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Understanding ADHD Care: Exploring Assessment Waiting Times, NICE Recommendations and Care Pathways in the UK and RoI

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This paper provides an overview of ADHD in the UK and the Republic of Ireland, including prevalence rates among children and adults. The paper explores the challenges that recent increases in demand for ADHD services present for service providers and patients, the extent of delays in accessing an ADHD assessment, developments in NICE guidance, and recent developments in diagnosis and treatment policies.

This information is provided to Members of the Legislative Assembly (MLAs) in support of their duties, and is not intended to address the specific circumstances of any particular individual. It should not be relied upon as professional legal advice, or as a substitute for it.

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Key Points

Attention-deficit/hyperactivity disorder (ADHD) was, until recently, perceived as only present in young people, with little or no impact later in life. In reality, ADHD can be a debilitating neurodevelopmental disorder that often persists beyond childhood in a significant number of patients.

Prevalence data that is available for the UK suggests a significant rise in adults presenting with the condition in recent years, particularly since the COVID-19 pandemic. However, there is also evidence to suggest that the upward trend predates the pandemic.

Gaining a clear understanding of ADHD service provision across the UK and RoI is challenging due to differences in health service organisation by region. However, a recurring finding from research that has attempted to map ADHD service delivery for children and adults suggests that there is a postcode lottery concerning both access to and availability of diagnosis and treatment services across the regions.

Moreover, while NICE guidance on ADHD offers a blueprint for what effective care and support should entail throughout the ADHD care pathway, available research suggests that it is seldom fully implemented.

Current waiting times across the UK for an ADHD diagnosis are indicative of a system under pressure. In Northern Ireland, Belfast HSC Trust level data indicates that the longest current wait for an adult ADHD assessment is eight years and the longest current wait for a child is five years. Although these figures are at the extreme end of reported waiting times, the data presented in this briefing paper suggests that the majority of children and adults in NI are waiting unduly long times for a diagnostic assessment. This trend is reflected in waiting times across the UK.

In Northern Ireland, there are no commissioned services for adult ADHD services and, as with child ADHD services, any provision that is available has grown organically in response to growing need. The Southern, Belfast and South Eastern Trusts suggest that their services struggle to comply with NICE guidelines.

The escalating problem of ADHD waiting times has been exacerbated by a lack of specific targets for these waiting times and the absence of routinely collected national data. Stakeholders have proposed integrating a national target for starting diagnostic assessments within three months into NICE guidelines and developing data collection systems to monitor compliance with targets.

Mental Health professionals, patients and families have stressed the urgent need for change, emphasising that while efficiency improvements and alternative service models may help, substantial progress will only come with additional funding and a shift in approach.

Recent developments in ADHD diagnosis and treatment in Scotland and Wales signify a shift in approach, departing from solely relying on traditional Child and Adolescent Mental Health Services (CAMHS) and Community Mental Health Teams (CMHTS) to the development of neurodevelopmental assessment pathways.

Research indicates that neurodevelopmental pathways are likely to make better use of resources, significantly reduce assessment costs and improve the experiences of people families engaged in the diagnostic process.

NHS England has also recently announced that it is setting up a taskforce to undertake a review of ADHD services amid concerns about a rise in diagnoses. The purpose of the taskforce is to examine how services can provide a joined-up response improving to ADHD services.

RoI has recently developed a comprehensive model for care for adults with ADHD that is closely aligned with NICE guidelines, however, media reports suggest the model has yet to be fully implemented and there are funding challenges with aspects of the service.

1 The Epidemiology of ADHD

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterised by persistent patterns of inattention, impulsivity, and hyperactivity that can significantly impact daily functioning.

The diagnosis is recognised by the American Psychiatric Association and the World Health Organisation.¹ Historically, ADHD was first diagnosed and treated during childhood; however, recent studies recognise that the core symptoms persist into adulthood in a significant proportion of individuals.² In the UK prevalence of ADHD in adults is estimated to be between 3 and 4%.³ The prevalence of ADHD in children in the UK is estimated to be between 2 and 5%.

The cause of attention deficit hyperactivity disorder (ADHD) is unknown, but it involves the interplay of multiple genetic and environmental factors that are thought to lead to altered brain neurochemistry and structure.⁴

There is substantial evidence for a genetic contribution to ADHD. Family, twin, and adoption studies consistently demonstrate a familial pattern of ADHD.⁵ Environmental factors most strongly associated with ADHD are low birth weight and maternal smoking during pregnancy. Other risk factors include preterm delivery, epilepsy, acquired brain injury, lead exposure, iron deficiency, alcohol exposure during pregnancy, psychosocial adversity, and adverse maternal mental health.⁶

1.1 Prevalence of ADHD: Global and local estimates

Understanding the epidemiology of ADHD is important for service planning, education and resource allocation. However, obtaining prevalence estimates for

¹ Lovett, BJ, et al (2021) [Assessing adult ADHD: new research and perspectives](#). J Clin Exp Neuropsychol 43(4): 333–9.

² Song, P et al (2021) [The prevalence of adult attention-deficit hyperactivity disorder: a global systematic review and meta-analysis](#). J Glob Health 11: 04009

³ [Attention deficit hyperactivity disorder: How common is it?](#) NICE Guidelines

⁴ [Attention deficit hyperactivity disorder: What causes it?](#) NICE Guidelines

⁵ Faraone SV et al (2019) [Genetics of attention deficit hyperactivity disorder](#) Mol Psychiatry. 24(4): 562–575.

⁶ Cited in fn 3

ADHD can be challenging due to several factors. Changes in diagnostic criteria over time, such as updates in diagnostic manuals like the DSM (Diagnostic and Statistical Manual of Mental Disorders) and the ICD (International Classification of Diseases), can influence how ADHD is diagnosed and reported. Furthermore, variations in screening methods, assessment tools, and diagnostic practices across different regions and healthcare systems can affect the consistency of prevalence estimates.⁷

1.1.1 Global prevalence rates

The global prevalence of ADHD in children is estimated to be around 5%.⁸ Studies based on US populations, where rates of diagnosis and treatment tend to be highest, estimate the rate at between 8% and 10%.⁹ Compared with childhood ADHD, adult ADHD is relatively neglected in epidemiological studies. A study in 2020 estimated the global prevalence of persistent adult ADHD from childhood and that of symptomatic adult ADHD to be 2% and 6%, respectively.¹⁰

1.1.2 Prevalence rates in the UK

In the UK, national healthcare data on ADHD rates, in particular adult rates, has been limited and in some cases, nonexistent. Nevertheless, the prevalence of ADHD in children in the UK is estimated to be between 2 and 5%. For example, a study published in the *Journal of Attention Disorders* in 2018 found that approximately 3.4% of children aged 5-15 in the UK were diagnosed with ADHD.¹¹

Prevalence of ADHD in adults in the UK is estimated to be between 3% and 4%.¹²

⁷ McKechnie DGJ (2023) [Attention-deficit hyperactivity disorder diagnoses and prescriptions in UK primary care, 2000–2018: population-based cohort study](#). *BJPsych Open*. 9(4):e121

⁸ Salari N (2023) [The global prevalence of ADHD in children and adolescents: a systematic review and meta-analysis](#) *Ital J Pediatr* 20;49(1):48.

⁹ [Attention deficit hyperactivity disorder: How common is it?](#) NICE Guidelines

¹⁰ Song P, et al (2021) [The prevalence of adult attention-deficit hyperactivity disorder: A global systematic review and meta-analysis](#) *J Glob Health*. 2021 Feb 11;11:04009

¹¹ Hire, AJ, Ashcroft, DM, Springate, DA, Steinke, DT. [ADHD in the United Kingdom: regional and socioeconomic variations in incidence rates amongst children and adolescents \(2004–2013\)](#). *J Atten Disord* 22(2): 134–42

¹² National Institute for Health and Care Excellence (2023) [Attention deficit hyperactivity disorder: How common is it?](#)

During the pandemic, mental health services observed a surge in ADHD diagnosis requests, especially among adults.¹³ The ADHD Foundation in the UK reported a 400% increase in adults seeking support compared to pre-COVID-19 levels.¹⁴

It is suggested that the rise in referrals during the pandemic stemmed from individuals having more time for introspection about ongoing challenges in their lives, coupled with increased awareness of the condition, partly driven by social media. Notably, the role of the social media app TikTok has been highlighted, with videos tagged #ADHD garnering over 11 billion views.¹⁵

Despite this, recently observed increase in demand for diagnosis and ADHD services, there is evidence to suggest this upward trend predates the pandemic. A recently published study by University College London that examined UK-wide data from 2000 to 2018 identified significant increases in the proportion of people with ADHD diagnoses and prescribed ADHD medications.¹⁶ The increase in the number of people diagnosed with ADHD was greatest among adults aged 18–29 years. The authors of the study report that the trend can be partially explained by a cohort effect of children with ADHD ageing into adulthood, as well as by an increased rate of new diagnoses in that age group, suggesting more ADHD diagnoses are now being made in adulthood.¹⁷

1.2 Impact of ADHD

ADHD can have a significant impact on a child's academic, social, and occupational functioning. Children with ADHD may struggle in school, have difficulty forming and maintaining relationships, and experience low self-esteem.¹⁸

¹³ Topping, A (2023) [ADHD services 'swamped', say experts as more UK women seek diagnosis](#) The Guardian Newspaper

¹⁴ Glyn Jones, T (2023) [ADHD: Women tell of their diagnosis struggles](#) BBC News Website

¹⁵ Korducki, KM (2022) [TikTok trends or the pandemic? What's behind the rise in ADHD diagnoses](#) The Guardian Newspaper

¹⁶ McKechnie DG, et al (2023) [Attention-deficit hyperactivity disorder diagnoses and prescriptions in UK primary care, 2000–2018: population-based cohort study](#) *BJPsych Open*. 2023;9(4):e121.

¹⁷ Cited directly above

¹⁸ Peasgood T, et al. (2016) [The impact of ADHD on the health and well-being of ADHD children and their siblings](#). *European Child & Adolescent Psychiatry*; 25(11)

Adult ADHD can have negative consequences for individuals' self-esteem and the quality of their interpersonal relationships, with both colleagues and significant others.¹⁹ Adults with ADHD can also experience challenges with time management, organisation, and self-regulation, which can result in employment and financial problems.²⁰

The burden of ADHD extends beyond the affected individuals to their families, schools, and the healthcare system. A UK-based study highlighted the impact of ADHD on the quality of life of children with ADHD and of their siblings.²¹ The economic burden includes healthcare costs, educational support services, and lost productivity for individuals and caregivers.²²

Research suggests that adults with ADHD can also demonstrate:

- Lower life expectancy.²³
- Difficulty with parenting, including inconsistency with discipline and lack of supportiveness with respect to children's emotions.²⁴
- Increased incidence of accidental death.²⁵
- A higher prevalence of drug and alcohol misuse.²⁶

ADHD is more commonly diagnosed in boys than girls. In children and young people, prevalence ratios are generally estimated at 2–5:1, while clinic populations show a ratio as high as 10:1. This sex difference may be due to the fact that boys present more often with disruptive behaviour that prompts referral, whereas girls are more

¹⁹ Das D, et al (2012) [A population-based study of attention deficit/hyperactivity disorder symptoms and associated impairment in middle-aged adults](#). PLoS One ;7(2):e31500.

²⁰ Cited directly above

²¹ Peasgood T, et al. (2016) [The impact of ADHD on the health and well-being of ADHD children and their siblings](#). European Child & Adolescent Psychiatry;25(11)

²² Biederman J, et al (2006) [The effects of attention-deficit/hyperactivity disorder on employment and household income](#). MedGenMed ;8(3):12.

²³ Schiavone, N, et al. (2022) [Mortality in individuals with childhood ADHD or subthreshold symptoms – a prospective perinatal risk cohort study over 40 years](#). BMC Psychiatry; 22: 325.

²⁴ Mokrova, I, et al (2010) [Parental ADHD symptomology and ineffective parenting: the connecting link of home chaos](#). Parent Sci Pract; 10(2): 119–35.

²⁵ London, AS, et al (2016) [Attention deficit hyperactivity disorder and adult mortality](#). Prev Med ; 90: 8–10

²⁶ Grazioli, VS, et al (2019) [Attention deficit hyperactivity disorder and future alcohol outcomes: examining the roles of coping and enhancement drinking motives among young men](#). PLoS One 14(6): e0218469

likely to have internalising symptoms, resulting in a later diagnosis, and greater time for developing strategies to mask core symptoms.

Certain populations may also be more likely to have ADHD. The condition is associated with poverty, lower family income and social class. In adults, it is more frequent in the unemployed and in people with disabilities. A 2018 meta-analysis estimated that up to one in four prisoners had a diagnosis of ADHD, although a more recent re-analysis of this data reported that, after accounting for an outlier and restricting to studies that used random sampling of adults in prison, prevalence was much lower at around 4.5% in men.

1.3 How does ADHD manifest in children and adults?

The primary features of ADHD include inattention and hyperactive-impulsive behaviour. A person with ADHD can display predominantly one type of behaviour or a combination of both. Symptoms start before age 12, and in a minority of cases, are noticeable as early as three years of age. Compared with the childhood phase, the core symptoms of ADHD that progress to adulthood are predominantly inattentiveness and mild hyperactive-impulsive behaviour.²⁷

Various health bodies have highlighted that many of the symptoms associated with ADHD can also be typical developmental behaviour for children and young adults.²⁸ Typically, a child or adult will only be considered to have ADHD when symptoms become severe enough to disrupt more than one area of their lives. This could be home and school life for children, or socially and at work for adults.²⁹

Differences in the way that the core ADHD symptoms of inattention and/or hyperactive-impulsive behaviour manifest in adults and children are considered in more detail below.

²⁷ Lee, KC, et al (2020). [Development of an innovative adult attention-deficit hyperactivity disorder clinic](#). *Ment Health Clin*; 10(5): 296–300

²⁸ [Attention-deficit/hyperactivity disorder \(ADHD\) in children](#) Mayo Clinic

²⁹ [When to suspect ADHD](#) NICE Guidelines

1.3.1 Hyperactivity/ Impulsiveness

For ADHD patients with predominately hyperactive symptoms, a child may display incessant and demanding extremes of activity with constant movement that are above and beyond normal age-appropriate levels in severity, duration, or both. As a young or older adult, hyperactivity may be more likely to present as a sustained inner sense of restlessness. For example, adults may have trouble sitting still through longer meetings, and they're often described as 'always on the go'.³⁰

Impulsive ADHD behaviour in children and adults may involve speaking out of order or acting without thought to consequences. Adult ADHD traits include impulsiveness in more "grown-up" experiences, such as impulsive spending, interrupting and monopolising conversations, or displaying risk-taking behaviours such as careless driving.³¹

1.3.2 Inattention

Perhaps the closest resemblance between children and adults with ADHD comes with inattention symptoms. In adults, inattention may diminish in absolute terms and attention span normally improves with age; however, it usually lags behind that of unaffected people, and behind the level that is expected and needed for everyday attainments.³² The ADHD patient is more likely to lose everyday items like school supplies, keys, or glasses, avoid attention to detail in tasks, leave tasks or projects incomplete and have constantly shifting attention.³³

As a young person with ADHD matures into adulthood, they can develop strategies to cope, however, they may continue to struggle due to increased behavioural

³⁰ Franke, B, et al. (2018) Live fast, die young? [A review on the developmental trajectories of ADHD across the lifespan](#). Eur Neuropsychopharmacol. 28(10): 1059–88.

³¹ Franke, B, et al. (2018) Live fast, die young? [A review on the developmental trajectories of ADHD across the lifespan](#). Eur Neuropsychopharmacol. 28(10): 1059–88.

³² [Attention deficit hyperactivity Disorder](#) NICE Guideline ng87

³³ Thorell, LB, et al (2019) [Quality of life in older adults with ADHD: links to ADHD symptom levels and executive functioning deficits](#). Nord J Psychiatry 73(7): 409–16.

expectations of them, for example, the expectation of being able to function independently.³⁴

ADHD in adults is often accompanied by other psychiatric comorbidities (such as major depressive disorder, anxiety disorder, and alcohol abuse). Adults with ADHD are more likely to present to a psychiatric clinic for treatment of their comorbid disorders than for ADHD, and their ADHD symptoms are often mistaken for those of their comorbidities.³⁵

2 Diagnosis of ADHD

ADHD is a clinical diagnosis requiring a detailed evaluation of current and previous symptoms and functional impairment. Best practice indicates that a full family, gestational, and developmental history should be taken.³⁶

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was published in 2022 and is considered one of the principal guides of psychiatry, along with the International Classification of Diseases (ICD).³⁷ The DSM-5 defines ADHD in children (younger than 17 years) as the presence of six or more symptoms in either the inattentive or hyperactive and impulsive domains, or both. Fewer symptoms (at least five symptoms in either domain) are required to meet the adult diagnostic criteria. The age of symptom onset was modified from before age 7 years in DSM-4 to before age 12 years in DSM-5 to permit greater flexibility when diagnosing adults. Additionally, whereas DSM-IV divided ADHD into three subtypes on the basis of the predominant symptomatology (inattentive, hyperactive and

³⁴ [Disorders of attention and activity](#) American Psychological Association Website

³⁵ Ginsberg Y (2014) [Underdiagnosis of Attention-Deficit/Hyperactivity Disorder in Adult Patients: A Review of the Literature](#) Prim Care Companion CNS Disord. 2014;16(3): PCC

³⁶ Posner, J (2023) [Attention-deficit hyperactivity disorder](#) The Lancet Seminar| Volume 395, ISSUE 10222, P450-462.

³⁷ [Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision \(DSM-5-TR™\)](#) American Psychiatric Association.

impulsive, or combined), DSM-5 replaced the term “subtype” with “presentation” to emphasise that symptom clusters can change as patients mature and develop.³⁸

The ICD has updated its diagnostic formulation to bring it into line with DSM-5, moving ADHD from the disruptive to the neurodevelopmental disorder domain, exchanging the label hyperkinetic disorder with ADHD, and including inattentive and hyperactive–impulsive presentations of symptoms.³⁹

Distinct from DSM-5 and ICD-10, ICD-11 describes the essential features of the disorder without giving a precise age of onset, duration, or number of symptoms.¹⁵

2.1 Managing the symptoms of ADHD

ADHD seldom affects only one functional domain but impacts many aspects of an individual's wellbeing, including physical health, and academic, social, and occupational functioning.

With respect to the management of ADHD symptoms, US,⁴⁰ Canadian,⁴¹ Latin American,⁴² and European⁴³ medical organisations all recommend the use of psychostimulant medications. Most organisations recommend beginning with psychoeducation and behavioural management, particularly for individuals with mild symptoms and impairment.⁴⁴ US guidelines differ and suggest that medication is considered with initial treatment.⁴⁵

³⁸ Posner, J (2023) [Attention-deficit hyperactivity disorder](#) The Lancet Seminar Volume 395, Issue 10222, P450-462.

³⁹ Reed GM et al. (2019) Innovations and changes in the ICD-11 classification of mental, behavioural and neurodevelopmental disorders. *World Psychiatry*. 2019; 18: 3-19

⁴⁰ Pliszka S (2007) [Practice parameter for the assessment and treatment of children and adolescents with attention-deficit/hyperactivity disorder](#). *J Am Acad Child Adolesc Psychiatry*. 46: 894-921

⁴¹ Canadian ADHD Resource Alliance [Canadian ADHD practice guidelines](#). 4th edn. Canadian ADHD Resource Alliance, Toronto, ON2018

⁴² Palacio JD et al (2009) [Algoritmo latinoamericano de tratamiento multimodal del trastorno por déficit de atención e hiperactividad \(TDAH\) a través de la vida](#). *Revista Colombiana de Psiquiatría* ; 38: 35-65

⁴³ [Attention deficit hyperactivity disorder: diagnosis and management](#). NICE Guidelines

⁴⁴ Pliszka SR et al. (2006) [The Texas Children's Medication Algorithm Project: revision of the algorithm for pharmacotherapy of attention-deficit/hyperactivity disorder](#). *J Am Acad Child Adolesc Psychiatry*; 45: 642-657.

⁴⁵ Posner, J (2023) [Attention-deficit hyperactivity disorder](#) The Lancet Seminar| [Volume 395, ISSUE 10222](#), P450-462.

The psychostimulant medications that are used for ADHD consist of formulations of methylphenidate and amphetamine. The mechanisms of action for both are similar. The side-effect profiles of these drugs are similar, with the most common side-effects being appetite suppression, insomnia, dry mouth, and nausea, but amphetamine might be somewhat more prone to side-effects.⁴⁶ Side-effects are generally similar for adults and children, but might be more common in young children (i.e. aged five years and younger).⁴⁷ There is an association between the effects of long-term stimulant treatment on growth, specifically height and weight. Although studies have yielded mixed results, most suggest that consistent stimulant use over several years can affect growth trajectories.⁴⁸

NICE guidelines recommend that medication treatment should begin with methylphenidate for children older than five years, but then switch to amphetamine if the response is inadequate. For adults aged eighteen years and older, the NICE guidelines recommend starting with either methylphenidate or the amphetamine formulation, lisdexamfetamine.

For children younger than 6 years old, there is consensus that treatment should start with behaviour management in the form of parent training and that medication should be reserved for more severe or unresponsive cases. The National Institute for Health and Care Excellence (NICE) guidelines, for example, recommend that medication management for children younger than five years be considered only when parent training has been attempted and a second opinion has been obtained from a provider with expertise in ADHD in young children.⁴⁹

2.2 Developments in ADHD diagnosis and management

⁴⁶ Faraone SV (2010) Comparing the efficacy of stimulants for ADHD in children and adolescents using meta-analysis. *Eur Child Adolesc Psychiatry*. 2010; 19: 353-364.

⁴⁷ Schachter HM (2001) [How efficacious and safe is short-acting methylphenidate for the treatment of attention-deficit disorder in children and adolescents?](#) A meta-analysis. *CMAJ*. 165: 1475-1488

⁴⁸ Reenhill LL et al. (2019) [Trajectories of growth associated with long-term stimulant medication in the multimodal treatment study of attention-deficit/hyperactivity disorder.](#) *J Am Acad Child Adolesc Psychiatry*.

⁴⁹ [Managing ADHD](#). NICE Guidelines

Large-scale epidemiologic studies have demonstrated the global occurrence of ADHD. However, there is increasing recognition of the limited research available for certain populations, with emerging studies aiming to fill these knowledge gaps. For instance, researchers are investigating how cultural factors influence the expression of ADHD symptoms and response to treatment, as well as addressing the underrepresentation of females in ADHD research. Additionally, there is a need to explore the extent and impact of ADHD in older adults.⁵⁰

Stigmatising attitudes towards ADHD are also widespread and may influence socially and clinically significant outcomes. These negative perceptions impact patients throughout their lives and have been observed among individuals of all ages and in various groups, including family members, peers, teachers, clinicians, and even among individuals with ADHD themselves.⁵¹

2.2.1 Developments in the etiology of ADHD

Regarding the causes of ADHD, researchers continue to investigate how genes and the environment combine to cause the disorder and affect the brain to produce symptoms and impairments. Several reviews have highlighted the need for future work to focus on exploring the biological and psychological causal mechanisms to find intervention points that will improve the effectiveness of medical and non-medical treatments and, eventually, prevent the onset of the disorder.⁵²

2.2.2 Developments in diagnosis

There are several new directions for diagnosis. One is to better understand the nature and causes of emotional symptoms in ADHD and whether these should be

⁵⁰ Faraone SV (2021) [The World Federation of ADHD International Consensus Statement: 208 Evidence-based conclusions about the disorder](#) *Neurosci Biobehav Rev.* Sep; 128:789-818.

⁵¹ Lebowitz, M. S. (2016). [Stigmatization of ADHD: A Developmental Review](#). *Journal of Attention Disorders*, 20(3), 199-205.

⁵² Esposito G (2018) [Gene x Environment Interaction in Developmental Disorders: Where Do We Stand and What's Next?](#) *Front Psychol.* 26;9:2036

incorporated into diagnostic criteria.⁵³ Another is to determine if and how mild or sub-threshold cases of ADHD should be diagnosed and treated.⁵⁴

Researchers are also trying to develop computerised or biological tests using information about the patient's behaviour, brain, and/or genetic makeup. The hope is that such tests could diagnose the disorder in the future, predict a personalised approach to treatment, or assist clinicians in these areas. Others are working on methods that use the vast data available from medical records to predict which patients with ADHD are at the greatest risk for adverse outcomes later in life.⁵⁵

For example, researchers have developed a risk calculator for childhood characteristics, such as intelligence quotient (IQ) and childhood maltreatment, that collectively estimates the risk for adult ADHD. Establishing robust predictors of clinical course would aid treatment decisions, informing, for instance, the duration of interventions and periods of elevated risk.⁵⁶

2.2.3 Developments in treatment

The future of treatment for ADHD includes new medications currently under development and a stronger evidence base for innovative non-medication treatments aimed at addressing ADHD symptoms and related impairments.

Medication-based treatment strategies have proven effective and cost-effective in the short term and a number of compounds are available, recommended, and widely used.⁵⁷ However, the long-term effectiveness of these treatments on key educational, vocational, and social outcomes remains uncertain.⁵⁸ Furthermore, such effects are compounded by low adherence, especially after extended use in

⁵³ Faraone. SV (2019b) [Practitioner Review: Emotional dysregulation in attention-deficit/hyperactivity disorder. Implications for clinical recognition and intervention.](#) J Child Psychol Psychiatry 60,133–150

⁵⁴ Kirova, AM (2019) [Are subsyndromal manifestations of attention deficit hyperactivity disorder morbid in children? A systematic qualitative review of the literature with meta-analysis](#) Volume 274, April, Pages 75-90

⁵⁵ Posner, J (2020) [Attention-deficit hyperactivity disorder](#) The Lancet Seminar| Volume 395, ISSUE 10222, P450-462

⁵⁶ Caye A et al. (2019) A risk calculator to predict adult attention-deficit/hyperactivity disorder: generation and external validation in three birth cohorts and one clinical *sample*. *Epidemiol Psychiatr Sci.*; 29: e37

⁵⁷ Scheffler RM et al. (2007) [The global market for ADHD medications.](#) J Health Affairs. 26: 450-457

⁵⁸ Cited in footnote 57

adolescence. These limitations are probably the result of both biological and psychosocial processes (e.g. the build-up of medication tolerance, ADHD-related stigma, and social resistance to medication).⁵⁹

There is consensus within the field of ADHD that there is a pressing need for better long-term treatments. For example, genetic risk factors for ADHD have been identified, however, a significant gap exists in the translation of this knowledge into identifying therapeutics with clinical usefulness. Researchers are currently trialling Fasoracetam (NFC-1) as a treatment for ADHD in teens with specific gene variations affecting neurotransmitter signalling. Research is in the early stages of determining whether this may help a specific group of ADHD patients with certain genetic differences.⁶⁰

One of the non-medication treatments is trigeminal nerve stimulation. The trigeminal nerve, a set of nerves in the head that connects directly to the brain, has been the focus of some research. Studies suggest that using a device that stimulates this nerve, known as an external trigeminal nerve stimulation (eTNS) device, could improve ADHD symptoms in children⁶¹. Game-based treatments are another area of active investigation.⁶²

Additionally, more data are needed to enhance existing non-medication treatments and to assess the efficacy of traditional therapies such as acupuncture, yoga, and ayurvedic practices. Furthermore, there is a lack of understanding regarding how medical conditions such as cardiovascular disease and asthma co-occur with ADHD interact with ADHD treatments and how the symptoms of the disorder impact medical outcomes. There are similar questions concerning how ADHD co-occurs with somatic

⁵⁹ Cited in footnote 57

⁶⁰ Elia J, et al (2018) Fasoracetam in adolescents with ADHD and glutamatergic gene network variants disrupting mGluR neurotransmitter signaling. *Nat Commun.* 16;9(1):4

⁶¹ Loo SK (2021) [Trigeminal Nerve Stimulation for Attention-Deficit/Hyperactivity Disorder: Cognitive and Electroencephalographic Predictors of Treatment Response](#). *J Am Acad Child Adolesc Psychiatry.*60(7):856-864.e1

⁶² Craven MP, Groom MJ (2015) [Computer games for user engagement in Attention Deficit Hyperactivity Disorder \(ADHD\) monitoring and therapy](#). 2015 International Conference on Interactive Technologies and Games (ITAG), Nottinghamshire, United Kingdom, 22-23 October. IEEE Computer Society conference proceedings, pp. 34-40.

disorders (where physical symptoms are present despite no identifiable medical explanation, often stemming from psychological factors).⁶³

3 National Institute of Clinical Guidance (NICE) and ADHD

NICE guidelines cover England and Wales. In Northern Ireland, decisions on how they apply are taken by the Department of Health, who are often involved and consulted with in the development of NICE guidelines. Scotland's clinical guidance is provided by the Scottish Intercollegiate Guidelines Network (SIGN).

NICE provides technology appraisals, clinical guidance and quality standards for treatments and care. This consists of recommendations on how to best identify, refer, diagnose, treat and manage patients based on the best evidence available. NICE is internationally recognised for its scientific robustness and the quality and accuracy of its recommendations.⁶⁴

When put into practice, NICE guidelines have the potential to effectively target health and care resources to significantly improve patient outcomes, in line with the best available evidence of clinical and cost-effectiveness. Although healthcare professionals and commissioners are not legally obliged to follow NICE guidelines, they are expected to take them into full account when making decisions on treatment and care for patients.⁶⁵

With regard to ADHD, NICE guidelines provide an approach for assessing and managing ADHD in the NHS, with service organisation and delivery centred around multidisciplinary specialist ADHD teams.⁶⁶

The guidelines describe a process of assessment and treatment from multidisciplinary specialist teams or clinics, a smooth transition from child to adult

⁶³ Instanes JT, et al (2018) [Adult ADHD and Comorbid Somatic Disease: A Systematic Literature Review](#). J Atten Disord. Feb;22(3):203-228.

⁶⁴ [About National Institute for Health and Care Excellence \(NICE\)](#) RNID Website

⁶⁵ [Benefits of implementing NICE guidance](#)

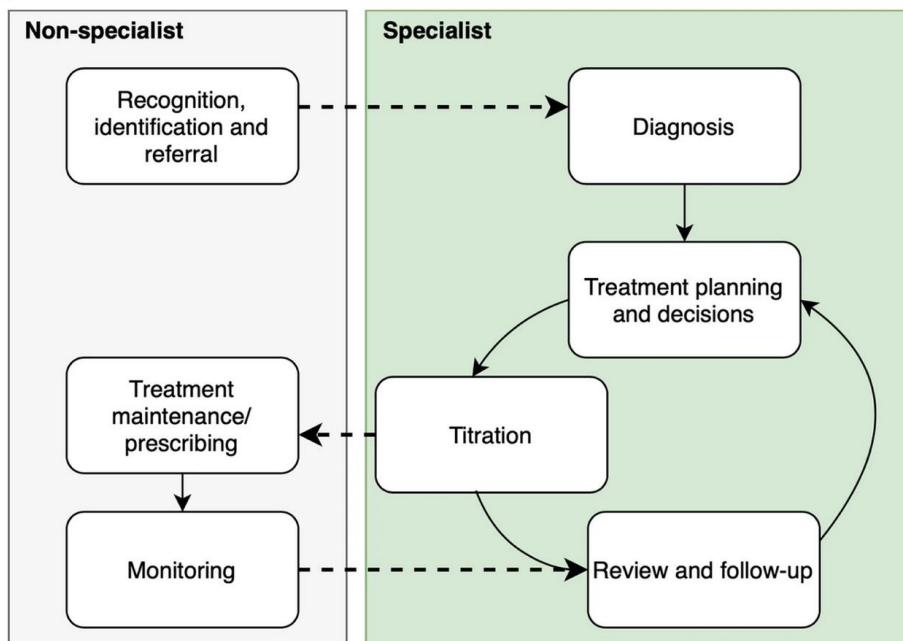
⁶⁶ National Institute for health and care excellence. [Diagnosis and management of ADHD in children, young people and adults](#). London; 2018.

services for children with ADHD persisting into adulthood, advice on environmental modifications, psychoeducation, and medication for children and adults with moderate or severe symptoms who have continuing impairment despite environmental modifications.⁶⁷

Once a diagnosis has been made, psychoeducation delivered and medication initiated and titrated to a maintenance dose, NICE recommends that routine prescribing and physical monitoring is transferred to primary care through shared care protocols.⁶⁸ Once yearly specialist reviews are then recommended.

Figure 1 provides a simplified schema for the roles taken by non-specialist (primary care) and specialist healthcare providers in the treatment of ADHD according to NICE guidelines. Dashed lines indicate key areas of communication between general and specialist healthcare providers.

Figure 1: Roles taken by non-specialist and specialist healthcare providers in the treatment for ADHD.⁶⁹



⁶⁷ National Institute for health and care excellence. [Diagnosis and management of ADHD in children, young people and adults](#). London; 2018

⁶⁸ Cited directly above

⁶⁹ Cited in Fn 69

3.1 History of NICE ADHD guidelines

The first guidance notes on ADHD issued by NICE were in the form of a technical recommendation TA13 and concerned medication for ADHD.⁷⁰

Following this, comprehensive NICE guidelines on ADHD were introduced in 2008, providing recommendations for the diagnosis and management of ADHD in children and adolescents. These guidelines were based on available evidence at the time and aimed to standardise ADHD care practices across the UK.

The 2008 guidelines were also a landmark document in the development of services for adult ADHD. Chapter five of the guidelines addressed the question of the validity of the diagnostic construct in both children and adults, which is the first and only time that NICE has conducted such a review for a clinical condition.⁷¹

These guidelines clarified that ADHD frequently persists into adulthood, that treatment effects are like those seen in children and that access to cost-effective diagnostic and treatment services is required and should be available throughout England and Wales.

The publication of the 2008 NICE guidelines led to a rapid expansion in the number of clinics across England and Wales after 2008, particularly in the last decade. Many regions set up specialist tertiary clinics for ADHD or neurodevelopmental disorders (ADHD plus autism), although some regions lacked any services for ADHD. As with the early service models for children, adult ADHD diagnosis and treatment were restricted to specialist tertiary services. However, in recent years, an increasing number of ADHD services have been integrated into generic secondary adult mental health care and, in a few cases, even into primary care.⁷²

⁷⁰ [Methylphenidate for the treatment of attention deficit hyperactivity disorder in children and adolescents | Guidance | NICE](#)

⁷¹ NICE. [Attention deficit hyperactivity disorder: the NICE guideline on diagnosis and management of ADHD in children, young people and adults](#): The British Psychological Society and The Royal College of Psychiatrists; 2008.

⁷² [Mainstreaming adult ADHD into primary care in the UK: guidance, practice, and best practice recommendations | BMC Psychiatry \(springer.com\)](#)

NICE periodically reviews its guidelines to ensure they remain up-to-date with the latest research and clinical practices. These reviews typically occur every few years and involve input from experts in the field, stakeholders, and patient representatives.

The 2008 NICE guidelines, were reviewed and updated in September 2019. New recommendations were added on recognition, information and support, managing ADHD, including non-pharmacological treatment, medication, follow-up and monitoring, adherence, and review of medication and discontinuation.⁷³ The updated guidelines also highlighted the potential for girls and women to be underdiagnosed and that diagnosis should account fully for any environmental factors that may be at play.⁷⁴

In December 2021, NICE undertook an exceptional surveillance review of the 2019 ADHD guidelines. During the development of NICE's evidence summary on melatonin for treating sleep disorders in adults who are blind, researchers identified evidence about the use of melatonin in people with ADHD that may impact the recommendations in the guideline.⁷⁵

NICE was also made aware that melatonin has recently been licenced for insomnia in children and adolescents aged 6 to 17 with ADHD, where sleep hygiene measures have been insufficient. NICE reported that while there is evidence that melatonin can advance sleep onset times in adults and children, evidence for its effect on quality of life and ADHD symptoms is lacking or equivocal.⁷⁶

In correspondence with the Research and Information Service of the Northern Ireland Assembly NICE confirmed that it takes a proactive approach (with an assessment of priority) to surveillance rather than reviewing a guideline at a fixed point in time. This allows the body to respond to events that may impact guideline recommendations

⁷³ [Update information | Attention deficit hyperactivity disorder: diagnosis and management](#) NICE Guidance

⁷⁴ [Attention deficit hyperactivity disorder: diagnosis and management \[NG87\]](#) NICE Guidance

⁷⁵ [Melatonin for treating sleep disorders in adults who are blind](#) NICE Guidance

⁷⁶ [Evidence reviews for pharmacological efficacy and sequencing pharmacological Treatment](#) NICE guidance

after guideline publication (for example, a safety alert, or the publication of a key study).⁷⁷

3.2 Recent scrutiny of NICE ADHD Guidelines

Stakeholders have highlighted that the escalating problem of ADHD waiting times has been exacerbated by a lack of specific targets for these waiting times and the absence of routinely collected national data. This stems primarily from a lack of set targets for ADHD, as exist for other conditions, such as autism spectrum disorder.⁷⁸ This issue was highlighted in the UK government's response to a parliamentary debate held in February 2023 on ADHD waiting times.⁷⁹ The response concluded that, in the absence of a specified NICE target, local commissioning organisations, rather than central government, should resolve the problem of waiting lists.^{80,81}

Stakeholders have proposed integrating a national target for starting diagnostic assessments within three months into NICE guidelines and to prioritising ADHD treatment in health policy as starting points.⁸²

Underfunding of NHS adult ADHD services has resulted in a significant growth of independent providers, whose numbers have increased in response to the unmet demand. The large number of providers in both the NHS and the independent sector presents a challenge to patients, clinicians and commissioners tasked with navigating a complex and fragmented system and determining the quality and reliability of these services. Although NICE provides guidance on the assessment and treatment of ADHD, it is not specific on what constitutes quality assessment and treatment to ensure the required consistency between providers.⁸³

⁷⁷ Email correspondence between RaiSe and NICE received on 13/03/2024

⁷⁸Smith MCF et al (2024). [UK adult ADHD services in crisis](#). *BJPsych Bulletin*. 48(1):1-5.

⁷⁹ UK Government and Parliament. Review Management of ADHD Assessments and Increase Funding (Department of Health and Social Care Response to Parliamentary Debate). UK Government and Parliament, 2023

⁸⁰Smith MCF et al (2024). [UK adult ADHD services in crisis](#). *BJPsych Bulletin*. 48(1):1-5.

⁸¹ Cited directly above

⁸² Cited directly above

⁸³ National Institute for Health and Care Excellence. [Attention Deficit Hyperactivity Disorder: Diagnosis and Management](#) (NICE Guidance NG87). NICE, 2018

3.3 Application of NICE guidelines across the UK and RoI

NICE guidelines cover England and Wales. In Northern Ireland, decisions on how they apply are taken by the Department of Health, who are often involved and consulted with in the development of NICE guidelines. Scotland's clinical guidance is provided by the Scottish Intercollegiate Guidelines Network (SIGN).

The NICE guidance on ADHD offers a blueprint for what effective care and support should entail throughout the ADHD care pathway. However, available research suggests that it is seldom fully implemented. A recurring finding from research that has attempted to map ADHD service delivery for children and adults across the regions suggests that there is a postcode lottery concerning both access to, and availability of diagnosis and treatment services.

For instance, a 2018 mapping exercise of services for adults with ADHD across the UK found 44 specialised adult ADHD services, but only 12 of them provided a comprehensive range of NICE-recommended services. The majority were in England, with one each in Scotland and Wales. Notably, no specialised adult ADHD services were identified in Northern Ireland.⁸⁴

3.3.1 England

NICE guidelines were published for use in England, however research published in 2020 on ADHD services in England revealed variations across the country in terms of service providers' understanding of the ADHD population, waiting times for diagnosis and treatment, spending, and data collection. As such many regions in England still experience limited access to comprehensive NICE-compliant ADHD services.⁸⁵

3.3.2 Wales

In Wales, clinical guidelines produced by NICE apply, although decisions on medication are often subject to approval by the All Wales Medicines Strategy Group (AWMSG). All NICE guidance used in Wales is subject to Welsh legislation. The

⁸⁴ Price A et al (2020) [Mapping UK mental health services for adults with attention-deficit/hyperactivity disorder: national survey with comparison of reporting between three stakeholder groups - PMC \(nih.gov\)](#) BJPsych Open. Jul 29;6(4):e76.

⁸⁵ Will the doctor see me now? Investigating adult ADHD services in England. An audit of ADHD service provision for adults in England

delivery of ADHD services in Wales is the responsibility of local health boards. However, the limited availability of data on ADHD service provision at a national level makes it difficult to assess whether NICE guidelines are being implemented. This is discussed in more detail in section 5.2.

3.3.3 Scotland

In Scotland, the Scottish Intercollegiate Guidelines Network (SIGN) is responsible for developing evidence based clinical practice guidelines. A separate body, the Scottish Medicines Consortium (SMC) produces guidance on medicines. Both bodies fall under Healthcare Improvement Scotland (HIS), which was established in 2010 to support the Scottish Government's Healthcare Strategy. SIGN also published guidelines for children and young people with ADHD in 2008, however, adult ADHD was not recognised. In 2019, SIGN withdrew its 2009 advice on ADHD in children for being out of date but did not replace it with updated advice. SIGN has never published guidance on adult ADHD.⁸⁶

3.3.4 Northern Ireland

In Northern Ireland, NICE guidance is reviewed by the DoH to check for legal, policy and financial consequences related to its implementation in NI. As a result, the guidance may be endorsed with caveats to advise local HSC organisations of any equivalent legislation, policy, or any specific instructions/requirements. Where guidance is adopted by the DoH, Health and Social Care Trusts (HSCTs) are expected to disseminate the guideline, appoint leads, and plan implementation within three months.⁸⁷ Clinical guidelines can often be complex and have financial and sometimes, wider strategic implications. The working assumption is that HSC Trusts will implement clinical guidelines within a further nine months following the initial three-month planning period.⁸⁸

Where regional commissioning or investment is required, there will be occasions where the timescale for implementation will take longer than nine months, depending

⁸⁶ [The History of ADHD - ADHD UK](#)

⁸⁷ Department of Health (2022) [Circular HSC \(SQSD\) 13 22 - NICE Clinical Guidelines](#)

⁸⁸ Cited directly above

on the complexity and scale of the issue, available resources and other existing commissioning priorities. The Strategic Planning and Performance Group (SPPG) in conjunction with the PHA will agree on commissioning arrangements for these through negotiations with HSC Trusts and/or other relevant providers such as the voluntary and community sector.⁸⁹

The 2008 NICE guidelines on ADHD were endorsed by the DoH in the same year. Those guidelines were updated and replaced by new guidelines in 2018, which again were endorsed by the DoH in 2018.⁹⁰

Recent correspondence between the Department of Health and the Research and Information Service of the Northern Ireland Assembly revealed that services for ADHD diagnosis and treatment have grown organically across HSCTs in response to population demand and the development of expertise within those teams.

The DoH noted that while this growth has ensured a level of provision across all Trusts, they recognise inconsistencies between HSC Trusts, including in their ADHD pathways and the waiting times for assessment and treatment for individual children, young people, and adults.⁹¹

Limited capacity within trusts to meet demand, coupled with the prevalence of child and adult ADHD, is resulting in longer waiting times for assessment and support than recommended in NICE guidelines.

3.3.5 Republic of Ireland

In the Republic of Ireland, the National Clinical Effectiveness Committee (NCEC) is responsible for promoting cost-effective healthcare that is evidence-based, with the aim of subsequent improved clinical decision-making and clinical outcomes. The NCEC collaborates with other guidance agencies, including NICE. The recently developed National Clinical Programme (NCP) for adults with ADHD reports that its

⁸⁹ Cited in Fn 89

⁹⁰ [NICE - Endorsed Clinical Guidelines 2008/2009](#) Department of Health (health-ni.gov.uk)

⁹¹ Email correspondence between RaiSe and NICE received on the wed 13/03/2024

model closely aligns with NICE guidance. The model is covered in more detail in section 8.5.

4 Waiting times for diagnosis of ADHD across the UK and ROI

Waiting times for children and adults seeking a diagnosis of ADHD can be long and there are geographical variations within and across the regions of the UK, as well as variations in how this information is recorded or whether it is recorded at all.

Campaigners have highlighted that there is a need for consensus on effective and efficient data collection methods.

4.1 England

In England, there is significant variation in waiting times for assessments for children and adults across health trusts. For example, in the South London NHS Maudley Trust, there is a wait of approximately 25 weeks for a child ADHD assessment, whereas in Dorset Healthcare University NHS Foundation Trust, the average number of weeks for an ADHD assessment for a child is nine. In the Birmingham Community HealthCare NHS Foundation Trust there were 1,560 children waiting for an ADHD assessment, with an average waiting time of 27 weeks. However, the longest wait time was 83 weeks.⁹²

For adult ADHD assessments, the variation in wait times is also evident, with a wait of approximately 12 weeks at Dorset Healthcare University NHS Foundation Trust and a wait of 550 weeks (over 10 years) at the Herefordshire and Worcestershire Health and Care Trust. In Sheffield Health and Social Care NHS Foundation Trust the average wait for an adult ADHD assessment is 140.7 weeks.⁹³

⁹² ADHD UK (2023) [ADHD UK'S Report Into NHS ADHD Assessment Waiting Lists](#)

⁹³ ADHD UK (2023) [ADHD UK'S Report Into NHS ADHD Assessment Waiting Lists](#)

4.2 Wales

In Wales, the delivery of ADHD services is the responsibility of local health boards, and as such, the Welsh Government has reported that there is no centrally accessible information on ADHD waiting times for adults.⁹⁴ However, freedom of information requests submitted by ADHD UK to health boards across Wales indicate that some are experiencing significant waiting times for adult ADHD assessments. The Hywel Dda University Health Board (UHB) in Wales reported that waiting time was an average of 157 weeks for males and 164 weeks for females, with the longest wait being 443 weeks. The UHB also confirmed that they had 253 children waiting for an ADHD assessment, with the longest waiting time being 347 weeks. With regard to children's waiting times for an ADHD or autism diagnosis, at a national level, figures published in March 2023 revealed that 9,014 children were waiting for a diagnosis of either condition in Wales, more than a third of whom (3,331 children) have been waiting for over a year.⁹⁵

4.3 Scotland

A public health audit in Scotland revealed significant increases in ADHD medication prescriptions between 2010 and 2019, indicating potential unmet needs for assessment and diagnosis. Local services also report large increases in referrals for ADHD assessments, indicating growing demand. For example, in 2012, Central Fife (population 150,000) received 59 referrals for ADHD assessment in one year. In 2022, the same area received 297 referrals for the year. This reflects an increase of 500% in referrals over 10 years.⁹⁶

NHS Greater Glasgow & Clyde (NHS GG&C) is the largest health board area in Scotland and serves a population of 1.2 million, distributed across six Health and Social Care Partnerships. There was a 1,000% increase in referrals for assessment

⁹⁴ [ADHD and ASD diagnosis referrals rates and wait times in Wales - a Freedom of Information request to Welsh Government](#) WhatDoTheyKnow Website

⁹⁵ Hicks, D (2023) [Urgent call for action on autism and ADHD assessment waiting times in Wales](#) InYourArea Community

⁹⁶ National Autism Implementation team (2023) [Waiting times for neurodevelopmental assessment in Scotland for adults](#). National Autism Implementation Team, May 2023

of adult ADHD to Community Mental Health Teams over the past three years. NHS GG&C is currently receiving over 2,000 referrals for ADHD assessments per year.⁹⁷

A national review conducted by the Neurodevelopmental Assessment and Intervention Team (NAIT) aimed to understand wait times for neurodevelopmental assessments. The review found lengthy waiting times, with a median total wait for diagnosis from referral to receiving diagnosis being 252 days for adults.⁹⁸

4.4 Northern Ireland

In March 2023, the Research and Information Service of the Northern Ireland Assembly asked the DoH to provide adult and child ADHD assessment waiting list information for the five HSC Trusts. The DoH responded that this information is not recorded in the Western, Northern, and Southern Trust areas, as these referrals are included within their adult mental health services. The data that the DoH was able to provide is outlined below:

- In the South Eastern Trust, the longest wait for an adult ADHD diagnosis is approximately 7.5 years.
- In the Belfast Trust, the longest wait for an adult ADHD diagnosis is approximately eight years.⁹⁹

Paediatric ADHD assessment waiting list information is recorded in all five trusts. Table 3 indicates the number of children waiting for an ADHD assessment as of the 28 February 2024, by HSC Trust and waiting time bands.¹⁰⁰

⁹⁷ [Understanding demand and capacity - NAIT Adult Neurodevelopmental Pathways report](#) gov.scot website

⁹⁸ Cited directly above

⁹⁹ Email correspondence between RaiSe and NICE received on the wed 13/03/2024

¹⁰⁰ [AQW 8352/22-27 Northern Ireland Assembly Questions](#)

Table 3. Number of children waiting for an ADHD assessment as of 28.02.2024, by HSC trust and waiting time bands

Waiting time Bands	Belfast	Northern	South Eastern*	Southern	Western*
0-4 Weeks (0-28 days)	61	1	21	36	5
>4 to 8 Weeks (29-56 days)	56	67	39	48	14
>8 to 13 weeks (57-91 days)	65	56	38	45	16
> 13 to 18 weeks (92-126 days)	49	170	34	46	11
> 18 to 26 weeks (127-182 days)	70	69	171	78	26
> 26 to 39 weeks (183-273 days)	102	237	152	128	36
> 39 to 52 weeks (274-364 days)	124	162	91	127	23
> 52 weeks (365+ days)	614	102	529	124	308
Total Waiting	1,141	864	1,075	632	439

*Please note that the South Eastern Trust could only provide information as at 08.11.2023 as their latest position, and the Western HSC Trust provided information as at 29.02.2024.¹⁰¹

In 2023, as part of their report on waiting times for an ADHD assessment across the UK, the charity, ADHD UK, filed freedom of information requests with the five HSC Trusts. Each trust was asked to provide the expected waiting time for a child/adolescent ADHD assessment in 2022-2023 and the longest time that a child/adolescent was waiting for an assessment during that period (in weeks). Table 4 sets out the information provided by the Belfast,¹⁰² South Eastern¹⁰³ and Southern¹⁰⁴ HSC Trusts. No data was provided by the Northern or Western HSC Trusts.

¹⁰¹ [AQW 8352/22-27 Northern Ireland Assembly Questions](#)

¹⁰² [ADHD UK FOI Belfast Trust](#)

¹⁰³ [ADHD UK FOI South Eastern Trust](#)

¹⁰⁴ [ADHD UK FOI Southern Trust](#)

Table 4: expected and longest waiting times (in weeks) for a child/adolescent ADHD assessment for the year 2022/2023 across the five HSC Trusts.

Trust	Expected wait times (weeks) for 2022/2023	Longest waiting time (weeks) for 2022/2023
Belfast	264 weeks	5 years, 1 month
South Eastern	66 weeks*	99 weeks
Southern	23 weeks	23 weeks

* The SE Trust reported that this was due to the implementation of expedition criteria (no explanation as to the nature of the expedition criteria was available at the time of completion of this report).

The Belfast and South Eastern HSC Trusts both state that a children's ADHD service has never been specifically commissioned in their trust areas. The clinics that are in place have grown organically as a result of service demand. They are run by Community Paediatricians without formal input from CAMHS and demand significantly outweighs capacity.

The Belfast and South Eastern HSC Trusts also report that all referrals are triaged at a weekly referral meeting by a Consultant Paediatrician. Referrals that meet the service criteria are allocated to the ADHD waiting list. The child's parents or carers, the referrer and the social worker, if involved, will be notified of all appointments offered.¹⁰⁵

The Southern HSC Trust (SHSCT) reports that it does not have a commissioned children's ADHD service but has funding for 1.1 full-time equivalent in Band 6* employed to support ADHD assessment.¹⁰⁶

¹⁰⁵ [ADHD UK FOI South Eastern Trust](#)

¹⁰⁶ [ADHD UK FOI Southern Trust](#)

In relation to adult ADHD assessment referrals, the Belfast Trust reports that it currently works on limited information when triaging and accepting adults for ADHD assessment. The aim is to develop a more robust and in-depth triage to assist general practice when making referrals.¹⁰⁷ For 2022-2023, the expected wait for an Adult ADHD assessment in the Belfast Trust was 432 weeks. The longest wait recorded for that time period was 193 weeks. There were 1,710 adults waiting for an ADHD assessment at the end of the 2022-2023. This represents a significant increase on the number of adults (837) waiting for an assessment at the end of 2021-2022.

The SHSCT also reports that it does not have a commissioned ADHD service for adults and there is no assessment pathway in place for new referrals. If a person diagnosed with ADHD in children's services requires ongoing medication management by a psychiatrist, they will continue to receive regular reviews by a psychiatrist in adult mental health services.¹⁰⁸

4.5 Republic of Ireland

There is limited publicly available information on the prevalence of ADHD in RoI. Similar to patterns identified across the UK, there is also limited data on waiting times for assessment and treatment of ADHD. As a result, it is not possible to provide this information here.

5 Recent policy developments across the UK and RoI

Stakeholders argue that the current provision of services for adults with ADHD in the UK is in crisis due to increasing demand and inadequate resources, exacerbated by the COVID-19 pandemic. Recently, a group of researchers and clinicians from different health trusts in England, highlighted that delays in treatment for ADHD

*An FTE is equal to the number of hours a full-time employee works for an organisation. For example, if an organisation considers 40 hours per week as full-time and there are four employees who work 10 hours each per week, the hours for those four employees add up together to make 1.0 FTE.

¹⁰⁷ [ADHD UK FOI Belfast Trust](#)

¹⁰⁸ [ADHD UK FOI Southern Trust](#)

“carry a human and financial cost, imposing a burden on health, social care and the criminal justice system” and added that a rethink of service procurement and delivery is needed.¹⁰⁹

The authors stressed the urgent need for change, emphasising that while efficiency improvements and alternative service models may help, substantial progress will only come with additional funding and a shift in approach.¹¹⁰

Recent developments in ADHD diagnosis and treatment in Scotland and Wales signify this shift in approach, departing from solely relying on traditional CAMHS and CMHT services to the development of neurodevelopmental assessment pathways. Research indicates that neurodevelopmental pathways are likely to make better use of resources, significantly reduce assessment costs and improve the experiences of people and families engaged in the diagnostic process.¹¹¹

It has been recognised that the current approach through general mental health services, both adult and child, can result in ADHD patients being screened out due to not meeting the threshold required for acceptance into these services.¹¹²

Additionally, there can be a lack of specialist knowledge within CMHT services to provide a comprehensive response to ADHD patients.¹¹³ The lengthy waits for existing mental health services indicate that there is little room to accommodate the additional demands of neurodevelopmental disorders such as ADHD and autism.

There have also been notable demands for the GP services to be reassessed, aiming for enhanced shared care arrangements.¹¹⁴ A recent report recommended the development of an ADHD specialism within primary care, suggesting that

¹⁰⁹Smith MCF, et al (2024) ([UK adult ADHD services in crisis](#) BPsych Bulletin. 48(1):1-5

¹¹⁰ Cited directly above

¹¹¹ Hale, I., et al (2020) [Should clinical services for children with possible ADHD, autism or related conditions be delivered in an integrated neurodevelopmental pathway?](#) Integrated Healthcare Journal, 2(1), p.e000037

¹¹² [Children and young people - national neurodevelopmental specification: principles and standards of care - gov.scot \(www.gov.scot\)](#)

¹¹³ [A-No-Wrong-Door-Approach-to-Neurodiversity-.pdf \(childcomwales.org.uk\)](#)

¹¹⁴ [Neurodivergence improvement programme: engagement events](#) November 2022, GOV.WALES Website

treatment could be initiated by appropriately qualified clinicians in primary care.¹¹⁵ The authors suggest that the relegation of adult ADHD diagnosis to specialist services is ‘at odds with its high prevalence and chronic course’ and that GPs with extended roles should take up a greater role in treating the condition.¹¹⁶ Given the current strain on GP services, this could be a role that members of the multidisciplinary team, such as mental health practitioners, could take on under supervision from specialist mental health teams. These are roles and specialisms that will take time to develop.¹¹⁷

5.1 England

The Department for Health and Social Care (DHSC) has acknowledged that “we are not where we want to be with support for ADHD, whether on diagnosis, support or access to assessments”. The DHSC has also reported that it is investigating options for improving data collection and reporting on waiting times for ADHD assessments and diagnoses.¹¹⁸

In March 2024, NHS England announced that it is setting up a taskforce to undertake a review of ADHD services amid concerns about a rise in diagnoses. The taskforce will bring together expertise from across a range of sectors, including the NHS, education and justice, to better understand the challenges affecting those with ADHD and help provide a joined-up approach in response to concerns around rising demand.¹¹⁹

Public concern about the lack of ADHD services has also been increasing. In 2023, 10,573 people signed a petition calling on the government to review the management of ADHD assessments and increase funding. A further 21,147 people signed a

¹¹⁵ Asherson P, et al. (2022) [Mainstreaming adult ADHD into primary care in the UK: guidance, practice, and best practice recommendations](#). BMC Psychiatr 22, 1, 640

¹¹⁶ Cubbin S, et al (2020) [Attention deficit hyperactivity disorder in adults: common in primary care, misdiagnosed, and impairing, but highly responsive to treatment](#). Br J Gen Pract

¹¹⁷ Kahn, N (2023) [ADHD and the rise of the private diagnosis](#) British Journal of General Practice; 73 (733): 358-359

¹¹⁸ [Attention Deficit Hyperactivity Disorder: Diagnosis](#) Wednesday 1st February 2023 Westminster hall debate

¹¹⁹ [NHS to launch cross-sector ADHD taskforce to boost care for patients in England](#), NHS England Website.

petition calling on the government to create an emergency fund for ASD (autism) & ADHD assessments.¹²⁰

5.2 Wales

In 2023, the Welsh Government announced significant investments in improving neurodevelopmental services, particularly for autism, ADHD and Tourette's syndrome. They plan to allocate £12 million to support a new national improvement programme for neurodevelopmental conditions until 2025.¹²¹

The purpose of the programme is to support the development of timely and consistent all-age neurodevelopmental services, including additional advice and support services for parents and carers.

The decision came after acknowledging the increasing demand for assessment and support services, exacerbated by the pandemic. An independent review highlighted the need for faster access to support and emphasised the importance of services being based on need rather than diagnosis.¹²²

To help understand where action should be targeted, the Welsh Government commissioned an independent demand and capacity review. The review highlighted where existing reforms have worked well, where there are gaps, and where urgent attention is needed.¹²³ The review confirmed long-standing concerns that swifter access to support and assessment is needed. Furthermore, the review highlighted that services should be based on need rather than led by diagnosis; this echoes the Wales Children's Commissioner for Wales' 2020 'No Wrong Door' report about children's mental health and wellbeing.¹²⁴

¹²⁰ <https://petition.parliament.uk/petitions/597840>

¹²¹ [Written Statement: Improvements in Neurodevelopmental Conditions Services](#) 6 July 2022 GOV.WALES Website

¹²² Cited directly above

¹²³ Holtom, D and S Lloyd-Jones (2022). [Review of the Demand, Capacity and Design of Neurodevelopmental Services: Full Report](#). Cardiff: Welsh Government, GSR report number 47/2022

¹²⁴ Children's Commissioner for Wales (2020) [No Wrong Door: bringing services together to meet children's needs](#)

The improvement programme will have three main workstreams: the first is taking immediate action to provide additional support to reduce some of the here-and-now pressures on assessment services and to quickly put in place much-needed support for parents and families. The second workstream will co-produce and test models to reform neurodevelopmental condition services so they meet identified needs and are sustainable in the long term. The third workstream will develop cross-cutting priorities, including developing a workforce strategy, improving data collection and monitoring, and making the best use of digital opportunities to support services in the future. The work will be supported and monitored by a new Ministerial Advisory Group on neurodevelopmental conditions.¹²⁵

5.3 Scotland

In 2021, Scotland identified the need to enhance experiences and outcomes for autistic adults, adults with ADHD, and those with co-occurring neurodevelopmental conditions throughout the diagnosis process and beyond. The Scottish Government COVID-19 Mental Health Recovery and Renewal Fund provided funding to support focused local work aimed at developing a Stepped-Care neurodevelopmental pathway.

The pathway encompasses local partnerships across four tiers, involving third sector and community teams, employers and employment support providers, further and higher education, new Primary Mental Health Teams (PMHTs) and CMHTs.¹²⁶

- Tier 1-2: Includes third sector and Community services, with access to self-help, peer support, psychoeducation and a range of provision before, during and after diagnosis.
- Tier 3: Is based on primary care neurodevelopmental teams, with prescribing and differential diagnosis capability as well as direct access interventions and supports.
- Tier 4: Involves secondary care neurodevelopmentally informed teams.

¹²⁵ [Neurodivergence improvement programme: engagement events](#) November 2022, GOV.WALES Website

¹²⁶ Rutherford, M. et al (2023) [Adult Neurodevelopmental Pathways: Report on Actions, Outcomes and Recommendations from Pathfinder Sites in Scotland](#), National Autism Implementation Team

Overall, the aims of the pathfinder sites are to:

- Prepare to introduce a single-step care pathway for adult autism and ADHD, with staff confident enough to identify, assess and diagnose both conditions.
- Develop local pathways that deliver graded and proportionate support before, during and after diagnosis with strong links between Tiers 1, 2 and 3 to avoid unnecessary blockages and waiting lists.
- Undertake work linked to four key areas: workforce development, mechanisms for change, identifying where this service will be offered and developing support to meet needs.¹²⁷

The Children and Young People's Mental Health and Wellbeing Taskforce reported in 2019 and recommended that the Scottish Government and partners should develop a neurodevelopmental service specification for use across services in Scotland. The Children and Young People's Mental Health and Wellbeing Programme Board, and the subsequent Joint Delivery Board, assumed responsibility for developing these principles and standards of care.

The National Neurodevelopmental Specification sits along with the NHS Scotland National Service Specification for CAMHS and the same principles underpin both specifications. It sets out the standards and availability of services that people aged up to 25 years old can expect. Most areas in Scotland are developing neurodevelopmental pathways for children and young people, but not all areas have this fully in place. Different health boards are seeking models and guidance to support their local pathway work with a shared approach between education professionals, Allied Health Professionals, Community Child Health and CAMHS.¹²⁸

The aim of the specification is to ensure that children who have neurodevelopmental profiles and their families receive support and access to services that meet their needs at the earliest opportunity. The specification sets out that for many children

¹²⁷ Rutherford, M. et al (2023) [Adult Neurodevelopmental Pathways: Report on Actions, Outcomes and Recommendations from Pathfinder Sites in Scotland](#), National Autism Implementation Team

¹²⁸ [Children and young people - national neurodevelopmental specification: principles and standards of care](#), 2021, Scottish Government Website

and young people, such support is likely to be community-based and should be quickly and easily accessible.

Children, young people, and their families will be able to access additional support appropriate for their neurodevelopmental needs through universal services, community-based mental health and wellbeing supports and services. Universal services will be expected to collaborate closely with professionals working in neurodevelopmental services, relevant health and social care, and education services. These professionals should be connected with CAMHS so that children and young people with both neurodevelopmental and mental health support needs can receive the additional support they require. ¹²⁹

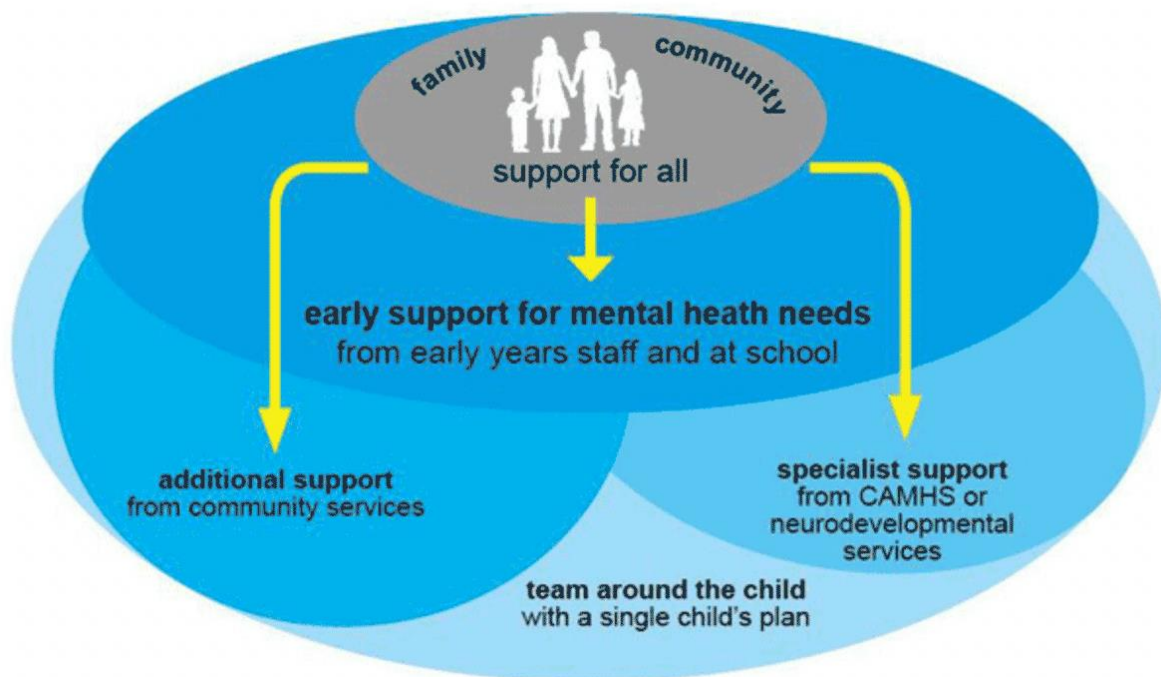
Professionals providing support in neurodevelopmental services will assist both universal and additional children and young people's services, including new and enhanced community mental health and wellbeing supports. They will do so by offering consultation, advice, and training and, where appropriate, by supervising staff supporting children and young people with neurodevelopmental needs. These services should be available for all children and young people aged 0–18 years, and young adults aged 18-24 (and up to age 26 for care-experienced individuals).

Professionals providing support will also conduct assessment, formulation, recommendations, and, where appropriate and beneficial, diagnostic assessment for those children and young people to help them understand their neurodevelopmental differences and support needs. Understanding support needs can be enhanced by diagnosis, but should not wait for diagnosis. ¹³⁰

¹²⁹ [Children and young people - national neurodevelopmental specification: principles and standards of care, 2021, Scottish Government Website](#)

¹³⁰ Cited directly above

Figure 2: Neurodevelopmental Services within the agreed Children and Young People's Mental Health and Wellbeing model in Scotland.



5.4 Northern Ireland

The DoH reports that the Strategic Planning and Performance Group (SPPG) is committed to working closely and collaboratively with HSC Trusts to develop innovative, cost effective, co-produced, quality and evidenced based services that can meet NICE compliant pathways for ADHD diagnosis and support.

However, as there are no regionally commissioned services for adult ADHD, there is no requirement for HSC Trusts to manage a dedicated and comparable ADHD waiting list. Similar to the situation in England, a lack of comprehensive information on adult ADHD could make planning ADHD services more difficult.

Currently, in Northern Ireland, following an ADHD diagnosis in childhood, appropriate care and medical intervention are discussed and agreed upon with the child and their family. In circumstances where a child requires medication following a diagnosis, they will remain under the care of a lead professional within CAMHS, or Community Paediatrics. HSC Trusts offer a range of additional post-diagnostic ADHD support to children and their families, such as online parental workshops, family support packs,

signposting to community or voluntary organisations, and post-diagnostic interventions by ADHD nurse specialists.¹³¹

Access to integrated assessment and support pathways for people with neurodevelopmental presentations, such as ADHD, is currently being considered as part of the Emotional Health and Wellbeing Services Framework. These services may not be identified as ADHD specific but will be designed to meet the needs of all children and young people, including those with ADHD and those awaiting an assessment for the diagnosis of ADHD. These pathways will include help and support for parents and families identified as in need of emotional health and well-being support.¹³²

In the longer term, the Mental Health Strategy 2021-31, which sets out the strategic direction of mental health services over the next 10 years, commits to continued development of an understanding of specialisms within a general mental health service, and this includes services for those with ADHD. In particular, Action 23 acknowledges that some individuals will always need specialist help and support, often in the long term. All practicable help and support will be provided to people in need, keeping in line with the vision of person-centred care and a “no wrong door” approach.¹³³

5.5 Republic of Ireland

In Ireland, assessment and treatment for children and adolescents with ADHD are offered through the CAMHS. ADHD is one of the most frequently diagnosed conditions within CAMHS, particularly in the 5 to 9-year-old age group.¹³⁴ Similarly, individuals with comorbid ADHD and intellectual disabilities have access to Mental Health Intellectual Disability Services, which provide comprehensive care for ADHD. However, prior to 2017, there were limited public services available for adults with

¹³¹AQW 2052/22-27 [To ask the Minister of Health what support is available to children with a diagnosis of ADHD: and whether he intends to expand those services.](#) AIMS Portal

¹³² Cited in fn 156

¹³³ Department of Health (2021) [Mental Health Strategy 2021-2031](#) Northern Ireland

¹³⁴ HSE National Clinical Programme (2020) [ADHD In Adults Attention Deficit Hyperactivity Disorder. Model of Care for Ireland.](#) Clinical Design and Innovation, Health Service Executive.

ADHD who did not have an intellectual disability.¹³⁵ The Health Service Executive, which provides all public health services in Ireland, recognised this as a deficit and established a working group in 2016 to develop a model of care for adults with ADHD.

There is currently no specific data on the prevalence of ADHD in Ireland, however, recent research published in 2023 revealed that approximately 15% of working-age adults attending general adult CMHTs may have undiagnosed ADHD.¹³⁶

Data on mental health disorders among Irish young people is limited, and studies showed significant variance in rates.¹³⁷ One source of data is from the 7,563 children and families that participated in the large-scale longitudinal study ‘Growing Up in Ireland’ and were surveyed at 9 months old (in 2008-09), at three years, five years and nine years (in 2017-2018). Results from the 2017-18 survey indicated that 6% of the children had ADHD.¹³⁸

In January 2021, the National Clinical Programme (NCP) for adults with ADHD in Ireland was formally launched by the Minister of State for Mental Health and Older People.¹³⁹ Developed in partnership with ADHD Ireland and the College of Psychiatrists of Ireland, the program involves a multidisciplinary working group chaired by a clinical lead and including service user representation. Together, they developed a model of care aligning with NICE guidelines, covering core values, assessment, treatment, service organisation, governance structures, required resources, and education/training.¹⁴⁰

The Model of Care is based on the Sláintecare (strategy for reforming Ireland’s health and social care system) principle of integrated care across mental health, primary care, voluntary services, and third-level education/employment services. It

¹³⁵ Cited directly above

¹³⁶ Adamis, D et al (2023) Prevalence of attention deficit hyperactivity disorder in an adult mental health service in the Republic of Ireland. *Int J Psychiatry Med*; 58(2): 130–44.

¹³⁷ [Prevalence of mental health disorders in children and adolescents in the Republic of Ireland: a systematic review - PubMed \(nih.gov\)](#)

¹³⁸ [Growing Up in Ireland Key Findings: Cohort '08 At 9 Years Old](#)

¹³⁹ [Health Service Executive Ireland. ADHD in Adults. HSE, 2021](#)

¹⁴⁰ [Health Service Executive Ireland. ADHD in Adults. HSE, 2021](#)

also fulfils a key recommendation of Sharing the Vision (national mental healthcare policy), requiring phased implementation and evaluation of appropriate service responses to support adults with ADHD, in line with the National Clinical Programme for Adults with ADHD.¹⁴¹

The NCP has collaborated with the voluntary sector, ADHD Ireland, and academic partner UCD School of Psychology. Several projects have been completed, including a study on suicidality and self-harming in people with ADHD, with ongoing studies focusing on ADHD in third-level students, women, and the psychosocial impacts of ADHD in adults.¹⁴² Additionally, two service augmentations – an app on adult ADHD and the Understanding and Managing Adult ADHD Programme – are underway; both are currently undergoing formal evaluation. However, recent reports indicate that no funding has been provided by the HSE for the programme in 2024.¹⁴³

The NCP for adult ADHD recommends developing adult ADHD clinics aligned with the National Model of Care to offer assessment and multi-modal treatment. Based on prevalence evidence and existing mental healthcare policies and structures, the NCP suggests establishing one ADHD clinic team for every 250,000 - 400,000 working-age adults. With the current population, this implies the need for 11 such teams, along with an extra team to collaborate with Forensic Psychiatry Teams serving Dublin prisons.¹⁴⁴

Each adult ADHD clinic is proposed to be led by a consultant psychiatrist and comprise a multidisciplinary team including a senior psychologist, senior occupational therapist, clinical nurse specialist, and administrator. These public clinics would serve adults over 18 years old and accept referrals from general adult and child CMHTs, with team premises provided by the local mental health service.

¹⁴¹ Raaj S, Wrigley M, Farrelly R. [Adult ADHD in the Republic of Ireland: the evolving response](#) *BJPsych Bulletin*. Published online 2023:1-4.

¹⁴² Cited directly above

¹⁴³ [Adult ADHD awareness on the rise, but State services falling far short, committee told](#), the journal, June 2023

¹⁴⁴ Cited in fn 139

This model of care ensures that adults with a potential diagnosis of ADHD can access a specialist multidisciplinary service providing an integrated, person-centred and evidence-based multi-modal response in accordance with NICE guidelines.¹⁴⁵

The model includes ADHD-specific medication and non-pharmacological interventions, both group and individual. The focus is on enabling people with ADHD to manage their symptoms and develop strategies to do so, with a view to discharge within a 6-12-month period in line with the ethos of enablement.

However, the full implementation of these proposed clinics hinges on additional funding.¹⁴⁶ Following the 2021 launch, the Department of Health allocated 1.3 million euros to establish three pilot services, overseen by the clinical lead. By 2022, three pilot services were operational, and further funding from the 2022 Estimates Process funded an additional four ADHD teams. As per the latest report, two of these teams are operational, a third was slated to begin in summer 2023, and the fourth was expected by Quarter three of 2023.¹⁴⁷

Recent media reports have highlighted that additional funding to complete the rollout of the 11 clinics has not been provided, leaving at least 50% of the country without access to dedicated adult ADHD services through the HSE.

As part of the implementation of the adult ADHD NCP, an evaluation of the three pilot sites is underway, conducted by the University College Dublin School of Psychology over a two-year period. This evaluation aims to assess various aspects, including the referral rate, confirmation of ADHD diagnosis, demographic and psychosocial attributes of ADHD patients, interventions provided, outcomes, and patient feedback on the service received. Additionally, there is a separate evaluation arm focusing on the impact of the service model on adult mental health services. Based on the evaluation results, adjustments to the model of care will be made as necessary.

¹⁴⁵ National Institute of Health and Care Excellence. [Attention Deficit Hyperactivity Disorder: Diagnosis and Management](#). NICE, 2018.

¹⁴⁶ Cited in fn 139

¹⁴⁷ [Adult ADHD Public Service Provision](#)

6 Conclusion

The UK's services for ADHD are struggling to cope with increasing demand, particularly since the COVID-19 pandemic. The waiting times for both child and adult ADHD assessments have reached unprecedented levels.

The escalating problem of ADHD waiting times has been exacerbated by a lack of specific targets for these waiting times and the absence of routinely collected national data. Treatment delays carry a human and financial cost, imposing a burden on health, social care and the criminal justice system.

Stakeholders highlight the need for a different approach to ADHD service delivery for both adults and children.

Recent developments in Wales and Scotland suggest that developing neurodevelopmental pathways for assessment could provide a responsive solution. Reconfiguring GP services, including developing specialist roles, has also been suggested.

Integrating a national target for starting diagnostic assessments within three months into NICE guidelines and developing data collection systems to monitor compliance with targets has also been proposed as a starting point.

Undoubtedly, early identification, diagnosis and effective management of ADHD are critical to removing some of the challenges faced by people with ADHD. It is unlikely, though, that most UK residents with ADHD will have access to this unless there is a substantial change in the financing and resource allocation of ADHD treatments.