NHS
Lancashire and South Cumbria
Integrated Care Board

Listening to people and communities – Adult ADHD pathway transformation

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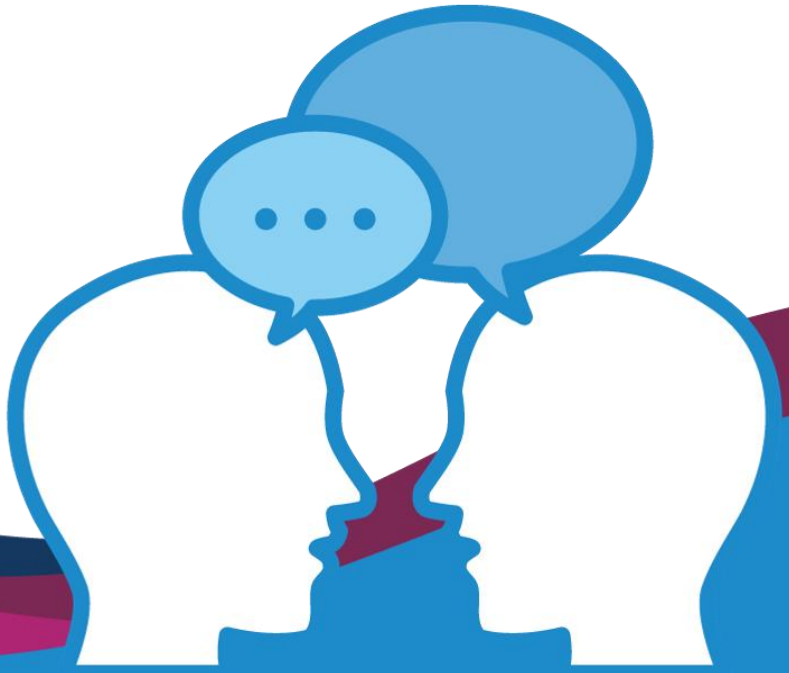

Contents

Acknowledgements

Thanks to everyone who gave up their time and shared their personal experience, journey and insight to help improve adult ADHD services for the people of Lancashire and South Cumbria.

Introduction

Adult ADHD services nationally have been under pressure. In Lancashire and South Cumbria demand for assessment has outpaced financial capacity and appears to be growing year on year. People frequently experience waiting lists that are several years long, and there is no current 'while you wait' support offered. This increases the pressure on other parts of the system as those awaiting ADHD assessments often experience worsening mental health.

The current system is unsustainable and doesn't meet the needs of patients, staff or services. Funding is increasingly taken from one part of the system to provide for another – in this case, funding is moved from mental health services into adult ADHD services. Services are unable to meet the demand on them; patients don't get the help, support and diagnosis they need.

The ICB mental health commissioning team want to look at more efficient ways to provide high quality services. At the moment, adult ADHD assessments are undertaken either by local Place mental health teams, or by private providers under the Right to Choose legislation. These arrangements are costly and frequently don't offer patients any support beyond diagnosis and medication.

Lived experience is a vital part of designing meaningful services in health care. People were invited to join workshops to discuss how the system could be improved and meet the needs of patients more effectively. Participants were asked to consider multiple key elements to influence the commissioning of services in the future.

Executive summary

During February and March 2026, Lancashire and South Cumbria Integrated Care Board (ICB) held six online public engagement workshops to look at lived experiences of Attention Deficit Hyperactivity Disorder (ADHD) assessment and support. Fifty people shared their experiences, including people with a diagnosis, people waiting for an assessment, people supporting someone with ADHD, and people considering ADHD diagnosis for themselves. Ten main themes emerged from the sessions, with a range of opinions shared.

Summary of themes:

- The negative impact of late diagnosis and masking
- The negative impact of long waiting lists
- Fragmented services and professional knowledge gaps
- Families, parenting, and transgenerational impact
- Medication is only part of the solution
- Peer support, lived experience and health inequalities
- Impact of ADHD on girls and women
- Need for pre-diagnosis and skills-based support
- Diagnosis and validation
- Discrimination at work

Participants had a wide range of experiences and perspectives; some had experienced long waits for assessment and treatment but found diagnosis had been validating, or helpful in accessing adjustments. Some participants were still waiting for a diagnosis or had decided not to go through the assessment process. Participants felt that women often mask ADHD symptoms and face misdiagnosis or

mislabelling. They highlighted that medication is often the first and only treatment offered and felt skills-based interventions would offer better support.

A key theme of validation, understanding, skills, and connection emerged. Participants shared that being understood and listened to was more helpful than diagnosis alone. A need for interim care and support whilst on long waiting lists was highlighted; participants were concerned that long waits may actively worsen mental health and employment prospects. Some participants highlighted issues with late-in-life diagnosis and suggested better support for people navigating fragmented services. Participants felt that there needs to be more awareness of alternative or parallel forms of support, both for clinical staff and the general public. Some participants described positive experiences of peer support, coaching, and learning at their own pace. Peer support was frequently described as very powerful in reducing isolation and self-blame.

Concerns were also raised that uneven access to services makes health inequalities worse. Participants felt that people who are articulate, digitally confident or financially well-off are more able to access support. Participants saw services as reactive with gaps in professional knowledge, particularly in primary care. Diagnosis of children and family members was seen as an opportunity for intervention and support that was often missed. Peer support and community-based approaches were seen as vital yet under-used by the NHS.

There was a consistent sense throughout that as well as looking for diagnosis, people were also looking for earlier understanding, validation and practical support. Some people's needs could have been met before accessing a diagnostic pathway. or whilst waiting for assessment. This suggests an opportunity to consider ways support can be offered earlier and in different forms, rather than relying on diagnosis as the main route into care.

Overall, participants called for flexible, trauma-informed and person-centred approaches focusing on impact and functioning, rather than a single pathway or solution.

What have we been talking to people about and why?

The NHS nationally and locally has seen huge increases in demand for people requesting support for symptoms of Attention Deficit Hyperactivity Disorder (ADHD). Lancashire and South Cumbria ICB has not received any additional funding to help with this, resulting in considerable strain on services and long waits for care.

Even after making significant investment from mental health funding, the system can't keep up with demand – in the current model, this will grow as more people require ongoing care and medication monitoring. We are concerned that this is unsustainable, and people will wait even longer for support than they do now.

We wondered if the majority of people referred for and awaiting ADHD assessments would want medication, if diagnosis was seen as the ultimate goal, and whether

referral and assessment criteria needed to be used more effectively to reduce the number of new referrals.

We wanted to hear from people with lived experience about their experiences of adult ADHD services – getting referred, waiting times, assessment, diagnosis, medication, and post-diagnostic care.

Who have we heard from and how?

Deciding who to talk to

We thought about which groups were most likely to be interested in changes to adult ADHD services, and wanted to hear from:

- People already diagnosed with ADHD
- People who support someone with ADHD
- People awaiting ADHD diagnosis
- People who have not yet sought an ADHD referral, but suspect they might have it

To make sure we heard from as many of those people as possible, an invitation to join one of five initial workshops was sent to colleagues across Lancashire and South Cumbria in:

- Local and district authorities – communications and engagement, libraries, support services, employment, public health
- Other NHS organisations e.g. Lancashire and South Cumbria NHS Foundation Trust, Talking Therapies
- All Further/ Higher Education colleges and universities in Lancashire and South Cumbria
- ADHD/ neurodivergent/ disability specific voluntary, faith, community and social enterprise (VCFSE) groups
- Mental health peer support groups
- Other VCFSE and social groups
- Statutory organisations - Department for Work and Pensions, fire and rescue, Lancashire Constabulary
- Local networks e.g. SPARKS network in Blackpool

We asked that the invitation was cascaded throughout their organisations, and shared with colleagues, students, patients, friends and family. The invitation was also cascaded by people sharing independently.

How did we speak to people?

We offered five initial workshops, plus an extra workshop for people who had not been able to attend but had let us know they would like to. We held all workshops online via MS Teams, and offered a range of days and times:

1. Wednesday 25th February 9.30am – 12pm
2. Friday 27th February 9.30am – 12pm
3. Monday 2nd March 2.30 – 5pm
4. Tuesday 3rd March 9.30am – 12pm
5. Wednesday 4th March 6 – 8.30pm
6. Thursday 12th March 9.30am -12pm (additional)

Workshops

All workshops were online-only. Workshops consisted of two presentations to the whole group from either John Haines (Adult ADHD programme manager) or Dr Jim Hacking (Clinical Care and Professional Lead- Mental Health), followed by smaller breakout rooms where participants could discuss what they had heard in the presentations. See appendix 1 for presentation slides.

After the first presentation participants were asked to consider these questions in their discussions:

- How can we understand who is most at need of a diagnostic assessment or clinical treatment?
- What do we mean in describing someone as having “significant impairment” and how should this be evidenced? e.g. letter from employment, self-report measures, etc.
- When should we consider other problems first? e.g. mental health, environment, lifestyle, relational problems
- Are there particular things we should consider for prioritisation? e.g. at risk of losing children, going to prison, other mental health problems such as depression

After the second presentation Participants were asked to consider these questions in their discussions:

- What have you found helpful in managing your own condition?
- What would you have benefitted from knowing at the beginning of your journey, from what you know now?
- If we were to develop a non-clinical support function, what should it include? e.g. Reading materials, online self-assessment, groups, peer support, one-to-one coaching, letters to employers/university etc.
- What should we measure to understand the impact of care we offer, and what should we do if it isn’t working (whether clinical or non-clinical)?

Questionnaire

We had intended to run a questionnaire alongside the workshops; however, the programme leads felt it would be better to use the insight from the workshops to develop a public questionnaire to focus on specific elements of feedback.

We hope to have the questionnaire developed and open by July 2026.

How many people got involved?

The workshop invitation was shared with approximately 1500 individuals across the organisations listed above.

Across the six workshops, 50 Participants gave up their time to share their experiences; 89 people had registered their interest in attending via Smart Survey, giving an attendance rate of 56.17%.

Date and time	Number registered	Number attended
1. Wednesday 25th February 9.30am – 12pm	13, 14.61%	5
2. Friday 27th February 9.30am – 12pm	18, 20.22%	7
3. Monday 2nd March 2.30 – 5pm	17, 19.1%	10
4. Tuesday 3rd March 9.30am – 12pm	12, 13.48%	6
5. Wednesday 4th March 6 – 8.30pm	29, 32.58%	6
6. Thursday 12th March 9.30am -12pm (additional)	Invitations sent to 89 previous registered people	16

The majority of people who registered were waiting for an ADHD assessment or referral (41.57%). Just over a third were diagnosed with ADHD. Just under a quarter supported a person with ADHD, and a further quarter had other reasons for registering – interest in the topic or considering diagnosis themselves.

The majority were over 46 years old (45), with fewest young people aged 18 – 25 years old (5). Seven were 26 – 35 years old, and 32 were 36 – 45 years old.

The majority of participants were women, based on how participants presented or identified during engagement activity. We did not formally collect gender identity data.

We asked registrants to share the first part of their postcode so we could see how widespread across Lancashire and South Cumbria they were.

- FY (Fylde Coast): 26
- LA (North Lancashire and South Cumbria): 23
- BB (East Lancashire and Pendle): 20
- PR (Central Lancashire): 16
- WN (West Lancashire): 2
- OL (East Lancashire): 1

See appendix 3 for more information.

What did we hear?

Following the first presentation (see appendix 1), participants were asked to consider how people should be prioritised for assessment, how 'significant impairment' could be evidenced, and when should other diagnoses be looked at first. Six main themes emerged from these discussions (*for direct quotes from participants, see appendix 2):*

The negative impact of late diagnosis and masking

"I honestly think the trauma came from growing up unidentified, not from the ADHD itself."

Participants described the profound impact of late ADHD diagnosis – often missed because they were seen as well-behaved or academically capable. They described trauma from years of misunderstanding, mislabelling, and self-blame.

For many, being diagnosed as an adult was transformative: it improved personal understanding, relationships, and emotional wellbeing. Major life changes such as menopause, career changes, parenting, and bereavement often triggered the pursuit of diagnosis to make sense of the transitions and symptoms. The cumulative impact of late diagnosis included deteriorating mental health, educational and employment difficulties, and strained relationships. Many stressed that age should never be a barrier to assessment; they felt that the lived impact matters most.

School experiences were frequently described as traumatic, with experiences of bullying, inaccessible teaching, and labelling such as "naughty", "thick", or "lazy". Participants described experiencing repeated punishment and social withdrawal impacting their self-esteem and confidence. This led to many adopting "masking behaviour" - hiding difficulties to fit in - which caused emotional exhaustion and burn-out. Antidepressant treatment and talking therapies were not seen as consistently helpful.

Participants described having to constantly justify their needs and fight for basic adjustments, but having their experiences dismissed by professionals and loved ones. Participants stressed the necessity for compassionate and trauma-informed approaches. Earlier identification was seen as preventing harm and reducing trauma. The majority of participants felt that ADHD should be viewed as a lifelong condition shaped by circumstances and environments, and not just its symptoms.

The majority of participants described feeling shame, low self-esteem, and burnout. Many felt like failures prior to diagnosis, comparing themselves negatively to others, and enduring chronic anxiety and depression. Diagnosis brought relief and self-compassion. Participants described ADHD as often invisible and exhausting to mask, leading to others underestimating both their strengths and their needs. Understanding the reasons behind their struggles was considered to be as important

as treatment. Validation of their condition and circumstances helped to reduce a sense of self-blame.

Auditory processing delays and executive dysfunction were highlighted as common experiences. Participants described constant mental activity and emotional strain. Social isolation and cycles of ‘overdoing then withdrawing’ were frequently mentioned. Participants stressed the need for understanding, flexible, tailored support, and social connections. Stigma and trivialisation - characterised by participants as “everyone is a bit ADHD” - minimised their lived experiences, feeding into misinformation and stereotypes.

The negative impact of long waiting lists

“You get put on a list and then you’re just left. Life doesn’t pause while you wait.”

Participants described long waiting times for assessment as the most damaging aspect of the current system, linked to deterioration in mental health, employment stability, confidence, and family life. Many participants experienced waits of several years for assessment, and stated they had not received any contact, guidance or support. Participants emphasised people usually seek ADHD assessment because life is *already* not going well, making unsupported waiting harmful. Some participants shared that being put on a waiting list often feels like a stopping point rather than the start of help.

Waiting was not seen as a period of neutrality, and participants felt this led to actively worsening outcomes rather than simply postponing care. Participants felt that the negative impact of long waits could be prevented or reduced if support were available immediately after referral rather than after diagnosis. Several participants reflected that believing diagnosis was the only route to support may have delayed them looking into other forms of help.

Participants described waiting as a clinically meaningful period requiring support. Several participants reported that their mental health got significantly worse while on waiting lists, describing it as a period where “everything else collapses” - meaning work, family relationships, mental and physical health.

Absence of follow-up, monitoring, or review once on the ADHD pathway was criticised and participants contrasted this with children’s services where they reported that monitoring and check-ins occur. Participants were concerned that there is no oversight of worsening mental health, safeguarding risks, or life changes. Participants saw a system where people only receive attention once they reach crisis point. They felt that static waiting lists fail to reflect changing risk, need, or vulnerability over time.

Many highlighted how challenging, slow, and exhausting the assessment journey can be. Participants shared feeling dismissed, disbelieved or not listened to, regardless of age or life stage.

Pre-diagnosis help, peer groups, interim validation letters, and practical guidance while waiting were strongly supported.

Fragmented services and professional knowledge gaps

"By the time we go to the doctor to ask for an assessment we've probably been thinking about it for years. It's not because we've seen it on social media!"

Participants described fragmented services as a major barrier, citing disjointed systems across mental health, neurodevelopmental, education, and employment sectors. There was a perception that crisis care frequently receives more funding than prevention, and access often depends on location, mobility, income, or the ability to self-advocate.

Participants consistently highlighted professionals' lack of awareness and varying standards which delay or prevent support. Early and preventative help was strongly advocated for, with calls for regular feedback, check-ins and wider screening. They felt this would avoid the need for crisis interventions.

Participants criticised single-diagnosis pathways, believing that ADHD rarely exists in isolation; participants suggested holistic assessments that consider commonly co-existing conditions such as autism, trauma, anxiety, depression, and sensory sensitivities. Current service design means being placed on multiple waiting lists and co-occurring conditions are often overlooked. Many reported that services have high thresholds or require medication trials before offering post-diagnostic support, which was described as inadequate.

Services are often arranged around organisational boundaries, making diagnosis a barrier rather than a tool. Participants shared experiences of repeatedly having to recount their histories or risk falling between services. They called for joined-up, holistic, person-centred support that adapts to individual needs and acknowledges the impact of ADHD beyond just symptoms.

Immediate post-referral access to practical toolkits, local resources, and clear signposting was recommended, along with step-by-step explanations for both patients and professionals. Participants saw the lack of post-diagnosis support as a significant gap. Their lived experiences suggests that many people are left without guidance or practical help. Integrated, adaptive approaches and human connection were favoured over generic, condition-specific, digital-only pathways.

Professional knowledge gaps, especially in primary care, were a concern. Participants felt that neurodivergence is rarely considered initially, leading to inappropriate prescriptions and referrals. Assessment experiences varied and often

relied on outdated views, dismissing lived experience. Participants stressed that ADHD and autism are neurological, not mental health conditions, and should be treated as such.

Dual or multiple diagnoses appear to be poorly understood. Women frequently faced misdiagnosis leading to frustration and distress. Participants supported neuro-affirming approaches, personalised strategies, and structured, skills-based interventions over traditional talking therapies.

Families, parenting, and transgenerational impact

"People seem to understand much more about ADHD and autism when it's children, but they don't seem to realise that it's adults too."

Participants described ADHD as impacting entire families, not just individuals. They suggested family-inclusive approaches, as support for adults can benefit children, reduce stigma, and aid understanding at home. They saw a clear need for practical resources aimed at families and supporters. Participants described the intergenerational impact of undiagnosed ADHD in parents affecting parenting and family relationships.

Participants described how neurodivergent parents face greater pressures and little support for their own or their children's emotional regulation and sensory needs. They shared their experiences of not being prompted to consider their own neurodivergence when their children were diagnosed, which they described as a missed opportunity for support.

Participants caring for adults with ADHD also highlighted emotional and family strain. Carers are often overlooked and supported only in crisis. They described the ripple effect of unmet ADHD needs across families and highlighted the importance of recognising family systems and intergenerational patterns in providing effective support.

Medication is only part of the solution

"I didn't want pills, I wanted help."

Participants took a nuanced approach to medication. They felt that medication *alone* could not address the full impact of ADHD and should be a tool rather than a solution. Some felt pushed towards it due to lack of alternatives. They were very clear that skills-based support – potentially in addition to medication – was essential.. They felt strongly that medication should not be the only option, and that people need informed, supported choices. There was some concern that health professionals see medication as the solution, which risks neglecting psychological, social and practical support.

Several participants described trial-and-error experiences with regimes resulting in side effects and interactions with other medications. They shared frustration at being prescribed medication without being taught how to get the best from it. Others had significant side effects and were disappointed that stimulant medication wasn't right for them. Multiple participants described medication as "life-altering" for focus, mental clarity, emotional regulation, and daily functioning.

Participants stressed that ongoing strategies and support structures remain essential *even when* medication is effective. They felt that over-reliance on medication risks neglecting practical or environmental changes.

Participants reflected that stimulant medication is not universally desired and reinforced the view that choice, rather than a single treatment option, is important. Participants saw the need for non-medical, skills-based interventions alongside or instead of medication, feeling that "pills won't teach the skills that you need."

Peer support, lived experience and health inequalities

"Hearing other people's stories is what helped me understand myself – not the clinical leaflets."

"It's hard enough to get taken seriously by doctors when you're educated and articulate. For people who struggle to explain or stand up for themselves, what happens to them?"

Participants reported that peer support is a vital lifeline for individuals with ADHD, providing understanding without the need for repeated explanation. It significantly reduces isolation and shame, offering relatability and practical strategies that clinical encounters often lack. Hearing others' stories aids early recognition of ADHD traits and fosters a sense of belonging.

Many participants preferred peer groups, coaching, and community-based support over clinical routes, especially during the lengthy wait for assessment or treatment. There was strong support for local, in-person peer groups, facilitated networks, and ongoing support before and after diagnosis. Individuals often learned more from peers than from clinical services. Peer support helped them understand their traits, strengths, and challenges, which in turn had an affirmative, positive effect for them, their families and communities. Peer connection was described as transformational, providing important validation and reducing feelings of isolation.

Shared stories and accessible educational resources were considered more meaningful than clinical descriptions, emphasising the need for neurodivergent-informed communication. Individual coaching and mentoring for managing overwhelming thoughts and maintaining accountability were seen as valuable. Participants noted the need for written information and extra time. Both in-person

and online communities enabled individuals to find mutual support and a sense of belonging, with human connection more effective than self-directed or digital tools.

However, risks such as misinformation and the importance of clear boundaries were acknowledged. Traditional support groups were often seen as inaccessible, with participants preferring activity-based groups where shared activities aid connection. Creative and physical activities were viewed as legitimate self-management strategies. Empowerment, strengths-based narratives, and sharing achievements and resilience were emphasised. Many participants offered to help co-produce services, expressing a desire for ongoing engagement and service design led by lived experience.

Health inequality was a major concern. Participants noted that people with education, resources, or support are more likely to secure help, while socially and economically disadvantaged or isolated individuals are often missed. Systems favour articulate and resourced people; vulnerability isn't always visible, putting less articulate and resourced people at a disadvantage. Participants shared that adverse childhood experiences intensified neurodevelopmental difficulties and felt that invisible distress can be as severe as observable risk.

Participants described support that is largely reactive rather than preventative, and how deprivation and limited digital access show the need for inclusive and flexible delivery models. Participants advocated for systems that trust lived experience, address the whole person, intervene earlier, and reduce reliance on crisis as the gateway to care. Participants felt strongly that when support or medication fails, environmental factors should be examined and support reassessed; thriving is possible with the right help and environment.

Following the second presentation (see appendix 1), participants were asked to consider condition management, non-clinical support, impact of care, and reflect on what would have helped them. Four main themes emerged:

Impact of ADHD on girls and women

"Women especially seem to reach crisis points later in life, when hormones or caring responsibilities tip things over."

A strong theme emerged around women's experiences, particularly the interaction between ADHD, autism, hormonal changes (puberty, pregnancy, perimenopause/menopause), and mental health. Multiple participants described coping strategies collapsing during hormonal transitions.

Female participants explained that their ADHD symptoms were less outward disruption and more internalised dysregulation. They described masking in response to social and environmental factors, how exhausting it is, and how it contributed to

late diagnosis, misunderstanding and a lack of support. Participants shared experiences of being dismissed as “just anxious” by medics. Women felt their difficulties were more likely to be minimised, medicalised, misdiagnosed as anxiety, or attributed to personal failure. Participants felt that gendered expectations and diagnostic models contribute to under-recognition, and current diagnostic processes seldom account for masked and non-stereotypical presentations.

Single-gender peer spaces were described as valuable, allowing open discussion of personal issues, reinforcing the need for flexible, inclusive support. ADHD medication and HRT, for emotional regulation as well as focus, was described by some as life-changing.

Need for pre-diagnosis and skills-based support

“People need support while they’re waiting, not years later when the damage is done.”

The need for pre-diagnosis support was a significant issue for participants. They suggested joined-up early intervention, community-based psychoeducation, group support, and preventative approaches. Participants emphasised that meaningful support can reduce impairment for some people without requiring medical intervention.

Participants spoke about experiencing intense emotions, being highly sensitive to rejection, struggles to “cool down” and regulate emotions. They described the impact on employment, relationships, and parenting. They highlighted that standard mental health pathways (short-term CBT, generic counselling) were insufficient or inappropriate for neurodivergent adults. Many felt that support for executive functioning, emotional regulation, and daily strategies would be more valuable than traditional talking therapies.

Early access to practical skills, peer groups, or coaching was seen as an effective way to prevent crisis situations; suggestions included education about ADHD traits, access to peer groups and courses, signposting, self-directed resources, and an easy-to-navigate source explaining both clinical pathways and practical coping methods. Participants advocated for skills-based approaches such as distress tolerance and DBT-informed skills and expressed frustration about limited and regional inequity in provision.

Some participants were concerned about unregulated coaching, particularly if payment was involved. NHS talking therapies were seen as under-used assets, having governance and neurodiversity expertise,. Many felt services had become more distant post-pandemic; digital-only support was seen as impersonal, and participants preferred local, in-person contact to build trust and community.

Peer-informed approaches and coaching were seen as empowering and accessible, and participants shared strategies developed through reflection and experience.

Non-clinical options like walking groups, peer spaces, and practical courses were seen as effective and welcoming. Improved signposting while awaiting assessment or treatment was suggested to prevent more serious difficulties later. Participants linked early intervention to better long-term outcomes.

Diagnosis and validation

“When I was diagnosed it finally felt like someone else had believed that things really were as hard for me as I knew they were.”

Participants repeatedly described formal diagnosis as valuable and emotionally significant, regardless of whether medication was pursued. Many participants said it reframed lifelong struggles as understandable rather than personal failings, helping with self-management and identity. They described diagnosis as more than a medical label, supporting practical coping, workplace recognition and validation,

Participants emphasised that diagnosis is necessary to be believed by employers, schools, health professionals, family, and friends, and essential for accessing reasonable adjustments. Participants shared the pressure to “prove” their difficulties when workplaces and schools require formal diagnosis for accommodations. They reported that an official ‘label’ improved their lives more broadly and provided language to describe their needs. It gave them increased confidence to disclose requirements in work, education, and personal contexts.

Relief and validation - described by participants as “permission to like yourself”- were recurring themes, especially as participants had experienced harmful invalidation from multiple sources, describing dismissive comments such as “everyone is a bit ADHD”.

Social media was seen as both validating and distorting, sometimes trivialising ADHD but also providing information. There was broad support for accepting self-identification and needs-based support, with recognition of the wider societal issues and impact of ADHD. Participants felt that ADHD and neurodivergence are still poorly understood, especially in adults.

However, diagnosis alone was seen as insufficient. Many participants with a formal diagnosis described being “sent on their way” without structured follow-up, creating uncertainty and anxiety. Participants stressed that while diagnosis can be profoundly validating, it is not an endpoint.

Discrimination at work

“My boss wouldn’t take me seriously until there was something official.”

Participants highlighted workplaces as challenging environments for neurodivergent people, largely due to misunderstanding, stigma, and ineffective reasonable

adjustments. Many participants had experienced bullying, capability procedures and stalled careers after disclosing their condition. Reasonable adjustments were often inconsistently applied or treated as optional rather than a legal requirement, and occupational health recommendations were ignored by management.

Diagnosis was viewed as essential for legal protection and validation, and participants had faced pressure to “prove” their impairment. Coaching or ‘Access to Work’ support was described as beneficial but difficult to access and highly dependent on managers’ attitudes. While supportive employers could be transformative, unsupportive environments led to stress and burnout.

Participants felt that information and documentation for employers and educational institutions would be useful, effective in reducing stress. They suggested increased education and awareness to improve understanding, encourage disclosure, and ensure adjustments are effectively implemented.

What we have learned

What our patients have told us

Services are most helpful when they offer holistic, integrated and joined-up approaches.

Some people will benefit from diagnosis and medication; some people don't want a diagnosis, just practical skills-based support.

ADHD support should be based on lived impact, risk, and complexity.

Medication is a helpful tool when used alongside practical skills-based approaches.

Adult ADHD services can build on the progress made by children's ADHD services in delivering interim care.

Human connection and a sense of belonging are transformative and can make clinical assessment and medication more effective.

Assumptions and stereotypes about why people seek ADHD diagnosis prevent people coming forward.

Neurodivergent adults can experience trauma from the systems that are supposed to help them.

Clear, easy-to-understand and trustworthy information from credible sources is helpful to patients and staff alike.

Anxiety and depression may stem from undiagnosed ADHD and lack of support.

Clinical diagnosis alone is only part of the story – incorporating peer-led support feels welcoming and helpful.

Diagnosis with ADHD gives people validation and legitimises their need for support.

Medication must not be the ***only*** support available.

More than anything else, people want to feel heard, supported, listened to, and believed.

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Conclusion and recommendations

Conclusion.

There was a strong sense from participants that by the time they came forward for an ADHD assessment they had been struggling with their symptoms for many years. Participants often described their journey as a series of stages rather than a single pathway. Greater visibility and discussion of neurodivergence in the media and on social media platforms has allowed people to think about their life-long struggles in a different context. There seems to be a lot of misinformation, and negative stereotypes about ADHD are common.

Participants felt that women are most likely to have masked their symptoms until the point where they can't mask any more, often a hormonal event such as pregnancy or menopause. Common co-occurring conditions are often treated in isolation, such as anxiety and depression, food intolerances, sleep disorders and joint problems. The current health system looks at body parts rather than the whole person, so complex presentations are often missed, dismissed or ignored.

Currently, adult ADHD services focus on diagnosis and medication. Participants had found that there was little pre- or post-diagnosis care or education available. They felt strongly that medication is only part of the answer – if it's the only solution offered people feel they have to accept it. Support needs were described at each stage, rather than only at the point of diagnosis. This highlights the importance of thinking about ADHD support as a broader journey, with different types of help available at different times.

Education, peer support, community and human connection were highlighted as being the most valuable support people with ADHD can have. Medication can help with focus and concentration, and emotional regulation to a degree. Emotional regulation, behaviour management and practical strategies are helpful skills that can be taught, if the right support is available.

Considerations for future engagement.

The workshop invitation was widely shared across Lancashire and South Cumbria. However, only 89 people registered and 50 arrived at the workshops. This may have been due to dates and times – people may have been interested in the topic but had other commitments. We noticed that there were few registrations from West Lancashire, which suggest future engagement might focus more on that area.

It is also possible that online-only workshops were not accessible for people without access to digital resources. Participants told us that digital groups can feel intimidating and impersonal; many said they would have preferred to meet in person. We know that a number of people had difficulties either registering or accessing the workshops due to broken links, scheduling errors and email idiosyncrasies. In future we would manage registration so people received direct invitations and multiple event reminders.

There were more female participants than male at each workshop. There was limited engagement from specific groups such as people involved with criminal justice and substance misuse services. This suggests there may be a need for targeted

engagement with men and people involved with services beyond health and social care.

Taken together, these findings suggest an opportunity to develop a broader and more flexible approach to ADHD support. This could include a range of options, from early information and guidance through to more structured interventions and specialist assessment where needed. Participants' experiences indicate that a single, diagnosis-led pathway would be unlikely to reflect the diversity of needs described.

Recommendations.

Recommendations have been drawn from the participant's lived experiences and themed by priorities which emerged from the engagement workshops.

The pre-assessment period

Providing early, clear information about ADHD traits, overlapping mental health experiences and available support options, including non-clinical routes, is the earliest opportunity to support those seeking an ADHD diagnosis and treatment. Developing and commissioning skills-based, psychoeducational, and peer-supported interventions that can be accessed with or without formal diagnosis addresses inequalities in access and provision.

This could look like:

- Offering skills-based training and support around emotional regulation and practical habits at the point of referral for assessment.
- A 'self-service' option for people awaiting assessment to access information and supporting documents for their employers or educational institutions, their families and themselves.
- Regular check-ins with people as they await assessment, offering guidance and signposting.
- NHS and commissioned VCFSE peer-led groups and networks providing pre-diagnostic support, information and guidance to people on waiting lists.

Referrals and assessments

Improving transparency about what diagnosis can and cannot offer, aligning expectations with available follow-up support, and providing holistic, person-centred approaches that recognise overlapping and complex presentations will address gaps in and demand on service provision.

This could look like:

- Prioritisation of assessment and treatment based on the impact to that individual.
- Robust, thorough pre-referral screening ensuring people are offered the right support and services.
- Experienced, well-trained clinicians using validated referral/ assessment tools.

- Thorough assessment of impairment and risk at the point of referral, considering subtle presentations as well as overt risk factors.
- Exploring the use of digital tools (such as online information, self-assessment, or guided support) to provide more accessible and ongoing support alongside existing services.

Diagnosis and treatment

Offering a range of therapeutic interventions, including medication where appropriate for that individual, will address the increasing financial pressure faced by commissioners, whilst aligning care with national best practice models and improving accessibility for patients.

This could look like:

- Stimulant medication offered as part of a broader package of care.
- Robust, long-term commissioning and contracting arrangements between the NHS and VCFSE organisations supporting people with ADHD.
- Personalised outcome measures, using a combination of validation tools and personal lived experience.
- Providing clear, reliable information in multiple formats – leaflets, group discussions, video shorts and websites provide multiple accessibility options.
- Offering information and guidance to all patients who request it, regardless of diagnosis status.
- Designing outreach and access routes for people who may struggle to self-advocate or navigate digital systems.
- Ensuring face-to-face options are available alongside digital provision where possible.

Broader support

As a trusted organisation, the NHS in Lancashire and South Cumbria has an important role in learning from and improving the experiences of neurodivergent people accessing health care. Greater understanding and knowledge will address health inequalities in some of the most vulnerable and marginalised populations by providing staff, families, carers and individuals themselves with insight, awareness and proficiency.

This could look like:

- Actively combatting negative stereotypes about ADHD through credible and validated staff training.
- Offering predominantly in-person support and prioritising the patient's preferences where possible.
- Targeted training for primary care staff, who are often the initial point of contact for patients seeking an ADHD assessment.
- Considering ADHD and autism as neurodevelopmental conditions distinct from mental health.

- Offering parents and carers assessment in their own right when ADHD or autism are identified in a child or young person.

Appendices

Appendix 1 – slides from the public engagement workshops. The same slides were used each time.

NHS Lancashire and South Cumbria Integrated Care Board

Adult ADHD Pathway

Public Engagement – Spring 2026

1

NHS Lancashire and South Cumbria Integrated Care Board

Introduction

- Our healthcare system has seen huge increases in demand for people requesting support for symptoms of Attention Deficit Hyperactivity Disorder (ADHD)
- We have not received any additional funding to help with this, putting considerable strain on available services and long waits for care
- The current model is heavily dependent on secondary care clinical services, based on clinical assessment and medication-based treatment, with limited access to holistic support
- Even after making significant investment from mental health funding, we cannot keep up with demand, which will only grow year-on-year as people require ongoing care to manage the provision of medication
- We are concerned that the current model is unsustainable. Without changes people will wait even longer for support, as we cannot help everyone with the current ways of working
- We urgently need your help to design a future model, including who should be prioritised for treatment, and what should be offered as alternative support

2

Version 1.0 June 2026
Prepared by: LSCICB communications and engagement team

What is wrong with the current system?

NHS Lancashire and South Cumbria Integrated Care Board

- People are waiting years for secondary care intervention that feedback suggest they may not even need
- Some of those people won't need medication and would have benefitted from recognition and support much sooner
- Others have more complex needs and can't access treatment due to an overwhelmed system
- People with mental health conditions known to make ADHD symptoms worse have limited joined-up care that considers *all* their difficulties
- Many people do not understand ADHD and we know there is a lot of inaccurate information being circulated on social media, making life harder for those with symptoms
- There is emerging evidence to highlight the roles of modern life, such as mobile phone use, in exacerbating symptoms of ADHD, yet there is no support within our system to help with this

3

We want to…

NHS Lancashire and South Cumbria Integrated Care Board

- … transform support for people with ADHD so nobody goes without appropriate care
- … offer support for the variable needs of people with ADHD- both core symptoms and connected difficulties
- … understand how secondary care services can be structured to ensure necessary assessment and treatment for people who need more support
- … have a range of treatment offers, so people have a genuine choice in what can help them
- … have strong clinical principles that will help make sure people get the right help at the right time
- … have fully joined-up care between ADHD and other services

4

Version 1.0 June 2026
Prepared by: LSCICB communications and engagement team

We know…

- … services are currently not good enough to meet needs of people with ADHD or suspected ADHD
- … diagnosis can be helpful for people in understanding their difficulties, but should not be necessary to receive high quality care
- … medication can be an important tool for managing ADHD, and available for those who need it
- … some people will be supported with non-clinical treatments, with a strong focus on self-management
- .. people need holistic treatments looking at both symptoms of ADHD *and* the impact of living with ADHD
- … services need to be joined up, with people experiencing ADHD symptoms able to access services appropriate to their needs

5

Part A: How should we define who is offered which service?

- We would like you to consider the following questions and share your thoughts openly within a dedicated break out room. There are no "right" answers – we want to hear your views.
- **How can we understand who is most at need of a diagnostic assessment or clinical treatment?**
- **What do we mean in describing someone as having "significant impairment" and how should this be evidenced? e.g. letter from employment, self-report measures, etc.**
- **When should we consider other problems first? e.g. mental health, environment, lifestyle, relational problems**
- **Are there particular things we should consider for prioritisation? e.g. at risk of losing children, going to prison, other mental health problems such as depression**

6

Version 1.0 June 2026
Prepared by: LSCICB communications and engagement team

Part B: What should we focus on in developing a model of care?

NHS Lancashire and South Cumbria Integrated Care Board

- Please consider the following questions and share your thoughts openly within a dedicated break out room. There are no “right” answers – we want to hear your views.
- **What have you found helpful in managing your own condition?**
- **What would you have benefitted from knowing at the beginning of your journey, from what you know now?**
- **If we were to develop a non-clinical support function, what should it include? e.g. Reading materials, online self-assessment, groups, peer support, one-to-one coaching, letters to employers/university etc.**
- **What should we measure to understand the impact of care we offer, and what should we do if it isn’t working (whether clinical or non-clinical)?**

7

Version 1.0 June 2026
Prepared by: LSCICB communications and engagement team

Appendix 2

Direct quotes from workshop participants.

The negative impact of late diagnosis and masking

“I wasn’t a naughty child, so nobody ever paid attention. By the time I was diagnosed, the damage was already done.”

“She got to her A-levels and everything fell apart. Looking back, the signs were there all along, but no one joined the dots.”

“There’s this feeling that you’ve failed at life.”

“I always felt like an alien who’d been dropped on the wrong planet!”

“You try so hard to be like everyone else and it seems so easy for them.”

“I honestly think the trauma came from growing up unidentified, not from the ADHD itself.”

“I look back on my whole life, as far back as school, and realise it was all ADHD related.”

“Being diagnosed later in life shakes everything up.”

“My ADHD diagnosis made me question literally everything about my life and who I was.”

“You start thinking about how different things might have been if you’d known earlier.”

“There’s a sense of loss - of what could have been.”

“Sometimes when I think about who I could have been if I’d been diagnosed as a child, I get really angry and upset.”

“It’s not just ADHD; it’s the impact of a lifetime of misunderstanding.”

“I spent my whole life being called over-dramatic or too sensitive. I never heard anything good about myself, just that I was annoying.”

“I coped by masking for years, so no one saw the problem until I burnt out.”

“Girls and women don’t present in obvious ways, so they’re missed again and again.”

“By the time it’s recognised, people are already exhausted.”

“I’ve left so many jobs and had so much time off sick because I can mask right up to the point when I can’t do it any more.”

“People think ADHD means you’re loud and bouncing around, but my brain never shuts off.”

“You don’t see the paddling under the water. On the surface everything looks fine, but underneath it’s exhausting.”

“It drives me mad when people say ‘we’re all a little bit ADHD’. They think it’s a funny thing, they don’t realise how devastating it is for people who’ve got it.”

“It’s really set my career back years. I’ve had to take time off when I’m struggling and people don’t understand.”

“Someone might look like they’re coping, but inside they’re not.”

“Some people don’t show it outwardly. It goes inside, and no one knows.”

“On the outside I look like a normal person, but on the inside I’m absolutely drowning.”

“No one talks about the physical effects. When you’ve got ADHD you don’t sleep well, you can have trouble with digestion and allergies.”

The negative impact of long waiting lists

“People are struggling because they’re waiting, and they’re struggling badly while they’re waiting.”

“My son didn’t even bother going on the waiting list. He says there’s no point, it won’t help.”

“You get put on a list and then you’re just left. Life doesn’t pause while you wait.”

“Being on the waiting list wasn’t neutral — things got worse while we waited, not better.”

“You’re left sitting there while your mental health declines, and no one knows until it becomes a crisis.”

“You feel hopeless on a waiting list.”

“People could sit on a waiting list for years and not even know there’s another route.”

“I’ve lost jobs and friendships while waiting. I don’t feel like there’s any support there at all.”

“You’re struggling now, not in five years’ time.”

“Who’s looking out for that person while they’re on a waiting list? Who manages the risk if their mental health gets too bad?”

Fragmented services and professional knowledge gaps

“Everything is siloed. You’re either here for ADHD or there for mental health, but never the whole person.”

“They weren’t joined up together, mental health and ADHD.”

“I dread having to say the same things time and time again to yet another person!”

“You’re under one service, then suddenly you’re not, and nothing replaces it.”

“Life doesn’t come in neat boxes, but services do.”

“People should only need to tell their story once.”

“ADHD and autism are always put in with mental health, and they’re not – they’re more like neurological conditions. If you said Parkinsons everyone would understand it’s not mental health!”

“It should be a holistic assessment, not just looking at one thing.”

“I went back again and again, and each time I was given antidepressants. No one ever asked about neurodiversity.”

“I was told over and over again it was just anxiety. It wasn’t just anxiety, but no one would listen or take me seriously.”

“My GP laughed and said ADHD doesn’t exist, it’s just trendy to have it nowadays. I came away feeling absolutely mortified.”

“Six years of medical training and not a single session on neurodiversity. That’s terrifying.”

“For about 30 years of my life I was on and off antidepressants, and nobody ever thought to consider it wasn’t just depression.”

“A lot of people may have been misdiagnosed with another condition and believed for years that was the issue.”

“By the time we go to the doctor to ask for an assessment we’ve probably been thinking about it for years. It’s not because we’ve seen it on social media!”

“When you hear hoofbeats, you think anxiety or depression – that’s how they’re trained.” *[relates to a saying medical students are often told – ‘when you hear hoofbeats, think horses not zebras’ meaning that the most obvious answer is often the right one]*

Families, parenting, and transgenerational impact

“When you help the parent understand themselves, the children benefit as well.”

“It doesn’t just affect one person, it affects the whole family.”

“It runs in families, I can see it in my parents and grandparents as well as in my kids.”

“No one knew about ADHD then, you were just mad!”

“Both my children were diagnosed, and nobody ever suggested I should be assessed.”

“Parents are trying to manage their own ADHD while supporting neurodivergent children, and that pressure is huge.”

“Surely it would make sense to assess the whole family at the same time? If one child is getting assessed check Mum and Dad too!”

“People seem to understand much more about ADHD and autism when it’s children, but they don’t seem to realise that it’s adults too.”

“There are clear genetic links, but services still treat everyone in isolation.”

Medication is only part of the solution

“Medication helped my focus, but not the emotional regulation.”

“Pills won’t teach the skills that you need.”

“Some people can’t tolerate the medication, so what are they doing? How are they coping?”

“Medication alone doesn’t fix everything.”

“Starting the medication was magical for me – for the first time in my life I felt what I imagine it’s like to feel normal”

“I didn’t want pills, I wanted help.”

“Medication should be offered to the people who really need it. It might not be everyone.”

“What help is there for people who don’t want medication?”

“Medication helped with focus, but it didn’t teach me how to manage my life.”

“I don’t take them every day, but when I do the difference in how much I can concentrate and get things done is incredible!”

Peer support, lived experience and health inequalities

“Hearing other people’s stories is what helped me understand myself – not the clinical leaflets.”

“Peer support makes you feel normal, not broken.”

“Just knowing you’re not the only one makes such a difference.”

“Talking to people who know exactly what it’s like helps much more than talking to a doctor or a counsellor.”

“Exercise is really good for my ADHD. It would be great if there were ADHD exercise or walking groups!”

“That peer support group helped me before I even got diagnosed.”

“Being in a group of other people with ADHD… you feel understood, and you start to accept yourself.”

“We’ve got the experience - use us.”

“The people who get diagnosed are often the ones with the resources to push for it.”

“What about those not in education, not in work, not in supportive families? They’re invisible.”

“The way things are now is really unfair. The people who need help most have to wait for years and even then it’s just a diagnosis – there’s no help or support after that.”

“It’s hard enough to get taken seriously by doctors when you’re educated and articulate. For people who struggle to explain or stand up for themselves, what happens to them?”

“I ended up paying for a private diagnosis because I just couldn't wait the four or five years it would have taken to be seen on the NHS.”

“You have to fight so hard to be taken seriously. People think you’re lying to get benefits.”

“If you’re just surviving, you don’t have the energy to advocate for yourself.”

“Support depends on where you live and how hard you can fight.”

“It shouldn’t have to be such a battle to be believed.”

“Just because someone hasn’t gone to prison or lost their children doesn’t mean they’re not suffering.”

“People think you just want a diagnosis to get benefits, they’re very suspicious of your reasons.”

Impact of ADHD on girls and women

“I managed fine until perimenopause. Then all my coping strategies disappeared overnight.”

“Women especially seem to reach crisis points later in life, when hormones or caring responsibilities tip things over.”

“I was a good girl, so no one ever thought I needed help in the same way my brother did.”

“My symptoms have massively increased since I went through the menopause.”

“Everything fell apart during perimenopause — what used to work just stopped.”

“Hormones affect everything. Having a women-only space makes a huge difference.”

“Menopause on its own is hard — add ADHD and it can be an absolute nightmare!”

“Pregnancy and becoming a parent made everything ten times harder.”

“Girls are told they’re being dramatic and over-sensitive because ADHD is seen as just being naughty little boys.”

“I’ve never been able to sleep well but when I started perimenopause I was down to about three hours per night but you’ve still got to function!”

Need for pre-diagnosis and skills-based support

“People say, ‘use strategies’, but they’re not told what they are or how to do them.”

“What really helped me were the skills I learned — not just the medication.”

“Courses, coaching, and practical tools made more difference than anything else.”

“It’s not about talking about your problems, it’s about dealing with today better.”

“If it’s not written down, my brain forgets it exists.”

“I don’t want to sit and talk about my problems, I want someone to help me learn how to fix them!”

“I had loads and loads of rounds of CBT but it didn’t help because it wasn’t teaching me how to manage the practical stuff.”

“Hearing what other people with ADHD do to cope is very helpful. They know what it’s like!”

“The NHS should have some kind of course for people with ADHD to learn how to manage their symptoms.”

“I found DBT really helpful but it stopped when I moved away and I’ve never been able to get it again.”

“As soon as someone gets put onto the waiting list, there should be something ready to go for them.”

“You get put on a waiting list and then there’s nothing. Why can’t there be classes for people to learn how to cope with ADHD while they’re waiting?”

“You don’t need a diagnosis to start helping people understand themselves.”

“People need support while they’re waiting, not years later when the damage is done.”

“Even if someone doesn’t end up with an ADHD diagnosis, those skills would still help them.”

“Support shouldn’t depend entirely on a formal diagnosis.”

“There’s nothing offered while you wait, and that’s when people need help most.”

Diagnosis and validation

“I didn’t want a label - I wanted to be believed.”

“If you haven’t got a diagnosis you just get dismissed.”

“That diagnosis was a relief. I cried because it finally made sense.”

“For me, the diagnosis is far more important than medication. It’s the validation.”

“I don’t want medication, but I need the diagnosis. That piece of paper changes how people listen.”

“People think that you’ve just seen it on social media, like you can’t think for yourself.”

“Until you’ve got that piece of paper people think you’re just a drama queen.”

“It’s not even about getting to medication… it might not work anyway.”

“It gives you somewhere to start.”

“When I was diagnosed it finally felt like someone else had believed that things really were as hard for me as I knew they were.”

“No one believes you unless you’ve got that rubber stamp.”

Discrimination at work

“You shouldn’t need a diagnosis to be treated with understanding, but you do.”

“My boss wouldn’t take me seriously until there was something official.”

“Occupational health made recommendations, but management ignored them.”

“As soon as I disclosed, everything changed — I was suddenly being performance managed.”

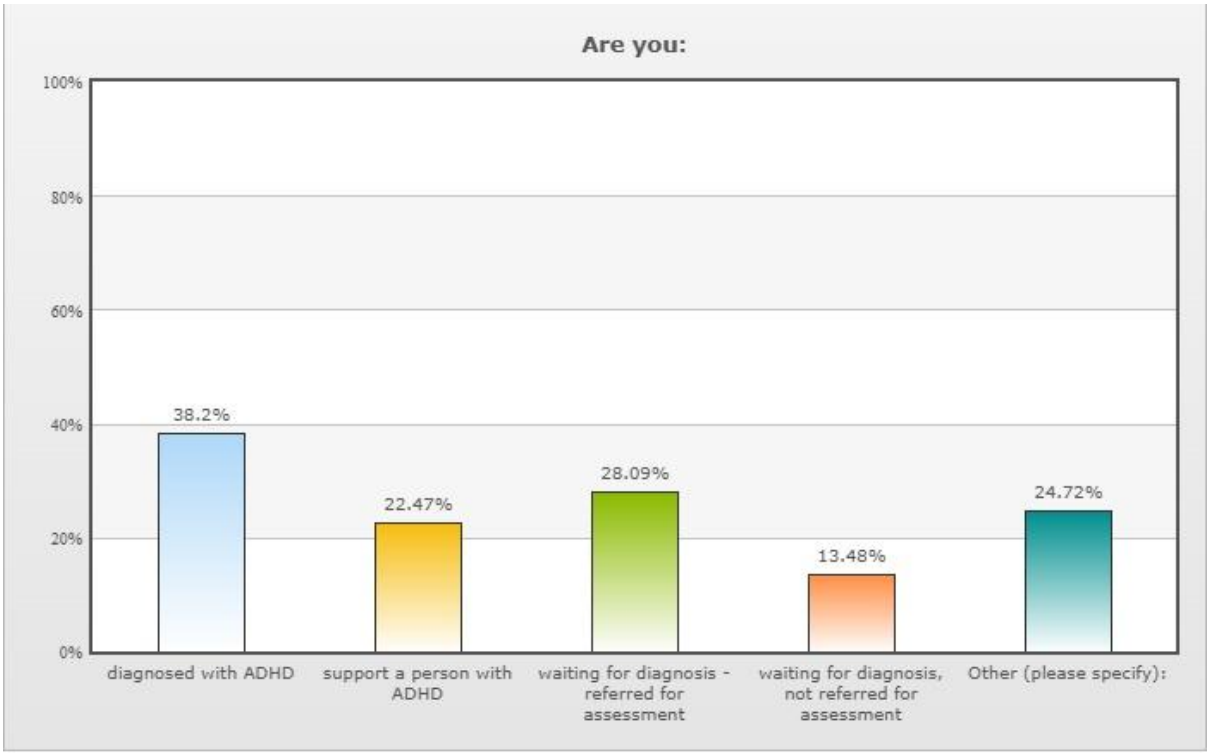
“Reasonable adjustments exist in theory, but in practice they don’t always happen.”

“Managers are making reasonable adjustments with the best intentions, but without the understanding of why.”

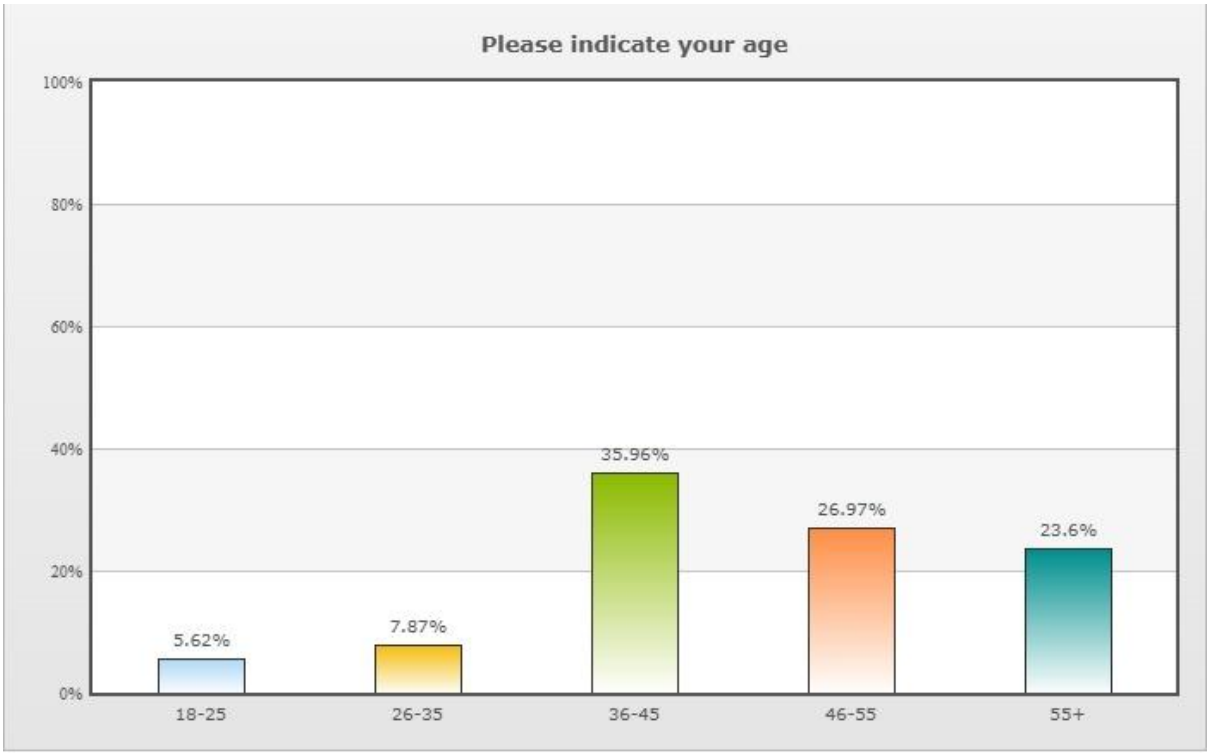
“I was bullied in every job and couldn’t understand why. When I was diagnosed my boss didn’t believe me, because they already didn’t like me.”

Appendix 3 – demographics

The majority of people registering for workshops were waiting for an ADHD assessment or referral (41.57%). Just over a third (38.2%) were diagnosed with ADHD. A little less than a quarter of people (22.47%) had registered as they support a person with ADHD, and a further quarter (24.72%) said that they had other reasons for registering – many were just beginning to think that they might have ADHD, or did not want a formal diagnosis but were interested in the topic.



The majority of people who registered were over 46 years old (45), with people aged 18 – 25 years old the fewest (5). Seven people were 26 – 35 years old, and 32 were 36 – 45 years old.



We had not asked people to share their gender when registering; however, the majority of workshop participants were women, so we assume this may have been similarly reflected at registration if we had captured that information.

We asked registrants to share the first part of their postcode so we could see how widespread across Lancashire and South Cumbria they were.

- FY (Fylde Coast): 26
- LA (North Lancashire and South Cumbria): 23
- BB (East Lancashire and Pendle): 20
- PR (Central Lancashire): 16
- WN (West Lancashire): 2
- OL (East Lancashire): 1