

ADHD and ASD Pathways and Support

Consultation response from RCGP Scotland

The Health, Social Care and Sport Committee is undertaking an inquiry into Attention Deficit and Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) pathways and support. The inquiry seeks to:

- Understand why waiting times for diagnosis and management of ADHD and ASD are reportedly long, including the drivers of increasing demand,
- Understand how these conditions are diagnosed and managed,
- Understand the impact of delays on individuals,
- Explore solutions to improve capacity of services, referral pathways and support.

The inquiry will consider the following in relation to neurodevelopmental pathways for ADHD and ASD:

- Referral pathways
- Assessment, criteria and treatment thresholds
- Waiting times
- "Waiting well" and support pre-diagnosis
- Transitions between services
- Funding
- Workforce
- The impact on individuals of receiving a diagnosis or waiting for a diagnosis
- 1. Please tell us your views on the aims of the inquiry, in relation to the people you support, and describe any opportunities for improvement you have identified.

Please provide your response in the box provided.

RCGP Scotland welcomes the opportunity to respond to this consultation. As the membership body for general practitioners in Scotland, we exist to promote and maintain the highest standards of patient care.

Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD) are neurodevelopmental conditions that can have a profound impact on an individual's wellbeing, as well as how they interact with others, and process information. We note from the Committee's press release that, as of March 2025, there were 42,530 children awaiting neurodevelopmental assessments across Scotland (excluding NHS Grampian).

ADHD is typically characterised by symptoms such as hyperactivity, difficulty concentrating, and impulsive behaviour. It is estimated that ADHD affects approximately 5% of school-aged children and between 2.5% and 4% of adults.

ASD is a developmental condition that influences how a person communicates, interacts socially, and processes sensory information. Individuals with ASD often experience challenges with social communication and may engage in repetitive behaviours. Current estimates suggest that around 3% of the population are affected by ASD.



To illustrate the scale of need, if 4% of Scotland's population were affected by ADHD, this would equate to approximately 220,000 individuals. However, RCGP Scotland does not advocate for universal assessment and diagnosis for all individuals within this group. Rather, we believe that diagnosis, treatment, and support should be prioritised for those who face significant functional impairment as a result of ADHD and/or ASD.

We recognise that current waiting lists for ADHD or ASD assessments by psychiatry are extremely long and that this can have a negative impact on patients who require assessment, diagnosis and support. There are particular challenges facing adults who are seeking a diagnosis for neurodevelopmental disorders. The National Autism Implementation Team (NAIT) examined the provision of adult neurodevelopment assessment pathways and found that in 2021 only 1/14 Scottish health boards provided ASD and ADHD assessment for adults; 1/14 provided for neither and 12/14 provided for one but not both. This goes some way to explaining a poor responsiveness by the NHS to a large increase in adults seeking assessment. Often there has been no local provision, or even if there is patients may face long waits.

Mental health workload, demand and capacity.

ADHD and ASD represent a growing and increasingly significant area within mental healthcare in an NHS with significant workforce and resource constraints. This disconnect between resource, workforce and demand is particularly acute in the context of neurodevelopmental disorders. Specialist mental health services are already under considerable strain, and as a result, many individuals seeking a diagnosis turn to their GP. These patients often face long waits for specialist assessment and, in the interim, repeatedly return to general practice, further exacerbating pressures on already overstretched primary care services. We urge the inquiry to take these systemic challenges into account in its deliberations.

In September 2023, <u>Audit Scotland published a report</u> on adult mental health in Scotland, noting that "An estimated 41 per cent of GP appointments involve a mental health issue. Increasing the availability of mental health and wellbeing services in primary care could help to prioritise prevention and early intervention and decrease pressure on specialist services." We echo the concerns of GPs across Scotland who feel that general practice is not being adequately resourced at a time when patient need and case complexity are rising. This persistent mismatch between demand and available resources has resulted in a service that is increasingly under strain.

Waiting times, diagnosis and management.

RCGP Scotland welcomes the Committee's proposed investigation into waiting times for neurodevelopmental assessments. We emphasise the importance of clarifying the term "reportedly long" in this context. It is unclear whether this phrasing reflects a lack of reliable data or an absence of transparency regarding waiting times for assessment and diagnosis of neurodevelopmental conditions. Greater clarity is essential to inform effective policy responses.

Audit Scotland's 2023 report on adult mental health noted that, "NHS boards are still struggling to meet waiting times standards. The system is fragmented, and accountability is complex, with multiple bodies involved in funding and providing mental health services. This causes complications and delays in developing services that focus on individuals' needs."



We observe significant variation across Health Boards in how neurodevelopmental assessments are managed. The absence of clear and accessible information on waiting times creates uncertainty for both GPs and patients. This lack of transparency undermines trust and can damage the therapeutic relationship, particularly when patients are left to manage their condition for extended periods without specialist input.

Moreover, the current model of single-condition pathways may not be appropriate for individuals with co-occurring conditions such as ADHD and ASD, which frequently occur together. A more integrated and person-centred approach is needed.

The Royal College of Psychiatrists in Scotland has highlighted that 2.5–4% of the population may benefit from treatment for ADHD, aligning with English estimates of 1 in 20 children and 3–4% of adults. This represents a substantial proportion of the Scottish population. It is also important to recognise that current demand includes a significant element of 'catch-up' as awareness of these conditions increases among both patients and professionals.

In April 2023, <u>NHS England acknowledged</u> that demand for autism assessments had exceeded capacity, attributing this in part to rising awareness and expectations. Scotland's specialist mental health and psychiatry services are similarly under pressure, and GPs are increasingly required to manage patients awaiting assessment for prolonged periods. This additional workload must be recognised in future funding and workforce planning decisions.

RCGP Scotland recommends that the Committee's aim to "understand how these conditions are diagnosed and managed" be expanded to explicitly include general practice. We propose the revised aim: "To understand how these conditions are diagnosed and managed, including in general practice."

Similarly, the aim to "understand the impact of delays on individuals" should be broadened to consider the impact on the healthcare workforce and on other patients with mental health needs. We are concerned that the increasing number of presentations involving mild symptoms of ASD or ADHD may be affecting access to care for individuals with more severe mental illness and greater functional impairment.

Finally, we strongly urge the Committee to include a specific line of inquiry on health inequalities. In Edinburgh, for example, referral rates for adult neurodevelopmental assessments are lower in socioeconomically deprived areas - despite evidence that need is likely to be higher. There are well-established links between deprivation, co-morbidity, and poor mental health outcomes. NICE guidance highlights that individuals with ASD are at increased risk of social and economic exclusion, and that their needs are often overlooked by healthcare, education, and social care professionals.

Pathways for ADHD and ASD.

RCGP Scotland believes that the patient journey for ADHD and ASD begins well before referral and presentation to general practice. Many individuals and families navigate a complex landscape of symptoms, uncertainty, and informal support before seeking medical advice. It is therefore essential that the inquiry considers the pre-referral phase and the pivotal role of GPs in guiding patients through this process.



GPs are often the first point of contact for individuals concerned about ADHD or ASD, and play a critical role in managing expectations, providing interim support, and navigating fragmented referral pathways. The inquiry must recognise and reflect the centrality of general practice in ADHD and ASD pathways and support.

Assessment threshold.

RCGP Scotland welcomes the Committee's intention to review assessment criteria and referral thresholds for neurodevelopmental conditions. We would encourage the Committee to broaden this focus to include how such information is communicated to the public. Clear, accessible communication is essential to managing expectations and supporting appropriate help-seeking behaviour.

Historically, Scottish Government campaigns have encouraged individuals experiencing mental health difficulties to consult their GP. However, these messages have not always distinguished between the need for early diagnosis of severe mental illness and more transient or self-limiting emotional distress. This lack of nuance risks the overmedicalisation of normal human experiences and contributes to increased pressure on general practice.

We are also concerned about recent reductions in funding for third sector organisations that provide vital support to people with mental health challenges. These cuts have further strained general practice, which is already operating under significant pressure.

While mental health nurses can play a valuable role within the expanding multi-disciplinary team (MDT) in general practice, our members report that such roles remain uncommon. Moreover, mental health care is not typically managed by other MDT professionals, meaning that this responsibility continues to fall largely on GPs.

We regret that previously promised funding to recruit an additional 1,000 mental health specialists has been paused. This workforce was meant to support general practice, delivering "a mental health and wellbeing service for every practice by 2026." We urge the Committee to consider this as part of its deliberations.

Both NICE and SIGN guidelines recommend that patients with mild symptoms of neurodevelopmental conditions be managed within primary care without referral. As a result, the workload associated with these conditions has increased significantly, often beyond what is reflected in referral numbers to secondary care. However, referral remains the only route to specialist assessment and formal diagnosis. This creates a challenging dynamic, particularly when parents are convinced that a diagnosis for their child would be beneficial.

GPs are left to manage a complex and often emotionally charged set of responsibilities; addressing patient expectations, explaining referral criteria, supporting those with mild symptoms, and caring for individuals, often in distress, who face long waits for assessment and support. It is essential that the Committee recognises the impact of these demands on general practice as it considers the broader system of care for neurodevelopmental conditions.

Waiting well and transitioning between services.

RCGP Scotland welcomes the Committee's decision to consider the concept of "waiting well" and the support available to patients prior to assessment and diagnosis. This is a critical area of concern, particularly given the extended waiting times for specialist



neurodevelopmental assessment. Consideration must be given to how information and guidance can be effectively communicated to both GPs and patients. GPs are increasingly managing patients in the community who may wait years for specialist input, and patients need clear, realistic expectations about what support is available during this period.

As previously stated, the establishment of clear and consistent referral thresholds would benefit both clinicians and patients. Members report instances where referrals are rejected after significant delays, requiring GPs to re-refer patients and resulting in a second prolonged wait despite clear evidence of substantial impairment due to ADHD or ASD. This not only undermines patient trust but places additional strain on general practice and specialist services alike.

We welcome the Committee's focus on the impact of receiving or waiting for a diagnosis. It is essential to recognise the emotional and practical toll on individuals who remain on waiting lists for extended periods, often without adequate support. The inquiry should also consider the systemic strain this places on general practice, which is left to manage patients who await secondary care assessment.

Funding and workforce.

RCGP Scotland urges the Committee to ensure that its considerations around funding and workforce planning fully reflect the increasing workload associated with neurodevelopmental conditions in general practice. As previously outlined, the high demand for services and ongoing workforce challenges within specialist psychiatric care have resulted in a growing number of patients with ADHD and ASD being managed in primary care settings, often for extended periods before specialist assessment is available.

It is important to note that current referral criteria typically require patients to demonstrate significant functional impairment before they are eligible for referral to secondary care. As a result, the rise in referrals does not accurately capture the full extent of the workload in general practice, where GPs continue to support individuals with milder symptoms or lower levels of functional loss who nonetheless require ongoing care and monitoring.

Since 2010, the proportion of NHS Scotland's budget allocated to general practice has declined from 11% to just 6.5%, despite a growing population and increasing patient complexity. This reduction in funding has occurred alongside a significant expansion in workload. <u>Audit Scotland's recent review</u> of the 2018 GP Contract found that funding for general practice had decreased by 6% in real terms since 2021/22.

Workforce trends are equally concerning. Since 2013, the number of Whole Time Equivalent (WTE) GPs in Scotland has fallen by 6%. Any investigation into ADHD and ASD pathways must therefore acknowledge the dual crises of workforce and workload currently affecting general practice.

We strongly recommend that the Committee consider the implications of these trends on general practice when making recommendations on service design, funding allocations, and workforce planning.

Private assessment and shared care agreements.

RCGP Scotland firmly believes that any investigation into ADHD pathways and support must include consideration of private care and the implications of shared care agreements. In response to long NHS waiting times for neurodevelopmental assessments, a growing



number of patients are turning to private providers for diagnosis and treatment recommendations.

This trend is placing increasing pressure on general practice. ADHD now constitutes the majority of adult neurodevelopmental referrals, and patients who receive a private diagnosis frequently request that their GP initiate or continue prescribing high-risk medications under a shared care agreement. However, there are significant concerns regarding the consistency and quality of private assessments, particularly when compared to NHS secondary care standards.

Following a private diagnosis, GPs are often expected to:

- Assess the validity and clinical robustness of the diagnosis and the credentials of the assessor, many of whom may be unfamiliar or operate remotely.
- Compensate for the lack of access private providers have to a patient's full medical history, comorbidities, and current medications.
- Enter into a shared care agreement with a non-NHS provider, a practice not endorsed by the <u>British Medical Association</u>.
- Ensure appropriate specialist follow-up, which would typically be arranged automatically within NHS pathways.

These responsibilities are time-consuming, clinically complex, and currently unfunded under the General Medical Services (GMS) contract. Some GP practices have adopted policies not to prescribe medication following private assessments, which has led to instances of GPs facing threats of legal action.

RCGP Scotland urges the Committee to investigate:

- The quality and regulation of private ADHD assessments and diagnoses.
- The volume of patients accessing private providers.
- The impact of shared care arrangements on general practice workload.

We strongly advocate that general practice be appropriately resourced and reimbursed for any work arising from shared care agreements with private providers. These arrangements are not mandatory, carry significant clinical and legal risk, and represent a growing burden on an already overstretched workforce.

Solutions to improve capacity, referral pathways and support.

Public understanding

Estimates suggest that between 10–20% of the population may exhibit traits or milder symptoms associated with neurodevelopmental conditions. RCGP Scotland has a longstanding ask of the Scottish Government for a national conversation to promote public understanding of what the NHS can realistically deliver, which is relevant in this context. It is neither appropriate nor feasible for all individuals with mild traits to receive specialist assessment and diagnosis.

Increasingly, the responsibility for managing public expectations has fallen to GPs, who are often left to explain long waiting times and limited capacity of specialist services. This places additional strain on general practice and risks undermining the doctor-patient relationship.



We urge the Scottish Government to lead a sensitive and well-informed public messaging campaign that provides clear, accessible information for individuals with mild symptoms or traits. This should include guidance on when specialist assessment is appropriate, and support for self-management strategies, including signposting to third sector organisations and community-based resources. Such an approach would help ensure that specialist services are prioritised for those with the greatest need, while still offering meaningful support to others.

Child and Adolescent Mental Health Services (CAMHS)

RCGP Scotland recognises that Child and Adolescent Mental Health Services (CAMHS) offers an ideal route for early diagnosis, treatment, and support for children and young people with ADHD and ASD. Early intervention is strongly associated with improved long-term outcomes, including better functioning and prognosis in adulthood.

However, we acknowledge that CAMHS is under significant and sustained pressure. GPs report considerable inconsistencies in access and outcomes. Some children and young people receive extensive assessments, while others with more pronounced functional impairment wait for longer periods without specialist support. Furthermore, GPs with strong clinical confidence in identifying neurodevelopmental conditions report that their referrals are still being rejected, despite <u>national initiatives</u> aimed at reducing such occurrences. In many cases, these patients must be re-referred and placed at the back of the queue, compounding delays and distress.

It is also important to recognise that young people and adults with untreated, severely impairing ADHD are at <u>increased risk of developing substance use disorders</u>. This highlights the urgent need for consistent and timely pathways for ADHD assessment, diagnosis, and treatment, particularly in the context of Scotland's ongoing drug and alcohol death crisis.

We are also concerned that referrals from socioeconomically disadvantaged backgrounds are not being prioritised, despite deprivation being a well-established adverse prognostic factor associated with higher levels of need and poorer outcomes. This raises serious questions about equity of access and the alignment of services with population health needs.

General practice

General practice delivers the majority of mental health consultations in Scotland, and this represents a growing share of GP workload. While earlier presentation to general practice can be beneficial for patients with severe mental health conditions, the increasing number of presentations involving relatively minor or transient mental ill-health is placing additional pressure on an already overstretched system.

GPs are committed to delivering whole-person care to all patients presenting with mental health concerns. However, the current workforce is not equipped to meet the rising demand. Distinguishing between transient symptoms and more severe mental illness is inherently complex and requires time, expertise, and continuity of care, further underscoring the urgent need to expand the GP workforce.

The growing number of presentations for neurodevelopmental conditions also demands recognition from decision makers. GPs are often the first point of contact for individuals with symptoms of ADHD, ASD, and other mental health issues. These consultations are



frequently extended and repeated, reflecting the complexity of care required. This increase in workload must be matched by parallel increases in funding and workforce capacity.

National guidance places significant responsibility on GPs to assess functional impairment and determine referral eligibility. SIGN 145 notes: "Impairments in each of the areas relevant to ASD diagnoses occur along a continuum from minimal to severe and categorical diagnoses inevitably involve defining a cut-off." Similarly, the Royal College of Psychiatrists Scotland's good practice guidelines for ADHD state: "We recommend that a threshold is set for referral to specialist services, as ADHD is a spectrum disorder and ADHD traits are ubiquitous." Given the importance of the initial GP consultation in the patient journey, additional resources must be directed to general practice to support this role.

Furthermore, ASD and ADHD represent a growing and increasingly complex area of healthcare. To ensure GPs are equipped to provide high-quality care, RCGP Scotland calls on the Scottish Government to ensure Protected Learning Time (PLT) is accessible for all GPs. Currently implementation is patchy, and arrangements for PLT should be easily understood, with support at a national level. This would support ongoing education and training in neurodevelopmental and mental health conditions, ensuring that general practice remains a safe and effective first point of contact for patients.

Public expectation

RCGP Scotland supports the development of a public health campaign, or broader national conversation, focused on managing expectations around ASD and ADHD. With estimates suggesting that 10–20% of the population may exhibit mild traits or symptoms, it is essential to communicate clearly that individuals who are functioning well are unlikely to be referred for specialist assessment. Instead, these individuals should be offered psychoeducational support, which could be delivered through digital platforms, group sessions, or third sector organisations.

The Scottish Government and NHS Scotland must take responsibility for communicating referral thresholds clearly and consistently to the public. This will help ensure that specialist services are reserved for those with significant functional impairment, while still providing meaningful support to others.

Public expectations can also be tempered through greater transparency in waiting list management. Patients should be prioritised based on clinical need, as is standard practice in other areas of healthcare. Additionally, further investigation is required to understand why practices serving socioeconomically deprived populations have lower referral rates, despite poverty and lower educational attainment being recognised adverse prognostic indicators for ASD and ADHD.

Improving assessment

In March 2023, the National Autism Implementation Team (NAIT) published findings from its examination of neurodevelopmental referral and assessment pathways. The report concluded that diagnosis rates for patients referred to specialist services was 86.14% indicating that referrals are, in most cases, appropriate. However, it also highlighted significant challenges, stating: "There will be a need to consider ways that existing resources can be used differently or ways teams can work differently, along with the need for new resources to meet a previously unmet need... There is no route map or existing plan to emulate and roll out." RCGP Scotland recommends the Committee consider the findings of this report in its deliberations.



GPs continue to report wide variation and a lack of coherent planning in assessment pathways. As previously noted, some patients receive comprehensive and potentially overly lengthy multidisciplinary assessments, while others, despite presenting with more significant functional impairment, remain on waiting lists for extended periods. This inconsistency undermines equity and efficiency within the system.

We encourage the Committee to examine the variation across referral and assessment pathways and to consider how both general practice and specialist services can adapt to absorb growing demand and address unmet need. One potential solution may lie in the development of GPs with Extended Roles (GPwERs), who could contribute additional capacity to ADHD and ASD pathways. These clinicians could operate either as part of the specialist workforce or within enhanced service models in primary care, helping to bridge the gap between generalist and specialist provision.

Conclusion

RCGP Scotland hopes that this Committee's consultation on ASD and ADHD pathways and support will shed light on the current challenges facing both specialist psychiatry and general practice, the resulting impact on patients, and ultimately contribute to ensuring timely access to assessment and diagnosis for individuals experiencing impairment, and support for those with moderate to mild traits and symptoms.