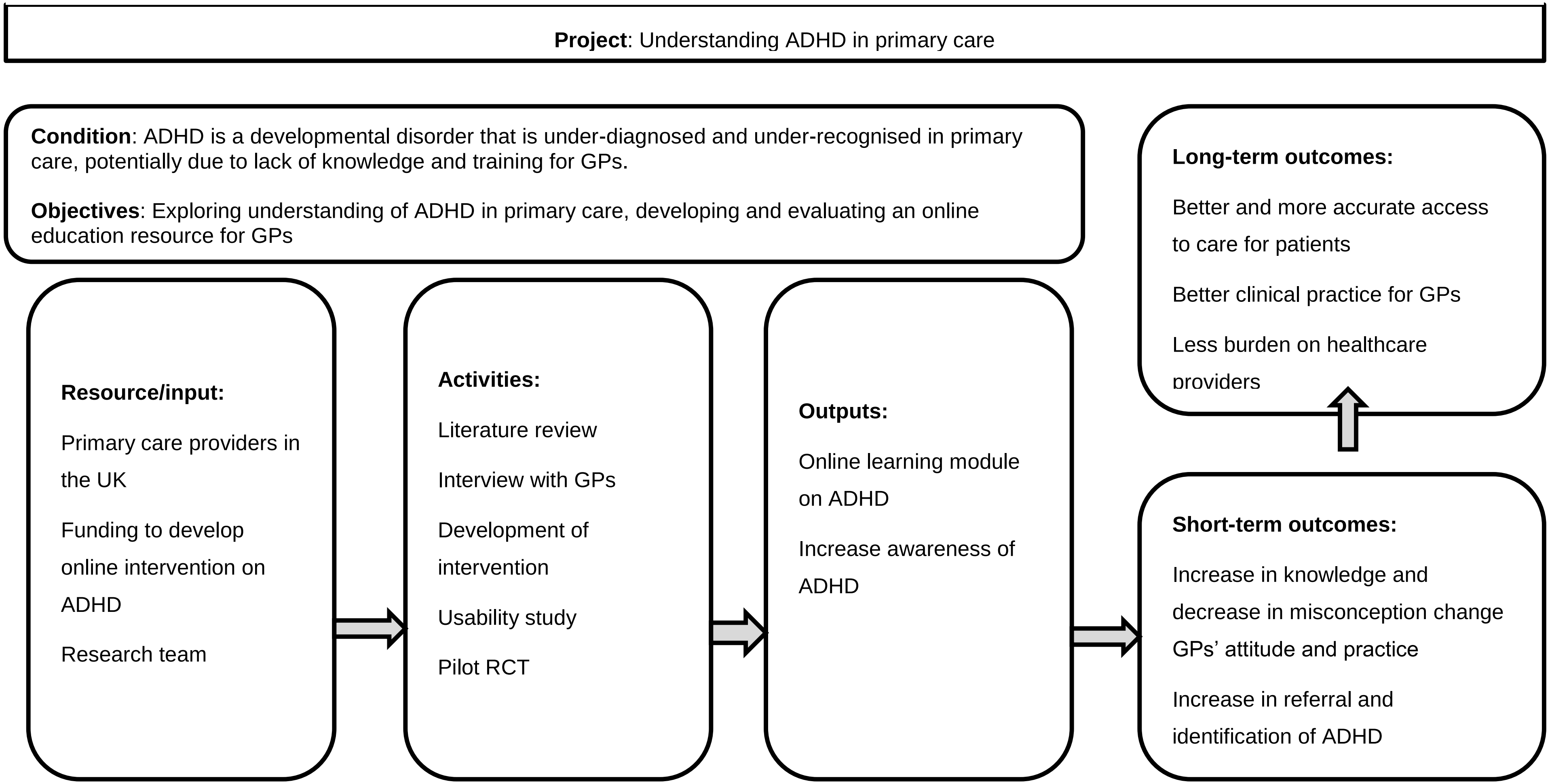
This thesis further explores the understanding of ADHD in primary care. It aims to establish the barriers and gaps in GPs' knowledge of ADHD and develop a tailored psycho-education resource to address these gaps and facilitate GPs' understanding and better practice. This thesis also aims to evaluate the efficiency of this resource in practice. To address these aims, four stages are proposed. Firstly, a systematic review aims to highlight the barriers and facilitators experienced with ADHD in primary care. Secondly, a qualitative study further explores the views of GPs, GP trainees and other stakeholders on ADHD and how it is addressed in primary care settings. Thirdly, upon gaining this understanding, a psycho-education online resource is developed to address training, knowledge and misconceptions. Finally, this resource is evaluated with GPs through a usability study and a pilot RCT to gauge its efficacy in clinical settings. The long-term use and impact of this resource are also explored after 12 months.

Facilitating a greater understanding of ADHD and the role of GPs in the care pathway has many implications for practice. It will first directly impact patients as increased recognition and knowledge should increase access to care, quality of management and long-term quality of life. Families of patients will also be impacted as the burden of caring for undiagnosed or untreated issues will be lessened. Furthermore, this intervention will directly impact GPs as their knowledge and practice could improve. Understanding the source of chronic issues can reduce the overall appointment sought over time, reducing the burden on GPs and GP practices. It will finally impact secondary healthcare professionals as a better understanding from GPs will facilitate their clinical work and better pathways to care.

The logic model below represents the overall project plan (Figure 2).

Figure 2

Project Logic Model



Project: Understanding ADHD in primary care

Condition: ADHD is a developmental disorder that is under-diagnosed and under-recognised in primary care, potentially due to lack of knowledge and training for GPs.

Objectives: Exploring understanding of ADHD in primary care, developing and evaluating an online education resource for GPs

Resource/input:

Primary care providers in the UK

Funding to develop online intervention on ADHD

Research team

Activities:

Literature review

Interview with GPs

Development of intervention

Usability study

Pilot RCT

Outputs:

Online learning module on ADHD

Increase awareness of ADHD

Short-term outcomes:

Increase in knowledge and decrease in misconception change GPs’ attitude and practice

Increase in referral and identification of ADHD

Long-term outcomes:

Better and more accurate access to care for patients

Better clinical practice for GPs

Less burden on healthcare providers

Chapter 2 Systematic literature review of the understanding of ADHD in primary care

2.1 Chapter summary

The process of access to care for ADHD is complex and variable across countries. In general, those impacted or their caregivers will seek help through their primary care practitioners, who are then often responsible for referral to other professionals for diagnosis and provision of treatment. Previous studies have highlighted that many barriers to recognition exist in primary care settings (such as misconceptions, lack of education, or lack of resources), preventing access to care for individuals with ADHD and potentially impacting diagnosis rates. This systematic review establishes the barriers and facilitators relating to attitudes, beliefs and experiences of ADHD within primary care. Electronic searches of multiple databases identified 3898 articles, of which 48 met our inclusion criteria – primary care professionals from any country, understanding, knowledge, awareness, attitude and recognition of ADHD. Four main themes were identified, 1) need for education, 2) misconceptions and stigma, 3) constraints with recognition, management and treatment, 4) multidisciplinary approach. The findings suggest many interacting factors were at play in recognition of ADHD by primary care practitioners with a strong recurring theme of a significant need for better education on ADHD. Implications for research and practice are discussed, suggesting that primary care practitioners' educational interventions could improve the recognition of ADHD in this setting.

2.2 Outputs

- Parts of this chapter were peer-reviewed and published (cited 18 times):

French, B., Sayal, K., & Daley, D. (2019). Barriers and facilitators to the understanding of ADHD in primary care: a mixed-method systematic review. *European child & adolescent psychiatry*, *28*(8), 1037-1064. https://link.springer.com/article/10.1007/s00787-018-1256-3

2.3 Introduction

2.3.1 Rationale

As outlined in the previous chapter, GPs are often gatekeepers in accessing care for individuals with ADHD. However, studies have shown that many factors impact recognition in primary care, such as misconceptions and stigmas about ADHD or lack of training and experience (Adamis et al., 2019; Tatlow-Golden et al., 2016; Wright et al., 2015). Understanding the barriers in GPs' awareness and understanding of ADHD is, therefore, crucial. This systematic review scopes the published literature of barriers and facilitators in understanding ADHD in primary care. A specific definition of what this review considers as primary care is given below, but to facilitate the narrative of this chapter and due to the varied terminologies used across different countries, all terms referring to primary care personnel considered in this chapter such as GPs, family practitioners, family doctors etc. are described as primary care professionals (PCPs).

Many studies have looked at the attitudes of PCPs about ADHD, and two systematic literature reviews have summarised this evidence (Tatlow-Golden et al., 2016; Wright et al., 2015). However, a few restrictions were implemented in these reviews. The first (Tatlow-Golden et al., 2016) looked at attitudes and knowledge of ADHD since 1994 when the Diagnostic and Statistical Manual of Mental Disorders 4th edition (DSM 4) was published, focused only on General Practitioners and only included studies about children. By not including all primary care professionals and focusing on GPs only, this review missed studies published in the US, which do not use the term GPs to refer to primary care professionals. This might have influenced the results as a considerable proportion of ADHD studies are from US research groups (i.e., half of the studies in our review). This review also excluded adults. Considering adults' experience is important as under-diagnosis of ADHD is more prominent in adulthood than childhood (Kooij et al., 2010), with stronger stigmas and misconceptions as many health professionals believe ADHD to be a childhood-only disorder (Asherson et al., 2012). The second review (Wright et al., 2015) looked broadly at the barriers and facilitators in the pathway to care for ADHD. While PCPs' attitudes and knowledge were part of the themes developed from the review, broader determinants were established, such as parental involvement or treatment issues. It did not focus solely on PCPs' understanding, the impact related to primary care being a small component of the review.

2.3.2 Goals of the present review

The systematic review builds on the previously published reviews (Tatlow-Golden et al., 2016; Wright et al., 2015). It enhances the focus on primary care by including all primary health care settings in all countries, adult ADHD studies, all studies from the inception of the databases and establishing facilitators and barriers in access to care for ADHD. It sought to develop a segregated synthesis (Sandelowski et al., 2013) of quantitative and qualitative research to identify and synthesise current barriers and facilitators to the understanding of ADHD in primary healthcare.

2.4 Methods

This review was written following the Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols (PRISMA-P) guidelines (Moher et al., 2015). A protocol for the review was registered with the International Prospective Register of Systematic Reviews (PROSPERO; CRD42017071426) in July 2017.

2.4.1 Inclusion criteria

2.4.1.1 Type of studies

Published and peer-reviewed quantitative and qualitative studies were included. The qualitative component of this review considered qualitative studies of any design exploring ADHD in primary care, including beliefs, understanding, attitudes, and experiences.

The quantitative component of this review included quantitative studies of experimental and observational designs (including but not limited to cohort studies, case-control studies, randomised controlled trials).

Mixed-methods studies were also included; relevant qualitative and quantitative components were extracted separately.

2.4.1.2 Type of Population

This review explored studies in primary care settings. Primary care is defined as the day-to-day healthcare provided in the community for people making an initial approach to clinics for advice or treatment (Van Lerberghe, 2008). Within the context of this review, primary care includes all public services health professionals that act as the first port of call for families and patients seeking medical advice (referred to as PCPs in this review). Therefore, professions such as physicians, family doctors, GPs, paediatricians, nurses and practitioners were considered depending on the country in which the study was conducted. Each study was thoroughly examined to determine - depending on the country of origin - whether the professionals studied were the initial approach healthcare providers. For example, in the UK, PCPs are often referred to as general practitioners, but they might be referred to as paediatricians, family practitioners, or physicians in the US. However, US paediatricians can have primary and secondary care roles, so careful consideration was given to their role in US-based studies. Studies involving private practices were excluded from countries where a public health system was available.

If more than one professional population was studied, primary care findings were extracted and reported separately if the study reported different professional groups separately. Studies from countries where PCPs were not gatekeepers and part of the primary care system were excluded if no reference to primary care settings was given.

2.4.1.3 Type of phenomenon of interest

This review examined the understanding of ADHD in primary care and looked at beliefs, attitudes and knowledge, focusing on barriers and facilitators within these contexts. For this study's purpose, barriers and facilitators were defined as perceived factors that hinder or facilitate the recognition or management of ADHD. As these definitions and concepts varied between studies, this review looked at these concepts broadly in the context of wider aspects of ADHD. This review considered studies focusing on the understanding of ADHD throughout the lifespan and therefore included adult, adolescent and child studies.

2.4.1.4 Context

This review included any primary care settings. It took an international perspective and was not restricted to the English language, including relevant studies of all languages, translation being produced on an ad hoc basis. The review's time period was not limited, and the search strategy covered all publications from database inception up to the 29th of January 2018.

2.4.2 Exclusion criteria

Unpublished studies, literature reviews, case studies, opinion pieces, grey literature and non-peer-reviewed studies were excluded. Studies were also excluded if they did not specify the type of health professionals examined or did not report PCPs' results separately from other groups. Studies focusing solely on ADHD medication and treatment efficacy or evaluation were also excluded.

2.4.3 Search strategy

Databases (PsychInfo, Embase, Scopus, ASSIA, Medline and Google Scholar) were searched from inception to extract published studies. Following the search of the five primary databases and removal of duplicates, an initial search and preliminary analysis were conducted of the subject headings (MeSH) and text words related to ADHD contained in the title and abstract (Appendix 1). PROSPERO was also checked for ongoing or already published systematic reviews on the subject.

The search strategy comprised a combination of keywords (e.g., 'ADHD,' 'Primary care') and controlled vocabulary (e.g., 'doctors,' 'general practitioners'). The search was first performed on the first of May 2017 and updated on the 29th of January 2018. Date and language limits were not imposed. For reproducibility purposes, the search strings can be found in Appendix 1

While hand searching was not a significant component of our planned search strategy, the reference lists of all selected papers that met the inclusion criteria were hand searched to check for additional studies.

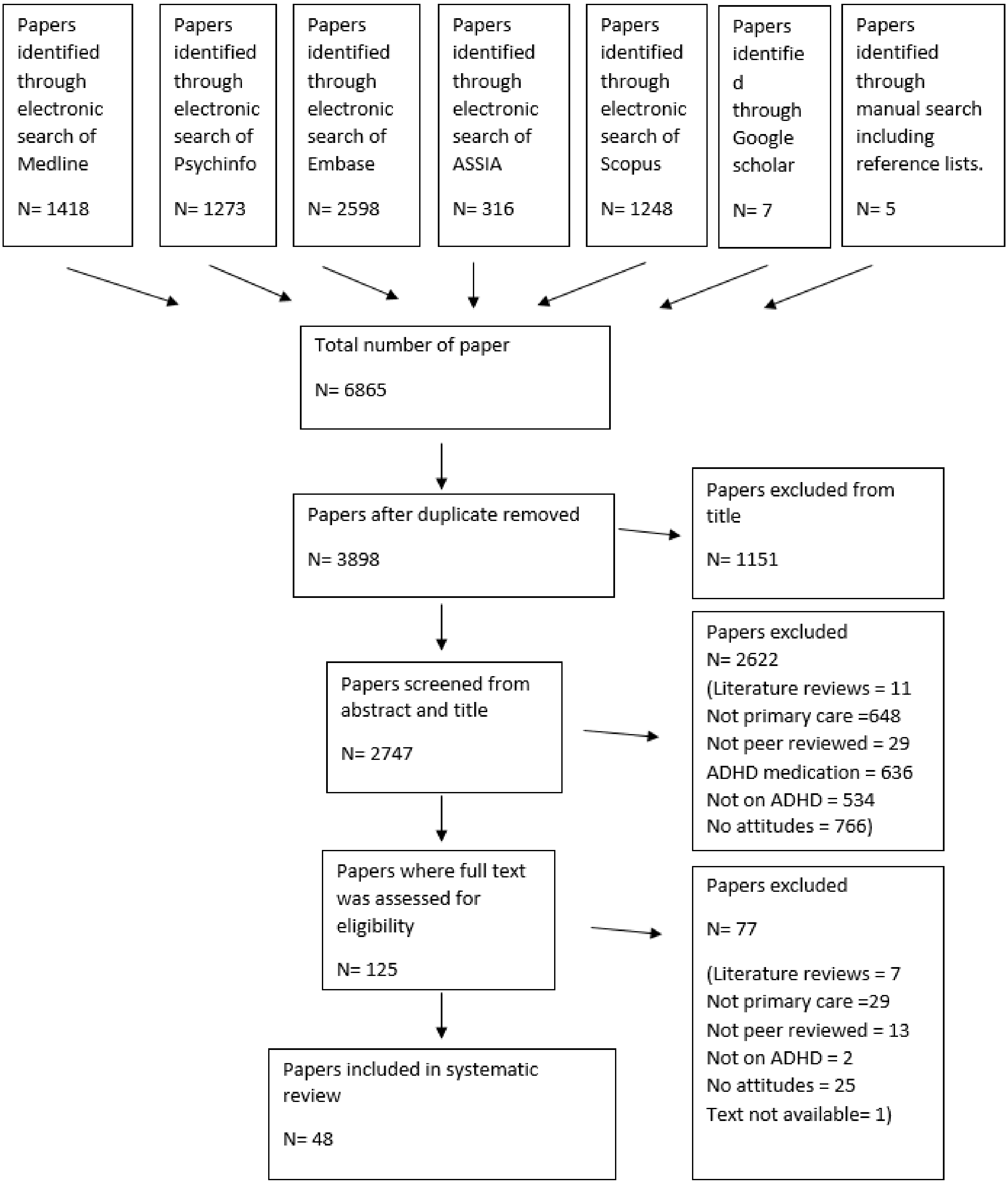
2.4.4 Study selection

Upon completing the search, all identified citations were uploaded into Endnote and duplicates were removed. Two reviewers (BF and DD) screened the titles and then the abstracts against the search inclusion criteria with 100% agreement. Full reports were obtained for all titles that appeared to meet inclusion criteria and imported into a dedicated folder on Endnote.

The same two reviewers screened and assessed the full texts in detail against the inclusion criteria; one full-text article was not available despite multiple inter-library loan requests. Disagreements on selected studies were resolved through discussion without seeking guidance from a third reviewer (KS). Studies that did not meet the inclusion criteria were excluded and presented in the flow diagram below (Figure 3).

Figure 3

Flow Diagram of the Different Selection Processes



2.4.5 Data extraction and outcomes

2.4.5.1 Data extraction

Two reviewers (BF and DD) extracted qualitative and quantitative data from the 48 included studies informed by a standardised data extraction tool for qualitative studies (JBI-QARI - JBI, 2014) and quantitative studies (JBI- MAStARI - JBI, 2014), aiming to answer the review’s primary objectives. For studies reported in a foreign language, French studies were translated by BF, a native French speaker, and translation was sought for other languages. Primary authors of relevant studies were contacted when additional information was needed.

2.4.5.2 Outcomes

The primary outcome was the description and interpretation of PCPs’ understanding of ADHD, including what hinders and facilitates their recognition of the condition. Multiple factors reported in the selected studies were evaluated, such as beliefs, attitudes, knowledge and understanding. These factors were synthesised into themes and were discussed in the context of barriers and facilitators.

2.4.6 Assessment of methodological quality

Following mixed-methods review guidelines (Pearson et al., 2015), the quality assessment process was separated between qualitative and quantitative studies. BF and DD critically appraised all selected studies for methodological quality using standardised quality appraisal tools for qualitative studies and quantitative studies (Kmet et al., 2004). These instruments assessed the quality of evidence across studies, including but not limited to criteria such as sampling strategy, analysis and sample size. Any disagreement between reviewers was resolved through discussion.

2.4.7 Data synthesis

Due to this review's mixed-methods nature, a segregated synthesis was conducted where two distinct analyses involving qualitative and quantitative evidence were made before conducting a mixed-methods synthesis (Pearson et al., 2015).

A meta-synthesis summarised the qualitative findings, informed by JBI-QARI (JBI, 2014). This aggregation or synthesis of findings generated a set of statements representing the aggregation through assembling the findings rated according to their quality and categorising them based on similarity in meaning. These categories were then subjected to a thematic analysis informed by Braun and Clarke (Braun & Clarke, 2006) to produce a single comprehensive set of synthesised findings that can be used as a basis for evidence-based practice. Where textual pooling was not possible, the findings were presented in narrative form.

Quantitative data were synthesised in a comparable manner as statistical pooling was not possible due to high heterogeneity levels within the included studies. The findings were presented in a narrative form, including tables.

The two analyses were aggregated through configuration (Pearson et al., 2015). The results of the syntheses were combined in the form of qualitative themes. The synthesised findings of the qualitative syntheses served as themes and, together with the quantitative syntheses, were summarised in thematic statements by the reviewers, involving the configurative conversion of all numerical results into qualitative thematic statements. These ‘converted’ findings and the qualitative thematic statements were then assembled. The aggregation/configuration of all themes generated a set of statements representing the final aggregation, qualitative and quantitative findings complementing each other.

BF and DD conducted the syntheses in sequential order, one reviewer developing the synthesis and the second checking the findings. Any disagreements were discussed and/or mediated by a third reviewer (KS).

The barriers and facilitators extracted for this review were categorised into four themes:

- Need for education – issues discussing the lack of training on ADHD for PCPs, lack of accurate awareness and a lack of confidence around ADHD
- Misconceptions and stigmas – issues linking ADHD to general stigmatisation and misconceptions and the role of labels and media.
- Constraints with recognition, management and treatment – issues with time constraints and complexity of ADHD and issues with treatment options for ADHD.
- Multidisciplinary approach – issues with the role of different specialists, the school, parents and people with ADHD themselves.

2.5 Results

2.5.1 Study selection

The study selection process is shown in Figure 3 (p.37). Reasons for excluding papers after full-text assessment are provided in

Appendix 2. In total, 48 studies published between 1987 and 2017 met the inclusion criteria, of which six were qualitative, two mixed-methods and 40 quantitative. The quantitative studies were all based on surveys and questionnaires except for one free-listing exercise, while the qualitative studies were based on interviews (n=4), focus groups (n=2); no observational studies were identified. Characteristics of each study and their review themes are given in Table 2 (below).

A range of countries was represented with most of the studies originating from the US (23 studies), UK (eight), Australia (three), Canada (three), Netherlands (two), South Africa (two) and one each from Iran, Brazil, Finland, France, Pakistan, Switzerland and Singapore.

Table 2

Included Studies Characteristics

Reference	Measure	Population of interest and sample size	Quality rating	Synopsis of findings	Themes
QUALITATIVE STUDIES					
Fiks et al. (2011b) US	Semi-structured interviews	30 Paediatricians and 60 parents	High	• Shared decision making (SDM) • GPs think SDM is more about convincing parents to follow their lead. Difficulty in determining how much involvement families should have. • Clinicians reported the importance of the involvement of other stakeholders, psychiatrists, schools in decision making • Half mentioned difficulty communicating with other specialists	Constraints with recognition, management and treatment Multidisciplinary approach
Guevara et al. (2005) US	Focus groups	3-4 focus groups of 19 family physicians	High	• Highlighted breakdown of communication between parents, schools, physicians, not from a lack of will or desire. “System failure”- lack of accountability, discontinuity of care, lack of support, limited knowledge and resources and finger-pointing. • Issues with treatment options available • Limitation in training provided, even with previous knowledge, finding the constant change difficult to keep up with • Lack of support from administration and lack of time to communicate with other schools	Need for education Constraints with recognition, management and treatment Multidisciplinary approach
Hassink-Franke et al. (2016) Netherlands	Interviews	15 GPs	High	• Most GPs did not see a role for them in the diagnosis process • Barriers: Lack of knowledge and experience • Too little time to get all information • Resistance towards prescribing medication • Importance of long-lasting relationships • Felt more confident and competent after an online course on ADHD medication	Need for education Constraints with recognition, management and treatment Multidisciplinary approach
Klasen and Goodman (2000) UK	Semi-structured Interviews on hyperactivity (not ADHD per se)	10 GPs And 37 parents	Moderate	• Parents felt that GPs did not believe hyperactivity was a medical problem; most were unsure about boundaries between normality and abnormality • Parents felt that professionals were against labels, that GPs were often badly informed and that it was a matter of chance whether they received useful help and information • GPs felt that labelling did more harm than good. • Many GPs felt that parents’ views of hyperactivity as a medical problem were an attempt to avoid dealing with shortcomings in their parenting and an effect of dysfunctional families • GPs were not aware of specialist help available in their area and not certain of who to refer to • Parents and GPs felt that information on hyperactivity was often conflicting and ambiguous • GPs also felt they hadn’t had sufficient training in the assessment and treatment of hyperactivity	Need for education Misconceptions and stigmas Constraints with recognition, management and treatment Multidisciplinary approach
Klasen (2000) UK	Semi-structured Interviews on hyperactivity	10 GPs And 37 parents	Moderate	• Only 2 out of 10 GPs had diagnosed children with hyperactivity • Two felt labelling ADHD was not useful • Uneasiness around medication	Need for education Misconceptions and stigmas

					Constraints with recognition, management and treatment
Shaw et al. (2003) Australia	Focus groups	28 GPs in 4 groups	High	• GPs believed the main causal factor of ADHD was increased stress in daily life, contributing to parenting difficulties. The use of labels has led to labelling bad parenting as ADHD • Importance of involvement of specialists • Time, training needs and medication management identified as constraints in ADHD management • Lack of knowledge and training, need for more multidisciplinary support • Negative media representation of medication	Need for education Misconceptions and stigmas Constraints with recognition, management and treatment Multidisciplinary approach
MIXED-METHODS STUDIES					
Leslie et al. (2006) US	Vanderbuilt rating scale. Likert scale Interviews	16 paediatricians	Moderate	• Need for better tools and training to identify discrepancies between parents and teachers' reports • Material accessible for families from different background and in different languages	Constraints with recognition, management and treatment
Salt et al. (2005) UK	Questionnaire survey and Interviews	GPs. 93 surveys and 13 interviews	High	• Mixed results on factors believed to influence ADHD, causes and diagnosis procedures • Some thought quality of parenting was relevant • 75% thought some non ADHD symptoms were ADHD symptoms, despite non-inclusion in DSM criteria • Only 3 GPs in surveys restricted themselves to the three main symptoms • GPs agreed of the strong stigmatisation and controversial nature of ADHD; Importance of the media in attitude towards ADHD • All GPs were uncertain about prevalence rates in the UK • Lack of adequate training on ADHD	Need for education Misconceptions and stigmas Multidisciplinary approach
QUANTITATIVE STUDIES					
Alder et al. (2009) US	Survey on adult ADHD. Likert scale	400 Primary care physicians.	High	• Only 13% reported that they had received good training • 77% believe adult ADHD is not well understood • 72% agree that it is more difficult to diagnose in adulthood than in childhood. • 48% reported a lack of confidence in diagnosing adult ADHD, and 44% believed that there are no clear criteria • 75% reported poor quality of assessment tools, with 85% indicating they would take a more active role if a reliable tool existed	Need for education Constraints with recognition, management and treatment
Ayyash et al. (2013) UK	Delphi methodology from consensus statement to questionnaire. Level of agreement on a scale of 1-4 of 40 statements	122 specialists, of which 6 trainee doctors	Moderate	• Variation in scoring on ADHD consensus between subgroups, trainee doctors had the lowest agreement scores • The variation in scoring across each of the subgroups of respondents may prove useful in understanding the different perspectives offered by each sub-group • Shared cared, integrated pathways between primary and secondary care • Need to raise awareness in primary care regarding ADHD, especially with GPs. Commissioning may be developed collaboratively across multiple GP consortia. Failure to treat ADHD effectively has a significant social and economic impact • Primary care clinicians need to be educated to recognise the diagnostic signs of ADHD	Need for education Multidisciplinary approach

Ball (2001) UK	Questionnaire on attitudes and use of methylphenidate	150 GPs	Moderate	• Only 6% had received formal ADHD training • 28% gained information from articles and 21% from the media • 11% don’t prescribe ADHD medication due to lack of knowledge • Complex views on the role of different professionals • Over 60% felt they would change their view with clearer advice from specialists and clear protocol on monitoring • 80% wanted further training and 88% specifically on medication	Need for education Constraints with recognition, management and treatment
Baverstock et al. (2003) UK	A questionnaire with 11 open-ended questions	45 GPs in university and college settings.	Low	• Transitional care for university students • 39 GPs had not attended any courses on ADHD • GPs commented that it is likely to be underestimated (due to complexity and inaccuracy in the way ADHD is recorded) and that most students with a diagnosis are from the US. Some surgeries said that they had no awareness of university students with ADHD unless students were on medication. • Patients fail to attend follow-up	Need for education Multidisciplinary approach
Chan et al. (2005) US	Survey with 53 Likert scale questions	861 Paediatricians and Family physicians	High	• Variation in time and number of visits to gain evaluation, getting teacher information is difficult • Only 57% use formal criteria to make a diagnosis, of which only 27% used DSM. Most don’t follow AAP guidelines • Increased volume of ADHD evaluation associated with increased use of formal criteria and increased use of teacher/school information • Decreased volume of ADHD evaluation associated with increased likelihood of using laboratory test (lead level, thyroid) and more likely to feel inadequately trained • 36% felt inadequately trained and 66% inadequately trained with comorbid	Need for education Constraints with recognition, management and treatment Multidisciplinary approach
Clements et al. (2008) US	Survey with Likert scale	35 Paediatricians and Family physicians with ADHD patients	Moderate	• 80% used parent and teacher information for diagnosis • 74% reported getting information on ADHD through self-training, 80% on continuing medical education and 45% from medical school	Need for education
Copeland et al. (1987) US	Survey, 21 multiple choice questions	290 Paediatricians	High	• Only 20% based their definition of ADHD on DSM • The majority identified main symptoms; 35% said social difficulties and anger were also symptoms. • 79% said increased activity in GP office contributed to diagnosis and 20% dysmorphic features. • Over 60% used parents and teachers scales	Need for education
Daly et al. (2006) US	Survey of 18 questions	303 Family physicians	High	• 54% were not aware of AAP guidelines • 90% used DSM diagnostic criteria • 77% used lab test (lead, EEG etc.) • Barriers to diagnosis included lack of training and education, time constraints and complexity	Need for education Constraints with recognition, management and treatment
Dryer et al. (2006) Australia	117 items questionnaire, Likert scale	670 medical professionals, of which 82 GPs	High	• GPs thought that behaviour and concentration were characteristics of ADHD as well as low self-esteem and adjustment problems • For causal factors, GPs agreed that it was mainly due to brain function as opposed to home, school or toxins	Need for education

Evink et al. (2008) US	Questionnaire and vignettes	66 Physicians	High	• Comparison between different types of physicians • 55% of family physicians vs 100% of paediatricians use DSM criteria. • 100% will seek specialist input when presented with complicated cases • The main difference in treatment and assessment is in medical speciality • Pressure from parents and schools	Multidisciplinary approach
Fiks et al. (2011a) US	Free listing and interviews of word related to ADHD	30 Paediatricians and 60 parents	High	• ADHD was linked to the words school, impulsive, hyperactive and focus • Clinicians associated help with medication, time (negative), side effect, psychologist and frustration • Talking to families was associated with: time, learning and explaining	Need for education Constraints with recognition, management and treatment
Fuermaier et al. (2012) Netherlands	stigma questionnaire on adult ADHD	228 professionals, of which 74 physicians	High	• This shows that a control group (matched in age, sex and education) and physicians do not differ in the level of stigmatisation towards ADHD • The only subscale where they showed lower stigmatisation is a misuse of medication • Reflect different training and experience and different dimensions of stigmatisation	Need for education Misconceptions and stigmas
Gamma et al. (2017) Switzerland	Survey on ADHD	75 physicians	Moderate	• 44% of presenting cases were diagnosed by PCPs • Difference in diagnosis and management between GP and paediatricians • Only 7% of PCPs felt competent in diagnosing ADHD, lack of competence the primary reason for not diagnosis • GPs felt less competent than paediatricians	Need for education
Gardner et al. (2002) US	Survey on mental health with small elements of ADHD	395 Primary Care Clinicians	High	• Physicians were more likely to find ADHD in boys when presented with boys and girls with similar levels of parent-reported problems • Therefore bias of treatment for different genders	Misconceptions and stigmas
Ghanizadeh and Zarei (2010) Iran	Self-reported questionnaire to assess knowledge and attitude	665 GPs	Moderate	• 20% reported ADHD is not a serious problem, 1/3 believed sugar is a cause • Nearly all reported a higher risk of delinquency; 80% believe it's a risk factor for truancy • Different beliefs on IQ and educational levels • Half believed it's due to dysfunctional families, only 6% believed it can be lifelong • Not sufficient information about ADHD	Need for education Misconceptions and stigmas
Gomes et al. (2007) Brazil	Interviews	2117 professionals, of which 128 general practitioners	High	• 7% of GPs did not know of ADHD even after reading a definition • GPs expressed the least agreement with the statement "ADHD must be treated with medical products." • 5% believed it is not a disease • 19% believed you can live without treatment	Need for education Misconceptions and stigmas Constraints with recognition, management and treatment
Goodman et al. (2012) US	Survey with a clinical vignette on adult ADHD	1924 professionals, of which 1216 Primary Care physicians	High	• 30% reported being not confident in diagnosis, 38% in treatment, 35% in managing adult ADHD • The greatest barrier was limited experience • Reported difficulty distinguishing ADHD from other things • Main barrier: complexity of disorder, stigma, concerns around meds and adherence to therapy • Gaps in communication between specialists • Almost 50% believed ADHD is caused by absent parents or bad parenting	Need for education Misconceptions and stigmas Constraints with recognition, management and treatment Multidisciplinary approach
Heikkinen et al. (2002) Finland	Questionnaire, 16 items, not just about ADHD	499 Physicians	High	• 44% of male and 60% of female physician felt confident in their skills in assessing ADHD	Need for education

Jawaid et al. (2009) Pakistan	Questionnaire	194 Primary Paediatric care providers	High	• Colleagues were reported as the main source of information • Only 13% of GPs and 21% of paediatricians were shown to have sufficient knowledge • 50% showed inadequate knowledge • No training for GPs in ADHD in Pakistan	Need for education
Kwasman et al. (1995) US	A 48 item survey Likert scale	380 Paediatricians	High	• 8% reported being “burned out” by ADHD children • 39% reported barriers in time required • Want more interdisciplinary contact, Only 8% follow-up • Misconceptions about ADHD included poor dieting, the child does it on purpose, medication can cure ADHD and children outgrow ADHD • 44% believe ADHD medication is addictive	Misconceptions and stigmas Constraints with recognition, management and treatment Multidisciplinary approach
Kwasman et al. (2004) US	51 item survey	786 School nurses	High	• 89% attended a presentation on ADHD • Most agree that they tried to get written report from school to physician • Most disagree of integration of communication between school and physician • Most disagreed that physicians did a good job of educating parents and children about ADHD • A higher estimate of boys vs girls	Need for education Misconceptions and stigmas Multidisciplinary approach
Lanham (2006) US	55 item survey	235 Physicians	High	• Only 22% are familiar with guidelines • 70% use child behaviour in GP office to make an official diagnosis	Constraints with recognition, management and treatment
Lian et al. (2003) Singapore	Cohort study on developmental disorders-4 questions on ADHD	48 GPs	Moderate	• 31% agreed that children might show all signs at home but not in school • 25% believed sugar to be the cause • 73% agreed that it improved in adolescence • 85% believe that medication alone is sufficient	Need for education Misconceptions and stigmas
Louw et al. (2009) South Africa	Survey 22 items multiple-choice questions	229 GPs	High	• 57% reported average to good knowledge of ADHD in children. Only 10% in adult • 7% felt they had adequate training in children and 1% in adult • Self-study most prominent education tool, lack of training at university level • Most felt the need to know more about ADHD, in adults 89% and children 81% • Need for appropriate screening tools • Main barriers in management: uninformed parents, limited funds, time and difficult parents	Need for education Constraints with recognition, management and treatment Multidisciplinary approach
Miller et al. (2005) Canada	Questionnaires	405 GPs and FPs	High	• 47% reported low comfort with diagnosis, 52% high • 51% low skill in diagnosis, 48% high • 51% low comfort with management, 48% high • 50% low efficacy in management, 49% high • Comfort skills are a predictor of GPs tendency to take responsibility and are related to previous educational exposure	Need for education
Morley (2010) US	Case studies vignettes with a survey	187 Primary care physicians	High	• Race and insurance status don’t affect diagnosis • Respondent effective at discriminating between ADHD cases or not	
Murray et al. (2006) UK	Questionnaires	40 GPs	Low	• Only 22% were aware of the three diagnosis criteria • Almost half identified the need for more information • Seven thought causes of ADHD were due to family management approaches	Need for education Misconceptions and stigmas

Power et al. (2008) US	Questionnaire, 24 items with a Likert scale.	121 Primary care providers	High	• PCPs believe assessing ADHD is within their scope of practice, as well as prescribing medication • Issues with initiating communication with school professionals • Additional training related to assessment, school collaboration, family education and collaboration with mental health providers	Need for education Multidisciplinary approach
Quiviger and Caci (2014) France	Questionnaire, 23 items	57 Paediatricians	High	• 13 / 49 didn’t know what TDAH (Trouble Déficit de l’Attention / Hyperactivité - ADHD) stood for • 72% responded having insufficient training on ADHD • Education on ADHD is mainly self-taught from articles, colleagues or the internet. • 24% thought it was a disorder constructed abroad and imported to France, 36% thought it was societal, 15% believed it is due to bad parenting • 77% believed mothers worry too much about hyperactivity • 62% based their decision on the child’s behaviour in the practice	Need for education Misconceptions and stigmas Constraints with recognition, management and treatment
Ross et al. (2011) US	38 item Cross-sectional survey	100 Primary care paediatricians	High	• Communication with psychiatrist is low and changeable, would prefer closer collaboration. • 15% reported receiving communication with psychiatrists • Depend on parents to provide information	Multidisciplinary approach
Rushton et al. (2004) US	37 items survey about diagnosis and treatment measures.	723 Paediatricians and Family Physicians	High	• 77% familiar with AAP guidelines and incorporated them in their practice • Laboratory test still conducted by up to 39% (lead, iron) • 20% believe parents are reluctant to accept a diagnosis • 55% believe teachers pressure them to get a diagnosis and 70% to prescribe meds • 43% believed misuse of meds which was associated with less prescription • Most did not believe stigma was a barrier to access to care • Lack of awareness of guidelines, only 44% used DSM criteria	Need for education Constraints with recognition, management and treatment Multidisciplinary approach
Sayal et al. (2002)UK	Questionnaire	16 GPs	High	• GPs were less likely to agree that children could be managed solely with primary care	Multidisciplinary approach
Shaw et al. (2002) Australia	Questionnaires	399 GPs	High	• A majority believed inadequate parenting was influential • Importance of multimodal assessment • Variation in DSM knowledge of features of ADHD, lack of confidence • 17% believed stimulant is an inappropriate treatment • Most GPs were unhappy managing respondents in general practice as it is too difficult and time-consuming	Need for education Misconceptions and stigmas Constraints with recognition, management and treatment Multidisciplinary approach
Stein et al. (2009) US	8-page survey with fixed responses	745 paediatricians	High	• 12% reported they neither treat nor report ADHD • 53% responded that paediatricians should not be responsible for referring ADHD • Continuity of care associated with enquiring and treating ADHD • Debate over whether prevalence in practice and higher level of attendance at lectures/conferences are causes or consequences of inquiring and treating/managing. Once paediatricians are more aware of a problem, it is likely that they will pay more attention to it.	Need for education Multidisciplinary approach
Thomas et al. (2015) US	37 item survey with closed responses	298 professionals, of which 59 physicians and 138 nurses	High	• Only 38% believed ADHD to be a problem • Half of the respondents felt comfortable in their ability to recognize ADHD symptoms, nurses being the least comfortable • Over 85% stated the need for more research in college students and ADHD	Need for education Constraints with recognition, management and treatment Multidisciplinary approach

Venter et al. (2003) South Africa	51 item survey	143 GPs	Moderate	• Problems area identified were: coordination of intervention and liaising with schools • 45% found parents difficult • Management of ADHD could be improved by teacher education, parent education, interdisciplinary contact and improved training of medical professional • The majority believed chaotic home situation and bad parenting were strong influences • 68 and 67% of GP and nurses thought it was difficult to diagnose ADHD in college student	Need for education Misconceptions and stigmas Multidisciplinary approach
Ward et al. (1999) Canada	One-day course. Three-part needs assessment: 42 items survey.	100 family physicians 34 provided data before and after	High	• An educational programme showed a significant difference in ADHD knowledge pre and post-test. And altered management of ADHD • Pre-course, 17% referred for diagnosis with a minimum of history taking, 4% post-course	Need for education
Wasserman et al. (1999) US, Puerto Rico and Canada	Questionnaire	401 Paediatricians	High	• AHP (attentional and hyperactivity problems) rather than ADHD • DSM criteria used in only 38% and school report in only 53%. Lack of standardization in primary care assessment • Children 7-10 years old, twice as likely to be diagnosed as those older with higher scores • No evidence of use of labels by clinicians to children with family or social issues, racial or ethnic status. Gender bias	Misconceptions and stigmas
Williams et al. (2004) US	Interviews on behavioural health diagnosis	47 Paediatricians	High	• High level of comfort in making ADHD diagnosis and prescribing meds • 48% spend time focused on ADHD, information about the cause of the disorder, school modification, organization skills, parenting • Great interest in future training for updates on ADHD, not so much basic information	Need for education
Wolraich et al. (2010) US	Surveys in 1999 and 2005	551 Paediatricians in 2005, 452 in 1999	High	• Increase in use of APA guidelines over the two surveys • More used diagnostic criteria • More used both teacher and parent rating scales • A large proportion in both surveys felt training in treatment and evaluation was inadequate	Need for education

2.5.2 Data methodological quality

Results of study quality are reported in Table 2. Following Kmet, Lee and Cook's guidelines (2004), an original quality score from 0 to 1 was calculated for each study. Scores were then classified from low (0-0.44), moderate (0.45-0.69) and high (0.70-1.00). Study quality was assessed by two reviewers (BF and DD). Agreement between reviewers was 88% overall (92% for quantitative studies, 85% for qualitative studies).

The studies showed some variation in their quality. The average quality score was 0.73, with 36 studies receiving a high-quality rating, ten a moderate rating and two a low rating (quantitative studies mean score of 0.75; qualitative studies mean score of 0.70). The two studies that received a low-quality rating were not used to inform our review results and conclusions.

2.5.3 Data extraction and summary of results

2.5.3.1 Need for education.

The central theme highlighted by this review related to the need for education on ADHD. Thirty seven papers identified issues related to a lack of education on ADHD, representing a wide range of countries, 14 from the US (Alder et al., 2009; Chan, Hopkins, Perrin, Herrerias, & Homer, 2005; Clements, Polaha, Dixon Jr, & Brownlee, 2008; Copeland, Wolraich, Lindgren, Milich, & Woolson, 1987; Daly, Rasmussen, Agerter, & Cha, 2006; Fiks, Gafen, Hughes, Hunter, & Barg, 2011; Goodman, Surman, Scherer, Salinas, & Brown, 2012; Guevara et al., 2005; Kwasman, Tinsley, & Thompson, 2004; Power, Mautone, Manz, Frye, & Blum, 2008; Stein et al., 2009; Thomas, Rostain, Corso, Babcock, & Madhoo, 2015; Williams, Klinepeter, Palmes, Pulley, & Foy, 2004; Wolraich, Bard, Stein, Rushton, & O'Connor, 2010), seven from the UK (Ayyash et al., 2013; Ball, 2001; Baverstock & Finlay, 2003; Klasen, 2000; Klasen & Goodman, 2000; Murray et al., 2006; Salt et al., 2005) , three from Australia (Dryer, Kiernan, & Tyson, 2006; Shaw, Mitchell, Wagner, & Eastwood, 2002; Shaw, Wagner, Eastwood, & Mitchell, 2003), two from the Netherlands (Fuermaier et al., 2012; Hassink-Franke et al., 2016), two from South Africa (Louw et al., 2009; Venter et al., 2003), two from Canada (Miller et al., 2005; Ward et al., 1999) and one each from France (Quiviger & Caci, 2014), Singapore (Lian et al., 2003), Pakistan (Jawaid et al., 2008), Finland (Heikkinen et al., 2002), Brazil (Gomes et al., 2007), Iran (Ghanizadeh & Zarei, 2010) and Switzerland (Gamma et al., 2017). These papers highlighted both a lack of initial training, as well as inadequate training on ADHD. They also highlighted a lack of awareness, experience, understanding and knowledge of ADHD. Most PCPs also reported a lack of confidence about ADHD and in treating ADHD. These factors often hindered general knowledge and understanding of ADHD.

Lack of initial training and inadequate training

Many studies recorded a lack of training on ADHD. This included studies reporting a lack of training at undergraduate and postgraduate medical education level (Alder et al., 2009; Ball, 2001; Baverstock & Finlay, 2003; Klasen & Goodman, 2000; Kwasman et al., 2004; Louw et al., 2009; Quiviger & Caci, 2014), with studies suggesting that only 1% (Louw et al., 2009) to 28% (Quiviger & Caci, 2014) of PCPs receive specific training about ADHD. In a quantitative study from the UK, Ball (2001) found that only 6% of 150 PCPs surveyed received formal training on ADHD and 80% reported wanting further training. This was more prominent for adult ADHD, with two studies reporting a more significant lack of education (Alder et al., 2009; Louw et al., 2009). Even when studies reported training on ADHD, the training was often considered to be inadequate (Chan et al., 2005; Jawaid et al., 2008; Salt et al., 2005), with up to two-thirds of PCPs feeling inadequately trained to evaluate children with ADHD (Chan et al., 2005). While a strong need for training on ADHD was observed, three studies also highlighted the importance of updated training incorporating new knowledge (Guevara et al., 2005; Power et al., 2008; Williams et al., 2004). This lack of education impacted many aspects of patients' primary care experience, from referral and diagnosis (Ayyash et al., 2013; Jawaid et al., 2008) to management of ADHD.

Lack of awareness, experience, understanding and knowledge of ADHD

The need for education was also highlighted through the lack of general awareness, experience, understanding and accurate knowledge of ADHD. While two studies directly reported a lack of knowledge and experience (Goodman et al., 2012; Hassink-Franke et al., 2016) as a barrier to dealing with people with ADHD, eight investigated these concepts through knowledge of the DSM criteria or clinical guidelines (Chan et al., 2005; Copeland et al., 1987; Daly et al., 2006; Evink et al., 2000; Lanham, 2006; Murray et al., 2006; Rushton et al., 2004; Wasserman et al., 1999). Accurate knowledge of guidelines and procedures for identification of ADHD were low, for instance, only 20% (Copeland et al., 1987) - 27% (Chan et al., 2005) of PCPs were using DSM criteria, and only 20% were using official guidelines (Lanham, 2006). One study from the UK (Salt et al., 2005), using a mixed-methods approach, found that 75% of PCPs could not identify ADHD DSM criteria correctly, and all PCPs were unsure of ADHD prevalence and diagnostic procedures. Two studies investigated these concepts through questions on treatments, prevalence, and symptoms, reporting different levels of knowledge and awareness; inaccurate beliefs such as believing that there was no need for treatment (Gomes et al., 2007) or that ADHD was not a medical problem (Klasen & Goodman, 2000) were highlighted. Additionally, very few studies reported that most PCPs in their sample could accurately identify ADHD characteristics. Studies reported that PCPs did not know what the acronym TDHA (ADHD in French) stood for

(Quiviger & Caci, 2014), or that they did not know about ADHD even after reading its definition (Gomes et al., 2007), demonstrating an evident lack of general knowledge about ADHD.

Lack of confidence about ADHD and its treatment

The final aspect relating to the need for education highlighted PCPs' lack of confidence about ADHD, most specifically in treating ADHD. This review and the included studies focus principally on recognition of ADHD, but a few studies also raised a lack of confidence, encompassing treatment and management. In these studies, it is unclear whether the lack of confidence is solely around recognition or all aspects of ADHD management; therefore, it was essential to include this aspect in our findings. While two studies reported a general lack of confidence (Alder et al., 2009; Shaw et al., 2002), three (Gamma et al., 2017; Goodman et al., 2012; Miller et al., 2005) reported low confidence and competence in diagnosis and management of ADHD. Some studies reported a lack of confidence towards treatments, with PCPs reporting being uncomfortable with medication for ADHD. Goodman et al. (2012) reported that 38% of PCPs had no confidence in treating ADHD. Alder et al. (2009) also highlighted a considerable lack of confidence in treating adults with ADHD, and Ball (2001) reported that 11% of PCPs were not willing to prescribe medication at all due to lack of knowledge, while 88% of PCPs wanted further training in the drug treatment of ADHD.

Facilitators

While the need for education underpinned many barriers and issues towards the overall understanding and knowledge of ADHD, a few positive outcomes were observed. In contrast to our overall findings (where a lack of knowledge and confidence was evident), three studies reported above-average ratings of confidence and knowledge of ADHD (Heikkinen et al., 2002; Thomas et al., 2015; Williams et al., 2004). Evink et al.(2000) reported that all paediatricians in their studies used the DSM criteria. These different findings are unclear but could be due to the high number of paediatricians in the studies who might have received specialist paediatric training.

Despite the overall lack of training and awareness of ADHD, studies reported that PCPs had a keen interest in wanting to gain more knowledge (Williams et al., 2004) and sought more information through strategies such as asking colleagues, self-education, online inquiries etc. (Ball, 2001; Ghanizadeh & Zarei, 2010; Louw et al., 2009; Quiviger & Caci, 2014; Stein et al., 2009). Two studies (Hassink-Franke et al., 2016; Ward et al., 1999) explored the benefits of educational programmes for PCPs and reported increased awareness and confidence in ADHD after taking part. The first study (Hassink-Franke et al., 2016) focused on an educational programme for prescription and monitoring of ADHD medication. Ward et al.(1999) evaluated a one-day course that aimed to teach PCPs how to manage ADHD and observed a significant difference between pre-test and post-test knowledge. Furthermore, Wolraich et al. (2010) reported a marked increase in the use of APA guidelines between 1999 and 2005 by PCPs (13% to 50%), suggesting an increased interest and awareness in ADHD.

2.5.3.2 Misconceptions and stigmas

Linking to the previous theme, misconceptions and stigmas surrounding ADHD were often strongly present in the literature. This notion was explored by different studies, either directly reporting the experience of stigma within primary care or reporting inaccurate facts about ADHD. These stigmas included gender biases (‘it only happens in boys’), misleading causes of ADHD (due to high sugar level or lead poisoning) or, most prominently, that ADHD was caused by bad parenting. Seventeen studies discussed elements related to misconceptions, five from the US (Gardner et al., 2002; Goodman et al., 2012; Kwasman et al., 1995, 2004; Wasserman et al., 1999), four from the UK (Klasen, 2000; Klasen & Goodman, 2000; Murray et al., 2006; Salt et al., 2005), two from Australia (Shaw et al., 2002; Shaw et al., 2003), and one each from the Netherlands (Fuermaier et al., 2012), Iran (Ghanizadeh & Zarei, 2010), Brazil (Gomes et al., 2007), Singapore (Lian et al., 2003), France (Quiviger & Caci, 2014) and South Africa (Venter et al., 2003).

General stigmas and misconceptions

Most studies reported general misconceptions about ADHD. In a mixed-methods study in the UK, Salt et al. (2005) reported that over 50% of PCPs agreed on the controversial nature, the strong stigmatisation of ADHD and the disadvantages the diagnosis brought. In a quantitative survey of 380 US PCPs, Kwasman et al. (1995) reported strong misconceptions about ADHD, including ADHD was “caused by poor diet” (21% agreed), “the child does it on purpose” (15%), “medications can cure ADHD” (10%), and “ADHD medications are addictive” (48%). Many studies reported participant views that sugar levels were a cause of ADHD (Ghanizadeh & Zarei, 2010; Kwasman et al., 1995; Lian et al., 2003), while others reported a gender misconception that ADHD was only present in boys (Gardner et al., 2002; Kwasman et al., 2004). Other misconceptions were more surprising. Ghanizadeh and Zarai (2010), for instance, reported that 82% of PCPs, believed children with ADHD misbehaved because they do not want to obey rules and do their assignments, while Quiviger and Caci (2014) stated that 24% of the PCPs surveyed thought ADHD was a disorder constructed abroad and imported into France.

While it could be expected that PCPs should not hold stigmas towards ADHD due to their expected knowledge of the disorder, a quantitative study in the Netherlands (Fuermaier et al., 2012) reported no difference in stigmatisation levels between physicians and a control group of non-medical professionals.

Bad parenting

Ten studies reported that PCPs believed ADHD was due to bad parenting (Ghanizadeh & Zarei, 2010; Goodman et al., 2012; Klasen, 2000; Murray et al., 2006; Salt et al., 2005; Shaw et al., 2002; Shaw et al., 2003; Venter et al., 2003). The numbers varied from 15% (Quiviger & Caci, 2014) to over half (Ghanizadeh & Zarei, 2010; Goodman et al., 2012) of PCPs surveyed believing that dysfunctional families were predominately to blame for ADHD symptom expression. In semi-structured interviews with UK PCPs and parents, Klasen and Goodman (2000) reported that most PCPs saw symptoms of hyperactivity as an effect of dysfunctional families, and many felt that parents' views of hyperactivity as a medical problem were an attempt to avoid dealing with possible shortcomings in their parenting practices.

The role of the media and labels

Four studies linked the presence of misconceptions with negative media coverage and the use of labels. For instance, Klasen and Goodman (2000) reported that parents felt PCPs were against labels, trying to normalise hyperactive behaviours, while Klasen (2000) reported that 25% of PCPs felt labelling was not helpful. Salt et al. (2005) highlighted, through a targeted questionnaire, the media's influence on the general public's conception of ADHD. In contrast, Shaw et al. (2003) argued that negative media coverage and labels impacted medication representation and had led to labelling bad parenting as ADHD.

Facilitators

Although very few facilitators can be observed within this theme, it is important to note that misconceptions and stigmas were only explored in a third of the included studies. This suggests that stigmas about ADHD did not emerge from studies as much as might have been anticipated. Studies identifying stigmas reported misconceptions from a wide variety of different countries and cultures, suggesting that stigmas surrounding ADHD were not specifically culturally determined.

2.5.3.3 Internal and resource constraints with recognition, management and treatment

As PCPs are often responsible for recognizing and managing ADHD, a few barriers were observed surrounding these procedures. The first considered the barriers experienced around recognition, referral and diagnosis of ADHD, mainly referring to resource constraints such as time and the need for appropriate screening tools. Concerning treatment options, the main barriers observed included the limited treatment options available and uneasiness around medications. Twenty studies discussed aspects related to recognition and treatment, with 11 studies from the US (Alder et al., 2009; Chan et al., 2005; Daly et al., 2006; Fiks et al., 2011; Fiks, Hughes, Gafen, Guevara, & Barg, 2011; Goodman et al., 2012; Guevara et al., 2005; Kwasman et al., 1995; Leslie, Stallone, Weckerly, McDaniel, & Monn, 2006; Rushton et al., 2004; Thomas et al., 2015), three from the UK (Ayyash et al., 2013; Klasen, 2000; Klasen & Goodman, 2000), two from Australia (Shaw et al., 2002; Shaw et al., 2003) and one each from Brazil (Gomes et al., 2007), the Netherlands (Hassink-Franke et al., 2016), France (Quiviger & Caci, 2014) and South Africa (Louw et al., 2009).

Time constraint and complexity of ADHD

The resource constraint mainly experienced in the recognition and management of ADHD was related to time and the complexity of ADHD. Many studies found that the time necessary to gain all the relevant information was often too demanding (Chan et al., 2005; Daly et al., 2006; Fiks et al., 2011; Hassink-Franke et al., 2016; Kwasman et al., 1995; Louw et al., 2009; Shaw et al., 2002; Shaw et al., 2003) especially taking into consideration the complex nature of ADHD (Daly et al., 2006; Goodman et al., 2012; Thomas et al., 2015). After interviewing 19 PCPs in focus groups in the US, Guevara et al. (2005) reported that limited resources and lack of time to communicate with schools led to limited access to care, while Klasen and Goodman (2000) found in their interviews in the UK that information necessary for management and recognition was often conflicting and ambiguous. Five other studies mentioned the need for better assessment tools (Fiks et al., 2011; Klasen & Goodman, 2000; Leslie et al., 2006; Venter et al., 2003), especially for adults (Alder et al., 2009). Finally, one other barrier experienced was that PCPs make decisions on assessment for referral based on the child’s behaviour in their office (Copeland et al., 1987; Lanham, 2006; Quiviger & Caci, 2014), leading to potential misdiagnosis as the child might behave very differently at home or school (Leslie et al., 2006).

Treatment

Numerous issues were also highlighted around treatment; the lack of available treatment options and uneasiness around medication. While studies reported a general unease with ADHD medication (Goodman et al., 2012; Kwasman et al., 2004; Shaw et al., 2003; Thomas et al., 2015), this at times led to resistance or refusal to grant prescriptions by PCPs (Ball, 2001; Hassink-Franke et al., 2016; Rushton et al., 2004). In a series of interviews with 128 PCPs, Gomes et al. (2007) reported high levels of uneasiness around medication, limited knowledge of treatment options, and a lack of knowledge of the pros and cons of medication and other treatments. This reflected other findings describing confusion around treatment options concerning professionals' knowledge of what is available and limited availability of treatment (Fiks et al., 2011; Goodman et al., 2012; Klasen & Goodman, 2000).

Facilitators

Despite the constraints explored in these studies, attempts to address these issues were reported in only two studies. After participating in a one-hour educational online course on ADHD medication, Hassink-Franke et al. (2016) found that most PCPs felt more confident and competent about prescribing and monitoring medication. As this was a qualitative study, information was not available on any change in confidence in the participating PCPs. Ward et al. (1999) evaluated a one-day course that aimed to help PCP manage ADHD. Results demonstrated some impact on practice in the form of increased levels of ADHD referrals. However, the study was based on only 34 clinicians, was not controlled and did not verify the appropriateness of referrals.

2.5.3.4 Multidisciplinary approach: the role of other specialists, teachers, parents and patients

The final theme encompassed the concepts of a multidisciplinary approach. This mainly referred to the role of different specialists and the importance of shared care, but it also included the role of other parties involved, such as patients with ADHD, parents and teachers. Twenty-two studies explored issues pertaining to a multidisciplinary approach, twelve from the US (Chan et al., 2005; Evink et al., 2000; Fiks et al., 2011; Goodman et al., 2012; Guevara et al., 2005; Kwasman et al., 1995, 2004; Power et al., 2008; Ross et al., 2011; Rushton et al., 2004; Stein et al., 2009; Thomas et al., 2015), five from the UK (Ayyash et al., 2013; Bussing et al., 2003; Klasen & Goodman, 2000; Sayal et al., 2002; Wolraich et al., 2010), two from Australia (Shaw et al., 2002; Shaw et al., 2003), two from South Africa (Louw et al., 2009; Venter et al., 2003) and one from the Netherlands (Hassink-Franke et al., 2016).

The role of specialists and the importance of shared care

When discussing the concept of a multidisciplinary approach, many studies explored the communication between specialists, principally between primary and secondary care. With the belief that integrated care pathways and a collaborative approach were essential (Ayyash et al., 2013; Evink et al., 2000; Sayal et al., 2002; Stein et al., 2009), issues with communication between specialists was expressed as a significant barrier (Goodman et al., 2012; Kwasman et al., 1995; Power et al., 2008; Shaw et al., 2002; Shaw et al., 2003). In semi-structured interviews in the US (Fiks et al., 2011), PCPs reported the importance of involving other stakeholders, psychiatrists, and schools in decision-making. Over half of the professionals interviewed mentioned difficulties in communicating with other specialists. Furthermore, Ross et al. (2011) reported that only 15% of PCPs surveyed received communication from psychiatrists. Guevara et al. (2007) found similar issues with communication and a need for shared care. However, this paper acknowledged the breakdown of communication between parents, schools and physicians but not from a lack of will or desire, rather as a ‘System failure’- lack of accountability, discontinuity of care, lack of support, limited resources and finger-pointing.

Ambiguity about the role of different professionals (Hassink-Franke et al., 2016; Salt et al., 2005; Stein et al., 2009; Thomas et al., 2015) was also noted as a barrier to access to care. Klasen and Goodman (2000) highlighted that most PCPs were not aware of specialist help available in their area and were unsure of whom to refer to.

The role of the school, parents and patients

Communication with other parties such as schools, parents, and people with ADHD was also a barrier. For instance, four studies mentioned that patients failing to turn up for appointments limited the PCPs’ ability to assess them and provide appropriate care (Ayyash et al., 2013; Baverstock & Finlay, 2003; Goodman et al., 2012; Kwasman et al., 1995). Other studies found that PCPs experienced considerable difficulties in getting information from parents and schools (Chan et al., 2005; Power et al., 2008; Ross et al., 2011) as well as reporting feeling continued pressure for diagnosis from schools and parents (Evink et al., 2000; Louw et al., 2009; Venter et al., 2003). In a US survey of 723 PCPs, Rushton et al. (2004) found that 55% felt intense pressure from teachers to diagnose ADHD, while 70% felt pressure to prescribe medication. Kwasman et al. (2004) reported that their large sample of school nurses expressed a lack of multidisciplinary communication between PCPs and school staff and suggested that PCPs and schools would benefit from a greater understanding of the contribution that each could make for an effective ADHD assessment.

Facilitators

An integrated pathway between primary care and secondary care may provide the optional solution for ADHD assessment. Hassink-Franke et al. (2016), in their study of Dutch PCPs, highlighted that greater support and more constructive long-term relationships with secondary care enhanced PCPs confidence about ADHD. More significant support for Dutch PCPs also allowed families to received care from PCPs with whom they had a long-lasting relationship and allowed care to be provided in a more informal primary care context rather than more formal secondary care.

2.6 Discussion and conclusion

This review concurs with previous reviews' findings (Tatlow-Golden et al., 2016; Wright et al., 2015). By adding a larger body of literature, two new themes (internal and resource constraints and multidisciplinary approach) were explored. This review found that many barriers, such as lack of education, time and resource constraints, misconceptions and integrated pathways prevent PCPs from effectively supporting ADHD patients. By identifying these factors impacting access to care, this review establishes multiple areas of needs, enabling recommendations to facilitate PCPs' ability in identifying and managing ADHD.

Overall, the need for education was the most highly endorsed factor, with PCPs reporting a general lack of education on ADHD. The need for education was observed worldwide; this factor was discussed in over 75% of our studies in 12 different countries, suggesting that lack of education and inadequate education were the main barriers to understanding ADHD in primary care. While this review reported both barriers and facilitators, barriers were mainly identified with very few facilitators. Overall, PCPs held a keen interest in gaining knowledge of ADHD, and educational programmes helped increase this knowledge. Studies investigating the presence of shared care and integrated pathways reflect it to be the optimal solution. In conclusion, the leading facilitator encompassing all themes in this review highlights the importance of providing any form of resources that would help PCPs facilitate access to care for individuals with ADHD.

However, resource constraints overall were a critical barrier. While this factor was discussed as a separate theme, it also encompasses several other themes. Indeed, time and financial constraints impact the opportunities for PCPs to seek extra training and education and impact communication with other professionals such as secondary care professionals, teachers and parents. This highlights further the difficulties faced daily by PCPs in recognising and managing patients with ADHD.

Strength and limitations

This review included different methodologies, qualitative, mixed-methods and quantitative studies. Following the methods presented in our analyses, studies were considered separately (according to their methodology) at the analysis stage. Different methodologies were expected to highlight different findings, adding extra information to the other; however, this was not the case. The different methodologies complemented each other and highlighted similar factors in understanding access to care for people with ADHD.

This review included a broad sample of studies from a worldwide perspective. Similar barriers were identified internationally, highlighting that these factors may not be culture dependant and appear to be widely generalisable. However, most studies were based in developed, western countries, and more research in this area from developing countries in Africa, Asia and South America may allow subtler differences to emerge.

In many countries, pathways to care for adults and children were very distinct; therefore, divergent findings within adult and child studies might have been expected. However, no distinction was observed, with similar factors impacting both children and adults alike, determining that the barriers discussed in this review were relevant to different age groups and systems to care.

This review focused primarily on PCPs' understanding and knowledge of ADHD by including studies on PCPs. A small but significant number of studies also included views from other parties such as parents and other professionals. It was interesting to notice that their views were in agreement with the findings generally observed and were not conflicting, adding validity to our overall observations.

By including different methodologies from multiple languages and following a strict systematic approach with clear transparency of the review process (including quality assessment, numerous reviewers and thorough data extraction method), this review included all relevant published studies on the subject and minimised the risk of biases.

However, a few limitations can be observed in this review. There was considerable variability in the quality of the included studies. Studies also varied considerably in the extent to which they contributed to the review, with some studies bearing more weight on our observations.

Barriers and facilitators were initially defined for this review to identify them as accurately as possible. However, most studies did not explicitly mention the terms ‘barriers’ and ‘facilitators,’ and therefore, these concepts were subject to our interpretations.

Only a small proportion of studies included in this review were published within the last decade (11/48 studies since 2010). Thus, it is possible that while these findings were more relevant a decade or so ago, they might not be as significant if focused only on recent studies. While unlikely, possible reasons for fewer recent studies in this area might be that these issues were no longer as salient or that fewer studies were required as existing findings were still felt to be relevant. Further research is needed in this critical area.

Studies adopted different methodological approaches, including six qualitative and two mixed-methods studies. While a direct comparison between different methodological approaches brings some limitations, most of this review’s findings were supported by both quantitative and qualitative studies, with the exception of the role of the media, which was only highlighted by qualitative studies.

It is important to note that the sample selected by these studies was selective. It has been observed that some PCPs do not believe in ADHD (Saul, 2014). Therefore, it could be assumed that participating PCPs who have some openness or strong views about ADHD would not take part. PCPs having strong beliefs about the existence (or not) of ADHD might not have been willing to partake in these studies, and therefore, their representation will be lacking from our findings. Finally, as this was a systematic narrative review rather than a meta-analysis, it was impossible to explore publication bias and its impact on the study conclusions.

Implication for practice

The potential barriers faced with knowledge of ADHD in primary care may lead to under-diagnosis or misdiagnosis, delays in being referred and lack of access to the right support (Sayal et al., 2002). Highlighting knowledge gaps can inform future research, targeted interventions, or psycho-education programmes for established PCPs and professionals in training. Increasing accurate knowledge of ADHD within this chosen population could improve recognition rates, benefiting patients and healthcare professionals alike. Improvement in diagnosis could subsequently follow, either by more timely referral to secondary care services responsible for diagnosis (for instance, in the UK population) or by quicker diagnosis in settings where PCPs can make a diagnosis (for instance, in the US population). Therefore, better training of PCPs on ADHD is necessary, but dedicated time and resources towards education need to be put in place by service providers and local authorities. While the development of educational programmes for PCPs seems to be the most characterised need, this issue requires further exploration and investigation as only two studies investigating the benefits of an interventional programme on PCPs (Hassink-Franke et al., 2016; Ward et al., 1999) were identified in this review, both with limited generalisability.

Implications for research

Although the need to develop educational programmes was strongly present, before instituting such programmes in primary care settings, research on relevant and appropriate methods needs to be conducted. Developing the right intervention is essential as PCPs have minimal time, and a lengthy full-day workshop, for instance, would not be easily accessible or provided for this population. Future research will also need to address resource constraints, misconceptions, and multidisciplinary approaches to overcome more specific challenges. These findings can then be used to develop more targeted strategies in enhancing access to care for ADHD.

While most studies in this review were quantitative, mixed-methods studies could be more beneficial in investigating these factors. Quantifying the effect of such factors on access to care is essential but gaining an insight into the experience and attitudes of PCPs adds valuable knowledge on their individual beliefs, awareness and experiences that would be difficult to access through quantitative methods. In the context of this review, for instance, the link made between misconceptions and the role of the media and label was only made through the use of qualitative enquiries; quantitative methods might not have allowed this theme to emerge.

It is important to note that while this review focuses on primary care, our findings and previous studies (Wright et al., 2015) suggest that training teachers and parents could also be strongly beneficial in the process of continuing access to care for ADHD.

Many barriers impacting PCPs' awareness of ADHD were identified in this review. Principally, PCPs' lack of experience and knowledge is the main factor influencing their awareness and understanding of ADHD. This issue can be addressed by providing training and up-to-date information on ADHD. Educational programmes could increase PCPs' awareness and understanding of ADHD and address some other barriers identified in this review, such as PCPs' misconceptions and stigmas on ADHD.

Chapter 3 Qualitative studies

3.1 Chapter summary

The qualitative element of this thesis was an essential component in the development of the research. By further exploring the experiences of ADHD in primary care, a deeper understanding of the gaps in ADHD awareness was evaluated. This understanding, in turn, aimed to inform the content of the intervention, making for a more targeted and specific approach. These qualitative studies consisted of two parts: a pilot study with analysis conducted on pre-collected data investigating GP trainees' understanding of ADHD and semi-structured interviews conducted with multiple stakeholders.

In order to start the ADHD care pathway, GPs will generally refer to secondary care services where individuals receive an assessment, and if appropriate, diagnosis and access to care. It is, therefore, essential that GPs have a clear understanding of the disorder and its care pathways. While previous studies have highlighted potential barriers to GPs' ADHD awareness, this qualitative study further explores individual stakeholders' primary care experiences. This qualitative study had two parts. Firstly, a pilot study analysis was conducted on pre-collected data investigating GP trainees' understanding of ADHD. Semi-structured interviews explored the views of eleven GP trainees. Secondly, semi-structured interviews were conducted and explored the perspectives of multiple stakeholders, healthcare specialists (n=5), GPs (n=5) and patients (adults n=5, parents n=5) with experience in diagnosis and treatment of ADHD in primary care. All interviews were transcribed and analysed using thematic analyses and following principles of grounded theory. Stakeholders described ADHD assessment, diagnosis and treatment as an intricate process. Many factors impacted this process, such as complex pathways, lack of services, limited GPs' recognition and knowledge, and challenging communication between multiple stakeholders. Highlighting the significant impacts of receiving (or not) a diagnosis, this analysis explored the muddled ADHD pathways in more depth, with a substantial lack of GPs' identification and a shortage of adult services. Implications for practice and future research are discussed, suggesting a strong need for more commissioned pathways and GP-specific educational programmes.

3.2 Outputs

This chapter produced a few open access outputs

- Parts of this chapter were peer-reviewed and published (cited three times):

French, B., Vallejos, E. P., Sayal, K., & Daley, D. (2020). Awareness of ADHD in primary care: stakeholder perspectives. *BMC family practice*, *21*(1), 1-13.

https://rdcu.be/b2kaY

- A Video abstract was also produced for this publication (viewed 236 times):

https://youtu.be/Or3p2z77HFc

3.3 Introduction

While GPs play a gate-keeping role in the ADHD pathway to care, their limited recognition of ADHD is a key barrier in accessing diagnosis and treatment (Sayal et al., 2015). The systematic review presented in Chapter 2 examined some of the obstacles related to GPs understanding and recognition of ADHD and highlighted four main issues: 1) need for education (lack of training and knowledge), 2) lack of resources (time and financial), 3) presence of misconceptions and 4) need for a multidisciplinary approach. These issues present a challenge to GPs' recognition of ADHD and, consequently, impact their willingness and ability to refer for an assessment and diagnosis.

Qualitative interviews with healthcare practitioners have helped highlight specific issues experienced in ADHD referral, such as viewing the diagnosis process as inherently complex (Bhugra et al., 2011) and requiring time and experience (Kovshoff et al., 2012). Understanding stakeholders' experiences through individual interviews from multiple perspectives will facilitate a better understanding of individuals' experiences and difficulties within primary care. This qualitative study further explores the experience of GPs with referrals and the management of ADHD. To gain this deeper insight, a pilot study was first conducted with GP trainees. GP trainees are an important group as they have limited experience in dealing directly with patients within primary care, and their knowledge results mainly from training and clinical placements. GP trainees might also be more flexible in their attitudes and beliefs as these have not been informed by years of experience. To further our understanding, semi-structured interviews were then conducted with GPs and other stakeholders directly involved with GPs and ADHD diagnosis - parents of children with ADHD, adults with ADHD and secondary care workers dealing with ADHD diagnosis.

This qualitative chapter reflects two sets of interviews. Firstly, a pilot study was conducted using interviews with GP trainees. The interviews were not conducted by the lead researcher (BF) but by a medical student of KS in 2013. These interviews explored ADHD awareness in GP trainees and were not analysed or transcribed. Therefore, it was proposed to use these data to gain a more in-depth and slightly different perspective on the topic, lending itself perfectly as a pilot analysis to this study. The second analysis was conducted with GPs, patients and secondary care professionals and further investigated their experiences of recognition, diagnosis and treatment of ADHD in primary care.

3.4 Grounded theory

Both studies followed a grounded theory approach. Established by Glaser and Strauss (1967), grounded theory is a "systematic methodology that involves the construction of theories through the analysis of data" (Corbin & Strauss, 2008). Following clear guidelines, this inductive approach begins with collecting qualitative data and is followed by identifying themes or categories through a coding procedure (Chamberlain, 2004). These categories are developed on an ongoing process throughout the research, and the overall process of data collection and analysis is continuously re-evaluated. The core themes developed from this process then provide a new theory structure (Corbin & Strauss, 2008).

Grounded theory operates with the concept that knowledge is constructed. A key method in psychological research, grounded theory has no preconceived hypothesis with a continual comparative analysis of data, allowing theories to emerge inductively from it (Hydén & Bülow, 2003).

Grounded theory is a pertinent methodological approach in understanding new phenomena, providing more straightforward explanations to otherwise complex events. As data collection and analysis are integrated, findings and methods are redefined continuously, not set by preconceptions and theories; interviewers being active and reflective in the integral process. Interviewers also have to be open-minded, taking in different standpoints.

A few aspects of this methodological approach may, however, raise concerns. The principles of data collection recommend continuing until theoretical saturation (Willig, 2013). However, this concept is difficult to define and a challenging goal to reach as there are no ground rules on when saturation happens. Another difficulty may emerge by having no preconception on the data or the results before starting the study; a concept challenging to adhere to at the start but also throughout the experimental process (Thomas & James, 2006).

The ontological aspect of grounded theory suggests that individuals' knowledge, understanding, beliefs and interactions are meaningful properties of what is reality (Willig, 2013). Their perceptions are of utmost importance, and the methods of interviews and focus groups firmly adhere to these beliefs, with data collection at the source.

3.5 Pilot - Interviews with GP trainees

These interviews explore GP trainees' beliefs about ADHD. As GPs hold such an important role in access to care for ADHD, it was essential to explore general awareness of ADHD during their mandatory post-graduate medical training. GPs have knowledge and experience in dealing with hundreds of patients and are more likely to have come across ADHD than GP trainees. However, GP trainees are an important group as they have limited experience in dealing directly with patients and their knowledge results mainly from training and clinical placements.GP trainees can also be more flexible in their attitudes and beliefs as they have not been informed by years of experience.

3.5.1 Methods

3.5.1.1 Study design

Semi-structured interviews were conducted in 2013 as part of a clinical research study by a medical trainee. Due to unforeseen circumstances, the researcher who conducted these interviews was unable to analyse the findings. As this project was strongly linked to this thesis's research, it was agreed that the data would be transcribed and analysed by BF as a pilot study for the purpose of this chapter. The original study included interviews with eleven GP trainees and was approved by Nottingham University Hospital NHS trust R&D. The interviews explored the understanding of ADHD in primary care among GP trainees. The analytic strategy was based on thematic analysis (Braun & Clarke, 2006) in a “bottom-up” or inductive manner.

3.5.1.2 Participants

The eleven participants were selected as they had completed a comprehensive part of their medical training and had experienced working in GP practices, which allowed them to have had some contact with patients. Unfortunately, no further information was available about the participants as the researcher conducting the interviews wasn’t able to disclose the participants' demographics or other details on the recruitment process. Several attempts were made to contact the original researcher, but these attempts were unsuccessful.

3.5.1.3 Data collection and analyses

The interviews were conducted in autumn 2013. After the participants were familiar with the information sheet and written consent was obtained, the interviews took place in a public café or over the phone, depending on the participants’ preference. The semi-structured interviews were based on an interview schedule devised to elicit information about the participants’ understanding and experience of ADHD from their professional standpoint. The interview schedule was initially formulated from the interviewer’s professional experience as a CAMHS practitioner. Pre-established topics and questions were generated and prompted throughout the interviews; specific aspects of ADHD as a disorder were covered, such as recognition, diagnosis procedure, treatment, causes and beliefs about medication. All interviews were audio-recorded and transcribed verbatim.

These semi-structured interviews were analysed using thematic analysis; Informed by grounded theory. This method aimed to answer a research question by identifying meaning patterns across a dataset (Braun & Clarke, 2006). In this study, thematic analysis lends itself perfectly to the data analysis as it is especially well suited for exploratory studies and research questions relating to people's experiences or understanding. It facilitates the exploration of the data in an inductive manner, allowing themes to emerge in a context that has not yet been explored. An inductive approach to data analysis allows for concepts to be freely explored while adopting a view with minimal biases (Creswell, 2009).

After the interview recordings were transcribed verbatim, using methods described by Braun and Clarke (2006), a thematic analysis was used to identify, analyse and report emerging themes from the interview. Thematic analysis is a six-step deductive or inductive approach telling an interpretative story about a research question through immersion in the data (Braun & Clarke, 2006). Following this process, BF transcribed the interviews and first familiarised herself with them by listening to the audiotapes and reading through the transcripts several times. As this first step was being followed, BF took notes of her preliminary thoughts on the interviews' content. From this close familiarisation with the transcripts, preliminary codes were identified. After familiarisation with these codes, they were then collated and combined to be classified into broader themes. Finally, as BF became more accustomed to the data, these broader themes were reviewed and refined and generated the final themes proposed. To get a meaningful analysis, it was ensured that each theme's data were coherent with each theme and subtheme and within the overall dataset context. Ongoing analyses allowed for a clear definition of the final themes.

This analysis method was selected as this was a novel, explorative and descriptive study with little theoretical background and was particularly well suited for this research type. This study did not set out to support or contradict a theory but sought to explore an understanding of this topic. While other analytical methods often expect specific themes to emerge from the data based on pre-existing theories or literature reviews (deductively), thematic analysis is a flexible method that can be used deductively or inductively. In this instance, an inductive process was followed, allowing themes to become apparent from the data naturally. This method is of particular relevance when exploring topics that have not been explored before, most especially when these topics aim to investigate personal understanding and standpoints on specific issues. As little theoretical background was established before data collection, this approach seemed perfectly suited. The strength of this approach is illustrated by some of the emerging themes presented below. While misconceptions and lack of awareness were expected, the recurring concern around parenting and environment and how the participant links it to many aspects of ADHD was unanticipated at the outset.

3.5.2 Results

Following the inductive process discussed above, five themes, each with multiple subthemes, emerged from these interviews' thematic analysis (Table 3).

Table 3

Main Themes Extracted from the Pilot Study

Themes	**Description**	**Subthemes**	**Exemplar**
Negative connotations of ADHD	GP trainees expressed strong negative views towards ADHD, often supported by the presence of stigmas and misconceptions	Issues surrounding the label of ADHD It is a problem, reinforced by the media? Stigmas	"There is so much stigma surrounding it that actually it could potentially be unhelpful to an individual."
Parenting	The impact of parenting on ADHD was often discussed both as a solution and causation of ADHD	The positive and negative impact of parenting Causation or factor?	"I think (ADHD) is a quick label to give somebody, and it kind of excludes some parent's responsibility in the child's behaviour."
Social background - impacts of the environment	The impacts of society, the environment and most specifically, SES on ADHD were discussed	Socioeconomic status Change in society over time	(when asked about ADHD causes) "I think it is a mix of changes in society, changes in the way we live and changes in parental behaviours."
Lack of experience/knowledge	GPs' lack of knowledge, training and experience on ADHD strongly impacted their attitudes towards the disorder.	Insufficient training Causes, diagnosis and treatment	"I'm not very sure to be honest… I don't know anything about guidelines or whatnot."
Diagnosis / consultation procedure	The diagnostic procedure is complex, strongly influenced by the fact that it involves a multidisciplinary approach, and GPs only have short consultation time to assess.	Consultation Need for a multidisciplinary approach	"seeing a child for 10 minutes, it is very hard to make a true assessment… it is very challenging, and I don't think it falls within the remit of general practice, to be honest."

3.5.2.1 Negative connotations of ADHD

The first theme explored the negative connotations associated with ADHD. This theme emerged throughout the interviews and was discussed in relation to multiple aspects of ADHD, such as causes, recognition and management of ADHD and help-seeking. This theme was explored through various subthemes, as presented below.

Label

The label of ADHD in itself was of concern to the GP trainees. Negative connotations seem to be linked to the term ADHD, and it was felt that, at times, they wouldn't want to give this diagnosis because of this. This label might negatively impact patients' lives, as it carried strong stigmas or was associated with stereotypes. While the label of ADHD had a negative connotation in the "outside world", this was also experienced within GP practices. ADHD seemed to be understood as a condition that implied children were difficult to manage and control. This led to professionals feeling wary and uneasy upon hearing the label ADHD. It also led the professionals to believe that the label was just an excuse for misbehaviour. It was felt that it was overused and misused to label challenging behaviour.

> *"I guess, it might influence when you see a child, and you see on record that they have ADHD, you might think, oh gosh, this consultation is going to be more difficult" (P8)*

> *"Having a label of ADHD in a way excuses you of having a naughty child and excuses you of having to discipline the child" (P4)*

It is a problem reinforced by the media?

The influence of the media was also widely discussed by participants. In a similarly negative fashion, professionals explained how ADHD was seen as a problem, reinforced by negative media portrayal. The media seemed to perpetuate a negative connotation about ADHD, which influenced people's beliefs (health professionals and laypeople alike) that ADHD was negative and linked with challenges. While some interviewees explained that they consciously tried to avoid watching the media or listening to these stories, they stated that it was pretty tricky. For instance, even when making a conscious effort to ignore this, they find that friends and family might bring up ADHD in conversation after seeing something in the media.

> *"…the media doesn't portray them (children with ADHD) in a positive manner by any means" (P10)*

> *"…realizing that people have got quite negative views about it. Which mostly doesn't come from any kind of sensible references, it's largely through mainstream media" (P8)*

Stigmas

Finally, many of the negative connotations related to ADHD were discussed through the concept of stigmas. The interviewees agreed that stigmas were strongly present both within and outside the healthcare profession, reinforcing the negativity around ADHD as they struggle to dissociate the facts from the stigmas. It was acknowledged that once the stigmas were experienced, it was difficult to change their own opinions about these stigmas but also to change other people's opinions. Some stigmas were so strongly ingrained and reinforced by the media or friends' reactions that while they feel they should know better, it is hard to "let go."

> *".. there's so much stigma surrounding it (ADHD) that actually it could potentially be unhelpful to an individual" (P1)*

These negative connotations around labels, stigmas and the media also emerged in the next theme of parenting.

3.5.2.2 Parenting

This theme was discussed throughout all the topics addressed in the interview and seemed a critical aspect of ADHD for GP trainees. It included positive and negative connotations about ADHD and was sometimes cited as a potential causal factor of ADHD-related issues and sometimes a solution to enable better management of ADHD.

Positive and negative impacts of parenting

While an adverse effect of parenting was often implied throughout the interviews, parenting strategies were discussed in both a positive and negative light, reinforcing the importance of exploring parenting styles in GPs' experience of ADHD. Negative parenting strategies hindered the recognition, expression and management of ADHD. On the other hand, the use of positive parenting strategies also had a successful impact on the management of ADHD. Parenting strategies can, therefore, mitigate the expression of ADHD symptoms in children. Many professionals believed that by adjusting parenting skills, the presentation of ADHD in children might be helped

> *"I would probably push for the social interventions and help with parents managing their child and see how that helps…. And if they can adjust their parenting skills, for example, that might help" (P2)*

Causation or just a factor

The interviewees discussed the effect of parenting on managing children's behaviour at different levels. They explored, for instance, how parents' approaches can impact their child's behaviour and the management of ADHD through the use of medication. However, most expressed a strong link between parenting strategies and ADHD, parenting potentially at the source of children's challenging behaviour. Interviewees explained that it was difficult to disentangle whether challenging behaviours arose from the disorder itself or from bad parenting. However, this could be circular as complex behaviour raises challenges in parenting and vice versa.

The generational difference in parenting styles over the years and how this could be a potential cause of ADHD were also explored. Significant differences in family dynamics (for instance, increase use of screens) and discipline (for example, physical punishment) over the past decades were discussed and how this could relate to different family members' behaviour, either the child's or the parent's.

The effect of parenting was also discussed in its impact on family life and family dynamics. For instance, the concept of stress points within the family (such as divorce or moving house) was mentioned when acknowledging the child's history. The effect of ADHD on siblings and all family members was also recognised, discussing the impact of ADHD on all family members' wellbeing and behaviour and how this could be a factor in the expression of ADHD.

> *"Whether parenting has a causative effect or just influences, it's difficult to tell" (P10)*
>
> *"I suppose parenting is the main one (the commonest cause of ADHD)". (P4)*

While parenting strongly impacted views on ADHD, the environment of the families was also significant.

3.5.2.3 Social background- impacts of the environment

The third theme that emerged related to the impact of the environment and how GP trainees believed social backgrounds were strongly linked to ADHD. Like the theme of parenting, it was explored both as a potential cause or a factor in ADHD.

Socioeconomic status

Socioeconomic status (SES) was discussed in the context of its impact on ADHD. Many interviewees believed that SES had a considerable influence on ADHD, specifically that ADHD was a disorder of lower-class status. Some interviewees explained that only patients from lower social backgrounds experienced ADHD but struggled to explain why this was. It might be that more patients from lower SES seek help for the disorder. Many participants saw children from inner-city areas and explained that there was a strong association between the two. Aspects such as social stimulation and situations in these environments seem to be unfavourable for ADHD.

> *"I'd probably say more environmental than medical because I think the fact that if you look at a child's upbringing, you'll see that in certain groups of children you've had in their upbringings, the instance of ADHD is a lot higher and I think that's beyond coincidence. I think that's environment more than any underlying causes" (P2)*

Change in society over time

Similar to issues explored in the parenting theme, it was often mentioned that changes (such as family interactions, screentime etc.) in society over time were strongly linked to ADHD. Many interviewees believed that ADHD was a "new" disorder that didn't exist a few decades ago. While some thought that it was present in the past but not recognised due to minimal knowledge, others believed that recent generations use ADHD as an excuse to explain challenging behaviour. This seems to be a prominent belief in the cultural change over time and how modern society has "created" this disorder. This concept was explored on multiple levels. For instance, ADHD was created to justify societal failings, such as bad parenting or children's naughty behaviour.

Modern society's impact was also explored with topics such as diet, social media, gaming, and lack of outdoor play potentially at the source of ADHD symptoms. For instance, more indoor activities limiting children's ability to be energetic and faddy diets being more readily available. Finally, parents societal pressure in our modern society seems to have created a generation of children with very little boundaries and discipline. The change in discipline over time was cited as a significant factor in ADHD.

> *"What my understanding is, about 10-15 years ago, I don't think this diagnosis was around, to be honest... But I also have this inkling that diet has a play to it as well because even 20 years ago, kids used to go outside, play sports, having more of a fresh and varied diet I suspect where now there's fast-food environment and computer at home. So I think that a lot of environmental factors have a role in contributing to ADHD, not necessarily physical, medical. (P11)*
>
> *"It is a mix of changes in society, changes in the way we live and changes in parental behaviours" (P4)*

While the previous themes related more to family factors, other factors specifically associated with GPs were discussed.

3.5.2.4 Lack of experience/knowledge

Lack of awareness of ADHD from professionals was often cited as a barrier to understanding ADHD. This lack of knowledge was discussed in a generic context of the disorder and, more precisely, on the causes, referral process, and treatment of ADHD.

Insufficient training

The main issue regarding the lack of knowledge was expressed by the absence of training. Training on ADHD is not mandatory, and interviewees explained that their lack of knowledge was not caused by a lack of interest but rather a lack of training at medical school. Interviewees, who had some knowledge of ADHD, explained that they gained it through personal interest, either through personal experience, the media, or actively looking into it online through journal articles. A strong desire to gain this knowledge led those interviewees to seek it, having had no training.

> *"…we haven't been taught or had teaching in it or know any of the criteria it is very hard for us to know what is what, but that comes with experience" (P9)*
>
> *"(on experiences of ADHD) I guess mine is more media rather than teaching as there has been very little teaching on it and not having that paediatrics either I guess, and there has been very little time in my medical training where they would have focused on it" (P9)*

On causes, diagnosis and treatment

The causes, referral and treatment process of ADHD were the main factors that participants linked to their lack of experience and knowledge. While clear guidelines aim to guide through the recognition process (NICE, 2018), few interviewees were familiar with the steps to follow. While exploring causes and symptoms, interviewees explained that they had very little knowledge of the matter. This poses a problem within the pathway to diagnosis as this might stop them from picking up on critical symptoms.

> *"I mean; I have no idea of the prevalence of ADHD really" (P1)*
>
> *"I don't know much about it (causes) to be honest with you" (P2)*

While the lack of knowledge and experience around diagnosis impacts the referral process, the lack of knowledge on treatment impacts patients at the end of the diagnosis pathway. Interviewees seemed to know what potential treatment options were available and were familiar with medication but were not entirely sure on the best route to take. At most, it was an educated guess, but no clear understanding of treatment options was expressed.

> *"(On treatment) I don't know a huge amount about the different options" (P7)*

Factors directly impacted by the GPs' experience and environment also included difficulties in consultation and diagnosis.

3.5.2.5 Diagnosis / consultation procedure

The final theme that emerged from the interviews explored the concepts of diagnosis and consultation procedure and the difficulties experienced during these processes. While it has been discussed above that interviewees felt that they had limited knowledge of diagnostic procedures, more technical issues were also explored both within the consultation and the subsequent diagnosis pathways.

Consultation

During consultations, many issues were discussed concerning the diagnosis process. In the first instance, interviewees discussed that patients' behaviour in the consultation doesn't always match their beliefs/ expectations of ADHD. For example, when they see a calm child perfectly still. In that case, they have greater difficulty making a referral for an ADHD assessment as the child's behaviour doesn't match their understanding of ADHD symptom expression. This was especially worrying as decisions are often based on a 10-minute snapshot, and parents' concerns could be overlooked. This leads to another issue experienced during consultations, which was the lack of time. Interviewees felt strongly that a 10-minute appointment was not enough to get a broad overview of the situation and gain enough information to make an informed decision. Therefore, multiple appointments are necessary, but despite this, they find that getting the right information in a timely manner was very difficult.

> *"Because based on my experience of the child, which was 10 minutes, very short, sat in the corner quietly and not saying very much, she exhibited no symptoms whatsoever of ADHD" (P10)*

> *"How they just come in into the doctor's room and how they behave, so being impulsive and hyperactive in my room compared to the child I saw 10 minutes ago who sat nice and quietly and did what we said, there is a big difference" (P11)*

Need for a multidisciplinary approach

These issues lead to a strong need for a multidisciplinary approach in the pathway to care for ADHD. The interviewees expressed how they felt that teachers, parents, and secondary care professionals all played a strong role in diagnosing and treating ADHD. In keeping with NICE guidelines, they did not feel they had the right experience and knowledge to go through diagnostic and treatment procedures alone. Clearer pathways and communications between all parties were vital, and support in this process was also of great importance. The lack of clear communication between teachers and GPs, for instance, can delay referral processes but also muddles the information gathered.

> *"It is very challenging (seeing a child for a 10-minute appointment), and I don't think it falls within the remit of General Practice to be honest" (P4)*

3.5.3 Discussion

These semi-structured interviews explored GP trainees' beliefs and understanding of ADHD. Five main themes emerged from these interviews, giving an overview of GP trainees' issues and considerations on ADHD. These themes primarily highlighted problems with knowledge and beliefs around ADHD. With a distinct lack of knowledge and stigmas related to the condition, the environment and the individuals presenting with ADHD, a strong need for better education seems to be prevalent. These themes were explored throughout the proposed topics developed in the interview schedule and give a comprehensive approach to different aspects of ADHD.

Strengths and limitations

Few studies have explored attitudes and beliefs about ADHD in primary care using a qualitative approach. In our recent systematic review (Chapter 2 - French et al., 2018), only four studies worldwide explored GPs' understanding of ADHD through the method of interviews; of these, none interviewed GP trainees. Therefore, the interviews hereby presented explored a novel population that has not been published and has little theoretical background or prior study referential point. However, studies investigating the understanding of ADHD in GPs - including our systematic review - highlighted a few recurring themes: a need for education, misconceptions and stigmas, internal and resources constraints, and need for a multi-disciplinary approach (Guevara et al., 2005; Hassink-Franke et al., 2016; Salt et al., 2005). While similar themes emerged in this study, this pilot study also highlighted new findings. The themes of parenting and environment/SES did not appear as prominent themes in the literature review but were strongly present in this study. This was an interesting outcome of the study, and the inductive approach taken in the analysis allowed exploration of this. The reasons why these themes were discussed in this study but did not emerge from the literature review are unclear. It could be due to the specific portrayal of ADHD in UK settings, while the literature review covered worldwide settings. Alternatively, it could be explained by the limited clinical experience of this particular population (GP trainees in this study as opposed to fully trained GPs in the literature review).

The limitations observed in this analysis were principally related to the study's unusual circumstances as the researcher analysing the data did not conduct the interview. It created considerable complications throughout the transcription and analysis of the data. Transcribing and analysing these interviews was unexpectedly complex, and many issues arose from this process.

The first point of difficulty emerged during the transcription of the data. From a logistical point of view, it was difficult to understand at times what both the interviewee and interviewer said due to the quality of the recording. In some instances, interviews took place in a café, and the background noise was very disruptive. As BF was not present, it was difficult to decipher what was said with no personal memory from the interviews themselves. This was also incredibly complex as English is not her first language. When speaking a second language, a conscious effort is continuously made in understanding accurate meanings of conversations, tones, accents and language subtleties. This issue was especially difficult in this transcription as BF had no referential points such as body language, facial expressions, or first impressions.

Secondly, as standard procedure when conducting interviews, notes were taken during and after the interviews, writing down impressions and details. It was not known if the interviewer did this, but if it was, no access to the notes was given, which feels like a loss of potentially important information. BF was also unable to include her own communication skills and experience in interviewing. Therefore, the way the interviews were conducted was very different from BF’s personal approach.

Thirdly, the transcription was also surprisingly frustrating at times, experiencing second hand “loss of data.” As some issues were being discussed, more elaboration was wanted or going back to specific points that felt important, but the interviewer did not. At times, some questions were not being answered by the interviewee, and, again, BF experienced a feeling of a missed opportunity for lack of redirection to the topics discussed.

Additionally, the lack of demographic information from the sample was also a limitation in this study. As BF was not aware of the GP trainees’ experience and background, it was challenging to put their experiences into context. For instance, BF noticed that a lot of GP trainees associated ADHD with lower SES. If all the interviewees from this study only had work experiences in inner-city primary care sites, their views would be skewed.

Finally, another substantial limitation in this study was the sample selection. It can be assumed that this study comprised of a self-selected sample with an interest in ADHD. Therefore, the participants were keen to talk about ADHD and share their experiences, but GP trainees who might have negative views or views that ADHD doesn't exist, for instance, might not have willingly taken part in this study. Similarly, the sample also reflected clinicians' views in training only rather than a more diverse viewpoint of all stakeholders within primary care. Therefore, the experiences of these groups were not represented by this sample.

3.6 Semi-structured interviews

These semi-structured interviews aimed to explore further GPs' awareness and knowledge of ADHD. To gain a comprehensive view of ADHD experiences in primary care, multiple stakeholders' views were included. It was important to examine the views of GPs, but including the experiences of patients and other healthcare professionals working directly with them was also crucial. As gatekeepers, GPs' attitudes towards ADHD have a direct impact on patients. Their knowledge also directly impacts the workload of secondary care workers. For instance, if GPs struggle to recognise differences between ADHD and other disorders, they might not refer the patients on, or they might refer patients with an inappropriate referral, making it difficult for secondary care professionals to assess.

3.6.1 Methods

3.6.1.1 Study design

Semi-structured interviews were conducted over three months in late 2018 with participants from across the UK. The interviews were conducted by BF, who has received extensive training in qualitative methods and were analysed using thematic analysis (Braun & Clarke, 2006). The study received ethical approval from the University of Nottingham, Faculty of Medicine and Health Sciences Research Ethics Committee (Ref: 18/HRA/0418, 2^{d} of January 2018) and from the Nottinghamshire Healthcare NHS Foundation Trust R&D department (IRAS PROJECT ID 237332) (Appendix 3).

3.6.1.2 Participants

Nineteen participants were interviewed for this study, representing the views of twenty individuals. One participant explored issues related to diagnosis both as a parent and as an adult patient as her son's diagnosis triggered her own referral and diagnosis. The participants were selected from four different stakeholder groups: 1) GPs, 2) secondary care professionals who specialised in ADHD diagnosis, 3) adults with ADHD and 4) parents of children with ADHD. These participants' groups were carefully selected to give a representative sample of the stakeholders directly involved in ADHD diagnosis, integrating patients' and professionals' perspectives. Participants were interviewed in no specific order to limit biases from particular groups and were each given a monetary inconvenience allowance for their participation.

GPs: Three males and two females GPs were interviewed (mean age: 33y.4m, range: 44y.7m-29y.4m). They were recruited from the local Clinical Research Network and through direct contact with practices.

Adults with ADHD: Nine participants gave consent, but only five took part in the study. Two male and three female adults with ADHD were interviewed (mean age: 48y.8m, range: 63y.3m-29y.2m) from across the UK. The adults were recruited from ADHD adult support groups known to BF.

Parents: Five female parents of children with ADHD were interviewed (mean age: 41y.2m, range: 62y.10m-29y.5m) from across the UK. The parents were recruited from parenting support groups known to BF.

Secondary care professionals: Three male and two female secondary care specialists from the UK were interviewed (mean age: 46y.5m, range: 63y.5m-36y.6m). Two participants worked with adult patients and dealt with adult diagnoses. Three participants worked in child diagnosis settings (two in CAMHS and one in a community paediatric team). These participants were selected purposely to represent secondary care workers, both with adults and children.

3.6.1.3 Data collection and analyses

Three interview schedules (one for GPs, one for patients and one for secondary care professionals - Appendix 4) were developed based on our recent literature review and a pilot study conducted with GP trainees. They included targeted questions as well as open-ended questions. Topics highlighted by the two previous studies from these doctoral studies were included to confirm these results' validity.

The topics that emerged from the systematic reviews were:

- Misconceptions
- Lack of knowledge
- Multidisciplinary approach
- Lack of resources

The topics that were highlighted by the pilot study were:

- Negative connotations of ADHD

- Parenting
- Social background - impacts of the environment
- Lack of experience/knowledge
- Diagnosis / consultation procedure

We ensure most of these topics were included to further explored these previous findings. The issues around misconceptions/negative connotations were addressed, and more specific questions around SES, parenting and behaviour in consultations were also prompted. The extent of GPs' knowledge was also discussed. Finally, the lack of resources and multidisciplinary approaches were discussed indirectly through services and communication between multiple stakeholders.

Individual semi-structured interviews were conducted to explore GPs' attitudes and understanding of ADHD. After the participants were made familiar with the interview process, written consent was obtained. Participants were offered a choice of telephone or face-to-face interviews. All except one interview took place over the phone. The use of these different data collection methods had no impact on the data analyses. Both interview methods reflected similar themes, which supports previous research on the comparability of the two methods (Sturges & Hanrahan, 2004). Three interview schedules were developed based on our recent literature review. They included specific topics as well as more open-ended questions. The three interview schedules covered the same topics but from different standpoints according to participant groups. GPs were asked a greater number of specific questions as this group was our main focus of interest. Following a grounded theory approach (Glaser & Strauss, 1967), the interview schedule was applied flexibly and regularly reviewed with data analysed continually throughout the process. Questions were changed or added as different topics emerged. Specific questions were also omitted depending on the participant's experience. Detailed notes were taken and recorded after each interview, following each analysis, and included in an analysis diary. All interviews were audio-recorded and transcribed verbatim, and all transcripts were anonymised.

This study's analytic strategy was based on thematic analysis (Braun & Clarke, 2006) using an inductive approach, enhanced by the principles of grounded theory (Chamberlain, 2004). Themes and subthemes were identified using an adapted approach of Braun and Clarke's six-stage process. While previous literature reviews (French et al., 2018; Tatlow-Golden et al., 2016) and a pilot study highlighted topics that needed to be explored, the interview schedule was developed to allow new topics to emerge inductively, aiming to explore the participants' experiences freely. The analytic process began by transcribing each interview verbatim shortly after being conducted. Following this process, BF first familiarised herself with the interviews by listening to the audiotapes and reading through the transcripts multiple times. Following verbatim transcription, the lead investigator took notes in a diary of her preliminary thoughts on the interviews' content. From this close familiarisation with the transcripts, preliminary codes were identified in a coding manual. After familiarisation with these codes, they were collated and combined into broader themes using constant comparative analysis both within and between transcripts. Finally, as the analysis evolved, these broader themes were reviewed and refined and generated the final themes proposed. To get a meaningful analysis, it was ensured that data within each theme was coherent in relation to each theme and subtheme as well as within the context of the overall dataset. Ongoing analyses allowed for a clear definition of the final themes.

Themes were finally reviewed by a second researcher (EPV) to ensure they mapped to the original transcripts. EPV also confirmed that theoretical saturation was reached and that no new themes emerged in the last few interviews, as suggested by thematic analyses guidelines and studies with similar methodologies (Aarons et al., 2009; Baker & Edwards, 2012).

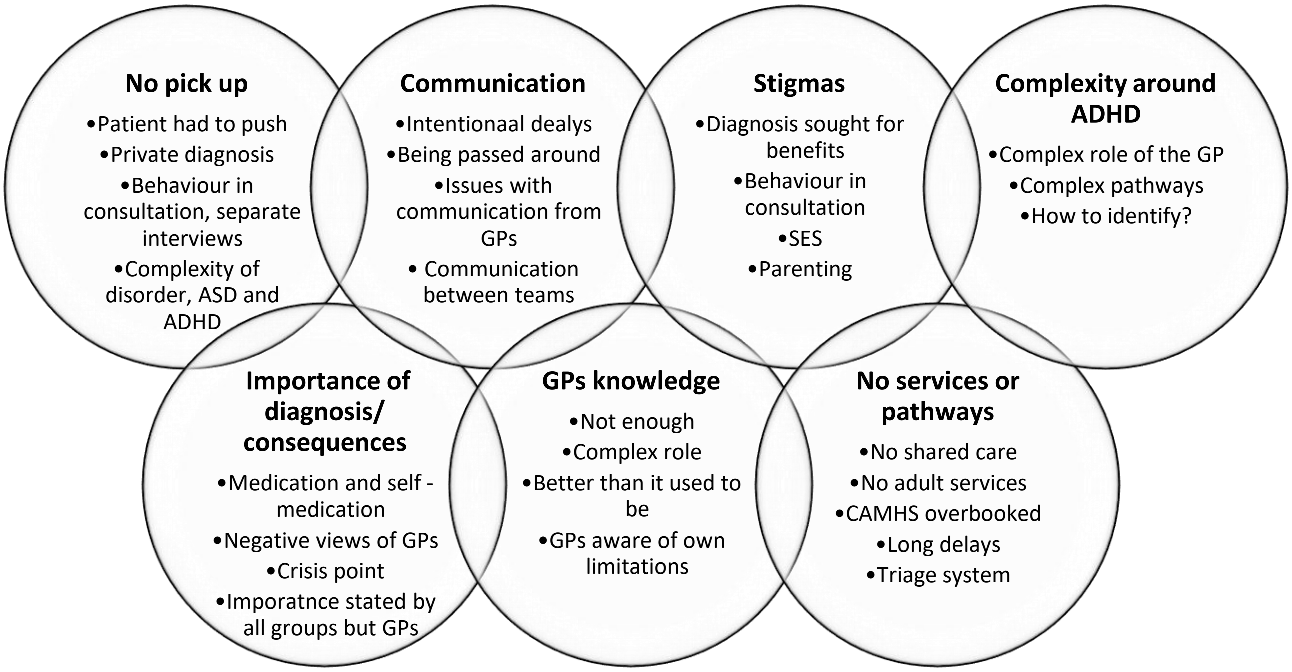
EPV checked the coding manual and theme extraction along with the individual coding of transcripts. Inter-rater reliability was tested on a small proportion (20%) of the transcripts' themes and sub-themes. The results were validated collectively as a team, and any discrepancies were discussed and reconciled.

3.6.2 Results

Upon initiating theme extraction, seven themes were identified (Figure 4)

Figure 4

Thematic Map of the Preliminary Themes and Subthemes Extracted



However, through the analysis process, themes and subthemes evolved and were renamed. Most specifically, after going through the transcripts again, some themes seemed to overlap strongly and were consequently merged.

The final identified codes highlighted five main themes (Table 4 *Main Themes and Subthemes Identified*). While some themes overlapped strongly with previous findings from our literature review and pilot study, new topics emerged from our synthesis. The new themes highlighted by this analysis were: GPs not identifying ADHD and the lack of services and pathways to care. These concepts were present within all interviews and reflected by all stakeholders and impacted the other themes.

Table 4

Main Themes and Subthemes Identified

Themes	Description	Subthemes	Exemplar
Lack of identification in primary care	GPs are not identifying ADHD. ADHD referral is sought by the patients and not recognised by GPs	No Identification in primary care Patients' led approach and strategies	"ADHD was not picked up, they didn't pick it up, not for many years" (P2- adult)
Lack of clear diagnosis pathway and services	The children and adult diagnosis pathways and services vary widely in terms of availability, existence and waiting times.	Complexity of services Long waiting lists and triage Age-specific issues	"In my locality […] there is no pathway or easy pathway to obtain a diagnosis" (P6- GP)
GPs' knowledge of ADHD and misconceptions	GPs have limited knowledge of ADHD. They know enough to refer but not enough to identify. Their limited knowledge is also reinforced by their beliefs in common ADHD misconceptions.	Insufficient knowledge and complex role Misconceptions	"In my experience, the overall knowledge is lacking […], but if they don't know what to do, they know to refer into specialists" (P3- secondary care) "(the GP) had lots of misconceptions and so do all the doctors I meet in my day to day life" (P8-adult)
Difficult communication between multiple stakeholders	The multidisciplinary nature of the ADHD diagnosis pathway creates issues with communication. Both between services and within services.	Communication between services Communication with patients	"I felt it was a stacking system" (P4- patient)
Impact of diagnosis and the risks linked to no diagnosis	Receiving a diagnosis has many positive impacts on patient's lives. Patients and secondary care professionals feel very strongly about the necessity and benefits of receiving a diagnosis, while GPs had a more negative view of the diagnostic label.	Impact of a diagnosis on the patients GPs negative view of ADHD label	"I'm always cautious […] you have a child who's labelled as ADHD and one day he's misbehaving, and you say, oh it's the ADHD, and you attribute all the problems to the diagnosis" (P6- GP)

3.6.2.1 Lack of identification in primary care

No ADHD identification in primary care

The central theme highlighted by this analysis, related to the concept of identification of ADHD. Specifically, GPs indicated that they were not the ones identifying ADHD symptomatology when faced with patients' issues. When asked who was responsible for identifying, all interviewees ADHD agreed that it principally came from the patients. Only one GP described identifying ADHD in his patients, and then only around 10% of the time. All other GPs acknowledged that they had never identified ADHD in a patient. It was more common for patients to raise concerns of ADHD with their GPs, identifying symptoms being triggered by personal reflection or a third party. Third-party identification was also often started either by schools or through the diagnosis of a first-degree family member (child or sibling).

> *"My experience has always been a parent has brought their child in saying, "I want a referral to paediatrics. I think my child has ADHD." It's either the school suggesting it to the parents or the parents suggesting it" (P11- GP)*
>
> *"ADHD was not picked up, not for many years […] my wife picked it up, my wife who works in a school […] but the doctors never picked it up" (P2- adult)*
>
> *"I was looking into it for my sons and then realised that actually, I've probably got it myself" (P4- adult)*

Patient-led approach and strategies

Patient-led approaches have implications both for the initiation of referrals and the subsequent process of referral. As the process is usually not led by the GPs, patients stated that as well as having to ask for a referral and initiating an ADHD enquiry, they also had to push to get a diagnosis. Strength of character and stubbornness were key factors in getting through the process, and patients believed that without a constant effort on their part, they wouldn't have received a diagnosis.

> *"So yeah, there was basically nothing on their part, it was just me pushing for it and me being proactive about it" (P5- adult)*
>
> *"They need to say, what can we do to help you? That was never done. I'm lucky because I'm strong and feisty, and I knew that there was something wrong" (P13- parent)*

To address the lack of recognition by the GPs, patients developed strategies to bypass GP gatekeeping. For instance, some patients sought private diagnoses to access care. In particular, private diagnoses were sought when patients felt that they had reached a dead-end, or strongly needed access to care, or perceived that GPs lacked awareness and were not acknowledging their issues.

> *“We didn’t want to wait, so we paid to see a private guy, and he did the diagnosis very straight forward and very quickly for us” (P12- parent)*

One patient explained that she had to “trick her GP” into giving her a referral for a diagnosis after years of issues.

> *“No one had picked it up […], So it was only when I read something online that sounded like me, and then did some further research and then tricked my GP into giving me a referral” (P5- adult)*

While patients revealed being impacted by issues surrounding lack of identification, this experience was something that GPs also acknowledged. GPs expressed that the identification of ADHD was a very complex process and difficult to conduct in a consultation.

> *“So, we rely a lot on what parents tell us and parental concern as well. If we see the child, we’ll only have a brief interaction with the child, so our impression of the child is mainly based on history and parental concern [...] it comes from the parents mainly” (P14- GP)*

> *“I don’t think I’ve ever had anybody come and say, there’s this, this and this and I’ve said, I think that’s ADHD” (P15- GP)*

3.6.2.2 Lack of clear diagnosis pathway and services

The next theme identified in the interviews related to the issues around diagnosis pathways and services. Despite clear guidelines, diagnosis pathways vary considerably between different areas. This is due to distinct commissioning priorities between different healthcare localities (NHS Trust), resulting in resources being allocated differently and consequently impacting services. All interviewees agreed that their diagnosis and management experience depended strongly on the services provided and the pathways in place. A ‘good’ service was perceived as one in which pathways were clear, communication facilitated, and management processes were relatively straightforward. However, in most cases, services and pathways were reported to be very unclear, muddling the referral, diagnosis and management process.

Complexity of services

The complexity of the services was discussed at different levels, firstly through lack of service availability, secondly through GPs’ lack of knowledge about what services were available and thirdly through variations in services depending on geographical areas. The lack of service availability greatly hindered the diagnosis and management processes.

> *"It can be difficult to get somebody assessed for ADHD […] So in my experience, I have had to send somebody out of area in the past in order that they can get a diagnosis or get some help and support for it" (P6- GP)*
>
> *"So parents sometimes come to us and say they have waited a long time to see us, and I've never really been sure why they've waited" (P18- secondary care professional)*
>
> *"There isn't a pathway because it's not a commissioned service" (P19- secondary care professional)*
>
> *"It was tough, there was nowhere for me to go to get a diagnosis or to see anyone who could give me a diagnosis" (P4- adult)*

It was also discussed that even when there were services, the services were not known about, or were often changing, making the referral process confusing.

> *"So I think some GP's may not even know that we (specialist service) exist actually" (P1- secondary care professional)*

Finally, the referral process was often so complex that GPs had to refer to different services according to many variable factors, including geographical location, making it very difficult to keep track of which pathways they were supposed to follow.

> *"So I've tried referring them to the paediatricians locally here, and I've had it bounced. I've referred them to the psychiatrist, and I've had them bounced. I've asked is there a community and mental health team that can see this patient, and they say it doesn't cover their remit. So I find it to be a very difficult referral process" (P7- GP)*
>
> *"Because we're a tertiary service and we don't have the resource to be able to case hold and so case holding needs to take place in secondary care, not adult mental health services […] we don't accept referrals from the GPs […] Because there's conflict between the GPs and secondary care about who takes on the prescribing, so the area prescribing have not managed to reach agreement to develop a shared care protocol" (P19- secondary care professional)*

Waiting times and triage

This lack of services and clear pathways had strong repercussions on the referral process, principally creating long waiting times. With services overloaded due to limited resources, patients and professionals felt very frustrated by the excessive delays they often experienced.

> *"After waiting a year and a half to actually get an appointment at the ADHD clinic" (P10- adult)*
>
> *"It does take a long time (to get a diagnosis). There is a very slow process, and we're trying to look at ways of making it better" (P9- secondary care professional)*

Many specialist services set up a triaging system in response to the significant delays and overloaded services, putting in place different strategies such as stricter referral criteria or extra layers of screening or information gathering to manage waiting lists. These approaches aim to optimise scarce resources but risk potentially losing patients due to the long waits or to stricter criteria that may not get to the root of the problem.

> *"Services are either not funded, or they'll see people who fit very specific criteria, and I know there is no management service" (P6- GP)*
>
> *"Actually, that is partly a deliberate off-putting tactic to try and reduce referrals, which is a terrible thing to say, but I'm sure that's part of the motivation that it's another obstacle to this flood of referrals that we get." (P1- secondary care professional)*

Age-specific issues

The lack of services had different implications depending on whether it related to children or adult referral pathways. With children, issues related to workload within secondary care services were often mentioned. These issues included difficulties with medication management and the difficulties of getting hold of specialist services in a timely manner. This directly impacted GPs as patients felt that GPs should be able to take over when other services are overbooked.

> *"(with regards to medication) CAMHS they're overloaded and understaffed […] GP surgery is far more accessible than trying to see a mental health professional out of your specified appointment time. So the GP can prescribe, but all he does is sign off on scripts, he can't see them with regards to meds" (P12- parent)*
>
> *"I think they should be able to contact CAHMS to talk about medication, 'cause you can't always get hold of CAHMS because the mental health system is so stretched, so the only other point of call you've got is your GP" (P16- parent)*

The main issue with regards to adults' diagnosis was the nonexistence of services. Most GPs mentioned that their area had no adult services and did not know where to refer adults. This lack of commissioning, in turn, impacted the few existing services with extra referrals and, therefore, more delays.

> *"My experience of referral is only with children because there isn't an adult service here in L." (P11- GP)*
>
> *"like I say then when you get to adults, and there isn't that kind of support around, effectively you're giving them a diagnosis, and you're not able to do anything for them" (P15- GP)*

Difficulties with children transitioning from children to adult services were also raised. In these instances, not knowing who takes care of these individuals was a worry for all professionals. Having no transition services in place implied that GPs might have to carry on managing these individuals with no training or competence.

> *"When a child turns 18, and they're no longer… they're discharged from paediatrics, but there's no adult follow up. There is no pathway at all at the moment, everything just seems to stop" (P11- GP)*
>
> *"I think probably one of the issues we're going to be having is that as kids come out of paediatric care and they're still on these medications, who is taking responsibility, and I think at the moment it just defaults to the GP, basically" (P15- GP)*

3.6.2.3 GPs' knowledge of ADHD and misconceptions

Insufficient knowledge and complex role

GPs' limited knowledge of ADHD was often discussed throughout the interviews. It was felt overall that GPs were helpful and open to the idea of ADHD. However, all participants agreed that while they had some knowledge, they didn't know enough. GPs generally felt that when ADHD was first mentioned, they were able to refer on to specialist services yet did not know enough to identify ADHD or give clear information on pathways and services. This concept of not knowing enough was expressed by healthcare professionals, GPs and patients alike. It was also acknowledged that there had been a general increase over the last decade in GPs' understanding and awareness of ADHD. However, GPs were aware of their own limitations.

> *"So no, I feel like we're very much in the dark when it comes to it, and it's a shame because we are usually the first port of call for parents when they're*

> *concerned about this. I think there definitely is a lot room for improvement in this area" (P14- GP)*

> *"General knowledge has really improved over the last 15 years […] Most know what they don't know if that makes sense. So if they don't know what to do, they know to refer into specialists." (P3- secondary care professional)*

> *"He (the GP) had an understanding of it but was quite open, and he would say "Okay, I will pass you on to the people that know about this more" (P4- adult)*

The limitation of GPs' knowledge mainly related to the process after referral, directly impacting both patients and specialist services. GPs did not know enough about pathways to diagnosis and management. Patients reported feeling frustrated as they had no information on the next steps after referral.

> *"No mention of any kind of support except for private support that was far too expensive" (P8- parent and adult)*

> *"They put us on a waiting list with no other help or assistance, and after a couple of years, she went to be assessed" (P13- parent)*

From a specialist standpoint, many secondary care workers reported that the lack of sufficient information received from the GPs meant that many referrals had to be sent back or that it created longer delays.

> *"The problem was that some of the referral letters are so brief that there isn't anywhere near enough information" (P1- secondary care professional)*

This issue was especially pertinent in terms of the lack of a clear understanding of the differences between ADHD and ASD. As these diagnoses can have different referral pathways, confusing them implies greater delays and/or the refusal of referrals.

> *"It's like ASD and ADHD […] I get the impression that GPs don't really know what either of these things are" (P1- secondary care professional)*

The GP's role in ADHD diagnosis and management is rather complex, which often created confusion for GPs and patients alike. GPs felt that they were not sure about their role and that they would like to give more support to their patients but didn't have the relevant information.

> *"There's a mismatch between an expectation of my role as a GP and what secondary care think we can and can't do" (P6- GP)*

Misconceptions

GPs' knowledge was also discussed in relation to misconceptions. Stigmas around ADHD were still at times expressed, with the stigma of the "naughty child" often mentioned. One secondary care worker reported that one GP surgery in their area did not believe ADHD was a valid diagnosis. But this instance seemed to be the exception rather than the norm. A change in the last decade around a more accurate understanding of ADHD and less stigma around ADHD was noticed. Rather than stigmas per se, broader misconceptions were expressed.

> *"So some peoples' GPs tell them that only children get it, although that's less often now" (P1- secondary care professional)*

The main misconception was related to the concepts of social-economic status (SES) and parenting. GPs often brought these topics up as causal factors of ADHD. Parents expressed that they felt their parenting was questioned during the diagnosis process, and GPs mentioned that they sometimes wondered if seeking a diagnosis was used as an excuse for bad parenting.

> *"Sometimes a feeling, almost of the parents are letting their child stay up really late, giving them fizzy drinks, sugary snacks, they've got all this sugar and fuelling the hyperactivity" (P6- GP)*
>
> *"Is it ADHD or is this just bad parenting […] because their parents either want a diagnosis for financial benefit or they feel like if I give my child a diagnosis, it absolves me of the fact of parenting" (P7- GP)*
>
> *"I was made to feel a little bit like it was my parenting discipline, which I was very upset about 'cause I've been a qualified nursery nurse and a nanny for, like, over 20 years, so I found that quite insulting" (P16- parent)*

GPs felt that SES was a strong risk factor and that they had biased views on patients from lower SES, expecting them to seek diagnosis more often. The biases stem from a strong belief that diagnosis is sought to gain access to welfare benefits. Colleagues' opinions regarding this specific misconception impacted GPs' beliefs, and colleagues' mentalities strongly influenced their biases towards patients from lower SES seeking an ADHD diagnosis.

> *"However, there is also in my mind whether that is a bit of prejudice on my part and the medical professions part, that we're almost looking for these problems in people of lower socioeconomic means which, if we saw perhaps*

> *a very affluent middle-class parent with a child, we might not necessarily jump to that conclusion" (P6- GP)*

> *"When I see individuals, unfortunately, who are trying to con the system, and not only do I see this, but I have my colleagues in my general practice come to me to say, another one trying to get her child a diagnosis. So I don't think it's just my personal bias, but it's also the practice bias" (P7- GP)*

> *"It seems like a lot of parents who are saying 'I think my kid has ADHD' are generally of a lower socio-economic class and maybe single mums and maybe have lots of children, and maybe their life is a bit chaotic […] maybe, asking for an explanation or an excuse in poorer families" (P15- GP)*

GPs also had misconceptions about individuals' behaviour in consultation. They stated that even though it doesn't impact their final decision on referral, the patients' behaviour strongly influenced their beliefs regarding whether the patient might have ADHD.

> *"I've had people ring me up and say, this person says they've got ADHD, but they sat beautifully still and concentrated well for the whole eight-minute consultation?" (P3- secondary care professional)*

> *"So, sometimes the parents will describe the child in a certain way, and you think, oh my goodness, when this child comes he's going to be bouncing off the walls […] Then they come in, they sit on the chair, and they're quiet, they're polite, they're okay, and then you think to yourself, this doesn't sound like the child that mum was describing earlier on. So sometimes it makes it a little bit difficult to marry that up" (P14- GP)*

Finally, the last misconception related to ADHD in high-functioning adults and in girls. High-functioning individuals and girls seem to go under the radar as they often do not meet the GPs' assumptions about ADHD. They might be less hyperactive, less disruptive in class and therefore might not fit some preconceptions attributed to ADHD.

> *"So anybody coming in as an adult is obviously not going to have really typical, really severe symptoms otherwise he would have been picked up, or you know" (P15- GP)*

> *"So, I think typically that stigma still exists for us, because GP's, professionals, even teachers will say, actually they're a quiet inattentive young girl rather than loud, noisy boy. They can't have ADHD because they're not shouting at me or causing a problem in the class, or they can't have ADHD because they're not running around […] So I think there's still*

> *that thought that if you’re not extreme, you don’t have difficulties warranting a psychiatric assessment” (P3- secondary care professional)*

3.6.2.4 Impact of diagnosis and the risks linked to no diagnosis

Impact of diagnosis on the patients

Patients and secondary care workers discussed the positive impact of receiving a diagnosis. The benefits of receiving a diagnosis, gaining access to care and gaining a greater understanding of individuals’ issues were often a great help and relief for the individuals.

> *“(upon receiving a diagnosis) I was relieved, and I think he (her son) was relieved […] I think he welcomed it. He was self-medicating a lot on drugs and not going down a very good route at all, and since he has been on the medication, he’s not really touched drugs very much” (P8- parent and adult)*

While gaining a diagnosis was linked to many positive outcomes, adult patients who had all received a diagnosis in adulthood felt many mixed emotions upon receiving an ADHD diagnosis. Receiving a diagnosis opened many doors and was an overall positive experience, yet frustration and anger were also expressed that this had not been picked up earlier. Adult patients felt a sense of loss and missed opportunities for the years they spent undiagnosed and expressed that they wished it had been identified sooner.

> *“I felt a bit annoyed really because I would have liked to have known way back, earlier than that. It came as a big shock […] what worries me is that many people are put on the wrong drugs, wrong medication when it isn’t being picked up” (P2- adult)*

> *“But I’m still cross… we’ve wasted years really” (P13- parent)*

The delay experienced in receiving a diagnosis also had other negative implications for adult patients. Some adults self-medicated with drugs or alcohol before seeking a referral or while waiting for their diagnosis in the absence of alternative coping mechanisms. Some patients stated that they sought a diagnosis when they were experiencing severe issues, and the additional wait led to distressing feelings, depression, time off work and at times led to risk-taking behaviours.

> *“So then people wait for 18 months to two years at the moment, which I think is not uncommon, but it’s very hard for them and for us really because we just know that they aren’t going to improve in that time and it may lead to lots of life problems […] at times it can be life-threatening if people do stupid things or feel suicidal and so on” (P1- secondary care professional)*

> *"So typically, we see teenage girls who come into the CAMHS service for self-harm or overdosing. They're very frustrated with their life, they're suffering educationally, something happens and their skills to be able to cope with things implodes or they just kind of struggle and do self-harm or something like that" (P3- secondary care professional)*

> *"and I had to get to that stage where I felt I was in desperate need 'cause I was just being passed around from pillar to post and if I hadn't have been quite strong, sort of thing, I can see how some people in that position would do something silly and would harm themselves […], and I tell you what, I drank a hell of a lot of alcohol and self-medicated on other things" (P4- adult)*

> *"The whole thing was quite upsetting if I'm being honest" (P16- parent)*

GPs' negative view of the ADHD label

While patients and secondary care workers expressed many benefits in gaining a diagnosis, GPs, on the contrary, expressed negative biases to the diagnosis of ADHD, wondering why patients would want this diagnostic label.

> *"Some GPs are very reluctant to make a label or a diagnosis because of stigma attached to it […] I'm consciously aware that it's a diagnosis that's probably not very nice for people to have" (P6- GP)*

They also expressed that they did not see the point of seeking a diagnosis in adulthood, given that adults had somehow managed so far. The ADHD label was linked with strong negativity from the GPs, and they struggled to see the positives associated with it in adulthood.

> *"I think I definitely wonder sometimes, as an adult, is this going to change anything for you? It's the case with any investigation we do or any referral, you're giving somebody a label. A diagnosis, is it actually helpful?" (P15- GP)*

3.6.2.5 Difficulty with communication between multiple stakeholders

The last theme identified from the interviews referred to issues with communications. The lack of clarity in the communication between services created more work and longer delays in the processes. This theme encompassed both difficulties with communication between and within services (primary care and secondary care) but also communication between services and patients.

Communication between services

The diagnostic process's complexity meant that communication was often very difficult between services with a general confusion about their designated roles. From the GPs' perspective, the lack of services and change in referral pathways resulted in GPs not knowing where to refer to and referrals being sent back. They also were unsure of the different information they were supposed to send and which services to refer to.

> *"You give them all the information, you think, wow this seems like it's really good information, but then they'll write back, and they'll say they don't necessarily think it's an appropriate referral and things like that […] so it would be nice if there was a little bit more of a way to communicate with community paediatrics" (P14- GP)*

The nature of an ADHD diagnosis meant that a lot of information from different stakeholders needs to be gathered. Waiting for information to be sent back from schools, patients, etc., created long delays both for primary and secondary care services. Communication through these processes was also often difficult.

> *"It can be a very quick process, or it can be a very strenuous process depending on the school" (P3- secondary care professional)*

> *"There was supposed to be a system set up where schools gave an awful lot of information to the GPs to pass on to the paediatricians, and for some reason that doesn't happen" (P9- secondary care professional)*

The lack of accurate information from specialist services, or not enough information from the GPs in general, meant that these services struggled to know how to proceed with diagnoses for specific referrals.

> *"We had a bit of a problem in that GPs were not giving some of the information that we needed, some of the letters were minimal […] At the referral stage, it's a bit frustrating for both sides, really. So if they send me a letter and I think, oh I don't really know what I need to know, I've sent it back to the CPE, the CPE have said to them fill in this form, then they send me the form, which is a bit of a hold up" (P1- secondary care professional)*

> *"In terms of primary care, it varies considerably because every GP practice, as you can imagine, has a different admin system and so some are much more efficient than others" (P18- secondary care professional)*

Communication to the patients

Following a referral, patients received very little information about ADHD regarding the diagnostic and management process. Many reported that once the referral had been sent through, they had no idea about how long it would take, what the process involved, and what was to come next. This implied a lack of communication both from primary and secondary care services.

> *"I asked for a callback and didn't get that. So eventually I made an appointment with my GP who referred me back to the ADHD clinic, and that got lost as well, so eventually I had to call the clinic again" (P10- adult)*
>
> *"So there wasn't clear communication between them and me either, so I filled in a questionnaire to get onto the waiting list, and I didn't hear anything. I assumed that they decided I didn't have anything, they weren't going to give me an appointment and then all of a sudden, 18 months later out of the blue, I got an appointment letter to go and visit them" (P5- adult).*
>
> *"We were left with this big bombshell, and not; "If you need help in the meantime, you can contact various agencies in your area." It was, "Nope, see you in four months, but I'll give you a ring in a month to see how you're getting on with the medication." (P16- parent)*

Patients felt that services were unwilling to take responsibility and lead the process with clear communication. One of the patients' main issues was being repeatedly passed around, with one service telling them to go to another and vice versa. Patients reported feeling dismissed and wondering why there was such a reluctance to provide information on the process.

> *"So, unbelievably frustrating, there just aren't the resources there, and you just ended up getting passed from pillar to post, and you got pushed onto someone else, and someone else, and someone else […] I felt it was a stacking system, you were being stalled" (P4- adult)*
>
> *"The school kept telling me to go to the GP, the GP said no, they can't refer us, the school had to. I was like a ping pong ball, you know, going backwards and forwards" (P17- parent)*

3.6.2.6 Waiting times

In addition to the semi-structured interviews, interviewees were asked how long it took from GP's referral to the first specialist meeting and receiving a diagnosis. It aimed to explore the experienced waiting time in gaining a diagnosis of ADHD. For most patients, it took between

12-28 months to receive a diagnosis. The different responses are presented in Table 5 below.

Table 5

Reported Waiting Times from Referral to First Being Seen by a Secondary Care Professional and to Getting a Diagnosis

Patients	Time to first being seen	Time to diagnosis
Adults	3 months	5 months
	Unsure	18 months
	6 months	18 months
	18 months	18-24 months
Parents	18 months	18 months
	6-9 months	Under 12 months
	4-5 weeks (private diagnosis)	12 months
	12 months	12 months
	3 weeks (private diagnosis)	Unsure
GPs	Unsure	Unsure
	Unsure	Unsure
	6-12 months	6-12 months
	2-3 months	4 months
	Unsure	Unsure
Secondary care	8 weeks	8 months
	3 months	Unsure
	36 weeks	Up to 6 months
(adult services)	2 years	Up to 2 years
(adult services)	18-24 months	24 months

3.6.3 Discussion

This thematic analysis yielded many inter-related themes from multiple perspectives on ADHD awareness in primary care in the UK, primarily focusing on difficulties with pathways, identification, and communication. The findings have the potential advantage of including standpoints from multiple stakeholders involved in the diagnosis and management process of ADHD, highlighting many similarities in their experiences of ADHD care.

This study's qualitative nature allowed for a strong focus on participants' own experiences and for more targeted topics to be discussed from a stakeholder perspective. A recent quantitative study investigating GPs' attitude and knowledge towards ADHD (Adamis et al., 2019) found that very few GPs had a positive attitude towards ADHD. While this was discussed in our interviews, our study allowed this topic to be explored further, emphasising specific difficulties with communication and misconceptions that are harder to capture in a quantitative format.

Our findings also strongly overlapped with previous research. In our systematic review, considerable lack of accurate knowledge, issues with services and difficult communication between multiple stakeholders were also barriers to access to care for ADHD. Semi-structured interviews conducted with UK and Belgium clinicians (Kovshoff et al., 2012) investigating decision-making in managing ADHD also reported issues around multidisciplinary communication and the lack of clear, operationalised guidelines and services. Finally, GPs and parent interviews on barriers to treatment of hyperactivity (Klasen & Goodman, 2000) also highlighted issues with pathways to care, misconceptions, GPs' lack of experience and knowledge. Klasen and Goodman (2000) conducted a series of qualitative interviews with UK GPs and parents and found significant differences between them in the conceptualisation of ADHD and treatment expectations. Parents viewed ADHD to be biologically mediated, benefitting from diagnosis and treatment. In contrast, many GPs viewed ADHD as transient, an expression of psychosocial stressors, being less clear about the merits of diagnosis or treatment. There was a concerning dichotomy with parents fearing blame and GPs viewing parental wish for diagnosis as a way to minimise or deflect from shortcomings in parenting, leading to significant barriers in accessing pathway to care.

GPs often act as gatekeepers to accessing care, and without their referrals, it is often impossible to access diagnosis or treatment. Therefore, it was interesting to find that this study's main topic was the lack of identification from GPs. This reflected previous findings on GPs' non-recognition being a principal barrier in the pathway to care (Sayal et al., 2002). While no patient or GP stated that GPs had ever refused or interfered with the referral process, the ADHD referral process was almost always a patient-led approach firmly based on self-education and awareness. Implications for patients with no understanding of ADHD are consequently compelling (Sayal et al., 2006). Suppose a patient does not know about ADHD or is not aware of the wide spectrum of ADHD symptomology (inattentive type versus hyperactive type, for instance). In that case, they might never seek a diagnosis or receive appropriate access to care. GPs stated that they also never had a referral refused. While this was interpreted as a very low diagnosis threshold, this is more likely to mean that the nature of a patient-led approach means that a wide range of patients may be missed, and ADHD may be often under-diagnosed.

The second difficulty relating to ADHD awareness is specific to the UK healthcare system and covered the complexity and lack of clear pathways for children and adults' services. These services vary widely across the country. Moreover, as the ADHD referral and diagnosis process involves multiple stakeholders (school, families, secondary care, etc.), this increases the complex communication between them as it requires several different individuals to respond appropriately. This was also highlighted by the concept of shared care agreements where GPs can agree to take over the prescription of ADHD medication. These agreements are not compulsory and vary widely between practices, but without them, patients have to go to overbooked secondary care services, making the process lengthier and more complex.

Waiting times were also an important topic highlighted in these interviews, often with a negative connotation. GPs reported not knowing how to support their patients during the long wait, and patients reported symptoms and mood worsening over time. Secondary care workers also reported feeling upset knowing patients had to wait a long time and not enjoying having to find ways to triage patients due to the ever-growing waiting lists. All stakeholders felt frustrated and helpless at addressing this particular issue. As patients reported years of struggle before being aware of their diagnosis and having only looked into ADHD once they had reached a crisis point, the extra time added to access care was felt to be very damaging. While waiting times were discussed in the interviews, all participants were asked about their own experience with delays, both in seeing a secondary care worker and receiving a diagnosis. A recent study (Fridman et al., 2017) investigated diagnosis times in Europe and found that the UK had the longest waiting time (on average 18.3 months) from the first visit to the GP to a formal ADHD diagnosis. They also reported that the UK time from first noticing symptoms to a formal ADHD diagnosis was on average 31.9 months. These findings strongly reflect the views expressed in this study, with great delays in accessing care and the nature of the patient-led approach creating further delays between first noticing symptoms and accessing care, at times of up to almost three years.

Strengths and limitations

Having four different groups of participants in this study provided a more holistic approach to understanding the referral process, allowing for multiple stakeholder perspectives to be taken into consideration. While the different groups had different experiences, the overarching themes were mostly expressed by all groups, indicating a strong relevance of the issues presented. This relevance was also reinforced by the facts that themes overlapped with previously published research in the literature and that participants were from different localities.

The findings presented by this study are of international relevance for countries where GPs hold a gatekeeping role in ADHD identification and referral (Sayal et al., 2018), having substantial implications for practice and research.

It is important to note that while this study reflects key concerns from multiple stakeholders' experiences, these are based on their individual experiences and practices and might not necessarily map onto other stakeholders' experiences.

The majority of GPs taking part in this study (4/5) were a self-selected sample of young GPs, newly qualified (within five years). While they expressed a strong interest in ADHD, they might have had limited experience in referral. The input of older GPs who might have had more experience in seeing ADHD patients is lacking. It is also the case that GPs who qualified over a decade ago might also be less likely to have received ADHD training. Secondary care professionals who had greater experience of ADHD noticed a change in ADHD awareness in the last decade. One participant stated that he delivered training to GP trainees annually and therefore knew that all GPs in his region did receive some ADHD training. Consequently, it could be assumed that younger GPs might have been more likely to have received training on ADHD and therefore have a better awareness of the disorder.

A few interesting points arose from our parent sample. For instance, no fathers were represented. Only mothers took part in this study, which limits our analysis by not including a paternal view. Similar studies have found that mothers' views tend to be reported much more often in the literature than fathers' (Cadman et al., 2012; Kildea et al., 2011). This could be potentially explained by mothers' cultural implications, often being the ones taking their child to the GP. However, two males were represented in our adult patient sample.

Implications for practice

These interviews have demonstrated that GPs are ill-equipped to identify and manage ADHD in primary care, in part due to barriers in access to care, lack of knowledge and resources, lack of clear pathways and services. These factors created discomfort around the process of diagnosing and supporting patients with ADHD. Our findings indicate a need for increased and more specific awareness training about ADHD, clearer pathways and more services to be commissioned to support the ongoing delays experienced in ADHD diagnosis and treatment, with a greater focus on adult services and transitioning patients. Better integration between primary and secondary care services may also address communication issues, further support GPs, and promote better services. Additional training on ADHD identification and awareness could also reduce GPs' uncertainties about ADHD. Finally, support during the diagnosis process is strongly needed, providing management strategies through the lengthy diagnosis process.

Implications for research

This study provides a more in-depth insight into the primary care experiences of ADHD, both from a GP perspective but also from other groups involved in ADHD diagnosis and management. An evident lack of knowledge and understanding was presented in this study, and future research should focus on addressing these issues. By increasing accurate knowledge and reducing misconceptions, validated psycho-educational interventions on ADHD - explicitly tailored to GPs - could address these issues. This study also potentially opens further exploration into how these findings might generalise more widely to other psychiatric disorders.

3.7 Conclusion

These findings highlight a strong need for early diagnosis and better identification from GPs. Many barriers prevent this from happening, and while some are difficult to address, such as the complexity of the diagnosis pathway in the UK, others can be addressed by better awareness and education on ADHD.

One of the main differences between the two studies was in the presence of stigmas. All interviewees in the pilot study expressed very strong stigmas and negative connotations towards ADHD. However, these were more mitigated in the second set of interviews, which several factors could explain. Firstly, this could reflect a real difference between GP trainees and practising GPs, highlighting the importance of clinical experience in understanding ADHD. Stigmas and misconceptions could arise from personal beliefs and impressions but having actual experiences of seeing more patients could soften these stigmas.

Secondly, this could be due to the time difference between the two studies. As stated by some participants in the interviews, there has been a substantial change in understanding ADHD over the years, with healthcare professionals gaining a better awareness as time goes by. As six years had elapsed between the two studies, this difference in misconceptions could reflect a general change of awareness over time and demonstrates that understanding of ADHD is improving. It is important to note that the nature of the stigmas was also different between the studies. The GP trainees' stigmas were broader misconceptions around gender, age and ADHD symptoms, whereas the misconceptions expressed by GPs were subtler and related to the environment, such as the role of parenting and SES.

The themes emerging from these interviews have many implications on GP trainees' experience of ADHD, such as a strong need for gaining education and experience and a shift away from negativity towards the disorder. An overlap in primary care professionals' issues was observed between the systematic review and this exercise, demonstrating consistent matters on this topic. However, it is important to note that the question explored was very complex and cannot be narrowed down to these themes alone. As was highlighted by the literature review and this study, many different aspects of understanding ADHD in primary care have emerged, giving a good overview but also underlining that many factors were involved and, therefore, the difficulty in obtaining a comprehensive overview

From a more general approach, it is essential to note that thematic analysis is very subjective. If many individuals were to analyse the same dataset, each individual might extract different themes. Therefore, this interpretation of the data was solely BF and might not be agreed upon by others, including the interviewer herself. Furthermore, as a literature review of this topic was previously conducted; this could have biased the analysis. While a clear effort was made to approach the interviews with an open mind and no preconception, it was difficult to guarantee that the extraction was not influenced by BF previous experience on some unconscious level.

3.8 Reflexive statement

These interviews raised many questions in the process of qualitative analysis. Guidance on reporting qualitative analyses recommends acknowledging the lead researcher's characteristics as this is an integral part of the analysis process (Tong et al., 2007). Despite considerable training, the nature of the issues that arose through the interview process and analysis process were unexpected. The main point of reflection stemmed from the different experiences and expertise BF brought to the interviews. BF approached the interviews from multiple standpoints:

- A patient standpoint. Firstly, having received a diagnosis of ADHD as an adult, BF had extensive experiences with primary care from a patient’s point of view.
- A clinical standpoint. Secondly, BF has been facilitating patients’ workshops for parents and adults with ADHD for the last eight years.
- A researcher standpoint. Finally, BF worked as a researcher before becoming a PhD student and conducted interviews as part of a research project.

These many experiences allowed for a comprehensive overview of ADHD. Following her clinical and personal experience, it was imperative to include a patient’s perspective, firstly to ensure that both sides of the argument were included and encompass BF‘s perspective and experiences. However, these doctoral studies' primary purpose was not to validate the lead researcher’s experience and beliefs but to take an objective view of GPs’ own experiences. Due to this thesis's medical stance and the institution in which this thesis is grounded, objectivity towards the project was encouraged, and a researcher standpoint should prevail. Therefore, BF had to continuously realign her own emotions, beliefs, and expectations to this thesis's main purpose. At times, these were conflicting, but it was important to regularly try to manage these and acknowledge the impact on both the analysis and interview process. Nonetheless, it is also essential that BF’s own experience of having ADHD herself and having worked with individuals with ADHD strongly influenced her doctoral studies' approach and should not be discounted either.

For instance, in the context of the interview process (for the semi-structured interviews), BF tried to follow the interview schedule as much as possible. While the schedule allowed for some freedom in exploring topics, BF was aware that her own experiences might influence these and tried to account for this when asking questions.

In the context of analysis, this was more difficult for the pilot study. As BF didn't conduct the interviews herself, it was important not to let personal beliefs and feelings impact the analysis process. This was at times difficult as some prompts that arose during the interviews were somewhat contentious (for example: "Some people see ADHD as being a medical disorder and others see it as arising from stress or diet, where do you see it as coming from?") and would not have been asked in the same manner by BF. However, in the context of the semi-structured interviews, it was more complex to appreciate how much BF's own experiences impacted the analysis process. Many factors influenced her standpoint by then, the results from the literature review, the pilot studies' results, and her personal experience leading to some strong preconceptions about the findings. Therefore, a distinct effort to be objective was made to ensure that all topics were discussed and represented in the analysis.

More specific reflections on the different experiences from the two studies are presented below.

Pilot study

The pilot study was the first thematic analysis of this scale conducted by BF. In contrast to the limitations discussed above brought by having a separate person transcribing and analysing the interview to the person who conducted the interview, a few positive aspects emerged from this process. Firstly, BF's acquired knowledge on the topic meant that she understood fully the topic and issues discussed. As BF had limited understanding of the interviewer's theories or reasoning behind the interview schedule and the interest in the specific topics asked, she had little preconceptions of the data. Similarly, as she had no control over the interviews, only analysing them, she could completely distance herself from the interview as she had no pre-established relationship with the participant. The nature of the relationship with the participant can strongly influence the interview and/or the analysis of the interview as you might assume you "know" what they mean from having already spoken to them, or you might have a positive or negative impression of them after the initial meeting (Edwards & Holland, 2013). Being an "outsider" helped BF look at the data in an unbiased way, without making assumptions, facilitating the analysis and transcription of the data.

However, the participant and interviewer's level of interaction is also important in building trust and conducting the interview. Therefore, the fact that BF did not conduct the interviews strongly impacted that important rapport; for example, possibly misinterpreting the intentions of some questions as she was unaware of what the interviewer’s standpoint was.

Semi-structured interviews

These interviews were conducted mainly over the phone. While this approach was taken to facilitate access to GPs and secondary care professionals, it had some limitations. In some interviews, the signal was lost or the quality not adequate, which either impacted the quality of the transcript or impacted the interview flow as BF had to ask participants to repeat themselves. This was minimised by instructing participants to be in a quiet place with a good phone signal and allowing plenty of time. However, some participants were only able to partake while driving to work, for instance, or in their break in a busy office. A pragmatic approach was taken, prioritising the participants interviewed over a specific method. When a face-to-face interview was conducted, the interview itself felt different. By seeing the individual’s body language and facial expression, the interviewer takes a different approach, a different flow occurred. It was difficult to reflect on how much this impacted the content or quality of the data or if one method is better than the other, but it is important to note a discrepancy between both methods.

It was long debated by BF about how much of her expertise was to be disclosed to the participants. As the interviewees represented different groups, it was difficult to decide whether to stick to just being a researcher or whether to disclose all aspects of expertise or even change her standpoint according to different participants. Presenting herself as a researcher felt the most relevant and appropriate (as this work is for a doctoral study), especially with healthcare professional groups. Disclosing personal experience of ADHD might have muddled the purpose and outcomes of this study and the message to health care professionals, potentially adding a personal agenda to the interviews, which would not be suitable. However, with regards to the adult patient and parent groups, some already knew BF’s background. A more flexible approach was taken with these participants as it was felt that being a peer might potentially facilitate the interview process. Therefore, a pragmatic approach was taken with these two groups, and on a couple of occasions, BF disclosed her own experience as it seemed essential to connect with these individuals.

In conclusion, these studies raised unexpected complex questions on the objectivity of analysing qualitative data. This required a constant adjustment and balance between BF’s intentions, work and personal experiences, work ethics and own beliefs. The primary purpose of these interviews was to understand gaps in GPs’ awareness and knowledge of

ADHD. While at times complex, having multiple standpoints eventually benefited and facilitated the outcomes of the robustness and informed contents of these studies.

Chapter 4 Psycho-educational intervention development

4.1 Chapter summary

The previous studies in this thesis have established key barriers and themes in understanding ADHD in primary care. The next step was to develop an online intervention informed by these findings. The psycho-educational intervention was developed over nine months. After careful consideration and research over the first year of the doctoral studies, a concrete plan in the development of the intervention was put in place to improve GPs' knowledge of ADHD and optimise appropriate referrals. This chapter explores how this intervention was developed with a specific focus on co-production with GPs. Involving end-users in co-creating interventions may enhance their clinical utility and impact routine clinical practice.

This chapter reports a step-wise, co-production approach towards developing the online ADHD education intervention for GPs. Preparatory work from our previous studies highlighted the relevant topics to be included in the intervention, from which educational videos were then developed. Workshops and reviews were then conducted with GPs, leading to further refinement of the video content and, subsequently, the final intervention.

The first step was to aggregate the first studies' findings to gain a more specific idea of the gaps to be addressed. The first studies aimed to highlight the many gaps and issues experienced in the awareness of ADHD in primary care settings. Therefore, careful considerations over the barriers highlighted by the systematic review and the issues highlighted by the qualitative study need to be given. As many obstacles and issues were unearthed, it was essential to decide which could be addressed or represented in the intervention and which were beyond the realm of these doctoral studies. For example, while the intervention aims to further GPs' knowledge, barriers such as lack of resources or lack of services cannot be addressed.

The second step in the development process was to film children with ADHD talking about their experiences. A similar film had already been produced by the Nottinghamshire Healthcare NHS trust adult ADHD clinic. This short video was compelling, and it felt important to include patients' experiences of the condition to convey a greater understanding of the condition in everyday life. Permission to use this video within the remit of this thesis was granted, and it was decided to create a similar one with children. The same filming company was used to ensure coherence between the two videos. A short version (5 minutes) and a long version (20 minutes) were created for adults and children, the short version to be included in the intervention and the longer version as an extra reference accessible online at any time.

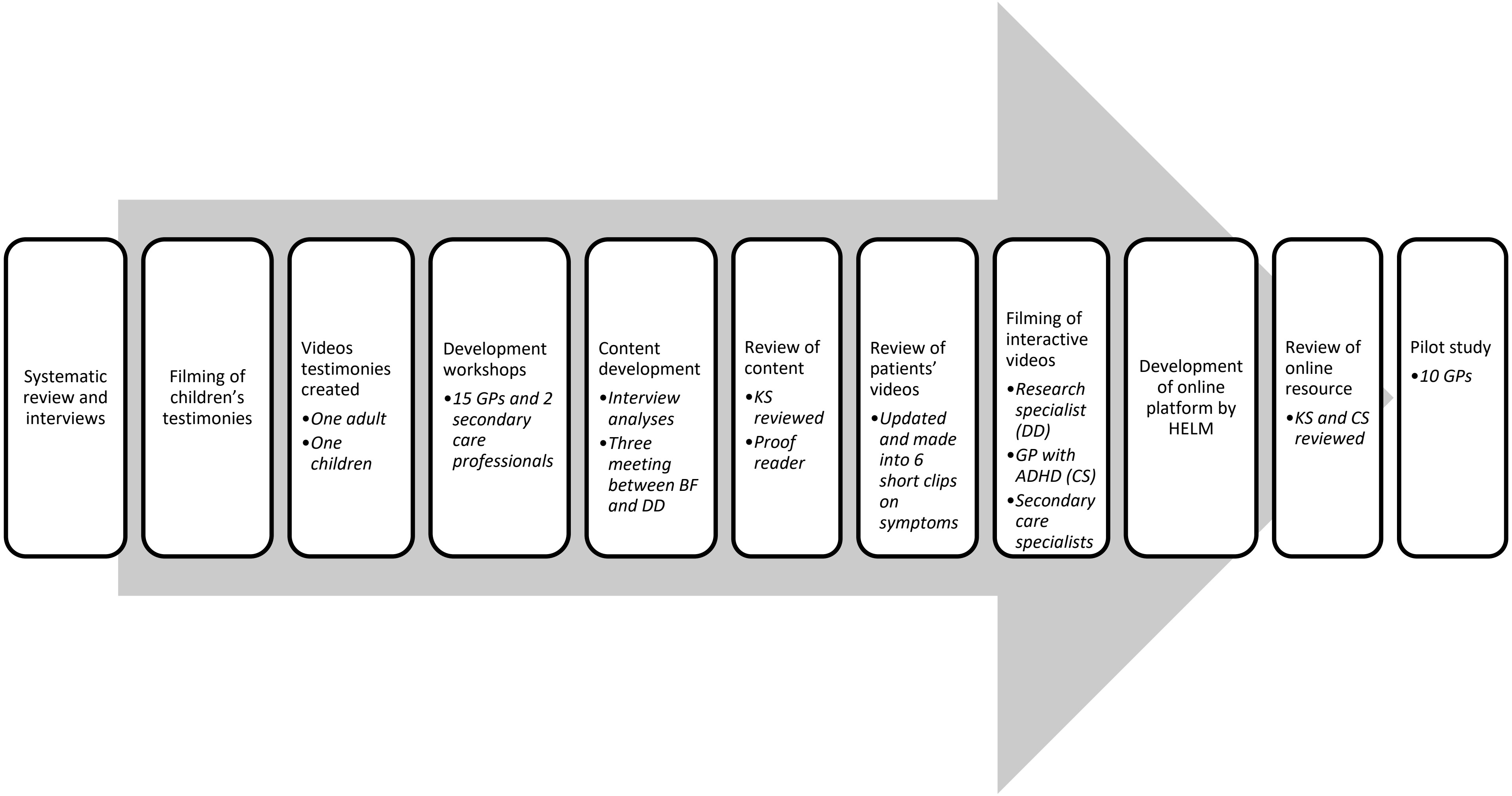
The next step in the intervention development process was to create the online resource. For this, and after researching different options, a team from the University of Nottingham School of Health Sciences, specialising in health e-learning resources (HELM) was selected. A specific development programme was followed according to their own tested methods, which involved working together as a team - BF and DD developing the content of the intervention and HELM creating the learning platform. This process took around six months, involving multiple steps and a final product was ready to be tested by July 2019.

The involvement of GPs greatly facilitated the development of the online intervention. Having a co-production development process ensured the constant adaptation of the intervention to meet GPs' needs. The importance of co-development was highlighted in developing an intervention that addresses specific needs for GPs.

The flowchart below (Figure 5) represents the development process of the intervention.

Figure 5

Intervention Development Process



4.2 Outputs

This chapter produced a few open access outputs.

- Parts of this chapter were peer-reviewed and published (cited twice):

French, B., Daley, D., Perez-Vallejos, E., Sayal, K., & Hall, C. (2020). Development and evaluation of an online education tool on Attention Deficit Hyperactivity Disorder for General Practitioners: the important contribution of co-production. *BMC family practice, 21, 224*

https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-020-01289-5

- Videos of children testimonies:

Short version (viewed 129 times):

https://vimeo.com/306201810

Long version (viewed 233 times):

https://vimeo.com/309301001

- An online psycho-education resource (accessed 593 times):

www.adhdinfo.org.uk

4.3 Introduction

ADHD awareness in primary care is minimal. Currently, there are few evidence-based interventions aimed at improving GPs' knowledge and confidence of ADHD. The development of interventions targeted at increasing their knowledge and confidence is therefore essential.

To address the issues raised in the previous chapters, an online intervention aimed to increase GPs' understanding and awareness of ADHD was developed. By increasing ADHD awareness and knowledge, this intervention aimed to increase support for ADHD in primary care and facilitate identification and appropriate referral.

Healthcare professionals' use of online training has significantly increased over the last two decades (Casebeer et al., 2010; Harris et al., 2010), with a US study reporting an increase of physicians taking part in online learning activities from 605,410 to 4,365,014 between 2002 and 2008 alone (Casebeer et al., 2010). An online education resource offers many advantages for healthcare professionals and GPs. It can be easily accessible at times that work around GPs' busy schedules and from any location, which is particularly beneficial for those in remote areas. A recent literature review demonstrated that online training could significantly improve GPs knowledge and practice (Thepwongsa et al., 2014). However, to promote uptake of these interventions in routine practice, it is essential that the developed intervention meets the end-user's needs and is deemed feasible and acceptable. Interventions tailored to address identified barriers have been shown to improve professional practice (Baker et al., 2010). Co-produced research offers the opportunity to enhance this. Although co-production is becoming a familiar term among healthcare researchers due to the opportunities for innovation and service improvement it provides (Batalden et al., 2016), little is known about how to achieve the positive outcomes derived from co-production and the mechanisms/processes involved in co-production activities. Valued co-production occurs in particular when users (i.e. GPs, patients, carers) can personalise their experiences and influence specific research tasks and outputs. This process requires active collaboration by users and researchers to create value. Embedding co-production activities into research is a way to promote responsible innovation and to ensure that the research outputs are relevant, engaging and desirable for end-users (McDermott et al., 2010; Nulli & Stahl, 2018).

Researchers acknowledge that co-produced research may be challenging, involving a tricky balance of different expectations, goals and experiences; however, studies have also found that researchers learn a lot from involving end-users in their studies (Staley, 2017). The majority of papers do not describe their methodological development process beyond publishing their protocol (Hall et al., 2019). However, sharing experiences of the process of co-producing interventions provides the opportunity for a greater critical appraisal of interventions and may facilitate knowledge exchange.

This chapter reports the methodological development of an online education resource. To ensure that the intervention met the end-users' needs (GPs), the intervention was co-produced by GPs and underwent many iterative steps, with input from GPs at each stage.

4.4 Outcomes of the systematic review and qualitative study

The previous studies described in this thesis aimed to inform this study - the development of an online education resource. More specifically, it informed the nature of the content rather than the format. The systematic review allowed for a broad international overview and discussed internationally relevant barriers. On the other hand, the qualitative study focused more specifically on individuals’ own experiences, highlighting country-specific issues to the UK. The findings of these two studies are discussed in relation to the broader impacts on the online resource development and how it informed its content.

4.4.1 What did we learn from the literature review?

Four main themes were discussed in the systematic review.

- Need for education – issues discussing the lack of training on ADHD for PCPs, lack of accurate awareness and a lack of confidence around ADHD
- Misconceptions and stigmas – issues linking ADHD to general stigmatisation and misconceptions and the role of labels and media.
- Constraints with recognition, management and treatment – issues with time constraints and complexity of ADHD as well as issues with treatment options for ADHD.
- Multidisciplinary approach – issues with the role of different specialists, the role of the school, the parents and people with ADHD themselves.

Two key overarching concepts emerged from these findings.

Firstly, due to the nature of ADHD, the pathway to diagnosis is very complicated. With multiple professionals involved, it has many sequential steps and depends on the local services available.

Secondly, issues around knowledge, awareness and attitudes towards ADHD were strongly present. Whether it was discussed in the concept of misconception, lack of training, or lack of recognition, increasing accurate knowledge is crucial.

4.4.2 What did we learn from the qualitative study?

The pilot study and the multidisciplinary interviews highlighted many overlapping themes in the awareness of ADHD in GPs.

Pilot study

- Negative connotations of ADHD – issues around the label of ADHD, stigmas attached to the disorder and the role of the media in reinforcing these.
- Parenting – the positive and negative impacts of parenting and its role on ADHD presentation.
- Social background – the impact of the environment, socioeconomic status and changes of society overtime on ADHD.
- Lack of experience/knowledge – issues with insufficient training and lack of knowledge on causes, treatment and diagnosis processes.
- Diagnosis/consultation procedure – the need for multidisciplinary approaches and the consultation process.

Two key overarching concepts emerged from these findings.

Firstly, issues around knowledge and experience were a strong barrier in understanding and awareness of ADHD. ADHD was linked to negative connotations and misconceptions. Including misleading beliefs about the parent or society's role in ADHD, stigmas, and uneasiness were strongly present.

Secondly, issues around the complexity of the diagnosis and identification but also more specifically around the consultation process were discussed. This is related to many aspects, including the notion of multidisciplinary approaches and lack of resources.

Interviews

- Lack of identification in primary care – the pathway to ADHD diagnosis is a patient-led approach. ADHD, as a disorder is not identified in primary care.
- Lack of clear diagnosis pathway and services – issues around the complexity of services, long waiting list and more specifically, the lack of adult services.
- GPs' knowledge of ADHD and misconceptions – GPs' insufficient knowledge and misconceptions on ADHD
- Difficult communication between multiple stakeholders – Complex communication between and within services as well as with patients.
- Impact of diagnosis and the risks linked to no diagnosis – the positive impacts of receiving a diagnosis and issues around GPs' negative views of ADHD diagnosis and label.

The concepts emerging from the semi-structured interviews encompass three similar overarching concepts.

Firstly, and similar to previous findings, many issues around knowledge were presented. This implicated issues around identification, and GPs not picking up ADHD, communication with patients, lack of accurate knowledge of the disorder and services and misconceptions.

Secondly, issues with services were also present. These issues included a lack of services and pathways but also difficulties with communication between the different services.

Finally, the impact of receiving a diagnosis was presented. This impacted the patients who saw many benefits in receiving a diagnosis and the GPs who had somewhat a more pessimistic view towards it.

4.4.3 How did this impact the psycho-education development?

The findings from the systematic reviews and qualitative studies strongly impacted the content development of the online resource. These highlighted specific barriers in GPs' understanding of ADHD - Table 6 summarises the main themes unearthed by these studies.

Table 6

Summary of Themes Relating to Awareness and Understanding of ADHD in Primary Care

Systematic review	**Pilot study**	**Semi-structured interviews**
1. Need for education	1. Negative connotations of ADHD	1. Lack of identification in primary care
2. Misconceptions and stigmas	2. Parenting	2. Lack of clear diagnosis pathway and services
3. Constraints with recognition, management and treatment	3. Social background	3. GPs' knowledge of ADHD and misconceptions
4. Multidisciplinary approach	4. Lack of experience/knowledge	4. Difficult communication between multiple stakeholders
	5. Diagnosis / consultation procedure	5. Impact of diagnosis and the risks linked to no diagnosis

The collective findings from these three studies can be broadly categorised into two main concepts, (1) issues around knowledge and (2) issues around the complexity of the diagnosis. Issues around the complexity of the diagnosis were somewhat challenging to address in the context of the intervention. However, by gaining a clearer understanding of various stakeholders' roles and understanding the diagnosis pathway, GPs could find the complexity around ADHD lessen. Access to tools and support was also included to facilitate communication, time constraints and referral processes. Within the context of knowledge, the different points highlighted above were addressed as thoroughly as possible in the intervention.

General knowledge was included, but more specific topics such as pathways and services and the GP's role were included to ensure more awareness around these issues. It was also felt that due to the presence of misconceptions, clear messages on prominent stigmas needed to be included. A particular slide on “myths and facts” was presented, and many misconceptions were addressed throughout the content. The content also addressed the common beliefs around SES, parenting and behaviour in consultations highlighted in the qualitative study. The negative connotations associated with ADHD were addressed by talking about the positives of ADHD, including testimonies from patients and a fellow GP with ADHD. The benefits of receiving a diagnosis were also discussed. However, to address the impact of not receiving a diagnosis, the risks associated with ADHD were also included.

The previous studies highlighted many gaps and issues. These issues directly informed the intervention's content, allowing for a targeted approach to address GPs' need in gaining a better awareness of ADHD.

4.5 Adult and children videos

4.5.1 Video of adults with ADHD

4.5.1.1 Participants

Five adults took part in this video, three males and two females (mean age: 32y4m, Range: 21-44y). These adults were recruited from the ADHD adult clinic and the ADHD adult support group in Nottingham. Both males and females of a wide age range were selected.

4.5.1.2 Settings

The video was filmed in Nottingham at the participants' homes and in different locations reflecting day-to-day situations (at their work, on the tram, etc.).

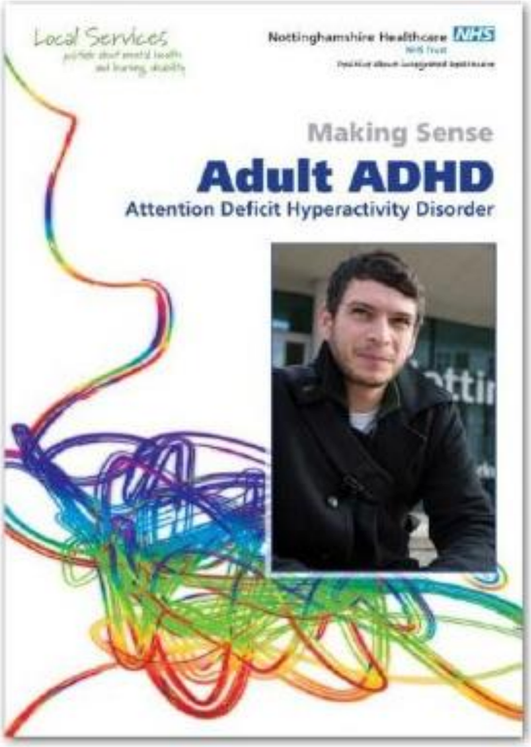
4.5.1.3 Method

The videos were initially designed by a consultant psychologist (AG) to help adult mental health services in Nottinghamshire. The filming company spent 2-3 hours with each adult, firstly filming them in their home environment and secondly filming them doing daily tasks. The interviewer had an interview schedule (Appendix 5) for all participants, which focused on their experiences at work, in relationships, at school and at home. Some topics were prompted more often with some participants, depending on their personal circumstances. For instance, one young man who went to university was asked more questions about the challenges of studying.

Once the videos were finished, the interviewer reviewed each one of them to pick out the most relevant quotes to include in the final video. The aim was to show how ADHD impacted individuals in different contexts and how their symptoms and impairments translate in daily life.

4.5.1.4 Videos

A 20-minute DVD was initially created and given to patients seeking understanding during the diagnosis process. An online version of the video was subsequently developed for easier access. A 5-minute trailer was also created to give a brief overview of the video.



The link to the short version of the video can be found below:

https://vimeo.com/64790626

The link to the long version of the adult video can be found below:

https://www.youtube.com/watch?v=sHwi1mjVwcs&t=31s

4.5.2 Video of children with ADHD and their parents

4.5.2.1 Participants

Eight children took part in this video, four girls and four boys (mean age: 10y8m, Range: 7-15y). The children were selected from a local charity, Parenting Special Children, for which BF had previously worked, and all parents signed a disclaimer form before their children being filmed. An email was sent out to the families registered with the charity, and participants who responded were included. It was decided that up to 8 children would be filmed, 4 in the morning, 4 in the afternoon has it was felt that it could be too overwhelming to have more than four children at the same time. Children were selected to represent a wide age range but also to ensure that both male and female children were represented. Twelve responses were received from families wanting to take part, and two were unable to attend due to conflicting schedules, and two were advised that they would be contacted if a participant dropped out.

Some parents also took part in the videos to talk about their experiences.

4.5.2.2 Settings

The videos were filmed at the charity Parenting Special Children in Reading. The venue had three rooms available, one for filming the children individually or with their parents, one where other children could wait while playing games or doing activities and one quiet room where parents and children could relax and have a beverage. The venue also had a garden, which was used to film the children playing in between interviews

4.5.2.3 Method

The filming was produced by an experienced company which specialises in health and social care topics. They were chosen as they had experience in filming with participants with varied health issues and were very adaptable and competent in dealing with this particular population

The families were invited to spend either the morning or afternoon filming. The younger four children came in the morning and the older four in the afternoon. Lunch was organised for all the families, which allowed them to meet and play together and allowed the team to film them as a group.

The interviews were semi-structured (Appendix 6); topics such as school, friendship and family were discussed during the interviews. Open-ended questions were scripted beforehand to gain specific information from the children ("What is your favourite thing to do at school?"). The interviews lasted between 15-20 minutes for each child. All the children were interviewed first, and then parents were interviewed for up to 5 minutes, depending on their availabilities. While each child was being interviewed, the other children played games and did activities in a separate room. Parents could go to the interview room if the child wanted their support or stay in the waiting room, depending on the child's preference.

In two cases, the children found it very difficult to be interviewed and "shut down". No pressure was placed on them, and a different interview format was approached: one child was filmed with her mother, which allowed her to open up a little bit; for another, only the parents were filmed and were able to discuss their child's difficulties.

The families each received a £50 voucher as a thank you for their participation (£20 for the children and £30 for the parents).

4.5.2.4 Videos

The interviews were edited to take out comments that were not relevant. The children's clips were all reviewed by BF to select the best parts to be included in the videos. The clips included covered all the topics discussed, such as family, school issues, leisure activities and friendships. Once these were selected, the film editing crew produced the final products.

The filming produced two videos.

The link to the short version of the video can be found below:

https://vimeo.com/306201810

The link to the long version of the adult video can be found below:
https://vimeo.com/309301001

4.6 Online resource

Following the video development, an initial outline of the intervention emerged, centred on the video discussions pertinent to the main barriers in understanding ADHD.

As such, the proposed content for the online intervention focussed on:

1) Understanding the different roles held by various stakeholders
2) Understanding the role of the GP
3) Understanding the diagnosis pathway
4) Improving general knowledge of ADHD
5) Dispelling common myths on ADHD
6) Socioeconomic status (SES), parenting and the child's behaviour in the consultation
7) Understanding and challenging common negative conations of ADHD
8) Benefits of receiving an assessment and/or diagnosis
9) Risks of untreated ADHD

The psycho-education resource was developed in partnership with the HELM (Health E-Learning and Media) team from the University of Nottingham School of Health Sciences. The HELM team specialises in media-based educational materials and intervention in health and was chosen to develop the online resource due to their expertise in the area. They have developed over 250 RLOs (reusable learning objects) over the last decade, all related to health education topics for nurses, practitioners, commissioners and patients. The RLOs development and online format have shown a robust template for these resources. One of the many benefits of developing the intervention with the HELM team was that the resources created will be freely available online and accessible by anyone, including the tens of thousands of HELM users.

The HELM development process has specific stages to ensure the most optimal final product and learning outcomes, which has established efficacy.

Stage one - a workshop is set up with service users or population of interest (in our case, GPs) to develop a targeted intervention. This workshop creates a set of storyboards that informed the content of the resource. This stage of the development process is essential as studies have demonstrated the importance of tailoring interventions to their target population and the need to be appealing and accessible to its users (Campbell et al., 2007). Specifications for the resource are then developed (by BF in this thesis), including but not limited to written content, exercises, interactive activities and assessment.

Stage two - A peer review process follows whereby the proposed content is reviewed by an expert on the topic that has not been involved in the development. The creation phase then starts and is solely conducted by the HELM team. Upon completing the online resource, another review process is undertaken where a reviewer and the team assesses the final product before dissemination.

The development process followed, paralleled this process but also incorporated an additional third Stage – a usability study to assess the intervention (Chapter 5).

For the thorough development of this intervention, a GP (CS) was recruited on a consultant basis. CS was uniquely placed to advise this thesis as she was diagnosed with ADHD as an adult during her GP training programme. Having the input of a GP who is also a service user was extremely valuable and allowed the team to ensure firstly that the information and format were relevant and useful to GPs. Secondly, it allowed the inclusion of a patient’s perspective from a peer who could give a targeted message to GPs about ADHD. CS involvement included being filmed at different points of the intervention and reviewing the content throughout the development phase.

4.6.1 Stage one - GPs workshops and content development

4.6.1.1 Workshops

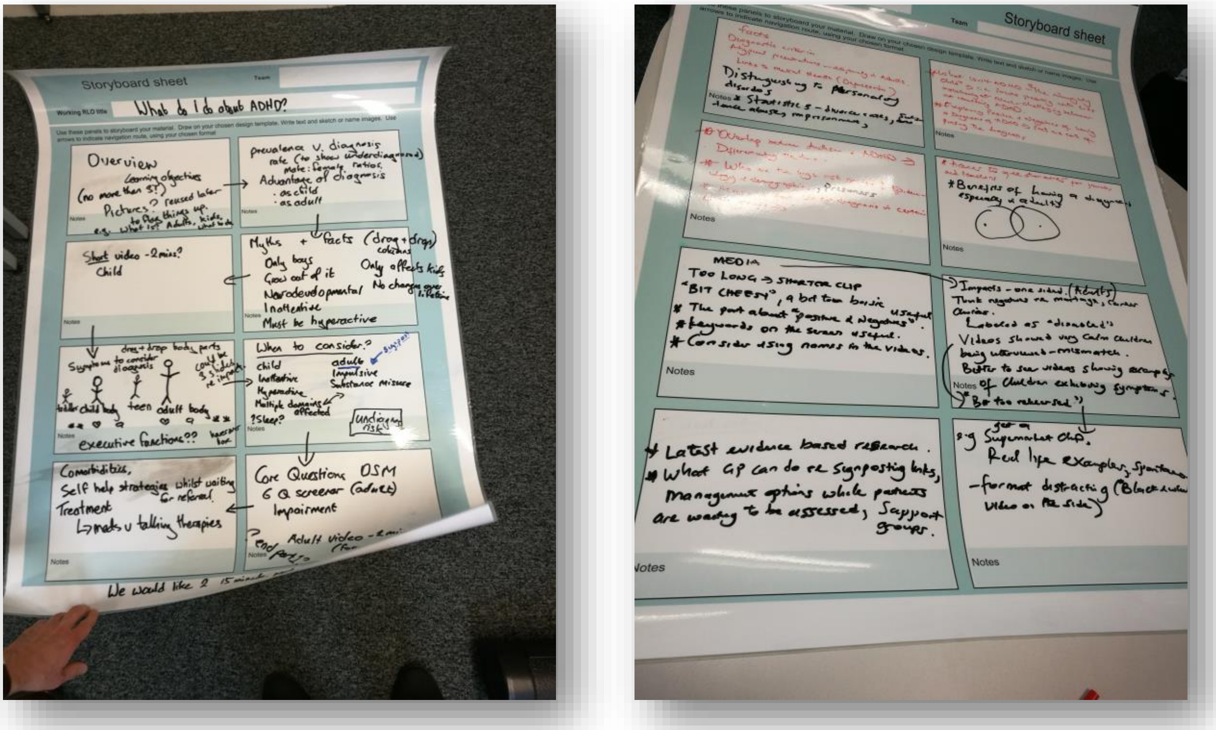
In the context of this study, two development workshops were conducted. This format was agreed upon as issues recruiting enough local GPs were experienced, but an opportunity to work with a GP team from Lincoln presented itself. Therefore, the first workshop ran in Lincoln and the second workshop in Nottingham the following week with different GPs at each workshop. Although running two separate workshops didn't follow the HELM workshop's standard format, it was beneficial as feedback from the first workshop was sought in the second.

Lincoln workshop

The first workshop was conducted at the University of Lincoln and had 11 GPs taking part. The workshop lasted 3 hours, and GPs were compensated for their time. After a brief presentation of the research project, the participants were split into three groups and asked to work on storyboards for the intervention. They were explicitly asked to think about the intervention's format and how they would like it to look rather than specific content. Examples of RLOs were presented to give them ideas about what could be done in terms of activities or media input, for instance. The different groups then presented their storyboards to explain how they wanted to interact with the resource and what they would like in it. Figure 6 presents examples of two storyboards, and Figure 7 shows the teams working on their storyboard.

Figure 6

Example of Storyboards



Storyboard sheet

Team

Working RLO title: What do I do about ADHD?

Use these panels to storyboard your material. Draw on your chosen design template. Write text and sketch or name images. Use arrows to indicate navigation route, using your chosen format

Overview
Learning objectives
(no more than 5!)
Pictures? reused later to flag things up.
e.g. What is? Adults, kids, what to do

prevalence v. diagnosis rate (to show underdiagnosed)
Male: female ratios.
Advantage of diagnosis
· as child
· as adult

Short video - 2 mins?
Child

Myths + facts (drag + drop) columns
Only boys
Grow out of it
Neurodevelopmental
Inattentive
Must be hyperactive
Only affects kids
No changes over lifetime

Symptoms to consider diagnosis
drag + drop body parts
toddler child body teen adult body
could be 3 slides re impact
executive functions??

When to consider?
child
Inattentive
Hyperactive
Multiple domains affected
?Sleep?
adult
Impulsive
Substance misuse
support
undiagnosed risk

Comorbidities,
Self help strategies whilst waiting for referral
Treatment
↳ meds v talking therapies

Core Questions DSM
6 Q screener (adult)
Impairment
Adult video - 2 mins
end part?

We would like 2 15 minute

Storyboard sheet

Team

Use these panels to storyboard your material. Draw on your chosen design template. Write text and sketch or name images. Use arrows to indicate navigation route, using your chosen format

Facts
Diagnostic criteria
Distinguishing from Personality disorders
* Statistics - divorce rates, substance abuse, imprisonment,

Prisoners

* Benefits of having a diagnosis especially in adults

MEDIA
Too long → shorter clip
"Bit cheesy", a bit too basic
* The part about "positive & negatives" useful
* keywords on the screen useful.
* Consider using names in the videos.

Impacts - one sided. (Adults)
Think negatives re marriage, career choice.
Labelled as "disabled"
Videos showed very calm children being interviewed - mismatch.
Better to see videos showing examples of children exhibiting symptoms.
"Bit too rehearsed"

* Latest evidence based research.
* What GP can do re signposting links, management options while patients are waiting to be assessed, Support groups.

e.g. get a Supermarket clip.
Real life examples, spontaneous
- format distracting (Black window video on the side)

Figure 7

Storyboard Teamwork

Nottingham Workshop

This second workshop was conducted at the University of Nottingham and had 4 GPs taking part as well as two secondary care professionals specialising in ADHD diagnosis - one from child services and one from adult services. The two secondary care specialists were included to gain a more specific input to the intervention's content. This workshop ran similarly to the one in Lincoln; however, a review element was added to it due to the smaller numbers. In addition to doing the storyboards, the participants in this workshop were presented with a summary of the Lincoln workshop's suggestions and asked to review these suggestions. The participants were split into two groups, and two different storyboards were created. These storyboards reinforced specific content suggested in the Lincoln workshop but also brought out some new ideas.

Altogether, these workshops were very informative, and many valuable suggestions were extracted to develop the online resource. A few ideas from the storyboard had to be discarded as they were either beyond the realm of these doctoral studies, too tricky to develop, too long for the context of this intervention, or too specific. Some of the ideas that were suggested are presented below (Table 7).

Table 7

Main Suggestions Presented at the Workshops

Suggestions from the workshops
Making two short online resources, one specific to ADHD (Symptoms, epidemiology…) and one specific to the GPs role in diagnosis and treatment
Including information on the benefits of diagnosis, what can happen without treatment (information on prison statistics, substance abuse, suicidality, etc.)
Shorter videos of patients focusing on symptoms
Adding expert videos on symptomatology and secondary care pathways. What happens after a referral
Separating child and adult pathways, having a child-specific module and an adult-specific module
Adding an assessment at the end in the form of a multiple-choice questionnaire
Including information on comorbidities in the form of a diagram
Including information on ADHD at different ages
Adding access to resources for management and for patients' information (Parenting websites, ADHD support groups, charities, etc.)
Comprehensive information on treatments
What is the role of the GP?
Drag and drop activities on myth versus facts
Including an example of a consultation
Information on local pathways

4.6.1.2 E-learning content development

Following the workshops, the specifications for the intervention were developed. All the information was first collated from the workshops, and how it would fit into the original concept was explored. A flow chart was first designed (Appendix 7) to gain a clearer idea of the content. The content was developed in detail over two full days by BF and DD, who synthesised the information from the workshop and developed a draft intervention. In the interim, development and formatting of ideas for activities, media input, etc., continued. After the first draft was completed, CS reviewed the content and changes were addressed from her feedback. Before starting the creation phase of this resource, the content specifications were sent to a reviewer (KS) and proofread. The content was then forwarded to the HELM team for development.

Integration of recommendations

Most recommendations from the workshop were integrated into the online resource. However, some recommendations had to be discarded. Table 8 presents these suggestions and the research team's rationale for or against implementation.

Table 8

Implementation of the Main Suggestions Presented at the Workshops

Suggestions from the workshops	Implementation
Making two short online resources, one specific to ADHD (Symptoms, epidemiology…) and one specific to the GPs role in diagnosis and treatment	Instead of one module, the content was separated into two modules: "Understanding ADHD" and "The role of the GP in the diagnosis and treatment process."
Including information on the benefits of diagnosis, what can happen without treatment (information on prison statistics, substance abuse, suicidality)	A page on the risks of undiagnosed and untreated ADHD was added with research statistic accentuating the importance of early intervention
Shorter videos of patients focusing on symptoms	The videos were changed to make them symptom-specific. The patients' testimonies were restructured, and six shorter videos were developed focusing on features of hyperactivity, inattention and impulsivity in adults and in children
Adding expert videos on symptomology and secondary care pathways. What happens after a referral	Expert videos were added. Four ADHD experts were filmed to give a specialist opinion on specific topics.
Adding an assessment at the end in the form of a multiple-choice questionnaire	A quick assessment of ADHD knowledge was added at the beginning and at the end of the modules to assess any changes in participants' knowledge
Including information on comorbidities in the form of a diagram	The diagram idea was added to the page on comorbidities to improve understanding of overlapping conditions.
Including information on ADHD at different ages	An infographic was created to show the development of ADHD symptoms through the ages.
Adding access to resources for management and for patients' information (Parenting websites, ADHD support groups, charities)	A toolkit was created at the end of the module where many resources on management, support groups, screening, etc. can be found
Comprehensive information on treatments	The pages on treatment were expanded to include pharmacological and non-pharmacological treatments with details on the specific types of medications
What is the role of the GP?	The first page of the second module included a concise summary of what the role of the GP is exactly and what it isn't.
Drag and drop activities on myth versus facts	An interactive drag and drop activity was created to address typical misconceptions about ADHD
Suggestions that could not be implemented	
Including an example of a consultation	GPs suggested including a video of a mock consultation. While it would have been very interesting to implement this idea, adding an extra 10 minutes of videos to encompass a whole consultation felt too lengthy. Furthermore,

	identifying ADHD in patients is very different depending on many factors such as the type of ADHD, age, or gender, and it was felt that all couldn't be represent accurately in one mock consultation.
Separating child and adult pathways, having a child-specific module and an adult-specific module	This suggestion was addressed to an extent by clearly specifying the differences in child and adult pathways when relevant. However, it seemed too repetitive to create separate modules for each as a lot of the information overlapped.
Information on local pathways	Information on local services and pathways was unanimously the one piece of information GPs wanted to receive the most. However, it is impossible to know the different pathways in each UK CCG as, firstly, there are so many, and secondly, services are constantly changing in response to commissioning decisions. However, a statement was added to explain that local services information needed to be sought by the GPs to offer the best access to care.

Following GPs' feedback about specialist input, four ADHD experts were filmed to give a specialist opinion on different topics.

- CS was able to input her powerful story into four pages of the intervention. She related her experience of ADHD to the GPs by putting it into a context they can all relate to, such as medical training etc. Her unique experience was felt to be a key impact factor of the intervention.
- DD, a lead researcher on ADHD, discussed strategies to help support ADHD patients during the diagnosis process and explained the value of non-pharmacological approaches such as parenting programmes.
- Two secondary care specialists (JK and AG) explained the secondary care process following referral. GPs wanted to know what happened in secondary care after a referral was sent. Both specialists have years of experience in ADHD diagnosis and treatment in adults (AG) and children (JK) and were able to describe in more detail the secondary care pathways to diagnosis and management.

4.6.2 Stage two - review

A thorough review process was implemented throughout the development process.

The final resource was produced in June 2019. BF reviewed the content to ensure the resource was developed according to the original specifications.

The modified online intervention (see Table 8) that developed from the workshops and development group review then underwent three further reviews:

- A GP first reviewed the content to ensure it was appropriately targeted to GPs. The content specifications were also sent to a reviewer (KS) who had not participated in the content development. Additionally, it was proofread by a professional proofreader.
- Following the online development, the final resource was produced. The lead researcher (BF) reviewed the content to ensure the resource was developed according to the original specifications. The resource was then sent to an external reviewer (VP) to assess time, accessibility, content and format.
- Finally, the resource was reviewed by the Royal College of General Practitioners (RCGP) to receive accreditation. Upon seeing the final version, a few details had to be addressed for the accreditation to be granted. This feedback was minor, easily addressed, and accreditation was received in July 2019.

Stage three - Once the final resource was reviewed and approved, a usability study was conducted with 10 GPs (Chapter 5, p.131). The usability study aimed to assess the resource usability to ensure that the resource ran in a timely manner and that no apparent errors occurred or were spotted by the participants.

4.6.3 Stage three - final resource

The online resource was finalised in early July 2019.

- The resource is available as two separate resources for the two different modules, module one focusing on ADHD and module two specific to the role of the GP in ADHD care:

Understanding ADHD

https://www.nottingham.ac.uk/helm/dev/adhd/understanding_adhd/

The role of the GP in ADHD care

https://www.nottingham.ac.uk/helm/dev/adhd/gp_adhd/

- The study links, including the questionnaires, can be found below

Intervention group:

https://nottingham.onlinesurveys.ac.uk/adhd-ip1

Control group:

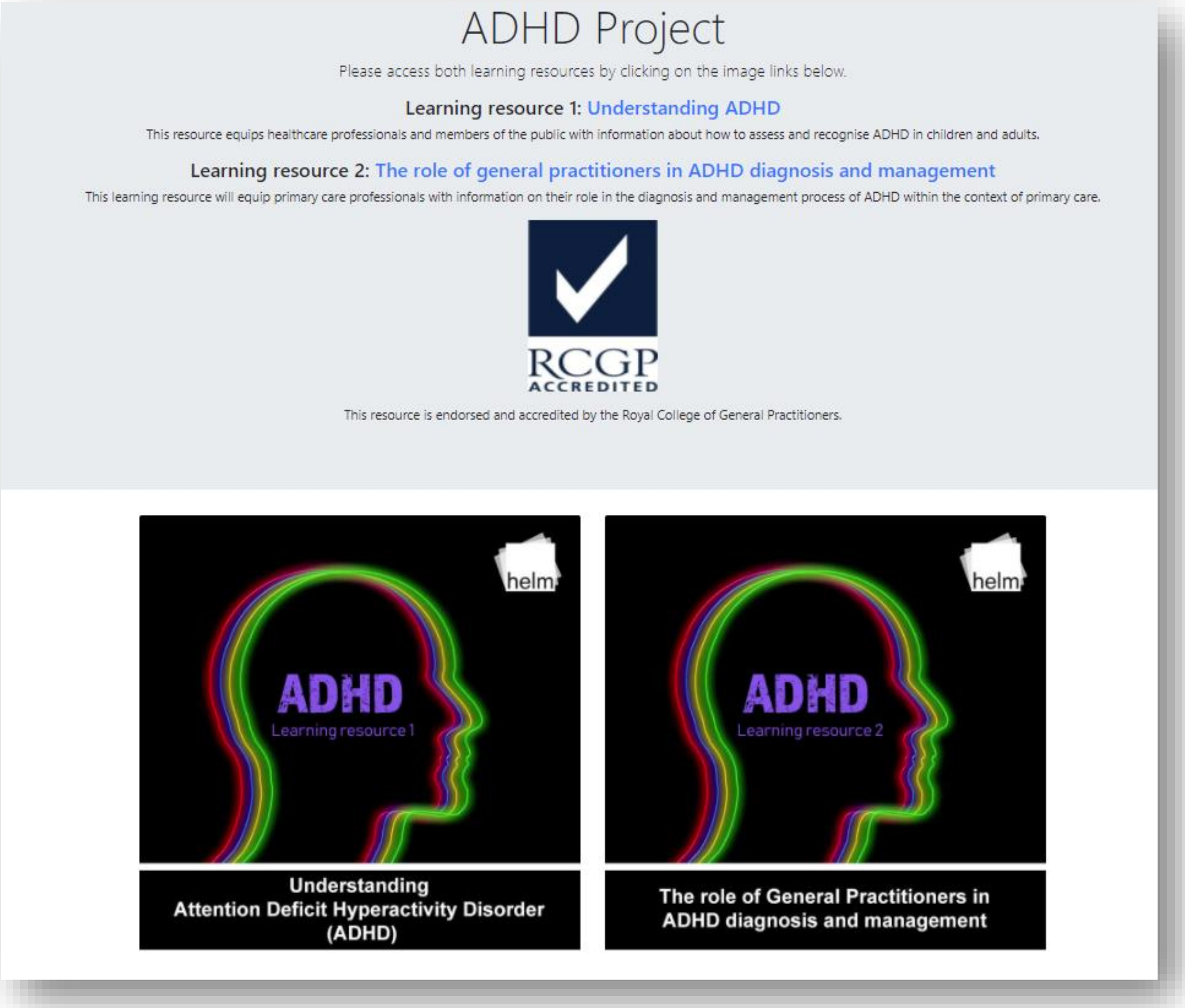
https://nottingham.onlinesurveys.ac.uk/adhd-cp1

- The online tool link a screenshot of the Home page (Figure 8) can be found below:

www.adhdinfo.org.uk

Figure 8

Screenshot of the Online Tool



ADHD Project

Please access both learning resources by clicking on the image links below.

Learning resource 1: Understanding ADHD

This resource equips healthcare professionals and members of the public with information about how to assess and recognise ADHD in children and adults.

Learning resource 2: The role of general practitioners in ADHD diagnosis and management

This learning resource will equip primary care professionals with information on their role in the diagnosis and management process of ADHD within the context of primary care.

This resource is endorsed and accredited by the Royal College of General Practitioners.

The complete online intervention consists of two 25-minute modules undertaken sequentially. The two modules follow the same format of having text on the left-hand side of the screen and interactive activities on the right. The activities varied and included patient testimonies, drag and drop games, videos and pictures.

Module 1: “Understanding Attention Deficit Hyperactivity Disorder” introduces the many aspects of ADHD. After a brief description of ADHD epidemiology and neuroscience, the core three symptoms are discussed with real-life settings examples. Other symptoms, common misconceptions and key impacts on children and adults are also discussed. Finally, comorbidities and risks associated with ADHD are presented.

Module 2: “The role of General Practitioners in ADHD diagnosis and management” introduces in more detail the GP’s role in the ADHD diagnosis and treatment pathways.

Clarifying the gatekeeping role held by GPs and the pathway to care in the UK, this module also expends on identifying ADHD, treatment options and the effect of gaining better ADHD knowledge on practice. Finally, an "ADHD toolkit" included various downloadable forms such as screening tools, strategies, or useful websites.

The resource was accredited by the Royal College of GPs (RCGP). As part of the accreditation process, the RCGP usually advertises accredited courses on its website and on social media. However, on this occasion, a delay was requested until November 2019 before advertising the resource openly, upon which time data collection was completed.

4.7 Clinical impacts

The main goal of the online resource is to increase GPs' understanding and awareness of ADHD. Previous findings from this thesis and other studies have highlighted that lack of knowledge and non-recognition were barriers in accessing care for individuals with ADHD. Therefore, by increasing awareness and knowledge, this intervention aims to:

- Increase support around ADHD in primary care
- Increase identification of ADHD in general practice
- Increase appropriate referral
- Improve patient's experiences of seeking a diagnosis by receiving better support and more accurate referrals
- Improve knowledge of the diagnosis process, which also implies that GPs might gather more information before referrals, which could reduce waiting lists.

The benefit of having a freely available online resource means that many healthcare professionals can access it in their own time and from anywhere. Therefore, it is hoped that the resource can be used as a support resource and an education resource. By including downloadable files, GPs can refer back to this resource and extract documents to support their practice, such as screening tools, support networks, etc.

Due to having two online resources, a broader spectrum of healthcare professionals and individuals can be reached. The first resource focuses solely on understanding ADHD and can benefit other stakeholders, such as parents, teachers, nurses, etc. Similarly, the second resource is specific to GPs and can be accessed at any time if they need clarification on particular issues in the referral and diagnosis pathway. Therefore, two shorter resources allow a broader clinical impact of this thesis.

Finally, interventions to assist clinicians in optimising assessment and diagnosis processes also improve individuals' clinical outcomes, such as quicker referrals, more accurate access to services, and better continuity of care. This approach, utilising an online education resource, could also be adapted and used to improve GPs' knowledge of other mental health conditions.

Upon completing data collection, the online training resource was adopted by two British leading primary care online training platforms and is now widely available to all GPs and GP training.

4.8 Discussion and conclusion

The objective of this process was to develop a robust and feasible online psycho-education intervention for GPs. In following a systematic step-wise development process and with the aim of co-developing a psycho-education resource to improve GPs' knowledge of ADHD, an online intervention involving GPs at each stage of development was created.

The online format of the intervention offers many advantages. The benefit of having a freely available online resource means that healthcare professionals can access it in their own time and from anywhere. As it is also easily accessible on smartphones, firewall restrictions from work desktops (such as the ones implemented by the NHS) were easily bypassed.

From the initial concept to the final product, the intervention changed in multiple ways. Through co-production, a significant discrepancy was highlighted between the product initially envisioned and the product that GPs wanted. As a result of this, changes were made to the format, the content and the delivery of the intervention. The format of the intervention evolved significantly throughout these doctoral studies. For instance, while it was initially thought that the patients' testimonies would hold a significant part of the intervention, the GPs' feedback meant that it was considerably cut out. The intervention's length was also a contentious point, with GPs preferring an intervention as short as possible while incorporating all the necessary information. A compromise was reached with a 45 minutes' online intervention. For similar reasons, the intervention's content was continuously adjusted and evaluated over the length of the development process. It was essential to find the right balance between enough information for GPs to learn and be engaged, as per the original research objectives, but not too much so that they become bored or overloaded. Finally, the mode of delivery was considered carefully. From early on, an online intervention felt the most suitable to meet GPs' needs, as opposed to web-based talks or workshops. Platforms of delivery were not significantly important, but accessibility was essential. Being able to access the resource from an NHS computer or a smartphone a requirement. Furthermore, accreditation from a reliable source (RCGP) was also essential to validate the resource itself and gain CPD accreditation points from taking part.

The co-production aspect of the development was the most informative part of this process. As stated above, the initial concept planned was completely different from the final product.

While this was frustrating as many original ideas and concepts had to be dropped, it was essential to develop a robust product that met the GPs' needs. Without this input and co-production process, the research team would have created a product that met their beliefs about what GPs needed but would not have engaged the GPs, which would have been pointless. It was also imperative to choose the right reviewers in the process. When the study team's academic members first scrutinised the template, their feedback sometimes differed from the GPs' preferences. The GP reviewers understood the decisions made about the format, content and delivery of the intervention.

By developing a resource that meets GPs' needs and increases their knowledge, this resource could also become a validated template for GP education, potentially being adapted towards other developmental disorders.

The final developed intervention had a few limitations. Completing the intervention takes approximately 45 minutes; in real-world practice, time may be a barrier to completion. While it is accessible on smartphones, the layout is not as intuitive on a small screen, and a much better impact of the videos and the interactive activities can be experienced on a computer. Finally, the intervention is specific to UK practice, and while the first module on Understanding ADHD is internationally relevant, the second has many country-specific limitations as it aimed to clarify the role of the GP in the UK system.

Similar to the interviews conducted in Chapter 3, the workshop participants were all young self-referred motivated GPs. The perspective of older and more experienced GPs is, therefore, lacking. While recently qualified GPs are used to online training resources, more experienced GPs might have had very different opinions on the format, the content and the delivery of the intervention. As has been reported, ADHD awareness has significantly increased in the last decade (Polanczyk et al., 2014); it could be assumed that GPs who completed their training over 20 years ago might hold different knowledge and attitudes towards ADHD. Their standpoint would have therefore been very valuable in the development of the intervention

4.9 Reflexive statement

The iterative process of developing the intervention was a considerable learning process. From the first concept to the final product, a consequent evolution happened with very few original concepts being kept, new concepts tried, and ideas continuously evolving. These doctoral studies were initiated by developing an adult ADHD testimonies video (used in this thesis). After experiencing the powerful message from this video on patients and service users, how this would translate into healthcare professionals was questioned. Initially, the intervention was solely based on the impact of using this video in healthcare settings. It was then discussed that the video could be embedded into an online resource and that a child version of this video would also be powerful. However, to produce such a resource, funding needed to be secured. A funding application to Takeda pharmaceutical was submitted at the beginning of these doctoral studies, and the outcome of this application strongly directed the development of this resource. The funding application was successful, and the intervention (impacting, format, PPI, outreach, complexity etc.) took on a whole new level as more freedom was allowed. It was still felt that the videos should play a central role in the intervention, and along those lines, two 5 minutes' videos of patients' testimonies were produced.

However, when running the GP workshops, the videos did not have the expected impact. GPs did not engage with them and were not interested in patients' experiences as such. In their own words, the videos were too mainstream, they did not show any significant atypical behaviour, and they were not showing the "extremes" of ADHD. GPs wanted more substantial impacts; they wanted to see children having meltdowns, patients struggling, or parents reacting.

This started a whole new thought process concerning the intervention. It highlighted the discrepancy between the product this thesis envisioned and the product that GPs wanted. The process of adjusting to the GPs' expectations was triggered, and adjustments were ongoing for a few months. This started a new process of finding a balance between what BF had in mind and what the GPs wanted - trying to address their needs without compromising on the original idea. Questions such as - Does the structure need to be changed? What is reasonable? What would be the impact of keeping the original plan? – continuously arose, and decisions on prioritising these issues had to be made. With a constant back and forth thinking between GPs and our expectations, compromises had to be reached. This impacted the intervention's format, the content, the activities and many more aspects of the final resource.

Format

The format of the intervention evolved considerably throughout this thesis. For instance, while it was initially thought that the patients' testimonies would hold a significant part of the intervention, the GPs' feedback meant that it was considerably shorter. As the videos were already produced, the videos' links were included for GPs to refer to in their own time, but six new videos were made, focusing more specifically on ADHD symptoms. Finding a way to include patients' views was important but needed to be adapted in a way that GPs would engage with.

Furthermore, GPs expressed the importance of having specialist videos in the intervention. This was not considered initially, but as they felt very strongly that having ADHD experts explaining pathways, services, etc., would help them interact with the resource, these were produced at a later stage.

How long should it be? As ADHD experts, the lead researchers could discuss and explore many aspects of ADHD to address gaps and issues in GPs' awareness of ADHD over perhaps a full-day workshop. However, this was not the purpose of the resource and time had to be carefully considered. As GPs explained that they would want a resource as short as possible, even just 15 minutes' snapshots, a 45 minutes-long intervention was decided. While a more succinct format would have suited the GPs better and potentially engage more participants, it felt impossible to cut it down to such a short time and still cover the necessary points.

Content

The content of the intervention was continuously adjusted and evaluated over the length of the development process. From the GPs' feedback, it was essential to find the right balance between enough information for them to learn and be engaged and not too much so they get bored or can't retain anything as it is too much. But how do you know when enough information is enough? What is too much? What is not enough? While developing the content, the lead researchers often wanted to add more information about specific topics, feeling that they were necessary. However, they had to reign it in as they didn't want to take the risk of including too much. The balance between being general and specific was difficult to reach. As ADHD experts, it was somewhat challenging to put yourself in the GPs' shoes and imagining what they want to know and how much of it. After the workshops with the GPs, there was a strong discrepancy between what the GPs wanted to know and what the researchers felt they needed to know. Reaching an understanding that did not compromise the researchers' original idea but addressed GPs' needs in a manner that they would engage with the resource was essential.

Delivery

Finally, the mode of delivery was considered carefully. From early on, an online intervention felt the most suitable to meet GPs' needs. A workshop or seminar could cause many technical difficulties and constraints. Web-based talks were also considered but seemed less convenient. The resource needed to be accessible from a convenient place and be short in time to accommodate GPs' busy schedules and workdays as well as competing with other training demands. The online e-learning resource was considered the most suitable. After consulting the GPs at the workshop, delivery platforms were not significantly important, but accessibility was essential. Being able to access the resource from an NHS computer was primordial, as well as being able to access it from a smartphone. Therefore, it was ensured that the online system was compatible with NHS systems (such as System One) and was easily accessible on smartphones. Furthermore, accreditation from a reliable source (RCGP) was also essential to validate the resource itself and gain CPD accreditation points from taking part. CPD accreditation from the RCGP was therefore sought.

Chapter 5 Intervention study

5.1 Chapter summary

After developing the online resource, the usability and efficacy of this intervention were explored in three distinct steps. Firstly, a usability study assessed the users' experience when interacting with the online resource and whether any changes were necessary. Secondly, a pilot randomised control trial (RCT) was conducted to gauge the intervention's feasibility and explore if a short online resource can increase GPs' awareness and understanding of ADHD. Thirdly, personal views on whether this intervention impacted the GPs' practice were also explored and investigated through interviews at three and six months post-intervention.

Usability

A pilot usability study (n=10) was conducted to assess the intervention's acceptability, feasibility and accessibility. A specific questionnaire on intervention usability and accessibility was developed. The usability study showed that the content of the intervention was suitable, easily accessible, engaging and delivered at an acceptable level of intensity, validating the development approach taken

Pilot

The pilot RCT (n= 131) assessed the efficacy of an online psycho-education resource on ADHD tailored for GPs. Participants were blindly randomised to either a control sham group or the intervention group and had to complete questionnaires on ADHD knowledge, confidence and attitude at three time-points (pre and post-intervention and two-week follow-up). GPs' knowledge, attitude and confidence significantly increased after taking part in the intervention, and these findings remained at two-week follow-up.

Interviews and survey

Participants in the pilot RCT intervention arm were invited to take part in a survey and follow-up interviews at three and six months. Twenty-three GPs took part in the interviews, and twenty-one responded to the online survey. Interviews and surveys demonstrated a change in practice over time and further explored the impact of the intervention.

The three components of this intervention study demonstrated that the online resource was usable, accessible and efficient. It indicates that a short online intervention can increase GPs' understanding and approach towards ADHD, improving patients' access to care by impacting their practice.

5.2 Outputs

This chapter produced a few open access outputs.

- Parts of this chapter were peer-reviewed and published (cited twice):

French, B., Hall, C., Vallejos, E. P., Sayal, K., & Daley, D. (2020). Evaluation of a web-based ADHD awareness training in primary care: A pilot randomized controlled trial with nested interviews*. JMIR Medical Education, 6(2), e19871.*

https://mededu.jmir.org/2020/2/e19871/

- A Video abstract was also produced for this publication (viewed 28 times):

https://vimeo.com/483147613

5.3 Introduction

Many barriers have been highlighted in GPs' understanding of ADHD, reflecting a general lack of education, awareness and training. These are critical barriers for individuals with ADHD in accessing care. The evaluation and development of interventions targeted at addressing these barriers and increasing their knowledge are, therefore, crucial.

GPs in the UK have to complete medical training and yearly Continuing Professional Development (CPD) to keep up to date with ongoing medical knowledge and change in practice. Although many training programmes are continually being developed to address the need for GPs to keep up to date with medical knowledge (Lester et al., 2009; Rosendal et al., 2007; Rughani et al., 2012; Sikorski et al., 2012), there are no current programmes aimed at ADHD. Some published evidence indicates that primary care training can improve care (Kolko et al., 2010; Sikorski et al., 2012), clinical outcomes (Kolko et al., 2010), knowledge, confidence and attitude (Butler & Quayle, 2007; Lewis et al., 2017), suggesting the potential benefit for a target ADHD education package.

One perceived barrier to GPs attending training may be having to travel long distances to attend training sessions, which may be particularly burdensome for GPs serving in remote communities. The development of online training may go some way in reducing this barrier offering GPs easily accessible training at any time and place that fits around their busy schedules. Indeed the use of online training by healthcare professionals has significantly increased in recent years (Casebeer et al., 2010). Online training is an efficacious mode of delivery, with a recent review demonstrating that online continuing medical education improved knowledge and changed GPs' practice (Thepwongsa et al., 2014). To the best of our knowledge, no studies have been published on online psycho-education programmes on

ADHD developed for GPs, and data are lacking on the efficacy of ADHD training programmes for GPs.

This chapter presents the assessment of an online intervention for GPs on ADHD. The online intervention followed a strict development process. In line with the MRC recommendations on the development and evaluation of complex interventions (Craig et al., 2008), the present study obtained preliminary findings on the impact of the online resource on GPs' ADHD knowledge, attitudes, misconceptions and change in practice. Although these are reported separately, the pilot RCT used a concurrent triangulation strategy mixed-method approach. The rationale for this design is that traditional quantitative findings only provide a statistical measure of improvement. The quantitative data were collected first and guided the results. The qualitative strand provided rich data that provided insight into how those improvements translated into the participants' everyday life, addressing a different question to the quantitative data.

This chapter reports the findings from three different studies: a usability study, a pilot RCT and follow-up interviews, which were conducted to gauge the usability, accessibility and efficacy of the resource in improving GPs' knowledge and understanding of ADHD. GPs' opinions on the intervention and perceived impact on practice were gained via qualitative interviews and a survey post-intervention.

5.4 Usability and acceptability study

The development of new interventions necessitates multiple levels of assessments. Firstly, the resource's usability and acceptability need to be assessed to evaluate the user's interaction with the resource and ensure that it is optimal and compatible with the user's needs. Secondly, the intervention's efficacy needs to be assessed to ensure that it is both user-friendly and improves GPs' knowledge of ADHD.

While the development process involved many steps to ensure the online resource was in line with GPs' needs, the resource's usability and acceptability needed to be further investigated to ensure it can be used productively (Jaspers, 2009).

Nielsen and Landauer (1993) propose five attributes to be considered in the development of products' usability.

- Learnability: the product should be easy to learn
- Efficacy: the product should be efficient to use to facilitate high levels of productivity
- Memorability: the product should be easy to remember
- Errors: the product should have a low error rate
- Satisfaction: the product should be pleasant to use

In line with these criteria, a usability questionnaire was developed, including these five attributes. This questionnaire was used in a short accessibility study conducted with 10 GPs to determine the intervention's usability. This study aimed to assess the intervention usability, to ensure that the intervention was acceptable, ran in a timely manner and that no technical errors occurred.

5.4.1 Methods

5.4.1.1 Participants

A selected number of GPs were contacted to take part in the usability study. GPs, who had registered an interest after taking part in the qualitative study and the development workshops, were contacted to review the online resource's usability. These GPs were emailed and asked to fill in an online consent form in order to take part. Nine GPs (3 females) consented to take part. As only seven GPs completed the study after three weeks and reminders were unanswered, three more GPs were recruited from our GP contact lead. Therefore, 10 GPs (4 females) took part in the study, seven who had previously taken part in some aspects of this thesis and three who had not.

5.4.1.2 Measures

All participants had access to a computer and the online resource. All measures were accessible online before and after the resource.

The principal outcome measure of this study was to assess the usability of the online resource. Three online measures were completed.

Usability questionnaire

A usability questionnaire was developed, containing 29 questions on key usability criteria such as learnability, efficacy and memorability (Appendix 8). Question type varied from force choice questions (“I will use this tool in the future”-agree, disagree, unsure) and free text questions (“Where any part of the tool not helpful?”). This questionnaire was completed after engagement with the online intervention (time 2 –T2).

KADDS questionnaire

This 39-items self-report scale was initially developed to measure understanding and knowledge of ADHD in teachers (Sciutto et al., 2000). However, the itemised questions were not solely relevant to teachers and were also pertinent to general knowledge and understanding of ADHD. Twenty-seven questions from this questionnaire were used (Appendix 9). As the aim of the questionnaire was to assess a change in understanding of ADHD after taking part in the online psycho-education intervention, eleven questions were excluded as they were not answered by the online resource. This questionnaire was completed pre-intervention (time 1 – T1) and immediately after completing the intervention (T2).

GPs' awareness of ADHD questionnaire

This questionnaire was developed to assess GPs' attitudes and experience of ADHD in Ireland (Adamis et al., 2019). Some questions were excluded as they were either relevant to the Irish healthcare system or were similar to those asked by the KADDS. Thirteen questions from this questionnaire were added as they were specifically tailored to GPs' experiences (Appendix 10). This questionnaire was completed before (T1) and after engaging in the online intervention (T2).

5.4.1.3 Intervention

The overall intervention lasted around 60 minutes and consisted of a short pre-intervention questionnaire (KADDS and GPs' awareness questionnaires), interaction with a 45-minute online resource (Understanding of ADHD in primary care) and post questionnaire (KADDS, GPs' awareness and usability questionnaires).

Understanding of ADHD in primary care online resource

Understanding ADHD in primary care online resource was built and delivered with an open-source learning management system from a University of Nottingham server. The complete online resource consists of two 25-minute modules undertaken sequentially. The two modules follow the same format of having text on the left-hand side of the screen and interactive activities on the right. The activities varied widely and included patient testimonies, drag and drop games, videos and pictures.

Details about the content and the resource are described in Chapter 4 (p. 121).

5.4.1.4 Procedure

This descriptive exploratory study aimed to test the usability and accessibility of the online intervention on ADHD awareness for GPs.

The study protocol was approved by the University of Nottingham, Faculty of Medicine and Health Sciences research ethics committee. GPs who had given consent to be contacted after taking part in previous studies were emailed details about the research and sent links to an online information sheet and a consent form to complete before taking part. Upon receiving consent, GPs who agreed to participate were then sent a link to the intervention with embedded outcome measures. While some participants had taken part in the initial development workshops, none were familiar with the final online intervention. GPs were advised to set aside 90 minutes to complete the study in one go. Although it was not encouraged, participants were able to stop the study at any point and come back to it at a later point. Participants completed time 1 measures (baseline) before commencing the intervention. Time 2 measures were completed immediately after finishing the intervention. Although this study did not seek to obtain efficacy data of the learning resource, the ADHD knowledge questionnaires assessing the efficacy of the learning resource were retained to assess the flow and length of the study design.

Upon completing all questions, participants were given an inconvenience allowance and a Continuing Professional Development (CPD) certificate from the RCGP.

Descriptive analyses were used to summarise the findings from this study.

5.4.2 Results

5.4.2.1 Usability and acceptability

Ten GPs took part in the usability study. Nine were aged between 25-35 years and one between 36-45 years. Years of practice since qualifying as a GP ranged from 10 months to 11 years (mean: 6y 7m).

The completion time (including the questionnaires and intervention) ranged from 45-72 minutes, although it was not possible to assess the response time of two participants as they did not complete the intervention in one seating.

Results from the usability questionnaire are presented below. Participants were asked to rate some questions on a scale of 1 to 10 (Table 9) and others if they agreed or disagreed with specific statements (Table 10). Free text questions on their overall interaction with the resource were also included

Table 9

Usability and Acceptability Evaluation on a Scale of 1-10 (1: not at all and 10: a lot)

Number of Responses for Each Statement

Scores	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Total mean (SD)**
How confident are you in your knowledge of ADHD											
Pre-intervention			1		5	1	1	2			**6.2 (1.56)**
Post-intervention						1	2	4	3		**7.9 (0.99)**
How useful did you find the information in this resource?								3	2	5	**9.2 (0.91)**
Did you like using the resource?								6	3	1	**8.5 (0.70)**
Do you feel the tool impacted your knowledge of ADHD?							2	2	5	1	**8.5 (0.97)**
How likely is this information going to inform your practice?								4	5	1	**8.7 (0.67)**
Do you believe the content was relevant to your practice?								3	2	5	**9.2 (0.91)**

Table 10

Usability and Acceptability Evaluation

	Agree	**Disagree**	**Unsure**
Through going through the resource, I understood its purpose	10		
I found the resource boring		10	
I think the resource will engage GPs	10		
The supporting material used helped the understanding of the content	9	1	
I like that the resource directed to other resources	9	1	
The resource is interactive enough	10		
The general presentation is clear	10		
The website appearance makes a good impression	10		
I will use the resource in the future	9		1
I believe the content is reliable and based on evidence	10		
The resource contained too much information	1	9	

The participants reported a high degree of satisfaction with the content and layout of the online intervention. All participants were able to easily navigate the resource, and only one suggestion was made to improve navigation. The wording and presentation of the content were well received; participants reported the content to be clear, interactive and easy to follow. All participants also felt that the resource was valuable, increased their knowledge and was relevant to their practice and confirmed they would recommend the resource. While a few suggestions for improvement were made, the feedback was overall strongly positive.

Positive feedback

All participants agreed that they would recommend the resource, and most found that no parts of the resource were unhelpful or that anything was missing from the content. The additional comment section contained mainly positive comments where participants principally highlighted that they liked the interactivity and resource structure. The participants especially liked the videos used to reinforce their learning.

> *"Great resource, videos help to give a true account" (P4)*
>
> *"Good mix of bullet point text and short videos. Interplay between the two helped reinforce points" (P10)*

While most agreed that the resource was the right length, the couple of participants who suggested the resource might be too long acknowledged that they wouldn't know which part to cut out despite feeling it might be a bit lengthy.

> *"It was (too long), hard to decide what was the least useful. All useful stuff" (P5)*

Suggestions for improvement

Only a few suggestions for improvement were made relating to the intervention's length and format, the content, and navigation.

Length and format

While participants were mostly satisfied with the intervention's length, one participant highlighted that it was essential to advise participants of how long it will take beforehand. Another participant suggested highlighting the key points from each slide to make it quicker, with take-home messages in bold.

Content

Two participants suggested improvement related to content. One suggested providing a bit more information on the difference between autism and ADHD. The other participant recommended including more information on treatments, management and monitoring.

Navigation

Finally, the last suggestion for improvement was about the navigation of the resource. The participant suggested that the two modules would flow better in one module rather than two separate modules.

5.4.2.2 Awareness and knowledge of ADHD

While changes in ADHD knowledge were not a primary outcome of this study, the results from the ADHD knowledge questionnaires were recorded to gauge the time spent on the intervention from beginning to end. Questions on the usefulness of the resource in practice were also asked to ensure that the content did help to increase awareness of ADHD. All participants agreed that the resource would help them identify ADHD patients better; all believed that they would retain the knowledge acquired from the intervention and that it impacted their attitude towards ADHD and ADHD patients.

While a full report and analyses of the ADHD knowledge and awareness questionnaire results are beyond the scope and aim of this study, a brief overview showed some interesting preliminary findings.

KADDS, ADHD knowledge questionnaire

Pre and post questionnaires on ADHD knowledge showed a rating change from 9.8 errors (out of 27 questions) to 3.2 (Table 11), demonstrating a change in ADHD knowledge in participants after engaging in the intervention.

Table 11

Pre and Post-Intervention Error Rates on ADHD Knowledge Questionnaire

Participants	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Total Mean (SD)**
Pre-intervention	8	7	6	7	10	14	10	11	12	13	**9.8 (2.74)**
Post-intervention	1	0	3	3	2	6	3	4	7	3	**3.2 (2.09)**

GP’s awareness of ADHD questionnaire

While the results from this questionnaire are too comprehensive to report, some interesting preliminary findings of changes in GPs’ awareness of ADHD were highlighted in this study. For instance, when asked the question “Parents seek an ADHD diagnosis as an excuse for their child behaviour”, five participants (50%) answered “Unsure” or “Yes” pre-intervention but changed their answer to “No” post-intervention, highlighting a shift in ADHD awareness post-intervention.

5.4.3 Discussion

The purpose of this study was to assess the usability and acceptability of delivering a psycho-education online intervention to increase GPs' awareness of ADHD. Overall, the participants' evaluative feedback was positive towards the content, design and usability of the online intervention, and little improvement was suggested.

In light of the suggestion for improvement, a few changes were made to the resource. To address issues related to length and format, bold statements of the most essential information on each slide were highlighted. No content was taken off as most participants agreed that the length was acceptable, and the couple of participants who disagreed struggle to identify which parts of the resource weren't helpful. However, a statement advising participants of the intervention's length was included when participants were invited to inform them of how long it will take.

The suggestions made about the content were addressed as followed. Further information on treatment and monitoring was added to the treatment section of the resource. The proposal for more information on the difference between autism and ADHD was not addressed. A slide on this topic was already included, and (as was stated on this slide) the topic is too comprehensive to cover within the remit of this resource. It was felt that the information included in the resource was enough to give the GPs a brief appreciation of the distinction between the two disorders; however, including any more information would lead the resource off on a tangent as so much would need to be covered.

Finally, the suggestion for navigation was assessed. One participant suggested one module, including the two resources, would help navigate better between the two. The feedback from the workshops in the pre-development phase had indicated that two separate modules would be more effective as they segregated the ADHD knowledge and GP's role, and GPs could focus more on one or the other depending on their expertise. Therefore, it was decided to keep it as two separate modules as the technicality of navigating between the two was a lesser concern to the technicality of increasing engagement by enabling a targeted focus within two modules.

Strength and Limitations

This study demonstrated that the online intervention was highly accessible, usable and acceptable. Very few suggestions were made in changing the resource, demonstrating the strengths of our thorough co-production development. Our findings validate the choices made regarding the length, format, delivery, and content of the resource. It also gave a preliminary overview of the questionnaire's acceptability to assess the efficacy of the intervention. It implied that the online resource was ready for delivery and testing in further studies.

A few limitations arose from this study. In the first instance, the self-selected sample might have biased our findings. Firstly, seven of the 10 participants in the usability study had been members of the workshops. While the workshops produced six storyboards and the participants were not aware of which suggestions would be implemented, those seven participants all had input at an early stage of the development process. However, the workshops were conducted early in the development stages when the final concept was not yet developed. The participants also took part in separate workshops, with distinct storyboards that had presented different ideas and therefore might have had very different preconceptions from one another. There was no difference in responses between participants from the workshop and those who did not participate, which might demonstrate that having taken part in the workshops did not impact participants' responses to the resource. The sample also comprised young GPs, mostly under 35, who might be more motivated to learn and might not demonstrate an accurate representation of the GP population. Finally, the usability study is restricted to the views of 10 self-selected GPs, so generalisation needs to be met with caution.

Implications for further studies

This usability study highlighted many implications in terms of recruitment and attrition for considerations for further studies. The GPs who were contacted and had taken part in our previous studies and workshops were very keen to further their involvement. A small majority consented to participate in the pilot study (10 out of 17), but two did not take part (attrition rate of 22%). Of these, three GPs were keen and took part in all three activities in this doctoral study (qualitative interview, workshops and pilot study). The different levels of engagement and expressions of interest observed during the recruitment and completion of the study are helpful in informing potential attrition rate and participation in further studies.

While participants were instructed and encouraged to complete the study in one seating, two participants did not (one completed within 24h, and one within 72h). This did not impact their response to the usability questions but might have influenced the preliminary findings on changes in ADHD knowledge and awareness. In this situation, it is difficult to assess whether any changes are directly related to the intervention or whether any outside factors had increased their knowledge and awareness.

5.5 Pilot of a randomised control trial

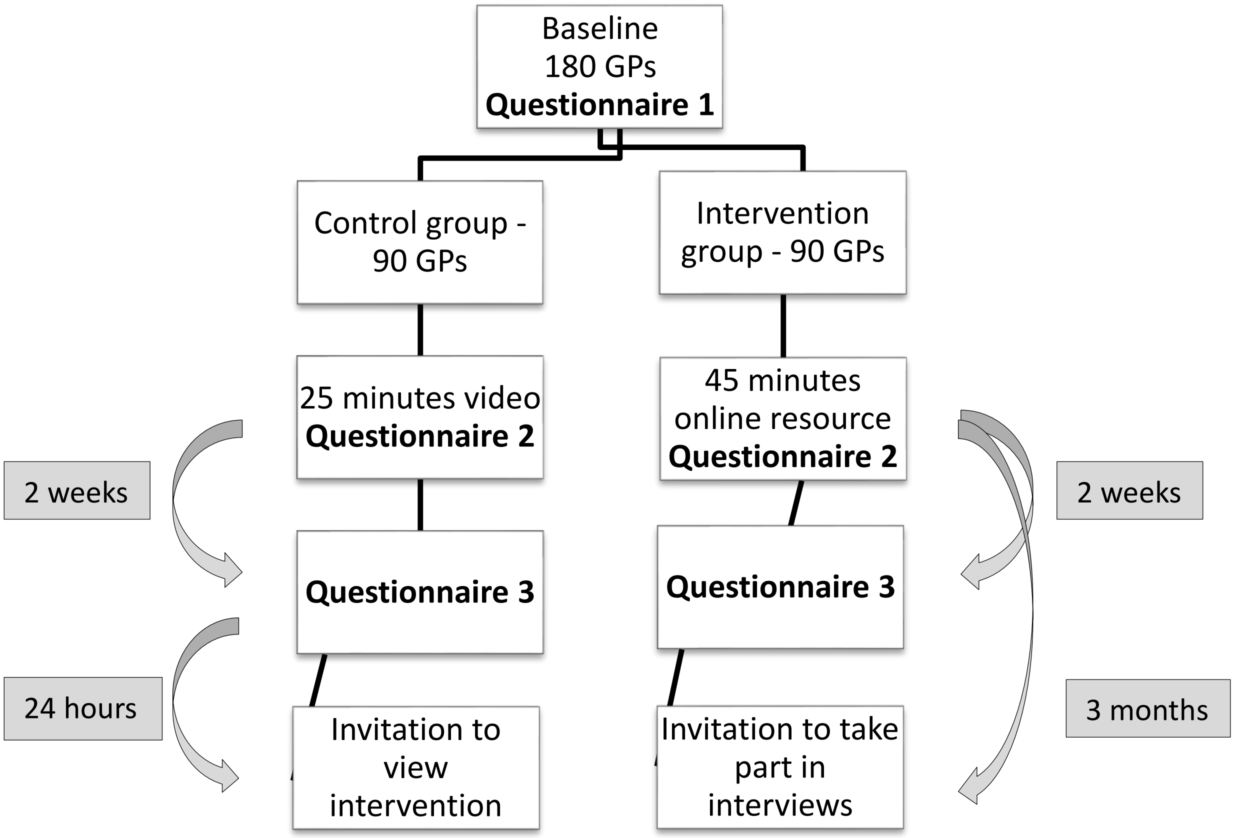
To gauge the intervention's efficacy, a pilot RCT with a final number of 131 GPs was conducted.

5.5.1 Methods

A proposed intervention process was developed before conducting the study and is illustrated in Figure 9.

Figure 9

Proposed Flow Chart of the Pilot RCT



5.5.1.1 Study design

The study was a pilot RCT registered with the ISRCTN registry (http://www.isrctn.com/ISRCTN45400501), with nested qualitative interviews. This parallel-group, single-blind randomised control trial was conducted between August and November 2019 in primary care services in England. The interviews took place post-intervention between December 2019 and March 2020. The study received ethical approval from the University of Nottingham, Faculty of Medicine and Health Sciences Research Ethics Committee (Ref: 19/HRA/1028, 20th of February 2019) and from the Nottinghamshire

Healthcare NHS Foundation Trust R&D department (IRAS PROJECT ID 257567) (Appendix 11).

5.5.1.2 Participants

Recruitment opened in July 2019 and closed within two weeks following an unexpectedly high number of expressions of interest.

GPs and GP trainees were recruited from multiple sites in England and responded to invitation emails from local clinical research networks (CRNs) sent out via their practices. Twelve out of 15 English CRNs distributed the study representing hundreds of practices. The GP practices then circulated the study details to their GPs with instructions to contact the lead researcher to express interest in the study. Participants who expressed interest were sent a link to an online consent form. Multiple expressions of interest were received representing all areas of England, and 231 consent forms were signed over two weeks. Unfortunately, it is not possible to know the exact number of expressions of interest; over 500 emails were received, and as the consent form only recorded email addresses, it was not possible to map which site consented after initial contact with us. Written informed consent was obtained for each participant before taking part. Participants who took longer than 48h to complete the first two questionnaires were excluded from the analyses. Participants received an inconvenience allowance for taking part.

170 GPs and GP trainees (60.5% female) took part in this study, 133 completed T1 and T2 (61.5% females), and 131 (61% females) completed all three time-points.

The map below (Figure 10) represents the multiple sites from which participants originated.

Figure 10

Map of the Included and Excluded Participants' Location

5.5.1.3 Measures and outcomes

Demographic questionnaire: Exploration of demographic variables included the impact of participants' demographics on result scores. Participants' demographics were recorded through a brief questionnaire developed by the study team at Time 1 (T1).

Primary outcome: The primary outcome was a change in GPs' knowledge assessed by the KADDS questionnaire scores (T1 to T2- primary endpoint). Participants' knowledge was assessed using an adapted version of the KADDS (Knowledge of Attention Deficit Disorders Scale, (Sciutto et al., 2016) and the GPs understanding of ADHD questionnaire (Adamis et al., 2019).

KADDS questionnaire: This 39-items self-report scale was initially developed to measure understanding and knowledge of ADHD in teachers (Sciutto et al., 2000). However, the itemised questions were not solely relevant to teachers and were also pertinent to general knowledge and understanding of ADHD in GPs. Twenty-seven questions from this questionnaire were used in this evaluation.

Secondary outcomes: Change in knowledge (assessed via KADDS questionnaire) was re-assessed two weeks after completing the intervention (Time 3 -T3). Analyses of subscales of the KADDS questionnaire were also explored. Other secondary outcome included:

GPs' confidence in ADHD: Change in confidence was explored through a self-rated visual analogue scale (1 being low 10 being high) assessing GPs' confidence in their knowledge of ADHD.

GPs' awareness of ADHD questionnaire: This questionnaire assesses GPs' attitude and experience of ADHD (Adamis et al., 2019). Some questions were excluded as they were not relevant to the British healthcare system or were similar to the ones asked by the KADDS. Thirteen questions from this questionnaire were used as they were specifically tailored to GPs' experiences.

These questionnaires were administered at three time-points: Baseline (T1), straight after taking part (T2) and two weeks after completing the study (T3). The time window for T3 was two weeks (-3 days/+10 days). The questions were the same at all time-points and with both groups.

Usability questionnaire: Participants in the intervention arm also completed two visual analogue scales on the usefulness of the intervention information and the likely impact on their practice, completed at T2 only.

Secondary outcomes also included exploration of attitudes towards ADHD and long-term self-reported change in practice. Change in practice was assessed through semi-structured interviews and a short survey (reported in the next section of this chapter).

5.5.1.4 Intervention

The understanding of ADHD in primary care online resource was the same as used in the usability study but did not include the usability questionnaire.

The link to the online resource can be found below.

www.adhdinfo.org.uk

Control online resource

Participants allocated to the control group watched an online 30-minute video on the University of Nottingham, Institute of mental Health (link below). No information related to ADHD was provided during this video. The control resources can be accessed here:

https://www.institutemh.org.uk/news/videos/223-tenth-anniversary

5.5.1.5 Randomisation

Once recruited, participants were randomised before baseline data collection into either the intervention or the control arm. Randomisation was performed online through a randomisation website (https://www.graphpad.com/quickcalcs/randomize1) in batches of 20. Due to the nature of the study, participants were blind to study arms but may have been able to guess once they started the study.

5.5.1.6 Procedure

Details of the study were sent to GP practices who registered an interest in research within local CRNs. Participants wishing to take part signed an online consent form. Upon receiving consent, they were randomly allocated to the intervention or control group. Post-randomisation, participants were then sent a link to the online resource of their allocated group. Upon following the link, both groups were directed to complete the baseline questionnaires (T1). After completion, an external link at the end of the questionnaire directed the GPs to their allocated intervention (i.e., intervention or control). Upon completion of the intervention, both groups completed the follow-up measures (T2). Follow-up measures were completed again two weeks post-intervention. All elements of the intervention were compulsory, and participants had to take part in all the stages to contribute to the study. An inconvenience allowance and CPD certificate from the RCGP were attributed to the participants upon completing the questionnaire at T3.

Three months after taking part, participants who had been allocated to the intervention group and had given consent to be contacted again were asked to take part in follow-up interviews. Participants who responded were interviewed over the phone for 15 minutes at a time of their convenience. All 56 participants from the intervention arm who had given consent were also sent a short final survey to complete online.

5.5.1.7 Statistical analysis

Data preparation

No power calculation was completed before conducting the study as this intervention is new, and no previous data had been collected about the possible magnitude of effect that could be used to inform a power calculation.

Protocol violation: Participants who took longer than 48h to complete the first two questionnaires were excluded from the analyses as it was not possible to gauge if any change in scores would be due to the intervention or external factors. Participants who did not complete all time points were also excluded from the completer analysis as an intention-to-treat analysis was not possible due to randomisation after baseline.

The KADDS questionnaire generated three types of responses: “True,” “False,” or “Don’t know.” These responses were classified into three categories: knowledge, misconception and confidence.

- Knowledge included responses that were the correct answers; if participants responded correctly to the questions, they gained an extra knowledge point.

- Misconception included wrong responses. If participants responded wrongly, then their misconception score increased.
- Confidence included responses of “don’t know.” By not committing to an answer, participants’ lack of confidence score increased.

Analyses strategy

IBM Statistical Package for the Social Sciences (SPSS) version 24.0 for Windows (SPSS, IBM) was used for all analyses. Preliminary checks were conducted to ensure no violation of the assumptions of normality, linearity, homogeneity of variances and reliable measurement of the covariate. A significant Kolmogorov-Smirnov test showed that the data was not normally distributed; therefore, non-parametric tests were used. Mann-Whitney U and Kruskal-Wallis tests were used to explore demographic differences between trial arms. A Spearman correlation was used to determine the relationship between KADDS and confidence scores. KADDS questionnaire scores were the primary outcome at T2, and self-ratings of confidence were also explored. Both variables were analysed using analyses of covariance, with T1 entered as the covariate as ANCOVA is robust to violation of the non-parametric assumption with moderate to large sample sizes, greater than 15 cases per cell (Green & Salkind, 2011)[1]. Outcomes at T3 were also explored using the same analytical approach. Both total and subscale scores of the KADDS were explored.

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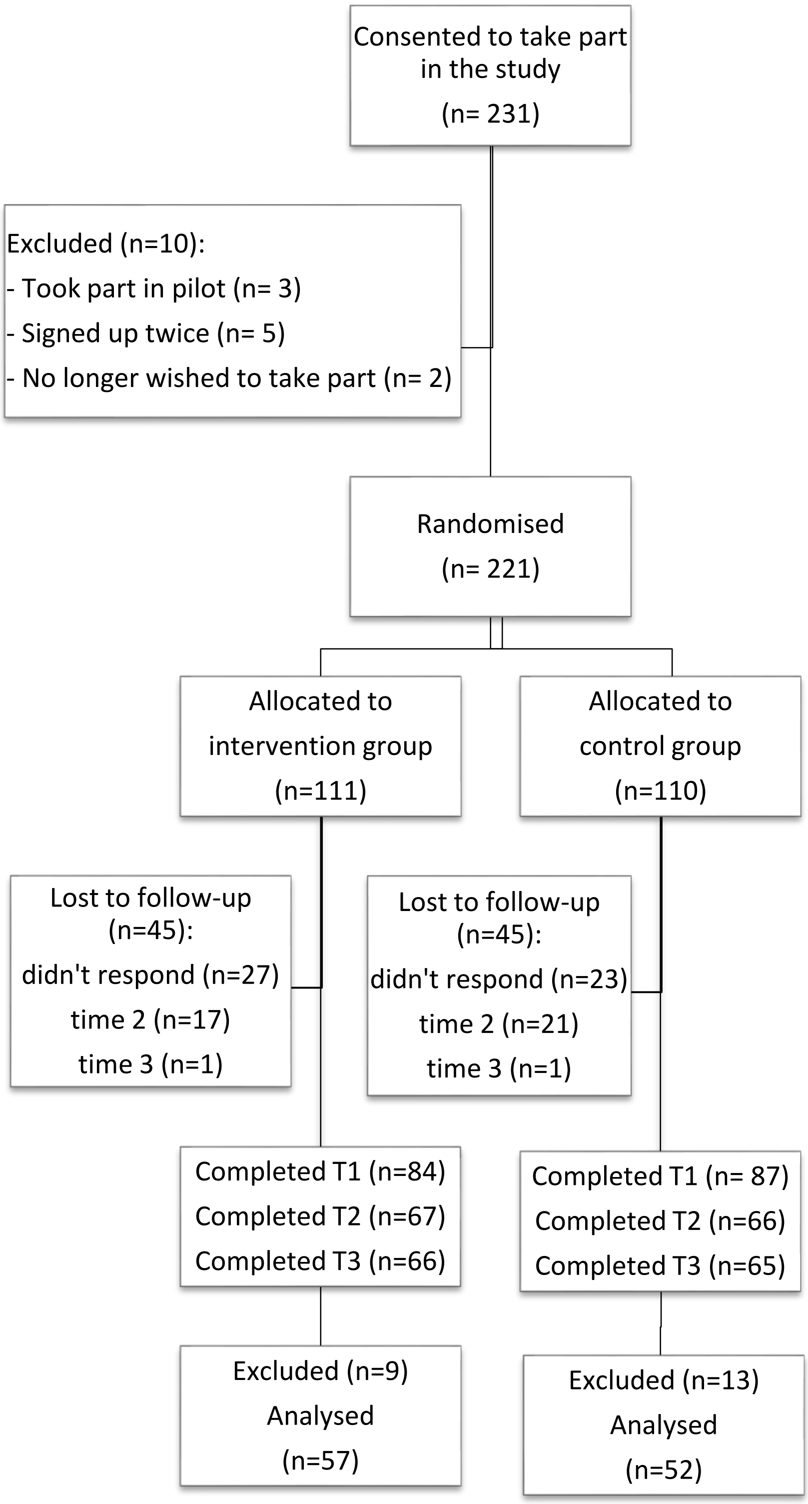
[1] The choice of analyses between ANCOVA and two way ANOVA has often been debated in clinical trial analyses (Liu et al., 2009). There is no “right” answer in choosing either method, however, it is important to understand that the choice of analysis answers different questions. The ANCOVA approach answers the question of whether the post means, adjusted for pre scores differ between two groups. This ensures that any post differences are truly due to treatment and also accounts for variation around post means that comes from variation pre-test and is optimal to gauge the size of the effect of treatment

5.5.2 Results

Figure 11

Consort Flow Chart of the Pilot RCT



Participants were recruited between the 10th of July 2019 and the 23d of August 2019. Figure 11 describes the consort flow chart for participants' recruitment and inclusion. A total of 231 GPs registered their interest in the study and consented to take part. Ten GPs did not meet eligibility criteria and were not enrolled in the trial.

Therefore, 221 GPs were randomised, 111 in the intervention group and 110 in the control group. Post-randomisation 51 GPs (27 intervention and 23 control) did not respond to the invitation to start the study. Figure 11 shows the numbers lost to follow-up at each point. Upon answering the baseline questionnaire, 37 GPs did not complete the post questionnaire (17 intervention and 20 control) at time 2 and two GPs (one intervention and one control) at time 3. 170 trainee or fully qualified GPs (103 Female: 60.5%, 6 GP trainees: 3.5%) completed Time 1, 133 completed Time 1 and Time 2 (84 Females: 63.1%, 5 GP trainees: 3.7%) and 131 (82 Females: 62.5%, 5 GP trainees: 3.8%) completed all three time points.

Twenty-two participants were excluded from the analyses following protocol violations. Eighteen were excluded as they took longer than 48 hours stipulated in the protocol to complete pre and post questionnaires (T1-T2), and four participants from the control group were excluded after T2 as they inadvertently received a link to the intervention before T3.

Figure 11 shows that both trial arms had similar numbers of recruitment, comparable levels of non-engagement, drop out and excluded participants.

Preliminary check for violations of assumptions

Normality: A significant Kolmogorov-Smirnov test, D(109)= 0.175, $p< 0.001$, showed that the data was not normally distributed; therefore, non-parametric tests were used.

Linearity: A grouped scattered plot checked that the linear distribution between the groups was linear.

Homogeneity of variances: A non-significant Levene's test of variance F(1,107)= 2.43, $p=0.12$ showed that the variance between the groups at baseline was approximately equal.

5.5.2.1 Baseline characteristics

Study group baseline characteristics are summarised in Table 12 below. Most participants were females (60.5%). The age range was split fairly across the age groups, but most GPs were under 45 years old. The estimated number of children with suspected ADHD ranged widely from 0 to 100. The number of individuals with a diagnosis also widely varied. The number of times participants identified ADHD in their patients was also spread, with most participants reporting they have not identified more than five patients. When asked if ADHD was part of their medical training, most GPs reported that it wasn't. Finally, the range of years of practice was very broad.

Table 12

Baseline Characteristics (some data missing for some questions)

		Baseline (n=170)		**Baseline per protocol participants (n=148)**		**Participants included in analyses (n=109)**	
		Control (n=87)	Intervention (n= 83)	Control (n= 74)	Intervention (n=74)	Control (n=52)	Intervention (n=57)
Gender	Male	29 (33%)	38 (46%)	24 (33%)	34 (45%)	15 (28%)	27 (47%)
	Female	58 (66%)	45 (54%)	50 (67%)	40 (55%)	37 (71%)	30 (52%)
Age	25-35	26 (30%)	23 (28%)	21 (28%)	21 (28%)	15 (29%)	16 (28%)
	36-45	34 (39%)	29 (35%)	30 (40%)	25 (35%)	20 (38%)	21 (37%)
	46-55	22 (25%)	24 (29%)	18 (24%)	21 (28%)	13 (25%)	14 (24.5%)
	56-65	5 (5%)	7 (8%)	5 (8%)	7 (9%)	2 (8%)	6 (10.5%)
ADHD of GP training[1]	Yes	17 (19%)	18 (21%)	13 (17%)	18 (24%)	12 (23%)	15 (26%)
	No	57 (66%)	52 (63%)	49 (66%)	46 (62%)	34 (65%)	35 (61%)
	Unsure	5 (5%)	4 (6%)	2 (3%)	2 (3%)	2 (3.8%)	1 (2%)
	Small part of teaching	8 (10%)	8 (10%)	9 (16%)	7 (11%)	4 (7.6%)	6 (11%)
Estimated n of children with suspected ADHD being seen in practice annually[2]	Mean	14	19	15	18	11	16
	Range	0-100	1-150	0-100	1-150	0-90	1-100
Number of individuals with a confirmed ADHD diagnosis currently in practice[3]	Mean	43	67	44	65	39	57
	Range	0 -400	2-500	0-400	2-500	0-400	0- 500
Number of times ADHD was picked up by participant[4]	Mean	4.1	5.4	4.1	5.4	3.2	5.1
	Range	0-30	0-50	0-30	0-50	0- 30	0-50
Years since medical qualification[5]	Mean	15.1	16.5	15.2	16.6;	14.7	15.9
	Range	0-36	0-36	0-36	0-36	0-33	0- 36

[1] (yes: 23%, no: 63%, unsure 3%, a very small part: 11%)

[2] (0: 0.7%, >5: 24%, >10: 22%, >20: 18%, >30: 10%, >50: 6%, ≥100: 8%, unknown: 10%).

[3] (0: 0.8%, >5: 6%, >10: 9%, >20: 9%, >30: 9%, >50: 10%, ≥100: 12%, ≥200: 5%, ≥300: 0.8%, ≥500: 1.7%, unsure: 34%, N/A: 1.7%).

[4] (0: 30%, 1: 13%, 2: 14%, 3: 8%, 4-5: 19%, ≥10: 9%, ≥20: 3%, ≥50: 2%, unsure: 2%).

[5] (GP trainee: 0.5%, >4: 5%, 4-5: 6%, 6-7: 8%, ≥10: 17%, ≥15: 14%, ≥20: 22%, ≥25: 11%, ≥30: 11%, ≥36: 5.5%).

A Mann-Whitney U test revealed no significant difference in the KADDs scores at baseline of included (M=9.22, n=109) and excluded participants (M=10.5, n=22), U=1,030, p= .29 as well as no difference in confidence scores between included (M=4.5, n=109) and excluded (M=4.3, n=22), U=1,170, p= .85

There was no difference in baseline responses between the groups on the KADDS questionnaire (M=16.78, n=109), U= 1,369, p= .49 and on self-rated confidence (M=4.5, n=109), U= 1,592, p= .47

5.5.2.2 Demographic

No significant difference in the KADDs scores at baseline between male (M=16.80, n=42) and female participants (M=16.76, n=67), U=1,435, p= .86 was observed as well as no difference in confidence scores between male (M=4.7, n=42) and female participants (M=4.4, n=67), U=1,284, p= .43

There was no significant difference in the KADDs scores at baseline between age groups (GP1, n=31: 25-35yrs, Gp2, n=41: 36-45yrs, Gp3, n=29: 46-55yrs, Gp4, n=8: 56-65yrs), X^2 (3, n=109) = 3.65, p= .32 as well as no difference in confidence scores between age groups, X^2 (3, n=109) = 5.95, p= .11

Prior ADHD training had no significant effect on the KADDs scores at baseline between participants who had received prior training on ADHD (M=17.5, n=26) and those who had not (M=16.5, n=80), U=900, p= .30. A significant difference in self-rated confidence was observed between the groups who had received training on ADHD (M=5.4, n=26) or not (M=4.25, n=80) U= 640, p= .003. However, there was no significant effect of KADDS confidence score on those who had received prior training (M= 6.53, n=26) and those who had not (M=7.39, n=80) U=1,151, p= .41

The relationship between scores and GPs years of practice was also investigated. There was no correlation between years of practice and KADDS scores, r= .13, n=109, p= .154 and between years of practice and confidence scores, r= .17, n=109, p= .06

The relationship between scores and the number of ADHD cases GPs had identified was also investigated. There was no correlation between identified cases and KADDS scores, r= .06, n=103, p= .49 and confidence scores, r= .0.2, n=103, p= .80

The relationship between scores and the number of suspected cases of ADHD and the number of ADHD diagnoses in the GPs' practices was also investigated. There was no correlation between KADDS scores and suspected cases of ADHD, r= .01, n=101, p= .89 and between KADDS scores and diagnosed cases, r= .17, n=71, p= .14

No relationship between confidence scores and suspected cases of ADHD was observed, r= .01, n= 101, p= .88 as well as between confidence scores and ADHD diagnosis, r= .24, n=71, p= .04

5.5.2.3 Study interaction

Participants were instructed to complete assessments in one go if possible; however, they had the option to log off and return if required. Participants who took longer than 48h between T1 and T2 were excluded from the analyses. Participants from the control group mostly completed T1 and T2 in one session (41, 78%), while fewer participants in the intervention group completed in one session (35, 61%). Most participants interacted with the video or intervention in both groups, suggesting that they were unsure of their group allocation.

The table below (Table 13) highlights the number of participants who completed T1 and T2 in one seating and the length of time they each spend interacting with the online resource (intervention group) or video (control group).

Table 13

Participants Interactions with the Intervention

		Participants (n=109)	
		Control (n=52)	Intervention (n=57)
Participants who completed T1 and T2 in one session		41 (78%)	35 (61%)
Minutes spent on intervention/video	Mean	39	55
	Range	13-85	28-125
	SD	20.79	13.50

5.5.2.4 Primary outcome

The primary outcomes for this intervention were KADDS knowledge scores at T2. Table 14 illustrates the responses from these scores and responses from KADDS scores assessed as a secondary outcome.

A one-way between-group analysis of covariance was conducted to compare the efficacy of the online intervention designed to change GPs’ attitudes towards ADHD. There was a significant effect of the intervention on ADHD knowledge after controlling for baseline responses, with the intervention group significantly increasing their knowledge of ADHD, F (1, 106) = 117.5, p<.001, partial eta squared = .52

Additionally, enhanced knowledge from the KADDS questionnaire was retained at two-week follow-up, F (1,106) = 96.25, p<.001, partial eta squared= .47

Table 14

Descriptive Statistics of the KADDS Knowledge (R:0-27) and Confidence Scores (R:1-10) for the Two Groups at the Three Different Time Points

		KADDS Knowledge		**KADDS Misconceptions**		**KADDS Confidence**		**Self-rated confidence**	
		M	SD	M	SD	M	SD	M	SD
Control group	T1	16.82	5.15	1.82	1.78	7.15	6.07	4.40	1.66
	T2	17.23	5.18	2.05	1.62	6.64	5.99	4.57	1.67
	T3	17.13	5.02	2.24	1.77	6.69	5.97	4.88	1.72
Intervention group	T1	16.65	3.88	2.16	2.20	7.12	4.30	4.66	1.70
	T2	23.71	2.00	1.54	1.55	0.73	1.35	7.40	1.05
	T3	22.96	2.13	1.70	1.65	1.22	1.71	7.36	0.89

KADDS knowledge scores represent the number of right answers, KADDS misconceptions the number of wrong answers and KADDS confidence the number of “Don’t know” answers. M= mean. SD = standard deviation.

5.5.2.5 ADHD knowledge, misconceptions and confidence

After controlling for differences in baseline responses, the intervention group showed a significant reduction in ADHD misconceptions compared to the control group, F (1,106) = 4.20, p=.04, partial eta squared= .03

This effect was retained at two-weeks follow-up, F (1,106) = 9.21, p= .03, partial eta squared = .04

Immediately after the intervention (T2), the intervention group also showed a significant increase in confidence compared to the control F (1,106) = 182.8, p<.001, partial eta squared= .63

This increased confidence was retained at two weeks follow-up F (1,106) = 110.08, p<.001, partial eta squared= .50

Factor subscales

The original KADDS questionnaire has three subscales: Associated features (general information about the nature, causes and prognosis of ADHD), Symptoms/Diagnosis and Treatment. These subscales aim to reflect content areas relevant to diagnostic decisions. The results of KADDS knowledge scores on these subscales were further explored. Table 15 presents the responses for each subscale

Table 15

Descriptive Statistics of the KADDS Scores Three Subscales (R: AF 0-11, SD 0-7, T 0-9) at the Three Different Time Points

		Associated features		**Symptoms/Diagnosis**		**Treatment**	
		M	SD	M	SD	M	SD
Control group	T1	6.94	2.32	4.19	1.26	5.90	1.84
	T2	7.13	2.27	4.34	1.29	5.90	1.95
	T3	6.98	2.27	4.34	1.18	5.90	1.89
Intervention group	T1	6.63	2.08	4.26	1.02	5.94	1.41
	T2	9.87	1.21	5.66	0.54	7.45	0.80
	T3	9.42	1.22	5.52	0.65	7.47	0.68

For participants in the intervention group, scores decreased on all the subscales post intervention at T2 and T3 - associated features subscale, T2: F (1,106) = 88, p<.001, partial eta squared = .45, T3: F (1,106) = 69, p<.001, partial eta squared = .39, the symptoms/diagnosis subscale, T2: F (1,106) = 69.8, p<.001, partial eta squared = .39, T3: F (1,106) = 57.9, p<.001, partial eta squared = .35 and the treatment subscale, T2: F (1,106) = 45, p<.001, partial eta squared = .30, T3: F (1,106) = 45.9, p<.001, partial eta squared = .30

The relationship between the KADDS knowledge scores at T1 and self-rated confidence was investigated using Spearman rho correlations. A strong positive correlation between the two variables was observed, r= .473, n=109, p<.001, with high levels of self-rated confidence associated with higher scores of ADHD knowledge.

Intervention group

At T2, participants in the intervention group were asked to rate, on a scale of 1-10, two feedback questions on the usefulness of the information and likelihood to inform practice. The results indicated participants found the information useful (M=8.2, SD= 1.48) and likely to inform practice (M=7.8, SD=1.5).

5.5.2.6 Attitudes towards ADHD

Another questionnaire on GP's attitudes towards ADHD was included at all time-points. Descriptive statistics for these 12 questions are presented below (Table 16).

Table 16 demonstrates that the majority of GPs do not endorse common misconceptions and non-scientific associations with ADHD. Slight changes in attitude can be observed in the intervention group, especially in the statements: "Most children with ADHD try to control themselves, "Parents seek ADHD diagnosis as an excuse for their child's bad behaviour", "ADHD diagnosis relieves families from stress and supports problem-solving. "

Table 16

Common Attitudes and Beliefs about ADHD in General Practice

		Control (n=52)			**Intervention (n=57)**		
		No	Yes	Don't know	No	Yes	Don't know
Children with ADHD misbehave because they don't follow rules	T1	48 (92%)	1 (2%)	3 (6%)	44 (77%)	8 (14%)	5 (8%)
	T2	49 (94%)	1 (2%)	2 (4%)	51 (89%)	5 (8%)	1 (2%)
	T3	46 (88%)	4 (7%)	2 (4%)	52 (91%)	4 (7%)	1 (2%)
Media coverage impacts people's conception of ADHD and its treatment	T1	0	52 (100%)	0	1 (2%)	55 (96%)	1 (2%)
	T2	1(2%)	50 (96%)	1 (2%)	2 (4%)	55 (96%)	0
	T3	1 (2%)	50 (96%)	1 (2%)	2 (4%)	55 (96%)	0
Most children with ADHD try to control themselves	T1	7 (13%)	31 (60%)	14 (27%)	14 (24%)	21 (37%)	22 (38%)
	T2	7 (13%)	34 (65%)	11 (22%)	13 (23%)	36 (63%)	8 (14%)
	T3	9 (17%)	32 (61%)	11 (22%)	10 (17%)	42 (74%)	5 (8%)
Parent seek ADHD diagnosis as an excuse for their child's bad behaviour	T1	29 (55%)	15 (29%)	8 (15%)	26 (45%)	23 (40%)	8 (14%)
	T2	28 (53%)	14 (27%)	10 (20%)	46 (81%)	8 (14%)	3 (5%)
	T3	32 (62%)	14 (27%)	6 (11%)	48 (84%)	5 (8%)	4 (7%)

Children’s inattentiveness is caused by unwillingness to please	T1	49 (94%)	0	3 (6%)	54 (94%)	2 (3.5%)	1 (2%)
	T2	50 (96%)	0	2 (4%)	57 (100%)	0	0
	T3	51 (98%)	0	1 (2%)	55 (96%)	2 (4%)	0
Parents primarily seek ADHD diagnosis to claim benefits	T1	47 (91%)	1 (2%)	4 (7%)	51 (89%)	3 (5%)	3 (5%)
	T2	44 (85%)	1 (2%)	7 (13%)	56 (98%)	1 (2%)	0
	T3	43 (83%)	2 (4%)	7 (13%)	55 (96%)	1 (2%)	1 (2%)
An ADHD diagnosis removes stigma of bad parenting	T1	20 (38%)	23 (45%)	9 (17%)	26 (45%)	25 (44%)	6 (10%)
	T2	21 (40%)	20 (38%)	11 (22%)	26 (45%)	27 (47%)	4 (7%)
	T3	20 (38%)	22 (42%)	10 (20%)	28 (49%)	27 (47%)	2 (4%)
An ADHD diagnosis is helpful for an individual	T1	2 (4%)	41 (79%)	9 (17%)	4 (7%)	49 (86%)	4 (7%)
	T2	0	42 (80%)	10 (20%)	2 (4%)	55 (96%)	0
	T3	1 (2%)	42 (80%)	9 (17%)	2 (4%)	53 (92%)	2 (4%)
An ADHD diagnosis is stigmatising for an individual	T1	14 (33%)	27 (52%)	11 (21%)	21 (37%)	29 (51%)	7 (12%)
	T2	11 (21%)	26 (50%)	15 (29%)	30 (53%)	21 (37%)	6 (10%)
	T3	16	26 (50%)	10 (20%)	25 (44%)	26 (45%)	6 (10%)
ADHD diagnosis relieves families from stress and supports problem solving	T1	6 (11%)	39 (76%)	7 (13%)	8 (14%)	42 (74%)	7 (12%)
	T2	2 (4%)	42 (81%)	8 (15%)	4 (7%)	50 (88%)	3 (5%)
	T3	4 (7%)	38 (73%)	10 (20%)	3 (5%)	51 (89%)	3 (5%)
Do you believe ADHD is a valid diagnosis?	T1	0	46 (89%)	6 (11%)	2 (4%)	50 (88%)	3 (5%)
	T2	0	49 (94%)	3 (6%)	1 (2%)	55 (96%)	0
	T3	0	50 (96%)	1 (2%)	1 (2%)	56 (98%)	0
Do you believe ADHD is society’s excuse for badly behaved children?	T1	42 (81%)	1 (2%)	9 (17%)	46 (81%)	2 (4%)	9 (15%)
	T2	42 (81%)	2 (4%)	8 (15%)	54 (94%)	2 (4%)	1 (2%)
	T3	43 (83%)	2 (4%)	7 (13%)	52 (91%)	1 (2%)	3 (5%)

5.5.3 Discussion

A pilot RCT was conducted to understand the potential clinical utility of an online psycho-education resource to improve GPs’ knowledge of ADHD. This study demonstrated that the intervention was potentially efficacious, with GPs reporting an increase in knowledge of ADHD, combined with a change in attitude, decrease in misconceptions, change in practice and excellent reported levels of acceptability. Previous studies in this doctoral project have demonstrated that some of the significant barriers in GPs’ understanding and management of ADHD are their lack of training, knowledge and presence of misconception. This study has shown that a short online education resource can be easily implemented and can address these gaps while also impacting practice. This study (with over 68% of GPs having never received any training on ADHD) and others (Alder et al., 2009; Salt et al., 2005) have highlighted the lack of initial GP training on ADHD. No difference was observed between participants who had and those who hadn’t had ADHD training, indicating that current training is ad-hoc and not effective. This intervention is, therefore, timely in addressing these gaps.

As opposed to previous studies on GPs’ misconceptions and attitudes (Adamis et al., 2019), our findings showed fewer misconceptions and widespread stigmas expressed by GPs. The intervention did address some of these; however, at baseline GPs were a lot less prone to stigmas than previously reported.

Few studies have investigated the implementation of online interventions for GPs. This study contributes to the work of increasing GPs’ awareness of specific disorders (Sikorski et al., 2012) and providing accessible online educational programmes. As GP training on ADHD is low, and no other targeted online education resource exists on the topic, it addresses a vital gap. Piloting is essential as it permits valuable methodological lessons to be learned. While many pilot RCTs struggle to establish significant results often due to small sample sizes (Ersser et al., 2012; Luby et al., 2012; Watts et al., 2013), this study indicates the potential efficacy of the intervention, despite limited sample size. However, it is important to note that definite efficacy would need to be established in a full scale RCT with a sample size calculated from the results of this pilot study to ensure sufficient power to measure effect.

Strength and limitations

The co-production approach taken in developing the online resource's design and format offers many strengths to this study. The resource is optimal for GPs as it is time-limited, easily accessible and freely available, minimizing GPs’ costs and time accessing training. Despite previous research on the difficulty to recruit GPs (Aerny-Perreten et al., 2015; Thepwongsa et al., 2014; Young et al., 2015), this study had no problem with recruitment.

On the contrary, recruitment happened very fast and had to close after only two weeks. This phenomenon could demonstrate the high interest in the topic or the vital need for training on ADHD. Alternatively, and similarly to advice given in recent studies, high monetary (£80) and nonmonetary (CPD certificate) incentives (Pit et al., 2014), as well as regular reminders (Aerny-Perreten et al., 2015) might have also contributed to the success in recruiting for this study.

A few limitations can be highlighted in this study. The sample was not balanced across gender and consisted of a high prevalence of women (66%) even though the findings showed no significant difference between gender. A recent report from England General Medical Council (2018) suggests that this is representative of part-time but not full-time permanent contracts in the NHS (only 35% of GPs on full-time permanent contracts are female, against 61% part-time). Unfortunately, no information was collected on whether the participants worked part-time or full-time, and this finding might imply that participants were more likely to take part if they work part-time and therefore have more time to complete the study. It is also important to highlight that this study is specific to the British healthcare system, where GPs act as gatekeepers and referrals to secondary care services for diagnosis and treatment are the norm. Therefore, recommendations presented in the online resource and the design for this study reflected this specific system and might not apply to countries using a different approach.

Limitations also arose from a lack of methodological rigour that had to be adopted for pragmatic reasons. Firstly, BF was not blinded to the study allocation, and although the participants were, they could potentially guess their group allocation. While this can be an issue in reporting this pilot RCT's rigour, the findings indicate that this had limited impact and are still worthy of a full RCT. Secondly, due to the online intervention format, randomisation had to be performed before baseline, which is not common practice. Conducting randomisation after baseline questionnaires would have added another step to the study, asking the GPs to spare time throughout more than one session and therefore was likely to increase attrition. Sending specific links to either control or intervention so GPs could complete T1 and T2 in one session seemed preferable to maximise completion rates. However, despite clear instructions, less than 50% of GPs completed in one session and therefore, randomisation after baseline might not have had a significant impact on attrition. The protocol also stated that completing T1 and T2 over 48h would not be reliable as it could not be ensured that any changes in scores would be due to the effect of the intervention and not external factors. Therefore 18 participants had to be excluded from the analyses after taking longer than 48h between the two time-points. While ideal for the purpose of this study, completion in one session seemed difficult for most participants.

A small minority of participants only interacted with the intervention for 15 minutes. This is, on average, the time it takes to answer both pre and post questionnaires. Therefore, it is reasonable to conclude that these participants did not interact with the course and did not gain any knowledge from taking part. However, our protocol did not initially anticipate such possibilities and these participants were included in the analyses. In the future, better control over study interaction or more robust exclusion criteria should be implemented to minimise the effects of such responses

While many participants who completed the consent forms did not take part in the study (24%), this drop out can be explained by multiple factors. Recruitment in general practice is complex, and often, practices are recruited for studies with a selective number of these practices GPs taking part. Either practices or practice managers will express interest in their practice. A couple of participants (who were excluded as they had previously taken part in our pilot study) explained that they had not signed the consent form for themselves but for their practice. A few more participants would likely have followed a similar process. Unfortunately, it was impossible to anticipate that participants might sign consent forms on behalf of their practice and had not put any structures in place to account for such possibilities. In the future, expression of interest and consent for individuals versus practice will be made more explicit. Attrition rates were moderate at 23% between T1 and T3. However, the attrition rate between T2 and T3 was very low (1.5%). A few retention strategies such as weekly reminders with clear deadlines and reinforcing the incentives were put in place, which seemed to minimise the attrition rate compared to the average attrition rates of RCT (Christensen et al., 2009; Fewtrell et al., 2008). A few strategies have been shown to increase retention compared to others (Pit et al., 2014). In this review, the authors highlight that monetary incentives, pre-contact with participants and regular reminders are recruitment and retention strategies that decrease attrition rates.

Implications for further studies

Future research should address the few methodological issues from this study. Yet, while they impacted attrition and exclusion rate, these issues do not seem to have impacted this study's findings per se. Some changes in practice were observed; however, due to the time restriction for this study (six months), it was impossible to assess these impacts over a more extended period fully. Future research should also consider a longitudinal assessment to explore whether changes in knowledge, attitude and practice are retained over a more extended period of time. Exploring this resource's impact on other healthcare professionals such as primary care nurses or secondary care professionals would also allow for broader impacts of this intervention to be investigated.

5.6 Interviews and surveys

To gauge the impact on practice, semi-structured interviews and surveys were conducted three and six months after the intervention. These aimed to gauge direct and specific changes in practice as well as self-reported changes in attitude and knowledge.

5.6.1 Methods

5.6.1.1 Study design

Semi-structured interviews were conducted over six months in late 2019 and early 2020 with participants from across England. The interviews were conducted by the lead investigator (BF), who has received extensive training in qualitative methods and were analysed using thematic analysis (Braun & Clarke, 2006). A brief online survey was also conducted six months after participants took part in the intervention.

5.6.1.2 Participants

Participants from the intervention group were invited to participate in a short qualitative interview and survey after completion of the intervention. Fifty-six of the intervention arm participants had given consent to be contacted again and were invited. Twenty-three took part in the interviews (53% females), and twenty-one (58% females) responded to a survey about the impact of the intervention on their clinical practice.

5.6.1.3 Data collection and analyses

Three months after taking part, participants who had been allocated to the intervention group and had given consent to be contacted again were asked to take part in follow-up interviews. Participants who responded were interviewed over the phone for 15 minutes at a time of their convenience. Semi-structured qualitative interviews were conducted over the phone. All 56 participants from the intervention arm who had given consent were also sent a short final survey to complete online.

The analytic strategy for this study was based on thematic analysis (Braun & Clarke, 2006) enhanced by grounded theory principles (Chamberlain, 2004). Themes and subthemes were identified using an adapted approach of Braun and Clarke’s (2006) six-stage process. The analytic process began by transcribing each interview verbatim shortly after being conducted. Following this process, the lead investigator first familiarised herself with the interviews and took notes in a diary of her preliminary thoughts on the interviews' content. From this, preliminary codes were identified in a coding manual. They were then collated and combined into broader themes using constant comparative analysis both within and between transcripts. Finally, as the analysis evolved, these broader themes were reviewed and refined and generated the final themes proposed. An ongoing analysis allowed for a clear definition of the final themes to be set out.

Themes were finally reviewed by a second researcher (EPV) to ensure they mapped to the original transcripts. Inter-rater reliability was tested on a small proportion (20%) of the transcripts' themes. The results were validated collectively as a team, and any discrepancies were discussed and reconciled.

The survey responses were reported descriptively and used to triangulate the responses from the interviews.

5.6.1.4 Measures

Interview

The interview schedule included questions about the intervention and its impact on GPs' attitudes and practice (Appendix 12). As the interviews aimed to gauge changes in practice, it was noticed that three months was too short to assess this effectively. Therefore, after conducting 11 interviews, the following interviews were conducted at the six-month time-point. Twelve further interviews were conducted at six months.

Survey

The four items open questionnaire (Appendix 13) was sent to all 56 participants from the intervention arm who consented and aimed to assess changes in practice and approaches after taking part in the intervention six months after taking part in the intervention.

5.6.2 Results

5.6.2.1 Interviews

The interviews were brief and lasted, on average, 10.30 minutes (R: 6.43-15.45 minutes).

All participants thought the format of the intervention was informative, valuable and appropriate. None believed that any content was missing. The only aspect that participants thought could be changed was the length of the text. A couple of participants expressed that there was too much text and that maybe the content could be more concise. The main points that participants benefited from were the videos, the information about adults and the genetic side of ADHD. Participants highlighted the benefit of understanding the epidemiology and long-term aspects of ADHD as well as having experts and patients' videos to help put ADHD into context, most especially the videos of the GP who had ADHD.

Participants were also asked about their reasons for signing up. While monetary rewards and demands to participate in research were cited as incentives, the main incentive in taking part was professional/personal interest in the topic. Most GPs stipulated that personal interest in ADHD was why they signed up, often acknowledging a lack of previous knowledge and/or Medical School training on the topic.

The interviews highlighted two main themes, both related to the impact of the intervention. The first theme explored the personal impact the intervention had on the participants, examining changes in their understanding, attitudes and knowledge. The second theme explored broader changes and the impact the intervention had on other individuals. This included participants' change in practice, directly impacting their patients but also impacting their personal lives and broader professional views.

Personal impact: GPs' change in knowledge and attitudes.

Increased knowledge and attitude was the first theme that these interviews highlighted. Most participants reported that taking part in the study significantly increased their knowledge of ADHD, especially since most had received minimal training on ADHD. Participants stated that it helped reduce misconceptions and demystify ADHD, which was especially useful for young GPs or trainees. Many participants found that they knew very little about the topic, most specifically regarding adult diagnosis and biological/genetic components, as many believed or were taught that ADHD was a behavioural problem only present in childhood. Increasing accurate knowledge was beneficial for GPs as they enjoyed learning about the positives of gaining a diagnosis and accessing the right treatment.

> *"The key thing was about dispelling the myths… gaining a better understand generally" (P6)*
>
> *"I was surprised how little I knew about it beforehand, to be honest… it's completely changed the way I view them (patients with ADHD), I am much more sympathetic" (P12)*
>
> *"I was always taught that people grow out of ADHD… I'm more willing to consider it as a diagnosis. I used to think you should have grown out of it, and you're just trying to get hold of amphetamines, drug-seeking." (P16)*
>
> *"The fact that I can remember so much about it is probably a testament to how good it was at reinforcing and retaining the information" (P12)*

Participants who had some preliminary knowledge of ADHD stated that the course was a good refresher and confirmed what they already knew while adding a few extra unknown facts. These participants often mentioned that their knowledge was acquired in informal ways throughout their practice and they felt reassured that this knowledge was accurate through this course. However, a couple of participants raised the issue that while the intervention was informative, it was a bit too simplistic for individuals who had previous extensive knowledge and was therefore not pitching to the right level for these few individuals.

> *"I knew a fair bit already although in a fairly random and bitty way… it was good to see it in one go, it's allowed me to have a better idea" (P3)*

> *"You pick up bits and pieces along the way, and I think most of those were covered in the programme, and then I reckon about 50% I wasn't aware of" (P9)*

Increased knowledge and information received from the course led to almost all the participants reporting a change in attitude towards ADHD. Most specifically, participants reported feeling more confident, more understanding and more empathetic towards ADHD. Participants also reported being more tolerant and patients towards patients seeking a diagnosis, having less prejudice and being less dismissive. By demystifying some of the stigmas around ADHD, the resource allowed participants to gain a more empathic approach toward the disorder and change their mindset.

> *"Actually, it has changed my attitude, it's not very often that some sort of learning will do that because attitudes are quite hard engrained. I found it very useful, and I'm a lot more open-minded to it as a diagnosis, and it will help me pick up faster" (P1)*

> *"Just being more confident of, look, I think this child needs seeing, they've got A, B, C, D…" (P9)*

> *"I've got a couple of adults with ADHD (who have been refereed), and I'm able to empathise with them a lot more whilst we are "holding them" until they get to the top of the list to see a psychiatrist" (P19)*

Broader Impact: Change in practice and beyond

The second theme these interviews highlighted referred to the broader impacts of the intervention. Many participants reported changing their practice in many different ways. Some reported an increase in identification and referral, acknowledging that the course enabled them to make these processes easier, quicker and develop a more structured approach to referrals. Others reported change in practice in relation to the tools and information they now use to refer and manage ADHD, increasing the use of local services and screening questionnaires. As one GP mentioned, "It is not so much What I do that has changed but How I do it." For instance, some of the knowledge that was gained in light of the relationship between ADHD and depression or symptoms in adulthood has helped GPs look more into patient's history and ask further questions when they probably wouldn't have before. The participants who did not report changes of practice reported that it was mainly due to lack of opportunities in their practices, including an above-average older population sample. Nonetheless, these participants reported that even after six months since taking part, they knew how they would change their practice in the future when they come across a patient with ADHD.

> *“(after referring an adult) I’m fairly convinced they did have ADHD from what I learnt from this course, it led to a faster diagnosis, in my head at least” (P1)*
>
> *“I offer them extra support, give them extra time in appointments… There are certain questions I might ask now that I wouldn’t before” (P2)*
>
> *“I found the resources useful, I saved the link somewhere as well” (P19)*
>
> *“(about a new referral service for ADHD) I didn’t know about that until I did the study and then found out subsequently that there’s a really new service set up. There are two children that I have referred that I probably wouldn’t have done before… I would have just waited a couple of years to see if anything came out in school years.” (P4)*
>
> *“My threshold to refer people for assessment would be much much lower now” (P12)*
>
> *“Over the past few months, I haven’t had a case of ADHD, but the knowledge is still there, the nuggets of information that I’ve learnt” (P14)*

Finally, many GPs reported impacts beyond their practice. These participants discussed how the course has allowed them to identify ADHD in family members or individuals they know in other settings. The participants also often disseminated the resource within their contact and practice, broadening its impact. Finally, participants also reported seeking further training as a result of taking part in this course. Participants asked if more modules on similar topics were available and also attended additional training on ADHD and other developmental conditions as they wanted to learn more.

> *“It helped me understand a little bit what was going on with my own son as well” (P18)*
>
> *“I do a church youth group, but there’s a couple of guys, now I can’t go diagnosing them, but it’s completely changed the way I view them, I’m much more sympathetic” (P14)*
>
> *“I was able to pass on the learning to other doctors in our doctor's meeting, so. I’m hoping that will have impact not just on me but doctors at the surgery too” (P2)*

> *"Subsequently to doing this bit of teaching, I've done a couple of other e-learning modules, and I went to a psychiatry lecture as well" (P19)*

5.6.2.2 Surveys

Twenty-one participants (48% females) also responded to a brief online survey six months after participating in the study. The responses included a mix of participants who took part in the interviews (58%) and participants who didn't (42%).

The responses were triangulated with the interview responses, and similar findings were observed. When asked the following questions:

"Did you gain any knowledge on ADHD?" and if there was "any difference in how you approach ADHD before and after your interaction with the course?", 91% of the participants agreed. When asked if the intervention had impacted their practice yet, 66% said yes, 19% no, and 15% not yet.

When asked to give an example of how it has changed their practice, GPs mentioned similar topics to the ones in the interviews, including increased referrals, more confidence in discussing and identifying ADHD, better use of assessment/screening tools, better awareness and understanding of ADHD patients.

Finally, when asked if the course impacted their attitude towards patients with or at risk of ADHD, 20% reported no changes. The participants who reported changes in attitude included increased empathy, better understanding, increased awareness of the positive impact of a diagnosis and the importance of quick referrals, and increased confidence. A decrease in common ADHD stigmas, such as bad parenting and ADHD only happens in children, were also mentioned.

GPs' responses from the group of GPs who didn't take part in the interviews triangulated with the interview themes. In reporting the personal impact that the course had, GPs felt that it did change their attitude and knowledge on ADHD

> *"Better understanding of the impact on individual and the support they need" (P14)*
>
> *"I am more sympathetic to parents" (P19)*
>
> *GPs also reported a wider impact in their change of practice*
>
> *"I have increased my referral to adult ADHD specifically rather than to psychological therapies" (P21)*
>
> *"I saw a young boy the day after the training, and It was very useful to know what questions to ask" (P8)*

5.6.3 Discussion

The interviews' findings demonstrated that the online resource had substantial impacts on participants' attitudes, knowledge and awareness, and their practice. This, in turn, impacted not only their patients by improving access to care but also other members of the community such as colleagues, families and extended relationships. While it was anticipated that GPs' knowledge and practice could change from taking part in this study, the acknowledgement of this broader, holistic impact was unexpected.

The themes extracted from the interviews confirm the topics highlighted by the previous studies in this thesis. Most importantly, it affirms a lack of accurate knowledge and awareness around ADHD and that this impacts GPs' confidence and practice. GPs strongly felt that having the correct information and up-to-date knowledge from a trustworthy source was essential for validating their practice and reassured them that they were either doing the right things or they now knew what to do. Previous studies have highlighted that increased knowledge and confidence through primary care training will increase clinical practice and patients' care (Butler & Quayle, 2007; Kolko et al., 2010; Lewis et al., 2017). These interviews demonstrate similar findings. It was also reassuring that even after six months, GPs were still able to report how the course has increased their knowledge and practice, demonstrating a long-term effect of the resource.

A couple of topics triangulating with the themes highlighted in Chapter three arose organically from the interviews, namely, lack of appropriate services and lack of training. Many GPs acknowledged that lack of training on ADHD prompted them to participate in this intervention in the first place as they wanted to learn more. Both newly qualified GPs and established GPs mentioned this issue around training which was not prompted by the interview schedule. Another recurring theme that was mentioned but did not fit in the analyses was the issue around services. The interview schedule did not prompt this topic, but a few GPs mentioned it. Often associated with frustration around access to care available, GPs stated that while the increased knowledge gained from the course was useful, lack of services to refer to, especially for adults, was limiting.

The findings also highlighted highly positive feedback on the usability and implementation of the resource. Participants enjoyed taking part in the intervention and found it helpful. When participants were asked in the interviews if they would change anything, no interviewees could think of anything they felt was missing. A few participants reached out personally to the researchers to inquire whether the resource could be shared with colleagues and GP trainees in their practice as they found it so informative. These findings strengthen the findings from the usability study in that the online resource is ready to be used as it is and that no further adjustment needs to be made.

The interviews and survey highlighted a few limitations in this part of the study. Firstly, all participants who took part had a positive interaction with the resource. This could either reflect that the intervention was very well done or that participants who did not like it did not reach out to be interviewed. Similarly, the few participants who had minimal interaction with the resource did not participate in the interviews. Therefore, the views of participants who might not have enjoyed the course are lacking, and it was impossible to gauge why some participants did not interact with the resource and what could be changed if they did not like it. Secondly, the interviewees' change in practice is limited to the six-month window that the doctoral studies timeframe allowed. While this shows changes over time, it is relatively soon after taking part in the study. It is unknown whether these changes would still be reported in a year's time, for instance, and whether they will be consistent over time. Similarly, although qualitative data on change of practice was gained in this study, assessing the impact on the number and quality of referrals was not possible within the context of this study. Future studies should include an assessment of referrals to gauge the change in practice more directly.

5.7 Conclusion

These studies allowed for a thorough assessment of the online resource. The usability study facilitated the evaluation of the accessibility of the intervention, while the pilot RCT and interviews allowed to assess its efficacy through changes in knowledge and changes in practice. The results demonstrate a highly usable, accessible and efficient psycho-educational online resource. These, in turn, have substantial implications for practice and future research.

Usability study

This usability study demonstrates that using this online psycho-educational resource on ADHD with GPs is feasible and acceptable. While a few minor changes had to be implemented, this study suggests that the online resource is usable on a small scale and ready to be used on a bigger scale.

Pilot RCT

The pilot RCT successfully answered the hypotheses that a short online psycho-education resource would increase GPs’ awareness, knowledge and attitude of ADHD. These findings need to be interpreted with caution as this is the only study investigating the efficacy of this online intervention, and further studies would need to validate these findings. However, they highlight significant clinical impacts on patients' care and policies. Through better GPs' understanding and knowledge, patients will receive quicker access to care, reducing the long-term impacts of untreated and undiagnosed ADHD. This online resource has already been adopted by the RCGP, which will impact the learning and awareness of many GPs beyond this study, having broader impacts on practice and potentially influencing commissioning decisions once the importance of training GPs on ADHD has been recognised.

Interviews and survey

The interviews and survey explored over time change of practice and retention of knowledge. This self-report exercise highlighted the impact of the intervention on the GPs and their patients. This change in practice encompassed multi-levels of changes, including increased referrals, more accurate information gathered, better use of screening tools, and more effective communication with patients. This part of the study was crucial in understanding exactly how the online resource and increase in ADHD knowledge impacted patients' outcomes.

5.8 Reflexive statement

The process of conducting this intervention study highlighted many unexpected challenges in recruitment, participation and methodology, which was a considerable learning curve.

Recruitment

The recruitment of GPs for the qualitative study in Chapter three (n=5) was difficult and took longer than expected. Therefore, it was anticipated that recruiting over 100 GPs would be almost impossible, and a way to facilitate recruitment was to get the study portfolio adopted by the National Institute for Health Research (NIHR). The application for NIHR adoption took some time and was not guaranteed to be successful. By getting the study adopted, the NIHR can facilitate recruitment by disseminating the study to their practices. The application initially only focused on local East Midlands CRN practices; however, extending to other CRNs was very straightforward once the application was approved. Therefore, the study was extended to all English CRNs. This triggered a series of positive and negative challenges that were never anticipated when designing the study. On the positive side, recruitment was very successful, and hundreds of expressions of interest were received along with hundreds of consent forms. Recruitment was so quick that it had to close after only two weeks. It allowed the team to meet our recruitment target but also to have a representative sample of English GPs. Out of the 12 CRNs which agreed to circulate our studies, some were a lot more active and enthusiastic than others. These CRNs generated a lot of recruitment quickly, and recruitment from these CRNs had to be stopped early to gain a representative sample and avoid clusters of participants from the same areas. Once this issue was acknowledged, each CRNs were instructed to limit recruitment to 20 participants. Similarly, issues around multiple recruitments from practice were not anticipated. No restriction was implemented, but BF realised that GPs from the same practice could sign up and therefore increase cross-contamination risks. Therefore, a limit of one GP per practice was initiated after recruitment started. However, once data collection was finished, it was noticed that, in a few instances, more than one GP from the same practice. It is impossible to know whether this allowed for cross-contamination to happen or not, but in the future, limiting recruitment to one GP per practise would be essential. Communication with different CRNs' leads was also very complex. The CRNs have specific ways of conducting studies and use specific terminology that does not always map with other research. For instance, GPs signing the consent forms on behalf of their practice was not expected as it was clear that these were individual consent forms. However, this seemed common practice, and CRNs were surprised that the protocol had not taken this into consideration

The portfolio adoption was beneficial but created some unexpected technicalities that the study's design did not account for, such as limiting the number of recruitment per practice or per CRN if wanted a representative sample. This was a considerable learning process and allowed for an interesting overview of how primary care studies are conducted in NIHR, which was different from our process.

Participation and methodology

Concerning participation in the study, a few unexpected questions arose. In running an RCT design, a few participants allocated to the control group were confused about this. Some participants emailed the lead researcher to ask why there was no information on ADHD and whether the link worked. It was explained to them that they had been allocated to the RCT control group; however, a couple then expressed their discontent of not being in the intervention group and felt that their time had been wasted. While clear information was given about the RCT process in the recruitment email and the information sheet, it was not clear enough for some participants. Reassurance that they would receive a link to the course as soon as they completed the study was also given; however, these responses were not anticipated and knowing what could be done differently in the future is tricky.

On the positive side, a few participants enjoyed the course so much that they asked if they could pass it on to colleagues. One, in particular, was the head of training for the local registrar and wanted to send it to them all. Receiving such a keen interest was not expected, and BF explained that this was not possible until data collection was completed. It was reassuring to receive such interest and acknowledge that the course was useful.

Follow-up was also difficult at times. It often took up to four weekly reminders for participants to complete the pilot RCT. In the interviews, two main unexpected follow-up challenges arose. In the first instance, after starting the interviews at the three-month timeline, it became apparent quickly that this was too short a time to gauge changes in practice, which was the main objective of the interviews. Therefore, it was quickly decided to change the timeline to six months. However, at the time, another eight interviews had been scheduled. After explaining the situation to each participant, all agreed to be contacted again three months later, but not all responded down the line. Some important insight might have been lost from these participants who were initially willing to take part. It is also important to highlight the timing of the second set of interviews. The six-month interviews started in March 2020, which was the start of the Covid-19 pandemic. The majority of the interviews happened before lockdown, but a couple happened afterwards, which was incredibly generous from the GPs. The contextual timing of these interviews might be why not all participants who were keen to participate responded to the second invitation.

The technicalities of running an RCT design were also, at times, challenging. There was a lot of information to keep track of, and very little could be automated. Good organisation, tracking system and daily logs were therefore essential. However, this did not stop mistakes from happening. For instance, once participants from the control group completed their last questionnaire, they were sent an expense claim form and a link to the course for their own usage. Upon realising that the link was wrong (through a participant raising the issue), a valid link was resent to them all. However, in confusion, the link was sent to four control group participants who had not completed the study yet, which meant their data were excluded.

In the grand scheme of things, these challenges did not strongly impact the results or the study, but it raised some very interesting issues and was a significant learning experience in undertaking RCT studies.

Chapter 6 Impact and implementation

6.1 Chapter summary

While a full-scale implementation process was beyond the scope of the research reported in this thesis, a preliminary overview of the online resource's impact and implementation is reported in this chapter. Data through written feedback and analytics of the website were collected to overview the medium-term impact and implementation briefly. These findings support the previous studies' findings, endorsing the intervention as a valid, feasible, and educational resource, transferable into real-life settings.

6.2 Introduction

Many interventions developed within the scope of RCTs struggle to include assessing the impact and implementation of these interventions (Danielson et al., 2007; Hotopf, 2002). Additionally, when implemented in real-life settings, few show that the findings are transferable (Audrey et al., 2006). Understanding whether the intervention works and is useful in routine practice is essential to inform the implementation of any intervention into the “real” world.

RCT designs raise many issues in terms of implementation and impact. The carefully managed nature of recruitment and data collection and the lack of longitudinal data pose some difficult questions about the real-life clinical implementation of these interventions. Gauging the impact of these interventions and how it translates into the real world is very complicated.

What do we mean by impact and implementation? The understanding of the term impact can vary widely depending on the context. For instance, the ESRC refers to research impact by distinguishing between “academic impact” and “economic and societal” impact (Nutley, 2003). In this chapter, the term impact will refer to economic and societal impact as longer-term benefits for individuals and organisations are explored. Impact, therefore, refers to the effectiveness of the intervention in changing knowledge, behaviour, and attitude beyond the scope of the study. On the other hand, implementation assesses how well this intervention works and how easy it is to use outside of a controlled environment. The implementation phase of the MRC framework introduced in Chapter one (1.4.1, p.25) refers to the dissemination, long-term follow-up, surveillance and monitoring of the intervention.

A comprehensive evaluation of the online resource’s impact and implementation is beyond the scope of these doctoral studies; however, a small evaluation was conducted to highlight preliminary findings of these essential considerations. To assess the implementation and impact of the resource, multiple methods were used.

6.3 Methods

The assessment of impact and implementation was conducted through three different methods. Firstly, optional feedback was recorded from individuals who had engaged with the resources in the twelve months' post-data collection. Secondly, Google Analytics recorded data on the numbers of unique users and logged in to the resource pages. Finally, informal feedback was also recorded from participants who took part in the pilot RCT.

The optional feedback post data collection included seven questions gauging both demographics and feedback from the resource. The questions included were as followed:

- Age
- Occupation
- Gender
- How useful did you find the information in this resource?
- How likely is this information going to inform your practice?
- Did you experience any problems in using this resource?
- Would you recommend this training to your colleagues?

These questions were asked after each module so that feedback could be received even if participants did not view the entire training. Individuals also had the option to email the research team directly if they wished.

Google Analytics was also used to assess the number of users, sessions, and page views on the 12th of January 2020 - after completing the intervention study and on the 4th of January 2021 - a year post data collection.

Finally, informal feedback from participants in the pilot RCT was obtained after the completion of the intervention. Participants had the option to leave written feedback or contact the lead researcher for any comments they had about taking part.

6.4 Results

6.4.1 Online feedback

The first module received 26 voluntary responses and the second module, specific to GPs, received 9 (Appendix 14). A few other external individuals contacted the team to leave comments (Appendix 15).

The participants were of varying ages and gender. In module one, the average age was M=42.3 (R= 22-61), and 88.5% (23) were female. In module two, the average age was M= 37 (R=22-58), and 87.5% (7/8) were female.

The participants' occupations for the first module varied, including midwives, practice managers, teaching assistants, SEN teachers, MH workers, nurses, and many more. Module two included GPs, speech and language therapists, paediatricians and GP trainees.

Table 17 highlights the answers to the first questions in both modules and the usability study conducted before the pilot RCT.

Table 17

Usability Evaluation on a Scale of 1-10 (1: not at all and 10: a lot)

Scores	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Total mean (SD)**
How useful did you find the information in this resource?											
Module 1				1		2	3	5	3	12	**8.6 (1.6)**
Module 2		1					1	3	2	1	**7.6 (2.2)**
Usability study								3	2	5	**9.2 (0.91)**
How likely is this information going to inform your practice?											
Module 1				1	2	3	2	6	5	7	**8 (1.7)**
Module 2		1					2	2	2	1	**7.5 (2.2)**
Usability study								4	5	1	**8.7 (0.67)**

When asked if they would recommend this training to their colleagues, 100% agreed for the first module and 89% for the second.

Most participants did not experience any problems using the resource (80%, 28/35), while a few (20%, 7/35) had technical issues but did not specify the kind of issues.

Feedback was received in the first module, and a couple of external participants reached out to the research team, all endorsing the resource.

> *"Really good e-module."*
>
> *"Very informative, I like the before and after tests."*
>
> *"I've just completed your two ADHD resources sent by the RCGP learning route and first want to say that they are useful and set at the right level for most generalists, so from a personal point of view, I think they are delivering what you sent out for them to deliver."*

> *"Would it be possible to give our two new GP registrars access to this course? I think this would be really useful for them to complete."*

Only one written comment was provided for module two. This negative comment was from the same participant who rated the resource below average. However, as can be seen from the quote below, this participant seems to have misunderstood the resource's aim and topic.

> *"It is very important that GPs get involved in recognising autistic spectrum disorder. The site does not go into the social awkwardness of Asperger's. It could do with more detail and clinical scenarios. Also important the association and differential diagnosis of other co-morbidities, addiction/personality disorders/anxiety depression. That may indeed be beyond the scope of this website."*

6.4.2 Google Analytics

Data from Google Analytics was recorded in January 2020, and in January 2021 (Appendix 16). In January 2020, 243 users had logged in over 414 sessions. The final report in January 2021 reported that 439 individuals logged in since September 2019 (beginning of the RCT), over 593 sessions. The average session duration was relatively low but was strongly affected by brief regular access from the research team to check the intervention. Table 18 reports the main findings from Google Analytics.

Table 18

Google Analytics Report Summary

	January 2020	**January 2021**
Users	243 (20% returning)	439 (15% returning)
Sessions	414	593
Average session duration	10m27s	06m26s

Eighty-four participants who had taken part in the intervention and were allocated to the intervention arm had received access to the resources. As 243 users had logged in by January 2020, this suggests an additional 159 external unique users had logged in. It isn't easy to assess who these users might be, but they are likely to comprise a mix of researchers from the team, control group participants, and external users. The control group participants (85) were sent the link after taking part, and the website was also made freely available after data collection. An additional 179 users viewed the resources in the following twelve months.

6.4.3 Informal feedback from participants in the intervention

Participants in the pilot RCT had the option to leave written feedback or contact the research team if they wanted to share any comments. These comments were collated (Appendix 15) and represented mainly positive feedback from the resources, including accessibility, educational aspect, likeability, and usefulness.

> *“Thank you for inviting me. It was very useful and has changed my perception and understanding of ADHD.”*
>
> *“As part of the control part of the study, it was great to then have access to the ADHD learning module, which I found very well set out and easy to complete. Thank you.”*
>
> *“Easy to do, lovely format, interesting, lots of knowledge.”*
>
> *“A must for GPs. Excellent should be included in GP training.”*

While most comments endorsed the resource, a couple of participants expressed dissatisfaction with the online resource.

> *“very useful but too long and could be reduced further. The information about ADHD, in particular, could be reduced. The role of GP resources was more interesting with video vignettes.”*
>
> *“It is generally well presented and technically on a par with similar CPD modules. Unfortunately, the content is too emotionally biased and laden with vested interests to appear credible. It comes across as pseudoscientific in places and clearly seeks to perpetuate the underlying problem, which is the tendency of the medical profession to peddle cures for every ill. I am afraid all of the expert testimonies (which I did listen to) have failed to alter my opinion!”*

A few comments were received from the control group about the sham video. Some participants were not happy being allocated to the control group and others were surprised about this design.

> *“I'm sorry I couldn't see the point of the video, and it's 26 minutes long, which is frustrating.”*
>
> *“I think maybe the wrong video was put in this link. There was just a video to watch about the Institute of Mental Health in Nottingham. There was no information about ADHD.”*

6.5 Discussion and conclusion

This brief evaluation aimed to explore the long-term impact and implementation of the online resource through written feedback, Google Analytics, and questionnaires. Gauging the impact and implementation of research intervention is complex, and often findings are not easily transferable in real-life settings (Audrey et al., 2006; Hotopf, 2002). However, this preliminary data highlight similar views and responses from real-life implementation and participants in the study. The feedback on impact and the usefulness of the information triangulates with previous chapters' findings, thus supporting the feasibility and benefits of implementing the resource in real life.

While this data reinforces the positive impact of the intervention in real-life settings, it is important to highlight the difference between the pilot RCT and the twelve-months post data collection. Having this online educational resource freely available to anyone suggested that a wide range of people could have accessed it. The individuals who responded post data collections included individuals from different occupational backgrounds beyond healthcare professionals. Therefore, some aspects of the resource might not have been as relevant. Their knowledge, experience, and understanding of ADHD could have also varied greatly. However, these individuals represent real-life demographics, reflecting a broader population sample and the resource's compatibility to other professions. The individuals also were not paid to take part; their incentive was solely driven by interest instead of the GPs who received a financial incentive and a CPD certificate. The motivation to take part is, therefore, different from the two groups.

The Google Analytics report highlighted a great interest in the resource, reinforcing the vital need for such programmes. The short average time spent on the resource can be explained by how the research team logged on to check, edit, and distribute the resource, which would considerably impact the average time. Despite being unable to identify the extra 159 users from the first report in January 2020, it can be reasonable to hypothesise that many participants from the control group logged on, implying that the study's impact reached many GPs beyond the intervention group. The second report also demonstrates the ongoing interest in the resource beyond the scope of the study.

Additionally, while a vast majority of participants were happy and enjoyed the intervention, a couple reported issues with the intervention. One participant thought that the intervention's length was too long and that the content could be reduced. This feedback had been received in the feasibility study, and while the content had been cut down, maybe it could benefit from making it more concise. The second comment referred to the emotional bias of the content, rendering the content pseudoscientific. This approach was intentional, and the research team felt that it was important to convey the strong emotional implications on families and patients. ADHD is a complex disorder, and understanding the many facets of the impact of symptoms is essential to gain a comprehensive understanding of its presentation in patients.

This exercise demonstrated that this resource had an impact on GPs who took part but also on a broader scale through interaction with individuals from different sectors, representing the need for education in many other professional bodies. The implementation of the resource seems realistic, and real-life data triangulates well with study data. However, it is important to remember that this exercise was a short, preliminary attempt to gauge the intervention's long-term aspects. These findings are limited; a more robust and better-developed assessment is essential to support and strengthen these conclusions.

Chapter 7 General discussion

7.1 Chapter summary

This chapter summarises and reflects on the findings of this four-year project. The systematic review and qualitative studies highlighted many factors impacting GPs' knowledge and understanding of ADHD. Primarily, lack of education emerged as a critical barrier in their understanding of ADHD. The development of an informed and targeted online intervention followed. The co-produced nature of this development process firmly guided the format, content and features of the final online education modules. The feasibility, efficacy, impact and implementation were assessed through different studies, including an RCT. These studies' findings demonstrate that the online intervention is feasible and acceptable while also impacting GPs' knowledge, practice, attitudes, and confidence in dealing with ADHD in general practice. Reflections on the implications of this research for research and practice are also presented.

7.2 Outputs

While this chapter did not produce any external outputs, an infographic of the whole thesis was developed for dissemination of the thesis's findings (Appendix 17).

7.3 Introduction

This set of linked studies investigate GPs' understanding and knowledge of ADHD. Informed by the MRC framework, it covers the different essential phases in evaluating complex interventions, namely: development, feasibility/piloting, evaluation, and implementation.

Firstly, barriers to GPs' understanding and gaps in their knowledge were identified through a systematic literature review and semi-structured interviews. The main findings from these studies suggest that there are limited recognition and a need for education and reduction of misconceptions of ADHD in primary care. Other barriers, such as the complexity of the multidisciplinary approach of the pathway to care and the lack of services, were also identified.

Secondly, an online psycho-education intervention was co-produced with GPs to address the gaps in knowledge and training, reduce misconceptions and clarify the role of the GPs. This development process involved multiple steps, including developing an online resource, producing patients' testimony videos and experts' videos, collating and editing relevant information, and a thorough review process.

Thirdly, a usability study was conducted once this intervention was completed, followed by a pilot RCT and a brief implementation evaluation. These demonstrated that the intervention significantly improved GPs' knowledge and attitudes towards ADHD, reduced their misconceptions and impacted their practice. It also highlighted that the intervention was acceptable and feasible in both controlled and real-life settings.

Similar to previous findings (Hassink-Franke et al., 2016; Ward et al., 1999), these doctoral studies thesis demonstrates that an educational resource on ADHD can significantly impact GPs' knowledge and understanding of ADHD. The main findings from this thesis on barriers to understanding ADHD support previous studies that highlighted lack of knowledge, recognition (Sayal et al., 2002; Wright et al., 2015) and training (Alder et al., 2009) as critical barriers in GPs' understanding of ADHD. The lack of training available to GPs was briefly acknowledged in some studies (Quiviger & Caci, 2014; Shaw et al., 2003; Wolraich et al., 2010) but emerged as a critical finding in these studies, highlighting the vital need for tailored training. Stigmas and misconceptions from healthcare professionals have also often been cited as a barrier to understanding ADHD (Ghanizadeh & Zarei, 2010; Klasen & Goodman, 2000; Shaw et al., 2003). For example, 25% of GPs believed that ADHD is caused by too much sugar (Lian et al., 2003). While some misconceptions are observed in this thesis's studies, it was interesting to find that these were somewhat attenuated (for instance, our findings highlight that only 6% believed it was caused by too much sugar). The RCT demonstrated the "don't know" responses were higher than the stigmas, suggesting the presence of a lack of knowledge rather than strong misconceptions. The change in understanding and attitude on ADHD over the last decades (McLeod et al., 2007) could explain this improvement, demonstrating a positive shift over time towards more accurate knowledge.

The choice of online training was a pragmatic one, supported by the GPs in the co-production phase. Online training is increasingly relied on for healthcare CPD (Casebeer et al., 2010) as an accessible learning mode. GPs expressed their preferences in developing an online resource rather than an app or face-to-face workshops through the development workshops. Like previous studies on online healthcare educational programmes (Lune et al., 2020; Thepwongsa et al., 2014), these doctoral studies show a significant improvement in knowledge, confidence, and practice while reducing misconceptions. It is also essential to highlight the benefits of conducting a co-production development process. Tailored online training has been shown to improve GPs' knowledge and practice (Baker et al., 2010; Thepwongsa et al., 2014). These studies support these findings and highlight the necessity and benefits of developing tailored, co-produced online training for GPs.

Previous systematic literature reviews have summarised the evidence on GPs' attitudes and knowledge of ADHD (Tatlow-Golden et al., 2016; Wright et al., 2015). The first review (Tatlow-Golden et al., 2016) identified factors related to stigmas, recognition rate, diagnosis, training and source of information. The second review (Wright et al., 2015) identified the need for training in GPs, the need for interventions enabling accessing care, the influence of socio-economic and environmental factors. These doctoral studies strengthen these findings in GPs' attitudes and knowledge by highlighting similar themes such as lack of education, misconception and a strong need for training. The intervention allowed for some stigmas and misconceptions such as ADHD in adulthood (Fuermaier et al., 2012), ADHD only presents in boys (Gardner et al., 2002; Kwasman et al., 2004), and ADHD is seen as a negative diagnostic label (Sayal et al., 2015), to be lessened. It also addressed issues with non-recognition in GPs (Sayal et al., 2002) and low levels of confidence in recognising and managing ADHD (Salmon & Kirby, 2007). This thesis demonstrates that tailored training can remedy some of the barriers experienced in primary care and adds solutions to issues highlighted in previous research.

7.4 Strengths and limitations of the thesis

These studies comprise a thorough development process to ensure the high quality and feasibility of an online psycho-education resource that addresses the barriers in GPs' understanding of ADHD. This process uncovered many strengths as well as limitations.

The multiple phases process of this thesis ensures that the intervention is as targeted and as efficient as possible. By understanding the gaps in GPs' awareness of ADHD through the literature review, the specific needs to address are established. The qualitative studies strongly reinforce these findings, ensuring that the right topics are covered. By including multiple stakeholders, with varied experiences of ADHD, these findings encompass the views of all the critical key individuals directly affected by GPs' knowledge and understanding of ADHD.

The co-production aspect of the development also considerably strengthens the final intervention. By involving GPs in the early development stage and throughout the reviews and usability stages, the intervention provides comprehensive, tailored content and format that suits this population. If a similar intervention for teachers, for instance, was to be developed, it would look quite different. The feedback received post-intervention from the participants validates this approach, but it is also interesting to see that other professional groups find the modules very informative.

Finally, the evaluation of the intervention through an RCT method strongly validates our findings. It is a rigorous method of hypothesis testing and is regarded as the gold standard for evaluating interventions' effectiveness (Evans, 2003). While it was not a full-scale RCT - as this would have been beyond the scope of doctoral studies - many essential elements of trial methodology were incorporated, ensuring rigour and reliability.

The research described in this thesis does have some limitations. Due to the scale and time restrictions of a doctoral research project, some studies such as the feasibility study, the RCT, and the implementation evaluation were not conducted at full scale. More rigorous assessments of the implementation and impact would have been included if more time and resources had been available. However, this could always be investigated more thoroughly at a later date through further research. Due to this intervention's novelty and the small number in the usability study, power was also not calculated. The numbers included in the pilot RCT showed significant trends; however, it is unsure whether the right sample size was recruited.

The lack of longitudinal data due to time limitations also impacts the true long-term effect of the resource. Participants were tested at a two-week follow-up, but a six-month or twelve-month follow-up would have been preferable to see long-term knowledge retention. A medical education review suggests that only two-thirds of basic medical knowledge is retained after a year (Custers, 2010). Assessing how well the information from the resource is retained over time would allow for a better understanding of its long-term impacts. However, a lot of the knowledge tested in the pre and post-questionnaires related to common misconceptions of ADHD rather than more in-depth knowledge. It can be argued that reducing misconceptions is more likely to have a long-term impact as these relate more to attitudes rather than knowledge. For instance, if prior to participating in the intervention, a GP believed that ADHD was caused by bad parenting and they understood post-intervention that this is not the case, it is doubtful that 12 months down the line, they would revert to their original beliefs.

In terms of recruitment, while the uptake was excellent, it is challenging to establish participants’ real motivation for taking part. The great interest in the study could be due to a strong need and desire to know more about ADHD. However, it could also be due to the monetary incentive received and easily accessible training for CPD. The use of incentives ensured that GPs would be compensated for their time, and that lack of time was not a factor that hindered their participation. This might have impacted recruitment; however, the comments from the implementation study where participants did not receive incentives triangulate with the main study's feedback.

The online element of the study was a pragmatic choice to access as many GPs as possible. However, this comes with some limitations to the data collected. It is complex to gauge the level of engagement in online studies. The intervention was set up in a way that allowed for time spent on it to be recorded. A handful of participants recorded very little time that would not allow them to read through the information. Similarly, it cannot be guaranteed that someone who spent a lot of time on it was not doing something else at the same time. While demographics did not impact the studies as much as in an experimental task design, it is important to acknowledge that online studies can be problematic in terms of checking for demographics and whether participants represent themselves truly (Lefever et al., 2007). The conditions and environment in which the intervention is completed could have also influenced how well participants pay attention or not.

Finally, the sample of participants recruited also brings some limitations. Due to the typical representative nature of the samples within research studies, some ADHD non-believers would not have taken part; therefore, the studies fail to represent these viewpoints and fail to understand further how to reach these individuals. The only negative feedback received for the intervention (6.4.3, p.173) demonstrated that some individuals' engrained beliefs about ADHD could not be easily changed despite the evidence presented. Additionally, while including multiple stakeholders allows for a comprehensive overview of different primary care experiences, it is difficult to reconcile these views and how much weight should be put on them. For instance, while the GPs wanted the intervention to be as short as possible, other stakeholders wanted to include more details to ensure GPs received a full, comprehensive overview. Managing this balance was complex, and it isn't easy to assess the opportunity cost of making decisions favouring one group rather than another.

7.5 Implications for practice and research

The implications of this online resource are two folds. Following the definition of research impact from the ESRC (Nutley, 2003) as 'the demonstrable contribution that excellent research makes to society and the economy, this can involve academic impact, economic and societal impact, or both:

- "Academic impact is the demonstrable contribution that excellent social and economic research makes in shifting understanding and advancing scientific method, theory and application across and within disciplines.
- Economic and societal impact is the demonstrable contribution that excellent social and economic research makes to society and the economy, and its benefits to individuals, organisations and/or nations".

The contribution of the online resource developed for these doctoral studies relates to both academic and economic/societal impact. This is further explored through the long-term implications of these doctoral studies, both in terms of research and practice.

7.5.1 Implications for practice

While this intervention directly impacts GPs as their knowledge was improved, the online resource and its developmental process highlight many other implications for practice.

By increasing GPs' awareness and identification of ADHD, many clinical benefits could be observed. Increased recognition and understanding directly impact patients, increasing access to care, quality of management, and long-term quality of life. Families of patients are also affected as the burden of caring for undiagnosed or untreated issues might lessen. It finally has implications for secondary care healthcare professionals as a better understanding from GPs will improve their clinical work, communication and facilitate better pathways to care.

However, these potential benefits come with ethical considerations. Increased identification and increased referrals will increase demands on specialist services. Secondary and tertiary ADHD services are often inexistent or overstretched (Norman, 2012; Singh, 2009; Tettenborn et al., 2008), and increased referrals will directly impact these services. Implications such as longer waiting lists and stricter triage systems need to be considered as they could negatively impact the patient.

It is important to note that the long-term implications for practice are very complex to gauge. Upon writing the proposal of these doctoral studies, one of the aims was to enhance appropriate referrals to CAMHS and other secondary care services. However, the challenges of capturing the impact of awareness training are tough to overcome, and it would be challenging to assess quantitatively how this online awareness resource has directly impacted the number and suitability of referrals.

The development process also demonstrated the vital need for involving GPs in educational programmes for primary care. The RCGP adopted the online resource as part of their online training, and upon investigation, very few other training activities featured on their website had been evaluated or thoroughly peer-reviewed. Therefore, this resource and the developmental stages offer a more rigorous template for future development and the processes to follow to achieve optimal outcomes.

Finally, a better understanding and identification of ADHD will create many wider impacts beyond improved practice. Schools could benefit from having children with a diagnostic label as they will be able to implement adapted educational strategies to manage problematic behaviours, directly impacting school performance and the learning environment. The long-term costs of untreated and undiagnosed ADHD are severe, with higher rates of offending behaviour, divorce, imprisonment, driving accidents, school dropout, unemployment, suicide, and mental health issues. By gaining early diagnosis and treatment, these factors will be reduced, directly impacting society overall, government bodies, and the national healthcare systems.

7.5.2 Implications for research

This thesis's findings show great potential for future research, both in terms of healthcare research and in other subjects such as education or even policymaking.

A longitudinal evaluation of the long-term impact and implementation of the resource would help support the preliminary findings highlighted in Chapters 5 and 6. Further investigation on how well participants retained the information from the resource and how they implemented it within their practice in the long term would greatly inform a more comprehensive implementation of the resource.

The developmental process also demonstrates how co-production strongly impacts and benefits the development of interventions. A lot was learned from involving GPs throughout this process, and the intervention produced was very different from what would have been done without their input. Involving the end-user into the development process is very important and shapes the research considerably. Therefore, future projects should strongly consider including end-users in the development of educational interventions at multiple stages.

Furthermore, this psycho-education resource could be adapted for other professional groups such as other healthcare professionals, teachers, and commissioners. This would allow for a comprehensive overview of the ADHD care pathway and clarify the role of different key stakeholders. An adaptation for teachers and parents would also address many more critical gaps. Parents often wait a very long time once their children are referred for an assessment (Fridman et al., 2017) and often have no resources or information on ADHD. A short psycho-education resource could facilitate understanding and signpost to support while going through the care pathway. Studies have also shown that teachers face similar barriers to GPs in terms of understanding and knowledge of ADHD (Dort et al., 2020; Poznanski et al., 2018; Sciutto et al., 2000). Therefore, an adapted resource for teachers would help address these gaps and facilitate an overall clearer pathway to care for ADHD.

Finally, adaptations of this resource for other neurodevelopmental disorders could also be very impactful. As highlighted previously, developmental disorders are not part of the compulsory GP training. Similar difficulties have been reported in identifying and managing other developmental disorders in primary care, such as autism (Cadman et al., 2012), Tourette’s syndrome (Yadegar et al., 2019), or dyspraxia (Missiuna et al., 2006). Thus, adapting this educational resource to different disorders would help facilitate a broader understanding of these conditions, providing accessible and essential training for GPs.

7.6 Conclusion

This thesis investigates the understanding of ADHD in primary care. It sought to establish the barriers and gaps in GPs’ understanding of ADHD in order to develop a tailored psycho-education resource that addresses these gaps and facilitates GPs’ knowledge and practice. It also set out to evaluate the efficiency of this resource, its impact, and its implementation. These aims were addressed through multiple studies and were conclusively answered.

The different methodologies used in this thesis allowed for a broad overview of the issues presented. Qualitative interviews enabled multiple stakeholders' views and inputs to be included and allowed for a deeper understanding, incorporating personal accounts on the topic. The pilot RCT enabled more GPs to take part, having a national impact. The use of qualitative and quantitative methods both have their strengths and limitations; however, in the context of this thesis, a mixed-method approach landed itself well to answer its research questions.

The results show that the barriers in understanding ADHD for GPs are somewhat complex, but the main issues with lack of training and knowledge can be quickly and efficiently addressed. This thesis's findings demonstrate that tailored education resources could facilitate better access to care for patients by increasing GPs’ knowledge and understanding of developmental disorders. The development of a short online resource is a cost-effective, accessible, and effective mean of furthering GPs’ training.

While these results demonstrate a clear benefit of this resource, a few experimental aspects could have improved these studies. A longitudinal evaluation of implementation could have been conducted to assess the long-term impact of the resources. It was challenging to plan the timeline of this thesis, but a more rigorous implementation study could have been conducted with insight. However, while there would have been enough time to do so, the timing of this would have been during the pandemic, which would have most likely been a barrier for collecting data.

It could be argued that the positive findings from these studies could be interpreted differently. The combination of a self-selected sample, accessible information, and easy questionnaires could have created a somewhat simplistic intervention. The resource's content did not go into many in-depth details, and the pre and post questionnaires were relatively straight forwards. However, an alternative form of training, evaluation, or sample selection would have been beyond the scope of this thesis due to a lack of time and resources.

In summary, this thesis encompasses many research processes, methods, forms of evaluation, and standpoints to gain a comprehensive overview of ADHD in primary care. The development of the online educational resource demonstrates both a strong need for adequate GP training and the efficacy of such resources. This comprehensive process benefited many individuals, principally GPs but also patients, other healthcare providers, and last but not least, BF, who developed extensive skills as an independent researcher.

7.7 Reflexive statement

Conducting these doctoral studies as an individual with lived experience was very enlightening, interesting, but at times also frustrating and challenging. Each study raised specific questions about the perspective BF undertook at each stage. As a patient with lived experience, a facilitator of ADHD parenting and adult groups, and a researcher, BF juggled three different identities throughout the study. Knowing when it was acceptable to change one identity for another without compromising the studies' rigour, and quality was challenging. Overall, as BF gained more experience in this constant adaptation of ner own experiences, it became easier to stick to one identity depending on the context. It also became easier to understand and assess when it was appropriate to reveal another identity. For instance, while conducting the interviews with the GPs, BF took the researcher's identity as the others might have influenced the responses from the GPs. However, when BF conducted the more informal workshops, she started as a researcher, but when a question was raised in the storyboarding exercise about what benefits would be gained from getting a diagnosis and receiving such a negative label, BF felt that it was appropriate to reveal her own experience and that her diagnosis allowed her to become a PhD student. After receiving her diagnosis and gaining a better understanding, BF was able to input strategies to complete a university degree and PhD.

Accepting the changes in the original idea for the intervention to the final resource was also a process. At first, BF had very set ideas about what the GPs needed to know from her personal and clinical experiences. Still, when the GPs informed her that it wasn’t interesting enough and they did not like the proposed prototype, it was at first really difficult to put the lived-experience identity aside and see it solely from a researcher standpoint.

Moreover, throughout these doctoral studies, certain negative viewpoints on ADHD were expressed that were difficult to ignore as someone with lived experiences and experience in helping parents. Misconceptions such as “it is mainly bad parenting” or “it is just an excuse for bad behaviour” were difficult to listen to. BF learned to keep a researcher’s identity on when these occurred, and it somewhat became more manageable throughout the thesis; however, emotionally, it still had an impact on her.

It is also important to acknowledge the many benefits of being a lived-experience researcher. Her own experience and having worked with ADHD patients for so long allowed

BF to genuinely understand the struggles of seeking access to care from many perspectives. She knew exactly what it felt like to be on this journey and understood first-hand the many barriers in this pathway. This allowed her to relate to the topic very strongly and empathise with participants throughout the studies. It also allowed her to have helpful insight into the right signposting for all the participants regarding the most appropriate resources. Finally, witnessing all the positive feedback, knowledge, and motivation from participants was heart-warming, especially the final interviews conducted after the participants took part in the intervention. A few thanked BF for making them see a different side of ADHD, breaking the stigmas around it, and changing their attitude. The knowledge that a few GPs had already started changing their practice or changing their approach to friends and families with ADHD traits made every single difficulty worthwhile. BF set out on these doctoral studies hoping to help individuals access care earlier. Even if she helped just one person by getting this person's GP to identify their struggles as ADHD, it might change their lives for the better the same way it did to her. Knowing that this had happened is pretty much the best outcome one can wish for in a doctoral study.

"Dear Blandine

I just wanted to say how much I enjoyed listening to your recent podcast and the work you have been doing on ADHD.

I am a 39-year-old woman with two children and I am only just beginning to join the dots of thinking I may have undiagnosed ADD.

The sad thing is my older sibling also I believe has lived with a more severe form of ADHD since childhood. He suffered major depression in his 20s and spent long periods in hospital.

This resulted in a major psychosis when he was 36 and he spent 3 years in a low secure mental health unit. He is now unable to live independently and his cognitive function has been severely impacted.

It makes me so sad that an intervention at an earlier age may have prevented all of the hardship we have endured as a family and my brother may have been able to live a happier, more independent life. I don't think even now he has received a diagnosis of ADHD.

Anyway, I wanted to connect to thank you for your work and to say I too will be championing the need for further research and training in this field.

I have followed you on Twitter so I can stay connected to all of the fantastic academic work you are doing."

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Appendices

Appendix 1 – Search strategy for systematic review

Topic	Database	Number of studies
Psychology	PsychInfo (OVID, 1887 onwards)	1273
Biomedical and Pharmaceutical	Embase (OVID, 1980 onwards)	2598
Science and medicine	Scopus (Elsevier, 1995 onwards)	1248
Social Sciences	ASSIA (ProQuest, 1987 onwards)	316
Medicine	Medline (OVID, 1948 onwards)	1418
Grey literature	Google Scholar	7
	Total	6860
	After duplicate removed	3898
	Scanned title (1122)	2747

MEDLINE- 29.01.2018

First searched on the 1st March 2017 and then again on the 12th of April 2017

Database: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Search Strategy:

----

1 exp Attention Deficit Disorder with Hyperactivity/ (24921)

2 (ADHD or "attention deficit hyperactivity disorder" or "attention deficit*" or "hyperkinetic disorder").ti,ab. (27801)

3 1 or 2 (34024)

4 exp Primary Health Care/ (131114)

5 exp General Practitioners/ (5511)

6 ("primary care" or "doctor*1" or "general practitioner*" or GP or GPs or consultant* or "health professional*" or physician*).ti,ab. (588152)

7 4 or 5 or 6 (669829)

8 3 and 7 (1418)

PSYCHINFO- 29.01.2018

Database: PsycINFO <1806 to May Week 2 2017>

Search Strategy:

----

1 exp Attention Deficit Disorder/ (23308)

2 exp Attention Deficit Disorder with Hyperactivity/ (18453)

3 (ADHD or "attention deficit hyperactivity disorder" or "attention deficit*" or "hyperkinetic disorder").ti,ab. (30215)

4 1 or 2 or 3 (31629)

5 exp Primary Health Care/ (15600)

6 exp General Practitioners/ (5466)

7 ("primary care" or "doctor*1" or "general practitioner*" or GP or GPs or consultant* or "health professional*" or physician*).ti,ab. (133811)

8 5 or 6 or 7 (137648)

9 4 and 8 (1273)

EMBASE- 29.01.2018

Database: Embase <1980 to 2017 Week 20>

Search Strategy:

----

1 exp attention deficit disorder/ (47665)

2 (ADHD or "attention deficit hyperactivity disorder" or "attention deficit*" or "hyperkinetic disorder").ti,ab. (37293)

3 1 or 2 (52700)

4 exp primary health care/ (134439)

5 exp general practitioner/ (76398)

6 ("primary care" or "doctor*1" or "general practitioner*" or GP or GPs or consultant* or "health professional*" or physician*).ti,ab. (756813)

7 4 or 5 or 6 (823496)

8 3 and 7 (2598)

SCOPUS 29.01.2018

(TITLE-ABS-KEY ("Attention hyperactivity deficit disorder" OR ADHD OR "hyperkinetic disorder") AND TITLE-ABS-KEY ("primary care" OR "general practitioners" OR "primary health care" OR "health professional" OR physician))

ASSIA 29.01.2018

Set#: S1

Searched for: (SU.EXACT("Attention deficit disorder") OR SU.EXACT("Attention deficits") OR SU.EXACT("Attention deficit hyperactivity disorder")) AND peer(yes)

Databases: Applied Social Sciences Index & Abstracts (ASSIA)

Results: 6516°

Set#: S2

Searched for: SU.EXACT("General practitioners") OR Doctor OR "health professional" or Physician

Databases: Applied Social Sciences Index & Abstracts (ASSIA)

Results: 82642°

Set#: S3

Searched for: SU.EXACT("Advanced practice nurses" OR "Contraceptive services" OR "General practice" OR "Practice nurses" OR "Primary health care" OR "Private primary health care") OR SU.EXACT("Primary health care professionals") OR SU.EXACT("Primary mental health care")

Databases: Applied Social Sciences Index & Abstracts (ASSIA)

Results: 10224°

Set#: S4

Searched for: (SU.EXACT("General practitioners") OR Doctor OR "health professional" OR Physician) OR (SU.EXACT("Advanced practice nurses" OR "Contraceptive services" OR "General practice" OR "Practice nurses" OR "Primary health care" OR "Private primary health care") OR SU.EXACT("Primary health care professionals") OR SU.EXACT("Primary mental health care"))

Databases: Applied Social Sciences Index & Abstracts (ASSIA)

These databases are searched for part of your query.

Results: 89863°

Set#: S5

Searched for: ((SU.EXACT("Attention deficit disorder") OR SU.EXACT("Attention deficits") OR SU.EXACT("Attention deficit hyperactivity disorder")) AND peer(yes)) AND ((SU.EXACT("General practitioners") OR Doctor OR "health professional" OR Physician) OR (SU.EXACT("Advanced practice nurses" OR "Contraceptive services" OR "General practice" OR "Practice nurses" OR "Primary health care" OR "Private primary health care") OR SU.EXACT("Primary health care professionals") OR SU.EXACT("Primary mental health care")))

Databases: Applied Social Sciences Index & Abstracts (ASSIA)

These databases are searched for part of your query.

° Duplicates are removed from your search and from your result count.

Appendix 2 - Excluded studies after full text read

Record of reasons for excluding studies after full-text assessment

1.	Aksoy, U. M., et al. (2015).	Not on primary care
2.	Ayyash, H., et al. (2013).	Not peer-reviewed
3.	Beirne, M., et al. (2013).	Not primary care
4.	Bennett, F. C. and R. Sherman (1983).	No mention of attitudes
5.	Blew, H. and G. Kenny (2006).	Not attitudes
6.	Bunik, M., et al. (2013).	Not attitudes
7.	Bussing, R., et al. (2003).	Not attitudes, not primary care
8.	Bussing, R., et al. (2012).	Not primary care
9.	Cardo, E., et al. (2017).	Not primary care
10.	Dennis et al. (2008)	Not just primary care
11.	Efron, D., et al. (2016).	Not primary care
12.	Epstein, J. N., et al. (2007).	Not attitudes
13.	Epstein, J. N., et al. (2008).	Not attitudes
14.	Epstein, J. N., et al. (2010).	Not attitudes
15.	Epstein, J. N., et al. (2010).	Not attitudes
16.	Epstein, J. N., et al. (2013).	Not attitudes
17.	Fitzgerald, M. and F. McNicholas (2014).	Not just primary care
18.	Foy, J. M. and M. F. Earls (2005).	Case study
19.	Frigerio, A., et al. (2013).	Not primary care
20.	Gardner, W., et al. (2004).	Not attitude
21.	Glod, C. A. (2001).	Full text not available
22.	Groen, W., et al. (2006).	Case study
23.	Gross, B. (2005).	Opinion piece
24.	Guevara, J. P., et al. (2008).	No mention of attitudes
25.	Hall, C. L., et al. (2013).	Not primary care
26.	Hays, R. B. (1999).	Opinion piece
27.	Hazelwood, E., et al. (2002).	Not primary care
28.	Healy, D., et al. (2013).	Not attitudes
29.	Hill, P. and M. Cameron (1999).	Not primary care
30.	Hinshaw, S. P., et al. (2011).	Not primary care
31.	Hirfanolu, T., et al. (2008).	Not sure if primary care
32.	Homer, C. J., et al. (2004).	Not attitudes
33.	Huss, M., et al. (2008).	Not attitudes
34.	Jensen, C. M. and H. C. Steinhausen (2015).	Not attitudes
35.	Khalil, M. S. and E. Jenahi (2015).	Not primary care
36.	Lazorick, S., et al. (2008).	Not attitudes
37.	Leitner, Y., et al. (2016).	Not attitude
38.	Lobar, S. L., et al. (1999).	Not primary care
39.	Luk, E. S. L. (2002).	Opinion piece
40.	Mann, E. M., et al. (1992).	Not primary care
41.	Marcer, H., et al. (2008).	Not primary care
42.	McCarthy, S., et al. (2013).	Not attitudes
43.	McClain, M. R., et al. (2014).	Not ADHD specific
44.	Montano, C. B. and J. Young (2012).	Literature review
45.	Morley, C. P. (2010).	Opinion piece
46.	Moser, S. E. and K. J. Kallail (1995).	Not attitudes
47.	Mueller, A. K., et al. (2012).	Literature review
48.	Noury, J. L., et al. (2010).	Not primary care
49.	O'Keeffe, N. and F. McNicholas (2011).	Not primary care
50.	Olfson, M. (2010).	Not peer-reviewed- editorial

51.	Oshodi, Y. O., et al. (2012).	Not primary care
52.	Patel, A., et al. (2016).	Not peer-reviewed
53.	Rafalovich, A. (2005).	Not just primary care
54.	Ramsay, J. R. (2014).	Opinion piece
55.	Reale, L., et al. (2015).	Not primary care
56.	Salmon, G. and A. Kemp (2002).	Not primary care
57.	Sax, L. and K. J. Kautz (2003).	Not attitude
58.	Senecky, Y., et al. (2007).	Not ADHD specific
59.	Sheldrick, R. C., et al. (2015).	Not just primary care
60.	Sundet, R. (2011).	Not ADHD specific
61.	Swift, K. D., et al. (2014).	Literature review
62.	Thapar, A. and A. Thapar (2002).	Opinion piece
63.	The, L. (2007).	Not attitude
64.	Toomey, S. L., et al. (2008).	Not attitude
65.	Toomey, S. L., et al. (2011).	Not attitude
66.	Venter, A., et al. (2004).	Not primary care
67.	Vierhile, A., et al. (2009).	Opinion piece
68.	Voigt, R. G. and P. J. Accardo (2016).	Opinion piece
69.	Waite, R. (2007).	Literature review
70.	Walton, J. et al. (2014).	Not attitudes
71.	Wetzel, M. W. (2009).	Not primary care
72.	Whitely, M. (2013).	Opinion piece
73.	Wolraich, M. L. (1999).	Review
74.	Wolraich, M. L. (2002).	Opinion piece
75.	Wolraich, M. L., et al. (2005).	Not attitude
76.	Young, S., et al. (2011).	Review
77.	Zima, B. T., et al. (2013).	Not just primary care

Appendix 3 - Ethical approval for the qualitative study

University of Nottingham
UK | CHINA | MALAYSIA

Research and Innovation
University of Nottingham
East Atrium
Jubilee Conference Centre
Triumph Road
Nottingham
NG8 1DH

Our reference: RGS 17096
IRAS Project ID: 237332

0115 8467906
sponsor@nottingham.ac.uk

Health Research Authority
Research Ethics Committee

Professor David Daley
Room B 24 Institute of Mental Health
Jubilee Campus
Wollaton Road
Nottingham
NG8 1BB

22 November 2017

Dear Sir or Madam,

Sponsorship Statement
Re: Awareness of ADHD in primary care, a qualitative study

I can confirm that this research proposal has been discussed with the Chief Investigator and agreement to sponsor the research is in place.

An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.*

Any necessary indemnity or insurance arrangements will be in place before this research starts. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

The duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.**

* Not applicable to student research (except doctoral research).
** Not applicable to research outside the scope of the Research Governance Framework.

Yours faithfully

Angela Shone
Head of Research Governance
University of Nottingham

world-changing research
from The University of Nottingham

Appendix 4 - Interview schedules for the qualitative study

Interview Schedule secondary care ADHD awareness

Topics to be discussed in the interview

Can you tell me a little bit about your experience of referral and diagnosis of ADHD?

Relationship between primary care and secondary care

- What are your beliefs and understanding about ADHD
- Do you think your colleagues in primary care share your views
- Do you think primary and secondary care professionals have similar understandings? Do you think primary and secondary care professionals talk the same language?
- Is there clear communication between primary and secondary care?
- Does it take a lot of time for information to be passed around?
- Do you feel that there is a clear pathway between all disciplines to ADHD diagnosis and treatment?

Misconceptions

- As a professional, have you ever been aware of stigmas or misconceptions about ADHD to patients or parents?
- Did you witness any stigma/misconceptions by any other professionals during consultations or team meetings?
- How important do you think patient behaviour is during the consultation is in helping to reinforce concerns about possible ADHD?

Need for education

- Do you feel GPs know a lot/enough about ADHD?
- Do you think GPs have relevant information on the nature of ADHD, treatment and or diagnosis process?
- Who first mentioned the possibility of ADHD (GP, teacher, parent?)
- Do you think GPs have enough information to refer to secondary care (teacher’s report, parents interview, child behaviour in office)

Speed of process

- How long does it take to get a referral from primary care from the first enquiry?
- How long does it take to get a diagnosis?
- What would you like GPs to know or to do differently before referring ADHD patients to secondary care?

Anything else you would like to add?

Interview Schedule patients ADHD Awareness

Topics to be discussed in the interview

Can you tell me a little bit about your experience of referral and diagnosis of ADHD?

Relationship between professionals

- During the diagnosis process, do you think there was clear communication between primary and secondary care?
- Did it take a long time for information to be passed around?
- Do you think primary and secondary care professionals shared your beliefs and understanding about ADHD?
- Do you think primary care professionals had similar beliefs about ADHD?
- Do you feel that there is a clear pathway to get an ADHD diagnosis and treatment? What was it like for you?

Presence of misconceptions

- Did your GP ever mention any stigmas or misconceptions about ADHD? Can you tell me a little bit more about them if they did?
- Did you witness any stigma/misconceptions by any other professionals during the diagnosis process?
- Did any professional mentioned causes such as parenting or society?
- Do you feel your/your child’s behaviour during consultation impacted the diagnosis process?

Need for education

- Did you find your GP knew a lot/ enough about ADHD?
- Did your GP give you information on the nature of ADHD, treatment and or diagnosis process?
- Who first mentioned the possibility that your child/ you may have ADHD (GP, teacher, parent?)
- Which criteria/information did the GP ask from you before referral to secondary care (teacher’s report, parents’ interview, child behaviour in office).

Speed of process

- How long did it take to get a referral to secondary care from the first enquiry?
- How long did it take to get a diagnosis?

Anything else you would like to add?

Interview Schedule GP's ADHD Awareness

Topics to be discussed in the interview

Can you tell me a little bit about your experience of referral and diagnosis of ADHD?

Relationship between primary care and secondary care

- What are your beliefs and understanding about ADHD?
- Do you think your colleagues in primary care share your views?
- Do you think primary and secondary care professionals have similar beliefs and understandings?
- Is there clear communication between primary and secondary care?
- Does it take a lot of time for information to be passed around?
- Do you feel that there is a clear pathway to ADHD diagnosis and treatment between primary care and secondary care?

Presence of misconceptions

- As a professional, are you aware of any stigmas or misconceptions about ADHD?
- Did you witness any stigma/misconceptions by any other professionals during the consultation process?
- Are you aware of having any negative connotations associated with the label ADHD?
- What role do you think parenting plays in the development and maintenance of ADHD?
- How important do you think patient behaviour is during the consultation is in helping to reinforce concerns about possible ADHD?
- What role do you think society or SES plays in the development and maintenance of ADHD?

Need for education

- Do you feel as a GP, you know a lot/enough about ADHD?
- Do you have relevant information on the nature of ADHD, treatment and or diagnosis process
- Who first mentioned the possibility of ADHD (GP, teacher, parent?)
- Which criteria/information do you use before referral to secondary care (teacher's report, parents interview, child behaviour in office)?

Speed of process

- How long does it take to get a referral to secondary care from the first enquiry?
- How long does it take to get a diagnosis?
- Do you feel adequately equipped to deal with such a diagnosis?
- Once a child gets a diagnosis of ADHD, does that mean extra work for you?

Would you welcome more education and training about ADHD?

What format would they like for intervention: paper, website, short clips daily or one 45 minutes etc.

Will it make a difference in their taking part if it was CPD?

Would you like to take part in the second stage of the study?

Anything else you would like to add?

Appendix 5 - Interview schedule for adult videos

ADHD in general
How does ADHD affect you?
Are you able to stay focus on things you like? All the time?
Does it take time for you to get better after you are upset?
Do you feel you may be a bit more sensitive than others?

School
How do you get on at school?
What are you like in the classroom?
What is it like trying to do your schoolwork? What about homework?
What makes a good lesson / more interesting / easier to learn?

How do you think the teachers see you? (Do they understand the difficulties or see you as a difficult/naughty child to manage?) Do they think/say you were lazy or stupid? Which lessons do you find interesting – which do you find boring? Which are the ones when you get into trouble?

What other problems do you have at school/ home? e.g. forgetful, losing things (books, homework, sports kit), disorganised, poor timekeeping etc. Are you easily distracted in class? Where do you sit? What helps you to manage at school (e.g. structure, one-to-one). What do you think your strengths are?

What role do you take at school? e.g. 'class joker.'
What do you like to do during break/playtimes?

Are you ever in any serious trouble? What about any accidents?

Home (filmed in situ if possible)
Tell us about your home

What is your family like?

What's it like trying to keep your bedroom clean and tidy?

Describe what it is like for you undertaking tasks such as helping with shore or doing homework (try to elicit example of starting things and not finishing, trying to multitask but can't do it).

Do you get bored easily?

Do you take on projects in the home, such as DIY? Or big cleaning projects? How do they tend to go? (relating to starting things but never finishing them, getting distracted, bored)

Family- parents
How do you get on with your parents/ siblings? Do you argue a lot – about what sort of things?
How do you manage your temper/ frustration – not getting your own way?

How do you think your parents/carers see the difficulties you are having related to ADHD? (e.g. any battles over getting to school, doing homework)
Do you think they see you as a 'naughty' child? (general behaviour within the home)
How does it affect your relationships with your siblings?

Friendships

Who are your friends?

Do you ever have any difficulties making or keeping friends? If so, can you tell me a bit more?

What's it like for you to have friends? (Get bored, arguments, changing partners frequently, risky sexual behaviours)

Do you have a lot of friends?

What about friendships, how are you at making and keeping friends?

How do they see you?

Do you think having ADHD affects you in terms of your social relationships? (remembering to turn up to social meetings, being late, not remembering birthdays or details about their lives; impulsivity/arguments; communication issues – becoming bored or distracted during interaction).

What are the positive aspects of your ADHD in terms of friendships? (exciting, fun, creative)

Leisure activities

What's it like for you when you are watching television or a film? (walking around, flicking channels, cant follow stories, interrupting others by talking through it)

What about reading?

Do you use a computer for games or go on the internet? What's that like for you in terms of concentration/ distractibility/ losing track of time and other activities (either work, household, or going to bed).

Do you do any outside activities? Any team sports? If so, what is it like?

Do you do any team sports? Do you find it easy to play in a team?

Additional issues

In addition to your ADHD, do you experience any other difficulties? (mental health, co-morbid conditions) e.g. anxiety, low mood-depression?

How does having ADHD affect your sleep?

Positive aspects of living with ADHD

What's good about having ADHD?

How does it help the things that you do? Your relationships? Work?

What are your strengths? (if you don't know, what would other people say?)

A parent's perspective of having a (now adult) child with ADHD

What is (insert name) like? (describe ADHD type behaviours)

When did you first notice was something different about his/her development? Were issues first raised by other people? e.g. school. what was their attitude to the difficulties? (were they sensitive to the idea of ADHD and understood it).

What do you struggle with in terms of daily life?

What difference does the diagnosis make?

What difference has any treatment or support made?

What are the positive aspects of having a child with ADHD?

What’s it like to have a child with ADHD? Did you understand the condition before the diagnosis?

How does him/her having ADHD affect your home life? (household chores, relationship with siblings)

Are there things you end up doing for him/her?
How does it affect co-parenting?

How did the diagnosis of ADHD affect the relationship? Are you now able to think differently about the things your partner finds difficult or the different strengths they bring to the relationship?

Do you feel your child is more sensitive than others?
Does it take longer to “get over” things once he is upset?
Is he able to concentrate on things he likes at all times?

Positive aspects of living with ADHD
What’s good about having ADHD?
How does it help the things that you do? Your relationships? Work?
What are your strengths? (if don’t know, what would other people say?)

Appendix 6 - Interview schedule for children videos

School

1. Tell me something you find difficult at school

(Prompt - why do you find it difficult?)

1. Alternative: Imagine your worst day at school – tell me all the things that would make it horrible

(distracted, hard to concentrate, noise, bored, naughty/get into trouble, bullied)

2. Tell me something you enjoy or find easy at school or that you really like

(Prompt – why do you like it so much?)

2. Alternative: Imagine the best school day – tell me what would make it so enjoyable

(quiet, one to one, lots of activities)

Home & Family

1. What do you enjoy doing at home?
2. What do you find difficult or boring at home?
3. What do you have the most arguments about? (finishing chores, homework, tidy room)
4. How do you manage your temper/ frustration?
5. If your family had to describe you – what would they say that was good, and what would they say was not so good?

Friendships

1. Tell me what it is like making or keeping friends?
2. How does having ADHD affect your friendships – what's good, what's bad?

(being impulsive at playtime, getting bored with friends) (exciting, fun, creative)

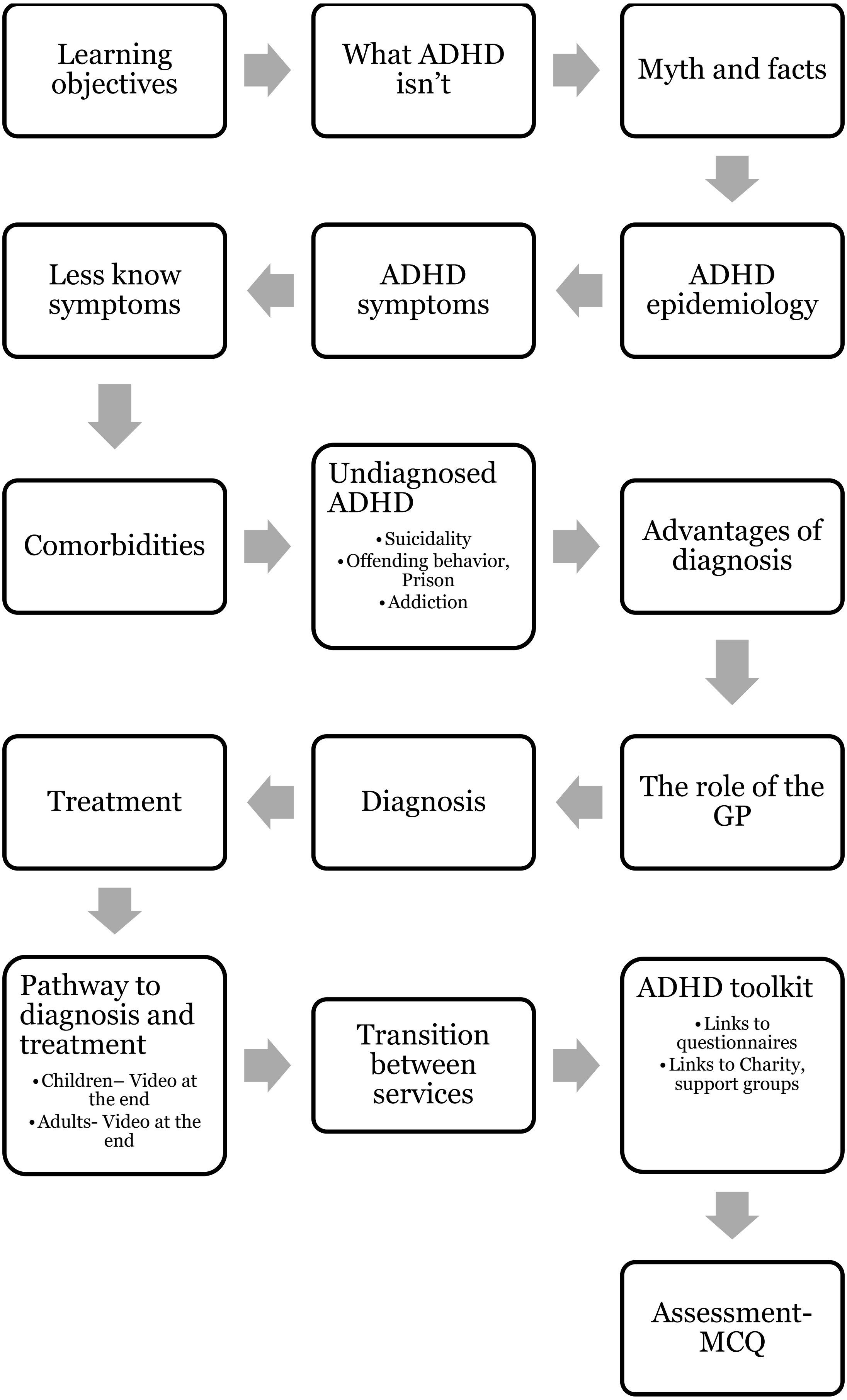
Leisure activities

1. What's it like for you when you are watching television or a film? (walking around, flicking channels, can't follow a story, interrupting others by talking through it)
2. What about reading?
3. What do you use a computer for, and does it cause any problems at home?
4. Tell me about the activities you do outside?
5. Do you do any team sports? (If not, why not? What's good or bad about them)

Additional

1. What do you think are the best things about having ADHD?
2. What do you think are the worst things about having ADHD?

Appendix 7- Flow chart for the first draft of intervention content



Appendix 8 - Usability questionnaire

On a scale of 1-10 (1: not at all, 10: a lot)

- How confident are you in your knowledge of ADHD?
- How useful did you find the information in this program?
- Did you like using the tool?
    - Which aspects did you like?
    - Which aspect did you dislike?
- Do you feel the tool impacted your knowledge of ADHD?
- How likely is this information going to inform your practice?
- Do you believe the content was relevant to your practice?

Agree- disagree- unsure:

- Through going through the tool, I understood its purpose
- I found the tool boring
- I found the tool unclear
- I think the tool will engage GPs
- The supporting material used helped the understanding of the content
- I like that the tool directed to other resources
- The tool is interactive enough
- The general presentation is clear
- The website appearance makes a good impression
- I will use the tool in the future
- I believe the content is reliable and based on evidence
- The tool contained too much information

Any additional comments

Where any part of the tool not helpful?

Is the tool too long? If so, which parts did you find the least useful?

Is there anything that you thought was missing?

Do you think it will help identify ADHD patients better?

Do you think you will retain the knowledge you acquired in this tool?

Do you believe this tool will impact your attitude towards ADHD and patients with ADHD?

Would you recommend this tool?

Any other feedback on this online program?

Appendix 9 - KADDS questionnaire – included questions

Please answer the following questions regarding Attention-Deficit/Hyperactivity Disorders (ADHD). If you are unsure of an answer, respond Don't Know (DK), DO NOT GUESS.

True (T), False (F), or Don't Know (DK) (circle one):

1. T F DK - Most estimates suggest that ADHD occurs in approximately 15% of school-age children.

2. T F DK - Current research suggests that ADHD is largely the result of ineffective parenting skills.

3. T F DK - ADHD individuals are frequently distracted by extraneous stimuli.

5. T F DK - In order to be diagnosed with ADHD, the child's symptoms must have been present before age 12.

6. T F DK - ADHD is more common in the 1st degree biological relatives (i.e. mother, father) of children with ADHD than in the general population.

9. T F DK - ADHD children often fidget or squirm in their seats.

10. T F DK - Parent and teacher training in managing an ADHD child are generally effective when combined with medication treatment.

12. T F DK - When treatment of an ADHD child is terminated, it is rare for the child's symptoms to return.

13. T F DK - It is possible for an adult to be diagnosed with ADHD.

15. T F DK - Side effects of stimulant drugs used for the treatment of ADHD may include mild insomnia and appetite reduction.

16. T F DK - Current wisdom about ADHD suggests three clusters of symptoms: One of inattention and two others consisting of hyperactivity/impulsivity.

17. T F DK - Symptoms of depression are found more frequently in ADHD children than in non- ADHD children.

18. T F DK - Individual psychotherapy is usually sufficient for the treatment of most ADHD children.

19. T F DK - Most ADHD children "outgrow" their symptoms by the onset of puberty and

subsequently function normally in adulthood.

21. T F DK - In order to be diagnosed as ADHD, an individual must exhibit relevant symptoms in two or more settings (e.g., home, school).

22. T F DK - If an ADHD child is able to demonstrate sustained attention to video games or TV for over an hour, that child is also able to sustain attention for at least an hour of class or homework.

23. T F DK - Reducing dietary intake of sugar or food additives is generally effective in reducing the symptoms of ADHD.

25. T F DK - Stimulant drugs are the most common type of drug used to treat children with ADHD

26. T F DK - ADHD individuals often have difficulties organizing tasks and activities.

28. T F DK - There are specific physical features which can be identified by medical doctors (e.g. paediatrician) in making a definitive diagnosis of ADHD.

29. T F DK - In school-age children, the prevalence of ADHD in males and females is equivalent.

30. T F DK - In very young children (less than 4 years old), the problem behaviours of ADHD children (e.g. hyperactivity, inattention) are distinctly different from age-appropriate behaviours of non-ADHD children.

31. T F DK - Children with ADHD are more distinguishable from normal children in a classroom setting than in a free play situation.

35. T F DK - Electroconvulsive Therapy (i.e. shock treatment) has been found to be an effective treatment for severe cases of ADHD.

36. T F DK - Treatments for ADHD, which focus primarily on punishment, have been found to be the most effective in reducing the symptoms of ADHD.

37. T F DK - Research has shown that prolonged use of stimulant medications leads to increased addiction (i.e., drug, alcohol) in adulthood.

39. T F DK - Children with ADHD generally display an inflexible adherence to specific routines or rituals.

Appendix 10 - GP awareness Irish study questionnaire – included questions

ADHD in general practice

In your experience, can an ADHD diagnosis be made based solely on a child's behaviour in your office?

Never ☐ Rarely☐ Sometimes ☐ Usually ☐ Always☐

Do you agree with these statements?

	Yes	No	Unsure
ADHD is society's excuse for badly behaved children	☐	☐	☐

Do you believe ADHD is a valid diagnosis?

Yes No Unsure

☐ ☐ ☐

In your experience of ADHD, do you believe that…

	Yes	No	Unsure
Children with ADHD misbehave because they don't follow rules	☐	☐	☐
Media coverage affects people's conception of ADHD and its treatment	☐	☐	☐
Most children with ADHD try to control themselves	☐	☐	☐
Parent seek ADHD diagnosis as an excuse for their child's bad behaviour	☐	☐	☐
Children's inattentiveness is caused by unwillingness to please	☐	☐	☐
Parents primarily seek ADHD diagnosis to claim benefits	☐	☐	☐
An ADHD diagnosis removes stigma of bad parenting	☐	☐	☐
An ADHD diagnosis is helpful for the individual	☐	☐	☐
An ADHD diagnosis is stigmatising for an individual	☐	☐	☐
ADHD diagnosis relieves families from stress and support problem solving	☐	☐	☐

Please answer the following questions and tick as appropriate

On a scale of 1 to 10 (1: not at all and 10: extremely):

How confident are you in your knowledge of ADHD?

1	2	3	4	5	6	7	8	9	10

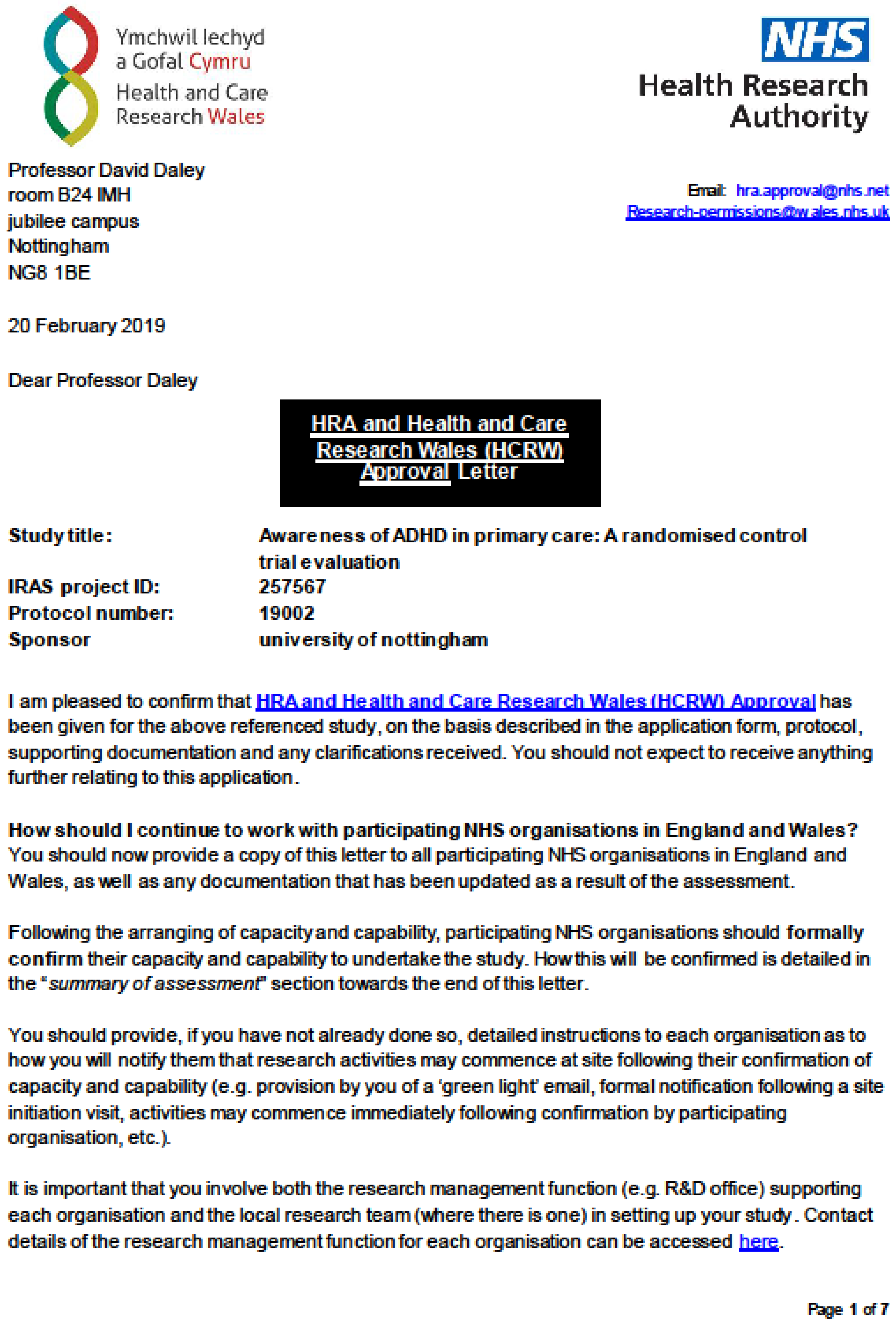
POST-How useful did you find the information on this program?

1	2	3	4	5	6	7	8	9	10

POST-How likely is this information going to inform your practice?

1	2	3	4	5	6	7	8	9	10

Appendix 11 - Ethical approval for quantitative study



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Professor David Daley
room B24 IMH
jubilee campus
Nottingham
NG8 1BE

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

20 February 2019

Dear Professor Daley

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

Study title: **Awareness of ADHD in primary care: A randomised control trial evaluation**
IRAS project ID: **257567**
Protocol number: **19002**
Sponsor **university of nottingham**

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

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

Appendix 12 - Interview schedule for RCT qualitative data

Barriers and facilitators to taking part in the intervention

- Why did you sign up?
- Was the format of the intervention appropriate?
- Is there anything you would change or add?
- Is there anything you would remove?
- Was the content informative
- Was the content impactful
- Was the intervention interactive enough, how could we make it more interactive

Impact of the intervention

- Did you gain knowledge about ADHD?
- Any difference in how you approach ADHD before and now?
- Did the intervention impact practice? Or do you think it will impact practice? Could you give me an example?
- Have you got any plans to change your practice going forward?
- How did it impact your attitude towards ADHD and patients with or at risk of ADHD?
- What do you consider the benefit for the patients might be?
- Have you any plans to change practice going forward?

Dissemination

- What would be the best way to disseminate this intervention, in your opinion?
- Where should we have this intervention for GPs to access it easily
- Should it be embedded into another training program, do you think that would make it more effective or more accessible?
- Anything else to add?

Appendix 13 - Survey questions for RCT

Following your participation in the online ADHD program six months ago:

- Did you gain any knowledge about ADHD?

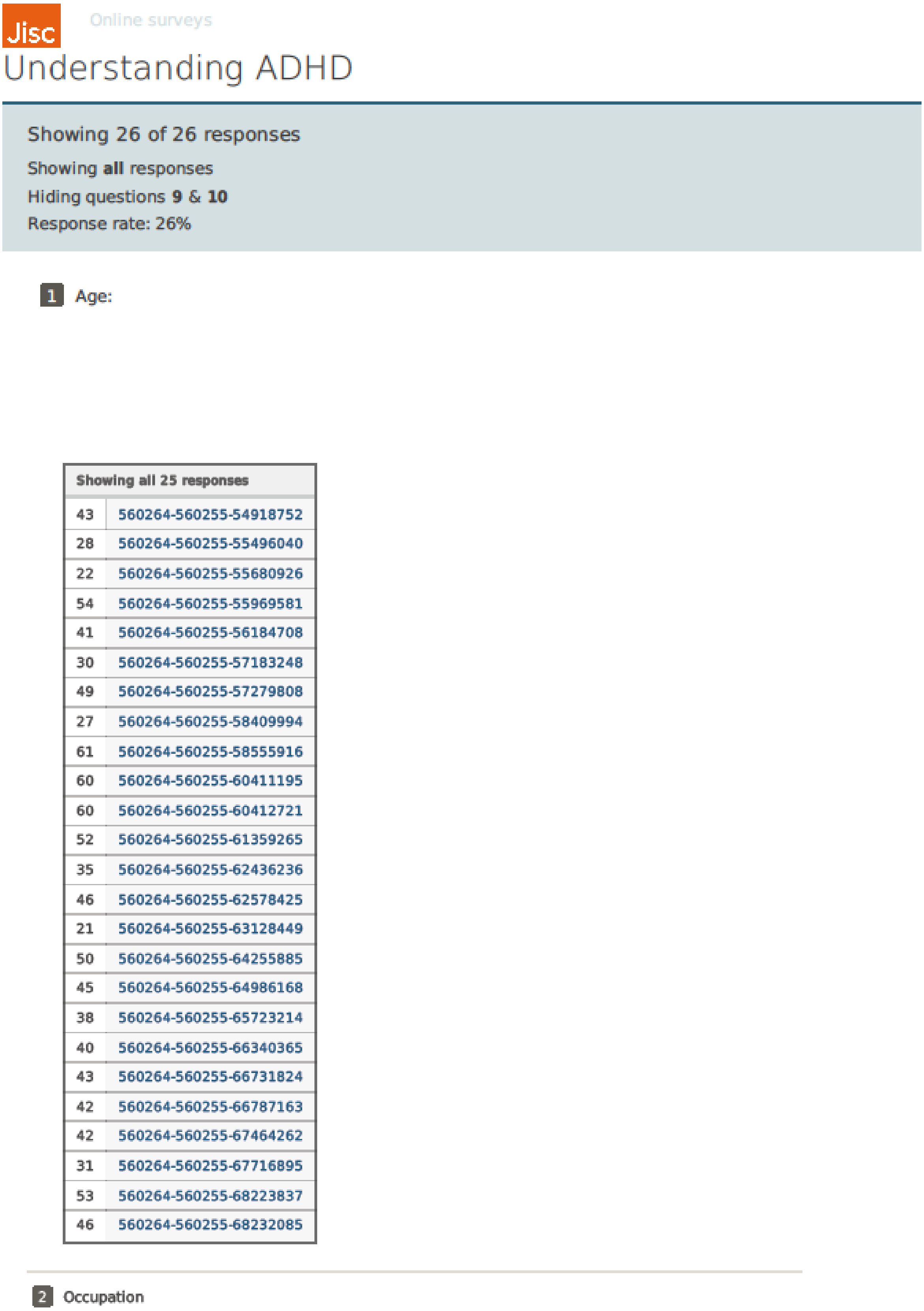
- Is there any difference in how you approach ADHD before and after your interaction with the tool?

- Has the intervention impacted your practice? Or do you think any changes are still to come?

If yes, could you give me an example

- How did it impact your attitude towards ADHD and patients with or at risk of ADHD?

Appendix 14 - Feedback from modules over 12 months post data collection



Online surveys

Understanding ADHD

Showing 26 of 26 responses

Showing **all** responses

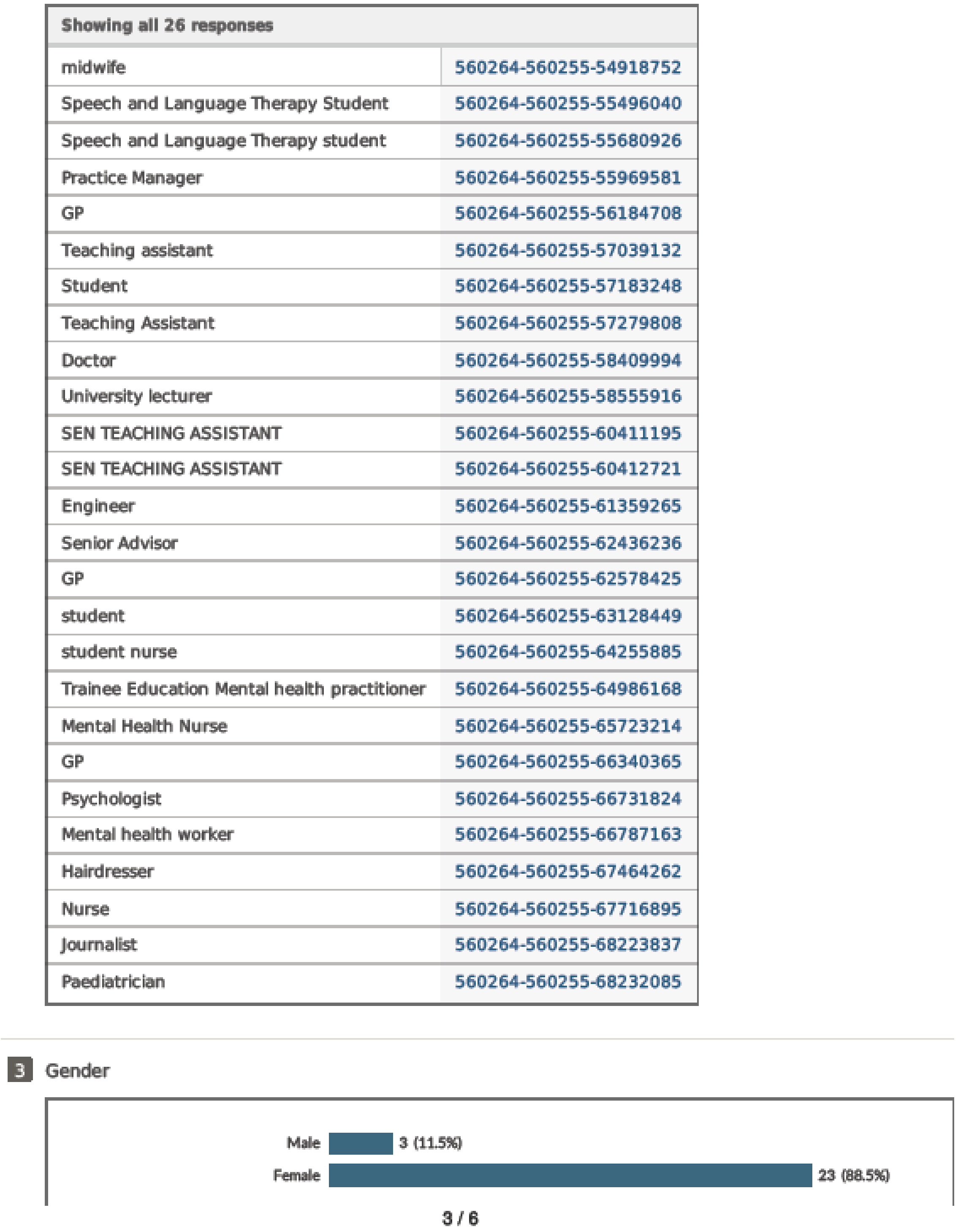
Hiding questions **9** & **10**

Response rate: 26%

1 Age:

Showing all 25 responses	
43	560264-560255-54918752
28	560264-560255-55496040
22	560264-560255-55680926
54	560264-560255-55969581
41	560264-560255-56184708
30	560264-560255-57183248
49	560264-560255-57279808
27	560264-560255-58409994
61	560264-560255-58555916
60	560264-560255-60411195
60	560264-560255-60412721
52	560264-560255-61359265
35	560264-560255-62436236
46	560264-560255-62578425
21	560264-560255-63128449
50	560264-560255-64255885
45	560264-560255-64986168
38	560264-560255-65723214
40	560264-560255-66340365
43	560264-560255-66731824
42	560264-560255-66787163
42	560264-560255-67464262
31	560264-560255-67716895
53	560264-560255-68223837
46	560264-560255-68232085

2 Occupation



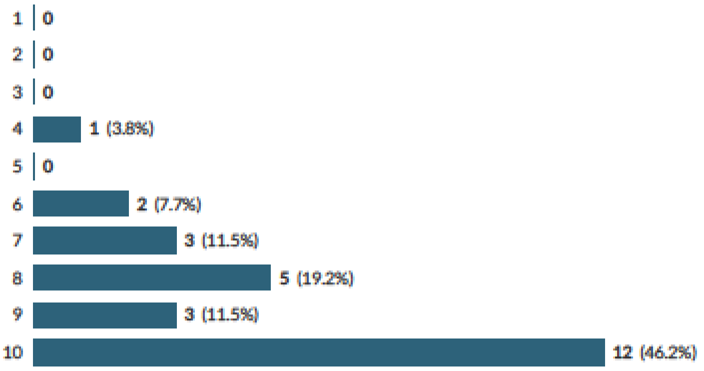
Showing all 26 responses	
midwife	560264-560255-54918752
Speech and Language Therapy Student	560264-560255-55496040
Speech and Language Therapy student	560264-560255-55680926
Practice Manager	560264-560255-55969581
GP	560264-560255-56184708
Teaching assistant	560264-560255-57039132
Student	560264-560255-57183248
Teaching Assistant	560264-560255-57279808
Doctor	560264-560255-58409994
University lecturer	560264-560255-58555916
SEN TEACHING ASSISTANT	560264-560255-60411195
SEN TEACHING ASSISTANT	560264-560255-60412721
Engineer	560264-560255-61359265
Senior Advisor	560264-560255-62436236
GP	560264-560255-62578425
student	560264-560255-63128449
student nurse	560264-560255-64255885
Trainee Education Mental health practitioner	560264-560255-64986168
Mental Health Nurse	560264-560255-65723214
GP	560264-560255-66340365
Psychologist	560264-560255-66731824
Mental health worker	560264-560255-66787163
Hairdresser	560264-560255-67464262
Nurse	560264-560255-67716895
Journalist	560264-560255-68223837
Paediatrician	560264-560255-68232085

3 Gender

3 / 6

4 How useful did you find the information in this program?

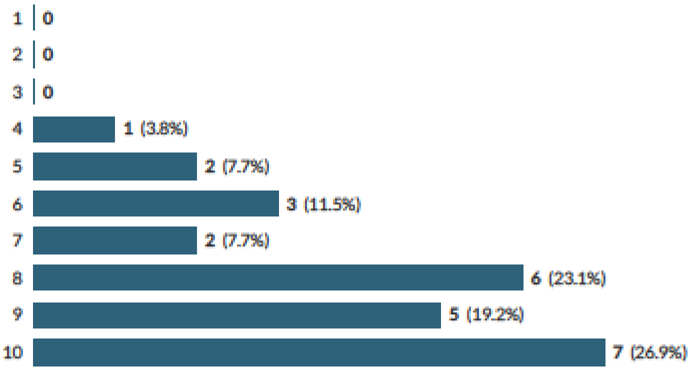
4.1 1:not at all vs 10:extremely



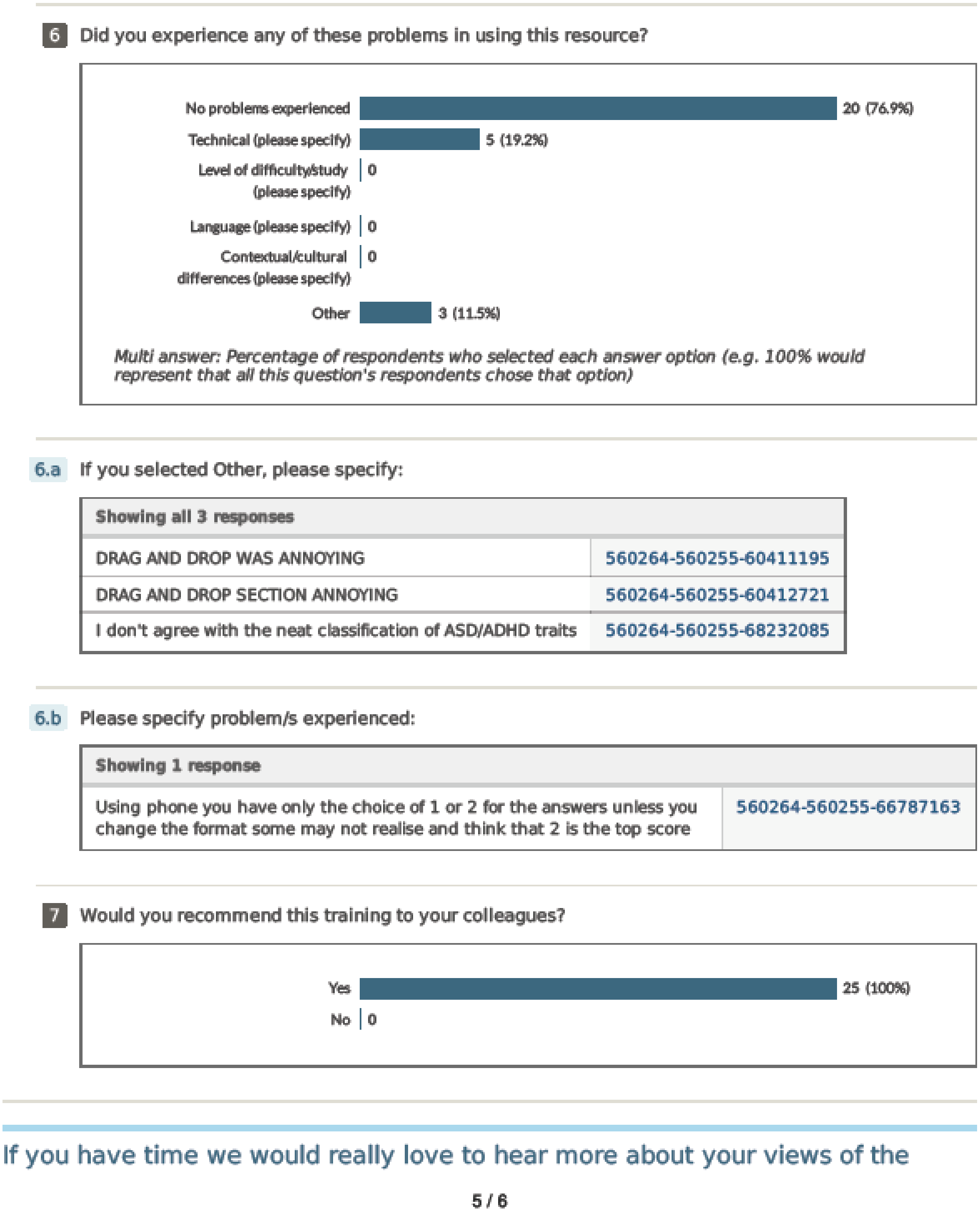
Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)

5 How likely is this information going to inform your practice?

5.1 1:not at all vs 10:extremely



Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)



6 Did you experience any of these problems in using this resource?

Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)

6.a If you selected Other, please specify:

Showing all 3 responses	
DRAG AND DROP WAS ANNOYING	560264-560255-60411195
DRAG AND DROP SECTION ANNOYING	560264-560255-60412721
I don't agree with the neat classification of ASD/ADHD traits	560264-560255-68232085

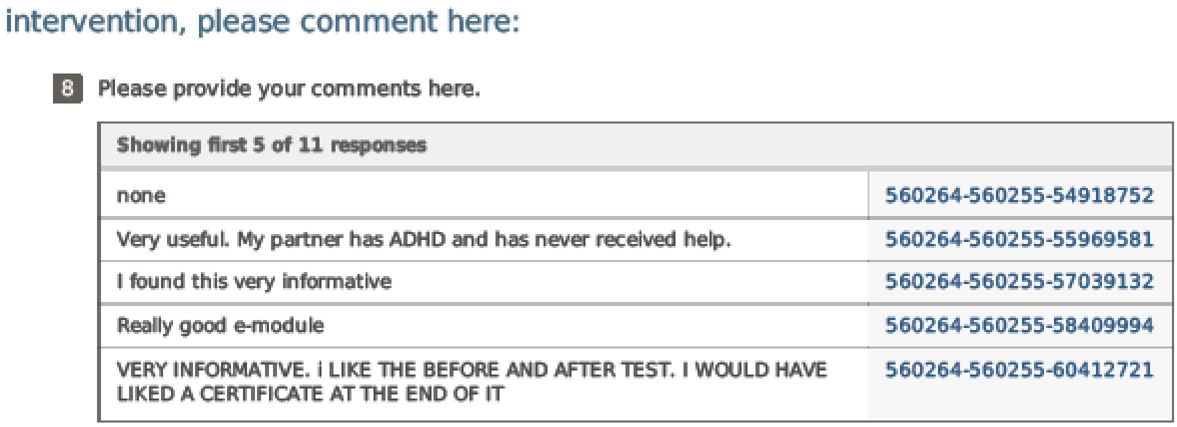
6.b Please specify problem/s experienced:

Showing 1 response	
Using phone you have only the choice of 1 or 2 for the answers unless you change the format some may not realise and think that 2 is the top score	560264-560255-66787163

7 Would you recommend this training to your colleagues?

If you have time we would really love to hear more about your views of the

5 / 6

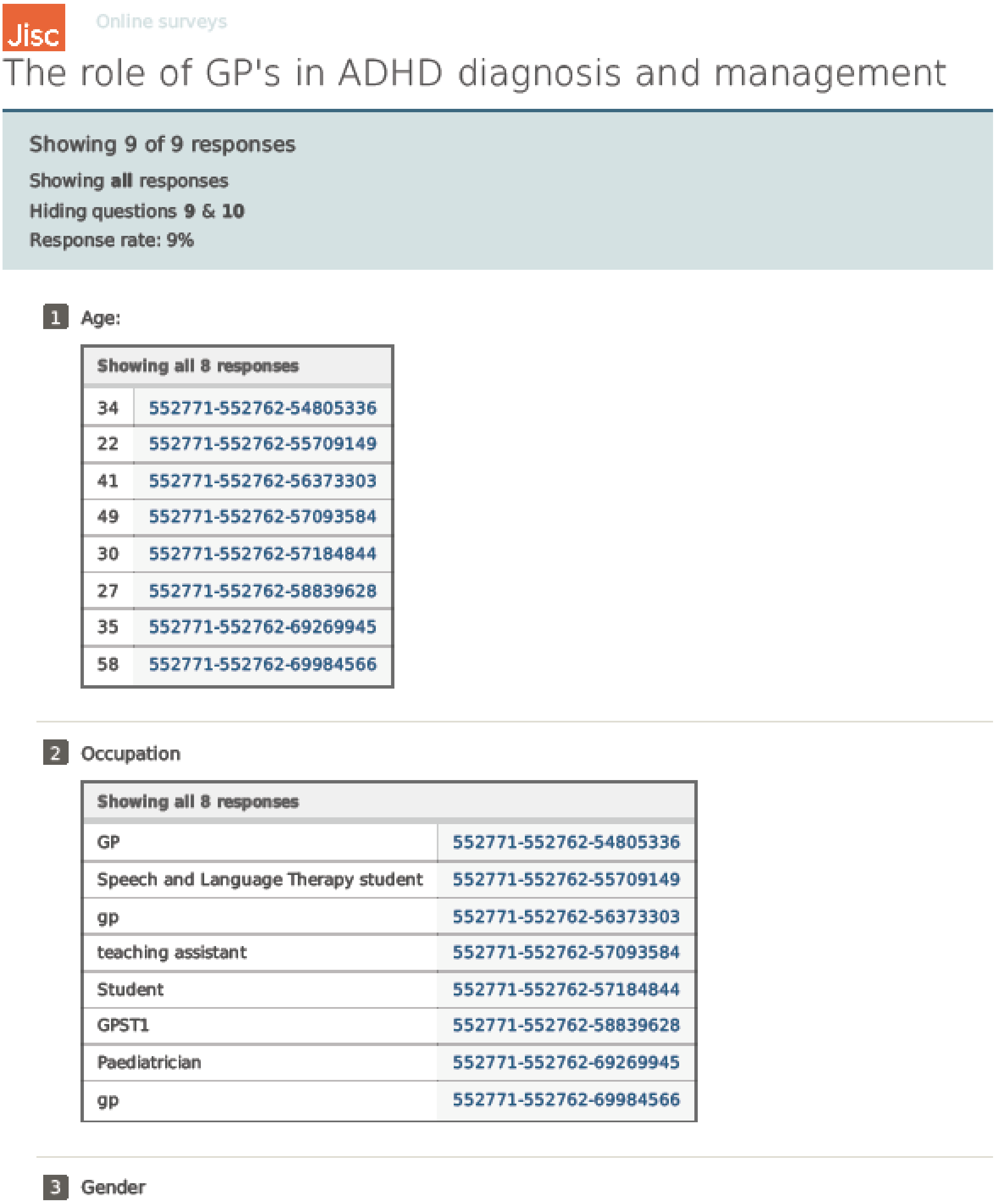


intervention, please comment here:

8 Please provide your comments here.

Showing first 5 of 11 responses

none	560264-560255-54918752
Very useful. My partner has ADHD and has never received help.	560264-560255-55969581
I found this very informative	560264-560255-57039132
Really good e-module	560264-560255-58409994
VERY INFORMATIVE. i LIKE THE BEFORE AND AFTER TEST. I WOULD HAVE LIKED A CERTIFICATE AT THE END OF IT	560264-560255-60412721



Jisc Online surveys

The role of GP's in ADHD diagnosis and management

Showing 9 of 9 responses

Showing **all** responses

Hiding questions **9** & **10**

Response rate: 9%

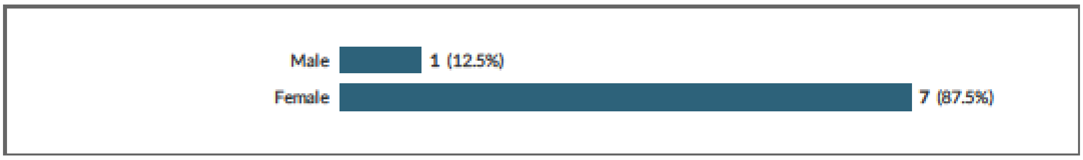
1 Age:

Showing all 8 responses	
34	552771-552762-54805336
22	552771-552762-55709149
41	552771-552762-56373303
49	552771-552762-57093584
30	552771-552762-57184844
27	552771-552762-58839628
35	552771-552762-69269945
58	552771-552762-69984566

2 Occupation

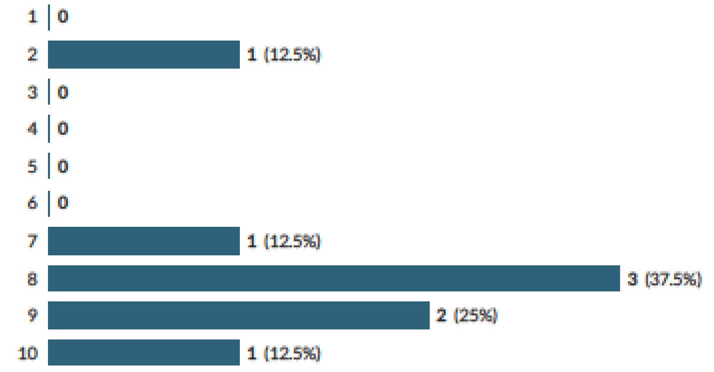
Showing all 8 responses	
GP	552771-552762-54805336
Speech and Language Therapy student	552771-552762-55709149
gp	552771-552762-56373303
teaching assistant	552771-552762-57093584
Student	552771-552762-57184844
GPST1	552771-552762-58839628
Paediatrician	552771-552762-69269945
gp	552771-552762-69984566

3 Gender



4 How useful did you find the information in this program?

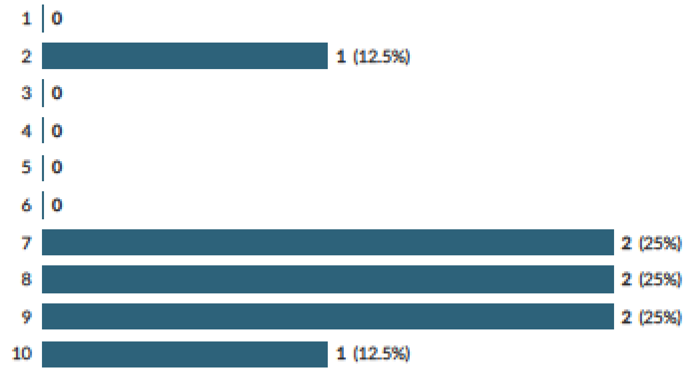
4.1 1:not at all vs 10:extremely



Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)

5 How likely is this information going to inform your practice?

5.1 1:not at all vs 10:extremely



Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)

---

6 Did you experience any of these problems in using this resource?

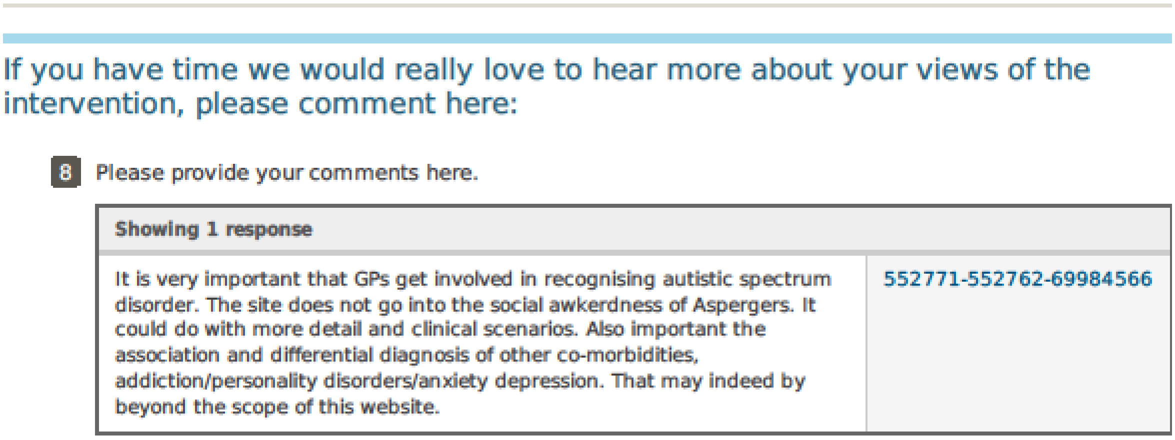
Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)

6.a If you selected Other, please specify:

No responses

---

7 Would you recommend this training to your colleagues?



If you have time we would really love to hear more about your views of the intervention, please comment here:

8 Please provide your comments here.

Showing 1 response	
It is very important that GPs get involved in recognising autistic spectrum disorder. The site does not go into the social awkerdness of Aspergers. It could do with more detail and clinical scenarios. Also important the association and differential diagnosis of other co-morbidities, addiction/personality disorders/anxiety depression. That may indeed by beyond the scope of this website.	552771-552762-69984566

Appendix 15 - Informal feedback received

Informal comments received from external individuals

I've just completed your two ADHD resources sent by the RCGP learning route and first want to say that they are useful and set at the right level for most generalists, so from a personal point of view, I think they are delivering what you sent out for them to deliver.

Also, usually after completing a resource, there's usually some type of CPD credit, i.e. evidence that you've actually taken on the self-learning action. But again, I could not see any way of recording that I completed this from a self-learning perspective?

Keep up the good work!

Informal comments received from the participants

Control

I'm sorry I couldn't see the point of the video, and it's 26mins long, which is frustrating.

I'm pretty sure I just watched the 'control' video. It was quite an annoying waste of my time which I resented as it clearly had no possible educational value and was of no interest to me. I understand that the idea was for control participants to spend the same amount of time as intervention participants watching a video (or I presume this). The pain of this experience could have been softened by either watching an educational video about another topic or just an entertaining video. Or I could have just dozed for the time - anything else really!

I am a bit confused about these last questions as I didn't receive any information in this program (only watched a video about the Institute of Mental Health 10-year anniversary). Is this because I was a control group member, perhaps? Hard to answer last questions! Only a very little bit about ADHD in the video, but that related to how it was being researched at the institute and not, e.g. my clinical practice.

This video I did not feel focussed on ADHD and was a great advertisement for the service in Nottingham but was limited otherwise

I don't think that I was in the education arm of the study; hence no improvement in my answers.

Interesting video describing lots of services. Not sure I can access them from Leicestershire?

Purpose too many different topics and some information more locally relevant?

I'm not sure I watched the correct video

As part of the control part of the study, it was great to then have access to the ADHD learning module, which I found very well set out and easy to complete. Thank you.

Very interesting & informative

Intervention

Thank you for inviting me. It was very useful and has changed my perception and understanding of ADHD.

Really good! well done, guys

very useful

Excellent succinct and informative online program about ADHD.

Very interesting!

The information was useful, as were the resources at the end.

Good useful update. Thanks

Useful summary, thanks

very informative

easy to follow resource

Easy to do, lovely format, interesting, lots of knowledge

Really helpful learning resource. Use of video was great

The only missing information was the ability for schools to refer directly for a diagnosis, which they are often reluctant to do but are critical in helping provide the evidence of a diagnosis.

very good, videos took ages to load but might have been my internet connection

A must for GPs. Excellent should be included in GP training

The online program is very enlightening. The online resource doesn't provide answers to the pre-resource evaluation questionnaires. There is still some uncertainty in answering all the post-test evaluation questions following from the online resource.

It’s great

Very useful information resource for ADHD

debunked myths and showed why diagnosis is important for adults and not just children. Useful examples of the positive benefits of diagnosis

It is generally well presented and technically on a par with similar CPD modules (apart from the odd spelling mistake - loses, not looses). Unfortunately, the content is too emotionally biased and laden with vested interests to appear credible. It comes across as pseudoscientific in places and clearly seeks to perpetuate the underlying problem, which is the tendency of the medical profession to peddle cures for every ill. I am afraid all of the expert testimonies (which I did listen to) have failed to alter my opinion!

Could not access on work desktop but could on smartphone although not the easiest interface

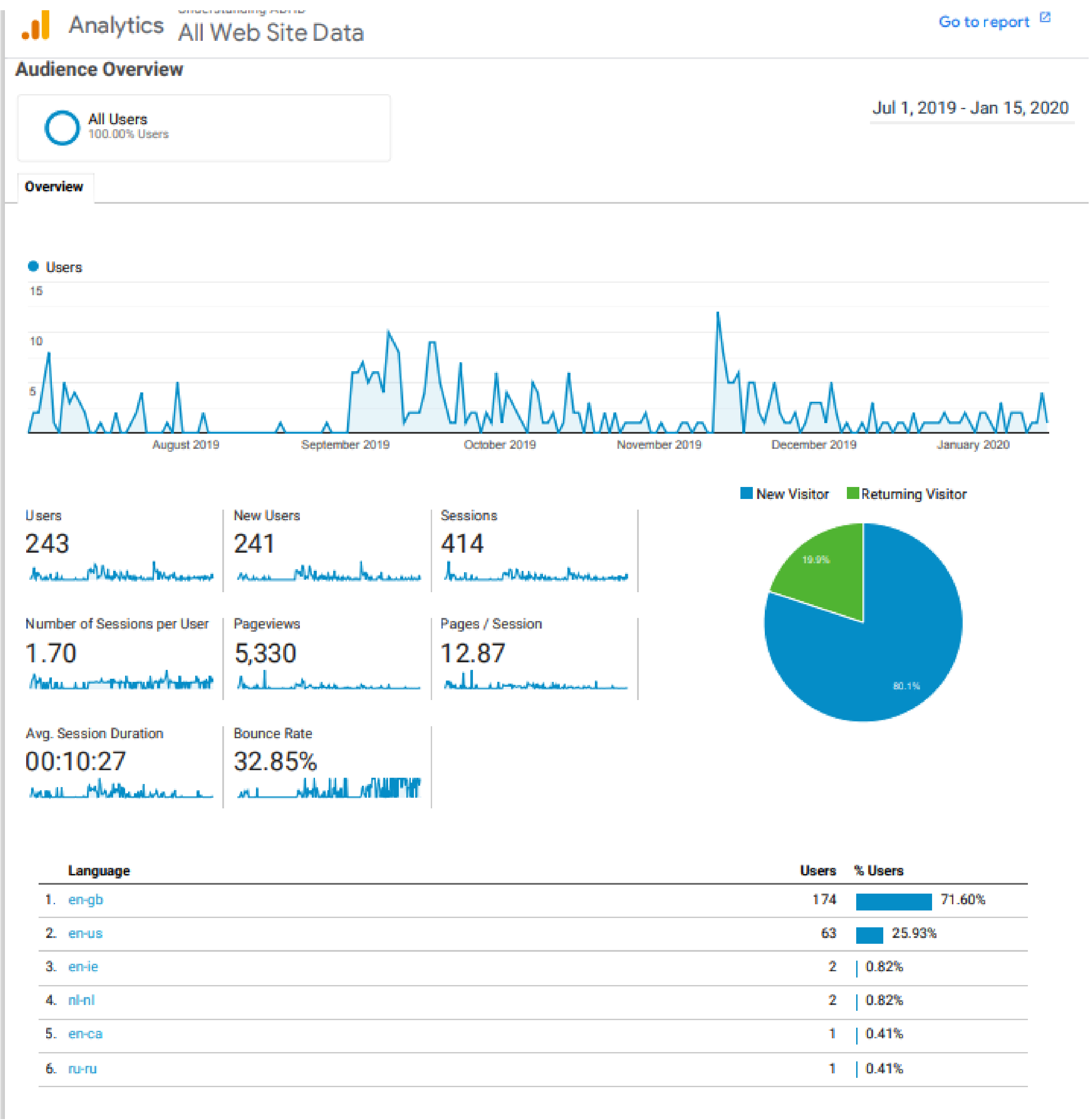
very useful but too long and could be reduced further. The information about ADHD in particular, could be reduced. The role of GP resources was more interesting with video vignettes

lots of info about the diagnostic criteria, which are relatively straightforward to look up, could be more info on comorbidities or slightly atypical presentation and treatments/helpful advice to give/other interventions that are helpful

Given the lack of access to resources for adults, it would have been good to have included some practical advice for patients struggling where there are NO local resources.

perhaps not given information more specifically about how to tease out/ getting suspicious about possible ADHD

Appendix 16 - Data from Google Analytics



Analytics All Web Site Data

Go to report

Audience Overview

All Users
100.00% Users

Jul 1, 2019 - Jan 15, 2020

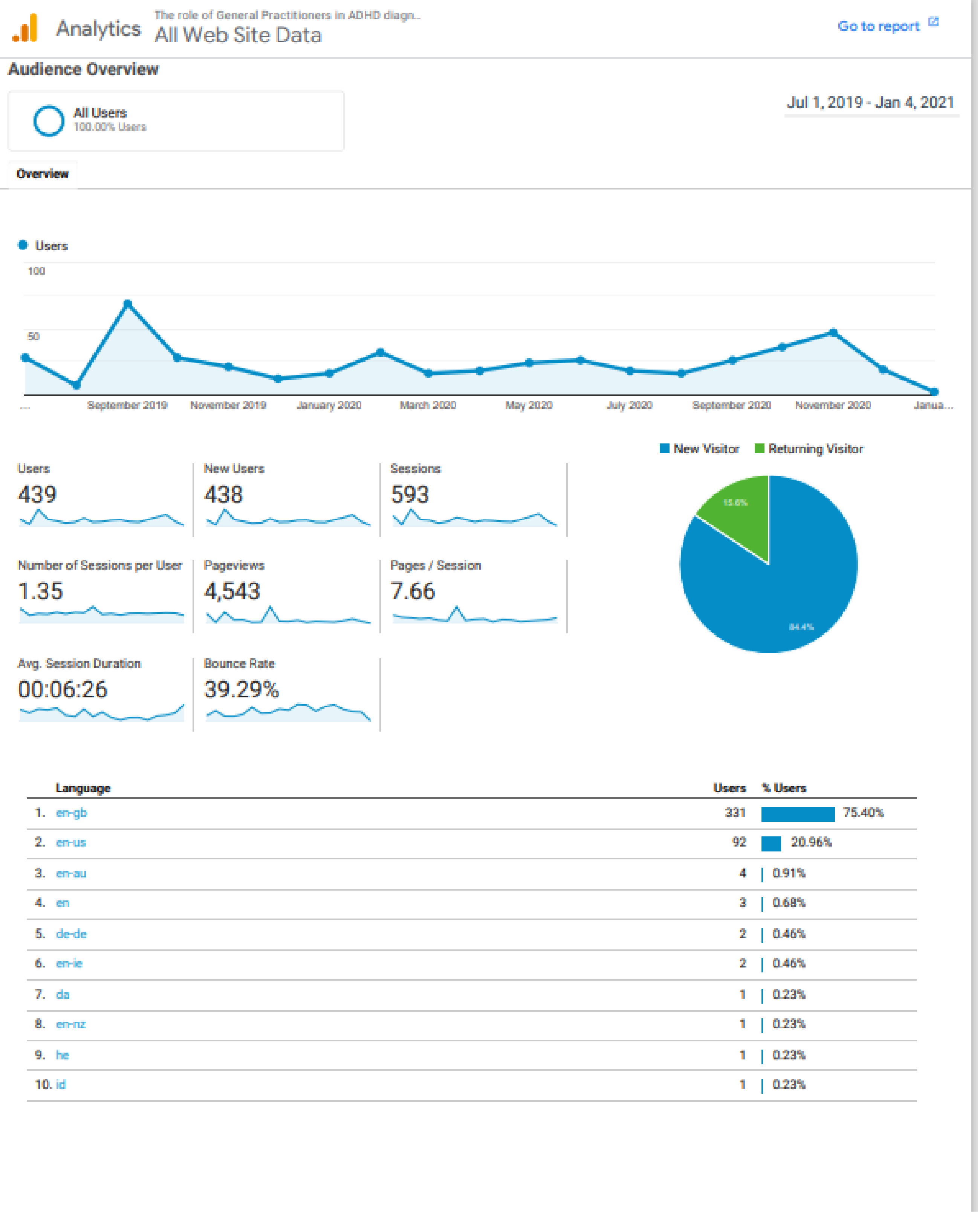
Overview

Users	New Users	Sessions
243	241	414

Number of Sessions per User	Pageviews	Pages / Session
1.70	5,330	12.87

Avg. Session Duration	Bounce Rate
00:10:27	32.85%

	Language	Users	% Users
1.	en-gb	174	71.60%
2.	en-us	63	25.93%
3.	en-ie	2	0.82%
4.	nl-nl	2	0.82%
5.	en-ca	1	0.41%
6.	ru-ru	1	0.41%



The role of General Practitioners in ADHD diagn...

All Web Site Data

Audience Overview

All Users
100.00% Users

Jul 1, 2019 - Jan 4, 2021

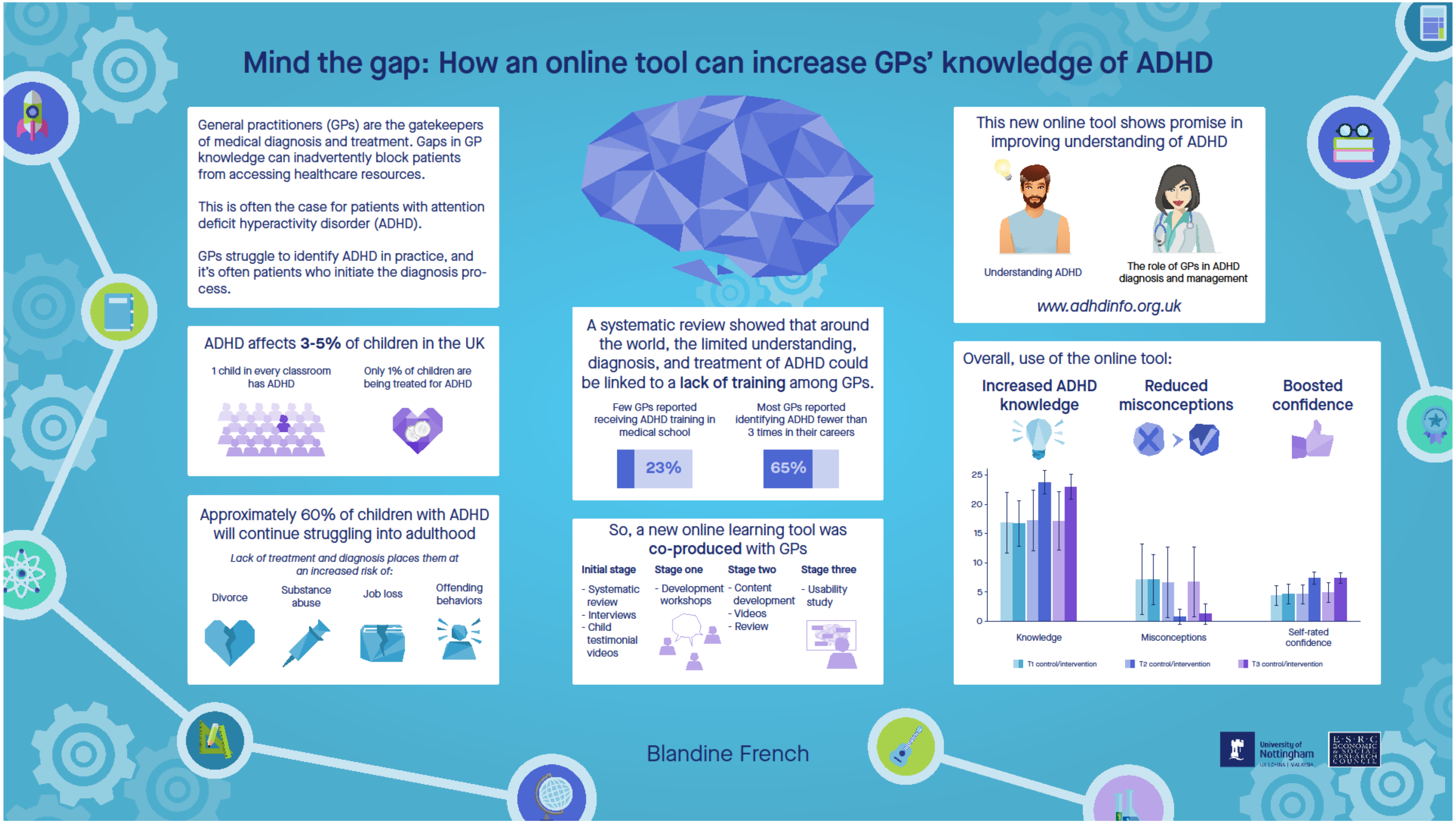
Users	New Users	Sessions
439	438	593

Number of Sessions per User	Pageviews	Pages / Session
1.35	4,543	7.66

Avg. Session Duration	Bounce Rate
00:06:26	39.29%

	Language	Users	% Users
1.	en-gb	331	75.40%
2.	en-us	92	20.96%
3.	en-au	4	0.91%
4.	en	3	0.68%
5.	de-de	2	0.46%
6.	en-ie	2	0.46%
7.	da	1	0.23%
8.	en-nz	1	0.23%
9.	he	1	0.23%
10.	id	1	0.23%

Appendix 17 – Infographic



Mind the gap: How an online tool can increase GPs' knowledge of ADHD

General practitioners (GPs) are the gatekeepers of medical diagnosis and treatment. Gaps in GP knowledge can inadvertently block patients from accessing healthcare resources.

This is often the case for patients with attention deficit hyperactivity disorder (ADHD).

GPs struggle to identify ADHD in practice, and it's often patients who initiate the diagnosis process.

ADHD affects **3-5%** of children in the UK

1 child in every classroom has ADHD

Only 1% of children are being treated for ADHD

Approximately 60% of children with ADHD will continue struggling into adulthood

Lack of treatment and diagnosis places them at an increased risk of:

Divorce

Substance abuse

Job loss

Offending behaviors

A systematic review showed that around the world, the limited understanding, diagnosis, and treatment of ADHD could be linked to a **lack of training** among GPs.

Few GPs reported receiving ADHD training in medical school	Most GPs reported identifying ADHD fewer than 3 times in their careers
23%	65%

So, a new online learning tool was **co-produced** with GPs

Initial stage	Stage one	Stage two	Stage three
- Systematic review - Interviews - Child testimonial videos	- Development workshops	- Content development - Videos - Review	- Usability study

This new online tool shows promise in improving understanding of ADHD

Understanding ADHD

The role of GPs in ADHD diagnosis and management

www.adhdinfo.org.uk

Overall, use of the online tool:

Increased ADHD knowledge

Reduced misconceptions

Boosted confidence

Blandine French

University of Nottingham
UK | CHINA | MALAYSIA

E·S·R·C
ECONOMIC & SOCIAL RESEARCH COUNCIL