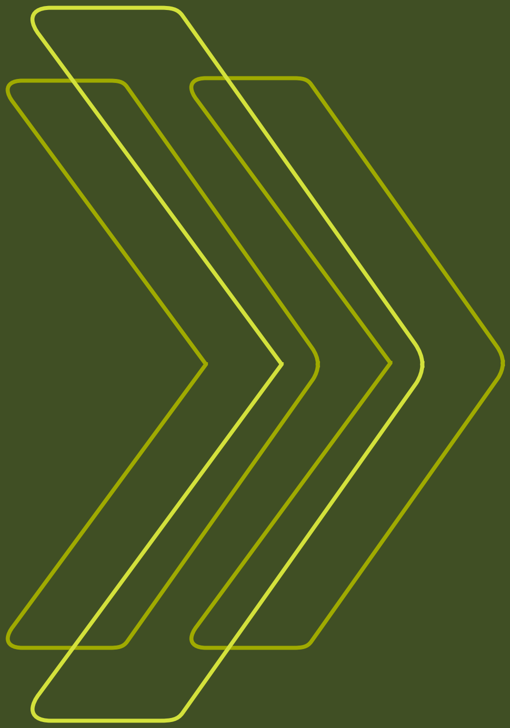
The King's Fund

Ideas that change
health and care

Adult ADHD assessments and diagnosis

Data and service provision



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About this report

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Contents

Key messages

- Evidence from a variety of sources indicates growing demand and long waiting lists for adult attention deficit hyperactivity disorder (ADHD) assessments. However, the full picture is unknown due to wide variation in data collection and reporting in local services.
- In the absence of national standards for adult ADHD data collection, different English NHS mental health and community trusts have developed their own measures, leading to significant variation in reporting on waiting times for adult ADHD assessments.
- Addressing variation in adult ADHD data collection and use will be fundamental to developing high-quality, comparable data that can be used nationally to understand, plan and improve services.
- Referral and triage data varies, with different trusts adopting different screening processes and clinical tools. However, this is a key intervention for managing demand for adult ADHD assessments. Current variation risks confusion for patients and quality concerns for staff.
- Inconsistent collection of demographic data makes it very difficult to measure and monitor potential inequalities in access to and experience of adult ADHD services. Similarly, a lack of patient outcome data means services cannot assure themselves meaningfully of the impact of their services.
- Services in many areas are attempting to address some of the issues they are facing. However, levels of demand for adult ADHD services limit staff capacity to make improvements to data collection and use.
- Providers and commissioners of adult ADHD services want guidance on and support with improving adult ADHD data consistency, but will likely find it difficult to implement consistency where staff are already struggling with capacity in their day-to-day work.

- We recommend the creation of national guidance and requirements on data collection and reporting for ADHD triage, assessment, diagnosis and treatment. We also recommend the development of national standards for ADHD records and coding, which both NHS and independent providers should be required to adopt.
- National bodies should do more to engage with providers and clinical staff to ensure a clear understanding of what data is needed, why it is important and why more consistent data collection is required.

1 Introduction

Attention deficit hyperactivity disorder (ADHD) is defined as 'a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development' (National Institute for Health and Clinical Excellence 2025a). It can impact on an individual's ability to focus, make decisions, and manage their emotions and behaviour.

There is no definitive national data on the prevalence of ADHD, but it is suspected to affect 3–4% of adults in the UK (National Institute for Health and Clinical Excellence 2025b). ADHD UK (2020) estimates that 80% of people with ADHD (including children) are undiagnosed.

In recent years, various sources have used freedom of information requests to shine a light on significant waiting times for adult ADHD assessments (Burns *et al* 2024; ADHD UK 2023; Smith 2023). These reports highlight waiting times that in many places extend over multiple years. There are also concerns that the length of wait for an ADHD assessment is growing as more people present with symptoms. A 'consensus group' of ADHD experts in the UK – including health professionals, academics and ADHD patient groups – declared in 2021 that 'evidence-based national clinical guidelines for ADHD are not being met' (Young *et al* 2021). Furthermore, when national policy initiatives have referenced ADHD in the past decade the focus has mostly been on services for children and young people.

The first guideline for ADHD from the National Institute for Health and Clinical Excellence (NICE) – including ADHD in adults – was published in 2008 and following this the first specialist clinics were established in various areas of England. More often, however, ADHD care was considered part of generic, secondary adult mental health care.

Different NHS services manage the ADHD assessment process in different ways; the screening or triage of people on the waiting list for assessment is one feature of this. Additionally, the Right to Choose policy means people can opt to be assessed by a non-NHS provider, and these providers also have widely varying processes and systems.

There is no official list of ADHD services, no agreed measure for calculating waiting times for assessments and no duty to report relevant data, so the full picture of ADHD assessment and diagnosis is unclear.

The growing demand for adult ADHD assessments (for example, McKechnie *et al* 2023) has no clear cause. There are suggestions that ADHD has historically been underdiagnosed; therefore recent demand levels are a feature of increased awareness and recognition of ADHD, particularly in adult services where previously it was assumed that people 'grew out of' ADHD (ADHD UK 2023; CHS Healthcare 2023; McKechnie *et al* 2023; Asherson *et al* 2022). Other reasons given for growing waiting lists include the Covid-19 pandemic (for example, CHS Healthcare 2023; Müller-Sedgwick and Sedgwick-Müller 2023), acute pressures and the underfunding of mental health services more widely (for example, CHS Healthcare 2023).

Although the data is limited, what evidence there is suggests that 'undiagnosed and untreated ADHD imposes a significant socioeconomic burden' (Vibert 2018). This is mostly associated with the impact on employment for adults with ADHD. There is limited data on how ADHD interacts with other health conditions. However, undiagnosed ADHD may impact on people's access to other health and care services – for example, where people are late for appointments for other health conditions and/or struggle to manage them consistently.

Additionally, issues around data privacy and use are relevant to this topic, and it is important to have clear and agreed data collection processes to reassure people about how their data is used for service improvement.

In this context of rising demand, coupled with limited official data, the Department of Health and Social Care asked The King's Fund to find out what data is available, collected and used to plan and manage adult NHS ADHD assessment services locally. While this is a narrow scope, having an accurate understanding of the data (in the absence of current agreed measures, as noted above) is a vital first step to understanding where improvements might be made.

② Methodology

This project had two overarching research questions:

- What data is available locally on ADHD assessment services for obtaining a diagnosis (that is, not the fuller pathway of assessments resulting in a diagnosis and a needs-based care plan) and waiting times for these services?
- How is this data used to plan and manage assessment services?

We undertook this work in three phases.

First, there was an initial scoping phase, which consisted of three activities:

- a rapid review of published literature
    - the King's Fund Library Database and online searches produced 57 documents, including research papers, policy documents, news/opinion pieces and other grey literature, with our search terms including [ADHD] OR [attention deficit] OR [neurodivers-] AND [data] OR [service]
- scoping conversations with senior clinicians
    - we approached the Royal College of Psychiatrists' special interest group on neurodevelopmental psychiatry, and they supported us to speak with four senior psychiatrists specialising in adult ADHD diagnosis
- a review of board papers
    - we randomly sampled 11 mental health trusts where we could identify a specialist adult ADHD service (but *see* the next bullet point) and accessed the two most recent trust board papers, as well as the two most recent integrated care board papers, to look for discussion of local ADHD services and what data was presented/discussed at this level
    - several articles in the literature review indicated difficulties in identifying adult ADHD services so we took the approach of searching mental health and community trust websites for 'adhd' or 'neurod', to cover neurodiversity and neurodevelopmental angles, and searching for references to adult ADHD and services – where this produced no search results, we also searched for the trust name and 'adhd' on an internet search engine and checked the first page of results.

Second, using our learning from the scoping phase, we chose sites that appeared notable in terms of their use of ADHD data – for example, undertaking data-focused improvement initiatives. This was to try to understand what might be working well in terms of the collection and use of data, but a key limitation of this approach is that the picture in our sites is inevitably biased towards places that are actively trying to understand and improve their use of data.

We aimed to include up to 10 sites in our research, with a maximum of 20 interviews, including a mix of providers and commissioners in each site, and initially contacted trust chief executive officers to facilitate this. In practice, we found recruitment challenging. While we do not know why some people chose not to respond to our research request, in general, we understand that participating in research might seem a low priority in the context of the wider system pressures that the NHS is facing. In the end, we successfully undertook 10 interviews in six sites, including nine providers and five commissioners, between February and May 2024. To deepen our data collection, we also completed a full review of board papers in mental health and community trusts where we could identify a specialist adult ADHD service (amounting to a further 25 services).

Third and finally, we undertook engagement with key stakeholders to sense-check our findings and test key messages. We convened a lived-experience panel of adults who had recent experience of being assessed and diagnosed with ADHD and reimbursed them for their time. We recruited these participants from NIHR People in Research. We also convened a separate panel of clinical leaders and leaders from the voluntary, community and social enterprise sector, chosen based on their interest in adult ADHD. In both groups, we presented the findings and then facilitated discussion to understand people’s perspectives and answer questions about the project. We made amendments to a draft of this report based on these conversations – for example, ensuring the report was clear and up front about why understanding the data is important, developing more sensitive framing of emotive findings, and ensuring points raised about the data in our research that were out of scope of the main research questions were still reflected in the report.

3 Research findings

In this section we first set out how data is collected in clinical information systems, the types of data collected and caveats that interview participants highlighted to us. We then explore how data is used, what providers and commissioners see as key points for data improvement, and the wider context that participants set their contributions in.

Clinical information systems

Clinical information systems are central to how services collect and manage their data. The board papers we reviewed rarely mentioned them, but we heard about four different patient information recording systems in use across our six fieldwork sites: CareDirector, RiO, SystmOne and a bespoke system. Three sites used RiO and another trust was planning to transfer to RiO – transitioning away from a legacy bespoke system built on Microsoft Access, due to the software being outdated and no longer fit for purpose.

All of the branded clinical information systems had certain limitations in terms of capturing data. One provider described how, in their experience, RiO was not good at capturing diagnosis data, so instead they kept it on an Excel spreadsheet. Similarly, they were not impressed with its ease of use: ‘Opening a referral on RiO takes [administrators] a longer time than it takes me to clinically triage it’ (site B provider). Meanwhile, a commissioner in another site described how they could not distinguish between first referrals, repeat referrals and other types of appointment on their system:

> *We can’t differentiate between people that have been referred into the service for an assessment for the first-time assessment, people that have been referred for an annual review, or people… [that have been] re-referred back because there’s a different issue… Because it’s not coded in that way on the system. So, we can only see those people that are being referred into the service and are waiting. So, in this top box here… ‘How many weeks have services users been on caseload?’, I can’t tell whether or not all of those people are waiting for the first assessment and diagnosis.*
> (Site A commissioner)

Another provider described SystmOne as ‘not a great reporter’, with no generic reporting mechanisms, and how this ‘creates a whole industry… in terms of clinical systems reporting’ (site D provider). They also discussed having to manually extract things like diagnosis and trend data as this is not facilitated in SystmOne. While working with this software in another trust, the provider had experienced similar issues there too. A further provider who used CareDirector described their inability to record socioeconomic information and review their diagnosis data (*see* the ‘Diagnosis data and conversion rates’ subsection for a fuller discussion):

> *We review the diagnostic data, that’s more difficult because our electronic patient record works on ICD-10 [International Classification of Diseases – version 10] rather than ICD-11. And ADHD isn’t a category in ICD-10, so we’re waiting for an update, so we’re trying to work around that.*
>
> (Site E provider)

(The International Classification of Diseases [ICD] is an international system for coding medical diagnoses and is reviewed and updated periodically, hence there are different versions.)

As with many areas of health and care, we also heard about a desire for local organisations to be on the same system.

> *Wouldn’t it be lovely if we were all on the same system?… Wouldn’t it be nice if we didn’t have to scrabble around and ask each other things and people have to repeat the story?*
>
> (Site B provider)

Finally, one set of board papers, and two sites, described how staff capacity to process referrals in these systems was an issue and, in some cases, meant backlogs of referrals awaiting processing:

> *We get 300 to 400 referrals each month that need to be processed. And then we also need to answer telephone and email queries for 10,000 people on the waiting list, so it just doesn’t move – nothing moves quickly.*
>
> (Site B provider)

Referral and triage data

Collection

Services in our study were gathering symptoms data (for example, past medical history and evidence of ADHD) and demographic data (for example, age, gender and ethnicity) through screening or triage processes to better understand and prioritise people on their waiting lists. Triage and referral processes varied across areas, and so did the data that flowed from them. Most sites talked about referrals coming solely from general practitioners (GPs). Two had additional routes through primary care mental health services/single point of access arrangements, where GPs would first refer people to these services for initial screening and they would then refer people on to specialist ADHD services as necessary.

We heard about several different ways in which data was collected and several different types of data processed for triage/screening purposes across the different sites. The examples presented here all come from different sites.

- A primary care mental health service does an initial screen for ADHD among other conditions (although this has led to issues regarding consistency of data). The ADHD service provider worked with this service to add a bespoke childhood screening element because they were getting referrals where symptoms did not start in childhood (a key criterion for an adult ADHD diagnosis).
- A clinical psychologist assesses GP referrals and uses a validated ADHD screening measure.
- An assessment is made of the data that both the patient and their GP have provided on the referral form.
- Regarding prioritisation, the numbers of contacts with other mental health services or other priority criteria (for example, pregnant people) are used.
- One commissioner highlighted that there was no standard referral form across the different services they commissioned in the same area, and a provider in another site described how, depending on their referral route into the service, a person might experience two different triage processes.

One provider described how previous work to understand the local waiting list had led to them bringing in a triage process. They had identified that many people were getting referred without the minimum necessary information, so the conversion rate from referral to diagnosis was low (less than 50%). However, they noted that they were still struggling to make this work with GPs, in terms getting them to understand why certain information was being requested at referral stage. The role of GPs was particularly highlighted in relation to referral as the data that trusts collect is based on this initial contact.

We learnt about work ongoing with GPs to improve the consistency of reporting and data in both our fieldwork and board paper analysis, such as through:

- training, for example to develop a common understanding of criteria for referral
- developing robust referral criteria and a screening tool to reduce the number of inappropriate referrals, and ensure information is transferred to secondary care as needed
- trying to reduce demand on GPs by asking patients to do an online questionnaire on referral to assessment.

Using data from referral and triage processes

Triage seemed to be a key intervention for services, to manage demand. Sites were using or planning to introduce online and/or clinical tools to collect further data to:

- support screening
- inform clinical prioritisation
- reduce assessment time.

> *We try to cut the data different ways. Initially, we were using it primarily to try and understand where, from a QI [quality improvement] perspective, we might be able to interrupt or make change or do things differently to address some of this demand [for example, introducing a screening tool to shorten assessment times].*
> (Site A commissioner)

We heard about four different tool types for these purposes in our interviews: the QbTest, the Wechsler Adult Intelligence Scale (WAIS) and the Adult ADHD

Self-Report Scale (ASRS), while one site was developing a bespoke tool. The diversity of approaches means data use might get better locally, but also become even more fragmented across England as a whole. Furthermore, despite triage being intended as a way to manage demand for ADHD assessment, some services were also overwhelmed with demand for triage. We heard about one- and two-year waits simply for triage in several sites.

> *I think the thing to be honest that we're all struggling with is… the level of demand is so high, it just feels to a certain extent it doesn't really matter how much you do about triage processes.*
> (Site C provider)

Waiting-list data

All services in our fieldwork reported recording waiting-list data. They used a variety of measures:

- numbers and sources of referrals
- waiting-list size
- shortest/longest wait.

Only one site described attempting to estimate how long people joining the list may have to wait. They did this by dividing the total number of people on the waiting list by the number of assessments their service could undertake a month. This assumed that the number of assessments conducted would not change, and was a rough estimate that they felt was more realistic than the wait for the person at the top of the list.

Board paper analysis indicated extensive variation in waiting-list data reporting across trusts. Several did not mention or report figures on adult ADHD in the two sets of board papers we sampled for each trust. Where they did report on it, different measures were used, for example:

- size of waiting list
    - number of patients waiting – for example, East London NHS Foundation Trust, Greater Manchester Mental Health NHS Foundation Trust and Leicestershire Partnership NHS Trust

    - number of referrals a month – for example, Greater Manchester Mental Health NHS Foundation Trust
    - number of services in the area where the waiting list has increased – for example, East London NHS Foundation Trust
- length of waits
    - referral to treatment/length of wait time – for example, Leicestershire Partnership NHS Trust and South West London and St George's Mental Health NHS Trust
    - length of the longest and shortest wait times – for example, Greater Manchester Mental Health NHS Foundation Trust and South West Yorkshire Partnership NHS Foundation Trust
- how far the trust is meeting waiting-list targets (some trusts are measuring this against the 18-week referral-to-treatment waiting-time standard, although this is not technically applicable to ADHD; others have their own waiting-time targets)
    - percentage meeting waiting-time targets/performance monitoring – for example, Leicestershire Partnership NHS Trust, Norfolk and Suffolk NHS Foundation Trust and Northamptonshire Healthcare NHS Foundation Trust.

Table 1 on page 15 shows the types of data that services in our fieldwork told us they were collecting. In almost every conversation, participants also talked about their waiting times, and made strong caveats about the quality of their data, so these are also discussed later in the report. Please note: we were not asking for sites' actual data (as opposed to types of data), so these examples are from more qualitative, semi-structured conversations.

Table 1 Data that the six sites in our research collected

	Site A	Site B	Site C	Site D	Site E	Site F
Data	Waiting times The number of referrals How many people are being referred on a monthly basis How many people are attending appointments on a monthly basis How many weeks service users have been on a caseload	Information about caseloads and the number of times people have been seen How many people have been assessed How many people have been assessed within four weeks How many people are waiting for assessment The longest wait for pending assessment The median wait for assessment The shortest wait	Referrals per month, waiting-list size per month and waiting times Referral-to-assessment times and referral-to-treatment times Caseload size The time from date of referral to date of assessment	A count of: • referrals into the service • several different waiting lists	Length of wait for patients and average length of wait Date of referral Referral numbers and numbers of people assessed	Who is referred A count of: • who is screened and it is agreed they should have a first assessment • assessment • diagnosis • ADHD caseload
Referral source	GPs	GPs	GPs and mental health single point of access (not possible to differentiate)	GPs refer to the primary care mental health service, which refers people on to specialist ADHD services	GPs	GPs

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Table 1 *continued*

	Site A	Site B	Site C	Site D	Site E	Site F
Referral numbers	100 referrals a month In 2023/24, every month, referrals have increased by 100%, going from 50 referrals a month to 100, to 200	300 to 400 referrals a month	Currently 200 referrals a month Also described as approximately 1,500 referrals a year by two different commissioners each	Pre-Covid-19, 800 referrals a year, roughly Post-Covid-19, 2,000 plus referrals a year		Peak of 700 referrals in a month but on average somewhere between 300 and 500 a month
Waits	Majority of people are waiting for assessment for more than 48 weeks	Nearly 10,000 people are on the waiting list The wait for an assessment is 5 to 10 years	2,600 people are waiting for triage to determine if they require assessment 3,000 people have been triaged as suitable for assessment There will be no new assessments for approximately 12 months*	Not currently doing assessments except for those flagged as high risk*	Currently seeing people from 2021 for initial assessments Waiting list is around 4,000 people	

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Table 1 *continued*

	Site A	Site B	Site C	Site D	Site E	Site F
Commissioning	Latest assessment is that an additional £700,000 would be needed to address the current level of demand (but it is increasing)	Commissioned as a block contract (no specific number of referrals but accepts every referral received)	A neighbouring place commissioned about 50 assessments a year in site C Site C commissioners do not commission a specified number The last service specification is from 2013 (for a service for autism spectrum disorder (ASD)/ co-morbid ASD and ADHD)	Commissioned to see 200 people a year (for assessments, titration – finding the right dose of medication – and annual reviews) Have only managed to do more than that 'once or twice since 2018'	Block contract commissioning	Spot purchasing arrangement (non-recurrent)

* There were different reasons for sites not doing new assessments. In one site, they described being short-staffed. In another, their integrated care board had asked them not to start anyone new on medication due to wider medication shortages, and so they were focusing on annual reviews of people already in the service rather than on assessing people for ADHD or starting medications.

Data for identifying risk of harm to patients

Several sites described collecting different types of data associated with risk as part of triage and referral processes. It was unclear why these were so variable, and it was not possible to follow this up in the fieldwork. The types of risk we heard about included:

- categorising people as routine or complex presentations
- long waits (that is, additional risks that may build up as people remain untreated)
- co-morbid mental health conditions
- pregnant people

- people who have children under the age of 12 where they are the primary caregiver
- prison leavers
- armed forces personnel/veterans
- people who have open safeguarding concerns.

One site described using its organisation-wide patient risk assessment. However, with the exception of routine or complex presentations and long waits, there did not appear to be a consistent way to categorise risk. Risk data was used in two main ways:

- to prioritise people for assessment (moving people identified as high risk to the top of the waiting list)
- to understand risk associated with waits.

Board papers discussed flagging service-wide risks. Some sites had ADHD waits logged in their formal risk register; others highlighted risk, but not in a formal register. Key aspects included increasing waiting times and risks associated with long waits. Two trusts – Devon Partnership NHS Trust and Kent Community Health NHS Foundation Trust – noted that there was no clear plan for the management of the waiting list, and no national framework or operational guidance for this pathway, so sites do not have a way forward in solving this issue. There were some other references to data collected about risk or the need to reprioritise waiting lists, but with no further detail.

Diagnosis data and conversion rates

Diagnosis data and conversion rates were not generally discussed in board papers. Fieldwork sites perhaps helped explain this, as several described struggling to record or make use of diagnosis data – for example, to understand conversion rates from referral to diagnosis.

> *I couldn't tell you, other than anecdotally, what percentage of people that sit on the waiting lists and are assessed receive a positive diagnosis, what percentage that is*

> *of the number of people that are referred and then what percentage are referred [for] a medication [assessment] – we just don't know.*
>
> (Site A commissioner)

Sites highlighted several different reasons for this, including a lack of consistent recording and an inability to properly code data. The codes available on patient information systems were not always able to distinguish the types of data that participants wanted – for example, data coding might be based on the International Classification of Diseases – version 10 (ICD-10) rather than ICD-11. ADHD is a diagnostic category in ICD-11 but not ICD-10. ICD is a global system for coding medical diagnoses and is reviewed and updated periodically, hence there are different versions. A few sites described holding diagnosis data manually (for example, in Excel spreadsheets) due to this.

Despite SNOMED CT – a collection of medical terms specifically designed for electronic records systems – being the agreed standard data coding terminology for NHS health care providers since 2014 (**NHS England 2023**), no one referred to this in interviews, using only the ICD-10 and ICD-11 terminology. This would benefit from further investigation.

When we asked participants what data they still needed, diagnosis data and conversion-rate data (as linked items) were the second most common type that providers and commissioners requested.

> *We have a quarterly meeting where we review the diagnostic data, that's more difficult… because our electronic patient record works on ICD-10 rather than 11. And ADHD isn't a category in ICD-10, so we're waiting for an update, so we're trying to work around that, so it's more complicated… we're looking at using hyperkinetic disorder [a related disorder] as a diagnostic instead but we need a disclaimer that whilst we're using it for coding, we're not using it for diagnosis. Because people that we would diagnose with ADHD might not necessarily have hyperkinetic disorder.*
>
> (Site E provider)

A further concern was regarding the quality or longevity of people's diagnoses. Examples included childhood diagnoses needing to be reconfirmed due to childhood ADHD sometimes being seen to improve in adulthood (remittance), or private diagnosis reports that do not meet the local quality standards that NHS professionals need to be able to diagnose and prescribe medication. Both issues speak to concerns about the quality of assessments – and therefore diagnosis data. These were described as leading to people rejoining waiting lists for assessment and contributing to overall demand.

Demographic data

Demographic data is important to understand the population with ADHD. Several previous research studies have suggested, for example, that gender is a key variable, with men much more likely to be diagnosed with ADHD than women. However, there is also evidence that this levels out with age, as women tend to be diagnosed later in life (McKechnie *et al* 2023; Nyein and Oyewole 2021).

Demographic data linked to ADHD data only appeared in one set of board papers, where waits for ADHD and autism assessments combined were presented, by ethnicity. In the fieldwork, sites described capturing several types of demographic data:

- ethnicity
- age
- gender
- gender identity
- pregnancy
- sexuality.

Data capture varied. Two sites described this data capture as standard at point of referral, with one having regular checkpoints to make sure the data was recorded accurately. Other sites had less success. One participant said that they considered that the NHS does not really understand why capturing demographic data is important – perhaps echoed by a colleague in another site who suggested that demographic data ‘doesn’t help us do anything’ in relation to service planning or provision. We also heard about missing data, including data on ethnicity and gender identity, often because it was not being recorded. These issues are not unique to ADHD services, however – issues with demographic data quality have been highlighted throughout the NHS (Raleigh and Goldblatt 2020).

Differing views on data quality could also exist between provider and commissioner. In one site where we spoke to people in both roles, while the provider thought they were capturing demographic data well, the commissioner described it as not being coded, suggesting some lack of communication between the two. Only one commissioner told us about using demographic data to explore their local population. They found that age seemed to have the biggest variability (mostly younger people seeking assessment), with gender and ethnicity 'pretty evenly split'.

Patient experience and outcome data

Almost all of the people we interviewed in the six sites wanted more patient experience and outcome data. Most only talked about using the Friends and Family Test (FFT) (a generic NHS-wide way for patients to provide feedback on whether they would recommend the service) when we asked what data of this type they collected. One trust, however, did describe a questionnaire they used to get feedback on the service, which assured the trust it was working well. This questionnaire asked about wellbeing, managing home life, family and relationships. It was sent out after people's medication had been agreed and finalised (so capturing the whole care pathway, not simply up to the point of diagnosis). The provider reported that the waiting list was the main issue people raised, rather than the service itself: 'We get really positive comments once people are actually in the service – it's the waiting times that is the issue' (site D provider). Another site shared a similar assessment from its analysis of complaints data – 'we don't get any complaints once people are in the service', compared with people who are waiting (site F provider).

We saw little discussion of patient experience or outcome data in the board papers – two trusts described gathering patient experience or patient satisfaction data. The Friends and Family Test was most frequently noted.

Data limitations

Participants described several concerns with or limitations to the data they discussed. For example, we heard about:

- being unable to be assured of the true picture of waits, due to:
    - coding limitations in the clinical information system, which meant it was not possible to differentiate between first-time referrals and reviews/re-referrals (whether people were waiting for a first assessment or a medication review)
    - not all referrals being logged onto the clinical information system or backlogs in inputting them due to volume and lack of capacity
    - internal waits, for example from first contact to assessment, not being measured
    - not being able to check how many waiting lists one person with ADHD is on (for example, an NHS waiting list and the Right to Choose provider waiting list)
- being unable to track referrals because:
    - they are incorrectly recorded or missing at source
    - the coding is too generic to support this
- being unable to track patient journeys due to limitations in the clinical information system
- inconsistency of coding, limited by human factors – that is, clinicians or others not entering data in the same way.

One commissioner noted that because the integrated care board did not require ADHD to be monitored, not much detail was recorded. Additionally, paper-based referrals were still in use in one site, meaning all data has to be manually entered into the system, limiting what they can analyse. Finally, a provider described not recording referral-to-assessment time as they were not currently doing new assessments – they were focusing their service capacity on reducing waits for people already diagnosed who were awaiting support.

Sharing data

Generally, data on waiting times was shared upwards to trust executives as part of performance monitoring, and on from there to integrated care board commissioners. The one exception was an integrated care board commissioning team for a service serving two integrated care board areas – despite being told about data going up ‘to integrated care board level’ from the trust, we heard this was not reaching the integrated care board team we spoke to.

However, we heard about various issues even when data was shared:

- getting the integrated care board to be responsive to the issues being shared
- a lack of money from commissioners to address the issues being shared
- a lack of consistency in the data different providers shared with the integrated care board
- the data requested not being that helpful for understanding the issues in the service.

In two sites, there appeared to be inconsistencies between what the provider said was happening and what the commissioners were able to see in the data.

We also heard one example of data being shared regionally (with NHS England’s regional team, after the trusts in the region had asked NHS England to review it) and nationally (as part of the NHS mental health services dataset). Board paper analysis highlighted several trusts using their data to escalate the issue of ADHD waits, locally with commissioners, and regionally and nationally.

A few sites mentioned the number of freedom of information requests they receive from journalists and others. As one provider noted, ‘that is an incredible amount of work… the journalist requests for information are quite burdensome’ (site C provider). Having data more readily available, such as national datasets, could reduce this burden (which may have positive knock-on impacts on capacity for other work in the service).

Local data sharing was also discussed. We noted difficulties with data flow between primary and secondary services, for example GPs not consistently filling in referral forms. More positively, one provider described internal data sharing within the trust to support developments in the service. They also discussed sharing data with the public in terms of making waiting-list data available, although they wanted to go further with being clear about what that means for a person joining the list.

Using data to improve services

In the fieldwork sites, many improvement plans were still hypothetical. Some promising examples we heard about in our scoping work turned out:

- to not be happening
- to be at very early stages of implementation
- to have failed due to capacity issues
- to be held up by wider service transformations.

The extract below demonstrates an example of this:

> *Interviewer: One of the reasons that we picked your area to look at, we saw somewhere that you had some QI [quality improvement] projects going on around your ADHD service.*
>
> *Respondent: Yeah. So originally, it was going to be the ADHD service that did it. Having had a look at the work that was involved and knowing how small our team is, we just could not commit to that.*
> (Site D provider)

We heard about hopes that with more data and/or more investment, service transformation could be possible, particularly for people on the waiting list. These were mainly around screening and triage to support assessment prioritisation and the speeding up of the assessment process (*see* the 'Referral and triage data' subsection above).

One provider talked about a monthly steering group where they share information such as activity and caseload dashboards. They discuss ideas for improvement and have lots of ideas for longer-term initiatives, such as introducing new roles. However, they also noted the constraints they faced:

> *Again, it goes back to – we've got what we've got, and we've got to make do with [that and do] the best job that we can do with that. And that's the main discussion really.*
>
> (Site F provider)

Although our interviewees often highlighted issues with data collection and use, almost all described having lots of data to understand what their services look like. One provider told us that, in their experience, ADHD data was relatively straightforward to collect compared with data for other local services. They also managed autism and young people's trauma services, and described how, in relation to these (with multiple services involved and a very high level of risk), the ADHD pathway is 'really clear', with routine data gathering at certain points. Services talked about different examples of using data:

- to forecast waits and inform modelling

  > *The second thing we were trying to do is to understand the demand and do some demand and capacity [analysis] and to be starting to think about future models and what that might look like. What is the optimum way of providing a service? How could we provide it differently?*
  >
  > (Site A commissioner)

- to understand where improvements might be made

  > *We've got tons and tons of data collection reports that we can have access to… It's useful in terms of painting a picture, in terms of where the service is at, especially when we're thinking about redesign and where we want to be… to explain how we know these things that we're doing. We're using Power BI [a data visualisation tool] at the moment and that's specifically for the wait-list validation, to try and show how many referrals we get from individual GP practices. How many of those would be classified as routine or complex? So then we can inform future models in terms of what it looks like on the ground of people walking into a GP surgery.*
  >
  > (Site B provider)

> *We provide an update weekly, which we will then share internally throughout the trust and use for [our] own development. We'll use that to look at our capacity, our efficiency. So, for instance, if we're looking at how many assessments we offered this week, if it's below our max capacity, we'll be looking at why that might be and where we need to be more efficient… because of the huge demand, we have to think about where we're allocating our resource, pretty much on a week-to-week basis. We don't have enough resource to offer enough assessments and to triage all assessments in a week. So, we might be looking at… reducing some time from triage in order to be able to boost our assessment numbers or vice versa. So, that would be where we were focusing on – where's the biggest demand at the moment, and how can we think about what we're offering accordingly?*
>
> (Site E provider)

- to inform a business case

> *As well as waiting-list numbers and what that tells us, it's interesting to analyse the costing. So, all of the different Right to Choose providers have different tariffs, and we're starting to pull all of that together. You can really start to see how much it costs to send somebody to them as opposed to [an NHS provider], and we're already starting to build up persuasive arguments to the ICB [integrated care board] and say: 'Actually, it's scary, yes, you're spending all this money there, but if we can somehow get control of it, and create a service that costs this much instead of that much, perhaps we can do more – we can reinvest locally, we can create pathways locally that are more efficient, that patients will then choose.' So you're not going against patient choice, you've just created something that's better, more efficient and more local.*
>
> (Site E commissioner)

Site E had included people with ADHD in its population health segmentation model. This enabled the site to identify the other health services that people with ADHD were using and intersections with other health-related data, to look for associations that might enable targeting of different interventions. Although this data concerned service use after the point of diagnosis, and so is outwith the scope of this report, it was a notable example of analysing data from ADHD services together with other health data.

In the board papers, a few trusts described using data dashboards to understand their services, for example to enable more timely reporting to the integrated care board and wider system (such as Gloucestershire Health and Care NHS Foundation Trust). Generally only references were made to these dashboards, but a commissioner showed us one of them in a fieldwork interview. They described how it enabled a quick summary of different waiting-list data types, but again highlighted data-quality issues.

In the board paper analysis, many trusts identified service redesign as a need. Examples of service redesign we heard about are as follows.

- East London NHS Foundation Trust described developing a self-referral pathway that has improved the quality of referrals.
- Sheffield Health and Social Care NHS Foundation Trust described developing a tiered service so service users can be assessed and/or diagnosed at point of entry.
- Kent Community Health NHS Foundation Trust described shaping new assessment and review models with provider partners.

More specific initiatives included:

- waiting-list validation – ensuring that people who have been seen by other services are removed from the ADHD service waiting list (South West Yorkshire Partnership NHS Foundation Trust)
- project/steering/working groups in multiple areas to address specific issues – for example, how GPs manage referral requests (East London NHS Foundation Trust)
- a task and finish group, including business managers, to agree a standardised methodology for tracking waiting times (Kent Community Health NHS Foundation Trust)
- Kent Community Health NHS Foundation Trust and Mersey Care NHS Trust are applying a clinical harm review process for those waiting more than 52 weeks.

Many of these redesigns have data implications.

Joined-up working

We heard about multiple examples of joint working between services or with commissioners to address issues relating to ADHD data, including:

- commissioning extra administrative resource to address a referral backlog and get the referrals onto the clinical information system
- commissioners looking at data regarding the join-up between ADHD services and neurodevelopmental and autism services or between ADHD services and addiction services to support patients
- work on a business case for the integrated care board on what the overall ADHD service model needs to look like to reduce waiting times
- agreed quality standards for diagnosis reports across the integrated care board and providers to reduce variation
- whole integrated care board work to improve consistency of reporting.

> *ADHD has got a specific workstream across [the integrated care board] looking at how can we do things differently… [The integrated care board] has got several main places, and we've been talking about actually aligning our referral processes, aligning our triage assessment processes.*
> (Site C provider)

> *There are conversations being had at [an integrated care board] level, trying to make it more consistent in terms of reporting, place by place, so that we know that we're comparing apples with apples, instead of apples with pears, in terms of, what's their first appointment, in terms of numbers.*
> (Site E commissioner)

What providers and commissioners want

ADHD data

We asked our interview participants (providers and commissioners) what data they did not currently have that would be helpful to them in terms of supporting their service. Patient outcome data was the most common type of data that they wanted. Diagnosis data (linked to conversion-rate data) was the second most common type that our interviewees requested. Two respondents also discussed wanting to have a better understanding of private sector demand, spend and impact on NHS services. Other types of data wanted were specific to providers or commissioners.

Providers' data needs could be broadly categorised into three themes:

- data relating to patients' co-morbidities and contact with other services
- data that enabled them to understand their patients' journey more clearly – for example, why appointments were missed, end-to-end contact with services and clearer trend data
- the ability to use the data – including cross-referencing co-morbidities, and systems that enabled the innovative use of data, for example being able to automate processes.

These themes are linked to prevalence and so may help providers in the identification of those likely to have ADHD (National Institute for Health and Clinical Excellence 2025b; Sarfraz *et al* 2017).

Commissioners also had some distinct data needs:

- a better understanding of:
  - who is waiting (for example, better demographic data)
  - how long they are waiting for
  - how this compares to other integrated care systems
- better consistency of:
  - requirements for providers to collect and share data
  - referral forms across different providers
- a clearer picture of Right to Choose contracts across different systems.

> *We've been talking to [providers] about this being an opportunity to record all sorts of social demographic data, risk factors, health inequalities, poor outcomes… We're not doing it yet, but it's an aspiration going forwards, to get much better at understanding our cohort.*
>
> (Site E commissioner)

We asked all our interviewees what would support improvement in the use of ADHD data, both locally and nationally. Consistency on a national level was a key theme. Several highlighted unwarranted variation and quality concerns due to a lack of standardisation. Consistency covered several topics, including:

- being able to benchmark/understand comparisons between different places (looking at the history of NHS Talking Therapies data from different areas was mentioned as a good example of this, although not fully positive)
- having consistency about definitions and how to report, such as agreed methods for calculating waiting lists:
    - consistency of what is captured and on what timescales
    - the need for a trusted assessment model.

> *If there was more of a national steer as to, 'this is what you will collect, and this is the frequency you will collect it', then that would actually make our lives a bit easier.*
>
> (Site B commissioner)

> *What it feels like, at the moment, is that there's very little standardisation. In the whole area. And as a National Health Service that's really weird.*
>
> (Site D provider)

Another key ask from the national level was for more public recognition – of the scale of the issue, and how everyone involved might go forward. Board paper analysis highlighted several related asks, including a clearer plan for how to manage waiting lists and new ways of working/service transformation to solve the problems.

> *Making it safe and mandatory for ICBs [integrated care boards] and trusts to be honest. Report your actual waiting time, let's see the actual true picture… And NHS England probably has a job there to make people feel safe to report the truth, 'cause otherwise they're not going to get the truth.*
>
> (Site E commissioner)

Providers and commissioners highlighted limitations of the guidance from the National Institute for Health and Care Excellence (NICE). This included a level of service that is not possible to resource, and being unable to discharge patients from the service due to a requirement for annual review. It was also highlighted that the way that ADHD sits with, but is not seen as part of, wider mental health services is an issue.

> *I would like some national guidance on who should have an ADHD assessment…, what that assessment should really consist of… who should be offered what. There's NICE guidance about what should be offered but not who should be offered it in terms of clinical severity. I think that would be really useful. And what services have to and should provide, 'cause at the moment it seems up to the services.*
>
> (Site B provider)

Finally, while Right to Choose and independent sector services were out of scope for this report, we heard concerns in the course of our interviews that insufficient data included in private sector assessments can lead to quality concerns, which mean NHS services have to redo these assessments. Managing waiting times well would need to take account of all waiting lists and capacity, not just those in NHS services. One commissioner also highlighted the inability of the NHS to currently compete with the independent sector and the knock-on impacts of this on cost, for example because independent providers are paid for every intervention under a nationally set tariff. They called for agreed quality standards for NHS and independent sector assessments, as well as a standard contract for Right to Choose providers across England and the ability to track the consequences of inconsistent assessment methods.

ADHD data beyond the scope of this research

Our research questions were limited to the point of ADHD diagnosis – we were not asking about data relating to support for people who had already been diagnosed with it. However, we did hear about this kind of data on occasion in our interviews.

For example, one provider told us that they were prioritising reducing the wait for support after diagnosis, rather than assessing people only to move them to another lengthy waiting list for support. We also heard about sites focusing on capacity to complete annual reviews for those prescribed ADHD medication. In another site, a commissioner highlighted a need to understand data around the transition from children's to adult services, because young people were ending up back on waiting lists for assessment rather than being handed over to adult services at the age of 18 and being given continued support.

> *In one of our areas, they're not [given continued support by the paediatric team]. They're literally dropped at 18, and then, they have to then wait for adult services.*
> (Site B commissioner)

Finally, some types of data are, by nature, not easy to collect. Data on waiting-list dropouts, numbers who were refused referral from their GP and misdiagnosis was not data that was discussed in the fieldwork. However, our lived-experience group flagged this data as of interest and it could shed light on patients' experiences.

Wider context of the findings

Although not directly related to our questions about data, most of our interviews inevitably strayed onto the wider context of ADHD. It was clear from the interviews that the services we spoke to were struggling in the context of high demand, a lack of national expectations for services and challenging financial circumstances.

> *We're all stuck here at the moment with [this] wicked issue.*
> (Site F provider)

A sense of unsustainability and a lack of clarity came through strongly in the interviews. And it was remarkably difficult to compare things across areas. Different sites experienced different problems, which related to the diversity of commissioning arrangements, service models, patient information systems and referral mechanisms, as well as human factors (staff capacity, training and so on). Additionally, the impacts of wider health system issues were apparent. For example, a lack of joined-up information technology, integrated care system restructures and recruitment challenges all impacted on how ADHD services could respond to demand. All sites described under-resourcing in terms of staff. We also heard about a lack of capacity limiting their ability to free up staff for training. Two of the most common themes were how to define or understand ADHD, and the extent of demand for services. We summarise the key issues raised below.

Defining ADHD

From our fieldwork interviews and our stakeholder conversations, it appears that the growth in the awareness of and demand for ADHD services has led to questions about the value and purpose of diagnostic categorisation, and its relationship to access to services for assessment and treatment. In particular, people seem to be raising questions about what is meaningful in terms of providing appropriate support and treatment.

There were some striking differences of opinion about reasons for the growth in demand among interviewees. We represent these here to highlight that, even among providers and commissioners of services, it is possible to detect sentiments that are detrimental to the ADHD community. One commissioner told us about debates they witnessed among their colleagues over:

> *…whether [ADHD is] a personality trait, or whether or not it's a mental health issue.*
> (Site A commissioner)
>
> *My concern really is about the growth of ADHD – I think there's massive overdiagnosis. I think the thresholds… of moderate to severe impact [have] gone.*
> (Site C provider)
>
> *I think to use the data to understand prevalence would be really helpful, and to challenge this perception at the moment, that, 'oh everyone's got ADHD'. No… that's not the case, it's just people with ADHD are realising they've got ADHD all of a sudden, and wanting some help and support, and realising that that's out there.*
> (Site E commissioner)

There were also different opinions about the value of diagnosis in the context of how to manage demand.

> *If the data can show us that people are really good at self-diagnosing, I think that could really help us with challenging the diagnostic process. Because if people are correct, why do we need to make assessments so rigorous? Why do we need to make assessments so expensive? If people can [say], 'I think I've got ADHD', and we [say], 'I think you're probably right', much more quickly, you can have those really*

> *helpful conversations with people more easily, and help them to look through the lens of ADHD more easily.*
> (Site E commissioner)

> *Are we asking people actually do they want a formal diagnosis, or actually would they be happy with just some support, to be able to live their lives, and what could that look like?*
> (Site F provider)

> *If everyone is receiving a positive diagnosis anyway, why are we spending so much time wanting them to take [an assessment]?*
> (Site A commissioner)

> *Will ADHD services and autism move in [the direction of other mental health conditions], where no one will care anymore about having a diagnosis, which seems so important now...? Because you can't get to medication without it. And I think there is a real trend of social identity that comes with having a diagnosis in those particular two fields. And because so many things have been gatekeepered against until you have a diagnosis.*
> (Site B provider)

Differing views as to the legitimacy of, or need for, an ADHD diagnosis may reflect the lack of awareness and the stigma that surrounds ADHD (Young *et al* 2021), as well as concerns about the increase in demand. Views that imply a negative perception of ADHD can be concerning to people seeking or holding this diagnosis and risk damaging or losing people's trust in NHS services, even if they are not widely held. This highlights the importance of ensuring services are 'on the same page' in relation to this issue.

Demand for services

All sites reported very high demand for ADHD assessment and diagnosis services. Often this demand, and their ability to meet it, were described with quite emotive words: ‘drop in the ocean, astronomical, chaos, bottlenecks, swamped, rabbits in headlights, exponential, silly’.

Recent growth in demand was highlighted, as was some variation in demand – for example between different groups or correlated with external factors such as media coverage or certain times of the year. A few interviewees suggested increased public awareness was a cause of increased demand.

> *If you break down the entire process [of ADHD triage, assessment and treatment] that goes along, there’s a bottleneck everywhere.*
> (Site D provider)

Several problems were associated with demand. Some commissioners highlighted a lack of understanding of or ability to predict demand to inform commissioning, or commissioning being unable to keep pace. Additionally, increased demand in ADHD services was cited as having a knock-on effect on other services, for example primary care. However, rising demand was stimulating initiatives to explore and address the issue – including how to maximise efficiency of existing resource or how to do things differently (*see* the subsection ‘Using data to improve services’ above).

4 Implications

Although the sample for our fieldwork and review of board papers was small and potentially biased towards those sites that were actively trying to understand and improve their data, there are still several implications that can be drawn from our findings.

We found extensive variation in the **collection and use of data**. This finding is in line with other work undertaken on NHS ADHD services (Innovation Agency 2022). Addressing it will be fundamental to developing high-quality, comparable data that can be used nationally to understand, plan and improve ADHD services.

Data quality is a related issue, due to the limitations of clinical information systems, and inconsistencies in, or a lack of capacity for, recording data. Screening, triage and risk data is potentially valuable to inform prioritisation but current variation risks confusion for patients and quality concerns for staff. Limitations in the collection of diagnosis data make it difficult to understand conversion rates in individual sites, and therefore this data needs to be collected more consistency locally before attempting to gather it at a higher level.

Inconsistent **collection of demographic data** will make it very difficult to measure and monitor potential inequalities in access to and experience of ADHD services. Similarly, a lack of **patient outcome data** means services cannot assure themselves meaningfully of the impact of their services. Additionally, commissioners and providers do not always have a **shared view** of data or issues in their areas. This suggests that addressing these issues will not be straightforward.

Services in many areas are attempting to address some of the issues they are facing, whether by making better use of their own data or trying to ensure better consistency of data across different areas. However, **levels of demand** for services (and therefore pressures on staff capacity) are a key limitation for this work. Providers and commissioners are clear on the need for **guidance and support** in relation to improving data consistency, but will likely struggle to implement this where staff are already struggling for capacity in their day-to-day work.

Recommendations

Data on ADHD should be improved so that it can support a wider programme of improvement in services and in access to them. Accurate, consistent and sufficiently comprehensive data will be fundamental to understanding the challenges that need to be addressed, adapting to variation and changes within them, and monitoring progress.

We make the following recommendations for NHS England and the Department of Health and Social Care to work together to achieve this. Responsibility for these recommendations will move from NHS England to the Department following NHS England's abolition, which the Labour government announced on 13 March 2025 (Streeting 2025). NHS England has told us that they have already taken action on their own initiative in some of the areas where we make recommendations (bullets 1 and 8).

1. Issue national guidance and requirements on data collection and reporting for ADHD triage, assessment, diagnosis and treatment, and the waiting lists associated with them. There are some resources already available, which may be explored as a starting point – for example, the UK Adult ADHD Network has developed an Adult ADHD Assessment Quality Assurance Standard (Adamou *et al* 2024).
2. Develop – with clinicians' and providers' input – model templates for adult ADHD referrals that are compatible with the above guidance.
3. Support the development of standards for ADHD records and coding. Standards could be developed by, for example, providers of clinical information systems, professional bodies, service providers or specialist standard-setting organisations – or a combination of these.
4. Include requirements in standard contracts for both NHS and independent providers to adopt the above guidance, templates and standards.
5. Support commissioners to take a whole-system approach that takes account of capacity and waiting lists across both NHS and independent providers.

6. Issue national guidance on good practice in assessing risk to patients and using that to inform screening and triage decisions. Also issue national guidance on managing risk in people yet to be assessed or diagnosed while on a waiting list. Guidance would need to be produced by or with clinicians, providers and patient organisations.
7. Disseminate examples of good practice in defining, collecting and using ADHD data, including outcomes data. This should be targeted at both providers and commissioners.
8. Engage with providers and clinical staff to raise understanding of what data is needed in order to drive improvement plans and the importance of collecting it consistently. This could be, for example, through training materials alongside the roll-out of national model referral templates.

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