



Understanding ADHD: Challenges, Barriers, and Pathways to Support

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healthwatch
Central Bedfordshire

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Background

Attention Deficit Hyperactivity Disorder (ADHD) is a condition where the brain works differently to most people; it may affect things like concentration and sitting still (¹ NHS, 2025). ADHD involves persistent inattention or hyperactivity-impulsivity that disrupts daily life. Globally, referrals and prescriptions have surged, but NHS services have struggled to keep up, with growing wait times worsened by medication shortages (² HWE, 2025).

To respond, NHS England launched a rapid review and formed an ADHD Taskforce in March 2024. The Taskforce aims to improve care through better data, service mapping, and coordination across sectors. Healthwatch England joined in early 2025, contributing insights from national surveys to highlight people's key concerns (² HWE, 2025).

Healthwatch England's Key Findings (May 2025):

- ◆ ADHD has a profound impact on people's lives.
- ◆ Diagnosis can be life - changing.
- ◆ Long waits are pushing people to seek private care.
- ◆ Many face hidden delays in getting referred.
- ◆ Most receive no support while waiting.
- ◆ People often feel unable to discuss ADHD with employers.

Under the NHS in England, patients now have a legal right to choose their mental healthcare provider and team.

This means, for example, if the waiting time for an ADHD assessment is too long, people can select an alternative NHS-approved provider based anywhere in England. The Right to Choose option has been available since 2018, but not all patients or clinicians are fully aware of it (³ ADHD UK).

Waiting times for an ADHD diagnosis in Central Bedfordshire and Luton are lengthy, with NHS providers reporting wait times exceeding five years for adults (18+ years), due to a high demand for services and limited resources. While some private providers offer faster assessments, the cost can be a barrier (⁴ Lea Vale, 2025).

To further support the Taskforce's work on ADHD, and to build a stronger evidence base for local decision-making, Healthwatch Central Bedfordshire (HWCB) undertook a survey between April and August 2025. The survey aimed to gain deeper insight into the experiences of people in Central Bedfordshire who are waiting for an ADHD assessment or diagnosis. By capturing the voices of local residents, HWCB sought to better understand the challenges they face, from lengthy waiting times and limited access to support, to the personal and social impact of delayed diagnosis. This work was also intended to highlight gaps in information, signposting and post-diagnostic support, ensuring that the lived experiences of residents help inform improvement to services, pathways and community support.

¹ ADHD in adults - NHS

² <https://nds.healthwatch.co.uk/reports-library/recognising-adhd-how-improve-support-people-who-need-it>

³ Right to Choose - ADHD UK

⁴ <https://www.leavale.nhs.uk/clinics-and-services/attention-deficit-hyperactivity-disorder-adhd-referrals-and-medication/>

Methodology

Healthwatch Central Bedfordshire (HWCB) designed a structured online survey to capture the lived experiences of residents in Central Bedfordshire who are seeking or undergoing assessment for Attention Deficit Hyperactivity Disorder (ADHD).

The survey, conducted between April and August 2025, aimed to explore key aspects of the ADHD journey, including:

- ◆ pathways to referral and diagnosis;
- ◆ awareness and understanding of NHS ADHD pathways and entitlements;
- ◆ experiences of waiting times and the assessment process;
- ◆ the impact of ADHD on daily life, relationships, education, and work;
- ◆ access to and effectiveness of available support and treatment options.

To maximise reach and inclusivity, the survey was:

- ◆ publicised widely through HWCB's digital platforms (website, newsletters, and social media channels);
- ◆ shared via key stakeholders and local networks, including education providers, voluntary sector organisations, and community groups;
- ◆ made available online in an accessible format, with alternative formats (on request) for those unable to complete it digitally.

No identifying personal data was collected to protect participants' privacy, and responses were anonymised prior to analysis. Participation was voluntary, and respondents were informed about how their data would be used in line with GDPR compliance.

Responses were analysed using a mixed-methods approach:

- ◆ Quantitative data (e.g., demographics, diagnosis pathways, waiting times) were summarised using descriptive statistics to identify patterns and trends;
- ◆ Qualitative data (open-text responses) were thematically analysed to capture deeper insights into lived experience, barriers, and perceived gaps in services.

Although the survey involved a relatively small sample (41 respondents), it was designed as a snapshot survey to highlight real experiences at a specific point in time. This does not detract from the seriousness or validity of the findings, which reflect significant and recurring challenges for individuals navigating ADHD pathways in the area.

This approach ensures the report reflects authentic community voices while providing a reliable evidence base to inform service development, policy discussions, and the work of the NHS ADHD Taskforce.

The survey results are summarised below with a full survey analysis located on pages 18–46.

Executive Summary

This report captures the lived experiences of individuals and families navigating ADHD assessment, diagnosis, and treatment. It highlights systemic delays, inconsistent clinical practices, and the profound personal and social impacts of inadequate support. One participant described how these challenges permeate every aspect of life:

“It feels like the system is completely working against you... this affects every part of my life – emotionally, socially, and career-wise.”

For others, the absence of timely support has left them feeling invisible and exhausted:

“Neurodivergent conditions remain very negatively viewed within society and workplaces... the process is traumatising and not neuro-affirming.”

Key Findings

Misdiagnosis and Inconsistent Assessment

Several participants reported being misdiagnosed by NHS Psychiatrists, often after rushed consultations that failed to explore full histories or apply structured diagnostic tools. In contrast, private assessments were described as longer, more thorough, and ultimately more accurate, though prohibitively expensive.

One person explained about their experience:

“The NHS Psychiatrist that I saw was late to my appointment, for which he did not apologise, nor did he offer to reschedule my appointment. This meant I only had 20 minutes instead of half an hour to get my entire life story across (I was 43 at the time and this was 10 years ago) and because I talked rapidly, and told him one of my sisters has bipolar, he got to the end of the appointment and simply said, “Oh you’re bipolar, here’s a prescription for Sodium Valproate”. I was very taken aback by this as I had never experienced any mania or depression the way my sister had. When I got home and told my husband of 22 years and my mum that the Psychiatrist said I was bipolar, they both disagreed and said I should go private, which I did. I had a far more thorough assessment (90 minutes) which included questionnaires that my mum and husband and myself completed about what I was like as a child and as an adult etc and after my private appointment (the cost of which I had to put on a credit card and took me a year to pay off) was far more accurate i.e. I have moderate to severe ADHD/OCD and anxiety.”

Others spoke of the confusion and conflict between services:

“Services arguing who should do the diagnosis.”

Parents, particularly of girls, highlighted the lack of understanding in educational settings:

“ADHD was discussed five years ago, but education had such a poor understanding of its presentation in girls that the process was dismissed by paediatrics – despite parent and child questionnaires concurring and meeting diagnostic criteria. It then took another five years and pushing, and securing an educational provision, post 16, through tribunal to be able to provide evidence to confirm a diagnosis via CAMHS.”

Barriers to Timely Diagnosis

Long waiting lists, confusion between services over diagnostic responsibility, and limited awareness of ADHD presentation in women and girls were repeatedly cited. These barriers have left individuals without support for years, often resulting in worsening mental health, family strain, and lost educational or employment opportunities.

Another respondent described the frustration of trying to navigate the ‘Right to Choose’ (RTC) pathway:

“The titration service under right to choose is an absolute joke. That whole part needs a massive overhaul. I initially went on the NHS waiting list five years ago. Then I had a private diagnosis shortly after. Then a few years later, as I really felt quite out of control in many aspects of my life, I pursued a diagnosis under ‘Right to Choose’ to enable me to access medication. I got the diagnosis, was told I’d have to go through my GP to access medication, and when I did that, was told they don’t offer that, and to go on the NHS waiting list. So, what’s the point of right to choose?!”

Another lady said, ***“Yes, having ADHD as a woman and going through any hormonal changes i.e. puberty, pregnancy, post birth, becoming a mother, perimenopause etc has been extraordinarily stressful and challenging for me. At least now I can understand why.”***

Challenges with Treatment and Shared Care

Even after diagnosis, many struggled to access or maintain treatment. Some were prescribed inappropriate medication, while others faced obstacles in transferring private prescriptions to NHS care. The ‘Right to Choose’ pathway was frequently described as complex, poorly understood by GPs, and inconsistently applied.



Being on the ADHD assessment waiting list has had a serious impact. Without a diagnosis, behaviour has been repeatedly misunderstood, leading to constant school complaints, disciplinary action, and even an accusation of assaulting a teacher. Previous involvement with the police, as he sometimes leaves the house without permission, which raises safety concerns. Socially, he struggles to maintain friendships and feels isolated. Emotionally, at times he experiences low self-esteem, racing thoughts, and poor sleep, and often says he feels like a failure. The lack of timely assessment is worsening his education, safety, and mental health – and delaying the vital support he urgently needs.

One person added how ADHD impacted their lives, ***“Has a huge impact on all aspects I my life, now moved into adult services as received a diagnosis just before my 18th birthday. I am also autistic – CMHT (Community Mental Health Team) just want to medicate, and that has not been straight forward as I have not tolerated most of the medications they have suggested. They are very poor at managing ADHD. Moving into adult services was appalling – transition policy was highlighted, and it should have taken a slow gradual process over 12 months, but they did it in two weeks and handed me over to a team that is frankly no better. The whole experience of CMHT, which has a very medicalised model, is useless.”***

Impact of Diagnosis and Treatment

Where individuals were able to access appropriate assessment and medication, the impact was described as transformative. Participants reported improvements in focus, self-understanding, work and home life, relationships, and parenting. However, gaps in follow-up support, such as ADHD coaching, counselling, or workplace adjustments, limit sustained progress.

Others noted that while medication brought positive changes, support remains inconsistent:

“Compassion for myself, adjustments at work, coaching, medication has changed my life.”

“Medication has provided me the first experience of being ‘less stressed’ (and I’ve tried lots of things before to help with stress management which turns out was mainly internal hyperactivity). It’s not ‘fixed’ me and I still have daily struggles. I realise that the focus on medication, means I text friends and families less, so oddly find it’s negatively impacted social relationships. Having a diagnosis has also enabled me to get work-place accommodations although I face stigma as someone who is perceived to be ‘high achieving.’”

Another person added, ***“It has had a positive effect, and everyone deserves the right to be diagnosed and understood.”***

Gender and Hormonal Factors

Women repeatedly spoke of how ADHD symptoms were amplified during hormonal changes, from puberty to perimenopause



It has been life changing, I have not been able to work consistently for 15 odd years, and I’ve just gone back to work. I’m being supported by access to work. I’ve learnt so much about myself, through my own research, no help from the NHS. I had previously been told I was depressed, anxious had a personality disorder but I didn’t, I had ADHD all along and knowing that has changed my life. I’m taking control of my life in my 40’s.

One participant managing family responsibilities alongside menopause described feeling completely overwhelmed: ***“Being deep into menopause has highlighted my ADHD symptoms even more... I can’t concentrate, sleep, eat properly, or keep to appointments. I’m also managing two ADHD teenagers, and the feeling of being overwhelmed is strong most days.”***

Education and Children

Parents spoke of the daily toll of navigating school systems while waiting for assessment or support.

Others reported discrimination or lack of understanding from educational professionals: ***“Discrimination by school staff, friends, and Local Authority.”***

Stigma and Misunderstanding

Stigma and systemic misunderstanding were recurring themes. One respondent explained:

One person said, ***“It is still poorly understood. I asked my employer for reasonable adjustments, but they didn’t provide any, saying it wouldn’t be suitable within my role. Or the minor adjustments they did offer were not used in practice. I don’t think others understand how challenging life can be for me; not just as an adult with late-diagnosed ADHD (and Autism), but as a single solo parent to two children who also have both conditions, (one of whom also has two physical health conditions that are commonly co-morbid with ADHD). I’ve asked for help with work, and it’s been denied. I’ve asked for help from the local authority, and despite many promises, nothing has come to fruition. My employer assumes it’s my mental health that’s struggling and offers to refer to mental health services, but I’m not depressed or anxious, I’m just overloaded. Yet without work, I’d be even more stressed about finances. People think everyone is getting an ADHD diagnosis because it’s ‘trendy’, without seeing how debilitating it actually can be.”***



Having ADHD as a woman and going through hormonal changes – puberty, pregnancy, perimenopause – has been extraordinarily stressful and challenging.



This is on behalf of my six-year-old son... taking him to school every day is a battle in both our mental health and wellbeing. He spends half of his time not in the classroom due to not being able to cope... he is behind on his education in all areas.



There needs to be a service where if a child has been diagnosed with ASD/ADHD then an assessment should be available to other family members or vice versa if an adult has been diagnosed then their children should be assessed.

Another respondent explained:

“It’s hard enough having ADHD without being medically gaslit by GPs saying, ‘but you don’t look like you have ADHD’ and doing everything they can to NOT refer you for diagnosis. Then you have to wait an average of three years for a diagnosis appointment unless you go through another tricky, paperwork-based system of Right to Choose – and even then, it still takes over a year. Within the time you are waiting for diagnosis, you’re still struggling with all your symptoms, all whilst not knowing 100% for sure that you have this disability, so feel guilty (especially as a woman as most girls and women aren’t perceived as ADHD because they’re not hyper boys) that you might be slightly identifying as something you’re not because socially at the moment it’s being ridiculed as a popular “phase” / “fad” because influencers are falsely self-diagnosing. Then you get a diagnosis – but treatment plans very wildly depending on who diagnoses you, whether they have funding, whether they can prescribe medication, whether they have actual long-term psychiatric help, whether your GP will partner with them. This disability (although socially it’s considered a childish nuisance rather than a real disability) affects EVERY part of my life– emotionally, socially, physically, mentally, educationally, and career-wise. If I manage to get prescribed medication, I might not even be able to collect it due to the nationwide lack of availability. It’s the most complicated diagnosis to get – especially for people who have ADHD. It feels like the system is completely working against you.”

Overall, this report paints a clear picture of a system that is failing too many people with ADHD. Delays in assessment, inconsistent diagnostic practices, and gaps in treatment and ongoing support are leaving individuals and families feeling unsupported, misunderstood, and, in many cases, in crisis. While timely and accurate diagnosis can be life-changing, this benefit is undermined by barriers that persist at every stage of the pathway. These findings highlight the urgent need for coordinated, neuro-affirming services that provide timely assessments, accessible treatment, and meaningful post-diagnostic support, ensuring that no one is left to navigate these challenges alone.





Survey Summary

To better understand the local experience of ADHD, a total of 41 individuals from across Central Bedfordshire shared their perspectives through the survey. While this represents a snapshot rather than the entire community, the responses provide valuable insight into the diverse demographics, diagnostic journeys, and everyday challenges faced by people with ADHD, or those seeking a diagnosis, in the area.

Respondent Demographics

There was a total of **41** survey responses of which:

- ♦ **79.4%** were women and **14.7%** were men
- ♦ **63.6%** aged between **25–49** years

ADHD Diagnosis Status

- ♦ Diagnosed with ADHD: **39%**
- ♦ On waiting list: **17%**
- ♦ Undiagnosed but suspect ADHD: **26%**
- ♦ No ADHD: **17%**

Diagnosis Experience

- ♦ **75%** of diagnosed individuals were diagnosed as adults
- ♦ **62.5%** received diagnosis via NHS; **31.25%** privately
- ♦ **62.5%** rated the process as 'negative' or 'somewhat negative'

Key issues: long wait times, lack of communication, insufficient support, paperwork complexity.

Treatment and Life Impact Post-Diagnosis

- ♦ **87.5%** said diagnosis helped understand their behaviour
- ♦ Only **50%** agreed medication was effective
- ♦ Less than **40%** saw significant improvement in daily activities like work, budgeting, or relationships.

Experience Waiting for Diagnosis

- ♦ **85.7%** had been waiting 1–2 years
- ♦ Waiting had a significant negative impact on education, employment, mental health, and family dynamics
- ♦ Only **28.5%** received any form of support while waiting

Barriers and Support Gaps

- ♦ **71%** said the information provided during the wait was poor
- ♦ Most helpful potential support: point of contact, work/study strategies, mental health resources

Private Diagnosis & GP Barriers

- ◇ **43%** considered private care for faster access
- ◇ Among those not pursuing diagnosis, **57%** struggled with appointments or feared rejection

Employment & Adjustments

- ◇ Only **37.5%** disclosed ADHD to their employer
- ◇ Common workplace support: work-from-home, ADHD coaching, flexible hours
- ◇ Fear of discrimination and lack of formal diagnosis discouraged disclosure

Co-occurring Conditions

- ◇ Anxiety: **62%**, Depression: **54.5%**, Autism: **20.6%**

Key Themes from Open Responses

- ◇ Misdiagnosis (especially in women) and lack of recognition in girls
- ◇ ADHD symptoms worsen during hormonal changes (e.g., menopause)
- ◇ Frustration with GP knowledge and service fragmentation
- ◇ Trauma from untreated ADHD and lack of support for families

Together, these findings highlight not only the varied experiences of those living with ADHD but also the recurring systemic barriers they face. From long waits and inconsistent communication to gaps in workplace support and co-occurring mental health conditions, the data underscores the urgent need for more timely, coordinated, and neuro-affirming services that better meet the needs of this community.





Conclusion

This survey reveals deep-rooted structural and systemic barriers in the diagnosis, treatment, and ongoing support for individuals with ADHD in Central Bedfordshire.

Across every stage of the pathway, referral, assessment, treatment, and follow-up, people reported delays, poor communication, and limited access to consistent care. These shortcomings are leaving many individuals and families feeling unsupported, misunderstood, and, in some cases, in crisis.

Long waiting times were one of the most striking issues, with some respondents reporting waits of one to two years or more, often without any interim support. One parent described the effect on their child: ***“Being on the ADHD assessment waiting list has had a serious impact... The lack of timely assessment is worsening his education, safety, and mental health – and delaying the vital support he urgently needs.”***

For adults, these delays are equally damaging, with many reporting job insecurity, relationship breakdowns, and deteriorating mental health. As one participant explained: ***“Services locally are awful and not supportive, particularly once you move into adulthood.”***

Misdiagnosis and inconsistency in assessments were also common themes. NHS consultations were often described as rushed or incomplete, with private assessments viewed as more thorough but financially inaccessible to many. This has created a two-tier system in which timely, accurate diagnosis often depends on the ability to pay.

Gender-specific challenges were a recurring issue, with many women feeling their symptoms had been overlooked or misunderstood for years, particularly during key hormonal stages such as puberty, pregnancy, and perimenopause. One respondent shared: ***“Having ADHD as a woman and going through hormonal changes – puberty, pregnancy, perimenopause – has been extraordinarily stressful and challenging.”***

Beyond diagnosis, many respondents reported serious barriers to treatment and ongoing care. The Right to Choose pathway, intended to give patients more options, was frequently described as confusing and inconsistently applied, with some GPs refusing to engage in shared-care arrangements for medication management.

Stigma and misunderstanding remain powerful barriers, both within services and in wider society. One participant summarised this experience: ***“There is very little support available. Neurodivergent conditions remain very negatively viewed within society and workplaces... I have had no help from the professionals I had hoped and expected to help us, and I would not wish the diagnosis process on anyone else. It is traumatising and not neuro-affirming. Things need to change.”***

Yet, where accurate diagnosis and appropriate treatment were provided, the impact was transformative. Participants spoke of better focus, improved relationships, and a greater sense of control and self-compassion. As one person put it: ***“Compassion for myself, adjustments at work, coaching, medication — it has changed my life.”***

The evidence from this survey makes it clear that timely, thorough, and neuro-affirming assessment, coupled with accessible treatment, tailored support, and better-informed professionals, would not only transform individual lives but also reduce long-term social and economic costs. The voices captured here are a powerful call for reform, for a system that listens, understands, and responds to the real needs of people with ADHD and their families.



Recommendations

1. Assessment Quality & Diagnostic Standards

Issues raised:

- ◆ Misdiagnosis (e.g., ADHD mistaken for bipolar disorder).
- ◆ Short, rushed NHS appointments (20–30 mins) vs private assessments (90+ mins with multi-informant input).
- ◆ Lack of childhood history gathering and questionnaires in NHS processes.
- ◆ Women and girls under-recognised due to stereotypes.
- ◆ Professionals defaulting to depression, anxiety, or personality disorder before considering ADHD.

Recommendations

- ◆ **National diagnostic standard:** Mandate a structured, evidence-based assessment process including:
 - ◆ At least 90 minutes with a psychiatrist/psychologist.
 - ◆ Multi-informant history (parent, partner, teacher forms).
 - ◆ Childhood developmental history.
- ◆ **Mandatory ADHD training** for Psychiatrists, GPs, Paediatricians, and CAMHS staff, with specific focus on female presentation and adult ADHD.
- ◆ **Double-check pathways:** where symptoms overlap with bipolar, BPD, anxiety, or depression, require a second professional opinion before prescribing.
- ◆ **Specialist ADHD screening clinics** to reduce diagnostic errors.

2. Waiting Times & Access to Care

Issues raised:

- ◆ 3–5 year waiting times.
- ◆ Patients bouncing between services (“who should diagnose?”).
- ◆ Confusion about “Right to Choose”.
- ◆ NHS reneging on shared-care agreements.

Recommendations

- ◆ Legally enforce NHS waiting time standards for ADHD assessment (e.g., maximum 12 months).
- ◆ Streamline pathways: single national referral form for ADHD (removes GP/local authority disputes).
- ◆ Improve RTC clarity: GP guidance and patient leaflets so people understand process.
- ◆ Shared care agreements must be standardised and non-negotiable between NHS and private providers.
- ◆ Digital triage and screening tools could be used (carefully designed for neurodiverse needs) to speed up pre-assessment information gathering.

3. Post-Diagnosis Support

Issues raised:

- ◆ Many receive diagnosis but no treatment or follow-up plan.
- ◆ Medication offered without coaching, therapy, or psychoeducation.
- ◆ Some can't tolerate medication and are left with no alternatives.
- ◆ Coaching and counselling unaffordable privately.
- ◆ Workplace/school accommodations inconsistent.

Recommendations

- ◆ Standard care package post-diagnosis to include:
 - ◆ Medication titration (with physical health monitoring).
 - ◆ ADHD coaching or CBT (NHS funded).
 - ◆ Psychoeducation for family members.
- ◆ Workplace/education liaison teams: ensure accommodations (noise-cancelling headphones, flexible deadlines, written instructions, task management tools).
- ◆ Ongoing support clinics: not just “diagnose and discharge”, but regular reviews (esp. during life transitions like perimenopause, job change, or moving into adult services).
- ◆ Holistic treatment: recognise co-morbidities (OCD, anxiety, PMDD, autism, hypermobility).

4. Transition from Child to Adult Services

Issues raised:

- ◆ Poorly managed transitions (sometimes 2 weeks instead of recommended 12 months).
- ◆ CMHT focus too medicalised and dismissive of ADHD.

Recommendations

- ◆ 12-month structured transition pathway between CAMHS and adult ADHD services.
- ◆ Dedicated ADHD transition coordinators to avoid people 'falling through the cracks.'
- ◆ Adult mental health teams must be trained in ADHD management, not just mood disorders.

5. Gender, Hormones & Life Stage Considerations

Issues raised:

- ◆ ADHD in girls dismissed by paediatrics and schools.
- ◆ Perimenopause and menopause worsen symptoms but not recognised.
- ◆ Pregnancy/postpartum not considered in ADHD care.

Recommendations

- ◆ National guidance on ADHD in women: puberty, pregnancy, perimenopause.
- ◆ GPs and psychiatrists trained to consider hormonal impact on ADHD symptoms and medication needs.
- ◆ ADHD screening in perimenopausal clinics and maternal health services.

6. Children & Families

Issues raised:

- ◆ Children left unsupported because they "do well" academically.
- ◆ Behaviour misinterpreted as "naughty" or "aggressive."
- ◆ Families stressed, parents burnt out, accusations of poor parenting.
- ◆ Schools and local authorities blocking assessment/support.

Recommendations

- ◆ Early school-based screening for ADHD traits (especially girls, quieter children, and racially minoritised groups).
- ◆ Schools legally required to follow through on ADHD referrals.
- ◆ Parent training programmes offered free by NHS (on emotional regulation, ADHD parenting strategies).
- ◆ Whole-family approach: if one child/parent diagnosed, others should be offered assessment.

7. Tackling Stigma & Bias

Issues raised:

- ◆ ADHD seen as a ‘fad’ or ‘trendy’.
- ◆ Employers denying reasonable adjustments.
- ◆ Racial bias leading to harsher discipline instead of diagnosis.
- ◆ Medical gaslighting (“*you don’t look like you have ADHD*”).

Recommendations

- ◆ **National ADHD awareness campaign:** highlight adult ADHD, female presentation, and racial disparities.
- ◆ **Workplace policy reform:** enforce ADHD as a disability under Equality Act, requiring reasonable adjustments.
- ◆ **Mandatory anti-bias training** for teachers and clinicians to address racial stereotypes.

8. Digital Systems & Accessibility

Issues raised:

- ◆ Online forms/surveys not neurodiverse-friendly.
- ◆ AI systems sending inappropriate messages.
- ◆ No feedback channels for patients to correct errors.

Recommendations

- ◆ Co-design digital tools with neurodivergent people.
- ◆ Ban automated AI-driven follow-ups without human oversight.
- ◆ Provide accessible alternatives to online forms (phone, paper, in-person).
- ◆ Create clear feedback and complaints channels for errors in digital systems.

9. Research & Policy Development

Issues raised:

- ◆ Links with hypermobility, PMDD, ARFID, Autism often ignored.
- ◆ Generational harm from decades of missed diagnoses.

Recommendations

- ◆ Fund research on co-occurring conditions (especially in women).
- ◆ Establish national registry to track waiting times, misdiagnosis rates, and patient outcomes.
- ◆ Prioritise retrospective justice: older adults finally accessing ADHD services should be supported, not dismissed.

Survey –

Full responses

Question 1 – Respondents were asked about their ADHD status using the following statements:

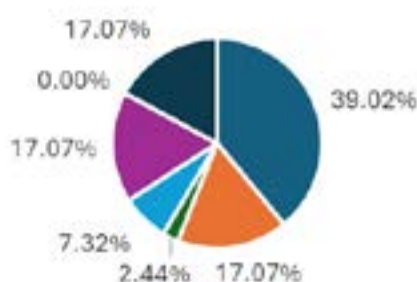
Of the 41 people that responded:

- ◆ 39% had been diagnosed with ADHD by the 'Right to Choose' scheme either by the NHS or privately.
- ◆ 17% had been referred by their GP and were waiting for an assessment.
- ◆ 17% of respondents think they have ADHD but have yet to visit their GP to ask about having a referral.
- ◆ 17% have spoken to their GP about a referral and are on the waiting list
- ◆ 7% think they have ADHD but are not seeking a formal diagnosis.
- ◆ 2% of respondents think they have ADHD but their GP will not refer them for an assessment.

Key Insights:

While a significant portion (39%) has been formally diagnosed, a sizable group remains undiagnosed or in the assessment pipeline, indicating ongoing demand and potential delays in ADHD diagnostic services.

Which of the following applies to you?



- I have been diagnosed with ADHD
- My GP has referred me for an ADHD assessment and I am on the waiting list
- I believe I have ADHD, but my GP has refused to refer me for an ADHD assessment
- I am not pursuing a diagnosis, but I think I have ADHD
- I believe I have ADHD, but I haven't yet seen my GP to ask for a referral
- I believe I have ADHD but I don't want to seek a formal diagnosis

Question 2 – For those people that had been diagnosed with ADHD, they were asked how long ago they were diagnosed;

Of the 16 responses:

- ◆ 12.5% were diagnosed within the last 12 months.
- ◆ 12.5% were diagnosed over five years ago.
- ◆ 75% were diagnosed one to five years ago.

Key Insights:

Most people diagnosed with ADHD in this group received their diagnosis within the past 1–5 years, reflecting growing recognition and assessment of ADHD in recent years.

How long ago were you diagnosed with ADHD?



Question 3 – The respondents with ADHD were asked when they were diagnosed;

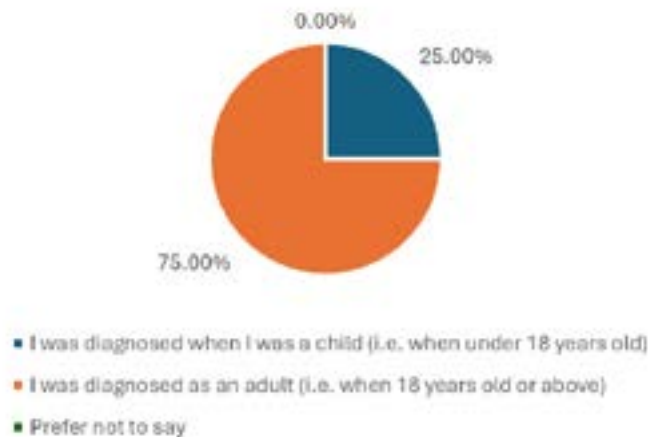
Of the 16 people that have been diagnosed with ADHD:

- ◆ 75% had been diagnosed as an adult.
- ◆ 25% had been diagnosed as a child.

Key Insights:

Most ADHD diagnoses in this group occur in adulthood, highlighting the need for earlier identification and support.

When Were You Diagnosed?



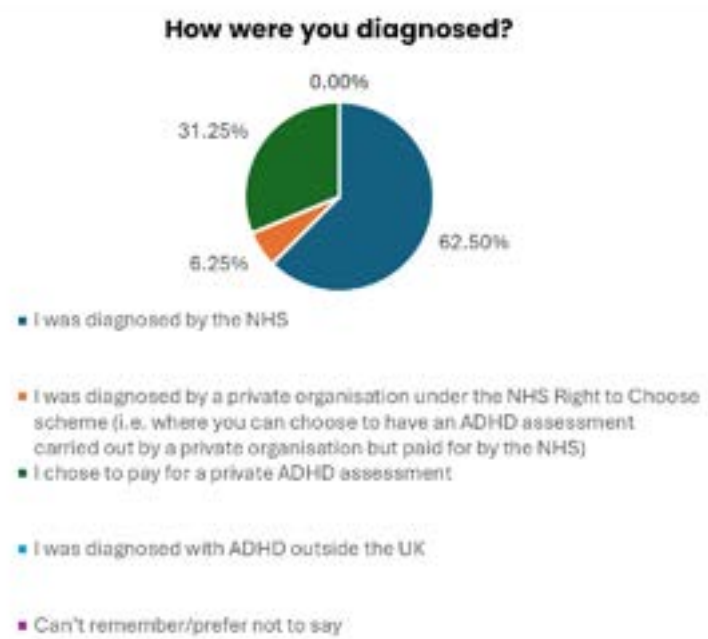
Question 4 – For those people who have been diagnosed with ADHD they were asked how they were diagnosed;

Of the **16 people** that are diagnosed with ADHD:

- ◆ **63%** of people were diagnosed on the NHS
- ◆ **31%** of people had paid to have a private assessment
- ◆ **6%** of respondents had been diagnosed with a private organisation under 'NHS Right to Choose.'

Key Insights:

Most ADHD diagnoses occur through the NHS, but a significant minority turn to private routes due to wait times, service limitations, or desire for a more comprehensive assessment.

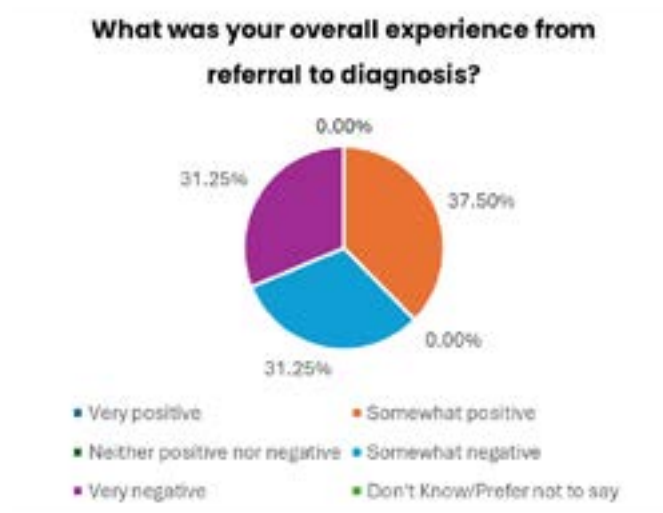


Question 5 – People diagnosed with ADHD were asked what their overall experience was from referral to diagnosis;

- ◆ **38%** of respondents had a 'somewhat positive' experience.
- ◆ **31%** had a 'somewhat negative' experience.'
- ◆ **31%** a 'very negative' experience.

Key Insights:

Most diagnosed individuals reported negative experiences, highlighting serious challenges in the ADHD referral-to-diagnosis process.



Question 6 – Those people that had been diagnosed with ADHD were asked which parts of the process from referral to diagnosis they found difficult (multiple options could be chosen);

Of the people that answered this question:

- ◆ 60% chose ***'lack of resources.'***
- ◆ 30% chose ***'persuading GP to make a referral.'***
- ◆ 50% chose ***'lack of support or resources.'***
- ◆ 40% chose ***'bringing together supporting evidence.'***
- ◆ 20% chose ***'understanding the diagnostic criteria.'***
- ◆ 70% chose ***'length of the process to get a referral.'***
- ◆ 60% chose ***'length of the process between referral and diagnosis.'***
- ◆ 60% chose ***'not knowing who to contact while waiting for diagnosis.'***
- ◆ 40% chose ***'I found the forms and paperwork complicated.'***

Which parts of the process from referral to diagnosis did you find difficult?



Other comments include:

“Additional wait and lack of clarity, as the first doctor I saw as part of the diagnostic process, had died and insufficient notes were on the system. Staff were nice but it felt odd knowing he’d died, and I worried I’d have to start all over again.”

“The continuing and worsening negative impacts of untreated ADHD.”

“The Local authority blocked the assessment and health care support.”

“I was misdiagnosed by the NHS after a rushed assessment and only received an accurate ADHD diagnosis privately, at great personal cost. Now, years later, I am still facing barriers to restarting treatment, with GPs unclear on the referral process.”

Key Insights:

This experience shows that NHS ADHD pathways can be rushed, inconsistent, and prone to misdiagnosis, leaving patients to pay privately for thorough assessment. GPs are not always clear on referral processes, creating further barriers. There is a pressing need for more consistent NHS pathways, improved professional awareness, and better continuity of care.

Question 7 – People with an ADHD diagnosis were asked to what extent they agreed to the following responses:

There were **16** responses.

Answer Choices	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Don't know/ Not applicable
I find it easier to work	12.50%	31.25%	12.50%	6.25%	6.25%	31.25%
	2	5	2	1	1	5
I find it easier to concentrate (e.g. at work or while studying)	12.50%	37.50%	12.50%	18.75%	12.50%	6.25%
	2	6	2	3	2	1
I find it easier budgeting and managing my money	12.50%	12.50%	31.25%	12.50%	18.75%	12.50%
	2	2	5	2	3	2
I find it easier to carry out daily household tasks	18.75%	25.00%	18.75%	0.00%	25.00%	12.50%
	3	4	3	0	4	2
I find it easier to maintain relationships with my partner, close friends or family	0.00%	43.75%	12.50%	6.25%	12.50%	25.00%
	0	7	2	1	2	4
I find it easier to take part in hobbies and personal interests	6.25%	43.75%	18.75%	6.25%	12.50%	12.50%
	1	7	3	1	2	2
I find it easier to socialise	0.00%	37.50%	31.25%	6.25%	12.50%	12.50%
	0	6	5	1	2	2

Key Insights:

From the 16 responses it appears that improvements are perceived more in social, relationship, and concentration areas than in practical or financial tasks, with changes tending to be moderate rather than strongly transformative. It suggests that while people notice some positive shifts, they are more modest and uneven, with uncertainty highest for work-related and task-based benefits.

Question 9 – Those people that have been diagnosed with ADHD were asked to describe the impact of getting an ADHD diagnosis on their life (considering the impact on: managing their ADHD traits, their work/education, managing relationships, and their health and wellbeing).

There were **16** responses, including the following:

Positive Impacts

- ◆ *“It has provided a much-needed clarity about my brain, work and life ‘habits’, mental health, and how to support my two children (who we think also have ADHD, but schools say they ‘do well’ so are not interested in supporting any testing). It’s helped my partner understand me better. The diagnosis and coaching have helped me understand a lot of my past, why I feel things intensely, and why movement is so important to me.*
- ◆ *“I am able to get more support in education and understanding of myself from both me, and other people.”*
- ◆ *“Accessing medication has been incredibly helpful, but I am still in the titration process and currently paused due to blood pressure issues. I notice a huge difference and find I’m a lot less productive when I don’t have my medication.”*
- ◆ *“With medication I felt more able to cope with the demands of work and home. It meant I was able to support my children better (one has multiple diagnoses/disabilities, and the other is awaiting assessments for ASD and ADHD). My home was cleaner and tidier, making day to day life easier in general. I also felt more confident within interpersonal relationships; more able to advocate for myself and enjoy myself without feeling too self-conscious. I do think I could benefit from ADHD coaching and other ADHD-specific support, but I can’t afford to access this privately.”*
- ◆ *“I have in the past found prioritising work challenging. Often get overwhelmed and flit from one task to another not completing anything. Recently I found apps such as Monday.com and task lists help me as I can priorities and tick jobs off once complete which gives me a sense of fulfilment. Breaking down tasks into priorities, dates and small tasks has helped me hugely. When I worked in a busy office, I had noise cancelling headphones as the noise around me distracted me. I have recently learnt to enjoy rest, slow down and take time to recharge.”*
- ◆ *“Getting the private diagnosis was very helpful as it made sense of my whole life up until that point. What is enormously frustrating is that I’m currently going through perimenopause and my ADHD symptoms are massively heightened and I’m struggling but NHS GP won’t help without me getting an NHS ADHD diagnosis – which could take years!”*
- ◆ *“Being able to start to understand why I’ve struggled to maintain jobs, education, relationships etc in the past to help prevent those issues in the future.”*
- ◆ *“It’s been revolutionary finding out what’s wrong with me but the frustrating thing is getting other mental health diagnosis reviewed (a lot of people are first diagnosed bipolar or BPD (Borderline Personality Disorder) when actually a lot of the symptoms are actually ADHD and that apart from medication there’s no additional services or counselling to come to terms with the diagnosis and it being missed for so long and working through the thoughts and feelings as it’s common for those late diagnosed to go through an identity crisis.”*

Negative Impacts

- ♦ *"I am understanding myself as well as my immediate and extended family has been eye opening and frankly life changing. Unfortunately, the NHS reneged on my 'Shared Care' agreement, so I went for years without medication. A few months ago, I was really struggling due to peri-menopause and I approached my GP about trying to get some ADHD medication again, this has been an ongoing challenge which I am still trying to navigate."*
- ♦ *"I have been provided a diagnosis but no treatment plan or medication so far (three months later) so there's been no drastic impact on my life – other than a bit of self-awareness/understanding/forgiveness."*
- ♦ *"It ruins my life, I hate it. I don't work or study, I'm not in a relationship, have no friends and my health both physically and mental my is very poor."*
- ♦ *"Made no difference apart from knowing why I was how I was when I was younger, and the impact it's had on friendships, relationships, and work as an adult."*
- ♦ *"Discrimination by school staff, friends and Local Authority."*

Key Insights:

Receiving an ADHD diagnosis is life-changing for most respondents, providing clarity, practical coping strategies, improved mental health, and better functioning at work and home. However, systemic barriers, inconsistent support from health services, and financial constraints can limit the benefits, leaving some individuals frustrated, underserved, or still struggling with significant daily challenges.

Questions 10-17 asked questions to respondents waiting for an ADHD assessment.

Questions 10 – Those people that are waiting for an ADHD assessment, were asked how many appointments they had with their GP before being referred for a diagnosis;

Of the responses:

- ♦ 43% had between two-three appointments with their GP.
- ♦ 14% had one appointment.
- ♦ 29% had another professional refer them.
- ♦ 14% did not visit a GP appointment but emailed the practice and submitted a request for a referral.

Key Insights:

Obtaining a referral for an ADHD assessment often involves multiple steps and appointments, with variation in pathways, reflecting potential barriers and inconsistencies in primary care referral processes.

How many appointments did you have with your GP before you were referred for an ADHD diagnosis?



Question 11 – Those people that were waiting for an ADHD diagnosis were asked, since their referral, how long had they been waiting so far for an ADHD diagnosis?

Of the responses:

- ◆ **86% have been waiting for one – two years.**
- ◆ **14% have been waiting for 0–5 months.**

Since your referral, how long have you been waiting so far for an ADHD diagnosis?



Key Insights:

Most individuals referred for an ADHD diagnosis face prolonged waiting periods of 1–2 years, which can exacerbate stress, mental health challenges, and difficulties in daily life while awaiting support.

Question 12 – People were asked what impact being on the waiting list for an ADHD assessment had on their daily life and wellbeing (considering the impact on: their work/ education, managing relationships their health and wellbeing):

Key Insights:

Being on an ADHD assessment waiting list profoundly disrupts daily life, education, work, relationships, and wellbeing, emphasising the urgent need for interim support, recognition, and resources to mitigate these negative impacts.

The responses included:

- ◆ ***“Work/education would have been able useful to keep my part time job . Managing relationships would have been given more time with my very unwell partner BEFORE he died. Consultants and Doctors should have a better understanding of my views and have been considerate. Health and wellbeing has suffered because all aspects are interconnected and my ADHD and Autism has never been considered at all until 2023. I was born in 1949.”***
- ◆ ***“Falling behind at school. Struggle to get the right support in place for school life. Mum struggled at home with behaviour and own mental health.”***
- ◆ ***“This is on behalf of my six year old son. It has had massively impacted my son with school. Taking him to school every day is a battle in both our mental health and wellbeing. He spends half of his time not in the classroom due to not being able to cope in the setting and becoming extremely dis-regulated. He is behind on his education in all areas. He struggles to make friendship with his children his own age. The list endless for my son for how much he is struggling. There is just not enough support out there.”***

- ◆ *“We’re waiting for my son. He’s had constant mental health problems, eating, weight problems, struggles with attending school, maintaining friends. As a parent I’m so stressed fighting for help and sick of waiting.”*
- ◆ *“I am unable to work; I have been given anti-depressants which have helped slightly.”*

Question 13 – Those people that were waiting for their assessment were asked if they had received any support during the waiting period;

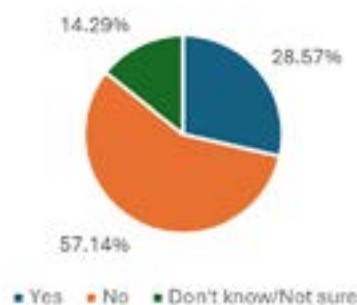
Of the responses:

- ◆ 29% said they had received support during the waiting period.
- ◆ 57% did not receive any support.
- ◆ 14% said they did not know / were not sure.

Key Insights:

Most individuals waiting for an ADHD assessment experience little to no support, underlining the need for proactive, accessible resources and clear communication to help manage symptoms and wellbeing during the waiting period.

Did you receive any support during the waiting period?



Question 14 – The people waiting for an assessment were asked what support they had received and from whom (e.g. family, friends, GP);

Responses included:

- ◆ *“Family and friends endlessly. Some parenting courses from the Children’s Centre.”*
- ◆ *“My family are very supportive. The GP I see also has ADHD, so she is very understanding and empathetic.”*

Question 15 – Those people that were waiting for an assessment were asked what the impact was of not getting the support that they needed;

Key Insights:

Waiting for an ADHD assessment without adequate support significantly affects emotional wellbeing, family dynamics, and daily functioning, highlighting the urgent need for interim resources and guidance.

Responses included:

- ◆ *“I became more stressed anxious and overwhelmed therefore needing to see my GP more frequently.”*
- ◆ *“We are the generation where our lack of concentration was put down to naughtiness and we were punished quite harshly at school and at home. I am now an adult living with years of mistreatment due to being undiagnosed and to be honest I feel tired and unheard. I also need access to medication – I have seen the benefit this has on my own children and can’t wait to be able to work/think/sleep and behave in a normal way.”*
- ◆ *“Having no support for my son means struggling at school.”*
- ◆ *“Stress for all.”*

Question 16 – People were asked how they would describe the quality of the information they were given on how to manage their ADHD traits whilst waiting for an ADHD diagnosis. They were given multiple options as follows;

- ◆ **Excellent** – more than enough useful information to help manage my ADHD traits.
- ◆ **Sufficient** – enough useful information to help manage my ADHD traits.
- ◆ **Poor** – not enough useful information to help manage my ADHD traits.
- ◆ **None** – I haven’t been given any information to help manage my ADHD traits.
- ◆ **Don’t know / prefer not to say.**

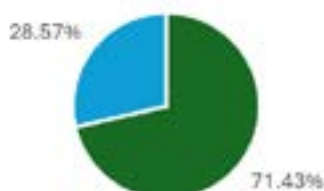
Of the responses:

- ◆ 72% said it was, **“Poor”**.
- ◆ 28% said they had no information.

Key Insights:

Nearly all respondents (100%) felt unsupported in managing their ADHD traits while waiting for a diagnosis, with 72% describing the information provided as “poor” and 28% receiving no information at all. This highlights a significant gap in pre-diagnosis guidance and underscores the urgent need for accessible, high-quality resources to help individuals cope during the waiting period.

How would you describe the quality of the information you were given on how to manage your ADHD traits whilst waiting for an ADHD diagnosis?



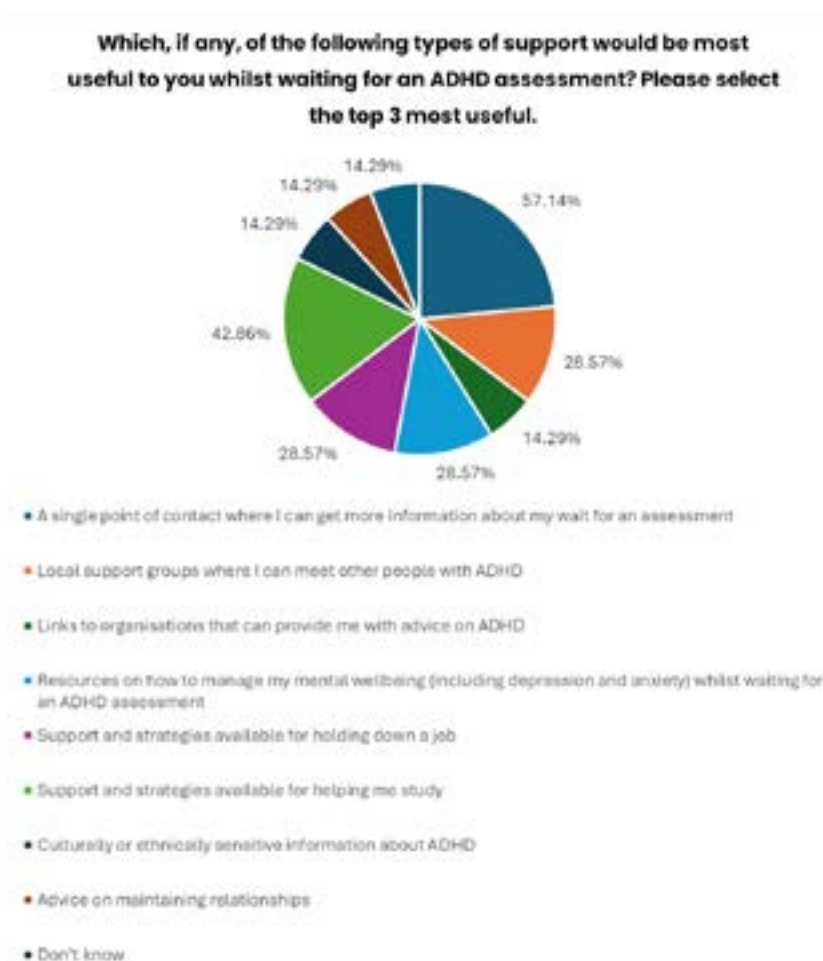
Question 17 – People were asked which, if any, of the following types of support would be most useful to them whilst waiting for an ADHD assessment? They were asked to select their top three most useful options;

Of the responses:

- ◆ 29% chose **'local support groups where I can meet other people with ADHD.'**
- ◆ 14% chose **'links to organisations that can provide me with advice on ADHD.'**
- ◆ 57% chose **'a single point of contact where I can get more information about my wait for an assessment.'**
- ◆ 14% chose **'culturally or ethnically sensitive information about ADHD.'**
- ◆ 14% chose **'advice on maintaining relationships.'**
- ◆ 43% chose **'support and strategies available for helping me study.'**
- ◆ 28% chose **'support and strategies available for holding down a job.'**
- ◆ 28% chose **'resources on how to manage my mental wellbeing (including depression and anxiety) whilst waiting for an ADHD assessment.'**
- ◆ 14% chose **'none of the above' but did not specify which.**

Key Insights:

Overall, the key insight is that people waiting for ADHD assessment want clear, accessible guidance, practical strategies for everyday life, and peer/community support to help manage the uncertainty and emotional impact during the waiting period.



Question 18 – People were asked if they were considering paying for an ADHD assessment from a private provider;

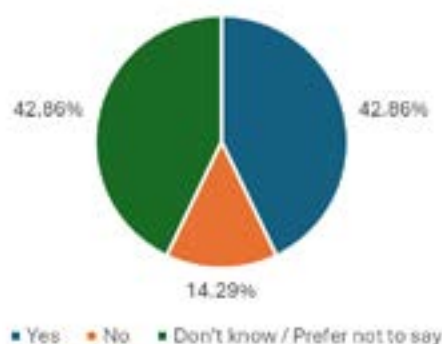
Of the people that responded:

- ◆ 43% said, **“Yes”**.
- ◆ 43% said they, **“Didn’t know”** or **“Preferred not to say”**.
- ◆ 64% said, **“No”**.

Key Insights:

There is significant uncertainty or ambivalence about paying for private ADHD assessments, with 43% unsure or preferring not to say, and only a minority (43%) actively considering it. This suggests potential barriers such as cost, access, or lack of information may influence decisions, highlighting the need for clearer guidance and support around private assessment options.

Are you considering paying for an ADHD assessment from a private provider?



Question 19 – Those people that were considering paying for an ADHD assessment from a private provider were asked the main reason why;

- ◆ 100% said, **“For a shorter wait”**

Question 20 – People were asked what their main reason was for not considering pursuing a private diagnosis;

Respondents gave a range of reasons for not seeking a private assessment, including:

- ◆ Cost barriers – **“I can’t afford it, or would have to borrow money to access a private ADHD service.”**
- ◆ Principled objections – **“I won’t access private healthcare, including an ADHD assessment, out of principle.”**
- ◆ Medication access concerns – **“I want to wait for an NHS assessment so that I can get ADHD medication on the NHS.”**
- ◆ Trust in the NHS – **“I trust the NHS process more.”**

Key Insights:

This indicates that while long waits may encourage some to consider private assessment, financial constraints, principles, and confidence in NHS pathways remain key factors preventing others from pursuing this option.

The following questions Q21 to Q23 were asked of people that had been refused a referral for an ADHD diagnosis by their GP.

Questions 21 – People were asked, in their opinion, why their GP did not refer them for an NHS ADHD assessment;

From the responses to the question, only two reasons were selected:

- ◆ **The GP didn't listen to me** (100% 1 response).
- ◆ **My GP refused to refer me without giving a reason** (100% 1 response).

All the other listed reasons (as examples in the survey) are given below which no one opted for:

- ◆ Had a telephone appointment with my GP and I feel uncomfortable talking to people over the phone.
- ◆ The appointment was too rushed.
- ◆ My ADHD symptoms/ traits weren't considered serious enough
- ◆ The ADHD diagnostic criteria used by GP didn't reflect my experience of ADHD.
- ◆ The GP didn't listen to me.
- ◆ The GP didn't consider all my symptoms/traits .
- ◆ The GP didn't want to refer me because of long waiting lists.
- ◆ I was recommended a private assessment.
- ◆ I find it difficult to express myself.
- ◆ My GP refused to refer me without giving a reason.
- ◆ None of the above/Don't know.

Key Insights:

The responses indicate that barriers to referral were not linked to appointment format, symptom presentation, or diagnostic criteria. This highlights that perceived dismissal and unexplained refusals, rather than clinical or systemic factors, are the key issues reported by respondents.

Questions 22 – People were asked which, if any, of the following did they plan to do next regarding ADHD support and management. Multiple options could be chosen.

When asked what actions they planned to take next regarding ADHD support and management, **all respondents (100%) selected "Don't know."**

No respondents indicated that they planned to:

- ◆ Contact PALS (Patient Advice and Liaison Service)
- ◆ File a formal complaint
- ◆ Seek private treatment options
- ◆ Explore alternative strategies (e.g., mindfulness, exercise, coaching)
- ◆ Change GP practice and begin the process again
- ◆ Take no action

Key Insights:

The unanimous selection of "Don't know" highlights significant uncertainty among respondents about how to proceed with ADHD support and management. This suggests a potential need for clearer guidance, signposting, or support pathways.

Question 23 – People were asked what the impact on their life had been by not getting an assessment or a referral:

There were no responses to this open question which may suggest the following:

- ◆ **Difficulty articulating the impact**
People may find it hard to put into words how not having something (like an assessment) has affected them, especially if they've lived with it for a long time.
- ◆ **Survey design issue**
The question might have been too open-ended, intimidating, or unclear, leading to skipped responses.
- ◆ **Emotional or sensitive topic**
The impact of not receiving assessment/referral could involve feelings of frustration, shame, or hopelessness. Some participants might have avoided responding because it felt too personal or painful.
- ◆ **Resignation or “normalisation”**
People who haven't been assessed may not recognise the specific ways it has affected their life – they may just see their struggles as “normal” and therefore had nothing to write.
- ◆ **Survey fatigue**
As the question came later in the survey, participants might have been tired and chose to leave it blank.
- ◆ **Implied impact**
In some cases, silence itself suggests a significant negative impact – people might feel that the consequences are so obvious (or overwhelming) that they don't know where to start.

Question 24 – People were asked which of the following, if any, are reasons why they haven't yet seen their GP to be referred for an ADHD assessment. Multiple options could be chosen;

Of the responses:

- ◆ **43%** said that in the past they had to wait a long time to see a GP when they needed one.
- ◆ **43%** are worried that their GP will not refer them for an assessment
- ◆ **28%** are worried that they will not be able to express themselves well enough at the GP appointment.
- ◆ **57%** feel that their ADHD traits make it difficult to book or attend a GP appointment.
- ◆ **29%** said that they have only recently realised they might have ADHD.
- ◆ **29%** said they are worried that they might not be able to express themselves well enough at the appointment.

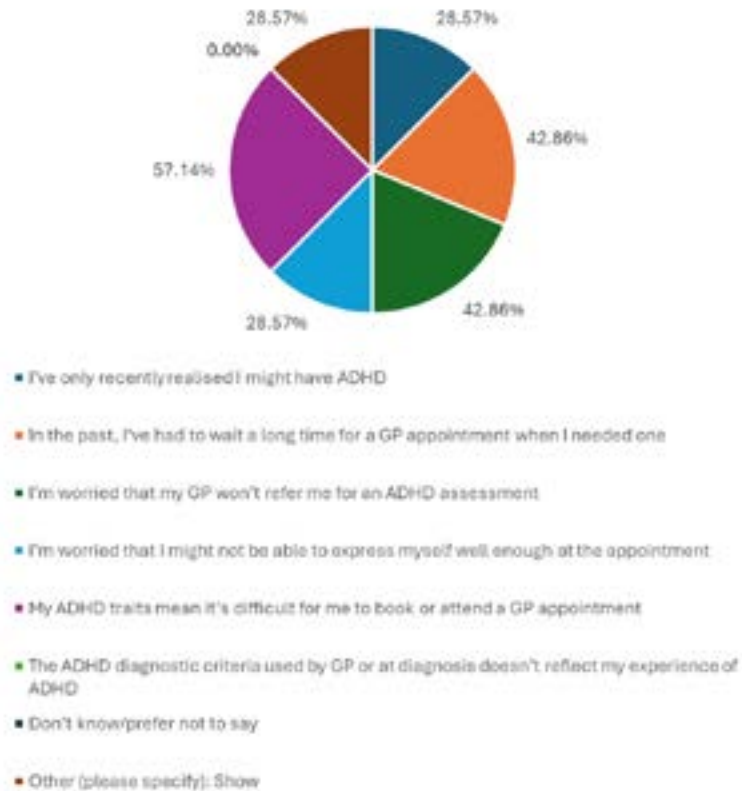
Additional comments included:

- ◆ ***“I think I have an Autism Spectrum Condition as well and I have heard they are assessed by different teams and this is putting me off.”***
- ◆ ***“The waiting times for assessment put me off too.”***

Key Insights:

The findings point to a double barrier: system-level issues (waiting times, referral uncertainty) combined with ADHD-related challenges (executive functioning difficulties, self-expression struggles). Together, these make accessing diagnosis and care disproportionately difficult for people with suspected ADHD.

Which of the following, if any, are reasons why you haven't yet seen your GP to be referred for an ADHD assessment?



Questions 25 and 26 were asked of those people that have not yet seen their GP about getting an ADHD diagnosis.

Question 25 – People were asked, which of the following, if any, are reasons why you have decided not to get a formal ADHD assessment. Multiple options could be chosen of the following:

- ◆ I am worried about the long waits for an NHS diagnosis
- ◆ I can't afford to pay for a private ADHD diagnosis
- ◆ I prefer to use natural or alternative remedies (e.g, lions mane capsules, magnesium) for treating my ADHD traits
- ◆ I believe I have ADHD and do not need a formal diagnosis – I am happy to self-diagnose at this stage
- ◆ ADHD Criteria used by GP or at diagnosis doesn't reflect my experience of ADHD
- ◆ My GP or other health care professional told me not to bother getting a diagnosis
- ◆ I haven't pursued a diagnosis because I am worried a diagnosis may negatively impact me
- ◆ Don't know/can't remember
- ◆ Other (please specify)

67% of respondents said they were worried that a diagnosis might negatively impact them. **33%** were concerned about the long waiting times for an NHS diagnosis. One respondent noted they are prioritising their child's diagnosis before pursuing their own.

Key Insights:

The data suggested that there are perceived risks such as stigma or potential negative consequences of a diagnosis are a major deterrent. System barriers like long NHS waiting times also play a significant role. Family responsibilities (e.g., prioritising a child's needs) can influence the decision to delay or avoid diagnosis.

Question 26 – Thinking about their life now... How positively or negatively, if at all, does ADHD impact the following aspects of your life?

Thinking about your life now... How positively or negatively, if at all, does ADHD impact the following aspects of your life?	Very positive impact	Slightly positive impact	Neither positive nor negative impact	Slightly negative impact	Very negative impact	Don't know/Prefer not to say
My ability to work	2.94%	0.00%	8.82%	17.65%	58.82%	11.76%
	1	0	3	6	20	4
My concentration at work or when studying	2.94%	8.82%	0.00%	20.59%	61.76%	5.88%
	1	3	0	7	21	2
My ability to carry out daily household tasks	2.94%	5.88%	11.76%	11.76%	64.71%	2.94%
	1	2	4	4	22	1
My ability to budget and manage my money	5.88%	5.88%	11.76%	17.65%	50.00%	8.82%
	2	2	4	6	17	3
My relationships with my partner, close friends or family	5.88%	8.82%	14.71%	41.18%	26.47%	2.94%
	2	3	5	14	9	1
My ability to take part in hobbies and personal interests	8.82%	8.82%	8.82%	26.47%	44.12%	2.94%
	3	3	3	9	15	1
My ability to socialise	2.94%	11.76%	8.82%	41.18%	32.35%	2.94%
	1	4	3	14	11	1
My physical health	0.00%	5.88%	29.41%	29.41%	35.29%	0.00%
	0	2	10	10	12	0
My mental health and wellbeing	5.88%	5.88%	5.88%	17.65%	64.71%	0.00%
	2	2	2	6	22	0
My self esteem	2.94%	8.82%	8.82%	17.65%	61.76%	0.00%
	1	3	3	6	21	0

Key Insights:

Work, concentration, daily functioning, and mental health are the area's most severely and consistently affected by ADHD, with very high rates of "very negative" impact.

Self-esteem is strongly compromised, showing ADHD has a deep personal and psychological effect beyond practical challenges.

While overall negative, a minority of respondents experience positives in hobbies, relationships, or social interactions, suggesting ADHD traits can sometimes be strengths when well-supported.

The findings highlight critical support needs in employment, mental health, and daily living skills, alongside opportunities to harness strengths in creativity and personal interests.

Question 26 – Also asked, thinking about their life now... How positively or negatively, if at all, does ADHD impact the following aspects of their life:

There were **34 responses** summarised in the table below:

Answer Choices	Very positive impact	Slightly positive impact	Neither positive nor negative impact	Slightly negative impact	Very negative impact	Don't know/Prefer not to say
My ability to work	2.94% 1	0.00% 0	8.82% 3	17.65% 6	58.82% 20	11.76% 4
My concentration at work or when studying	2.94% 1	8.82% 3	0.00% 0	20.59% 7	61.76% 21	5.88% 2
My ability to carry out daily household tasks	2.94% 1	5.88% 2	11.76% 4	11.76% 4	64.71% 22	2.94% 1
My ability to budget and manage my money	5.88% 2	5.88% 2	11.76% 4	17.65% 6	50.00% 17	8.82% 3
My relationships with my partner, close friends or family	5.88% 2	8.82% 3	14.71% 5	41.18% 14	26.47% 9	2.94% 1

My ability to take part in hobbies and personal interests	8.82%	8.82%	8.82%	26.47%	44.12%	2.94%
	3	3	3	9	15	1
My ability to socialise	2.94%	11.76%	8.82%	41.18%	32.35%	2.94%
	1	4	3	14	11	1
My physical health	0.00%	5.88%	29.41%	29.41%	35.29%	0.00%
	0	2	10	10	12	0
My mental health and wellbeing	5.88%	5.88%	5.88%	17.65%	64.71%	0.00%
	2	2	2	6	22	0
My self-esteem	2.94%	8.82%	8.82%	17.65%	61.76%	0.00%
	1	3	3	6	21	0

Key Insights:

The data paints a consistent picture of ADHD as a condition with pervasive and compounding negative effects, especially on work, concentration, household management, finances, mental health, and self-esteem, while highlighting only limited areas where individuals perceive positive contributions.

The following questions were asked of all respondents.

Question 27 – People were asked which of the following prompted them to think they might have ADHD? Multiple options could be chosen.

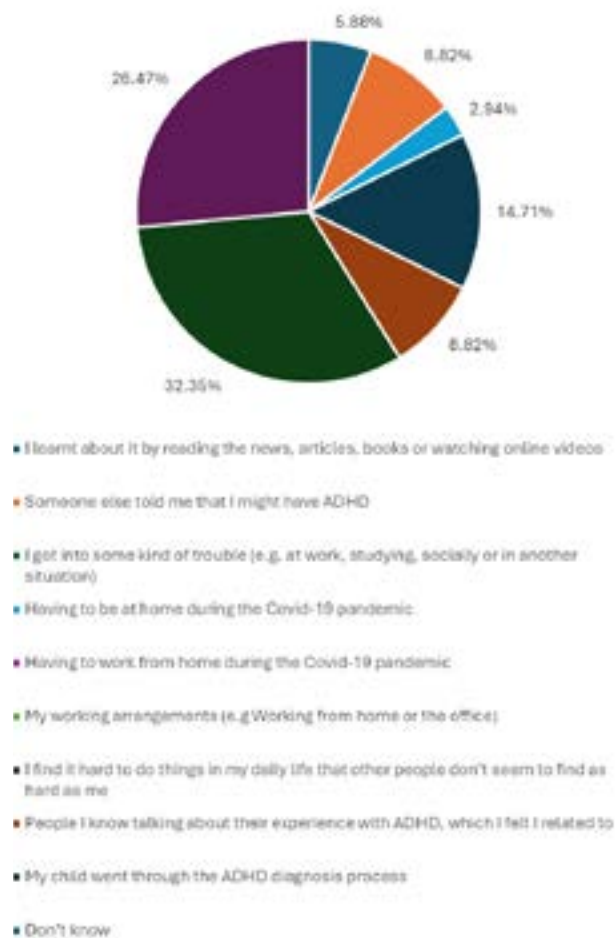
- ◆ 32% chose ***'My children went through the ADHD process'***
- ◆ 9% chose ***'People I know talking about their experience with ADHD, which I felt I related to.'***
- ◆ 15% chose ***'I find it hard to do things in my daily life that other people don't seem to find as hard as me.'***
- ◆ 3% chose ***'Having to be at home during the Covid-19 pandemic.'***
- ◆ 9% chose ***'Someone else told me that I might have ADHD.'***
- ◆ 6% chose ***'I learnt about it by reading the news, articles, books or watching online videos.'***
- ◆ 26% chose ***'Other'*** which includes the following comments:
 - ◇ ***"My eldest son was identified as being autistic about 12 years ago and as I did more and more research about neuro distinction in general, I kept seeing similarities to my life experiences with those of ADHD."***
 - ◇ ***"Unable to select more than one: online information, being home working and parenting during the pandemic, hard to do daily life. Other persistent feelings of not being good enough even after extensive Cognitive Behaviour Therapy (CBT) and therapy."***

- ♦ ***“ Almost all of the above options- except I don’t have children.”***
- ♦ ***One person chose all of the options, adding; “ My child went through the ADHD diagnosis process. People I know talking about their experience with ADHD. I find it hard to do things in my daily life that other people don’t seem to find as hard as me. I learnt about it by reading the news, articles, books, or watching online videos.”***
- ♦ ***Another person said; “I work in education and noticed the ADHD symptoms in myself, poor concentration, fidgeting, losing things and untidy.”***
- ♦ ***“My child being diagnosed as autistic.”***
- ♦ ***“I got my sister diagnosed with autism, and through learning about ASD in girls, I got an NHS diagnosis of ASD, but then the NHS waiting list was five years, so I paid to get privately diagnosed with ADHD.”***
- ♦ ***“Seeing TikTok and Instagram posts.”***

Key Insights:

ADHD recognition in adults is most often triggered externally (children, peers, or work) but is reinforced by internal struggles and digital information. Importantly, many describe a multi-layered process, where multiple experiences converge before self-awareness or diagnosis.

Which, if any, of the following prompted you to think you might have ADHD? Please select all that apply



Question 27 – People were asked what their main employment status is:

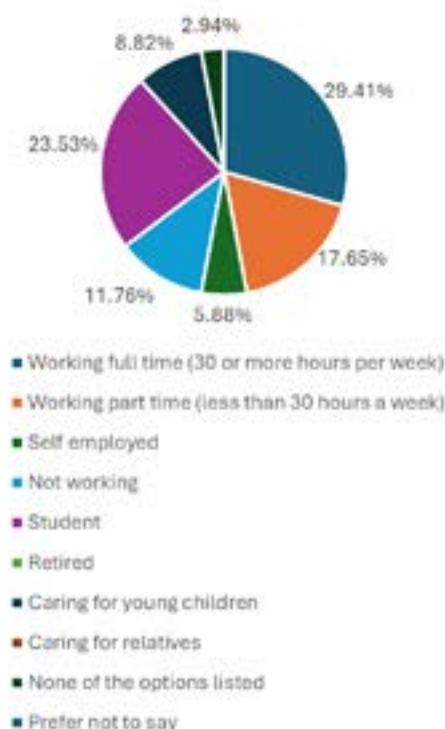
Of the **34** responses:

- ◆ 29% of respondents worked full time.
- ◆ 18% worked part time.
- ◆ 6% were self-employed.
- ◆ 24% are students.
- ◆ 12% are not working.
- ◆ 8% caring for children
- ◆ 3% preferred not to say

Key Insights:

The group shows a diverse mix of employment situations, with over half working, a strikingly large student subgroup, and one-fifth not currently in formal employment due to joblessness or caring responsibilities. This distribution may reflect the life stages, challenges, and adaptations often seen in neurodivergent populations.

What is Your Employment Status?



Question 29 – People were asked if they had told their employer they had ADHD:

Of the **16** responses:

- ◆ 63% of respondents had told their employer they have ADHD.
- ◆ 37% of respondents had *not* told their employer they have ADHD.

Key Insights:

While most respondents have told their employer about their ADHD, a sizable minority have not, pointing to a mixed picture of workplace trust and inclusion. This highlights the importance of safe, supportive policies and cultures that reduce stigma and encourage disclosure so employees can access the adjustments they need.

Question 30 – People were asked what their reasons were for choosing not to inform their workplace they have ADHD. Multiple options could be chosen.

Of the responses:

- ◆ 29% were afraid of the possible implications for their job
- ◆ 20% did not want to disclose personal information
- ◆ 20% said it doesn't make a difference to the job they do.
- ◆ 40% said they were waiting until they got a formal diagnosis to tell their employer.
- ◆ 10% said they were 'self-employed'.

Key Insights:

The biggest driver of non-disclosure is fear of negative consequences, reinforced by the need for a formal diagnosis to legitimise disclosure. At the same time, some respondents simply do not see disclosure as necessary, whether because of personal privacy, irrelevance to job performance, or self-employment.

Question 31 – People were asked, which, if any, of the following reasonable adjustments did their employer offer them; people could choose multiple options (by reasonable adjustments, we mean changes made in the workplace to support employees with specific needs, helping them perform their jobs effectively).

- ◆ 67% of respondents were offered work from home.
- ◆ 33% were offered flexible working arrangements.
- ◆ 50% were offered specialised software.
- ◆ 17% were not offered any adjustments.
- ◆ 50% were offered ADHD coaching and support.
- ◆ 17% were helped with access to work.
- ◆ 17% were supported with additional guidance or check ins from their Manager.

Key Insights:

Employers are more likely to provide structural adjustments (home-working, software, coaching) than relational or systemic supports (managerial check-ins, Access to Work guidance). While many are receiving meaningful accommodations, the 17% with no support shows inconsistency and highlights a need for greater awareness and standardisation.

Which, if any, of the following reasonable adjustments did your employer offer you?



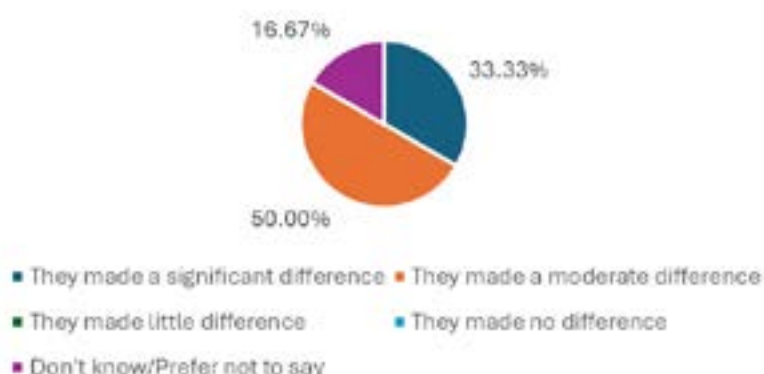
Question 32 – People were asked, to what extent, if at all, did these reasonable adjustments impact their ability to carry out their job? (by reasonable adjustments, we mean changes made in the workplace to support employees with specific needs, helping them perform their jobs).

- ◆ 33% said they made a significant difference.
- ◆ 50% said they made a moderate difference.
- ◆ 17% said they did not know.

Key Insights:

The survey indicates that reasonable adjustments in the workplace are broadly effective in supporting employees with specific needs. A combined 83% of respondents reported that these adjustments had a positive impact on their ability to perform their job, with 33% experiencing a significant difference and 50% seeing a moderate improvement. However, 17% were unsure of the impact, suggesting room for better communication and awareness about the adjustments. Overall, the findings highlight the value of reasonable adjustments in enhancing job performance and inclusion, while also pointing to opportunities for optimisation and clearer messaging.

To what extent, if at all, did these reasonable adjustments impact your ability to carry out your job?



Question 33 – For each of the following, people were asked to select the option ASD, Anxiety and Depression, and which narrative they felt best applied to them within the grid.

For each of the following, please select the option that best applies to you	I have been diagnosed with this condition	I think I have this condition but haven't yet seen my GP about it	I think I have this condition and am waiting for a diagnosis	I think I have this condition but am not pursuing a diagnosis	I don't think I have this condition	Don't know/Prefer not to say
Autism (ASD)	20.59%	20.59%	14.71%	14.71%	23.53%	5.88%
	7	7	5	5	8	2
Anxiety	61.76%	2.94%	0.00%	17.65%	17.65%	0.00%
	21	1	0	6	6	0
Depression	54.55%	0.00%	0.00%	9.09%	30.30%	6.06%
	18	0	0	3	10	2

Key Insights:

- ◆ **High self-awareness of mental health:** Anxiety and depression have high diagnosis rates, while Autism shows more uncertainty and people awaiting or not pursuing diagnoses.
- ◆ **Potential barriers to Autism diagnosis:** A combined 50% of respondents suspect Autism but are undiagnosed or not seeking diagnosis.
- ◆ **Mental health engagement:** Anxiety and depression show respondents are actively seeking support/diagnosis, whereas autism might require more awareness or accessible diagnostic resources

Question 34 – People were asked if there is anything else they would like to tell us about having ADHD;

Responses:

"With medication I felt more able to cope with the demands of work and home. It meant I was able to support my children better (one has multiple diagnoses/disabilities, and the other is awaiting assessments for ASD and ADHD). My home was cleaner and tidier, making day to day life easier in general. I also felt more confident within interpersonal relationships; more able to advocate for myself and enjoy myself without feeling too self-conscious. I do think I could benefit from ADHD coaching and other ADHD-specific support, but I can't afford to access this privately."

"It needs to be more widely recognised the co-morbid conditions linked with ADHD such as hypermobility, PMDD (Pre- menstrual Dysphoric Disorder), sensory issues, ARFID (Avoidant / Restrictive Food Intake Disorder) etc and there be further access to assessments."

"Neurodiverse" people often do not like or do not "do well with drop down menus", (especially ones that do not work) and there is never anyone to report their errors to or give feedback to. More care could and should be taken on preparing these surveys and also the ONLINE assessments I have sadly seen and read many faults (and noticed omissions or incorrect information that does not make any sense). Also, the A.I. used in 'problem shared' sends out disturbing abrupt follow up messages to applicants all during the night and early hours of the morning (We have proof of this). It can also be requested on their internal computer systems and all data control. Therefore, I found and find that the ONLINE Problem Solved type of approach is not user friendly nor helpful or appropriate for neurodivergent individuals. Hopefully feedback will be read eventually."

"I'm also interested in its links to hypermobility (also have) and PMDD (Premenstrual Dysphoric Order - also have); these seem to be covered less. I find that since I'm seen by the ADHD consultant/team, my GP ignores that I have it. Lack of recognition of it or my medication on the system or in appointments (even after being informed). There is a lot of stigma around ADHD and it requires a lot of vulnerability to share how it really impacts me."

"Yes. One of the biggest challenges with ADHD is that it's often misunderstood, Racial bias can play a huge role in how behaviours are interpreted — instead of seeing signs of neurodiversity, professionals may view the same behaviours as aggression, poor parenting, or bad attitude. This delays assessments, leads to harsher discipline, and increases emotional harm. For a child who is already struggling, being both misunderstood and racially profiled adds another layer of trauma. Getting an ADHD diagnosis isn't about labels — it's about breaking that cycle of blame and helping them feel seen, safe, and supported. The longer this is delayed, the more damage it causes to their education, confidence, and future."

"It's frustrating that it is so little understood and accepted in the UK. there are so many barriers and a sense that it is a bad thing to have."

"Have spent my life feeling like I don't fit in and don't understand why I am different in my attention and memory to others. This has had a huge impact over the years to my self-esteem and self-acceptance. It saddens me to see this still happening with my child and so many others! Things really need to change fast. Thank you."

"The symptoms become completely unmanageable when trying to take care of my ASD/ADHD child, battling for supports for him at school and supporting him to attend regularly as well as maintaining a home and a professional job. It affects my self-esteem, where despite working hard and studying hard I always feel stupid because I zone out so frequently in meetings and my mind feels like it is thinking about things that I don't want to be thinking about while trying to focus. The emotional dysregulation also feels heavy especially when caring for young children that require steady and emotionally safe parents. I am finding it harder to take care of my own personal hygiene due to poor time management and keeping my home in order. The clutter around my home makes me feel overwhelmed but I feel unable to find time or mental capacity to sort it. I have been told by the GP that I likely have PMDD (pre-menstrual dysphoric disorder), that has recently come about now I am in my early 40's and in peri menopause, which feels like ADHD symptoms more strongly (e.g. decrease in working memory, increase in emotional dysregulation)."

"Both my children have ADHD. My brother has it be never diagnosed officially as we are children of the 80's. My mum has characteristics of ASD (Autism Spectrum Disorder) but she is in her 70's now."

"It invites child abuse and vilification as if I deserve it."

"It needs to be understood better in females, so more girls get support in childhood."

"That professionals need to stop diagnosing women with everything else and never considering ADHD or ASD. If it had not have been for my child being diagnosed, I would have continued thinking I was depressed, anxious and broken."

"Please try to cut waiting times for an assessment."

"Just that people don't really understand how difficult it is not being able to focus, not being able to resist sweet things, not being able to manage money, having to fork out money on consequences of impulsive actions (ADHD tax) and so much more. I wish all children were screened for this if they show signs and that they could be supported and not shamed throughout school and life for things that are beyond their control."

"It needs to be more widely recognised the co-morbid conditions linked with ADHD such as hypermobility, PMDD (Pre- menstrual Dysphoric Disorder), sensory issues, ARFID (Avoidant / Restrictive Food Intake Disorder)etc and there be further access to assessments. Also, there needs to be a service where if a child has been diagnosed with ASD/ADHD then an assessment should be available to other family members or vice versa if an adult has been diagnosed then their children should be assessed."

Key Insights:

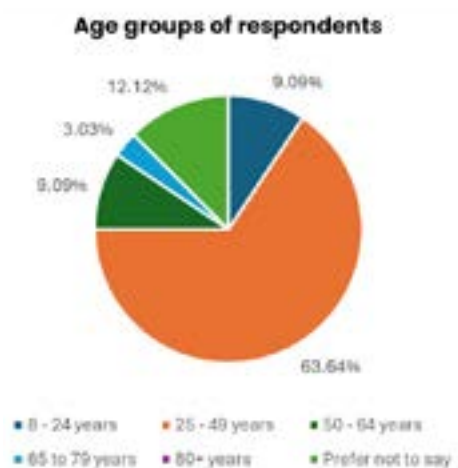
ADHD is a highly impactful, under-recognised condition, especially for women and neurodiverse individuals, with systemic barriers in healthcare, education, and workplaces. There is an urgent need for earlier, more inclusive, and family-centred assessment and support, as well as broader societal understanding to reduce stigma and improve quality of life.

Demographic Information

Question 35 – Respondents were asked how old they are:

Of the **33** responses:

- ◆ **64%** are aged between 25–49 years.
- ◆ **9%** are aged between 50–64 years.
- ◆ **9%** are aged between 8–24 years.
- ◆ **12%** preferred not to provide their age.
- ◆ **3%** are aged between 65–70 years.



Key Insights:

The **majority in working-age** range: Nearly two-thirds (64%) of respondents are between **25–49 years old**, suggesting most participants are adults in their prime working years. This could reflect when ADHD symptoms most impact careers, family responsibilities, and daily functioning.

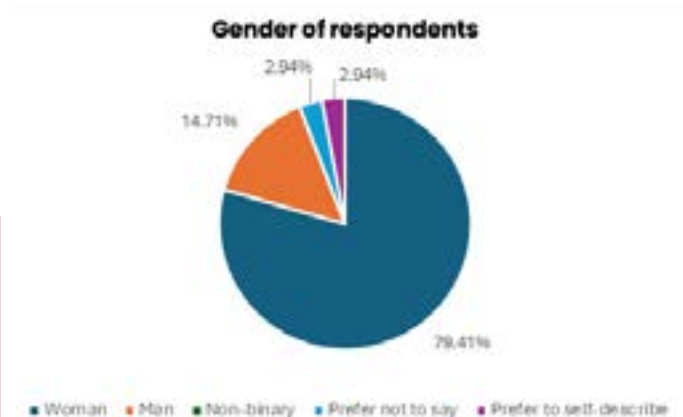
There is **limited younger representation**: Only **9%** fall between **8–24 years**, indicating fewer younger respondents. This may point to underrepresentation of students or recently diagnosed individuals, possibly due to survey reach or awareness.

There is **moderate older adult participation**: About **9%** are between **50–64 years** and **3%** are **65–70 years**, showing that older adults with ADHD are present but make up a small portion of respondents. This aligns with trends that ADHD is less frequently diagnosed in older populations.

There is **notable non-disclosure rate**: **12% preferred not to state their age**, which is relatively high and could suggest either privacy concerns or uncertainty about relevance.

Question 36 – Respondents were asked their gender:

- ◆ **79%** are women.
- ◆ **14%** are men.
- ◆ **3%** preferred not to say.
- ◆ **3%** preferred to self-describe however did not provide an answer.



Key Insights:

A key insight regarding ADHD from this data is that the majority of respondents are women (79%), suggesting that women with ADHD may be more likely to participate in surveys or engage in discussions about ADHD. This could reflect greater awareness, diagnosis, or willingness to seek support among women, highlighting the importance of considering gender-specific experiences and challenges in understanding and supporting people with ADHD.

This also points to a potential underrepresentation of men and non-binary individuals, which may affect how broadly findings can be generalised.

Question 37 – Respondents were asked if their gender identify is the same as their sex recorded at birth:

All respondents said that their gender identity is the same as their recorded sex at birth.

Question 38 – Respondents were asked which sexual orientation they identify with:

- ◆ 64% identified as heterosexual / straight
- ◆ 3% chose 'asexual'
- ◆ 6% chose pansexual
- ◆ 6% chose bisexual
- ◆ 3% chose 'gay man'
- ◆ 12% preferred not to say.
- ◆ 6% preferred to self-describe.

Key Insights:

Sexual orientation among this group is diverse, with a substantial minority (21%) identifying as non-heterosexual and another 18% either preferring not to disclose or self-describing. This suggests that people with ADHD may experience and express sexual identity in a wide variety of ways, highlighting the importance of creating inclusive spaces that respect multiple identities and allow for personal expression.

Sexual orientation of respondents



Of the two people that chose 'prefer to self -describe' only person did so, saying, ***"I don't understand any of the above terms I will look them up in case I am asked in the future I guess "straight" might be the correct one as I am not familiar with the meanings of all the others..."***

Question 39 – Respondents were asked their ethnicity:

- ◆ 82% are White British+ / English / northern Irish, Scottish Welsh.
- ◆ 9% are white 'any other background'.
- ◆ 9% answered 'other' with one person adding: ***"Prefer not to say as in theory this should not matter to anyone at all cultural differences and upbringing can of course be considered."***

Key Insights:

Only 9% of respondents selected 'Other,' with one individual noting that ethnicity should not matter, though cultural upbringing can influence experiences. These results highlight limited ethnic diversity within the sample, suggesting that the findings may not fully capture the perspectives of minority ethnic groups. Future surveys may benefit from more inclusive outreach to ensure a broader representation of experiences with ADHD.

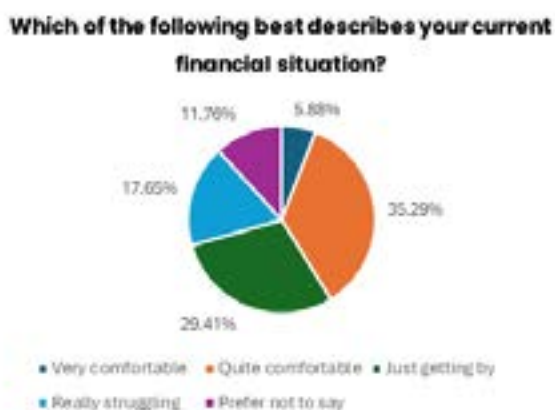


Question 40 – Respondents were asked which of the following best describes their current financial situation, with the following options provided:

- ◆ **22% 6%** Very comfortable (I have more than enough money for living expenses, and a LOT spare to save or spend on extras).
- ◆ **35%** of people said Quite comfortable (I have enough money for living expenses, and a LITTLE spare to save or spend on extras).
- ◆ **29%** Just getting by (I have just enough money for living expenses and little else).
- ◆ **17%** Really struggling (I don't have enough money for living expenses and sometimes run out of money).
- ◆ **4%** preferred not to say.

Key Insights:

While a moderate number of people feel financially secure, a substantial portion is experiencing financial pressure, highlighting a potential need for financial support, budgeting assistance, or economic interventions.



About Healthwatch Central Bedfordshire

Healthwatch Central Bedfordshire is the local consumer champion promoting choice and influencing the provision of high quality health, social care and wellbeing services for all across Central Bedfordshire.

Healthwatch Central Bedfordshire (HWCB) has significant statutory powers to ensure that the voice of the consumer is strengthened and heard by those who commission, deliver and regulate health and care services. HWCB engages and consults with all sections of the local population so that a wide cross-section of views are heard, understood and acted upon. Everything we say and do is informed by our connections to local people and our expertise is grounded in their experience.

Healthwatch Central Bedfordshire is one of three local Healthwatch in the County of Bedfordshire and belong to a network of local Healthwatch. Healthwatch England leads, supports and guides the Healthwatch network which is made up of the national body and local Healthwatch across each of the 152 local authority areas in England.

Healthwatch is the only body looking solely at people's experience across all health and social care. As a statutory watchdog our role is to ensure that local health and social care services, and the local decision-makers put the experiences of people at the heart of their care.

healthwatch
Central Bedfordshire

healthwatch

Central Bedfordshire

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