

# Recognising ADHD: How to improve support for people who need it

May 2025

# Contents

Executive summary	2
Introduction	4
What we did	6
What the surveys covered	7
1. Why is establishing ADHD prevalence difficult?	8
2. How does having ADHD affect people's lives?	12
3. Referrals and long waits for ADHD assessments	18
4. The support that people need	24
5. The benefits of diagnosis	31
Conclusion and recommendations	35

## **Executive summary**

In recent years, awareness of attention deficit hyperactivity disorder (ADHD) in society has increased significantly, as has the number of people seeking help for the condition.

We have heard from the public about the difficulties they have faced accessing support for ADHD. This report tells some of these stories, while also exploring people's experiences through national polling and self-selecting surveys.

The impact of ADHD on people and their challenges in getting the right support led to NHS England commissioning the independent ADHD taskforce in March 2024.

We support the work of the taskforce and aim to help NHS and government policymakers understand the challenges and the improvements those seeking support want to see. These changes include quicker access to diagnosis and treatment, more support while they wait, and more non-medical help from NHS and other teams, including employers.

#### Key findings

- The impact of ADHD on people's lives can be profound. Our findings on those diagnosed reveal significant negative effects on work performance (63%), mental wellbeing (56%), household management (57%), and relationships (44%). There are also impacts on those undiagnosed.
- An ADHD diagnosis can change people's lives, giving them a better understanding of themselves (84%), improving their ability to manage their mental health and wellbeing (58%), improving their self-esteem (54%), and helping them to concentrate at work or while studying (47%).
- However, people are experiencing long waits, pushing them to pay for private assessments. This, in turn, creates a two-tier system based on the ability to pay for care. Nearly half (45%) of those waiting for an assessment who responded to our poll had been doing so for over a year.
- There are hidden waits for ADHD referrals. Along with long waits for assessment, people shared stories of referral delays and a reluctance to seek support due to long waits.
- People want support while waiting for an ADHD assessment but most aren't getting any. Just under two-thirds (63%) of people in our poll waiting for an ADHD assessment want support to manage their mental wellbeing, while over two in five (44%) want a single point of contact. However, almost two-thirds (64%) of people with an ADHD diagnosis said they received either no information or poor information whilst waiting for their assessment.
- People with ADHD or suspected ADHD can be reluctant to speak to their employer about support. Only one in five (19%) people in our poll had done so. Reasons for not telling their employer included worrying about possible

implications for their job and not thinking that changes would make a difference. However, almost two-thirds of people (64%) who had told their employer were offered at least one reasonable adjustment to support them.

#### **Key recommendations**

There is a clear need for quicker access to NHS support for ADHD, as well as help from other sectors including employment. However, there are also challenges facing NHS teams, which are facing rising demand for a condition that is becoming more understood by the public.

To improve access, provide more consistent support to people waiting, and build capacity for specialist hospital teams to deliver more complex care, we have called on NHS decision-makers to:

- 1. Move ADHD assessments to the community. This includes providing NHS teams with the training and resources they need to deliver care closer to people's homes. This shift will require collaboration between NHS, social care, education, employment and criminal justice stakeholders.
- 2. Review National Institute for Health and Care Excellence (NICE) ADHD guidance to reflect this shift to more care delivered by general psychiatry and GP teams, as well as explore future prescribing of first-line medication from non-hospital settings.
- 3. **Provide better support to people waiting for ADHD assessments**, including keeping people updated with clear and accessible communication from the NHS.
- 4. Collect and publish official data on ADHD assessment waiting times, including demographic data, to understand and address health inequalities.
- 5. **Improve employers' support for those with ADHD** by raising awareness and proactive offers of reasonable adjustments and expanding support provided through the Access to Work scheme.

# Introduction

ADHD is a neurodevelopmental condition, characterised by difficulties with concentration, energy levels, impulsiveness, or a person's ability to manage their time.

ADHD can be diagnosed in childhood or adulthood, and sometimes, traits can change as people get older. Because of the range of behaviours affected by ADHD, presentation can often look very different from one person to the next. ADHD symptoms often impact a person's mental wellbeing and/or have a detrimental effect on existing mental health issues.

There has been a massive rise in demand for assessment, diagnosis and support related to ADHD. Between 2000 and 2018, there was approximately a <u>twenty-fold</u> increase in ADHD diagnoses.

Additionally, between 2019/20 and 2022/23, there was a <u>51% increase in the</u> <u>number of patients prescribed medication</u> for ADHD.

In the past two years, local Healthwatch have raised concerns with us about the concerning state of ADHD services. We have already published some of the public's <u>own stories of poor experiences</u>.

We shared this feedback directly with NHS England and have since pressed for – and joined – the first <u>national ADHD taskforce</u>. We supported the taskforce's development and directed their priorities by running <u>deliberative engagement</u> with people who experienced a long wait or a diagnosis for ADHD. This established eight priority areas:

- 1. Tackling stigma
- 2. Delivering more training for health and care professionals
- 3. More joined-up work between teams involved in delivering ADHD support
- 4. Better continuity of care
- 5. Earlier identification of ADHD
- 6. More support for people waiting for NHS diagnosis and treatment
- 7. Reduced waiting times
- 8. Easier access to support

We conducted the research outlined in this report to support the work of the ADHD taskforce. We decided to focus on adults rather than children and young people, as less research had been undertaken on this group. We wanted to further understand the impact of ADHD on people's lives, their experience of the assessment and diagnosis process, and long waits for support. We also wanted to understand why people who think they might have ADHD might not have sought an ADHD diagnosis.

In the coming chapters, we will share the scale of and stories behind long waits. We will conclude by making recommendations to decision-makers.

#### Key themes by chapter

**Chapter 1** looks at the difficulties of establishing prevalence of ADHD in adults in England.

**Chapter 2** highlights how ADHD affects people's lives. We show that ADHD has a profound impact on people's ability to work and study, mental and physical health, relationships with loved ones and friends, ability to manage money and undertake household tasks, and personal interests.

**Chapter 3** examines people's experience of referrals and waiting times for NHS ADHD assessments. We also look at the experiences and concerns of people who believe they have ADHD but are neither diagnosed nor waiting for an assessment. These groups could benefit from improved referral processes and access to ADHD assessments.

**Chapter 4** outlines the type of support that people need whilst waiting for an ADHD assessment and people's experience of and barriers to receiving support at work.

**Chapter 5** sets out the impact of having an ADHD diagnosis on major aspects of people's lives. We highlight the major benefit is validation and self-understanding rather than the ability to receive ADHD medication.

Our conclusions and recommendations can be found on pages 35 – 40.

# What we did

We commissioned YouGov to run two rounds of polling for us about adults' experiences of ADHD.

- The first round was a nationally representative sample of 1,888 adults aged 18+ in England. Fieldwork was undertaken between 8 and 23 January 2025 and the survey was carried out online. The figures have been weighted and are representative of all English adults (aged 18+). In this report, we will refer to this as 'our first national poll'.
- The second round was conducted between 8 to 27 January 2025. The survey was conducted online. The total sample size was 2,579 adults with ADHD in England. This sample comprises:
  - o 363 people who have already been diagnosed with ADHD
  - $\circ$  336 people who were waiting for an ADHD assessment
  - 109 people whose GP has refused to refer them for an ADHD assessment
  - o 808 people who haven't yet seen their GP for an ADHD assessment
  - o 963 people who don't want a formal ADHD diagnosis

The figures have been weighted and are representative of all English adults (aged 18+) with diagnosed and undiagnosed ADHD. In this report, we will refer to this as 'our second national poll'.

We also ran our own survey throughout January 2025 to gain complementary qualitative insight. The survey asked people with both diagnosed and possible ADHD to provide details of their experiences. The survey was self-selecting, meaning that we relied on people willing to complete the questions and could complete an online survey. We publicised this survey widely via social media. We had 1,161 completed responses in total. In this report, we will refer to this as 'our own survey'.

We received and incorporated feedback from stakeholders and people with lived experience of ADHD in designing the polling and survey questions. We'd like to thank them for their input.

# What the surveys covered

Our first national poll aimed to explore the proportion of people seeking or not seeking an ADHD assessment among the adult population of England.

Across the second national poll and our own survey, we explored:

- The impact of ADHD on people's lives
- The waiting time and support needs of people who've already been diagnosed with ADHD and the impact of a diagnosis on aspects of their lives
- The referral process, waiting times and support provided to people on the waiting list for an ADHD assessment
- The experiences of people who think they might have ADHD but their GP has refused to refer them for an assessment
- Why people who think they might have ADHD haven't yet seen their GP to ask for a referral for an ADHD assessment
- Why people who think they have ADHD don't want to have a formal ADHD assessment.
- People's experiences of telling their employer that they have ADHD and receiving reasonable adjustments

## 1. Why is establishing ADHD prevalence difficult?

#### External evidence on prevalence

At the time of writing, there are no official statistics on the prevalence of ADHD amongst the adult population of England. Indeed, estimating prevalence is not straightforward.

One measure is prescribing rates for ADHD medication. Research has found that diagnosis and prescription rates for ADHD have increased significantly, <u>with a 20-fold increase in ADHD diagnosis</u> and a 50-fold increase in prescriptions between 2000 and 2018. Research quoted by the <u>Nuffield Trust</u> shows that there was a 51% increase in the number of patients prescribed medication for ADHD between 2019/20 and 2022/23 alone.

But this only tells part of the story. Only people who are diagnosed with ADHD can get ADHD medication. Data obtained via <u>Freedom of Information (FOI) requests</u> by the BBC in 2024 suggested that 196,000 people were on NHS waiting lists for an ADHD assessment across the UK.

FOI data can only be sourced from public services, and there are no official statistics on the number of people diagnosed in the private sector.

<u>FOI data on waiting lists also doesn't show the full picture of unmet need.</u> ADHD UK found that the NHS was screening out significant numbers of people with ADHD referrals in some areas.<sup>i</sup> <u>Healthwatch York undertook an independent assessment</u> of a profiler used by the local Integrated Care Board (ICB) to screen people who had asked for an autism or ADHD assessment. They found that many people were screened out from referrals for assessment and got little or no support.

In some parts of the country (Oxfordshire, Leeds, and York), NHS ADHD diagnostic services have ceased taking new referrals or restricted the type of referrals they will accept.

Recent research also shows that <u>ADHD is considerably underdiagnosed in England</u> amongst both children and adults. Using estimates of adult general population and ADHD prevalence data, the research estimates that only 15.6% of expected adult ADHD population is diagnosed.

The National Institute for Health and Care Excellence (NICE) estimates the prevalence in adults in the UK to be between 3-4%, with a male-to-female ratio of approximately 3:1. This equates to between 1.3 and 1.8 million adults.<sup>ii</sup>

A meta-analysis of <u>studies across the world on the prevalence of ADHD in adults</u> indicates that the prevalence in adults is 3.10%.

From May 2025, NHS England will begin publishing <u>estimates of ADHD prevalence</u> for both people with a diagnosis of ADHD and people who may have ADHD.

#### Our findings

In our first national poll, we asked questions about diagnosed and possible ADHD. This meant that as well as asking how many people had a formal ADHD diagnosis, we also asked about other groups that people with lived experience of ADHD advised we should include:

- People who believe they have ADHD but whose GP has refused to refer them for an ADHD assessment
- People who believe they have ADHD but have yet to see their GP to ask for a referral for an ADHD assessment
- People who believe they have ADHD but have decided not to ask for a formal ADHD assessment

Group of people	Percentage of nationally representative poll respondents
I don't have ADHD	86.1%
I have been diagnosed with ADHD (by the NHS, a Right to Choose provider, privately, or outside the UK)	1.8%
My GP has referred me for an ADHD assessment, and I am on the waiting list for an assessment	1.8%
I believe I have ADHD, but my GP would not refer me for an ADHD assessment	0.7%
I believe I have ADHD, but I haven't yet seen my GP to ask for a referral for an ADHD assessment	3.9%
I believe I have ADHD, but I don't want to get a formal diagnosis	5.7%

Our polling is based on people self-reporting that they have been diagnosed with ADHD or believe they have ADHD.

As our research explores, some people may choose not to seek support; however, for others, a lack of support can have significant impacts on health, mental wellbeing, and ability to work.

These findings must be treated carefully. Not all people who believe they have ADHD will have it. Our polling should not, therefore, be taken as an estimate of prevalence of ADHD amongst adults in England.

Taken in combination with external research and prevalence estimates, our research adds to evidence that there may be significant numbers of people who

are yet to be assessed or come forward for support. However, accurately establishing prevalence requires robust further investigation and access to NHS data.

#### How did people come to find or believe they had ADHD?

Our research estimates, combined with the other research outlined above, that ADHD prevalence could be rising alongside unmet need for support. This is unsurprising, given that ADHD in adults was only recognised by the NHS and NICE in 2008, so awareness will continue to rise.

To be referred for an ADHD assessment, NICE recommends that people must meet the diagnostic criteria listed in either the International Classification of Diseases (11<sup>th</sup> edition) (ICD-11) or the Diagnostic and Statistical Manual of Mental Disorders (fifth edition) (DSM-5).

DSM-5 was updated in 2013 to lower the threshold for diagnosis, meaning adults must meet five or more of the 18 criteria listed, which include nine for inattention and nine for hyperactivity or impulsivity. This, too, could lead to a rise in the prevalence of ADHD.

In our second poll, we asked people what prompted them to think they had ADHD. These findings cover diagnosed and undiagnosed people.

How people came to realise they had or might have ADHD	%
Finding it hard to do things in daily life which others find easy	58%
People I know talking about their ADHD	50%
Someone else told me I might have it	43%
By reading about it in the news, articles, books or watching online videos	35%
I got into some kind of trouble	17%
My working arrangements	11%
Child went through the ADHD diagnosis process	11%
Being at home during the Covid pandemic	10%
Working from home during the Covid pandemic	8%
Other	11%
Don't know	3%

This shows that unmet need for support is a key driver of people believing they have ADHD, with 58% of respondents finding it hard to do things in their daily life, which others may find easy.

Discussion with other people is also behind people's beliefs, including 50% who have discussed with others they know with ADHD, and 43% being told they may have ADHD.

Increased awareness, negative impacts, and changing habits during the pandemic all contribute to some people's belief that they have ADHD.

## 2. How does having ADHD affect people's lives?

This chapter examines how ADHD affects people's health, wellbeing, education, and personal lives.

As part of our second national poll, we asked people to rate how ADHD impacted different parts of their lives. The results reveal significant negative effects on work performance, mental wellbeing, household management, and interpersonal relationships, with disparities across gender, age and socioeconomic backgrounds.

In this section, all figures refer to people who have been diagnosed as having ADHD unless otherwise stated.

The table below shows that people without a diagnosis report more negative impacts across most areas of life.

Area of life affected	Negative impact - diagnosed:	Negative impact - undiagnosed:
Concentration at work or when studying	63%	72%
Mental health and wellbeing	56%	67%
Carry out daily household tasks	57%	61%
Ability to socialise	46%	60%
Self-esteem	50%	59%
Ability to work	53%	50%
Relationships with partner, friends and family	44%	49%
Ability to budget and manage money	47%	46%

Area of life affected	Negative impact - diagnosed:	Negative impact - undiagnosed:
Ability to take part in hobbies and personal interests	40%	44%
Physical health	43%	41%

#### Impact on work and study

Over six in ten (63%) diagnosed respondents reported that their concentration at work or while studying was negatively impacted by their ADHD, and over half (53%) indicated that their overall ability to work suffered due to ADHD. Women (67%) were more likely than men (58%) to report a negative impact on concentration.

<u>A 2024 review of studies of people with ADHD</u> highlighted poor educational and employment outcomes such as lower attainment, leaving education early and more frequent job changes.

In our own survey, both diagnosed and undiagnosed people described how their struggles with focus led to task avoidance, procrastination and difficulties maintaining productivity at work or study.

"I struggle with concentration which affects my work, I struggle to focus for extended periods of time and often switch between tasks. If a work task isn't urgent or novel, I can put it off for long periods of time."

Black Caribbean woman, aged 25-49, London (undiagnosed, yet to discuss with GP)

We heard about how these difficulties with concentration and focus, along with other ADHD-related challenges such as forgetfulness, could lead to inconsistent work performance. People talked about frequent job changes, career stagnation, or a sense of unfulfilled potential.

"I find it hard to focus on my work which has meant my grades steadily falling over the years. This also impacts my self-esteem as it makes me feel stupid and not as good as the other people on my course."

White British man, aged 18 – 24, Manchester (undiagnosed, waiting for assessment)

#### Mental health and self-esteem

Our poll found over half (56%) reported a negative impact on mental health and wellbeing. Women (62%) were significantly more likely than men (50%) to report a negative impact on mental health.

When we looked at the undiagnosed group, we found the negative impact of their suspected ADHD on mental health was also higher (67%) compared to 56% for those diagnosed, possibly a result of the fact that those diagnosed generally have more access to support and medication.

"My family find it difficult to understand my difficulties. My self-esteem has been affected because I find it difficult to take in instructions and carry them out. I desperately try to be organised but cannot achieve it, to the annoyance of my children. It's as if I freeze.".

White British woman, aged 65 - 79, Essex (diagnosed)

In our own survey, people described how low self-worth and self-esteem both contribute to and stem from these mental health struggles. This was a common issue: 50% of diagnosed people in our national poll reported a negative impact of ADHD on self-esteem, with women disproportionately affected.

"Most of all, my mental health is awful - I have very low self-esteem and have spent my whole life thinking I'm inherently BAD. So I've been plagued by shame and spent much of my life depressed and suicidal."

White British non-binary, aged 25-49, Leicestershire (undiagnosed, yet to discuss with GP)

#### Carrying out household tasks

Over half of diagnosed people (57%) reported a negative impact of ADHD on their ability to carry out household tasks. This was most likely to affect women (63% compared to 51% of men), as well as people who were currently on the waiting list for an ADHD assessment (69%) or were yet to see their GP to get referred (70%).

People described wanting to do housework, shopping, gardening, household repairs and cooking, but not being able to get started or being distracted:

#### "My home is messy and untidy; I feel like I cannot bring anyone into my house; again, I feel shame."

White British man, aged 25-49, Bristol, (diagnosed)

#### **Relationships and socialising**

Half (50%) of respondents reported a negative impact on their ability to socialise.

Over two in five (44%) reported that ADHD had a negative impact on their ability to maintain relationships with their partner, friends and family. This aligns with findings from a recent <u>review of ADHD research studies</u>, which found that people with ADHD had increased difficulties with relationships and social interactions.

In our own survey, people described how executive function difficulties made it hard to keep in touch with friends and maintain relationships:

"I can forget to contact friends, and executive function difficulties mean it's hard for me to initiate contact, meaning I may not have the support I need and can impact the friendship. I experience rejection sensitivity dysphoria, meaning I can become very upset at perceived negativity or criticism towards me."

White British woman, aged 25-49, Hampshire (diagnosed)

#### **Financial management**

<u>Research</u> shows that people with ADHD have an impaired ability to make financial decisions.

Our poll found that 47% of people with a diagnosis reported negative impacts of ADHD on their ability to budget and manage their finances. People who responded to our own survey reported problems with impulse purchases, resulting in problem debt:

"I am £10,000 in debt, but I am clearing it slowly. I will never be in a position to invest in my health because I can't stop spending. I am honestly scared about my future and the financial impact of retirement and the life I have ahead of me constantly struggling."

White British woman, aged 25-49, Worcestershire (diagnosed),

People also reported problem debt arising because they forgot to pay their bills on time or forgot to cancel subscriptions at the end of the free period:

"I leave bills till the last minute. I have so many things to do that it seems too overwhelming to know where to start. I forget to cancel trial subscriptions, so I lose money." White British woman, aged 50 -64, Devon (undiagnosed, yet to discuss with GP)

#### Hobbies and personal interests

<u>Research indicates that having a hobby</u> is linked to good mental health and wellbeing. However, 40% of those diagnosed reported a negative impact on their ability to spend time on hobbies and personal interests.

Hobbies require maintaining interest and concentration over time, which is a challenge for people with ADHD. In our own survey, people talked about hyper-interest at the beginning, which didn't last:

"I'll get into a new hobby and get all the things to go with it before my interest wanes. A few years ago, I got into sewing. I bought loads of fabrics, clothes, and accessories to customise, and it fell by the wayside."

White Irish woman aged 25-49, Lancashire (undiagnosed, awaiting assessment)

#### **Physical health**

Over two in five (43%) people in our poll said that ADHD had a negative impact on their physical health. <u>A review of studies on the effects of ADHD</u> on people's lives found that there were a number of impacts on physical health, including quality of sleep, oral health, weight management, addiction and other health conditions. These were all things that people who responded to our own survey mentioned:

"ADHD also causes me to slip behind on exercise and diet and sleep, so I gain weight and get out of shape, which really affects my mental health."

White British man, aged 18-24 years, East Sussex (Diagnosed)

"I struggle with habit forming; for things like brushing my teeth, it's a struggle to remember to brush them on average more than once every other day, and my dental health is suffering from that."

White British man, aged 25-49, Birmingham (undiagnosed, awaiting assessment)

#### In summary

ADHD has a far-reaching impact on various aspects of people's lives, often beyond what is commonly recognised or understood. Far from a simple deficit of attention, the harder-to-quantify impacts on self-esteem, health, and opportunity shape lives in ways that may be hidden from view but are, nonetheless, destructive.

Our findings suggest that people who have not yet been diagnosed are more likely to report challenges - particularly around concentration, mental health and socialising – compared to those who have received a diagnosis.

By better understanding these complex struggles in people's own words, we can design policy and support that improves quality of life.

The evidence from this chapter and throughout the report points to the importance of timely assessment, support, and treatment.

# 3. Referrals and long waits for ADHD assessments

In this chapter, we examine people's experiences of referrals and waiting times for NHS ADHD assessments. We also examine the experiences and concerns of people who believe they have ADHD but are neither diagnosed nor waiting for an assessment. These groups could benefit from improved referral processes and access to ADHD assessments.

#### How are people referred for assessment?

In England, adults needing an ADHD assessment must be referred by GPs to a mental health professional specialising in ADHD. This could be an NHS specialist or a private organisation providing NHS services under the Right to Choose.

NICE guidance states that diagnosis should involve:

- a full clinical and psychosocial assessment of the person, including a discussion of behaviour and symptoms in the different aspects of the person's everyday life
- a full developmental and psychiatric history, and
- observer reports and assessment of the person's mental state.

#### Getting a referral for an ADHD assessment

For people who think they have ADHD, their GP must feel assured that the traits might constitute ADHD before a referral is given to join the waiting list for an assessment.

Our national poll and our own survey found that this process is not working well for many. This is perhaps unsurprising, considering research that <u>GPs themselves find it</u> <u>difficult to identify ADHD</u>.

Over a quarter of our second national poll respondents (28%) had been referred by their GP and were waiting for an assessment.

Our second national poll found that:

- More than two in five (41%) people who were on the waiting list for an assessment had had one appointment with their GP before they were referred
- Nearly two in five (38%) said it had taken more than one appointment.

In our own survey, we heard from people who said that they had had to have multiple visits to their GP to convince them to refer them for an ADHD assessment, as often the GP thought they had anxiety or depression.

"I went to see a GP six years ago believing I had ADHD only to be dismissed, told to lay off caffeine and sweets. I went back a second time but was then treated as having anxiety.

"I went back a third time, three years ago and got referred. I was struggling so bad with symptoms my relationship was struggling, work was challenging due to lack of concentration and listening. I then asked for a Right to Choose assessment provider who saw me within nine months of referral. Had I not done this, I would still be waiting."

White British man, aged 25 – 49, Yorkshire (diagnosed)

In 2023, we highlighted the <u>impact of this 'hidden wait'</u> (the time spent waiting for a GP referral) across all referrals for specialist care. These waits go unreported but add to the overall waiting times for treatment. In that research, we found that people needed to see their GP multiple times before they got a referral.

Our analysis of the 2023 data indicated that experiences of mental health referrals were worse for neurodivergent people, with one in five having to chase delays, compared with just 5% for all respondents.

The need to convince a GP to refer for an ADHD assessment was also cited as a problem by people who believed they had ADHD but hadn't been diagnosed or were waiting for a diagnosis.

In our second national poll, people whose GP had refused to refer them for an ADHD assessment cited the following reasons for the refusal:

Perceived reason for not referring	% of people giving this as a reason
My ADHD symptoms/traits weren't considered serious enough	26%
The GP didn't want to refer me because of long waiting lists	24%
I find it difficult to express myself	20%
The GP didn't listen to me	17%
The GP didn't consider all my ADHD symptoms/traits	17%
I was recommended a private assessment	17%

Perceived reason for not referring	% of people giving this as a reason
The appointment was too rushed	16%
I had a telephone appointment with my GP, and I feel uncomfortable talking to people over the phone	13%
The ADHD diagnostic criteria used by my GP didn't reflect my experience of ADHD	13%
Other	10%

People who hadn't yet been to see their GP or who had decided not to get a formal ADHD diagnosis had similar experiences and concerns.

Reason for not going to the GP yet for a referral <sup>iv</sup>	% of people giving this as a reason
I'm worried I might not be able to express myself well enough at the appointment	35%
I'm worried that my GP won't refer me for an assessment	29%
The ADHD diagnostic criteria used by my GP or at diagnosis doesn't reflect my experience of ADHD	5%

Reason for not seeking a formal ADHD diagnosis <sup>v</sup>	% of people giving this as a reason
I'm worried about long waits for an NHS diagnosis	20%
The ADHD diagnostic criteria used by my GP or at diagnosis doesn't reflect my experience of ADHD	5%
GP or other health care professional told me not to bother	4%

These experiences disproportionately affect women, young people, LGB+ people, those who are not employed and people who are financially really struggling.

Furthermore, over one in five (22%) people who were already diagnosed with ADHD found persuading their GP to refer them for an assessment a difficult part of the diagnosis process.

People who responded to our own survey talked about dismissive GPs who cited long waiting lists as a reason not to refer them:

#### "He said:

1) that only young boys have it.

2) that it would have been diagnosed by "this stage" in my life anyway (I was 46 at the time I saw him last year).

3) people only want a diagnosis so they can get strong stimulant medications (and can put in for a free computer from uni).

4) there's a six-year waiting list, so they're only referring children."

White British woman, aged 25-49, Wiltshire (undiagnosed; GP has refused to refer)

People who hadn't got around to asking their GP for a referral yet or had decided not to seek a formal diagnosis also explained how long waits for NHS assessments, fears their GP wouldn't respond to their request in a positive way and other factors combined to stop them seeking a referral for an ADHD assessment:

"Because trying to get a GP appointment is stressful. Trying to be understood/believed in the designated ten minutes is impossible for such a complex issue. Because being put on an endless waiting list would clash with managing my ADHD-related mental health. Because even if I did get a diagnosis, there's a shortage of meds even if prescribed. It all feels hopeless."

White British woman aged 50 - 64, Northamptonshire (undiagnosed, yet to see GP)

People described the impact of worry about long waiting times, the possibility or reality of being dismissed by their GP and their lack of confidence in expressing themselves well enough to get an appointment.

"Ashamed. I feel like I've already 'used up' my entitlement to health problems after cancer treatment. I feel like 'it's not about me' and am channelling resources into supporting my daughter with her diagnosis. I feel like I've coped for 45 years, so what will I gain? Exhausted by waiting for health care."

White British woman, aged 25-49, Cornwall (undiagnosed, yet to see GP)

Given our assessment in Chapter one that there could be a significant unmet need for ADHD assessment, many people could feel comfortable approaching their GP to ask for a referral if the system were improved.

#### Long waiting times for assessments

People told us they had been waiting a long time for ADHD assessments. Nearly half (45%) of people in our second poll who were waiting for an ADHD assessment said they had been waiting for an assessment for over a year. One in ten (10%) of these had been waiting for three years or more. And seven in ten (70%) of people who are already diagnosed said that the time taken from referral to diagnosis was a difficult part of the ADHD diagnosis process.

Waiting times also vary significantly by location. In a 2023 report, <u>ADHD UK used</u> <u>FOI data</u> to highlight this postcode lottery, with waiting times ranging from 12 weeks at Dorset Healthcare University NHS Foundation Trust to over 10 years at the Herefordshire and Worcestershire Health and Care Trust.

#### Turning to private care

Nearly two in five (38%) of those currently waiting said they were considering paying for a private ADHD assessment. People who were considering paying for a private ADHD assessment were more likely to be male, aged 18 – 34 and employed. In contrast, those who weren't were more likely to be female, aged 35 – 54 and not employed.



Our second national poll found that the long waiting times are the main factor pushing people towards private assessments, with two-thirds (65%) of those considering a private assessment citing this as their main reason. In contrast, over three in five (61%) of those not considering a private assessment said it was because they couldn't afford it.

In 2021, a 'consensus group' of leading ADHD clinicians and researchers warned that long waiting

lists, combined with a growing private assessments industry, were creating a 'twotier health service' that failed those from less affluent backgrounds. Four years later, waiting lists have ballooned, and the demand for private care has only increased. Our second poll also found that 21% of people who were already diagnosed with ADHD had been diagnosed privately, and 6% had been diagnosed outside the UK.

"The waiting list here is so long that they won't actually disclose the length. It's been three years so far. In the end, I went private as my relationship with

#### my husband was near breaking point. I was exhausted and constantly overwhelmed."

White British, unsure but female presenting, aged 25-49, Sussex (undiagnosed, awaiting assessment)

#### In summary

This chapter outlines the challenges many face when getting referred and long waits once they are on the waiting list. It is particularly worrying that some doctors are reluctant to refer due to long waiting lists, which may deny many an assessment that may lead to a diagnosis.

We also found cases of NHS doctors refusing NHS referrals but recommending costly private treatment to some. With nearly half of those waiting for assessment telling us they had been waiting over a year, there is a concern about a 'two-tier' system emerging where only those who can afford private assessment get it.

# 4. The support that people need

In this chapter we look at how people waiting for an ADHD assessment are coping, the support people want whilst they are waiting and people's experience of getting support at work.

#### How are people coping while they wait?



Our research shows that many people feel unprepared to wait long periods of time for an assessment. In our second national poll, just 40% of those referred for an assessment were confident in their own ability to manage their ADHD traits while they waited. Confidence was lowest among the unemployed (27%).

In our own survey we heard from some people who felt more able to cope, often because they suspected they had a milder form of ADHD or had developed selfmanagement strategies over time:

"I believe I may be a 'mild' case if that is an appropriate way to put it. At 48 years of age, I've fended for myself in terms of managing what I now believe is combined autism and ADHD. So I can probably cope with waiting a few more months. However, I would like greater clarity for the sake of my family and my work life."

White British man, aged 25-49 years, Norfolk (undiagnosed, awaiting assessment)

Over half of those (54%) who were already diagnosed cited a lack of support or resources as a difficult part of the diagnosis process.

Over two in five (43%) of those referred and awaiting assessment received no information at all about how to manage their ADHD traits while waiting. A further 21% said the information they received was poor. Only a third (33%) said the information they received was excellent or sufficient.

# What people thought about the information they got whilst they waited for an ADHD assessment

"I have no information, support groups or self-help tips in the interim as I continue to await assessment. I've had no unprompted communication from the service unless I contact them first."

White British woman, aged 25-49, London (undiagnosed, awaiting assessment)

People who responded to our own survey described the impact lack of support had on their lives. They talked about feeling anxious and depressed, feeling alone and left in limbo:

"It made me feel like there was no point in even reaching out for help. I tried to access support on several occasions and then was told nothing could be done until I was diagnosed, which I knew wouldn't be for a long time."

White British woman, Hampshire, 25 – 49 (undiagnosed, awaiting assessment)

People talked about having to do their own research to find support:

"Other than by googling coping mechanisms, there is no way to determine how best I should be managing this. In a way, feeling strongly that I have it but not knowing what I can do about it is almost worse than not knowing because I know I could be achieving so much more or at least not struggling so much."

White British man, aged 25 – 49, Yorkshire (undiagnosed, awaiting assessment)

While they waited, some people were burdened by self-doubt and uncertainty, left in "limbo" and unsure where to turn to for support:

"I'm questioning whether I really have ADHD or if I'm just looking for an excuse for being a bit rubbish at various things, which takes its toll mentally. It's difficult to know where you can find help in the meantime, and I've stumbled across some things by accident, such as the 'Access to work' scheme."

White British man, aged 25-49, Bristol, North Somerset and South Gloucestershire (undiagnosed, awaiting assessment)

People who had been waiting for longer periods described feeling let down and abandoned by the health service.

"My GP has reluctantly agreed to an NHS referral, and here I am three years later, still waiting. It makes me very frustrated to think that another three years have passed by without me being able to gain any proper support or medication, and I've just been left to struggle."

White British woman, aged 25 – 49, Lancashire (undiagnosed, awaiting assessment)

#### Support whilst waiting for an assessment

As waiting times for ADHD assessments can be long, people need support while they wait.

In our second national poll, the top three types of support wanted by people waiting for an ADHD assessment were advice on how to manage mental wellbeing, followed by a single point of contact about the wait for an assessment and information on organisations that could give advice on ADHD (see below).

What type of support people want while they wait	% who put in the top three
How to manage mental wellbeing	63%
A single point of contact about the wait for an ADHD assessment	44%
Information on the organisations that can give advice on ADHD	30%
Help and support to hold down a job	28%
Help and support to study	22%
Advice on maintaining relationships	17%
Information on local peer support groups	16%
Culturally sensitive information about ADHD	7%
Don't know	5%
None of the above	3%

People who responded to our own survey said similar things. They wanted self-care information, check-ins with medical professionals, and information on how long they would need to wait:

"I'd like the chance to learn more about ADHD and symptom management. Just a check in with my GP while I wait would go a long way to helping me feel listened to and supported."

White British woman aged 25 – 49, Liverpool (undiagnosed, awaiting assessment)

"Telephone contact from a professional to check in while on the waiting list. Four years on a waiting list is a long time."

Asian British woman, aged 18 – 24, Yorkshire (undiagnosed, awaiting assessment)

#### Support at work

We also asked people who were employed whether they had told their employer that they had or might have ADHD. We wanted to see whether employers could support employees with ADHD appropriately so that they could do their jobs to the best of their ability.

Equality law requires employers to make "reasonable adjustments" to ensure workers with disabilities or physical or mental health conditions are not substantially disadvantaged when doing their jobs. Depending on the employee's condition, these could include improving physical accessibility, providing additional equipment, or changing work arrangements.

Entitlement to reasonable adjustments does not depend on having a diagnosis. Therefore, in this section, we consider the experience of both diagnosed and undiagnosed people with ADHD.

Less than one in five employed people (19%) had told their employer that they had ADHD. This rose to seven in ten (70%) among those who had received a diagnosis.



Overall, just over one in three (36%) people who discussed their potential or diagnosed ADHD with their employer were offered no reasonable adjustments. Almost two-thirds (64%) who told their employer that they had ADHD were offered at least one reasonable adjustment. The table below shows the types of reasonable adjustment offered:

Reasonable adjustment offered	%
Flexible working arrangements	35%
Additional guidance or check-ins with their manager	30%
Working from home arrangements	25%
ADHD coaching or support	20%
Help with the Access to Work scheme	19%
Specialised software	11%

Over three quarters of those who had been offered reasonable adjustments said they had made a difference We found that reasonable adjustments could be beneficial to enable people with ADHD to work well. Over threequarters (76%) of those offered reasonable adjustments said they made a significant or moderate difference.

In our own survey, people talked about employers who were understanding and put in place adjustments that would help them. For example, people talked about being able to work from home or work in a quieter part of the office, being able to wear noise-cancelling headphones, having breaks, specialist software or regular check-ins with staff:

"Without my supervisor being supportive and implementing my proposals, I certainly would have faced disciplinary action. With the adjustments, I became productive and a useful member of the team, which contributed to my rising morale."

White other man, aged 25 – 49, Essex (undiagnosed, GP refused to refer)

However, people also shared experiences of managers expressing scepticism about neurodivergent conditions, with some outright denying ADHD exists or refusing to consider adjustments without a formal diagnosis, even though the Equality Act does not stipulate that people need a diagnosis to get reasonable adjustments.

After disclosing their condition, individuals told us they felt like they were labelled as "difficult," "problematic," or "attention-seeking". Whilst employers can refuse adjustments if they are not reasonable due to practicality, cost and organisational size, some employers appear to be breaching their legal duty:

"They showed complete disinterest and, when pushed, made excuses that they couldn't put anything in place to help as it would disrupt work and workflow and be unfair to colleagues. I'm now treated as a problem."

White British man, age not given, Wiltshire (undiagnosed, yet to discuss with GP)

It was concerning that over three-quarters of people hadn't yet told their employer that they had, or suspected they had, ADHD, including over a quarter (27%) of people who had already been diagnosed with ADHD. When asked why they hadn't yet done so, people cited barriers like not having a formal diagnosis and being worried about the implications for their job:

Reasons for not telling your employer	%
It doesn't make a difference to the job I do	39%
I'm waiting until I have a formal diagnosis to tell my employer	30%
I don't want to disclose personal information	26%
I'm afraid of the possible implications for my job	23%
Other	11%
Don't know/prefer not to say	5%

People who responded to our own survey were unsure of the response they would get from their current employer if they told them that they had ADHD. They felt that they would be judged for jumping on "the ADHD bandwagon". Some mentioned that they feared losing their job.

"Without a diagnosis, I don't expect to be listened to nor to understand what I might need. Also, it's really hard to share my neurodiversity journey with people who don't get it. People seem more interested in trying to tell me I'm probably 'normal' and that everyone is a bit like this than they do in listening to your story."

White British man, aged 25-49, Norfolk (undiagnosed, awaiting assessment)

#### In summary

This chapter highlighted how people cope and what support they want while waiting. There is a demand for practical and straightforward measures, such as regular check-ins, clear communication about waiting times, and a single point of contact that could be provided while people wait.

When looking at support at work, we found most people hadn't had a conversation with their employer about their diagnosis or possible ADHD. Concerningly, many said that this was due to fear of losing their job.

Targeted efforts to tackle stigma alongside clear guidance for employers on effective, reasonable adjustments could create more supportive and inclusive workspaces. Our research shows that this can improve conditions for those affected by ADHD, with almost three-quarters of those who had been offered reasonable adjustments saying that they had made a positive difference.

# 5. The benefits of diagnosis

In this chapter, we look at the impact of having an ADHD diagnosis on people's lives. We found that the journey to diagnosis was viewed positively by many, but came with its own challenges. Our results demonstrate that a diagnosis has a positive, wide-ranging and transformative impact on people's lives.

#### The diagnosis process

Only around three in five (57%) of people in our national poll who were diagnosed with ADHD had an overall positive experience of the process from referral to diagnosis. Those who were employed were more likely to have a positive experience, pointing to the potential of a diagnosis to unlock effective support at work.

Challenges in the process of being diagnosed are longstanding. <u>Research from</u> <u>over ten years ago</u> described the ADHD diagnosis process itself as an "uphill struggle", poorly designed for the traits and needs of those with ADHD. Responses to our own survey indicate this is still the case for people diagnosed more recently.

"Their process for assessment is not ADHD friendly with forms you cannot save. It took me several attempts to do the forms due to my inability to complete or because I didn't leave enough time to finish them. It was very frustrating that I couldn't save and go back.

"They send notifications, not letters or phone calls, when follow-up action is required. This led to me missing my titration notification. They only gave me a two-week window; I was two weeks late and got referred back to go. I had to be referred again, had to see a psychiatrist again and then wait again. Still waiting to start two and a half years later."

White British woman, aged 25 – 49, Derby (diagnosed)

#### How did a diagnosis change peoples' lives?

Despite the difficulties outlined above, our findings show the impact of an ADHD diagnosis was largely positive:

Area of impact	% Agree
My ADHD diagnosis has helped me to understand the way my brain works and my behaviour	84%
Since my diagnosis, I have new strategies (e.g. ADHD coaching, apps) that I can use to manage my ADHD traits	58%
I find it easier to look after my mental health and wellbeing	58%
My self-esteem has improved	54%
I find it easier to take part in hobbies and personal interests	51%
I find it easier to concentrate (e.g. at work or while studying)	47%
I find it easier to work	46%
I find it easier to maintain relationships with my partner, close friends or family	46%
I find it easier to carry out daily household tasks	45%
The ADHD medication I have been prescribed has made it easier to manage my ADHD traits	44%
I find it easier to look after my physical health	43%
I find it easier to socialise	33%
I find it easier budgeting and managing my money	30%

The most common benefit of a diagnosis, reported by 84% of respondents, was a better understanding of how their brain works and why they behave the way they do.

"I was diagnosed in September 2020 at the age of 52. The impact of my diagnosis was profound. For over 30 years, I had been labelled with anxiety and depression, struggling without ever knowing why. Suddenly, I had answers. I wasn't 'weird.' I wasn't 'lazy.' I wasn't 'stupid,' 'crazy,' 'broken,' or 'too much.' Receiving my ADHD diagnosis allowed me to stop blaming myself for things that were never my fault. It gave me the ability to start healing."

White British woman, 50-64, Wirral (diagnosed)

In our survey, the importance of validation and self-understanding was strongly highlighted. Emotional and psychological validation, alongside practical selfmanagement strategies, plays a key role in improving outcomes.

"It has given me validation and I felt a massive weight lift. I now know that my anxiety, food issues, sensory issues and OCD are just because of having an ADHD brain and I no longer need to keep searching and trying to fix me. I feel so much better and more accepting of myself and how I think, feel, behave and react."

White British woman, aged 25 – 49, Norfolk (diagnosed)

Nearly three in five (58%) reported that since their diagnosis they had gained new strategies (e.g. ADHD coaching, apps) to manage their ADHD traits:

"It changed my life -I was able to get medication, workplace adjustments and coaching. I got a promotion at work, earned almost twice as much and now have a long career ahead of me. I'm able to manage my emotional regulation much better now. I can look up specific ADHD tips to organise my house so I don't feel like I'm drowning in mess now."

Asian British woman, London, 25-49 (diagnosed)

Over two in five (43%) reported that they found it easier to look after their physical health as a result of their ADHD diagnosis.

"Getting an ADHD diagnosis has meant that I finally have the support to reach my full potential. I'm healthier, I'm able to schedule regular exercise, I maintain healthy habits and diet, and there's much less impulse and risky behaviour happening."

White British woman, aged 25-49, Hampshire (diagnosed)

We also heard from people about the impact of medication. This included people who responded to our own survey that they wanted additional support because medication didn't work for them.

"As an adult, the only follow-up offered in this area is medication. I have tried them, and they work, but the side effects were too difficult, probably because I'm also autistic, and we have different reactions to things. Help with non-medicated strategies for those adults who can't take medication would be really useful. But there's nothing available like that here."

White British woman, aged 50-64 (diagnosed)

This underlines that self-understanding and management strategies are valuable to people alongside access to medication. These areas deserve more attention in both treatment plans and policymaking.

We heard that mental health and wellbeing improved for many due to diagnosis. Almost three in five (58%) found it easier to look after their mental health following a diagnosis, and 54% noted an improvement in self-esteem.

Nearly half (46%) of respondents reported finding it easier to maintain relationships with partners, close friends and family after diagnosis, and a third (33%) reported finding it easier to socialise after diagnosis. This may be linked to the greater self-understanding reported by 84% of respondents.

#### "Since my diagnosis, friendships have become more authentic, and I've noticed that people genuinely draw to me when I'm not masking."

White British woman, aged 25-49, Leeds (diagnosed)

Concerningly, only three in ten (30%) reported improvements in their ability to manage their finances, indicating that this remains challenging even after diagnosis and treatment.

Not only can it take a long time to resolve debt and financial issues, but we heard cases of financial issues being exacerbated by the costs of a diagnosis or medication. In some cases, this was due to the NHS not accepting shared care from Right to Choose providers or diagnoses from private ADHD assessment companies.

"I started ADHD meds this month, but it's costing me £250 a month privately. I am £20k in debt and life is pretty awful right now."

White British woman, 50-64, Southend (diagnosed)

#### In summary

While a long diagnosis process remains frustrating, the impact of a diagnosis is positive.

Beyond a straightforward story of access to medication, diagnosis can unlock selfunderstanding, effective management strategies, improved mental health, selfesteem, and concentration. These improvements extend to relationships, work performance, and daily household tasks.

# Conclusion and recommendations

There has been recent media attention and discussion about the rising prevalence of ADHD. This includes commentary on the reasons behind the rise in demand for support and the ability of stretched NHS teams to deliver.

However, little has been reported about the experiences of people diagnosed with ADHD, those waiting for an assessment that may lead to diagnosis, and those who are reluctant to come forward for help.

Despite the hard work of NHS staff, our findings paint a picture of long waits, a lack of support, and the subsequent poor impact that ADHD traits and process delays have on people's lives.

People with ADHD deserve to receive timely support when they need it, and people with unmet needs should be encouraged to seek help from the NHS and other teams to understand whether they have ADHD or another health condition and if support can be provided.

If, as we recommend, ADHD assessments are delivered by community teams, we believe that rising demand for diagnosis, treatment, and signposting to other support can be met, while freeing up specialist teams to meet more complex care needs.

We are committed to playing our part in these improvements and have shared this report as part of our role in supporting the national ADHD taskforce.

We have set out specific recommendations below and look forward to working with the taskforce and government to implement them.

#### Our recommendations:

To address the issues highlighted in this report, we're calling for recommendations to achieve key objectives including moving care closer to home, speeding up access to NHS care, and getting people the support they need.

1. Use data to improve our understanding of current pressures	
Recommendation	The Department of Health and Social Care to support NHS teams to collect and publish official data on ADHD assessment waiting times. This must include demographic data to understand who is experiencing the longest waits and why.
Current policy	National waiting times are not currently published, though work is underway to introduce official reporting.

Evidence	We heard from people without an ADHD diagnosis who were reluctant to approach the NHS for support due to long wait times.
	There may also be variation across the country in terms of access times.
	And there is a lack of understanding among members of the public as to how to navigate long waits.
How our proposal will help	While we welcome moves from NHS England to publish waiting list, referral, and assessment estimates from May 2025, a move to official waiting list data in the longer term will help decision-makers better understand the demand for ADHD support.
	Transparent data on NHS and Right to Choose wait times will allow people to manage their wait for ADHD and make informed and meaningful choices about their health.

## 2. Provide those waiting for assessment with the support they need

Recommendation	NHS teams to implement new 'waiting well' guidance, produced by Healthwatch England and NHS England with the national ADHD taskforce.
Current policy	There is currently patient communication guidance for elective referrals, but nothing specific for the ADHD pathway.
Evidence	Two-thirds of people with an ADHD diagnosis cited they received either no information or poor information while waiting for their assessment.
	Our report shows that the impact of ADHD traits affects many if not all, aspects of people's lives. Our research shows that long waits for assessments and the impact of a diagnosis also have substantial impacts on people's wellbeing. People wanted a wide range of support, including information on how to manage their mental wellbeing and a single point of contact about the wait for an ADHD assessment.
How our proposal will help	Given the impact ADHD symptoms, long waits for assessment, and an ADHD diagnosis can all have on people, more bespoke guidance – if properly implemented – would benefit people referred for assessment.
	While the guidance is currently in development, it will include signposting to non-NHS organisations who can help with employment, education and other support.

Recommendation	The Department of Health and Social Care and NHS England to train and hire more care coordinators in primary care, and provide training to deliver admin support, interim support and care navigation for those with ADHD and other neurodiverse conditions.
Current policy	There is no specific additional primary care role to support neurodivergent people in primary care.
Evidence	People referred for ADHD care require support while waiting for an assessment. This could be for a variety of needs across health, care, and other services.
How our proposal will help	Cultural and competency training in neurodiversity for care navigators will enable them to advocate for people when interacting with the NHS.

3. Develop new neighbourhood-led pathways for patients	
Recommendation	The Department of Health and Social Care to support the development of primary and community care pathways for the assessment and management of ADHD.
Current policy	Specialist secondary care psychiatry teams manage ADHD assessments and treatment.
Evidence	Our report shows that people face long waits for ADHD assessments. Some people have been put off asking their GP for a referral for an ADHD assessment because of long waits.
How our proposal will help	Growing awareness and recognition of ADHD means demand could be better managed via the delivery of assessments and support from primary and community care teams. This could:
	Reduce waiting times for assessment.
	<ul> <li>Free up demand for secondary care teams to manage more specialised cases, including referrals for people with complex comorbidities or experience of trauma.</li> </ul>
	• Enable primary and community care teams to provide notes and advice to people's employers on the benefits of reasonable adjustments to those with or waiting for a diagnosis.
	<ul> <li>Support the government's shift for more care delivered closer to people's homes.</li> </ul>

Recommendation:	NICE to review NG87 to achieve a shift in more ADHD care delivered closer to people's homes.
Current policy	NG87 covers recognising, diagnosing and managing ADHD in children, young people and adults.
Evidence	Our evidence and existing evidence show that new models of care are needed to deliver ADHD support.
How our proposal will help	Should ADHD management move into primary and community settings, NG87 will require a review against best practice evidence to update guidance for appropriate teams.
	This review would also provide an opportunity to update the guidance on the recognition of ADHD in certain groups.
Recommendation	NHS England, the General Pharmaceutical Council, the Royal College of Psychiatrists, the Royal College of GPs and NICE to promote annual medication reviews from primary care.
Current policy	NICE QS39 sets out guidance for the annual review of ADHD drug treatment, including shared care arrangements for review in primary care based on patient choice.
Evidence	Our evidence and existing evidence show that new models of care are needed to deliver ADHD support.
How our proposal will help	Collaboration between pharmacy and prescribing teams could:
	<ul> <li>Allow reviews to be conducted from primary care, speeding up annual medicine reviews for people treated for ADHD.</li> </ul>
	<ul> <li>Lead to developing and piloting a future model of prescribing first line medication from primary care.</li> </ul>
Recommendation	NHS England to work with the Royal College of Psychiatrists (RCGP) and the Royal College of GPs to develop ADHD training for primary and community care staff, including promotion of the GP with extended role (GPwER) in ADHD.
Current policy	The RCGP has developed a framework to develop GPwERs in ADHD.
Evidence	Our report shows that nearly two in five people currently waiting for an ADHD assessment needed more than one GP appointment before they were referred.

	Our recommended shift for more ADHD care in the community will require training for staff in primary and community care.
How our proposal will help	Staff in primary and community care will be trained to deliver NHS support for ADHD outside of hospital settings.

# 4. Improve the support that employers provide to those with ADHD

Recommendation	The Department of Health and Social Care, the Department for Work and Pensions, and the Department for Business and Trade to work with employers to raise awareness of, and incentivise, the proactive offer and delivery of reasonable adjustments to staff who would benefit.
Current policy	Employers must make reasonable adjustments to make sure workers with disabilities or physical or mental health conditions are not substantially disadvantaged when doing their jobs.
Evidence	Our research found that over three-quarters of those whose employer had offered reasonable adjustments said they made a significant or moderate difference.
	However, others are put off speaking to employers for a variety of reasons.
How our proposal will help	More proactive offers of reasonable adjustments will remove stigma from people requesting support, and ensure people get the help they need.
Recommendation	The Department for Work and Pensions to maintain its central management of the Access to Work scheme and expand the scheme to provide:
	<ul> <li>Targeted funds to individuals to pay for workplace adaptations beyond reasonable adjustments.</li> </ul>
	<ul> <li>A 'marketplace of support' for aids, appliances and assistive technology to reduce costs and spread their adoption.</li> </ul>
Current policy	The Department for Work and Pensions is consulting on the future of Access to Work, as set out in the <u>Pathways to Work</u> <u>Green Paper</u> .
Evidence	Over two-thirds (68%) who told their employer that they had ADHD were offered at least one reasonable adjustment. Over

	three-quarters of these said that the adjustments had made a difference.
How our proposal will help	Recent increases in applications for the Access to Work scheme highlight the need for more support to help people work.
	Making support more proactive and easier to access will ensure that people have the help they need to be able to work.

<sup>1</sup><sup>v</sup> In addition, 40% said they had only recently realised they might have ADHD; 18% said their ADHD traits make it harder for them to book or attend a GP appointment; 19% said other and 7% said prefer not to say.
<sup>v</sup> 49% said they were happy to self-diagnose, 19% said they were worried that a diagnosis would have a negative impact on them, 17% said that they couldn't afford a private diagnosis, 8% said they prefer to use natural remedies to manage ADHD traits; 7% said they prefer to use other strategies to manage their ADHD traits; Other – 18%; Don't know/prefer not to say 10%.

<sup>&</sup>lt;sup>1</sup> This is where the NHS uses tools to validate individuals formally referred to them for ADHD assessments from their NHS list.

<sup>&</sup>quot; Based on 2021 Census figures

<sup>&</sup>lt;sup>III</sup> Of the remaining 22%, 6% didn't have an appointment as they submitted the request without one; 8% said another professional referred them; 4% said other and 3% couldn't remember.

### healthwatch

Healthwatch England National Customer Service Centre Citygate Gallowgate Newcastle upon Tyne NE1 4PA

www.healthwatch.co.uk t: 03000 683 000 e: enquiries@healthwatch.co.uk g @HealthwatchE f Facebook.com/HealthwatchE