ADHD Task Force Priorities:

A deliberative public engagement

Contents

Summary

In September 2024, members of the public with ADHD were invited to talk about what they think the priorities of the upcoming ADHD Task Force should be. Through their discussions, participants identified eight priority areas:

1. **Tackling stigma**
    - Tackle stigma associated with ADHD.
    - Make it easier to get reasonable adjustments at work and in education.
    - Increase awareness of how it affects people's lives, including education for family members.
    - Ensure people with ADHD are treated with empathy, respect, and understanding across society.
2. **Training for professionals**
    - Ensure all health and care professionals have appropriate training about ADHD.
    - Challenge stigma within the health and care sector, including around the validity of private diagnoses.
    - Increase awareness of the different ways that ADHD can present in different people.
3. **Working together**
    - Help people get joined-up care, centred around their needs as a whole person - this includes:
        - Better support for comorbidities, particularly mental health.
        - Better links between the health and care system and other sectors/organisations.
4. **Continuity of care**
    - Ensure people transition seamlessly, without a wait, from child to adult services.
    - Provide access to age-appropriate care, regardless of the age they are diagnosed.

- Help people get equitable access to support across the country.

5. Identifying ADHD earlier

- Help people to spot ADHD as early as possible, so that they get the support they need.
- Reduce the burden on those with suspected ADHD.
- Ensure that people get adequate information and support immediately after diagnosis.

6. Waiting well

- Ensure people have support while waiting, including signposting to local organisations that can help.
- Improve transparency around waiting.

7. Reducing waiting times

- Tackle waiting times across the patient journey, not just before diagnosis.

8. Easier access to support

- Make it easier for people to navigate the diagnosis and support pathway.
- Provide support and guidance on how to live well with ADHD.
- Help participants choose the treatment and support options that are right for them.

What we did

On 17th September 2024, 31 members of the public with ADHD were invited to a three-hour online workshop hosted by **Healthwatch England** and **NHS England**. The purpose of the workshop was to invite members of the public with lived experience to help shape the direction of the upcoming **ADHD task force**.

Recruitment

Healthwatch recruited participants using an online sign-up form, which was advertised through social media. Healthwatch also asked local Healthwatch to promote the sign-up form through their own networks.

Over 800 people signed up as potential participants, and participants were selected from that pool against a predetermined sample frame. We aimed to ensure we heard from a diverse group of people, including people from different ethnicities, financial and employment status, sexualities and genders. We also ensured we invited people from different parts of England, and that we included people with disabilities, long-term health conditions and carers[1]. Most participants (23) had a formal diagnosis of ADHD, but we also invited five people waiting for a diagnosis and three people who were not pursuing a formal diagnosis to capture their experiences too.

Workshop

The workshop used **deliberative engagement**, which encourages participants to consider an issue from different perspectives before making decisions together.

Throughout the session, participants worked together in groups of between four and nine to complete a series of activities. Each group also contained a facilitator and a note-taker from Healthwatch. One or two NHS England colleagues observed each breakout group, which let them hear people's experiences firsthand.

After welcoming participants to the session, participants were moved into their groups to **introduce themselves** to each other and share their experiences living with ADHD.

NHS England then delivered a **short presentation** highlighting different challenges facing the task force. Participants were able to ask questions about

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[1] See appendix for a breakdown of participant demographics.

the presentation to NHS England colleagues. After the presentation, participants returned to their groups, where they provided feedback on what they had heard.

Participants were then read one of three **case studies**. Each case study was a real story provided by someone with ADHD to either Healthwatch or NHS England.

After discussing the case studies, participants were invited to **work independently** for a short time to identify:

- What would have made the most difference to the person in their case study?
- What would make the most overall difference to people with ADHD?
- Who or what groups would need to be involved to make these changes happen?

Ideas from participants were **discussed with their group**, before being shared with people from other groups.

Finally, participants were asked to discuss in their groups which ideas should be the **task force's main priorities** and why.

How to read this report

This report summarises participants' discussions and outlines what they feel the task force should prioritise and why. The report is structured around summaries of participants' discussions and priorities, which are presented under the themes:

- Increasing awareness
- Joining-up support
- The right support, at the right time

The findings presented in this report are not just those from the final priority-setting activities. Conversations from across the whole workshop were analysed and included in the summary below.

For example, participants stated that increasing awareness of ADHD should be a priority. In earlier discussions, participants also talked about the need to tackle the stigma associated with ADHD and how increased awareness would help family members, teachers, and employers better understand and accommodate ADHD. The section on increasing awareness therefore incorporates all these findings.

Increasing awareness

> **“It’s not a Tik Tok reel. This is very real.”**

Tackling stigma

Tackle stigma associated with ADHD.

Throughout the workshop, participants told us about the need to tackle stigma associated with ADHD. This theme underpins several recommendations.

Participants told us about people not believing their diagnosis and doubting that ADHD itself was real. We heard about the detrimental effect this has had on their lives, including making it harder for them to get treatment and support, causing difficulties in their professional and work lives, and creating challenges in their personal lives.

> “I did manage to get a referral and then diagnosis and start treatment within a couple of months. Since then, people have been like ‘Woah, is that real’ […] A lot of people think it’s not real.”

People also told us about professionals dismissing their symptoms because they had successful careers. We heard about the impact of misconceptions about ADHD, including people who thought they couldn’t have it because their symptoms didn’t match their understanding of what ADHD is.

> “I initially went to get tested for Autism. I kid you not, I laughed at him. [I said] ‘I don’t have ADHD’, because of that misconception about what ADHD is. You think of kids behaving badly and disrupting everything.”

Participants who were diagnosed in adulthood told us about how internalised stigma had prevented them from getting help sooner. In one example, a parent told us about struggling to accept their child’s diagnosis, before later being diagnosed themselves.

> “My son was diagnosed quite young, and I didn’t want the diagnosis because I didn’t understand it and didn’t want the stigma. When I got my diagnosis it all made sense. My life could have been different if I didn’t have this.”

Make it easier to get reasonable adjustments at work and in education.

Participants told us about difficulties in work and education, particularly the lack of reasonable adjustments that enable them to flourish. Participants emphasised the importance of getting support throughout education, and the impact that not getting early support had on their lives.

> “In education, I was written off as a troublemaker. I left school with very little qualifications, and it wasn’t because of ability. It became more obvious in the workplace - our symptoms directly impact our behaviour at work.”

Participants shared how ADHD has affected them professionally, with participants talking about finding it hard to sustain employment or encountering challenges when colleagues don’t understand how ADHD affects them.

Through these conversations, participants emphasised the importance of working in supportive, accessible environments which help them to realise their potential.

> **Participant A:** “Hyper-focus is amazing, but I can’t seem to turn it on when I want. I want to challenge the toxic positivity on social media that it’s a superpower. It’s not always a superpower - in fact, it very rarely is.”
>
> **Participant B:** “You can only use your strengths if you’re in an environment that enables it. I've been in many work environments that don't.”

However, participants also spoke about not being sure of what support to ask for or what could be done to help them. Participants felt that getting examples of reasonable adjustments, and thinking through what could work for them, would be helpful.

Participants also discussed how important it was for educational and professional organisations, including the Department for Education, the Department for Work and Pensions, and Jobcentre Plus, to be involved in the task force moving forward.

Increase awareness of how it affects people's lives, including education for family members.

Participants described the impact of ADHD across their personal lives. They told us about the lack of understanding from family members, and how it had created difficult situations at home. We heard about people's parents not providing support and about relationship difficulties.

> "Me being ADHD, keeping conversation has been very difficult. My wife finds it annoying; she thinks I just don't want to keep a conversation. [I] keep on asking her "What did you say?" and she gets annoyed."

Two groups of participants explored a case study[2] that touched on tensions between parents, where the person's dad had challenged the validity of a private diagnosis, which resulted in the person stopping taking their medication. These participants had a deeper discussion about the importance of increasing family awareness and understanding, and participants suggested specialised training for parents to help take care of children with ADHD.

Ensure people with ADHD are treated with empathy, respect, and understanding across society.

Across conversations about the importance of raising awareness about ADHD, participants spoke about the importance of treating people with ADHD with empathy and respect. They felt that raising awareness, including through public information campaigns, would help people across society better understand what life with ADHD is like.

> "It's about treating us as people rather than a problem person. By changing assumptions, you are changing the world around them. The world wasn't designed for a person like me."

Participants told us about times when this hadn't happened in their lives, including examples of poor experiences in the health and care sector. Participants spoke about inequity, and how one's experience can vary depending on whether the person they're dealing with understands ADHD.

> "With GPs, it can be a gamble if you get someone who understands ADHD and if they're going to support you."

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[2] Summaries of the anonymised case studies participants explored are included in the appendix.

Training for professionals

Ensure all health and care professionals have appropriate training about ADHD.

To participants, training and information provision was key to raising awareness and tackling stigma associated with ADHD. Participants spoke about the role that training for GPs could have in making the diagnosis and support pathways easier to access and navigate.

However, other participants also highlighted the need to go beyond training and ensure that best practices are implemented.

> "When training is done there needs to be follow-up to ensure things are being put in practice. In my experience as a nurse, I see lots of meetings and training, but nothing being put in productive, effective practice."

Challenge stigma within the health and care sector, including around the validity of private diagnoses.

Participants also spoke about their wider experiences in the health and care sector. They told us about health and care professionals questioning their diagnoses, particularly when they had been obtained through a private service.

> "It's a lottery whether you get shared care. Diagnoses are often dismissed if they aren't through the NHS. It feels ridiculous that the right to choose has been used to relieve pressure on the NHS, but it's not seen as being on the same level."

Participants spoke about wider concerns that private diagnoses are seen as less legitimate, including one participant who pursued a diagnosis from the NHS because of their concerns.

> "[There's] lots of people thinking, 'God everyone has ADHD', so, for me, it was important it was an NHS diagnosis so that no one could say I had bought a diagnosis. For me, it felt more legitimate to get an NHS diagnosis."

Others spoke positively of their experience getting a private diagnosis, noting that it meant they avoided a multi-year wait and could access support sooner.

Increase awareness of the different ways that ADHD can present in different people.

Participants told us about their concerns about the lack of awareness of the different ways that ADHD could present. They spoke about their own experiences of being misdiagnosed or their symptoms being missed.

"In my late teens, I was misdiagnosed with bipolar because they did not know about ADHD in girls at that time. It's still underrecognized and misdiagnosed because of the different presentations of ADHD in women and men."

Participants highlighted health inequalities, speaking particularly about women and people from ethnic minority groups, and their concerns that their ADHD could be missed. They raised concerns that this could result in being diagnosed later in life, missing the opportunity to have support in place throughout education.

Participant C: "There's a lot missing in terms of cultural context, in terms of understanding why people may not be diagnosed until later in life. That includes gender, race, whether you're middle class, and where you grew up."

Participant D: "The way I see it, assessments are focused around the white male experience. There's not much understanding of how it presents in anybody different to that. If you're racialised you're more likely to be told you have behavioural problems at school rather than ADHD."

When discussing training about how to spot ADHD in different people, participants focused on GPs and teachers, who they saw as the main people responsible for identifying ADHD. Given the length of time they spend interacting with children and young people, participants focused on education professionals as being key to early identification.

"Better trained and supported teachers and school support staff would be transformative for children with ADHD, given the amount of interaction. [It] will help also into adulthood."

Joining-up support

> **“Everything is just done in siloes. Why can’t there be more integration, putting patients at the centre?”**

Working together

Help people get joined-up care, centred around their needs as a whole person - this includes:

- **Better support for comorbidities, particularly mental health.**
- **Better links between the health and care system and other sectors/organisations.**

Across conversations, participants spoke about the need for support across all aspects of their lives. Participants wanted to see joined-up working between professionals and professional bodies across:

- the education system
- the criminal justice system
- local authorities
- Voluntary and community sector (VCSE) organisations, and
- employment bodies, including Jobcentre Plus.

Participants expressed their own frustrations at siloed working - particularly when getting care for multiple conditions, including Autism and mental health issues. One person shared their own frustrations of the poor links between ADHD and Autism professionals they see.

> “I have Autism as well. I don’t understand in the NHS why it’s so compartmentalised. You speak to an Autism expert, and they don’t know anything about ADHD… and you speak to an ADHD expert and they don’t know anything about Autism.”

One participant told us that, after waiting nine months for a diagnosis, they had to wait a further three months to get their medication. The medication wasn’t right for them due to underlying mental health issues – so they then faced an additional two-and-a-half-year wait for mental health support before they could continue with treatment.

Continuity of care

Ensure people transition seamlessly, without a wait, from child to adult services.

In two groups, participants explored a case study where a person diagnosed at school transitioned from child to adult services while waiting for support - and now faces an additional two-year wait for help.

Participants spoke about the need for a smooth transition from child to adult services which doesn't add to the wait for support. Participants also spoke about the possibility of increasing the age at which the transition takes place, stating that 18 feels too young – particularly as many young people will be intending to continue their education at university. One participant also highlighted that people with ADHD may have an Education, Health, and Care Plan (EHCP), which remains in place until they're 25.

> "There should be support for young people up to the age of 25… as in, education, then transitioning to adult services. With the possible developmental delay in young people with ADHD it's essential we support them as long as possible."

Provide access to age-appropriate care, regardless of the age they are diagnosed.

Participants who were diagnosed with ADHD in adulthood spoke about the difficulties they had faced getting access to appropriate support. These participants told us about the gaps in care they have experienced.

> "I just feel like If there was an adult service within my NHS trust there would be more around other things I could do – organisational skills, other things to try, how to deal with rejection, things that can help. That's not available from the service that I have got."

Help people get equitable access to support across the country.

Participants also told us about the value of the support they'd received from VCSE organisations, particularly in parts of the country where people can't get adult ADHD support through the NHS. One person told us that the best support they had received had come through their local support group.

However, participants also spoke about the need to audit the services available across the country to identify where there are gaps in support, and then allocate resources to these areas.

The right support, at the right time

> **“There has been no soft support – not just drugs, maybe look at this or this might help. There’s just nothing like that.”**

Identifying ADHD earlier

Help people to spot ADHD as early as possible, so that they get the support they need.

Throughout the workshop, participants emphasised the need to diagnose people as early as possible. Participants diagnosed in adulthood shared their experiences of living with undiagnosed ADHD, the relief of diagnosis and their frustrations that it wasn’t identified earlier.

> “The impact of my undiagnosed neurodivergence was enormous. I’ve had a lifetime of chronic overwhelm, stress, constant cycles of burnout, feeling misunderstood and supported. The diagnoses helped me look at my life differently.”

Reduce the burden on those with suspected ADHD.

Participants told us about the burden placed on those seeking a diagnosis for ADHD. One participant said they really wanted to *“get across the difficulty of the diagnosis process”* through their participation, while another talked about challenges using the Right to Choose system.

> “I had to be very belligerent with it. […] I went through Right to Choose, and it was a nightmare. I had to negotiate with different companies, wait over a year for assessment, wait eight to 10 months to start titration and then that took a year.”

Ensure that people get adequate information and support immediately after diagnosis.

Participants also spoke about feeling grief and upset after diagnosis. These participants spoke about a sense of loss, and that they found that it had an ongoing effect on their mental health.

> "For me, I went through an unprepared cycle of grief with my diagnosis. I was not prepared for it, no one prepared me, no one supported me. I grieved and grieved and grieved for myself and what I've lost and what could have been. I had my diagnosis, but no one told me what it would mean for me."

Participants also highlighted that the early stages after diagnosis, before getting support, are a vulnerable and uncertain time. One participant spoke about feeling anxious after diagnosis, and others didn't understand what the next steps would be.

Participants wanted more information, both about what the diagnosis means, about what the next steps were and to set expectations about support.

> **Participant E:** "Reducing anxiety, uncertainty after you had your assessment. You should be there to make that person cope. You can act but you can also make things worse."
>
> **Participant F:** "A map of the journey, which includes steps on pre-diagnosis, diagnosis and after. What happens at each stage? This will help build people's confidence."

Waiting well

Ensure people have support while waiting, including signposting to local organisations that can help.

Participants talked about their experiences of waiting and their frustrations about the lack of support and communication while waiting. Participants discussed the need for support options while waiting, which centred on people being signposted to both local and online support groups or VCSE organisations.

> "There needs to be an interim 'how to deal with suspected ADHD' whilst you wait for a diagnosis, because the waiting lists are so long. You need to know what support will be available as an interim."

Improve transparency around waiting - this includes:

- **Providing updates while waiting.**
- **Providing information and setting expectations.**
- **Providing a point of contact, so those waiting know how to ask any questions they have.**

When talking about their experiences of waiting, participants spoke about the lack of clarity around their wait. Two groups also explored a case study that spoke about long waits for support, and these participants had deeper conversations about what should be happening while people wait.

Participants shared frustrations about being kept in the dark, both around the progress of their referral and on how long they should be waiting.

> "It's okay if GPs aren't completely sure, what's important is that they communicate that. Recognition from the ADHD service that they've received the referral and a clear timeline. Being honest about it and then sharing other resources to help people while they wait."

One participant was told they'd been referred for support. But after waiting for months, they rang for an update to be told the referral hadn't been processed. They described having to do their own research to find out what was going on and what should be happening.

Participants also wanted a point of contact, so they could contact someone for an update or if something changed.

> "In terms of waiting times, I use the NHS so I'm used to waiting, but it's clarity that's needed. Not knowing who to call about what issue."

Reducing waiting times

Tackle waiting times across the patient journey, not just before diagnosis.

Participants had very low expectations about waiting times and saw them as a 'fact' of the NHS today.

> "Reduced waiting times and support whilst waiting go hand in hand. But it's more difficult to tackle waiting times, it's just a fact of life at the moment. It's out of our hands."

However, participants did feel that tackling waiting times was a key priority. Participants spoke about the impact that waiting has on people's mental health, too. Those who got diagnosed quickly spoke about how fortunate they had been.

Easier access to support

Make it easier for people to navigate the diagnosis and support pathway.

Participants spoke about the importance of making it easier to get support. Their suggestions include:

- Visualising the patient journey.
- Providing an overview of local support options, while waiting and after diagnosis.
- Supporting parents and carers to navigate the health and care system.
- Training parents and carers to provide support at home.

> "I think the top priority for me is around easier to navigate the diagnosis pathway. That's really important is to have that understanding of what the steps are and what is going to be involved."

Participants talked about self-support options, and discussed having to find out what support was available themselves. They spoke about the need for more local support options, and for people to be signposted to a range of support options at the point of diagnosis.

> "There could be something put in about locally. Nationwide groups on Zoom are great but having local support would be useful. There is little in place locally for adults who are newly diagnosed. Self-support, potentially within the NHS, having prerecorded training and resources."

Provide support and guidance on how to live well with ADHD.

Participants spoke about the lack of wider support to help them live well with ADHD. Throughout the workshop, participants emphasised the need for support in different aspects of their life. Participants suggested NHS-branded resources containing different strategies for managing ADHD traits, alongside guidance on reasonable adjustments and a wider myth-busting campaign.

> "I can't help but thinking that, we love our NHS, but the NHS is overwhelmed. What support can be given? That feels important – put together resources and customise

them so that they suit those who are hyperactive and those who are inattentive. They could do more to help people learn to live with ADHD."

Choice

Help participants choose the treatment and support options that are right for them.

Participants spoke about the need for a wider range of support options. We heard from participants who were concerned that the medication might not work or might not be the right option for them. We also heard from people who couldn't take medication due to other health conditions.

One person no longer wanted medication but felt worried they would appear as though they could manage without support.

Another participant told us that they wanted medication in addition to other forms of support, but this wasn't available to them.

"When I went through Right to Choose, you could choose medication or choose therapy for support. I chose medication but I also wanted therapy, but was told that service wasn't available. It's like, 'Here's a diagnosis and here's some medicine and off you trot'. I felt really abandoned."

Appendix

Participant demographics

Diagnosis status	
I have been formally diagnosed with ADHD by a medical professional	23
I suspect that I might have ADHD, but I'm not pursuing a formal diagnosis from a medical professional	3
I suspect that I might have ADHD, but I'm still waiting to speak with a medical professional about a formal diagnosis	5

Financial status	
Just getting by (I have just enough money for living expenses and little else)	13
Prefer not to say	1
Quite comfortable (I have enough money for living expenses, and a LITTLE spare to save or spend on extras)	7
Really struggling (I don't have enough money for living expenses and sometimes run out of money)	9
Very comfortable (I have more than enough money for living expenses, and a LOT spare to save or spend on extras)	1

Employment status	
Caring for someone with long-term health conditions or a disability	2
Retired	1
Unable to work due to health issues or a disability	5
Unemployed and looking for work	1
Working full-time (employed or self-employed)	10
Working part-time (employed or self-employed)	12

Disability	
No	18
Yes	13

Long-term health condition	
No	17
Yes	14

Carer	
No	25
Yes	6

Ethnicity	
Asian/Asian British: Indian	2
Black/Black British: African	4
Black/Black British: Any other Black/Black British background	1
Black/Black British: Caribbean	2
Mixed/multiple ethnic groups: Any other Mixed/Multiple ethnic group background	1
Mixed/multiple ethnic groups: Black African and White	5
Prefer not to say	1
White: Any other White background	2
White: British/English/Northern Irish/Scottish/Welsh	12
White: Gypsy, Traveller or Irish Traveller	1

Sexuality	
Asexual	1
Bisexual	3
Gay man	1
Heterosexual/straight	20
Lesbian/Gay woman	1
Pansexual	2
Prefer not to say	2
Queer	1

Gender	
Man	13
Non-binary or gender-fluid	3
Woman	15

Age	
18 - 24 years	7
25 - 49 years	15
50 - 64 years	8
65 to 79 years	1

Region	
Barking and Dagenham	2
Barnsley	2
Birmingham	3
Brighton & Hove	1
Bristol	1
Cambridgeshire	1
Camden	1
Coventry	1
Kent	1
Lancashire	2
Leeds	1
Leicester and Leicestershire	3

Manchester	2
Newcastle	1
Salford	1
Southampton	2
Southwark	1
Surrey	2
Wiltshire	1
Wirral	1

Case studies

These are summaries of real stories, which have been anonymised for use.

Case study 1:

- Concerns about her behaviour were raised at the end of primary school.
- She struggled to attend secondary school, and her GP refused to offer any further support after previously referring her to a child psychologist.
- Her Mum arranged for her to see a private doctor for support, who diagnosed her with ADHD and prescribed her Ritalin.
- Her Dad disagreed with the diagnosis and discouraged her from using the medication.
- After going back to her GP for support, they refused to prescribe Ritalin until she had accessed support through Child and Adolescent Mental Health Services.
- During a period of rebellious behaviour in her late teens, she was arrested and attempted suicide.
- She was then detained under section 62, which means a person can be treated with or without their consent. After her release, she was arrested for violent behaviour.
- She is currently pregnant and still without support.

Case study 2:

- Suffered with anxiety and had ADHD traits in school, but this wasn't picked up.
- Age 16, he wondered if he could have ADHD.
- He was diagnosed just before his 17th birthday and placed on a waiting list for medication.
- Mental health declined while waiting, which led to symptoms of body dysmorphia and symptoms of an eating disorder.
- He was diagnosed with anorexia.
- He missed his A-Levels and had to take extended time off from his job.
- At 18, he was discharged from the children's ADHD clinic without ever receiving medication.
- He's now facing a wait of over two years to access support at the adult ADHD clinic.

Case study 3:

- She suspected she had ADHD in 2020, after consistently missing deadlines for work and university assignments.
- She was referred for assessment by her GP in 2021, and was told to expect a 14-month wait.
- She didn't hear from them for 37 months.
- She was diagnosed with ADHD and referred to her local ADHD service in March 2024, but four months later is still waiting to hear back.
- She has had to leave her job, in part due to her ADHD symptoms.
- She's struggling with other mental health challenges, too.
- She still doesn't know when she'll be able to get help or even what services are available.

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
@HealthwatchE
Facebook.com/HealthwatchE