Living with ADHD

People's experiences of changes to ADHD shared care in Suffolk

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Trusted Insights

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About us & this report

Healthwatch Suffolk is your local health and social care champion.

Our services are delivered by Healthwatch Suffolk CIC - a social enterprise delivering insight and co-production to shape health and social care services.

We gather people’s experiences, and we use them to influence and improve standards of local care and support. We passionately believe that listening and responding to people’s lived experience is vital to create health and social care services that meet local needs.

For more information about us, visit www.healthwatchsuffolk.co.uk/about-us.

Our core purpose is to...

collect and share lived experience to influence better standards of health and social care.

We live and breathe...

co-production in everything possible. We are inclusive, transparent, accessible, and accountable.

This report

Together with Healthwatch Essex, Healthwatch Suffolk has been calling for people’s experiences of living with attention deficit hyperactivity disorder.

This call for feedback followed a change in NHS policies regarding the way in which people’s care and medication is managed in primary care.

ADHD, or attention deficit hyperactivity disorder, is a neurodevelopmental condition that can affect attention, impulse control, and energy levels. If not properly supported, it can impact education, work, relationships, and mental health (NHS, 2025).

Many people with ADHD rely on medication to manage their symptoms and improve daily functioning. Some people receive ADHD medication and monitoring through their GP under a ‘Shared Care Agreement’ (SCA). Under an SCA, the GP agrees to prescribe medication and complete tests (e.g., blood pressure readings), referring people back to a specialist for issues to be addressed.

Policy changes in primary care

In January 2025, local medical committees (LMCs) in Suffolk and Essex advised GPs to stop prescribing ADHD medications, returning this responsibility to specialist services. They say this change will help to ease pressures on GP practices.

In particular, the LMCs say the changes are needed to allow GPs to focus on providing the services they must deliver under the terms of their contract. GPs are not required to prescribe shared care medications if they feel unable to do so or if they are not able to do this in a safe manner – it is not a part of their contract and has always been a core part of the specialist role.

This report explores how the local policy change advising GPs to stop prescribing ADHD medication affected individuals living with the condition. It also looks at broader experiences of accessing treatment and care.

For more information about the changes regarding shared care locally, please refer to [this page](#) on the Suffolk and North East Essex Integrated Care Board website.

A broader context

In general, data suggests that accessing help, support and medication for ADHD can be highly challenging.

In Suffolk and North East Essex, 4,831 people were in receipt of ADHD medication (2024/25), which is 11.9% of the total population estimated to be living with the condition. Nationally, the prescription rate is less than one in five of the actual ADHD population, which ADHD UK says is clear evidence of under-diagnosis[1].

People can also experience variation in the support available, depending on where they live. Analysis of ADHD prescription data by ADHD UK shows wide differences in ADHD prescribing nationally. It found an over three times difference between ICBs - ranging from 19.6% of their potential ADHD population to just 6.1% of their potential ADHD populaton.

In 2025, Healthwatch England commissioned YouGov to run two rounds of polling about adults' experiences of ADHD[2]. It also ran its own survey, asking people with both diagnosed and possible ADHD to share their experiences.

Key findings from this research included:

- The impact ADHD has on people's lives can be profound, affecting work, mental wellbeing and household management.
- An ADHD diagnosis can be life-changing – giving people a better understanding of themselves and improving their ability to manage their health and wellbeing.
- People are experiencing long waits, pushing them to pay for a private assessment. This is creating a two-tier system based on whether people can afford to pay for care.
- There are hidden waits for ADHD referrals. Along with the long wait for an assessment, people mentioned referral delays and a reluctance to ask for support due to the long waiting times.
- People want support while they wait for an ADHD assessment, but most are not getting any.
- People with ADHD or suspected ADHD can be reluctant to speak to their employers about support.

The research also revealed that, even after they are diagnosed, people faced another wait to get the medication they needed to help them manage their condition.

> "This survey has been an opportunity for people to tell us whether the change in policy for ADHD medication prescribing has had any impact on their lives.
>
> **"By giving feedback, we will be able to best understand if people's care, treatment and support have been affected, so that we can take action and help address those issues."**
>
> *- Dr Andrew Kelso (Former Medical Director, NHS Suffolk and North East Essex Integrated Care Board)*

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[1] ADHD diagnosis and access to medications in the UK (ADHD UK) - Click here to view reference

[2] Healthwatch England - 'How to improve ADHD support for people' - Click here to view this reference

In particular, some people described facing a battle with their GP to get them to take over shared care and give them NHS prescriptions (even where the assessment and titration were undertaken via Right to Choose). People with ADHD described how devastated they had felt having waited a long time for a diagnosis, a further wait for titration, and then being rejected by their GP.

With all of this considered, the aim of this report has been to support ICBs and primary care leaders to review:

- The impact of local policy changes regarding shared care agreements in primary care.
- How similar policy changes could be implemented differently in the future.
- The effectiveness of current ADHD support in Suffolk and how this presently varies across the county.

We hope the report will support our local decision-makers to learn from people's lived experiences.

The response to this report

We asked NHS leaders and the Suffolk Local Medical Committee to respond to people's lived experiences. You can find their official statements in the appendix of this report (see from page 22).

> "Not being able to have a reliably available supply of medication during the school/college exam season has a high and lasting impact."

Who took part?

A total of 87 people responded to the online survey.

- Fifty-three were individuals living with ADHD, and 34 were completed by parents or carers on behalf of someone with ADHD.
- All responses – including demographic information – refer to the person with ADHD, not the parent or carer.
- Almost half of respondents (48%; 42) were aged between 25 to 49. Additionally, 15% (13) were aged 50 to 64, and another 15% (13) were 12 years or younger.
- Participants were asked how old they were when they were diagnosed with ADHD. The largest group (46%; 40) were diagnosed between the ages of 25-49. This was followed by 24% (21) who were diagnosed at 12 or younger, and 13% (11) who were diagnosed between 50 and 64.
- Fifty-nine per cent (51) were female, and 39% (34) were male. One respondent was non-binary.
- Most participants were 'White: British/English/Northern Irish/Scottish/Welsh' (85%; 74), followed by 'White: Any other White background' (7%; six).

This document mentions the term 'Right to Choose (RTC)' in relation to ADHD care and support - what does it mean?

Under the NHS, people have a legal right to choose a mental healthcare provider and to make a choice about their mental healthcare team. This important right means that, for instance, should people decide the waiting time for an ADHD assessment is too long, they can choose alternative providers.

There are a number of clinics throughout the UK that can offer Right to Choose ADHD and/or ASD assessments. To become a Right to Choose clinic provider, the clinic must supply the same service to the NHS somewhere in England, they cannot be a private only clinic.

People can access this NHS service by referral from their GP. Under the NHS Right to Choose policy, if people are referred for ADHD or autism assessment or treatment (including medication), it is possible to choose a provider that has an NHS contract, and the medication prescribed by that provider will be funded by the NHS.

While Right to Choose allows patients to choose their specialist provider for ADHD assessment and treatment, GPs are not obligated to automatically take over prescribing and shared care agreements.

Key results - changes to prescribing

Notice of changes

Of the 87 survey respondents, 35 (40%) had received prescriptions or monitoring from their GP. Of these, 24 (69%) said their GP had already stopped or would soon stop providing this support. For 16 people, shared care arrangements had already ended, and eight were told it would end soon.

We asked respondents how much notice they received that their GP would no longer be providing prescriptions or ADHD care. Most (13; 54%) reported receiving two to three months' notice. Five people (21%) said shared care ended with no notice, and two were unsure when it would stop.

The graph (right) shows the range of notice periods reported.

Most people received a few months' notice before their shared care stopped. Eight people had not been notified at all, or were unclear.

Impact on ADHD care

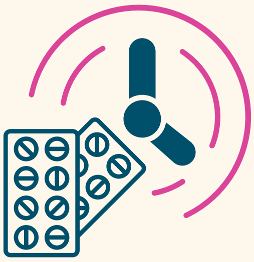
The table below shows a range of different problems people experienced when their shared care ended, and how many people reported each one.

The most common issues (reported by 63% of respondents) were increased stress and anxiety caused by uncertainty regarding their future care arrangements and a lack of information about which service/professional would become responsible to manage it with them. Problems with medication, like delays or running out completely, were also commonly reported amongst this sample.

The number of impacts individuals reported varied widely. While a quarter (25%) reported no difficulties, most people faced multiple challenges. The number of impacts reported ranged considerably from one to 10 (all the impacts listed in the survey).

	Count	%
Increased stress or anxiety due to uncertainty about care	15	63%
Being unsure who is responsible for your care and prescriptions	15	63%
Delays in receiving your medication	12	50%
Running out of medication entirely	10	42%

Receiving conflicting advice or information from healthcare providers	9	38%
Difficulty accessing appointments with your GP or specialist	7	29%
Needing to advocate for yourself more than usual	7	29%
Needing to travel further to access care and medication	6	25%
None of these apply to me	6	25%
Needing to pay for private treatment or prescriptions	4	17%
Changes to your treatment plan	4	17%



Twelve people said they had experienced delays to receiving their medication when their shared care ended, and ten indicated that they had run out altogether.

Qualitative feedback

Twenty people described what their experience had been like since they were told their GP would stop providing ADHD medication and monitoring.

Twelve respondents (63%) reported entirely negative experiences, citing issues with medication, communication and more. Six respondents described neutral or mixed experiences, while two patients had positive experiences, suggesting they had not encountered issues since they had been informed of the change.

	Count
Medication issues	7
Poor communication and information	7
Process complications	6
Anxiety and fear	5
Positive experiences	5
Impact on mental health and functioning	4
Lack of support and holistic care	3
Uncertainty and loss of trust	2
Lack of coordination between services	1
Cost barriers	1

Medication Issues

Seven people reported experiencing issues relating to their medication after transitioning from shared care, with five people indicating they had nearly or completely run out of medication. For two people, this happened because they had been unclear about who was responsible for their medication, or they were not contacted by the new service, leaving them to chase replacements.

For others, the medication was unavailable or simply not ready as expected. Other issues included two patients receiving unexpected changes to their medication, such as different doses. Finally, one person reported being notified only a day before their medication was due that it would be ready to collect, leaving no safety net.

> “Not being able to have a reliably available supply of medication during the school and college exam season has a **high and lasting impact.**”

> *“I am no longer taking medication as I do not know who is prescribing, who to talk to, or how to get my medication.”*

> *“I got the text asking me to confirm [I still needed the prescription], but then my prescription was not issued, and I had to chase it up.”*

> *“First prescription issued, but on a different basis to what was explained, so quite stressful. Due to pick up tomorrow, which is exactly 28 days since the last prescription issued, giving no safety net and only officially notified today.”*

> “It would be very difficult for my child to access their ADHD meds if they had to continually go to the service who originally prescribed them.”

Poor communication and information

Seven people reported poor communication and a lack of clear information during the transition from shared care.

A few said the information they received was not clear or enough - they did not understand the process, were not asked or spoken to about the change, or received no clear guidance. One person was not contacted by their original diagnostic service and later found out they were not on their system, also highlighting poor co-ordination during the transition.

Others were given incorrect contact details or not included in decisions about medication changes.

> *“There was no discussion with us about which alternative [medication to go with].”*

> *"When I first got the letter, I called the GP to find out how the new system would work, and staff had no idea. After a month, I called again. They still didn't know. [Suffolk GP Federation] called me quite near the deadline, so caused stress. When I filled out the permissions, I got no confirmation. The phone number and email provided for queries were wrong."*

> *"Our GP surgery didn't offer any explanation or support in this process, merely a notification that they would no longer be issuing ADHD medication."*

"The added stress, worry, and anxiety about not even getting a prescription **could lead to dire consequences."**

Process complications

Five people reported process issues or challenges that made it harder to access support or medication, or added more tasks to people's lives, increasing stress. People faced several prescription access issues, including expiring codes, failed deliveries, repeated online requests, rigid collection schedules, and unreliable confirmation systems – all adding stress and risking missed medication.

For example, one patient had to submit online requests and confirm their address for every refill, adding inconvenience. Another had anxiety about missing the eight-day window and losing access to their medication. A couple also reported difficulty accessing services, including having to travel further for routine check-ups and limited availability at private clinics.

> *"Height and weight could've been done at our GP but we had a 24-mile round trip in the car instead of a 10-minute walk."*

> *"Both processes, for mine and my son's medication, are now much more complicated and difficult to manage… when you have ADHD, things like this being overly complicated is not helpful."*

> *"It's now monthly. We were getting three months together, which made it easier for school."*

Anxiety and fear

Five people specifically described feeling anxious and concerned about their access to ADHD medication and care due to changes in the system.

Some were in the early stages of transferring, while others were already facing problems that caused ongoing worry. For example, one person said that text-based services made them feel their access to medication was uncertain or under threat.

> *"The text service is nerve-wracking because it gives me the feeling that my [child's] medication could be stopped or is under threat."*

> *"We are all very anxious and worried that my [child] will run out of their medication."*

> *"It caused a lot of anxiety, especially when my dosage was cut in half, as I was unable to function."*

> “I feel like adding extra steps to the process of ADHD when we already have executive dysfunction is annoying.”

> “It makes me wonder if GPs need more training on neurodiversity to feel more confident with shared care arrangements.”

Positive experiences

Five people shared positive experiences with the transition to new care arrangmeents. One person initially had issues that nearly led to them running out of their medication, but reported no problems had occurred since. Another described initial issues, but found their new provider to have been helpful and responsive.

Others felt the transition to new arrangements had been seamless. Two people noted that their medication is still sent to the same pharmacy they had been using, which may have made their transition smoother.

> *“Had to email them several times when they first took over, as my medication was running so low… I never received the text message the first month telling me my prescription was sent to the pharmacy. I now receive text messages first, and I’ve not had a problem.”*
>
> *“The new provider has been really helpful, always responding quickly, but there is an issue in the admin or automated system that hasn’t worked.”*
>
> *“We now get monthly text messages two weeks before medication is due, and it goes to the same pharmacy as before. It’s been fairly seamless thankfully.”*

Impact on mental health and functioning

Four people described a negative impact on their mental health or daily functioning following the transition.

One person, unable to access medication due to the cost, had to delay their studies. This meant that they will no longer graduate with their classmates. They highlighted the financial strain of needing to rely on private care as a student and explained that they try to access community food banks to free up the finances they need to afford their medication.

A parent reported that their child’s anxiety and suicidal thoughts had worsened, describing the situation as ‘one more nail in the coffin’. Another parent expressed concern that their son may run out of medication and be unable to attend school without it.

> *“My removal from shared care and lack of meds due to the change over/access to the new provider has impacted my study plans for this year. I will have to keep working through; studying without ADHD meds is not pleasant.”*
>
> *“We are already dreading it, as it will become yet another battle to try and support my child. Their anxiety and suicidal ideation has increased. This is just one more nail in the coffin.”*
>
> *“We are all very anxious and worried that my child will run out of medication. They cannot attend school without it.”*

Lack of holistic support and care

Three people described a lack of holistic support and continuity of care following the transition. Some no longer felt supported or looked after, with one person stating that they still did not understand how the new system worked a month after asking for information about it – staff at the time were unsure themselves.

Another person reported being contacted by Suffolk GP Federation about the change close to the deadline, which had caused them stress. Others felt uncertain about the changes and expressed concern that their care could be taken away completely. For one person, having check-ups with unfamiliar staff or new providers made it harder to feel safe and supported.

> *"I feel that I no longer have holistic care. The medication is only one element of wellbeing and support, and as I am now with a new provider, I dare not make any changes or rock the boat in case it gets taken away completely."*

> *"My child had to see a complete stranger for a check-up. They found it difficult to talk to a new person."*

> "I've had a lot of experiences where you fall down between services, and **no one will step up and help you**."

> "It's disappointing [that GPs are being advised to stop shared care]. It's another way for people to bury the responsibilities elsewhere, which happens frequently with any mental health but **it's very hard to get help for ADHD**."

Key results - general ADHD support

Seventy-eight people told us what it was like to access support, care and treatment for ADHD in Suffolk generally. Fifty respondents (64%) reported entirely negative experiences, 26 (33%) were mixed or neutral, and two (3%) were positive.

The table below shows the themes identified in the comments. These themes are grouped into bigger sections below that reflect key steps in people's experiences, such as obtaining a referral or accessing ongoing support and treatment.

	Count
Long wait times for diagnosis	34
Limited care and support	32
Private care-NHS barrier	25
Positive experiences	24
Forced into private care	19
Personal impact of waiting	17
Medication access issues	16
Care gaps and fragmentation	10
Struggling to get a referral	9
Delays caused by admin issues	9
ADHD-unfriendly systems	4
Beyond healthcare services	3

Getting help and referrals

Struggling to obtain a referral

Nine people experienced difficulties getting a referral for an ADHD assessment.

Some people reported that GPs lacked knowledge of referral pathways, including how to access Right to Choose, or were hesitant to use them. Others were advised against referral or told it was unnecessary, particularly in adulthood.

Some people were denied a referral based on feedback from schools or because the GP did not know them well enough. As a result, people needed to repeatedly request referrals, follow up on missed paperwork, or seek private assessment when NHS referral had not been provided.

> *"It was difficult getting my surgery to put me through for a referral for Right to Choose, but eventually they did after a lot of pushing."*

> *"Our child has a private diagnosis because they couldn't get a referral from the GP."*
>
> *"Told multiple times over the years there was no point referring me for an ADHD/autism assessment as I'm an adult and 'What difference would it make?'"*

Delays caused by admin issues

Nine people experienced delays in their ADHD assessment process due to administrative errors or inefficiencies.

Common issues included lost paperwork, referrals not being sent or followed-up, and long delays in communication between GPs and Right to Choose providers. Some referrals were mistakenly assumed to have been made, only for people to discover months later that no action had been taken.

For example, one patient thought their GP had referred them for Right to Choose a year earlier, but found out that the referral had never been made and had to wait an additional eight months. In other case, GDPR-related issues or staff absences caused further delays, with some patients waiting over a year without progress.

> ***"I waited a full year thinking my GP had referred me to an RTC company. When I questioned something after a year, it turned out the referral had never been made. I then had to request again, and it took a further eight months."***
>
> ***"The provider requested physical health information they needed to prescribe medication. The GP refused to share this, citing it would violate GDPR. We gave consent, and it was refused again, saying that it would be a chargeable service as the information requested was from a private company. We explained that this request came from a Right to Choose provider… eventually, the RTC provider accepted screenshots from the patient's online access to their records due to complete reluctance of the surgery to engage with them. This caused a six-month delay, on top of the earlier four months it took when the practice lost forms."***
>
> ***"I got a letter from the ADHD clinic with an appointment set. I thought the wait was finally over and I would start titration, just to receive a phone call a few days before saying they had to cancel my appointment due to staff illness and I would be next in line for an appointment as soon as the staff member came back to work. It has been nine months, and I still have not received another appointment."***

ADHD-unfriendly systems

Four patients described how the ADHD assessment process was difficult or poorly designed for people with ADHD.

The referral systems were described as disjointed, paperwork-heavy, and time-consuming – requiring individuals to fill in the same forms multiple times or manage complex steps without support. Patients were left to coordinate the process themselves, including chasing updates, organising assessments, handling administrative tasks and trying to find available medication, which they found overwhelming and inaccessible.

> ***"The process was stressful and time-consuming, requiring me to submit the questionnaire multiple times, which made me feel overwhelmed. The referral process did not feel very accessible and relied heavily on my own efforts rather than my GP advocating for me."***
>
> ***"The diagnosis process was ridiculous, and I do not know how some parents see it through***

> *– we had so many documents to complete, often asking the same questions."*

> *"I tried to get my children diagnosed but was told that I (struggling insanely with ADHD and perimenopause) have to organise this myself, look into what is best and then send them a form to sign. I am absolutely overwhelmed trying to help my children on top of trying not to lose my job."*

> *"My referral was delayed because my surgery did not complete the assessment and send on my initial referral to my provider of choice via RTC… I followed up a month later, as I had received nothing from the RTC provider and was told that the referral was never made and I would need to resubmit my assessment forms. No apology, no reason, no acknowledgement. It took me three months to regain the emotional and physical energy to put my assessment through again – ADHD makes this process so very hard and stressful."*

Getting a diagnosis

Long wait times for diagnosis

The most common issue reported within feedback was long wait times for an ADHD diagnosis, particularly through the NHS.

Thirty-four people (44%) had experienced long delays ranging, from nine months to over six years. Several individuals were still waiting or had not reached the first stage of screening. One person highlighted the severity of the situation, sharing that they were told the wait would be up to five years unless they were experiencing a mental health crisis. Another described needing multiple attempts over several years to finally receive a diagnosis.

> *"My personal wait for an ADHD diagnosis is long overdue. I am on the waiting list. I haven't had a single appointment, and I've been waiting four years. I don't think I will ever be assessed."*

> *"Diagnosis was a long process – over two years! Hard to watch my children struggle for so long with little support."*

> *"I have been on a waiting list for over three years on the NHS and still have not reached the first stage of screening."*

Forced into private care

Due to long NHS wait times, 19 people (24%) felt forced to seek private ADHD assessments. Some described waiting years without progress, leading them to pay out-of-pocket for diagnoses and treatment.

The high cost of private care was a recurring concern, with several noting they had no choice but to go private to access necessary support or medication. In some cases, patients faced further barriers when GPs refused shared care agreements after a private diagnosis, leaving them to cover the ongoing cost of prescriptions themselves (see more information about this below).

> *"We had to go private as we had been waiting too long and my child was becoming increasingly more down and internalising their struggles."*

> *"It's been a horrendous and expensive journey. Child diagnosed privately at huge expense and time because the NHS waitlist was so long. They had made several suicide attempts*

> “After receiving the (private) diagnosis, I contacted my GP. But unfortunately, I am having to pay for my prescriptions as **my GP would not support me**. Even being suicidal, not having any support network or financial means to pay for my prescriptions, leaving with a higher pile of debt.”

> *and were refusing school as they just could not cope any longer.”*

> *“Had to pay to get a private diagnosis as the NHS waiting list was too long and the impact on my child was too severe.”*

Private care-NHS barrier

While private diagnosis helped some patients to bypass lengthy NHS waiting times, 25 people (32%) found it difficult or impossible to access NHS care or medication afterwards.

Many people noted that their GP either refused or stopped providing shared care. In several cases, GPs initially agreed but later withdrew their support, leaving people to cover the full cost of prescriptions and follow-up care. Even when diagnoses were made through providers approved under the NHS Right to Choose, shared care was sometimes denied without any explanation. As a result, some patients were left with unaffordable monthly expense or were struggling to access medication.

> *“Sought NHS shared care via GP – this was refused. Child is now on a wait list for an NHS referral for diagnosis – advised this will take up to two years. Costs are met by me as a parent; they can’t function without meds. It’s an appalling system when you are trapped in ongoing financial costs.”*

> *“The NHS must take on diagnoses by private providers (as long as they were done according to NICE guidelines, which in our case, it was). This would bring down the waiting lists massively and allow those of us who have one access to meds without any barriers. Nothing about ADHD diagnosis and treatment for children and teens in West Suffolk works well. A huge change is needed NOW, starting with free access to medication and other therapies for anyone with a NICE-compliant diagnosis.”*

> *“People tend to assume that if you could afford a diagnosis, you can afford the meds – we had to use some savings and a very kind one-off gift from a family member. Paying for meds long-term is a huge burden.”*

> “We had to pay privately to get diagnosed. We pay for medication privately. We have been waiting for NHS referral. My child could not work without their medication, but **it is costing us £3,600 per year. No support anywhere.**”

Accessing ongoing support and treatment

Limited care and support

Thirty-two people (41%) described receiving limited support, particularly from their GP.

It was noted that GPs typically provide prescriptions directed by ADHD services but offer little else. Some people were told that if they could not access, or did not need medication, there was nothing available for them.

Many struggled to access appointments or received only brief phone calls with no follow-up. Advice was also limited while waiting for a diagnosis, leaving individuals to research their condition and manage symptoms alone. Some accessed webinars or recovery college classes, but felt these had been unhelpful, repetitive, or scheduled at inconvenient times.
People specifically noted the lack of one-to-one, face-to-face, or mental health support available to support them.

> *"I have had letters to give support for mental health and ADHD courses I can attend online and other signposting, but nothing face-to-face or one-to-one."*
>
> *"My overall experience is that there was not a lot of support or information. So, I had to do a lot myself. I went on to do a lot of training and learning."*
>
> *"Very little help with ADHD or autism issues from GP right from the get-go."*
>
> *"We were told that, unless we needed medication, they'd have nothing to offer us. When it came to discussing this further, the appointment was five minutes (if that) on the telephone. They promised they'd call me once my child was back in school to see if they required medication. They never called back."*
>
> *"No support from GP, and no support from services other than six monthly check-ups with consultants or prescribing nurses."*
>
> *"My mental health deteriorated, and GP refused to manage this due to me seeing a psychiatrist privately. So now, [I am] paying for ADHD and anxiety medication privately as no support is offered."*

Medication access issues

Sixteen people (21%) experienced difficulties accessing medication, with delays, supply issues, and lack of coordination between services.

Some reported long waits to access medication after a diagnosis, while others were told they could not use private prescriptions while waiting for NHS treatment without losing their place on the list. This left people with no way to bridge the gap between private and NHS care.

> **"The medication was helping, however there was a shortage, so I had to go onto something different.** I found it less effective, so I stopped taking it. I now don't take medication. Some days I find it harder than others."

Others faced medication shortages, failed deliveries, or had their treatment stopped due to checklist criteria they felt did not reflect their actual experience. These issues left many without consistent access to the medication they felt they needed.

> *"There are always issues with [medication] supply. It makes me understand why people give up."*

> *"Finally got diagnosed after a long wait, now on another long wait for medication. No possibility to bridge the gap with private medication as GP has told me I'll be kicked off the NHS wait list."*

Care gaps and fragmentation

Ten people (13%) described gaps in ADHD care, where some patients were sent in circles, discharged without support, or struggled to access what they needed.

A few noted that mental health services or GPs were unsure or untrained in ADHD, which meant they failed to recognise or manage it, especially in cases where people had multiple health conditions, for example perimenopause. Furthermore, one person shared that they had experienced difficulty getting a diagnosis from overseas recognised, which led to repeated assessments and disrupted medication access. Patients felt that these were areas where their care fell into gaps in systems, leaving them stuck and with no support.

> *"Services aren't joined up, lost count of the amount of times sent to a dead end or ignored... Having issues now as perimenopause is kicking in, and no one knows what to do. ADHD meds aren't as effective anymore due to this, need to wait two weeks to get a call from my GP. Tried to contact [the provider] who diagnosed me. They just tell me to go to my GP now. Huge gap as GPs not specialised in ADHD."*

> *"Accessing appropriate support hasn't been straightforward... GPs often lack the confidence or willingness to manage ADHD, leaving patients stuck between overstretched secondary services and unresponsive primary care. Given the prevalence of ADHD and its impact when unsupported, the system's failure to provide timely, joined-up care feels discriminatory."*

> *"My GP has no idea how ADHD works or what it really is, I don't think GP surgery staff have been trained or made aware of the condition and how late diagnosis affects people, why it's happening, and how ADHD relates to perimenopause."*

Wider impacts

Personal impact of waiting

Seventeen people (22%) mentioned the personal impact of waiting for an ADHD assessment or treatment.

Delays in accessing medication caused people to feel stressed, overwhelmed, and sometimes led to breakdowns in mental health. Two people noted that they had felt suicidal.

Waiting sometimes led to job losses, dropping out of school or university, and financial strain. For example, one person was left with rising debt after they were refused shared care following a private diagnosis. Parents reported struggling to manage their children while managing work pressures and their own mental and physical health, with one parent having to take on an extra job to cover private treatment costs.

> *"I have lost my job due to my difficulties, and I still have no access to medication that would help me. I just have to wait to try to cope with severe burnout and exacerbated ADHD symptoms."*

> *"Our child was in a desperate state, having waited six years on waiting lists. Their life collapsed. They had to leave uni, got arrested, have no friends, [and they] have been suicidal."*

> *"I know of no other condition where medication is so effective, so life-changing, yet care is denied. If I didn't physically have the money (for private medication), I dread to think where my child's and my mental health and physical health would be living at the levels of stress that we both endured during our first six years. A year ago, I was three stone overweight from emotional eating, suicidal, with a child in full-time alternative provision costing over 70k a year. In September, I'll be three stone lighter, back to my more robust outlook, with a child who is happier, has friends, can go places and participate more fully in life."*

> *"We have to pay for private medication. Now our child is on medication, they can finally concentrate, focus, and the difference in them is huge. With the support of medication, they will achieve their academic potential. We can only just scrape together the extra money for medication and psychiatrist reviews by me (his parent) taking on another job alongside my already full-time job."*

Beyond healthcare services

Three people mentioned issues they had faced outside of healthcare.

Two noted a lack of broader support in helping people with ADHD navigate work and education settings. For example, reasonable adjustments were not offered or explored, leading to difficulties with performance and mental health. In addition, one person had been refused Personal Independence Payment (PIP) despite difficulties related to a delayed diagnosis and a lack of support.

> *"Reasonable adjustments have not been offered or proactively explored – and even after disclosing my diagnosis, I've had to fight to be heard. In my own employment setting, the lack of timely accommodations and understanding has contributed to a serious deterioration in my mental health."*

> *"More work needs to be put into helping people with [neurodevelopmental] conditions fit into work and education, not moaning that it is over-diagnosed and expecting people to get out of the way!"*

Positive feedback

Positive experiences

Twenty-four people (31%) reported at least one positive experience with ADHD care, especially when supported by a proactive GP or accessing services through the Right to Choose (RTC) pathway.

The RTC process was described as straightforward, with providers described as knowledgeable, attentive, and supportive. Some people found referrals quick and easy, and shared care arrangements with their GP had been accessible. For example, one person found that their

> "Went to GP, explained symptoms, GP [asked if] I had considered seeking an ADHD referral. I explained that I had, was aware of Right to Choose.
>
> "GP agreed to fill out forms depending on which provider I chose. Sent the surgery the forms, which were sent in a timely fashion. **Was assessed and treatment started within six months of initial GP appointment.**"

private diagnosis was accepted when compliant with NICE guidelines. Other positive comments included smooth medication management, with regular reviews and timely access to advice. These positive comments highlighted inconsistencies in people's experiences, with some able to access shared care after a NICE-compliant private diagnosis, and others not.

> *"Since the diagnosis, prescriptions from the GP have always been efficient and the ADHD countywide service are always on top of their reviews in expected timeframes."*
>
> *"ADHD UK have been supportive and attentive, and I feel lucky to have had the treatment from them."*
>
> *"I was lucky the assessment time wasn't too bad. Six months from GP to screening assessment, and about another six months from then to diagnosis and treatment. Medication has completely changed my life for the better."*
>
> *"It was a long wait, but the service was supportive, and we've not had any issues. Whenever I've needed advice, I've been able to get it quickly."*

Appendix - response statements

Suffolk Local Medical Committee

Suffolk Local Medical Committee (SLMC) is made up of GPs elected on a constituency basis and represents all GPs in Suffolk, excluding those in the Waveney area. It shared a response to this report, copied below.

Suffolk LMC official statement

The Healthwatch report "Living with ADHD" rightly points to the considerable challenges around ADHD in our county and, prompted by recent changes in local policy and practice, how these have affected patients in Suffolk over the last 18 months.

In some areas, the patient experiences related in the report correlate strongly with GP practice experience of navigating such pathways alongside our patients. Descriptions of long waits to diagnosis, referral forms requiring reams of information and administrative difficulties are often burdens felt acutely by practices too.

Prior to considering the impact of prescribing changes – which form the mainstay of the aforementioned changes - the following points are worthy of reflection as helpful context:

- Estimates relating to the prevalence of ADHD vary, but generally suggest 4-5% of the entire population might receive a diagnosis if assessed. It is self-evident that meeting healthcare demand of this magnitude within a fixed resource envelope (such as primary care, or the NHS, at large) is likely to have a knock-on impact on provision in other areas of healthcare.

- Primary care holds longstanding concerns that overdiagnosis* and poor governance relating to RtC and private providers has been, and remains, reasonably widespread. Use of single disease diagnostic pathways, adverse incentives, lack of long-term follow-up & media coverage all appear to have contributed to this phenomenon and, by extension, the subsequent action taken by Suffolk practices.

- The actions taken occurred during a period of dispute between the government and GPs following an imposition of contractual changes.

- The boundaries between NHS and Private care have long been established and may be reviewed here. Whilst these boundaries may seem unfair, they exist to support the NHS principles of equity of healthcare irrespective of financial status.

- ADHD medications have always required specialist oversight via shared care arrangements (SCAs). Historically, one of the main drivers for introducing an SCA is a need for the patient to collect medication locally. This arises because the NHS does not regularly utilise a mechanism whereby hospital/specialist medications can be prescribed directly to community dispensaries or pharmacies – a relative & continuing anathema in the age of digital healthcare.

The above notwithstanding, our experience – mirrored in the distressing accounts set out in the report - of implementing of the transition away from practice-based provision of ADHD medication via SCAs has been that it has been extremely challenging. Whilst Suffolk practices have worked hard at trying to ensure provision is handed over without disruption, the complexities introduced by the myriad of providers (with highly variable degrees of responsiveness), historical – and often "generous to a fault" - variation in approaches to patients diagnosed in the private sector and intercurrent clinical pressures have meant, for some patients, their experience has not been that to which we would normally aspire.

In light of this, we continue to call upon national and local clinical leaders to consider the challenges set out above – perhaps via a broader review of ADHD (encompassing RtC governance) - and to provide meaningful solutions that safeguard our patients, practice and the NHS at large.

**The term here is used to describe the relative rarity of patients, upon assessment, not receiving a ADHD diagnostic label rather than increasing prevalence at a population level.*

Suffolk and North East Essex Integrated Care Board

The Suffolk and North East Essex Integrated Care Board (SNEE ICB) plans and buys healthcare services for the population of Suffolk and north east Essex.

SNEE ICB official statement

NHS
Suffolk and
North East Essex

We welcome the publication of these findings and would like to thank Healthwatch Suffolk and Healthwatch Essex for carrying out their surveys and producing this report. The voices of local people are essential in helping us shape and improve our services.

Over the past year, we have acted swiftly to maintain continuity of prescribing where appropriate. This includes ensuring patients are returned to the diagnosing provider for prescribing or supported through emergency provision via our GP federations. We continue to work closely with system partners and providers to improve pathways and ensure timely access to care.

We continue to explore ways to secure additional resources to better support patients throughout their care journey. Feedback such as this plays a key role in informing and strengthening our commissioning processes.

While we recognise there is still more to do, we are pleased that progress is being made. We would really welcome attending a listening event on the report and discuss in great detail the work we are doing in this space.

We will be making this report publicly available by publishing it on the Healthwatch Suffolk website.

We confirm that we are using the Healthwatch trademark (which covers the logo and Healthwatch brand) when undertaking work on our statutory activities as covered by the licence agreement.

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