# Failure of healthcare provision for Attention-Deficit/Hyperactivity Disorder in the United Kingdom: A Consensus Statement

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## ABSTRACT

**Background:** Evidence-based national recommendations are provided for services underpinning care for people with ADHD in the United Kingdom (UK) by the National Institute for Health and Care Excellence (NICE). Despite these guidelines, ADHD is under-identified, under-diagnosed and under-treated treated in the UK, similarly to other countries. Many of those seeking help for ADHD face prejudice, extremely long waiting lists, and patchy or unavailable services. Those who struggle to access clinical support turn to service-user support groups and/or private healthcare for help.

**Methods**: A group of UK experts representing clinical and healthcare providers from private and public healthcare, ADHD patient groups, educational and occupational specialists, met to discuss the shortfall in ADHD service provision. Discussions explored causes of under-diagnosis, examined biases operating across referral, diagnosis and treatment, and solutions to manage these issues.

**Results**: The current report describes cultural and structural barriers that operate at all levels of the healthcare system which result in a de-prioritisation of ADHD. Services for ADHD are either insufficient or unavailable in many regions, and problems with services provision have intensified as a result of the response to the COVID-19 pandemic, which has seen ADHD being further de-prioritised with many ADHD services being paused or delayed. Research has established a range of long-term adverse outcomes of untreated ADHD, which come at a considerable cost to society. The long-term personal, social, health and overall economic costs of untreated ADHD are high. The consensus group called for training across professions for those who may come into contact with people with ADHD, an increase in funding, commissioning and monitoring to improve service provision overall, and streamlined communication between health services to support better outcomes of people with ADHD.

**Conclusions**: Evidence-based national clinical guidelines for ADHD are not being met. People with ADHD should be able to access healthcare free from discrimination, and in line with their legal rights. UK Governments and clinical and regulatory bodies need to act urgently on this important public health issue, to support and uphold the rights of individuals and improve their long-term outcomes.

**Keywords**: Attention-deficit/hyperactivity disorder (ADHD), Service, Healthcare, Treatment, Intervention, Comorbidity, Consensus, ADHD Foundation, UKAP

## BACKGROUND

Attention-deficit/hyperactivity disorder (ADHD) is a common neurodevelopmental disorder characterised by persistent and impairing inattention and/or hyperactivity-impulsivity [1, 2]. ADHD usually first presents in childhood, and persists into adulthood in a sizeable proportion of cases [3, 4]. ADHD is common. Worldwide prevalence is estimated at between 5-7% in children and adolescents [5–7], and around 2-4% of adults [8–10]. Research indicates significant genetic influences, environmental risk factors, and differences in pattern of brain correlates in affected individuals as shown in neuroimaging studies [reviewed in 11]. Diagnosis is reliable and clinically significant treatment effects have been supported by meta-analytic evidence [12, 13].

ADHD is associated with a range of adverse outcomes. People with ADHD are more prone to accidents and injuries, and have a higher mortality rate compared to the rest of the population [14, 15]. They are more likely to experience social and relationship problems [16], be involved in delinquency, criminal behaviour and substance use [17, 18], experience early or unplanned pregnancy [19], and have problems in education and at work [20–23]. Associated problems and comorbidities are likely to accumulate during the lifetime; for example, research documents a trajectory of ADHD in childhood, leading to academic and social problems which, in turn, leads onto depression [24].

Timely detection and treatment is likely to moderate risks and improve outcomes [25, 26]. Pharmaco-epidemiological studies show that during periods on-treatment people, with ADHD have a lower risk of suicide [27] unintentional injury [14], motor vehicle accidents and substance use disorders [26], reduced hospital contact [28], better educational [21] and occupational [29] outcomes, as well as reduced criminality [28, 30]. Furthermorem, evidence suggests delays in treatment lead to high long-term personal and public costs, including reduced economic productivity, and increased health, social care and state benefit costs [31, 32]. Effective psychological interventions have been found to help to increase employment and education rates and reduce use of cash benefits and social services [33].

There has been a stepped change in clinical policy for treating ADHD in the UK over the past three decades. This has co-occurred with the mainstreaming of childhood ADHD into generic mental health services, and the publication of the first national clinical guidance on adult ADHD by the National Institute for Clinical Excellence in 2008. As a result of these changes and increased recognition of ADHD in the population, there has been a significant increase in rates of first diagnosis and prescribing of childhood ADHD [34, 35], and many clinicians have seen their ADHD patient caseload and waiting list increase significantly.

However, ADHD and its treatment remains controversial in public, policy and clinical spheres both in the United Kingdom (UK) and in other countries [36–39]. The controversy centres around the perception of ADHD as a medicalised social construct [40], represented in some newspapers as a catchall for naughty behaviour, laziness, poor parental discipline, or excessive screen time [see for example 41, 42]. The increase in ADHD medication prescription in the UK over the last two decades has been a cause of national concern, provoking responses from health and educational representatives [43, 44]. Concerns have also been expressed around the potential diversion and misuse of ADHD medication as a ‘study drug’ [45]. This leads to short-sighted calls to curtail prescriptions, but risks unfairly penalising those who genuinely need ADHD medication.

At present, service provision for ADHD does not meet demand. Evidence suggests that contrary to concerns of over-medication, ADHD still is more likely to be under-identified, under-diagnosed and under-treated in the UK [46, 47]. Those who seek help face patchy, unavailable inaccessible services, and extremely long wait lists [48–50]. Problems with access to services also affect young people with ADHD in transition from child to adult mental health services [51]. Patients report accumulated psychosocial burden from delays in diagnosis and treatment [52]. Those who struggle to receive support are being signposted to, or seeking out, local or national service-user support groups for help. These charitable organisations are inundated with support requests that they are not equipped or qualified to fulfil. Those who are able to afford it turn away from the National Health Service (NHS), and towards private healthcare.

Problems with access to clinical support and treatment for ADHD have been exacerbated since the advent of the COVID-19 pandemic. National measures to delay the spread of the virus have had a significant impact on both demand and capacity to delivery support for people with mental health needs. The pandemic is associated with a range of social, financial, educational, health and personal concerns, which are all stresses associated with mental health issues [53]. Individuals with ADHD are likely to be particularly ﻿vulnerable to the distress caused by the pandemic and physical distancing measures, and may display increased behavioural problems [54]. Whilst these additional issues with access to services have arisen more recently and are likely to increase the clinical needs of this population, they have compounded existing shortfalls, rather than creating new shortfalls in service provision.

Whilst acknowledging current challenges for mental health provision and the increase in service provision for ADHD over the past three decades, the existence of a significant unmet clinical need for individuals with ADHD in the UK must be scrutinised. With evidence of personal, clinical, social and economic benefits of investing in adequate treatment for ADHD, access to clinical support must be improved not only in the context of the pandemic, but also beyond. To do this we must unpick and examine the constrictions on ADHD provision in the UK, so that these can be alleviated looking forward. It is on the basis of this key issue that professionals specialising in ADHD convened for a consensus meeting to discuss the gap in ADHD provision in the UK.

## METHODS

The consensus group convened in London on the 11th February 2019. The meeting was hosted by three leading UK ADHD organisations; (1) the ADHD Foundation ([https://www.adhdfoundation.org.uk](https://www.adhdfoundation.org.uk/); (2) The UK ADHD Partnership (UKAP, [www.ukadhd.com](http://www.ukadhd.com)) and; (3) the UK Adult ADHD Network (UKAAN, [www.ukaan.org](http://www.ukaan.org)). Meeting attendees were academics, clinicians, mental health professionals, educational and occupational specialists, service-user support services and charity workers specialising in ADHD. Healthcare practitioners represented both those working within private practice, and the National Health Service (NHS), the UK-wide universal healthcare system providing free or low-cost healthcare to UK residents.

The meeting commenced with presentations on (1) ADHD provision in the UK from the viewpoint of the ADHD Foundation, and (2) an overview of research on treatment and short- and long-term outcomes of ADHD. This was followed by a question and answer session, after which attendees separated into three breakout groups, in which discussions were facilitated by group leaders. Following the group work, all attendees re-assembled. Group leaders then presented findings to all meeting attendees for another round of discussion and debate, until consensus was reached.

The National Institute for Health and Care Excellence (NICE) guidelines provide clinical guidance for the diagnosis and treatment of ADHD within the NHS across England and Wales [55, 56]. The Scottish Intercollegiate Guidelines Network (SIGN), provides the equivalent for Scotland [57]. NICE guidelines were used as a benchmark for service provision in these discussions, since these provide official guidance for England and Wales and there is good overlap between NICE and other recommendations for the management of ADHD in SIGN.

Group discussions included the following three main topics, each of which was explored for differences between children and young people (age <18) and adults (age >18):

1: How do we know children, young people and adults with ADHD are not being diagnosed and why is this happening?

2: Are the NHS services provided adequate?

3: What is happening to those with ADHD who cannot access NHS healthcare for their ADHD?

Presentations and debate amongst attendees were audio-recorded and transcribed. During group breakout meetings, a note-taker was allocated to each breakout group, and after the meeting their notes were circulated to participants in each breakout group for review and agreement. All materials (transcriptions, electronic slide presentations and breakout group notes) were synthesised jointly by the lead author and writer.

Where relevant and available, consensus discussion points are provided alongside references to the supporting research literature, grey literature, policy or legislative documentation. Where reports are anecdotal only and relate to the clinical or professional experiences of consensus attendees, these are described as such in the following report. A final draft was circulated to all authors for approval before submission. The consensus outcomes presented therefore represent the views and recommendations of the consensus group as a whole.

## RESULTS AND CONSENSUS OUTCOME

Shortfalls in detection and service provision can be inferred from discrepancies between community prevalence rates and administrative prevalence (the proportion of people with a clinical diagnosis; see Figure 1) [46]. Population prescription rates for ADHD medications are often used as a proxy for clinical diagnosis in administrative prevalence studies, but underestimate rates of diagnosis, since they do not take account of patients who are managed without ADHD mediations.

World estimates for community prevalence of ADHD in children have not changed in the past three decades, when considering studies using the same methodological approach to diagnose ADHD [58, 59]. By contrast, administrative prevalence in the UK has increased over this period of time [34, 60]. This increase in treatment rates shows that rates of idntification and access to treatment has improved over time, although diagnostic rates continue to remain low across all ages. Administrative prevalence of ADHD in children and adolescents in the UK has been estimated between 0.2%-0.9% since the mid-2000s [46]. This is well below worldwide prevalence estimates of between 5-7% [5–7], and remains below community prevalence estimates in the UK estimated at around 2.2% in 1999 and 2005 [61, 62], with more recent estimates of 1.6% in 2017, based on the more restrictive ICD-10 Hyperkinetic Disorder criteria [63]. Administrative prevalence of adult ADHD in the UK stands at around 0.1% [47, 64], far below estimated worldwide prevalence of 2-4% [8–10].

People with ADHD can face a long and difficult journey to reach diagnosis and long-term disease management, described in some cases as ‘an uphill struggle’ [52]. A number of hurdles to reaching treatment were highlighted during the consensus meeting and these are described in more detail in the sections below. Whilst pathways to care for children and adult are distinct, barriers to treatment are largely overlapping. After describing these barriers, we provide recommendations for improving provision and outcomes for people with ADHD.

Figure 1: Pathways to accessing longer-term treatment in the NHS for individuals affected by ADHD (including estimated prevalence rates, where available)



Legend: a) Sayal et al. 2018[46], b) Ford et al. 2003 [61], Sayal et al., 2010 [62] and NHS digital, 2018[63] c) Raman et al., 2018 [47], d) Willcutt et al. 2012 [8], Simon et al. 2009 adults [9]. Fayyad et al., 2017 [10].

### Barriers to ADHD diagnosis and treatment provision

#### 1.1 Detection of ADHD and associated problems

ADHD can only be diagnosed and treated as quickly as the condition is identified in the community. Expectations that ADHD expresses as hyperactive, restless and disruptive behaviour can limit detection of the many more subtle presentations.

Children and young people with ADHD with fewer hyperactive-impulsive symptoms and less disruptive, aggressive and antisocial behaviour are less likely to be detected, referred, diagnosed and treated. Those with higher intellectual functioning or using a range of compensatory strategies may also not struggle as obviously and remain undetected. Even once detected, they may not meet impairment criteria for successful referral to secondary health services. Although more subtle inattentive problems can present across both sexes, they appear more common in girls [65]. As children age and become more independent, their environmental support declines, whilst social, academic and environmental demands increase [66]. Over time demands may come to overwhelm their abilities and resources, and they may start to struggle to cope with their symptoms. Some may develop problems with emotional dysregulation and comorbid disorders (for example, mood disorders, eating disorders and self-harm) which could trigger inclusion into different treatment pathways. There is now increasing evidence that in at least some cases, the full-blown disorder emerges during the middle adolescent years, when more demands are made on individuals and they fall further behind their peers [67].

Comorbidity is very common and complicates identification and treatment in ADHD. Common comorbidities in children include autism spectrum disorders (ASD), mood, anxiety, oppositional and conduct disorders, as well as specific learning and language disorders, epilepsy and Tourette’s syndrome [68, 69]. In adults with ADHD, comorbid symptoms and disorders are also extremely common [70] and include ASD, mood, anxiety, impulse control and substance use disorders [71, 72]. The consensus group noted that with increasing age, people with ADHD typically present with more co-occurring problems, which can make diagnosis more complex and ADHD more likely to be missed. For example, inattention, restlessness, impulsivity, and associated features of ADHD such as emotional lability [73], are also common in trauma presentations and attachment difficulties [74], and other psychiatric conditions [e.g. personality disorders, mood disorders, 75, 76]. Symptomatic overlap and a lack of awareness of ADHD in clinical practice can lead to diagnostic mis-specification [77, 78].

People with ADHD may come in contact with a range of mental health, social care or criminal justice professionals in their lifetime. However, ADHD often remains unrecognised and provisions are put in place for co-occurring conditions or problems. This is evidenced by the high rates of unrecognised ADHD in patient populations treated for other psychiatric conditions (15.8-17.4% [79]), and in prison populations (25.5% [80]). Importantly, the consensus group noted that adults with ADHD may show poor response to the treatment of comorbid conditions if ADHD symptoms are not appropriately managed. Symptoms such as emotional instability, characteristic of many other mental health disorders, often improve when ADHD is treated [81].

ADHD symptoms tend to decline with increasing age [8], with greater decline typically seen for hyperactive-impulsive symptoms, but less so for inattentive symptoms [82]. Adults with ADHD can therefore have a more subtle symptom presentation characterised by more internalised symptoms rather than overt externalised behaviour [1]. The consensus group noted that with increasing age people with ADHD often present with a variety of additional problems (e.g. insomnia, anxiety, depression), and may be less likely to attribute their problems to ADHD, particularly if they were not hyperactive or disruptive in childhood. In older adulthood there may be confusion between the lifelong attentional problems of people with undiagnosed ADHD and prodromal dementia [83]. The experience of adult mental health clinicians in the group was that most patients presenting in adult ADHD clinics for the first time had not previously received an assessment or diagnosis for ADHD as children.

#### 1.2 Gatekeepers of ADHD assessment and diagnosis

In the UK healthcare system, a patient with ADHD passes through multiple stages in the help-seeking process (see Figure 1). The knowledge and attitudes of the network of gatekeepers (for example, parents/carers, teachers, primary and/or secondary care clinicians) can facilitate or hinder their access to support. One problem noted repeatedly during the consensus meeting is that there is no consistent referral route across all regions of the UK.

The initial stage of the help-seeking process is detection. Parents/carers are often the first to seek out referral and diagnosis for their children and their perception of the presenting problems is a key contributor to primary care referrals to CAMHS services [39, 84]. Similarly, the understanding and attitude towards ADHD of help-seeking adults is likely to affect their likelihood of self-referral. Teachers and educators are also in regular contact with a large number of children and young people and they are well-positioned to identify when a child or young person is struggling.

The next stage is contact with individuals with the power to refer on for assessment. Teachers are often the first (and may be the only) professionals approached by parents or carers [84]. However, teachers are more likely to raise concerns regarding ADHD when presenting with notable hyperactivity-impulsivity and associated disruptive behaviour [85]. Furthermore, referral may be hindered by overemphasising the role of adverse home environments as the primary cause of symptoms [86] and/or the perception that poor parenting is to blame [87]. A survey of 803 primary and secondary teachers in the UK found that only 62% agreed with the statement ‘I would always refer a child/ student I suspected of having ADHD to a health professional‘, and 63% disagreed with the statement ‘Teachers receive an adequate level of training and support in order to support children and students with ADHD symptoms‘ [88]. With the diagnostic requirement that ADHD symptoms are pervasive and present across two or more settings, school observations and teacher input can support or undermine a later diagnosis.

Primary care services are another main point of contact for parents/carers and are the usual first port of call for adults for onward referral for ADHD assessments. Unfortunately, some primary and even some secondary care physicians express uncertainty about the legitimacy of an ADHD diagnosis [89, 90]. They may have negative and unhelpful attitudes about ADHD [16, 52, 91], and may perceive parental help-seeking as reflects the desire to ‘shift blame’ or find a ‘quick fix’ for behavioural or disciplinary problems [92]. As a result, some affected people and their families may experience blame or dismissal [36, 90], which may lead them to seek out costly private healthcare [32]. Primary care physicians often play an important role in continuing medication and providing ongoing support, although this is not universally the case in all regions of the UK. Primary care physicians’ attitudes and understanding regarding ADHD is therefore key to facilitating access to care.

Progressive revisions to diagnostic criteria and clinical practice over the last 30 years have broadened the ADHD phenotype. Some healthcare practitioners may not be aware of these changes and/or may have limited ‘buy-in’ [16]. This means that they may still be discounting a variety of ADHD presentations, such as adult ADHD, ADHD comorbid with ASD, or more subtle (inattentive only) presentations. These ‘newer’ presentations of ADHD may be met with an extra dose of distrust, particularly adult ADHD for which the consensus group noted stigma remains particularly high.

The final stage in the help seeking process is diagnosis and treatment initiation, which is often completed within secondary or specialist health services [55], and more detail on healthcare provision and barriers to access at this stage are provided in the sections below. The consensus group noted that where secondary care/specialist services are lacking, patchy, or have varied referral criteria, it can be challenging for primary care practitioners to assist patients and families to negotiate this process and access the best and most timely care and assessment.

#### 1.3 ADHD healthcare organisation in the UK

The consensus group noted that there are local and regional idiosyncrasies in referral pathways and treatment arrangements for both child and adult ADHD services, which can make it challenging to navigate access to care. Insight into health service provision in the UK can be obtained from public authorities through legislative rights under the Freedom of Information (FOI) act of 2000 [93], which allows access to information on the daily workings of public services. However, the information provided may not be complete and non-response can reflect a reluctance to report on gaps in services or other constraints, such as lack of time or staff to respond [94]. Statistics such as waiting times can be misleading due to, for example, closure of referrals and waiting lists once services reach capacity [95].

##### 1.3.1 ADHD service pathways in children

At primary school age, ADHD is diagnosed and treated by Developmental Paediatricians in some regions or CAMHS in others; at secondary school-age it is usually managed through generic mental health services for children and young people (Community Child Health [CCH] or CAMHS); in older teenagers and in adulthood the service is provided by specialist ADHD services or Adult Mental Health Services (AMHS) with expertise in ADHD. After diagnosis and treatment titration (where indicated) in secondary care, clinical care is often, but not always, transferred back to primary health through shared care protocols. Where this is the case, GPs assume responsibility for prescribing and providing routine physical check-ups, whilst annual reviews of ADHD medication and treatment are then recommended by ADHD specialists [55].

A report from the Education Policy Institute using data from FOI requests from CAMHS Services revealed a ‘postcode lottery’ for access to general mental healthcare. Median waiting times ranged from one day to 6 months and there was broad variation in the rates of referral rejection, with specialist mental health services rejecting referrals from as many as one in four children (24.2 per cent) in 2017/18 [48]. The most common justification for rejection was that the referred mental health conditions were not serious enough to meet the eligibility criteria for treatment, which included young people who had self-harmed or experienced abuse. Whilst these statistics do not reflect wait times and rejection rates for ADHD in particular, they highlight problems with mental health provision across CAMHS. Long waiting times were also reported in a 2016 survey by the Royal College of Paediatrics and Child Health. They reported that the average time from referral to diagnosis for ADHD exceeded 6 months for Community Child Health teams [49, 50].

The consensus group discussed the erratic way in which exclusionary criteria from service provision is applied. From the experience of the consensus group, some services only accept children and young people with ADHD when a patient presents with comorbidity, with some services only accepting those presenting with acute comorbidity (such as self-harming behaviours, eating disorders). Charity representatives spoke of instances when access to services had been declined to children as young as 14 years due to waiting lists that were so long the child would exceed the age cut-off for the service before they were seen. The effect of these policies is that vulnerable young people and families seeking support are turned away.

##### 1.3.2 ADHD service pathways in adults

Evidence suggests a similar postcode lottery for access to adult ADHD services, albeit with even longer waiting lists. A national survey found patchy provision of services for adults with ADHD [94], and services simply did not exist in some local areas. In regions without ADHD specialist services, individuals should by right under the NHS Constitution be able to access these services elsewhere [96, 97], however service commissioners may delay or refuse to fund out-of-area ADHD treatment [98] (Figure 2). As a result of these obstacles, some people with ADHD are left in limbo, unable to access clinical care or social support, and unable to benefit from certain legal rights and support systems associated with their disability.



Figure 2: Successful and unsuccessful pathways to Adult ADHD treatment initiation and maintenance showing the interaction between NHS bodies and services, voluntary and charitable organisations and private health services. Shared care arrangements are shown on a dark green background. Note that in the experience of the consensus group, shared care between NHS and private practices (red dashed line) are infrequently supported. NHS, National Health Services.

Clinical Commissioning Groups (CCGs) are regional bodies of the NHS, which allocate, plan and provide services for populations within specific service regions. A review of ADHD provision in CCGs in England was undertaken in 2018 with FOI requests by Takeda pharmaceuticals and the report was supported and endorsed by the charity the ADHD Foundation [99]. This report revealed a lack of oversight for demographic need for ADHD services by CCGs: only around one-third of CCG respondents provided information about waiting times or budget spent on ADHD services. Less than one-third gave an estimate of the number of ADHD patients for whom they commissioned services. Where information was provided regarding the average wait time from referral to assessment, this spanned from 3 months to 3.8 years. In response to specific questions about waiting times, out of the 174 CCG’s contacted only 16 provided a mean waiting time and this averaged 14 months. Similar problems were reported in a patient survey completed by the charity ADHD Action [90], which describes that over half of adults diagnosed with ADHD waited at least 7 months for a diagnosis, and many for several years. Wait lists of up to 7 years in some parts of the country were described, with many areas having no services at all.

Internal reports from NHS governing bodies in certain parts of the country show the tensions that arise between the desire to reduce long patient waiting times, and likely additional costs from increased service investment and resultant increased prescription rates [100, 101]. These health economic decisions may effectively paralyse progress in terms of increasing service delivery for affected patients. Moreover, these financial constraints within individual services reveal the myopic nature of treatment and commissioning arrangements, particularly with patients with ADHD in whom treatment shortfalls are associated with significantly increased societal and personal costs, and which are likely to be shouldered elsewhere in the health, social care and judicial systems.

#### 1.4 Barriers to treatment

NICE guidelines emphasise the importance ﻿of recognition of ADHD, diagnosis and treatment, continuity of care, and ensuring that people with ADHD have a comprehensive, holistic shared treatment plan that addresses psychological, behavioural and occupational or educational needs [55]. However, access to treatment is not always straightforward, even for those who are already diagnosed. The consensus group identified four key areas of concern, outlined below.

##### 1.4.1 Lost in transition

Transition in healthcare refers to the process of transferring the clinical care of a patient from child to adult services, which occurs by the age of 18 years in most cases. There are multiple possible transition pathways in the NHS which vary regionally. These pathways include referral to AMHS, to specialist ADHD services or back to GPs in primary care.

NICE guidelines recommend that young people with ADHD receiving treatment from CAMHS or paediatric services should be assessed at transition age, and then if needed transferred to adult services, where they should be re-assessed [55]. Transfer of care should occur alongside a handover of full information, formal meetings between child and adult services, with planning of transition including the young person [55]. Specific guidance is available regarding the Implementation of NICE guidelines to achieve successful transition between services for young people with ADHD [103, 104]. However, in practice NICE guidelines on transition are often not implemented due to resource and time constraints and the multiple structural and organisational barriers in which service providers operate [89, 105, 106].

Transition takes place at a critical juncture in young people’s lives, where they may be completing schooling, or moving into higher education or employment. There are understandable concerns about the effects of sudden treatment cessation due to ineffective transition on their educational and/or occupational outcomes [107, 108]. One study of prescribing rates showed that rates of primary care prescribing of ADHD medication for young people in the UK declined more steeply than expected given the rate of symptom reduction from follow-up studies – suggesting that some may experience cessation of medication due to a change of services rather than due to symptoms declining [109]. The consensus group noted that treatment cessation can also arise because adolescents often disengage with treatment but then need further support when there are continued problems.

Young people with ADHD are likely to be discharged or lost to follow-up during transition [110], because there is no adult service to refer them to, they do not meet adult service criteria for severity or impairment, lack of knowledge or resources for treating ADHD within available services, or because the young person fails to attend their first appointment post transition [89, 105, 111–113]. Adult services often have ‘stricter’ policies around missing appointments than child services, and without support (for example from parents/carers), the change of culture may mean they miss appointments and are consequently discharged. Some child services do not discharge their transitioning patient until after they have been seen by adult ADHD clinics, so that if the patient fails to attend their first appointment after transition, the child services can help encourage the patient to attend. In cases where treatment is stopped during adolescent years, the consensus group noted that it can be difficult for young people to restart treatment where adult services do not exist or have long waiting lists.

When transition to adult ADHD services is unsuccessful, child mental health services may be left with the responsibility of continuing care, further decreasing their capacity to respond to new referrals [114]. In other instances, prescribing may fall to GPs who often have reasonable concerns about taking responsibility for an unfamiliar treatment, without specialist oversight as recommended in NICE guidelines, and may refuse to do so (see section 1.4.3). As a result, young people with ADHD may suddenly and unexpectedly lose access to their usual treatments during transition.

##### 1.4.2 Lost in communication

NICE guidelines state that ADHD diagnosis and medication initiation and titration should be conducted by a specialist in ADHD [55]. Once patients have been stabilised on medication, treatment can be managed and monitored jointly with primary care, under a shared care protocol. Specialist review is recommended on an annual basis, but routine check-ups and prescribing can be completed in primary health. This frees up capacity within secondary health services, allowing them to take on new referrals and manage more complicated cases.

However, often shared care arrangements fall apart, seriously disadvantaging patients caught in the middle. This can be due to lack of agreement or inadequate communication, or where primary care practitioners are concerned about assuming responsibility for an unfamiliar treatment [115]. Insufficient support from secondary health may undermine continuity of care for affected patients. For example, a Royal College of Paediatrics and Child Health report published in 2017 showed that only 11.4% of CCH services could always see ADHD patients when follow-up was due, and 60% could do so no more than half the time, raising issues of medication safety [50].

Primary care practitioners may feel that ADHD symptom monitoring is not in their remit, and some believe that prescribing for ADHD should not be carried out by primary care [92, 116]. Reasons for not prescribing include concerns regarding the diagnosis, the unavailability of non-pharmacological treatment, and potential inadequacy of physical monitoring in secondary care [116]. Primary care physicians may lack confidence in managing ADHD treatment, due to knowledge limitations, insufficient training and due to poor communication from specialist services [117]. In a survey of 150 General Practitioners (GPs), 64% felt that they would be likely to change their views on prescribing with clearer advice from specialists, and 67% stated that they would be influence if there was a clear protocol for monitoring a child on medication [117].

Problems with shared care may lead to patients navigating a complex system of referral for assessment, obtaining a diagnosis and initiating treatments under a specialist (sometimes after many years of seeking treatment), and then having their treatment denied during failure of shared care. These circumstances are highly distressing to the individual and their families. Transition between services is also a key point of vulnerability for shared care arrangements. In some regions, ADHD services for children are supported entirely by CAMHS without involvement of primary care services. On transition, primary care providers are suddenly expected to take over the unfamiliar role of long-term routine monitoring of ADHD medication in these same patients.

As well as posing a risk to the safety, health and wellbeing of patients, breakdown of treatment provision due to failure of shared care represents a waste of health resources that are already in short supply.

##### 1.4.3 Non-pharmacological treatment

Pharmacotherapy for ADHD as a standalone treatment is unlikely to fully address the needs and impairments associated with ADHD [118]. It does not provide direct support for common problems associated with ADHD, such as psychosocial, emotional and peer problems, behavioural difficulties and other comorbid conditions. A range of non-pharmacological approaches may be helpful working in cooperation with patients themselves, schools, parents/carers, educational and/or workplace settings. These include (provided in individual and/or group format) cognitive behavioural therapy (CBT), psychoeducation, parent mediated/training interventions, school/classroom interventions and occupational therapy [118]. Commissioners and healthcare practitioners usually recognise the value of multimodal treatments consisting of non-pharmacological interventions alongside medication [119], but psychological therapies for ADHD are often not implemented because they are considered to be expensive, because they are in short supply or are simply not available.

For children and young people, treatment options are often rigid in nature, and not tailored to patients’ needs. Parent training interventions are the main (and sometimes only) option. Most parent/carer training interventions have been developed to address behaviour, conduct or oppositional problems in children. These interventions are not always appropriate for supporting the needs of people with ADHD and primarily inattentive symptoms and/or subtler difficulties, or older children and adolescents who require more direct support.

Psychological interventions are only rarely available for adults with ADHD, and medication is often the only treatment offered. A recent mapping study found that only 12 out of 44 dedicated adult ADHD services (27%) provided the full range of treatments recommended by the National Institute for Health and Care Excellence including psychological therapy [120]. The consensus group noted that adults with ADHD may be more likely to be offered non-pharmacological treatments for coexisting conditions, although these frequently do not take ADHD and its associated difficulties into account.

#### Plugging the gaps

When faced with extremely long waiting times, patchy and unavailable services, and blame or dismissal, affected individuals and their families may turn to other services and sectors to gain the support they need (see figure 2).

Charitable and other support organisations provide a range of invaluable non-clinical services for people with ADHD at low cost or free of charge. These services include: information dissemination, signposting, peer and social support, friendship and preventing loneliness, coaching and psychoeducation, group and family therapy, and parenting programmes. Their websites provide access to freely available curated resources and/or help to direct people to relevant tools and support information. Services are not regulated however, and availability, resources and expertise vary considerably between areas and organisations, giving uneven coverage across the UK.

Support group representatives at the consensus meeting reported that patients are seeking out (and in some cases being actively directed to) local or national support groups for help. Informal referrals from the NHS led them to feel like a “secondary NHS” service, inundated with support requests that they felt ill-equipped an unqualified to fulfil. Their staff do not have the training or expertise to support extremely complex, vulnerable, distressed and at times suicidal individuals with ADHD, for whom help from clinical health services is being delayed or refused.

Some affected individuals and families are driven to seek out costly private clinical services [32]. For many, private treatment is not an option for financial reasons. This leads to a 2-tier health service, unfairly penalising lower income families and patients, and leading to a gap in provision for those likely to be the most vulnerable. Clinical assessments can be costly, and so too titration appointments, prescriptions obtained from private services and non-pharmacological services. These can become unaffordable in the longer-term even for middle income patients and families, particularly for those with more complex clinical presentation and treatment needs.

Patients and families may therefore seek ADHD assessment in private clinics in order to circumvent gaps or blockages in access to care, before returning to the NHS in the hope of reintegrating into public healthcare provision (e.g. figure 2). However, there is an absence of transparency regarding the expertise in ADHD and the quality of care provided in the private sector. NHS providers may have reasonable concerns regarding the validity of certain privately formulated diagnoses, which may leave NHS providers with no choice but to refuse treatment, leaving affected patients confused, as well as unable to continue to access the support that they need.

Concerns around the quality of assessments were an area of serious debate during the consensus meeting. Consensus participants (including private and NHS clinicians, stakeholders and support group representatives) reported problems with private healthcare providers capitalising on the desperation of patients who feel let down by the public healthcare system. The upshot is that some patients seeking out private services for ADHD do not receive appropriate assessments or treatment that follow national clinical guidelines. Consensus participants reported cases where patients arrive at NHS services with reports diagnosing ADHD written by assessors who do not have clinical qualifications and/or who are not registered with a UK health regulator (e.g. Health and Care Professionals Council, General Medical Council). In other cases, reports were provided without the required in-depth examination, making it impossible to establish whether patients were indeed suffering from ADHD.

### Recommendations

The consensus group identified essential changes that can and should be made to improve access and streamline service delivery to improve outcomes for people affected by ADHD. Solutions include training and education across all sectors, improving resource allocation, funding and commissioning for mental health and ADHD, and revising models of care to improve access to treatment and better joining up services, and broadening access to non-pharmacological treatments.

#### 2.1 Training and education across all sectors

Access to evidence-based training will address awareness and attitudes of key professional groups in the public sector and improve recognition and support of individuals with ADHD. Ideally, this should reach all healthcare professionals (including primary care providers), educational professionals, youth centre employees, social workers and those working with prisoners or youth offenders.

Training should incorporate heterogeneity of ADHD (described in section 1.1), to improve detection of more subtle presentations. Key professionals need to be informed of the biological and medical evidence to help shift blame away from parenting and the home environment. An emphasis on longer-term outcomes of effective treatment may help to reduce the perception that those seeking ADHD treatment are looking for a ‘quick fix’.

A model of ADHD training for educational professionals should be developed for schools and higher education institutions to improve referrals from the education sector. Where possible, educational psychologists or mental health professionals working in schools should be engaged to assist with development and implementation of training.

Awareness of ADHD also needs to increase within both further education and occupational settings to improve access to resources for people with ADHD. Many employers now have a good understanding of hidden disability and are likely to follow Advisory, Conciliation and Arbitration Service (ACAS) guidance on neurodiversity. People with a diagnosis of ADHD have the right to benefit from reasonable adjustments to the workplace and in education as specified under UK Equality Act 2010 [121]. Knowledge of government initiatives, such as Access to Work [122], can support the implementation of these adjustments to improve the lives and success of people with ADHD within these environments. Job centre employees should also be made aware of ADHD and potential support through government initiatives such as the Specialist Employability Support [123] and the Work and Health programme [124] which can facilitate access to a support worker or professional strategy coach.

#### 2.2 Improving consistency in diagnosis and treatment

Consensus meeting discussions highlighted the importance of regulating private ADHD practices to improve consistency of ADHD diagnosis and treatment, and to ensure adequate qualification of providers. The Care Quality Commission in the UK monitors, inspects and regulates healthcare services, including private and NHS healthcare services. Inspection reports can provide an initial overview of the quality of individual private services that have been inspected, and these are publicly available and downloadable on their website.

The consensus group also noted varying quality in ADHD assessments within the NHS, albeit to a lesser extent. There is a need for all services to meet specific minimum standards for diagnostic assessment (see table 1 for minimum standards agreed by the consensus group). Adhering to these minimum diagnostic standards may help to validate ADHD diagnosis obtained in private healthcare for those wishing to return to NHS treatment. These standards will also give patients insight into which investigations to expect when attending an assessment for ADHD at a private clinic, an understanding what to expect from their diagnostic report, and confidence in their diagnosis. These fundamental criteria should be disseminated amongst patient groups to ensure that patients receive a valid assessment.

#### 2.3 Empowering primary and secondary care in the management of adult ADHD

The consensus group agreed that competency in ADHD should ideally occur alongside competency for other common mental health conditions. Those who are able to diagnose and treat common mental health conditions such as anxiety and depression should and must also know about ADHD, not only because ADHD is a common mental health disorder but also because there is so much overlap and missed diagnosis is common. Better recognition of ADHD by professionals treating common mental health conditions may help to improve treatment quality and effectiveness. Further, the viewpoint of the group was that for clinicians already diagnosing and treating anxiety and depression, concurrent assessment and treatment for ADHD (where appropriate) would improve the targeting of treatments, lead to better outcomes, and reduce patient and clinical burden in those patients where ADHD diagnosis and treatment had been missed.

Assessment and treatment of adult ADHD is not always incorporated into generic adult mental health services. In NICE guidelines, an ADHD specialist is defined as a “psychiatrist or paediatrician or other appropriately qualified healthcare professional with training and expertise in the diagnosis of ADHD” [125]. This means that a broad range of mental health professionals can and should, with adequate training, acquire the necessary knowledge of ADHD to support its assessment and treatment. These can include professionals from primary, secondary or tertiary care sectors, with psychiatry, medical (including general practice), clinical psychology and mental health nursing qualifications. Some healthcare professionals, such as clinical psychologists, are qualified only to make clinical diagnoses but not for medical treatment management. Due to the high prevalence of ADHD, the consensus group was in broad agreement that there should be adequate knowledge and specialism of ADHD within all secondary mental health practices, as there is for other common mental health conditions.

Primary care physicians already have an important role in raising suspicion for a possible diagnosis, making a timely referral and helping with monitoring and continuation of prescription under a shared care protocol. Overall, the group was in agreement that a level of competence in the recognition and understanding of ADHD was key, as well as clear pathways to more specialist support. Providing and encouraging primary care practitioners in training on ADHD was considered to be an important first step, and encouraging some GPs and practice nurses in special interest training was considered practical and sustainable for improving expertise in in primary care in the first instance.

In the longer term, integration of ADHD into broader mental healthcare provision in primary care would be required to further streamline provision and remove bottlenecks. However, this arrangement has implications for GP workloads [117], and would require additional workforce management, staff and resource provision within primary healthcare. The new Primary Care Network model, described in the NHS Long Term Plan in 2019 [126], aims to pool expertise at a primary care level within local areas. Primary care at scale, with practices joining together to pool expertise and resources in larger primary care networks with 30,000–50,000 patients, may help to address implications for workforce management and resource provision.

#### 2.4 Joining up services

We have shown a disjoint between primary and secondary care, and child and adult services, which leaves patients with ADHD unable to access or maintain treatment. Improved communication is key to joining up services. When primary care services are asked to take over prescribing from secondary health providers there needs to be support and guidance available for treating clinicians, with specialist advice readily available. Examples of integrated care between GPs and specialist services for chronic illnesses such as heart failure have been reported previously, resulting in improved coordination, GPs feeling more confident in supporting their patients, and specialists receiving more detailed feedback from primary care, and patients themselves benefiting from more streamlined and holistic care [127].

Longer-term, specialist key workers within primary care networks, as described above, could help to close the gap in accessing diagnostic and intervention services, and liaise with and between secondary care services and psychological services as needed to provide the correct intensity of support and the required continuity of care.

#### 2.4 Improving access to non-pharmacological treatment

The consensus group agreed that access to non-pharmacological treatment should be improved for patients with ADHD. Treatment options for people affected by ADHD should include a broader range of non-pharmacological interventions, tailored to their developmental age and needs.

In accord with NICE guidelines, the group emphasised the importance of access to high-quality psychoeducation for everyone with a new diagnosis of ADHD and their families. Psychoeducation should be tiered based on severity and complexity of patient needs and factor in comorbidities. Evidence to date suggests that psychoeducation may help to give patients and families a foundation of understanding of their ADHD and associated needs, and improve clinical and subjective outcomes as well as medication adherence [128].

In children, parent training interventions are the main non-pharmacological treatment available for NHS-treated children and young people. However, Many parent training programmes have been primarily developed for children with externalising and conduct problems [129], they are less likely to meet the needs of teenagers and young people with ADHD [118], and those with inattentive symptoms or subtler or more nuanced difficulties. Additional age-appropriate psychological interventions (including psychoeducation and therapeutic approaches) should be made available for young people.

Psychological interventions are only rarely available for adults with ADHD, and this too should be changed. Psychosocial support in adults should address difficulties experienced by adults with ADHD (educational and employment problems, interpersonal difficulties, involvement with the criminal justice service, comorbid conditions such as anxiety and depression). Services such as IAPT (Improving Access to Psychological Therapies; [130]), which provide psychological therapies for adults with anxiety and depression in the community, could be useful resources if opened up or adapted for adults with ADHD.

#### 2.5 Funding and commissioning for ADHD

ADHD is a common mental health condition [9]. However, this stands in contrast to the clinical provision model, where diagnosis, treatment initiation and monitoring is frequently constrained to scarce and limited capacity specialist health resources. The combination of the high prevalence of ADHD with the relative paucity of services, means that many people with ADHD experience barriers in their access to care or long waiting times before accessing the care they need. The experience of the consensus group was that services struggle with the capacity versus demand conundrum, and that many service providers are passionate about providing the best support that circumstances and local commissioning parameters allow.

The rights of people with ADHD are supported by the UK Equality Act [121]. Clear guidance on clinical practice to support healthcare in ADHD is spelled out in national clinical guidelines. However, unfortunately clinical guidelines currently appear to reflect the best-case scenario rather than the standard for treatment delivery. They have not hindered people in key positions for referral, diagnosis and service commissioning from denying access to treatment and support to affected individuals. It is also clear that some CCGs are not commissioning adequate neurodevelopmental services for ADHD, and are therefore disregarding clinical evidence, national clinical guidelines, and their legal duty to prevent health inequality. This problem is most clearly shown for adults with ADHD, for whom services are simply not available in certain regions, and to whom access to NHS services in other areas is not being made available. In order for UK-wide clinical guidelines to be meaningful, and effectively implemented, funding and service development needs to increase to meet the burden of illness.

The fragmentation of funding across public services in the UK means that it can be difficult to convince health commissioners to see ADHD treatment as a broader investment in health, education, social services, the criminal justice system and the economy in general. Longer-term benefits are also a hard sell for commissioners who work towards a fixed annual budget, with competing needs from different mental health groups and services that are already over-stretched. A report by the Kings Fund examines the relationship between quality improvement and cost savings. In some cases, improving the quality of services can help to make these more effective and in turn help to reduce costs. In other instances the relationship between quality improvement and cost is spread more widely across the health and social system and over time, and this can make it difficult to tangibly measure any cost savings associated with higher quality interventions [131]. Commissioners need to be informed on the robust evidence for the long-term negative outcomes associated with ADHD (especially if untreated) and their economic implications [31, 132].

Long-term planning of funding as is now implemented in certain regions in the UK, rather than year-on-year budgeting may help to circumvent problems arising from ‘short-termism’ of care. Joined-up commissioning between state-funded health, social services and judicial services can help to reduce fragmentation of care and cost burdens.

The rights of people with ADHD in the UK are protected under the Human Rights Act 1998 (article 14: right to non-discrimination), and further under the UK Equality Act 2010, which protects people with a disability (including ADHD). People with ADHD also have rights under the Public Sector Equality Duty in England, Scotland and Wales, which places an obligation on public authorities to positively promote equality, not merely to avoid discrimination. Unfortunately, certain CCGs are ignoring these legislative rights. The group noted that in part, they are able to ignore their legal duties because their system of accountability is complex, and it is not particularly easy to file formal complaints and follow them through. However, these legislative duties and responsibilities can be leveraged to overcome the rationale used by CCGs for underfunding ADHD services, a tactic that has had some success in some parts of the country.

## OVERVIEW

ADHD is not rare. It is the most highly prevalent childhood condition. Worldwide estimates indicate it affects 5-7% of the child and adolescent population [5–7] and 2-4% of the adult population [8, 9]. There is robust evidence for negative health and social outcomes, including a strong association with accidental fatalities [15]. Yet many young people and adults are not able to obtain a timely diagnosis and treatment. Clinical guidelines are not being implemented and there is huge variation in the commissioning of ADHD services across the UK. Without the commissioning of adequate services, we are failing those who need them.

The greatest barrier to services for people with ADHD is lack of awareness and stigma associated with the ADHD diagnosis. From the patient perspective, stigma and lack of recognition create a barrier to recognition and access to treatment and support systems through the inaction and lack of support from referral gatekeepers and health professionals. From a commissioning and service delivery standpoint, lack of understanding and stigma constrict allocation funding and resources. As the current report shows, prejudice and lack of understanding influence ADHD provision on all levels of the healthcare system, resulting in a de-prioritisation of ADHD and its treatment. This also has an effect on the health and wellbeing of patients and their families who struggle to access the support they are entitled too and face ill-placed blame. Delays and inability to obtain treatment lead to increasing psychosocial burden and impairment.

Most importantly, we need to end acceptance of stigma against people with ADHD as a valid viewpoint in the healthcare sector. The growing strength of vocal and active support groups and charities across the country have provided an emergent patient voice and, together with the dissemination of ADHD-relevant information across news outlets [133–136], public visibility of the condition has improved. Widely publicised reports produced by, or in association with, these charities and support groups have also helped to raise the profile of ADHD and associated problems [32, 99, 137], and positively influence the nature of reporting around the condition.

We should now be looking towards improving access to treatment for children and adults who are affected by ADHD. Information provision and training for key professional groups could lead to more timely and appropriate referrals, assessment and treatment. Reducing stigma and increasing understanding of ADHD, its aetiology, long-term outcomes and the benefits of treatment, may help to improve understanding and increase referrals to clinical services.

Whilst the rights of individuals with ADHD are strong under current UK legislation and existing clinical guidelines, accountability of services and service commissioners to these rights and guidelines is uneven. Greater regulatory and legislative support for ADHD could go a long way towards reducing stigma and opening up pathways to healthcare and support. In the previous parliament an All-Party Parliamentary Group for ADHD met on several occasions [138] and was met with some interest from politicians. Whilst this provided a positive platform to debate the issues and demonstrate their importance to society and policy there have yet to be any tangible outcomes. In 2017 the charity ADHD Action called upon the Government to pass an ADHD Act (similar to the Autism Act) that would meet the needs of adults and children with ADHD [139]. Their petition received 11,806 signatures but was not supported by the government. Another petition was recently launched [140], currently reaching over 9,000 signatures.

However, legislation and regulation alone will not ease the problems of overly complex, overstretched and fragmented services. The current report recommends specific changes to service delivery and training of healthcare staff. Mainstreaming ADHD provision into general adult mental health services, and introducing new expertise within primary care across child and adult ADHD healthcare provision can help to improve detection, take the pressure away from over-stretched specialist services, and enhance communication throughout the healthcare system. Enhancing information flow between primary and secondary care services, and child and adult services can help to reduce the likelihood that diagnosed patients find themselves falling between the edges of service boundaries and finding themselves unable to access the treatment and services they need.

Whilst implementing the above recommendations will entail costs to the UK healthcare system in the short term, economic analyses indicate that leaving ADHD untreated or undetected is not a cost-saving exercise. Evidence suggests delays in effective treatment lead to high long-term personal and public costs, including reduced economic productivity, and increased health, social care and state benefit costs [31, 32]. Further investment in mental health is required to support the services which are groaning under the weight of demand. Mental health problems represent a large proportion of the global burden of illness [141]. In the UK depression alone is one of the top five contributors to disability adjusted life-years (DALYs) [142]. A 2016 report from the independent Mental Health Taskforce to the NHS in England describes that mental health services have been chronically underfunded, and calls for parity of esteem between physical and mental health conditions [143]. What we see for ADHD is a further lack of parity with other mental health conditions, meaning that the limited resources for mental health are often simply not available at all, and this needs be rectified.

As we move towards resuming mental health services in the post COVID-19 era, we must now look to how we can improve access and treatment in the future. Guidelines now exist on ADHD management and treatment initiation during the COVID-19 pandemic [54, 144]. Much can be achieved at distance using digital applications and social media, which can help clinics to resume patient contact, assessment and treatment monitoring. However, these are merely short-term solutions that alleviate problems at the tip of the iceberg. Much larger changes, in terms of workforce education, service delivery modelling and financial investment are needed to resolve the broader issues described.

**Declarations:**

**Ethics (and Consent to Participate)**

Not applicable.

**Consent for Publication**

Not applicable

**Availability of data and materials**

The data that support the findings of the more detailed analysis of the FOI report ‘Will the doctor see me now: Investigating adult ADHD services in England.’ are available from Takeda Pharmaceutical but restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are however available from the authors upon reasonable request and with permission of Takeda. No other datasets were generated or analysed during the current study.

**Competing Interests**

In the last 5 years: SY has received honoraria for consultancy and educational talks years from Janssen, HB Pharma and/or Shire. She is author of the ADHD Child Evaluation (ACE) and ACE+ for adults; and lead author of R&R2 for ADHD Youths and Adults. PH has received honoraria for consultancy and educational talks in the last 5 years from Shire, Janssen and Flynn. He has acted as an expert witness for Lilly. PM has received honoraria for consultancy and educational talks from Shire, Takeda and Flynn Pharma KvR has received honoraria for educational talks from Shire, Lilly, Janssen and Flynn. In addition, SY, SC, PB, WC, PH, PM and EW are affiliated on a full-time basis with consultancy firms/private practices. CJ has provided educational talks for Lilly and Janssen. MP reports honoraria for talks and advisory board participation, and travel support for conference attendance, from Shire/Takeda & Flynn Pharma. CS is employed by Cambridge Cognition. TND reports travel and consultation fee paid for attendance at Transition into Adulthood ADHD (TiAA) Advisory Board Meeting hosted by Shire, October 2018. BZ reports paid lectures for Flynn Pharma and working in private sector in ADDmire Clinic. MArif has received sponsorships to educational/scientific meetings and honoraria for consultancy and educational talks from Janssen, Lily, Takeda (Shire), and Flynn-pharma.The remaining authors have no disclosures.

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**Authors’ Contributions**

SY, PA and TL were responsible for the planning and scientific input of this consensus statement. All authors (except CS, AL) attended the consensus meeting. CS completed the first draft of the manuscript. It was revised by SY who consulted with authors about specific points. A second draft was then generated and circulated to all authors for comment. Following further amendments, the final draft was circulated for comment and endorsement of the consensus. All authors have read and approved the final manuscript.

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**Abbreviations**

ACAS - Advisory, Conciliation and Arbitration Service

ADHD – Attention-Deficit/Hyperactivity Disorder

AMHS – Adult Mental Health Services

ASD – Autism Spectrum Disorders

CAMHS – Child and Adolescent Mental Health Services

CBT – Cognitive Behavioural Therapy

CCH – Community Child Health

CCG – Clinical Commissioning Group

CQC – Care Quality Commission

DSM – Diagnostic and Statistical Manual of Mental Disorders

EHPC - Education Health and Care Plans

FOI – Freedom Of Information

GP – General Practitioner

GPSI – General Practitioner with Special Interest

IAPT - Improving Access to Psychological Therapies

ICD – International Classification of Disease

IQ – Intelligence Quotient

NHS – National Health Service

NICE – National Institute for Health and Care Excellence

UK – United Kingdom

UKAP – UK ADHD Partnership

UKAAN – UK Adult ADHD Network

SIGN - Scottish Intercollegiate Guidelines Network

**Table 1: minimum standards for ADHD assessment and report:**

ADHD diagnostic assessments should be of an adequate length to cover all aspects described below and provide detail and generate examples of behaviours or problems. The clinician completing the assessment should be highly familiar with and/or specialise in ADHD but will require specialism beyond ADHD to identify comorbidities and complexities. A thorough ADHD assessment can take up to 3 hours. Patients should not usually expect to receive their diagnostic report on the same day as their assessment.

*Assessments should include:*

* Structured clinical interview according to up-to-date DSM or ICD publications, including:
	+ Developmental history
	+ Medical and physical health history
	+ General psychiatric history
	+ Family history
	+ Mental state examination
	+ Educational/occupational history
	+ Impairments
	+ Exploration of potential comorbid problems/differential diagnosis
	+ Risk assessment
* Collateral information to inform assessment, if available e.g. rating scales, objective information from informants (including schools), school and/or other objective reports, and cognitive test results (for example, the QBTest [145]or CPT [146]).
* Mental state examination
* Physical assessment: physical observation, pulse, blood pressure, height and weight and referral for other types of physical examination if indicated.

*Diagnostic reports should include:*

* Description of diagnostic assessment completed (e.g. measures, corroborating information)
* Clear diagnosis and formulation.
* Outline of symptoms and impairments
* Coexisting diagnosis and associated problems
* Risks
* An outline of strengths in the assessment report
* Individualised recommendations, including treatment plans (pharmacological, non-pharmacological, multi-agency liaison).
* Contact details for local service-user support services

**Table 2: Overview and recommendations**

* Clinical provision for ADHD fails to meet national clinical recommendations in the UK, there is an urgent need to tackle the underlying structural, social and economic restrictions that de-prioritise mental health and ADHD in healthcare.
* Stigma with regards to ADHD is perpetuated by misinformation and misunderstanding. Training for ADHD should be provided across disciplines and sectors. Professional bodies need to better support member needs regarding ADHD support and treatment with training opportunities and/or formal practice guidance.
* Short-termism and fragmentation of funding reduce the likelihood of a ‘whole person’ approach, and disregard the longer-term deleterious effects of long waiting lists. Cost-effectiveness of treatment are likely to be seen in the context of longer-term planning and budgeting. Devolving of health and social care within one budget may help to reduce service fragmentation.
* Fragmentation of care undermines access to treatment for those who need it, leading to wasted resources and expenditure where patients drop out from care due to failures of communication between components of the healthcare sector. Additional efforts and investment are needed to join up components of service delivery (e.g. from child to adult services, and between secondary and primary health).
* Current healthcare provision for ADHD in the UK is overly complex, and regionally variable. We need to look towards new models of care to provide more streamlined and effective neurodevelopmental services.
* Due to its high prevalence, adult ADHD should be mainstreamed into secondary care, and ADHD should be viewed as part of common adult mental health, rather than a specialist diagnosis. Reinforcement from primary care is likely to be needed to support treatment in the longer-term.
* Future research should include:
	+ Health economic analyses to verify the longer-term health, social and economic benefits of ADHD treatment in the UK
	+ Costs and economic outcomes for missed appointments in people with ADHD within the NHS, Long-term outcomes of patients discharged from ADHD services with some focus on how they have accessed serviced and their journey through service
	+ Prevalence rates of undiagnosed and untreated ADHD within primary care and pupil referral units
	+ Effects of early versus later interventions in ADHD, to determine the need for early intervention services
	+ Qualitative data to track patient journeys: “What was your life like before and then after your diagnosis and treatment?”
	+ Research and audit of provisions in the private sector

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