NHS
Greater Manchester

Adult Attention Deficit Hyperactivity Disorder (ADHD) Services

Consultation Report

September 2025

Adult ADHD Services Consultation Report

Version control

Date	Version	Updates from	Reason for change
28/07/2025	1	A Mitton, A Rafferty, S Williams	-
23/08/2025	2	A Mitton, S Williams	Updating sections, adding in additional content, updating based on feedback, “Writing the report” section added

Contents

Executive summary

Following previous engagement with people with lived experience and a review of Adult ADHD services, an 8-week consultation was held to seek feedback on 2 proposed options for how services can be improved, proposed referral criteria, and ideas and feedback on what support would be helpful to people with ADHD.

This consultation report sets out the feedback from the over 2,500 people who engaged with NHS Greater Manchester in a variety of ways, including: focus groups, community group workshops, online survey, texts, phonecalls, emails, voicenotes, and pop-up stalls across Greater Manchester.

Through the consultation we heard that there is a need for a better, more caring service that supports everyone with ADHD symptoms, regardless of whether they are diagnosed. People want ADHD-friendly services with faster access to triage, diagnosis and more practical help along the way with issues around shared care resolved. They want to be involved in the design of the service to make sure it is competent to support people with neurodiversity.

People told us that they agree with the proposed new model of care, with reducing waiting times being their biggest priority. They also agreed with the preferred option out of the 2 options we presented. However, there were concerns raised and suggestions for tweaks as well as completely new alternatives proposed.

People also on the whole agreed with the referral criteria, but raised concerns that they would be too exclusionary, and potentially increase health inequalities, particularly for women and non-binary genders.

Concerns were particularly raised about access for ethnically diverse communities, people who live in deprivation, people with co-morbidities, older people, and in particular children transitioning into adult services.

There was also lots of support for the value of diagnosis as both validating and tool to access understanding and support from families and at work with concerns about barriers being added to getting a diagnosis being consistently raised.

With regards to the offer of support, people felt that a tailored approach needed to be taken, avoiding one-size-fits-all. Support for mental health, anxiety and sleep are the most important, with support for emotional regulation, and life skills being regularly mentioned as vital. There were calls for more details on how the support would be accessed, what it would look like, and who will provide it.

The report contains much more detail about the consultation, how it was promoted, who engaged with us and how, and what we were told.

It will be used – along with clinical and service evidence – to review the proposals and make final decisions on the how adult ADHD services will be improved.

Thank you to everyone who contributed throughout the consultation.

Section 1: Introduction and overview

Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a condition that makes it more difficult for them to focus, sit still, and control their impulses.

ADHD is part of a group of neurodevelopmental conditions that affect how our brain functions. Other neurodevelopmental conditions include Autism and speech and language conditions. Neurodevelopmental conditions are not mental health conditions. We estimate that there are approximately 25,000 adults waiting for an ADHD assessment across Greater Manchester, with more being added every day.

If the way we deliver services stay as they currently are, people could be waiting over 7 years for assessment and diagnosis and some could experience a wait of up to 10 years.

Some of these people will be experiencing much worse symptoms than others, but currently we don't take that into account and everyone goes to the bottom of the waiting list when they are referred. We are worried that this means that some people who are waiting desperately need help and are at risk of coming to harm, and this isn't ok.

If the demand for ADHD services continues at the current levels, it would also cost the NHS in Greater Manchester at least £10 million a year to fund assessment services and we will continue to have too few staff to see people quickly. This situation is the same across the country and is not unique to GM.

For these reasons adult ADHD services in Greater Manchester urgently need to change so they can better support the people who need them and we think that there are better ways to deliver these services so that they can quickly support the people who need them most. But there are no easy answers, as money is tight and there aren't lots of extra skilled staff, so we can't simply increase services to meet the increasing number of referrals.

This consultation was about two potential options for improving access to adult ADHD services and support.

This report sets out what we have learnt from 8 weeks of consultation with adults who have lived experience of ADHD services (or are on a waiting list), professionals, and communities from across Greater Manchester. In total, we engaged with over 2,500 people in different ways and reached many thousands more. It is an unbiased review of key themes people shared with us, however, whilst it is comprehensive it does not include every point, with much more detailed feedback included in the appendices.

The report will be used to take a decision on the future design of adult ADHD services. We will share updates on our website of what has changed because of the consultation, particularly around the recommendations.

Our thanks go to all our colleagues and partners who have supported us to involve people. Our greater thanks go to all those who took the time to engage with us and share their experiences, thoughts and ideas – we are very grateful. Particular gratitude goes to the members of our Lived Experience Advisory Group who have worked with us for over 12 months, advising, challenging and supporting throughout the development of the plans and the consultation.

This report will be published on our website and shared widely. If you would like it in a different format or language, would like a printed copy, or have any questions, please contact us.

Email: gmhscp.engagement@nhs.net

Call, text or WhatsApp: 07786 673762

What people told us – the key themes

- There is a need for a better, more caring service that supports everyone with ADHD, not just those who meet the 20-30%. People want ADHD-friendly services with faster access to triage, diagnosis and more practical help along the way with issues around shared care resolved.
- People strongly agree with the principles of the proposed model which include quicker access to support and prioritisation of those most in need.
- People want services to be provided by the NHS, but value Right to Choose offers.
- People value diagnosis as it helps them understand themselves and offers validation; it is also important to getting them access to support, particularly in the workplace.
- Option A is the most popular. People see it as fairer and more likely to get help to those who need it most and quicker.
- The majority agree or mostly agree with the referral criteria. However, some have concerns mainly due to inattentive presentations, masking, gender differences, and the requirement for severe comorbidities.
- Overall people agreed with the proposed support offer, and feel that support for mental health, anxiety and sleep are the most important. However, people thought that some elements were missing and made additional suggestions such as support with employment, life skills and understanding ADHD.
- Professionals including GPs, triage teams and those working with vulnerable people need appropriate skills to understand, recognise and support and refer people with ADHD.

- People are worried that unless more money and staff are put into the new service the plan will fail.
- People are worried about widening inequalities by creating a model that does not recognise and support at risk demographics such as people on low incomes, females, carers, parents with ADHD, people with co-occurring conditions, etc.
- There is a lack of understanding about ADHD amongst the public and stigma and myths are not helping with this.

Section 2: Consultation delivery

How we engaged

Online survey (support offered over the phone)

1038 people completed the survey, either online themselves or with help through our phone number. We have also had printed surveys and promoted the survey and involvement at all events across Greater Manchester. The details of who responded is on the next page.

Focus groups

We held 5 focus groups - 2 online and 3 face to face. The focus groups were open to anyone interested in the consultation to share their thoughts and feelings with us – they were predominantly attended by people with lived experience.

We also visited 7 community groups to hold targeted focus groups with their members.

In total, 168 people engaged with us through focus groups.

Locality engagement

We took our survey and information out into each locality on our information and engagement stalls throughout the period of engagement. Through this we interacted with approximately 1,341 people over 30 events across Greater Manchester.

Other engagement opportunities

On top of the activities above, we attended a number of meetings with colleagues and organisations across Greater Manchester to promote the consultation.

We are also:

- Received 30 emails
- Had 4 people call us, and spoke to a further 5 people over the phone who requested a call back
- Received 4 texts/WhatsApp messages. We texted a further 29 with details and an offer of a call back
- Received 1 audio file and 6 documents/letters through the option to submit a file online

Promotion

We promoted the consultation as widely as we could.

This included paid for advertising in local newspapers across Greater Manchester, social media (more details below), and communications across our networks with a reach of over 30,000 people without social media.

We also put up posters across Greater Manchester promoting both local engagement opportunities and the consultation more generally.

Social media

Through the engagement period we published 47 posts across our Facebook, Instagram, X, and LinkedIn accounts, including some paid for promotion.

The organic posts were seen a total of 63,117 times, with an engagement rate of 2.06% (above industry average). The paid for posts were seen a total of 121,365 times, with over 5,000 engagements.

In total, our social media activity was seen over 180,000 times.

In terms of engagement, our posts were shared or reposted over 400 times and there were 98 comments on our social media posts, all of which have been fed into the consultation responses to be included in this report.

We promoted the consultation activity in local community Facebook groups, which increased our local, targeted reach – for example, a post about Oldham and Rochdale being our “next stops” was seen in local community groups over 13,000 times. This approach led to people taking the time coming down to speak to us at engagement stalls across Greater Manchester.

Partners from across Greater Manchester, including hospital trusts, Healthwatch, community groups, and local councils used their social media to promote the activity to increase our reach, and we thank them all for this.

Website

During consultation, we had 7,552 visitors to the ADHD consultation page, making 12,963 visits.

The news item on the website was visited 468 times, and a pop-up reminder across the website during the last week was seen nearly 10,000 times.

The translation tool on the website was used to translate the consultation information into Urdu, Polish, Punjabi, French and Arabic.

Media

We paid for advertising in local papers, including:

- Bury – Bury Times
- Bolton – The Bolton News
- Manchester – Manchester Evening News (M.E.N) best circulation day (Friday)

- Oldham – The Oldham Times, Oldham Reporter
- Rochdale – Rochdale Observer, Heywood and Middleton Guardian
- Salford - M.E.N (no local paper)
- Stockport – Stockport Express
- Tameside – Tameside Reporter
- Trafford – Sale and Altrincham Messenger
- Wigan – Wigan and Leigh Journal, Wigan Observer

The collective estimated readership for these papers is 355,282 people.

As well as paid for advertising, we released press releases that led to the consultation being included in the following media pieces across Greater Manchester:

- Manchester Evening News – following the Board approval of the consultation
- Mancunian Matters – following launch
- MSN – following launch
- Wigan Today – following launch

Further to this, there were 2 interviews given, 1 with Global Radio and 1 with That's TV Manchester.

Who we engaged with

We wanted to make sure that we engaged with people from across Greater Manchester, with a particular focus on Bury, Manchester, Oldham and Rochdale where services are particularly challenged. Table 1 sets out how many people we reached in each locality, and how that compares to the Greater Manchester population.

We also targeted some specific demographic communities based on the information from the equality impact analysis. This is set out in Table 2.

Table 1. Reach by locality

Locality	Survey response**	Face-to-face reach	Total	% GM population	% of total response
Bolton	93	79	172	10.3%	6.5%
Bury*	66	68	134	6.8%	5.1%
Manchester*	203	141	344	19.2%	13.0%
Oldham*	37	125	162	8.4%	6.1%
Rochdale*	48	391	439	7.8%	16.6%
Salford	114	51	165	9.4%	6.3%
Stockport	136	265	401	10.3%	15.2%
Tameside	77	168	245	8.1%	9.3%
Trafford	125	100	225	8.2%	8.5%
Wigan	108	152	260	11.5%	9.8%
GM/ Other	17	62	79	-	3.6%
Totals	**1038****	**1602**	**2640****	**100%**	**100%**

*Localities that were targeted

**14 people did not answer this question but are included in the total as they answered other questions.

Table 2. Targeted engagement activities by demographic

Target group	Groups we engaged with:
Women	• Pakistani women, Oldham Centre of Wellbeing and Culture • Westwood & Coldhurst Women's Association event NB women are over-represented in the survey responses
Men	• Achieve Drug and Alcohol recovery service, Anthony Seddon Mental Health Group • Dad's Matters • Targeted paid for social media activity
LGBTQ+ (Lesbian, Gay, Bisexual, Transgender, Questioning, plus) communities	• Engaged with community group staff NB survey response is representative
Deprived communities	Stalls at: • Bolton Wanderers Wellbeing Centre • Emmeaus, Salford • Grand Arcade, Wigan • Harpurhey Shopping Centre, Manchester • Limelight Centre, Trafford • Manchester Royal Infirmary • Millgate Shopping Centre, Bury • Nye Bevan Centre, Heywood • OBA Millenium Cultural Centre, Oldham • Phoenix Centre, Heywood • Pendleton Gateway • Riverside One, Oldham • Rochdale Town Hall • Spinning Gate, Leigh • Talk English event • Tameside General Hospital • Wythenshawe Hospital
People in the criminal justice system	• Engaged with criminal justice system staff
Drug and alcohol users	• Anthony Seddon Centre, Tameside • Drug and Alcohol services (Kaleidoscope) Salford

Target group	Groups we engaged with:
People with learning disabilities	• Breakthrough • Trafford SEND Better Together event • Wigan SEND (Special Educational Needs and Disability) Local Offer Live Event

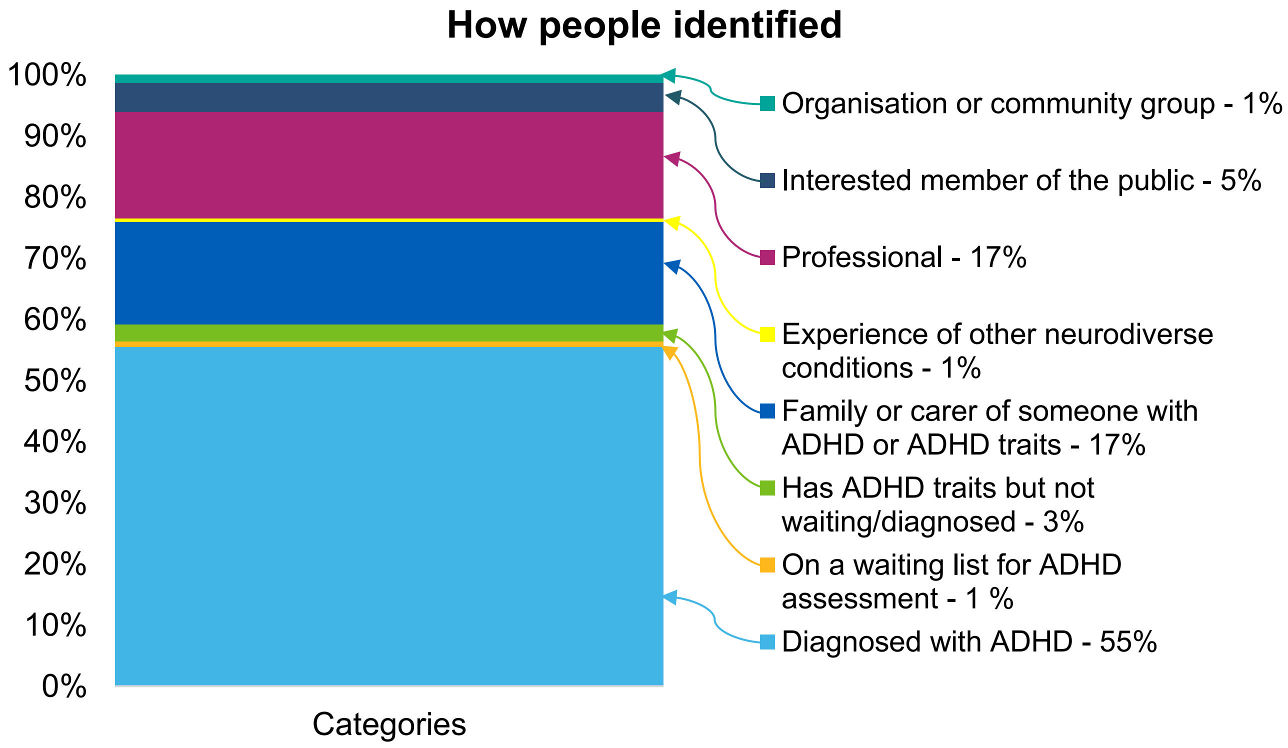
Who answered our survey

Whilst we were unable to collect demographic details in pop-up stalls or community groups, everyone who completed the survey was asked to complete demographic questions but could choose not to do so. Over 800 people chose to answer at least 1 of the questions. An overview of this demographic data is included below, with full details in Appendix 1.

As can be seen in the charts below the survey was mostly completed by people who have experience of ADHD in different ways.

Please note that some people identified as more than one category, for example, both as having ADHD and as being a professional.

Chart 1. The numbers of the different people who completed the online survey



Partnership work

To enable us to reach as many people as possible to have their say, we reached out to lots of organisations and contacts. We provided information in numerous ways including a facilitator pack to deliver own sessions to engage, one to one conversations, presentations and generic emails.

Whilst we don’t know what happened with all these organisations, we know that many of these contacts reached out wider to audiences they related to. Examples of the organisations can be seen on the next page, with a full list in Appendix 2.

Local Councils in all 10 localities

Local infrastructure organisations

Manchester Community Explorers

MHiST Bolton

Centre of Wellbeing, Training and Culture

SEND Better Together

Stockport Patient Engagement Network

NHS GM Fit for the Future Panel

NHS GM Neurodiversity Peer Support and Action Network

Local NHS provider trusts

GP practices across GM

Minikin ADHD group

LGBT Foundation

Breakthrough-UK Manchester

Women’s Empowerment Through ART

Rochdale Community Influencers

Adult ADHD Lived Experience Group

Health and Justice Team

Local Healthwatches

GM VCFSE Leadership Group

BAND Bolton

Neurokinetics club

Westwood Coldhurst Women’s Association

Local Participation and Equality Groups

MIND

Wigan SEND Offer Event

Manchester University

Writing the report

This report has been written by NHS GM's engagement team with the support of artificial intelligence (AI) analysis tools. This has included NHS GM's Go Vocal system which uses AI to support coding and theming of the thousands of responses and to identify trends. It is important to note that whilst AI has been helpful it has not been solely relied on but has been used to support the manual analysis.

Section 3: Political, clinical and organisational responses

We had no responses from MPs, councillors, organisations involved in the delivery of the services as part of the formal consultation, or any organisational responses from any Voluntary, Community, Faith, and Social Enterprise groups.

However, we did have 4 significant responses from 1 from Healthwatch Bury, 2 from clinical leads, and 1 from a community collective in Manchester.

Summaries of these are included below, with the full submissions in Appendix 5.

Healthwatch Bury

Healthwatch Bury raised the following key points:

- There appears to be a gap in care for individuals who age out of child services while waiting for assessment.
- Young adults may face additional barriers if required to restart the referral process in adult services.
- There is a risk that triage may inadvertently gatekeep essential services for those who still need support but may not receive a formal diagnosis.
- The current proposal lacks clarity on how services will be funded and whether budget constraints may limit availability or create unequal access.

They also raised concerns about the lack of holistic consideration for co-morbidities; the lack of clarity on the triage process and criteria which may mean patients don’t understand the decisions and raise concerns about the ability to meet the duty of candour when things go wrong; the alignment with NICE guidelines; the impact on the Right to Choose pathway which is valued by many; the risk of exacerbating existing inequalities; and, the perceived lack of public involvement in the development of the proposals.

They recommend:

- Ensure comprehensive assessment of multiple disabilities
- Embed NICE Guidelines and Duty of Candour
- Establish an independent oversight process
- Strengthen equity and accessibility
- Consult Healthwatch and service users early and often
- Reframe and relaunch the consultation process
- Include Healthwatch in service co-design

Mental health clinical lead and colleagues, Trafford Locality

Summary of Trafford Feedback

Trafford does not support either Option A or Option B in the Adult ADHD consultation. They believe both proposals will restrict access to diagnosis and treatment for many people who could benefit, and that this will have serious consequences for individuals and the wider health system.

Their main concerns are:

1. **Restricting diagnosis and medication**
    - Both options would limit diagnosis to only the most severe cases (around 20–30%), excluding many who meet internationally accepted criteria.
    - People who can partly "mask" or compensate for their symptoms would be denied recognition, treatment, and the chance to prevent their health from getting worse.
    - They argue that a diagnosis is an objective medical process, not something to ration based on perceived need
2. **Separating ADHD from other mental health services**
    - The respondents believe this is short-sighted because ADHD often overlaps with other mental health conditions, and accurate diagnosis needs a whole-person approach.
    - They highlight that the Royal College of Psychiatrists requires all psychiatrists to be competent in neurodevelopmental assessment, so professional barriers should be addressed rather than bypassed.
3. **Widening health inequalities**
    - People who can afford a private diagnosis will still get one; those who cannot will be left waiting and struggling, leading to people going back to primary care for other support.
    - A better approach would be to use existing skilled mental health practitioners to diagnose and treat ADHD where appropriate, avoiding duplicated assessments and freeing resources for those with straightforward ADHD cases outside the mental health system.
4. **Rising demand is not "over-diagnosis"**
    - They reject the idea that more people seeking an ADHD diagnosis is driven by spurious reasons and say it reflects decades of under-recognition—especially in women—and greater public awareness.
5. **Wider impacts of untreated ADHD**

  - Leaving ADHD undiagnosed and untreated has well-evidenced links to poorer health, family breakdown, relationship problems, parenting challenges, more accidents, lower educational and career outcomes, financial struggles, higher rates of criminality, substance misuse, homelessness, and even increased mortality.
  - All of these issues place a heavy economic and social burden on Greater Manchester's systems.

Overall, the practitioners believe that the two options are essentially the same and would make the current situation worse. They call for an integrated, patient-centred approach within mental health services, not a separate and restricted ADHD pathway.

Mental health therapist

Acknowledgement of current challenges

While the pressure on services is acknowledged, the proposed solutions focus too heavily on short-term crisis management, risking the creation of a service that is inaccessible, culturally unwelcoming, and unsustainable. Services should adapt to meet public need rather than restricting access to match limited capacity, and any redesign should aim for long-term excellence rather than quick fixes.

Cultural competency concerns

As a marginalised group, neurodivergent people already face exclusion from services, and a model that openly aims to reduce access will further damage trust. Both proposals conflict with the NHS principle of Parity of Esteem, risk alienating the community, and could deter neurodivergent staff, while also increasing the likelihood of legal challenges over accessibility.

Clinical and logistical concerns

Evidence from other regions shows that limiting access does not effectively manage waiting lists. The current proposals lack a clear evidence base, do not reference ADHD prevalence data, and risk misusing validated diagnostic tools. A "need-based" triage could deny assessments to individuals who meet clinical criteria, raising ethical and legal concerns, and there is no robust plan to support those refused assessment. These weaknesses could harm patient safety, disrupt care pathways, and damage service reputation.

Alternative Service Structure – Key Features

An improved model should allow both GP and self-referrals, using evidence-based tools to assess need and sharing results with patients. Waiting lists should be transparent, with both priority and non-priority pathways, and all patients clinically indicated for ADHD assessment should be offered one. Support should begin immediately after acceptance into the service, including access to high-quality ADHD resources, multi-disciplinary input, and opportunities to trial adaptations. Post-diagnosis, the service should ensure GP recognition of diagnoses, provide clear medication pathways, and offer ongoing support. Strong cultural competence, engagement with the ADHD community, and valuing neurodivergent staff will be essential for long-term sustainability.

Core Message:

Both current proposals risk being culturally insensitive, clinically unsafe, and operationally unsustainable. The practioner calls for an evidence-based, culturally competent, inclusive service that prioritises transparency, ND community trust, and sustainable long-term outcomes offering a detailed alternative structure as a starting point.

Manchester community collective

There were 11 respondents who wrote a letter as a collective. These respondents acknowledge that the proposed changes to the adult ADHD pathway are thoughtful, well researched, and contain many positive elements. They particularly welcome the recognition of long waiting times, the importance of prioritising risk, and the need to design a service that is cost-effective and sustainable. The consultation’s stance against over-medicalisation and unnecessary prescribing is also strongly supported.

However, concerns are raised about the impact of restricting access to diagnosis. Exclusion from diagnosis and treatment risks denying access to NICE-recommended care, even for those unable to work, sustain education, maintain relationships, or function in daily life.

Diagnosis provides more than a route to medication it enables access to reasonable adjustments, support in education and employment, and personal understanding of one’s difficulties. Reducing diagnostic assessments to 20–30% of current referrals risks undermining these benefits, particularly in the absence of wider campaigns to improve access to support without diagnosis. Respondents suggest that an informal “balance of probability” approach could provide individuals with a level of recognition and self-understanding, even where full diagnostic assessment is not available.

Further concerns are raised about the referral criteria, specifically the requirement for individuals to present with “other severe physical or mental health problems” in order to access assessment. Respondents argue that this would create inequities and exclude many people experiencing severe ADHD-related functional impairment who do not meet this threshold.

The letter highlights the lack of clarity on how severity would be measured and stresses that many people with ADHD face barriers accessing mainstream services, creating a paradox where the very condition being assessed prevents individuals from meeting the criteria.

Evidence further shows that ADHD severity does not always correlate with mental health comorbidity, and women in particular may be disadvantaged by criteria that favour hyperactivity-linked presentations.

ADHD is also associated with reduced life expectancy of 6–9 years (O’Nions et al., 2025), a fact not acknowledged in the proposed model.

The signposting pathway itself is another area of concern. Despite being proposed for the majority of referrals, it lacks detail and raises questions about what tools, apps, and interventions would be offered, and whether these are evidence-based, safe, and accessible. The availability and funding of peer support is unclear, and the reliance on primary care talking therapies is problematic, given research showing that generic Cognitive Behavioural Therapy can be unhelpful or harmful for adults with ADHD (William et al., 2024). Respondents stress that without clear, effective interventions, this pathway risks leaving many unsupported.

An alternative is proposed that blends elements of Options A and B. Under this model, people with severe comorbidities would follow Option A, while those with significant functional impairment but without severe health problems would initially be supported through Option B. If self-help and signposting do not reduce impairments, they would then progress to assessment and treatment. This would ensure that those struggling most, even without additional diagnoses, are not excluded from care.

Section 4: Model of care, options and preferred option

Summary

People on the whole were supportive of the model of care, using their lived experiences of the current services to demonstrate where they need to change. Reducing waiting times is the biggest priority. There were however, concerns raised about triage.

Option A was overwhelmingly preferred to Option B, with the majority of people supporting Option A over Option B when asked to specify.

Whilst generally people felt that Option B gave faster access to support, however, there were more barriers to access and it wouldn’t work for people with ADHD and it was more likely to increase health inequalities. This was consistent for all demographics with no major differences for people from different communities or with protected characteristics.

There were pros and cons raised for each model, but whilst most people had positive comments about Option A, such as people getting triaged and access to support faster, most people had negative comments about Option B.

Some liked neither model and a few suggested combining the best of both. However, most people felt that Option A would support the delivery of the model.

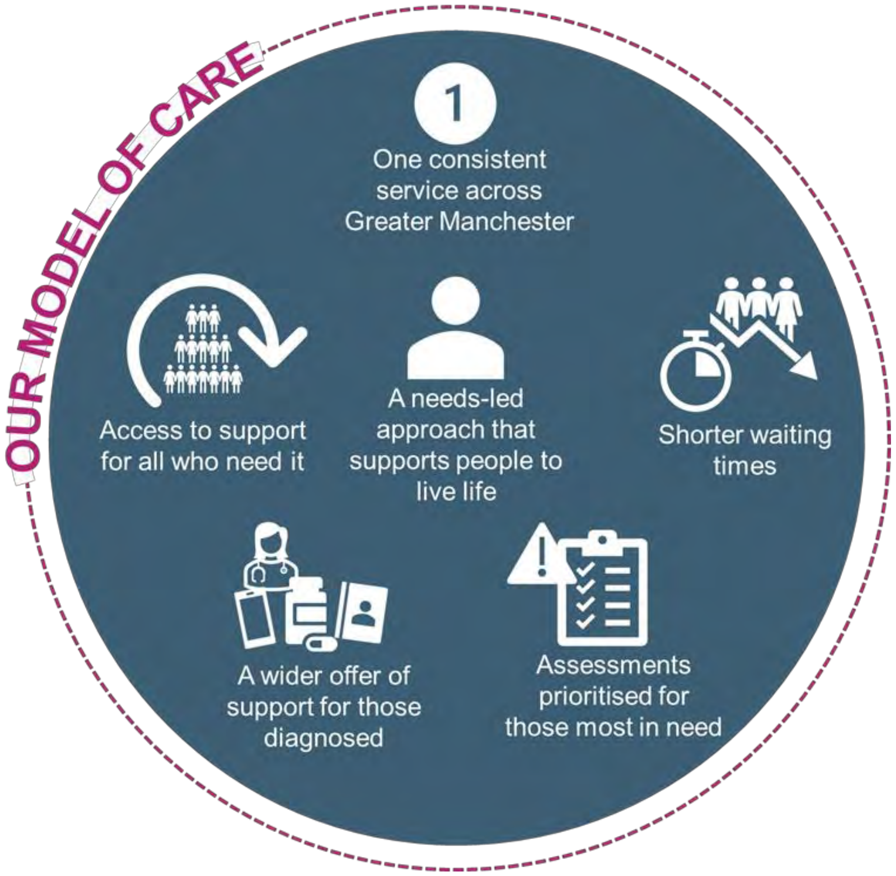
Lots of people reflected that anything is better than the current service, although many also felt that neither option would be successful unless there was more funding and staff provided.

Feedback on the model of care

As part of the consultation, we presented the model of care and asked for ideas and for things we needed to consider, or we hadn’t thought about.

The below image shows the model of care proposed for the new service.

Image 1: Model of care



Whilst people were very supportive of the principles behind the model (see Chart 3), we received lots of comments on it and the need to improve the service.

Chart 2: Heat map of how much people agreed or disagreed with the principles behind the model

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Everyone with symptoms of ADHD should get support quickly	6.42%	6.32%	9.68%	38.53%	39.05%
The people who are having the most difficulties should get help first	5.62%	7.13%	12.2%	29.27%	45.79%
It is more important to help those most in need, than make sure that everyone gets support quickly	7.63%	18.65%	22.68%	28.57%	22.46%

Most of the feedback and comments on the model was based on people's lived experiences of the current services.

People also talked about how hard it is to get any help, depending on where you live, some described it as a "postcode lottery." Others said they had no choice but to go private or use NHS Right to Choose, which often led to problems when trying to get follow-up care such as shared care.

Views on triage were mixed. Some thought it could help prioritise those with most need, but others worried it could leave people out, especially those who seem to be coping on the outside but are still struggling inside.

Some professionals expressed concern about the practicalities of triage, including the need for sufficient staffing, training, and resources. There was concern that triage must be done by skilled, experienced staff to avoid missing or mis-prioritising cases, especially for women or those who mask symptoms.

> *"…I have found that particularly women are going without diagnosis because their symptoms don't actually become apparent until much later in life when some potentially burn out or struggle to continue to mask their symptoms."*

Some professionals noted that triage could be perceived as another barrier or "gatekeeping" step if not implemented carefully.

The biggest problem with the current service people talked about throughout the responses was the long wait to get assessed, diagnosed, and treated; ideas to resolve this challenge included:

- More money
- More staff
- Better resources to speed things up and help more people

> *"GMICB need to fully invest in ADHD services, and they should be held by Pennine Care and GMMH and NOT private services."*

Many people said they feel unsupported whilst they're waiting or even after they get a diagnosis. They want help to be available throughout the journey, wherever it takes them that doesn't stop once they move to the next step of the process. People wanted to be seen, understood, and helped based on their individual needs.

Ideas for what this help might look like included:

- Tips on managing symptoms
- Peer support groups
- Coaching
- Regular check-ins after diagnosis
- Support with things like therapy, learning life skills, and help with work or daily tasks

These suggestions were very similar to the feedback and ideas people gave on what support they would find helpful (section 4 of the report).

A lot of people also said communication from services is really poor. Respondents want to know where they are on the waiting list, what to expect next, and have someone they can talk to.

Many people also highlighted that the current processes aren't ADHD friendly this included:

- Forms are too long
- Reminders are missing
- Services are hard to navigate if you struggle with focus or organisation

People said GPs and other professionals need better training in ADHD, especially in spotting it in adults, women, and people from minority backgrounds. Some said their GPs didn't take them seriously or didn't know how to refer them. They think people should be able to refer themselves, so they don't have to rely on their GP who are often seen as gatekeepers.

Lots of people who paid for a private diagnosis said their GP wouldn't accept it or enter in to shared care agreements. This means they either have to keep paying privately or join a long NHS waiting list. They want clear processes in place that say GPs should accept proper private diagnoses.

Young people moving from children's ADHD services to adult services lose support through the transition altogether. People said the move should be automatic, with better links between children's and adult services, so nobody is lost in the system.

People also want services that look at the whole person—not just medication. This includes help with emotions, work, relationships, and other conditions like autism or mental health problems. They also want their strengths to be recognised, not just their difficulties.

> *"My daughter is currently awaiting an appointment with Adult ADHD Services following internal referral at the age of 18. She is now 20 and still has not been seen. She is struggling significantly with her symptoms and requires a medication review urgently. Her symptoms are now progressing to manifesting as other mental disorders. I feel if this would have been dealt with swiftly then this would not have happened."*

> *"My daughter is 18 she got discharged from CAMHS but needs adult mental health and ADHD support. The waiting list we was told is 2 years to be seen it's not fair when she need support for years from CAMHS to just turn 18 and be told wait 2 years for support. My daughter's mental health in the past 10 months has declined she has poor ADHD management as well as a list of poor mental to be told she's on a waiting list. It would make more sense if a child is at CAMHS when they turn 18 they should automatically go over to adult services and not wait 2 years. Or if there is a 2 year wait put them on the list at 16 so the help can continue at 18."*

Other things people asked for:

- Better public information to help reduce myths and stigma about ADHD.
- A choice of support options including online and physical tools that can be applied to everyday situations, some people did say support tools etc shouldn't just be online.

  "I think an app to help with things like body doubling, task paralysis, emotional numbness and remembering to eat."

  "A lot of people with ADHD have internet addiction, including myself, so I would prefer to stay away from online options."
- Services that are the same across the country, no matter where you live.

From the new model, people generally want:

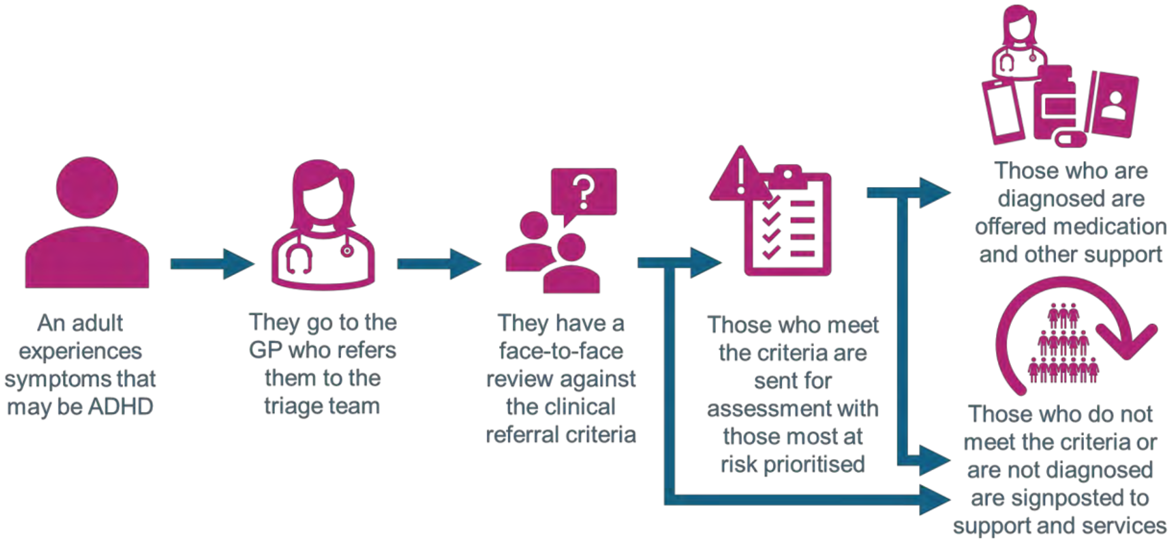
- Faster access to help.
- Use triage to give some support while they wait with more support (pre, during and post diagnosis).
- Better communication.
- Triage done by people who really understand ADHD ideally with lived experience, if not ensure that this is carried out by trained professionals.
- Easier ways to get referred.
- NHS to recognise diagnosis from private providers so they can get help.
- Smoother transitions from children to adult services.
- A fair equitable process that looks at the whole person and doesn't just focus on symptoms.
- Combined ADHD and autism assessments.
- Explore other ideas like having ADHD specialists in GP surgeries or using trainees to help reduce delays.

  "Having neurodiversity champions in GP practices would be helpful to get the message out, but raise the knowledge of neurodiversity with staff..."

Feedback on Option A

OPTION A (our preferred option): Everyone with potential symptoms is referred for a face-to-face triage against referral criteria and then offered an appropriate level of support.

Image 2: Overview of Option A



Within the survey we asked how strongly people felt about the 4 statements made in the table below that are the key principles behind the model of care. An overwhelming level of respondents that agreed or strongly agreed that Option A would support the achievement of the principles.

Chart 4: Heat map of how much people agreed or disagreed that Option A would support the principles behind the model

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Option A will mean that patients get help more quickly	7.28%	10.41%	15.57%	40.2%	26.54%
Option A means that people who need help most will be seen first	7.73%	10.34%	16.14%	38.64%	27.16%
Option A will mean people get more support	6.83%	12.06%	18.54%	36.18%	26.39%
Option A will improve adult ADHD services	8.51%	8.17%	21.91%	30.08%	31.33%

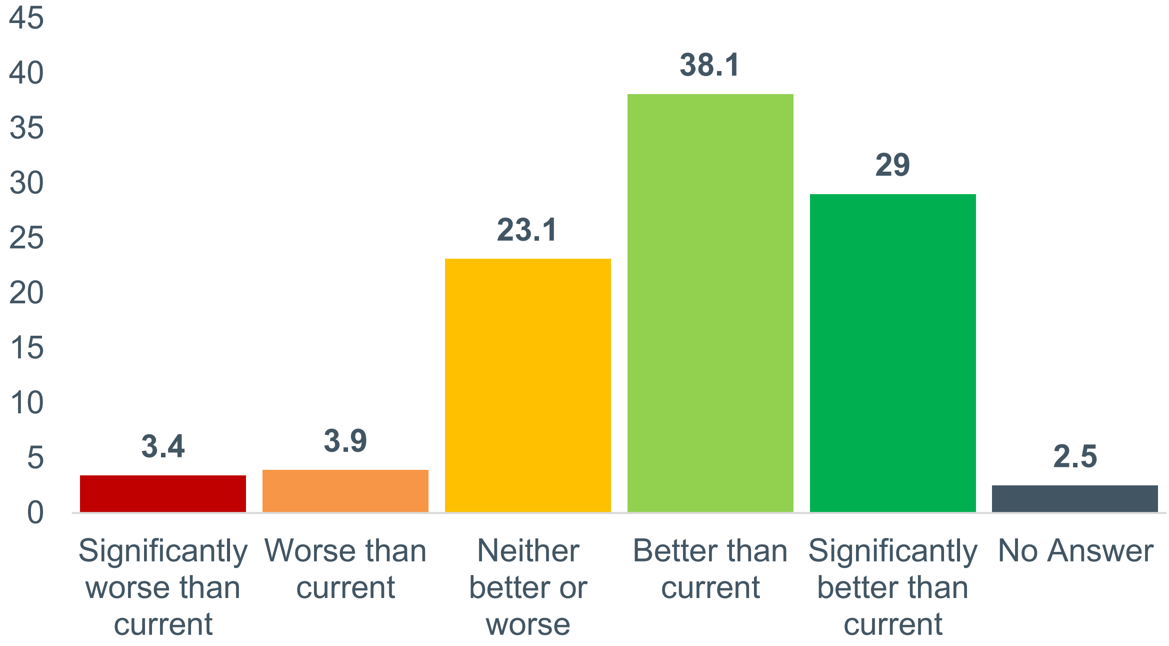
Impact of Option A

When asked how Option A would affect them personally, many people shared feelings about how the current service is “failing”. They said it felt like nothing was happening or no one was helping.

Some used phrases like “anything would be better” to describe their feelings. The lack of communication and support during the long wait was one of the hardest parts for many people.

In the graph below it shows how respondents to the survey scored the perceived impact.

Chart 4: How people felt Option A would impact them (%)



Many people felt that whilst there were multiple positives to Option A there were also negatives.

Across the engagement however, there was more people talking about the positives, which were repeated across all the methodologies, which reflects the scores above. So, whilst there were roughly the same number of pros to cons, the cons were mentioned less frequently.

Below is a table of the most mentioned pros and cons for option A (combining all aspects of our consultation engagement activity).

Table 3: Pros and cons for Option A

☑ Pros for Option A	✕ Cons for Option A
✓ Seen as better than the current service and better than Option B ✓ Offers faster access to assessment and support ✓ Being seen quicker by professionals and offered support seen as a positive step ✓ Could reduce feelings of being ignored or left behind ✓ Focused on individual needs rather than steps or delays ✓ If done properly, has the potential to be fairer and more consistent ✓ Seen as more supportive and responsive overall ✓ Triage could prioritise those with the highest needs ✓ Widely stated as a step in the right direction	× Concerns that triage could become another barrier if not properly staffed or resourced × Current problems (e.g. lack of communication, long waits) may still remain without change × If not backed by enough funding or staff, may not deliver on its promise × Risk of becoming a postcode lottery without consistent delivery everywhere × Some people unsure or unclear about how triage would work in practice × Worries that some groups (e.g. women, people who mask) might still be missed or overlooked

Most people thought Option A was better than the current service and also better than Option B, this was because it seems quicker and more focused on need. Many said it was a step in the right direction, especially compared to a service they described as “broken,” “too slow,” and leaving people feeling lost or ignored.

Professionals who answered the survey were also in support of option A over option B. This was due option A enabling those most in need to be seen first and for potentially reducing waiting times for those with the greatest difficulties.

People felt that being seen faster, having a conversation about their needs with a professional, and getting support early would be a huge improvement. However, many were also worried that new steps in the process, i.e. triage, might end up becoming another barrier, especially if the service isn’t given more staff and funding.

Some were concerned that certain people (women, people from minority backgrounds, or those who “mask” symptoms) might miss out or be disregarded under this proposed option.

Some people didn’t know how to feel and there were many comments where people just wanted things to get better and think Option A may offer that opportunity. People did say this will only work if the service is improved properly, with more resources, fairer processes, and better support at every stage.

"Without more funding and trained staff, none of this will work properly."

Faster Access

Many people said that Option A would help them get into services quicker and start the assessment process sooner. They felt this was urgently needed, given that waiting times are currently far too long. The idea of being seen by a professional quickly was one of the main things people liked.

"Everyone with ADHD symptoms struggles in some way – we should be assessed quickly."

Some felt even small changes would help, as the current system feels like it leaves people in limbo.

A few people were unsure if these changes would actually speed things up or just move the delays to a different part of the services.

Waiting Times

Waiting times were one of the biggest issues raised. People shared stories of waiting 2 to 10 years, with one person mentioning a 7-year wait in Manchester. This left many feeling forgotten and unsupported.

People thought Option A might help reduce waiting times by using triage to spot those who need urgent help and offering different types of support for others.

"A quicker triage system could help people who need urgent help get it faster."

But some worried that without extra staff or funding, the new process could just create more delays or confusion.

"It needs more investment… Without it, the waiting times will still be too long."

Support

Many liked that Option A offers some support while waiting, like signposting to resources. This was seen as a big improvement compared to the current service, which people said often offers nothing at all.

Face-to-face triage was also seen as a plus, as it could be more helpful than being left to deal with online forms or managing alone.

"Face to face is easier than filling in forms – people with ADHD often struggle with forms."

However, people also said support needs to be better tailored. Signposting alone isn't enough people asked for therapy, coaching, peer support, and regular updates while they wait as well as being able to check where they are on the waiting lists.

"Support should match each person, not just a one-size-fits-all."

Prioritisation

People liked that Option A would prioritise based on individual needs, which they said could help them feel heard and not dismissed. Being listened to and validated was seen as extremely important, even if someone doesn't go on to a full diagnosis right away.

But there were also concerns. Some were concerned that only the most "obvious" or "severe" cases would get help, and that people who "mask" symptoms, especially women or those with inattentive ADHD, might miss out, be left or would end up in a revolving door of services.

> *"Many women who don't show hyperactive symptoms will be overlooked."*

People wanted to know how prioritisation decisions would be made, who would make them, and whether they'd be trained to understand different ways ADHD presents.

There was also worry that triage could become a way of managing demand rather than providing meaningful help.

Worries or Concerns

Even though most people saw the potential benefits of Option A, they still had a lot of concerns. A big worry was that without more staff or money, it might not work properly and could even make things worse.

> *"NHS ADHD services need more staff and funding to meet demand."*

Another common concern was fairness. People feared that the triage system could miss people who don't look like the "typical" ADHD case, such as women or those from diverse backgrounds.

They also said GPs often don't understand ADHD and can block referrals, so there was a strong call for self-referral or involving other professionals who may be better informed.

> *"I found it hard to get my GP to take me seriously, self-referral would have helped."*

There were lots of comments about the need for better support while waiting. People not just a referral or medication, but regular updates, practical help, and someone to talk to. People said that being left without anything made them feel worse.

Many people felt that the current system didn't support those who didn't "tick all the boxes" for assessment. They want a more flexible service that understands each person's unique situation.

> *"People have different needs and experiences, so services should be flexible."*

Health inequality impacts of Option A

During our processes we paid particular attention to the perceived inequalities.

People felt that Option A:

- Reduces risk of exclusion for those with:
    - ADHD symptoms like inattention, disorganisation, and overwhelm
    - Co-occurring conditions like anxiety or autism
- Supports equity by ensuring that people don’t have to prove themselves or “earn” access to assessment through steps they may not be able to complete

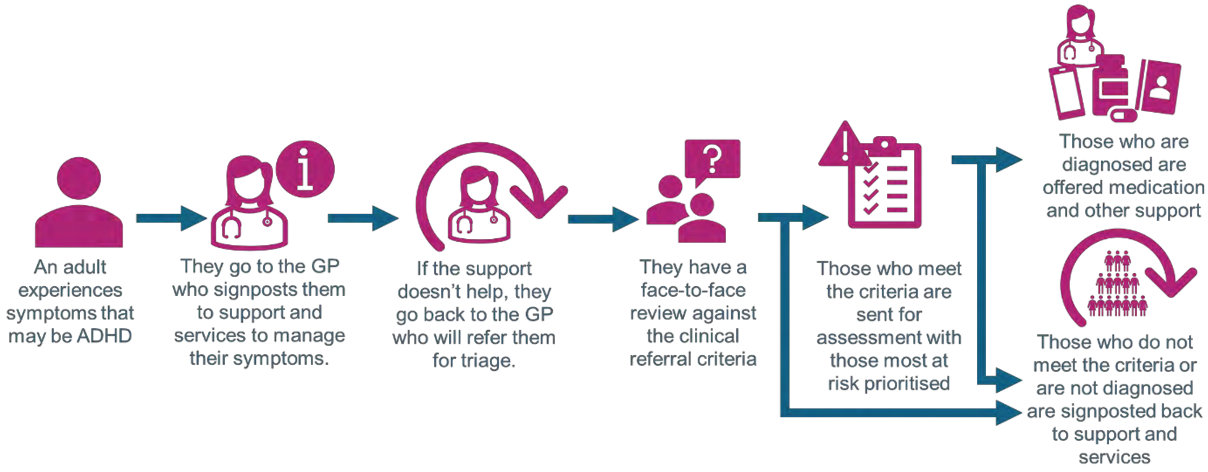
Option A in general was suggested as a better option for:

- Women (who may be missed or misunderstood during triage)
- Neurodivergent people who mask symptoms
- Those who’ve had poor previous experiences with mental health services

Feedback on Option B

OPTION B: Everyone with potential symptoms is first signposted to support tools and services. If these don’t help, they will then be referred for a face-to-face triage against the referral criteria and get offered an appropriate level of support.

Image 3: Overview of Option B



Within the survey we asked how strongly people felt about the 4 statements made in the table below.

It can be seen that the majority of people disagreed or strongly disagreed that Option B would support the principles behind the model.

This was in contrast to how people felt about Option A.

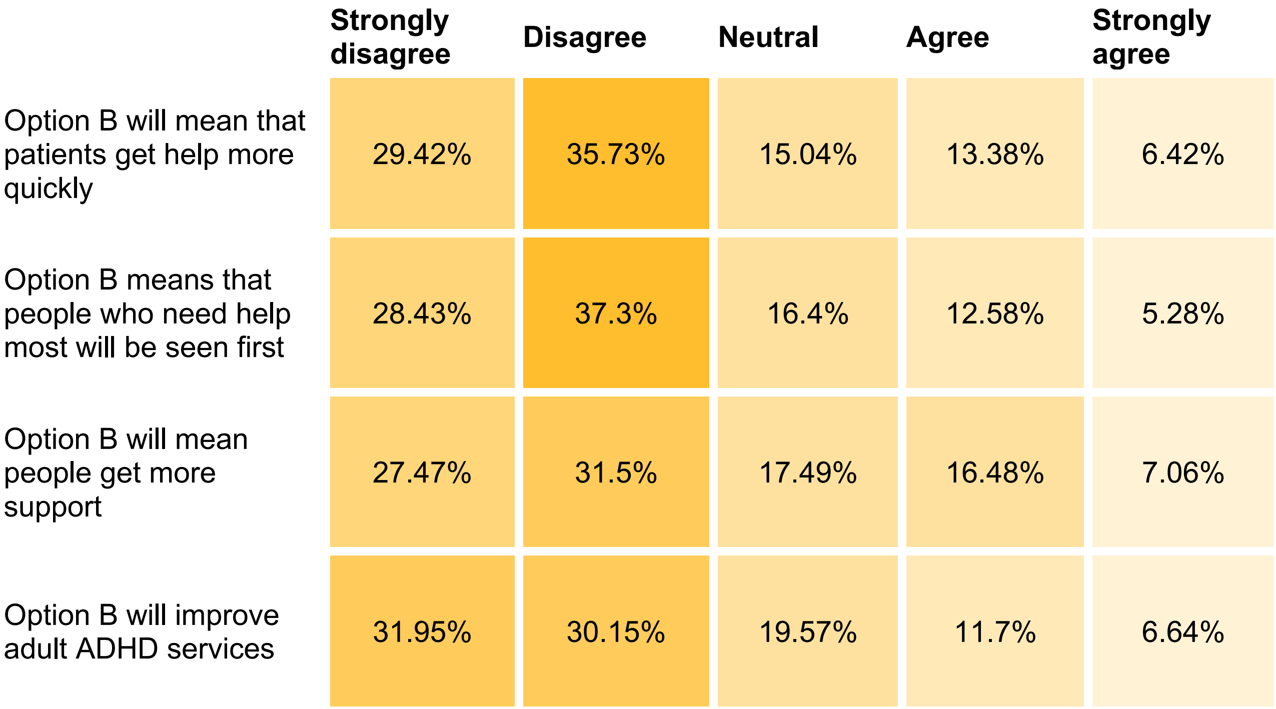
The majority of professionals were also critical of option B. Many suggested that signposting to support or self-help tools would not be effective for people with ADHD, due to executive function and difficulties with organisation and follow through.

Some professionals felt Option B would increase workload for GPs and primary care without improving outcomes.

> *"Option B will result in people falling through the cracks, those most in need may never return for a second appointment".*

However, in one face-to-face engagement event in Stockport, it was noted that the majority of people there felt Option A was better than Option B and would get people help more quickly. This was the only engagement activity that was in favour of option A.

Chart 5: Heat map of how much people agreed or disagreed that Option B would support the principles behind the model

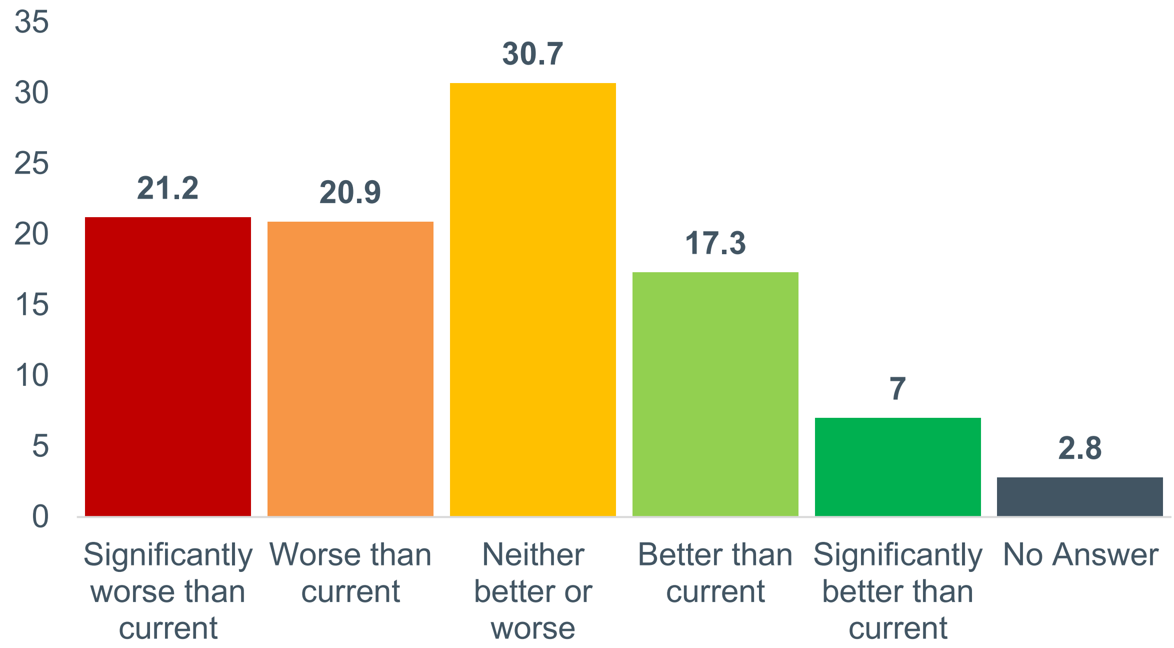


	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Option B will mean that patients get help more quickly	29.42%	35.73%	15.04%	13.38%	6.42%
Option B means that people who need help most will be seen first	28.43%	37.3%	16.4%	12.58%	5.28%
Option B will mean people get more support	27.47%	31.5%	17.49%	16.48%	7.06%
Option B will improve adult ADHD services	31.95%	30.15%	19.57%	11.7%	6.64%

Impact of Option B

How people felt the service described in Option B would affect them is reflected in the chart below. Over 40% of people said it would make things worse, with another 30% saying it wouldn't be better or worse than the current service.

Chart 6: How people felt Option B would impact them (%)



Most people felt that Option B would make things worse, not better. While a small number thought that any support is better than none, the majority said this model would add delays, create more barriers, and leave people behind.

Many said that although “anything is better than nothing”, Option B wouldn’t improve things – and might even make the situation worse. A recurring point was that by the time someone asks for an assessment, they’ve usually already tried self-help, done research, and struggled alone for a long time.

People worried about the practical barriers of the model. They said ADHD already makes it hard to stay organised or follow complex steps and that asking people to try support, then return for another GP visit, risks losing them completely. This model, they said, would lead to more people missing out on diagnosis and care.

There was also concern that delaying diagnosis means delaying everything else: support, medication, therapy, adjustments, and understanding. Some said generic support or CBT won’t work for core ADHD symptoms, and that services are already overstretched or unavailable in many areas.

Other issues people raised included:

- Unclear or inconsistent support depending on where you live or how well your GP understands ADHD
- People who mask their symptoms or struggle to advocate for themselves being missed
- Emotional impact of feeling rejected or dismissed when asking for help

While a small number of people said any support might be better than none, this was mostly in direct comparison to the current service – not because they thought Option B was a good long-term model.

A consistent message throughout the feedback was that although offering support is important, it should not come before or instead of access to an assessment. People explained that the diagnosis is what unlocks real help – such as medication, therapy, reasonable adjustments, or just a better understanding of themselves.

Many said the idea of having to try self-help tools before getting referred felt dismissive and disheartening. People worried they'd feel sent away, and that this would make them less likely to return or ask for help again. Some said they'd already waited months or years just to reach the point of seeking an assessment – often because of stigma, confusion, or being misdiagnosed in the past – so being asked to go away and "try a few tools" felt invalidating.

Others pointed out that core symptoms of ADHD, such as executive dysfunction, forgetfulness, and low motivation, make it harder to follow a process like this. People said that asking someone with ADHD to try support first, then come back for another GP appointment, ignores how ADHD works. They felt this model risks people falling through the cracks.

There was also concern that Option B might work okay for people already coping well but would be much harder for those with more complex needs, mental health issues, or little support. Many felt this would widen inequalities and create an unfair system.

Some did recognise that the idea of support could be helpful in theory – if it was offered alongside an assessment pathway, not instead of one. A few people suggested combining the strengths of both models, such as triaging need, providing support early, and still moving forward with assessment in parallel.

Below is a table of the most mentioned Pros and Cons for option B, this is a combined table from all aspects of our consultation engagement activity.

Many people felt that whilst there were some positives these were far outweighed by negatives. What was clear in the feedback is lots of people felt option B would offer far greater challenge and detriment to people's lives.

Table 4: Pros and cons for Option B

☑ Pros for Option B	☒ Cons for Option B
✓ A small number of people thought any support is better than none ✓ Could help those who are unsure if they have ADHD or have milder symptoms ✓ If support is offered straight away and assessment happens at the same time, some felt it could work ✓ Ideas such as digital triage and combining support with assessment were seen as more promising	× Majority felt it would make things worse, not better × Self-help before referral was widely seen as a barrier, not support × Risk of people falling through the cracks, forgetting steps, or giving up due to ADHD symptoms × Felt invalidating being told to try tools first after already waiting months or years to seek help × Would likely delay diagnosis, which in turn delays all meaningful support like medication or adjustments × Seen as unfair may benefit those who cope well but penalise people with more complex or hidden needs × ADHD symptoms like executive dysfunction make it hard to follow a two-step process × Could worsen inequalities affecting those who can’t self-advocate or mask their symptoms × Adds pressure to GPs, who may not be trained or have time to manage ADHD referrals properly × Emotional impact feeling rejected or dismissed after finally asking for help × Concern that proposed support would be inconsistent or depend on GP knowledge/location × Worry that services are already overwhelmed or unavailable, so support may not actually materialise

Self-Help First

One of the biggest concerns was the idea that people would be required to try self-help tools or services before being referred for an assessment. Many felt this was an unnecessary step that would delay access to real help, with some describing it as a barrier disguised as support.

People said this approach felt like they were being told to go away and sort it out themselves. For many, it was emotionally difficult to finally ask for help, and being told to try self-help first felt invalidating and discouraging. Several said this could stop people from ever going back.

Following Option B

People highlighted how ADHD itself can make this kind of model hard to follow. They described how symptoms like:

- Executive dysfunction
- Forgetfulness
- Low motivation

All of the bullet points above make it difficult to complete multi-step processes, like trying support, booking another GP appointment, and following through.

The idea that someone could manage this without dropping out of the process felt unrealistic, especially for those with more severe symptoms.

Fairness and Equity

People were worried that this approach would work better for people who are already managing okay but exclude those who are struggling the most – including people with co-occurring mental health conditions, low confidence, or no existing support.

Some said this would widen the gap between people who can advocate for themselves and those who can’t.

Pressure on GPs

There were also big concerns about the extra pressure this model places on GPs. People said that GPs already don’t have enough time or training to understand ADHD properly, especially in adults, women, or those whose symptoms don’t look “typical.” This would likely worsen the gatekeeping effect and make it harder for people to get support.

"GPs are not always best placed to triage ADHD. Self-referral or specialist triage would be better".

Emotional Impact

Several people talked about the emotional toll of being turned away or told to try self-help first. Some mentioned rejection sensitivity, which is common in ADHD, and said this model could leave people feeling ashamed, discouraged, or not taken seriously.

Health inequality impacts of Option B

It was perceived by many that Option B was likely to widen inequalities, by:

- Placing the burden on individuals to persist through extra steps
- Filtering people out who are unable to manage complex processes due to ADHD symptoms
- Disadvantaging people already struggling, including:
    - Those without a diagnosis or who don't have advocates
    - People from underserved communities who may face stigma or language barriers
    - Women and non-binary people, who may be more likely to have missed or misdiagnosed symptoms
- Could lead to inequitable outcomes, where only those with fewer needs or better self-management get through to assessment

Feedback on the preferred option

NHS Greater Manchester went to consultation with a preferred option, this was Option A, because people who are at risk of harm will be seen and helped faster in this option than in option B.

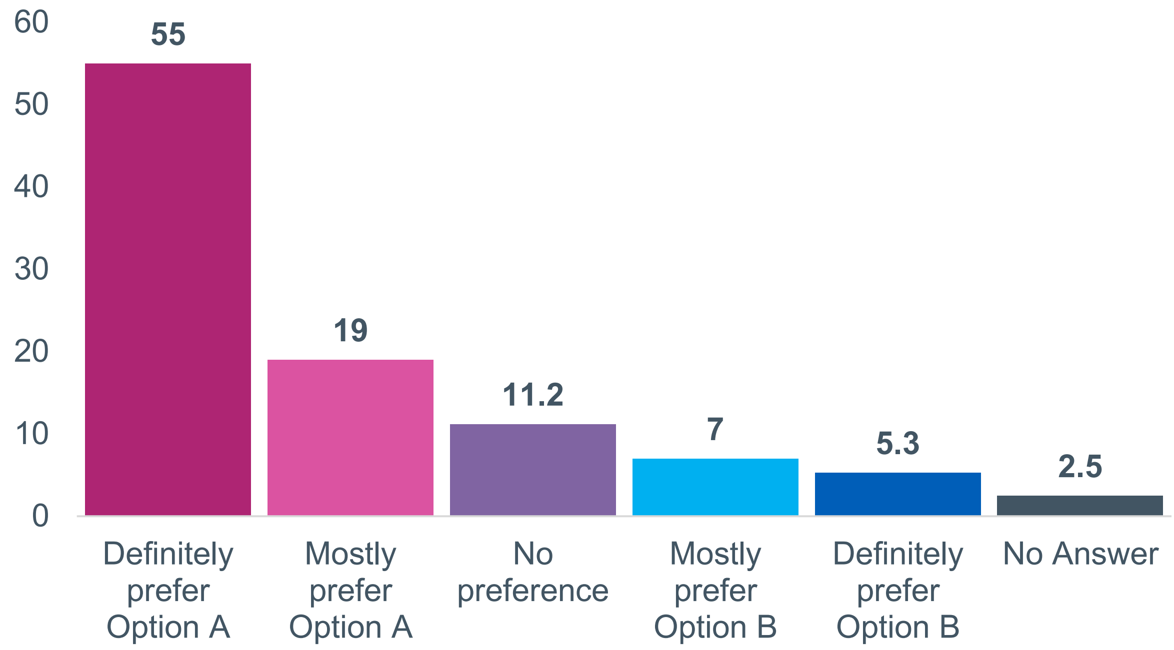
Option A was the most popular because in general it seems fairer and more likely to get help to those who need it the most and quicker.

People said that without major changes to the service especially more staff and better funding neither option would work well.

There was a need for a better, more caring service that supports everyone with ADHD. People want faster access to triage, diagnosis and more practical help along the way. There was a need for support for everyone, regardless of whether they meet the criteria for assessment.

The graph below shows that 55% definitely prefer option A with a combined 74% In support of option A in comparison to option B 12.3% combined. However, many also said that neither option was good enough, and there were serious concerns raised about both.

Chart 7: Which option people preferred (%)



There were many reasons for this, some of which have already been touched upon during the feedback and understanding impact of both the options.

The main reason people liked Option A was because it could help those with the most urgent or serious needs quicker. It was viewed by respondents that this could reduce harm, crisis, and delays for those who are really struggling.

People shared that in Option A, everyone would at least get spoken to or triaged by someone rather than being left to manage on their own.

Many people didn’t like Option B. They said it would add more delays and make it harder for people to get support. Some felt it would lead to people being ignored or “falling through the cracks,” especially since most adults have already tried self-help before reaching out for an assessment. A lot of respondents felt Option B was going to make things worse for people waiting.

The overview of how people felt about them both can be seen when we compare how people felt the options would deliver the principles of the model in chart 8.

Chart 8: Comparative heat map of how much people agreed or disagreed that the options would support the principles behind the model

		Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Patients will get help more quickly	Option A	7.28%	10.41%	15.57%	40.2%	26.54%
	Option B	29.42%	35.73%	15.04%	13.38%	6.42%
People who need help most will be seen first	Option A	7.73%	10.34%	16.14%	38.64%	27.16%
	Option B	28.43%	37.3%	16.4%	12.58%	5.28%
People will get more support	Option A	6.83%	12.06%	18.54%	36.18%	26.39%
	Option B	27.47%	31.5%	17.49%	16.48%	7.06%
Adult ADHD services will be improved	Option A	8.51%	8.17%	21.91%	30.08%	31.33%
	Option B	31.95%	30.15%	19.57%	11.7%	6.64%

There were lots of comments shared that either added to preferred options A or B or that sat outside the options, people opting to choose neither option, within the comments made by respondents’ themes emerged of potential concerns or challenges.

A lot of people felt that neither option would work unless the service has more staff, was better funded, and there were shorter waiting lists. People didn’t believe the system could deliver against the expected triage or support patients quickly.

Some worried that triage could be unfair especially for people who hide their struggles mentioned frequently was the term “masking” this included groups or identities such as women, people from minority backgrounds, or those who don’t show all the symptoms or who aren’t yet in a crisis. Lots of people also asked how need would be quantified fairly as everyone experiences things differently or may not be able to articulate their feelings and symptoms.

Throughout the feedback people said they want a service that supports people before they are in crisis. Many wanted support like peer groups, help at work or school, and emotional validation not just diagnosis and medication.

> *"… I have lost jobs due to my symptoms, and avoiding opportunities as I've lived without a diagnosis. These have set me back significantly.”*

For many respondents there was a theme of diagnosis being important to people and in both options 20-30% was not seen as high enough. People felt this was a gateway opportunity to wider support. It was also reflected throughout the comments that whilst diagnosis led to medication, this was not the sole goal for many who sought reasonable adjustments, support, validation and networks as an outcome.

> *“The label shouldn't be necessary but without it people feel like they cannot justify their experiences to others.”*

Health Inequalities

- Most people, no matter their age, gender or locality, preferred Option A.
- Disabled people and carers were the most strongly against Option B, because they said it would make things harder and leave people behind.
- Non-disabled people were more open to the idea of trying support tools first, but even then, Option A was still the most popular.

People also told us that ADHD services need to be easy to access, not harder.

Many said, direct assessment is the only route that feels fair and realistic. If services build in extra steps or ask people to navigate things on their own first, it could worsen existing inequalities especially for disabled people, carers, and those who are already struggling.

Section 5: Referral criteria

Summary

The majority (60%) of participants agree or mostly agree with referral criteria. However, respondents want to ensure that the criteria do not inadvertently exclude those at risk of not being prioritised due to the type of questions, how they are asked or the knowledge and skills of the triage team.

The most common concern among respondents is that the proposed criteria for adult ADHD assessment are too rigid, risk excluding people in need, and are biased towards hyperactive/impulsive presentations, often missing inattentive types especially in women and girls who tend to mask symptoms or present differently. There is also strong opposition to requiring additional severe mental/physical health problems for referral or prioritisation seen as unfair and likely to exclude many who need help.

Respondents suggest improvements to criteria and assessment tools to ensure that they are more inclusive and to reflect the full spectrum of ADHD presentations, including inattentive type, internalised hyperactivity, emotional dysregulation, and the impact of hormones (perimenopause/menopause) in women.

Several respondents note that requiring symptoms to affect at least two areas of life (work/education/social) may exclude those who are significantly impaired in just one area. Others point out that not everyone is in work or education.

Additional criteria were also felt to be needed to support a more holistic assessment including impact on home life, relationships and finances.

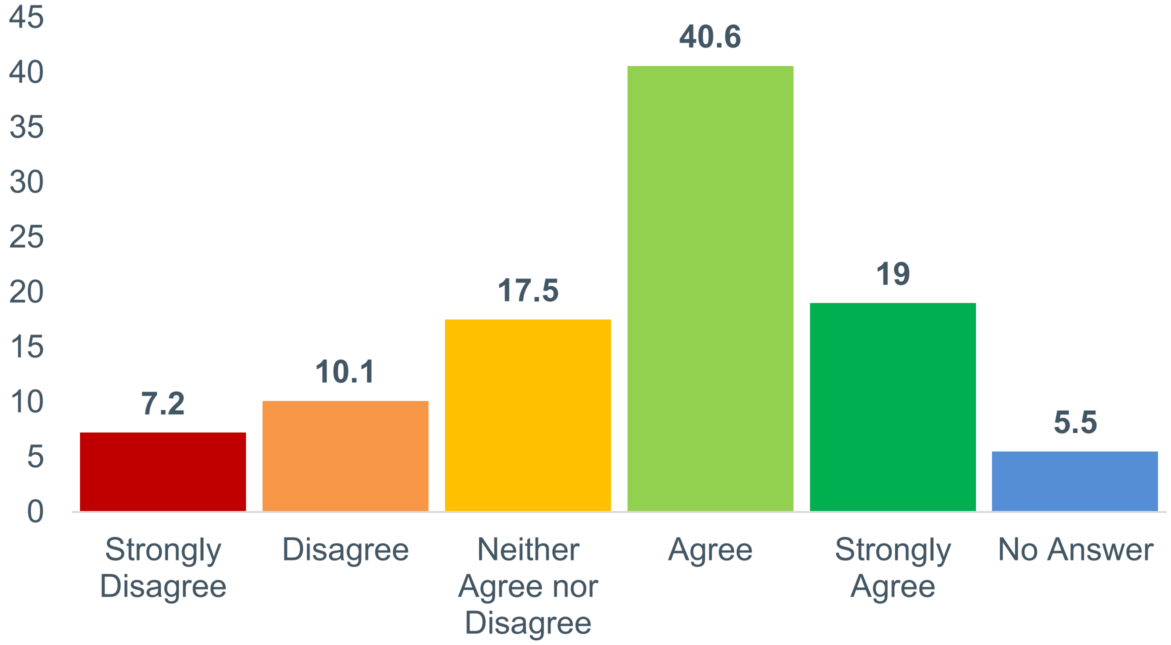
In relation to the assessment, there is strong support for assessors to be highly trained and aware of the full range of ADHD presentations, including inattentive and internalised symptoms and for the process to be flexible enough to account for individual differences and life circumstances.

There is no meaningful difference by geography, age, disability, carer status or gender in how far people agreed with these criteria. However there in is a difference in gender responses. Specific concerns are highlighted in section 5 of this report.

Feedback

The majority (60%) of respondents agree or mostly agree with the referral criteria (below).

Chart 9: How much people agreed or disagreed with the referral criteria (%)

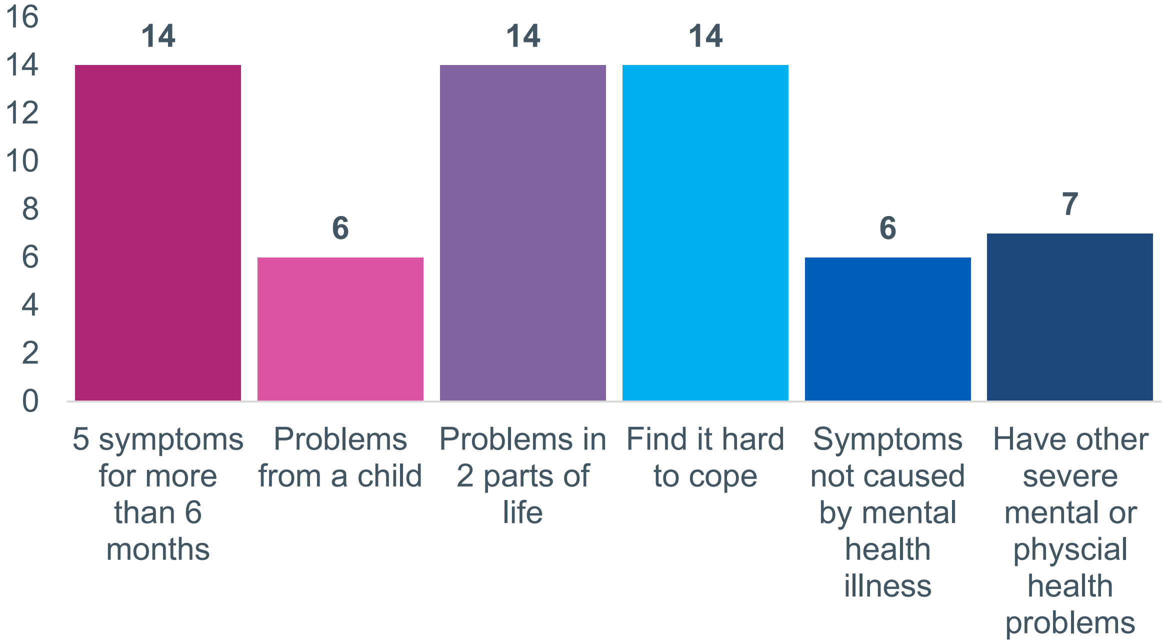


The referral criteria currently used elsewhere in the country we are considering includes:

- There has been at least six months of experiencing symptoms of hyperactivity and impulsiveness that are included in the standard Adult ADHD Self-Reporting Scale (ASRS)
- Some of the symptoms have been experienced since a young age, before the age of 12
- The symptoms are affecting at least two parts of life, for example, in education and work, or work and social situations, or education and social situations
- There is evidence that some of the symptoms are making it hard for them to cope and function in work, education or normal social situations
- The symptoms can't be explained by another health condition
- They have other severe mental or physical problems

We asked people in focus groups which of the individual criteria they were supportive of. There was little consensus across the groups, with lots of variety, showing that this was subjective. However, 3 of the criteria consistently had higher levels of support – at least 5 symptoms for more than 6 months, experiencing problems in 2 different parts of life, and finding it hard to cope.

Chart 10: Which referral criteria people were supportive of



The criteria

Additional severe conditions

The most common concern raised by respondents is the inclusion of the criteria that people must have “other severe mental or physical health problems” to access ADHD assessment or support. Many feel this is unfair, exclusionary, and risks denying help to those whose ADHD is causing significant difficulties but who do not have additional severe conditions.

Many state that this approach is reactive rather than preventative and could worsen outcomes by forcing people to deteriorate before being eligible for help.

Some described this as “discriminatory” or “unlawful”, arguing that it would mean people must reach crisis point or develop additional problems before being eligible for help.

> *“There should not be a need to hit crisis point before we address issues. Not every person with ADHD has severe mental or physical health conditions and there is much evidence that shows early diagnosis and support can prevent these things from happening. Early diagnosis and support can prevent escalation to crisis point. Diagnosis is as much about validation as it is support & medication!”*

Hyperactivity and impulsivity

A second major theme is that the criteria and assessment tools are too focused on hyperactivity and impulsivity, and do not adequately recognise inattentive-type ADHD or internalised symptoms.

Out of the responses that addressed the topic (over 100 individual responses), around 50% specifically raised concerns about hyperactivity being over-emphasised or misunderstood in ADHD assessment criteria. The majority of these highlighted the risk of missing those with inattentive-type ADHD or those who mask symptoms, especially women.

Several people specifically mentioned that inattentive-type ADHD (without prominent hyperactivity) is common and risks being overlooked if criteria focus too much on hyperactivity and impulsiveness.

> *"The criteria above and in the assessment was designed for men or boys with hyperactive ADHD. It does less well for women and girls and even boys who are combined ADHD or inattentive ADHD as they present differently."*

Symptoms before age 12

Many respondents highlight that requiring evidence of symptoms before age 12 is problematic.

Adults may not remember their childhood well, may not have supportive family to corroborate symptoms or records might be lacking. This was highlighted particularly in relation to people who have been in care, people who were migrants, asylum seekers or refugees as children.

Masking and coping strategies can also hide symptoms in childhood.

This criterion was also seen as unfair for women, people with co-occuring conditions and those from neurodiverse families. Some female respondents noted that many women are diagnosed later in life and may not recall or have evidence of childhood symptoms.

> *"Whilst symptoms at a young age can be a key indicator of ADHD, this disadvantages people who may not remember a lot of their childhood and/or do not have someone who knew them to advocate for them."*

Mental health conditions

There is widespread concern that the criterion "symptoms can't be explained by another mental health condition" will lead to misdiagnosis or exclusion from assessment and question the logic of this being ruled out before referral. This is felt to be a risk, especially given the high rates of misdiagnosis such as depression or anxiety and the overlap with other conditions such as trauma or autism and comorbidity.

Many people described personal experiences of being misdiagnosed with depression or anxiety for years before receiving an ADHD diagnosis. Some pointed out that women and high functioning individuals are more likely to be misdiagnosed with a mental health condition leading to a risk of gender inequality.

Professionals identified concerns about diagnostic overshadowing and the risk of misattributing symptoms to other mental health conditions.

Co-occurring conditions

Many respondents stressed that ADHD often co-occurs with other neurodevelopmental or mental health conditions (autism, anxiety, depression), and that assessment should be holistic and trauma-informed to avoid misdiagnosis or exclusion.

Many also felt that there is overshadowing for some individuals who have a previous diagnosis of autism or other neurodiverse conditions meaning that symptoms are ignored or attributed to other diagnosis.

> *"People who have a combined diagnosis of autism and ADHD may be overlooked"*

There was widespread concern and criticism of criteria that require "other severe mental or physical health problems" (as above) for referral or assessment. Many felt this would unfairly exclude people with "just" ADHD from accessing diagnosis and support.

> *"ADHD is often misdiagnosed as other mental health conditions, and that should be considered rather than a referral be ruled out because they have that other diagnosis. It would be discriminatory to rule a referral out because somebody has a severe health problem, be that physical nor mental. That condition could be being impacted by undiagnosed ADHD."*

Additional questions

Many respondents suggested additional questions, especially to capture the full range of ADHD presentations and want suggest criteria around:

- impact on home life
- impact on relationships
- impact on daily functioning
- emotional dysregulation
- rejection sensitivity
- impact on executive function
- substance use, criminal justice involvement
- sleep issues
- family history, and
- cultural/gender differences.

Exclusion of at-risk groups

A significant number of respondents raised concerns about how current or proposed ADHD triage and assessment criteria may disadvantage or exclude certain at risk and asked that consideration and prioritisation needed to happen for these groups as below:

- **Co-occurring conditions:** Respondents stress that ADHD often co-occurs with other conditions and that ruling out ADHD because of another diagnosis is inappropriate and risks missing those most in need (as described above).
- **Women and girls:** masking and coping strategies are frequently mentioned as reasons why people may not appear to meet criteria or may not recognise their own symptoms. Many pointed out that this is a particular issue for women and high-functioning individuals who are more likely to be diagnosed with mental health conditions.
- **Inattentive types**: Many people pointed out that people with inattentive-type ADHD are at risk of being overlooked. This is due to criteria and assessment tools focusing on hyperactivity and impulsiveness, which are more typical in boys/men and more visible presentations.
- **People in the care system:** People said understanding the needs of children who have been in care and asking them to recall this in adulthood, given the level of trauma and challenges can be particularly difficult. Some people in focus groups felt that care experienced adults should be prioritised due to adverse childhood experiences meaning they are more likely to experience health inequalities.
- **Neurodiverse:** Many people raised concerns that people who are neurodiverse often mask their symptoms or develop coping strategies, especially women and those from neurodiverse families, making it harder to identify ADHD. Some stated that neurodiversity is often hereditary and that family context can normalise symptoms, making self-identification difficult.

  Some people in focus groups also cautioned that asking neurodiverse people to answer questions in a linear or binary way is difficult due to executive function. Applying strict and rigid criteria can be a barrier for neurodiverse people.

  Many people spoke about the overlap with other neurodivergent conditions such as autism (ASD), dyslexia, dyspraxia, and sensory processing issues. People said that that referral criteria and processes must be careful not to dismiss ADHD if another neurodivergent condition is present or vice versa.
- **Ethnicity**: Respondents raised concerns that current ADHD assessment criteria and processes may disadvantage people from minority ethnic backgrounds due to cultural differences in symptom presentation, lack of access to childhood history, and reliance on diagnostic models based on white male populations.

There were calls for greater consideration of cultural and ethnic diversity in assessment, as well as intersectionality with gender. Some respondents explicitly recommended that ethnicity and culture should be taken into account to avoid further disadvantaging already underrepresented groups.

“Sometimes you cannot get that family history of childhood - e.g. if they have come as asylum seekers or from another country”

“If you grow up in a house of neurodiverse people, it’s hard to see what’s different about you to tell people about it, you just know that you struggle with life and usually blame yourself, the lens at which you look at your childhood is skewed. Also, if you aren’t a boy who got into trouble and threw chairs, it’s hard to see which is ADHD and which is you being ‘lazy and disorganised and making poor choices’ so this relies on people being very aware of ADHD symptoms and how they can be different for different children and genders.”

The assessment

Skilled assessors

There are repeated calls for assessors to be highly trained in recognising the full range of ADHD presentations, including gender differences and comorbidities and for the process to be trauma informed. For example, the need to recognise that masking and coping strategies can hide impairment and assessment should not rely solely on visible dysfunction in multiple areas.

Many stress the need for flexibility and professional judgement rather than rigid tick-box approaches.

Professionals also shared worries around GP lack of understanding of ADHD and how sometimes they act as barriers. Many called for more investment in staff and services.

"GPs lack specialist training in many areas which causes problems when assigning a level of triage... their assumptions of ADHD could be more prejudice to the ‘naughty little boy’ stereotype”.

There were repeated calls for more nuanced questions and for assessors to probe beyond surface answers.

“The person undertaking screening must be properly trained to recognise the different ways ADHD presents particularly between genders and when predominantly inattentive rather than hyperactive (as in the case of internalised hyperactivity which isn’t always obvious) Just because someone appears to be coping on the outside doesn’t mean they are truly coping.”

The role of GPs

Respondents made a significant number of comments about GPs in relation to ADHD and referrals, especially in relation to gatekeeping access to assessment, misdiagnosis, or overlooking ADHD.

Many respondents reported that GPs often attribute ADHD symptoms to depression, anxiety, or other mental health conditions, leading to misdiagnosis and lack of appropriate support.

Respondents expressed doubts about GPs' ability to recognise and appropriately refer for ADHD, especially for presentations that do not fit the stereotypical (hyperactive) profile and this becoming a barrier to referral.

> *"GPs could refer someone straight away where as mine said I can't have it because I am a girl/not naughty! Had to repeatedly see other GPs and get a form which extended the help I got, again I was offered anti-depressants with agreeance that I am not depressed! GPs need more training and awareness or just refer those that come to them with ADHD related queries, issues etc!"*

Standardised criteria

Some respondents support standardised criteria for fairness and consistency, but many caution that rigid application risks missing people who need help such as those who mask symptoms, have atypical presentations or cannot provide documentary evidence from childhood.

A minority of respondents (but a significant number) caution the standardised approach and the risk of this being abused for those seeking diagnosis for secondary gain such as benefits or exam concessions.

They expressed the need to apply flexibility, professional judgement, and awareness of the limitations and risks.

A few professionals stated strict referral criteria risk excluding women and those who mask symptoms, suggesting a more nuanced approach to criteria.

Clarity on number of questions

There was some confusion over the number of questions being asked, some felt it wasn't clear whether people needed to meet all the criteria, or just some. Many people expressed concern around having to meet all the criteria for assessment and the risk of excluding those who may be unable to answer some (similar to reasons above).

Respondents suggested nuance, flexibility and judgement taking into account those that present differently.

Adult ADHD Self-Report Scale (ARSR)

There was some confusion over why the triage wasn't using the standard Adult ARSR assessment that some people felt was more specific and relevant to people with ADHD. Some people advocated for using this instead.

Equality considerations

Results show there are no significant differences in agreement (or disagreement) with referral criteria for geography, disability, carer status or age. However, women and non-binary people are more likely to disagree with or be critical of the suggested referral criteria due to concerns about exclusion and lack of recognition for their experiences of ADHD.

There were differences in the concerns raised by specific groups as below.

Females: female respondents’ concerns are mostly about the requirement for symptoms before age 12, noting that many women are diagnosed later in life and may not recall or have evidence of childhood symptoms. Females were also more likely to raise issues about inattentive/masked ADHD, childhood criteria, and exclusion of women.

Males: there were fewer comments from male respondents about the criteria being exclusionary or problematic instead, they sometimes mentioned general issues with the criteria being too rigid or not inclusive of all presentations.

Non-binary and genderqueer: comments were similar to those of female respondents with concerns mainly around the criteria being based on male/childhood presentations, not accounting for masking, and being exclusionary for those with less typical or internalised symptoms. Some non-binary respondents also mentioned that the criteria do not account for intersectional experiences (e.g., being non-binary and neurodivergent).

Disability: While people with or without disabilities often select "agree" or "strongly agree", those with a disability are more critical in their comments and more likely to highlight potential problems with exclusion due to masking, gender, or co-occurring conditions. There is a quantifiable difference in both the distribution of scores and especially in the qualitative content of their answers.

Carers: Carers tend to be supportive of clear referral criteria but are particularly concerned about implementation and inclusivity; non-carers' responses are more varied and often focus on personal experience of being missed by rigid criteria.

Section 6: Support

Summary

Overall people agree with the support suggested with offers for mental health, anxiety and sleep getting the most support. Many people said that all the support listed was important. However, people thought that some elements were missing and made additional suggestions such as support with employment, life skills and understanding ADHD as listed below.

People also said that they want to see more holistic, person-centred offers that are knowledgeable and accessible for neurodivergence. For example, some stated that generic mental health or addiction services are often not suitable or effective for people with ADHD or that there is a high threshold to access.

Some are critical of the focus on “secondary” issues (anxiety, depression, substance use) rather than addressing ADHD itself as the root cause. And there is strong support around understanding ADHD and the impact on other areas of life to help manage everyday life such as relationships, work. Some request that this is a positive approach rather than deficit based.

Many caution the need to self-advocate or self-refer to support services, particularly given the difficulties for people with ADHD. Simply providing information or leaflets is often ineffective due to the very nature of ADHD.

A significant number of respondents want to see more skilled and knowledgeable professionals with a better understanding of ADHD who are able to refer and offer support appropriately. Some report being ‘fobbed off’ or not taken seriously by GPs.

Some respondents cautioned the reliance on VCFSE sectors to provide support and concerns around capacity and funding.

Access to support

In terms of accessing support, respondents overwhelmingly emphasised the need for a wide range of options, highlighting that no single approach works for everyone and that support should be tailored to individual needs and preferences. There were strong feelings about peer support groups with some saying they would be beneficial and others saying that they would not be suitable for everyone. The need to ensure people had access to trained professionals was important and sessions that considered individual commitments and ability to travel or access support online.

Some people mentioned the need for support to be available in the workplace and in university settings and to be free of charge or inexpensive and provided by the NHS.

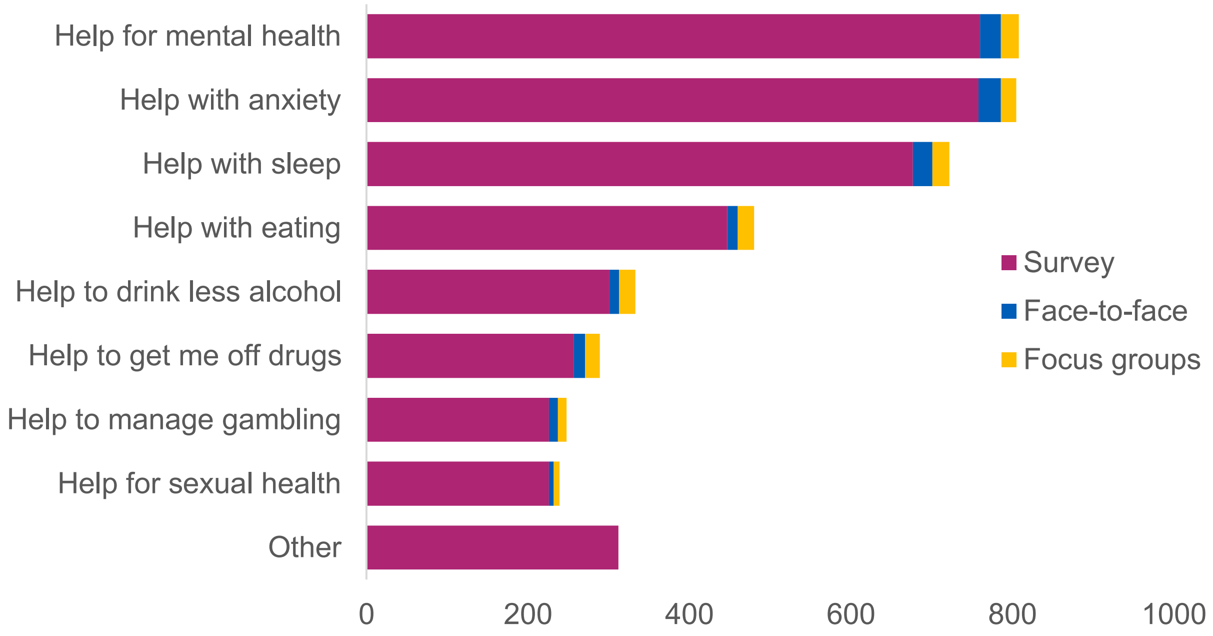
Respondents also want clear and accessible information about what is available and help to understand and navigate the support.

Feedback

What support would you find useful?

There were a significant number of comments about all the things on the list being useful. In the survey, help for mental health and anxiety (78%) were the most popular support choices followed by help with sleep (70%) as in the chart below. These were also the most selected in the face-to-face activities, both in an activity (included in the chart below) and from conversations and mentions (not included in the chart below).

Chart 11: Support people found useful (numbers)



Other support suggestions

Understanding and managing ADHD

Based on the extensive feedback, people identified many ways ADHD symptoms affect day-to-day life and stressed the need for support to understand their condition and how to manage day to day, including understanding executive function and help with things like time blindness, task initiation, forgetfulness and prioritisation.

People report that post-diagnostic support is often lacking and that diagnosis is not enough. Ongoing support to help process their diagnosis and its emotional impacts especially from trained professionals is seen as crucial. This came across very strongly in focus groups and at the pop-up events.

> *"I was then left feeling who am I... More specialised therapeutic services and more Information on the language of feelings. That mental health services relate to."*

“The list above is essentially by products of untreated, unsupported ADHD. Where is the support offer for strategies to support executive function deficits, support with impulsivity, hyperactivity, how this can affect relationships, friendships, work relations. How ADHD symptoms affect homelife, money management, parenting etc. If people understand why they do the things they do, they are more able and equipped to understand self and the impact of self behaviours on others and their work and home life.”

“None of these are going to be useful or stick without the ADHD also being brought under control and would be a waste of resources.”

Employment

There were a significant number of comments about the need for employment support including for those self-employed. Responses suggest ADHD has had a significant effect on people's ability to access, retain, and thrive in employment, and they need real, practical, and individualised support to overcome the structural and cognitive barriers they face at work.

Executive dysfunction (planning, organisation, memory, time management) was repeatedly cited as affecting people's ability to get, keep, and function in jobs.

Difficulties with procrastination, time blindness, impulsivity, focus, and emotional regulation interfere with productivity and performance at work.

Burnout, task paralysis, and rejection sensitive dysphoria (RSD) were also highlighted as common barriers to employment.

These symptoms often lead to inconsistent output, difficulty getting started, and inability to prioritise, which can be misinterpreted as laziness or lack of effort by employers.

Feedback also suggests that there is a belief that employment support is not available without a diagnosis first.

“...needing a diagnosis to get a reasonable adjustment and be protected under the ‘Equality Act’ at work. None of this will help with that.”

“Medical Opinion Carries Weight (Especially for Workplace Support)”

"We need medical opinion and support services to carry legal weight in the workplace."

A doctor’s or psychiatrist’s formal opinion is often necessary for reasonable adjustments at work, but this support is sometimes unavailable or lacks clarity.

There were a significant number of comments about people not feeling supported at work. This came across particularly strongly during the consultation at two hospital sites (MRI and Tameside) where people told us they did not fully understand how to access support at work. They also told us that they did not think their managers or employers fully understood how the needs of neurodiverse people or what support was available. Several told us that they did not think the organisation took neurodiverse seriously and it was not given equal parity to other conditions such as physical disabilities.

This was echoed in all of the focus groups. Many people said that they were not supported in the workplace and had been told that a diagnosis was necessary before any support could be offered. There was a general lack of knowledge about access to work-based support across the consultation.

University

Colleagues and students at Manchester University, and students who took part online or in other forums, echoed much of what was said about employment. There was concern about limiting access to diagnosis and support for students who were struggling with university life and studying, with at least one considering employing a psychologist specifically to support students who have are struggling with symptoms of ADHD – with or without a diagnosis. Mental health support remained the number one priority for this group.

Help with daily living

Many respondents said they need practical, consistent, and personalised support to manage daily living. This includes things like finances and housekeeping, relationships and emotional wellbeing. Some said that this can often be the difference between coping and crisis.

People emphasised that practical, hands-on support is crucial for managing day-to-day life with ADHD. Many described struggling with basic but essential tasks due to executive dysfunction, emotional overwhelm, and lack of routine.

Executive Skills:

- Time management, organisation, and planning
- Starting and completing tasks (task initiation and follow-through)
- Memory and managing appointments or deadlines

These difficulties affect everything from housework to paying bills to form-filling.

Finance:

- Overspending due to impulsivity
- Financial planning
- Forgetting bills or losing track of money
- Long-term financial instability

Household Management:

- Cleaning and tidying the home
- Building routines to manage laundry, meals, groceries
- Avoiding clutter and hoarding

Health, wellbeing and self-care:

- Meal planning and cooking
- Maintaining hygiene
- Exercise routines and physical health
- Sleep issues and managing energy levels

Social and Emotional Support:

- Communication skills and relationship management (including parenting and professional relationships)
- Peer support, coaching, and mentoring
- Support for loneliness, motivation, and self-worth
- Relationship management
- Behaviour and anger management

Navigating Systems:

- Healthcare systems (including diagnosis, medication, and therapy)
- Social care and housing
- Employment rights and adjustments
- Legal and justice systems (for those with criminal records or contact with police)

Accessible and tailored support

People want support to be tailored and person centred, many emphasised that support must be:

- Tailored to individual needs, not "one-size-fits-all"
- Ongoing and consistent, not one-off leaflets or advice
- Delivered by professionals who understand ADHD, not generalists

There is resistance to superficial or passive support. People want engaged, tailored, in-person help, not generic resources that they are expected to navigate on their own. People express concern about having to navigate and self-refer into services given the difficulties with executive function caused by ADHD.

> *"Signposting to help doesn't work if you have ADHD; you need a lot of support and without that as well none of the above may make much difference"*

> *"Don't Just Hand Out Leaflets"*

More knowledgeable and skilled staff

Many respondents emphasised the need for knowledgeable and skilled staff, particularly doctors, psychiatrists, GPs, and other professionals. People want support and advice from professionals who have received appropriate ADHD training. Many expressed a need for mental health providers to be specifically trained in ADHD.

People report frustration by being misunderstood or dismissed by provider who don't grasp the complexity of ADHD.

Many think that professionals should understand the full impact of ADHD and that instead they focus too narrowly on symptoms or medication and don't explain the broader impact ADHD has on emotions, relationships, daily functioning and identify.

People report negative experiences with GPs and feelings of being 'fobbed off' due to a lack of knowledge or recognition of ADHD.

"Just the diagnosis of ADHD and be heard and not ignored from the GP"

"We are just neglected in the system with GPs claiming they don't know enough to help us. You would do better updating your guidelines to stop feeding the narrative of mental health and actually making it more suited to neurodivergency"

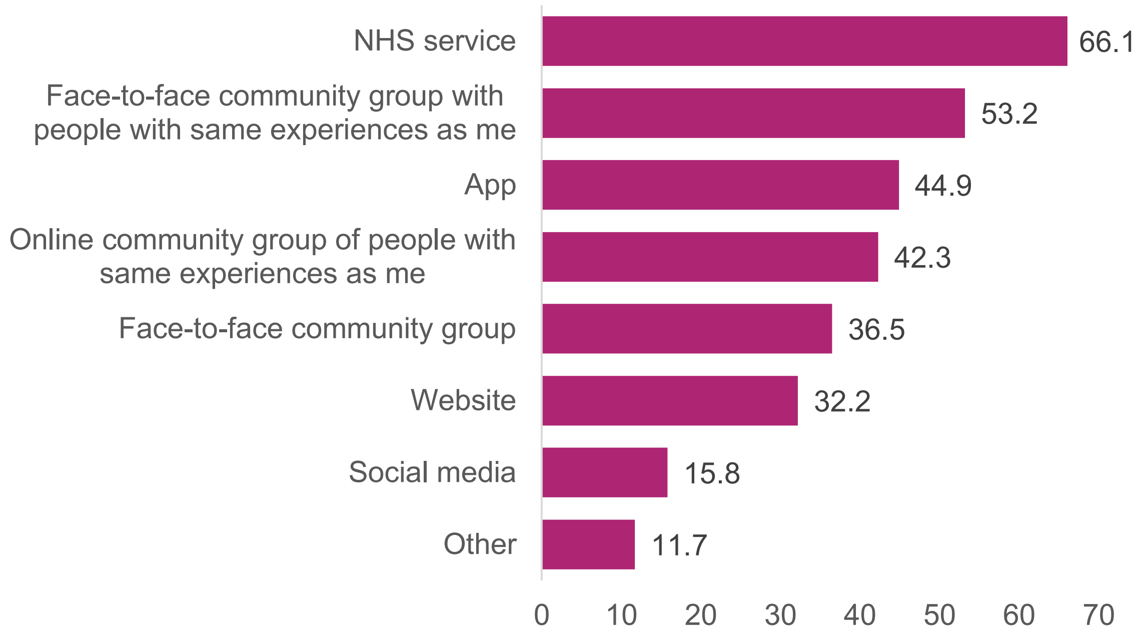
People are asking for joined-up care, ideally coordinated by someone knowledgeable, such as a GP or psychiatrist, who can ensure that all the person's needs are addressed and not fragmented across services.

"Management plan tailored to each person's needs to ensure everything is in one place."

Accessing support

Participants were asked how they would prefer to access support. There were mixed responses with a significant number (66%) saying they wanted support to be via the NHS. The least popular choice was via social media, such as Facebook, Instagram or TikTok.

Chart 12: How people want to access support (%)



Tailored to individual needs

A recurring theme across all engagement was the need to ensure that support was tailored to individual needs taking into account the type of support needed and individual access requirements e.g. some said they would be unable to attend support in work hours and others talked about family commitments or less ability to travel.

> *“…individual tailored services as no ADHD is the same - support groups, social groups, coaching networks, counselling and psychotherapy from ND specialists or ND people”*

Many stressed the importance of offering both one-to-one support, such as coaching, therapy, or mentoring and group options, as group settings are not suitable for everyone, particularly those who are also autistic or socially anxious.

> *“Groups are good but take a lot of time and confidence to attend. Access to support needs to be designed around what works best for the individual and their work/family commitments”*

> *“You need to provide one to one services with a trained professional!!! You assume that people can just drop work and go to a focus group as like most things they will be during working hours, not everyone can travel and I most certainly do not want to have to share my issues with large groups of people I do not know”*

> *“Somewhere you can phone and talk to a proper person in order to access the various support tools. Like how citizens advice will tell you info, but then they actually text you the phone number of the place they told you about AND send an email with outlines the phone call you just had... As soon as I put the phone down I just forget all the important information I was just told so this was so helpful for me!”*

“Though out of hours local community groups as a lot of adults do actually manage to have jobs but mask and it’s the home life that’s an issue - probably thru don’t have daytime availability”

One to one support with professionals

Some wanted direct access to clinical teams and not just signposting or peer support. While many valued peer support groups (both face-to-face and online), several noted that these are not suitable for everyone and can be overwhelming or exclusionary. There was also mention of the value of groups run by professionals with lived experience.

“One to one support. There's a high percentage of Autistic people also have ADHD, groups may not be for”

“One-to-one person-centred professional coaching and mentoring. I have over 28 years’ experience of self-help groups and peer support settings and services. They are limited in terms of the help they provide individuals to manage ADHD and in my case also being autistic.”

“I'll try anything. I've tried every single organiser app, no e of which work because I can't remember to fill the app in, if I could I wouldn't need the organiser... These are the issues. I would like, at some point, to speak to an actual medical professional who believes me and offers a scientific explanation; just talking to other people with ADHD I can do already, as we seem to gravitate towards one another as it is.”

Support tools

People asked for support tools to work alongside the offers including access to free or inexpensive ADHD aids like visual timers, whiteboards, planners and books.

Digital resources (apps, websites, social media) were seen as useful by some but not all, several respondents said they forget to use them or find them distracting.

“Just more information and tools. I would not want to share or be associated with a MH group!!”

“Podcasts, videos, books”

“Resources to learn more about symptoms and tools that would help manage them - delivered online or physical materials which could include both written or video content”

Section 7: Health inequalities

Summary

This section highlights the key findings around potential health inequalities for key groups in relation to the proposed new model. Survey responses have been disaggregated where possible for key demographics to understand any significant variance and qualitative data from all engagement activity has been explored to capture specific feedback in relation to inequalities.

There is strong evidence from these responses that multiple groups are concerned about being excluded or disadvantaged by the proposed changes. The most prominent concerns relate to gender (especially women), co-occurring neurodevelopmental conditions, executive dysfunction, caring responsibilities, financial hardship, ethnicity/language barriers, age, those who mask symptoms, prisoners and ex-prisoners and alcohol and drug users. People believe this is further compounded by intersectionality meaning that some people experience multiple barriers and will be at greater risk of inequalities e.g. women from ethnic minority groups or women with parenting responsibilities and in financial hardship.

Respondents specifically highlight potential inequalities in the proposed diagnostic criteria and service models and believe they are biased towards white, male, hyperactive presentations and do not reflect the experiences or difference in presentation of women, LGBTQ+ or people from minority ethnic backgrounds. Additional issues are highlighted by people with neurodiversity and comorbidities around referral criteria.

People with disabilities, neurodiversity, comorbidities and their carers are more likely to express concerns around option B creating additional barriers to diagnostics, potentially creating inequalities in access.

People want services and support to be offered in a variety of ways taking into account individual needs and appropriate and understanding of diversity including disability, neurodiversity, comorbidities, gender, LGBTQi and ethnicity. They want professionals working in these services to be specifically trained around diversity and intersectionality. They also call for wider awareness and understanding across the system and for the general public.

Respondents believe that the new processes could exacerbate existing inequalities unless these issues are specifically addressed in service design and delivery and advocate for people with lived experience to be involved in the design and evaluation of the new model. This came across particularly strongly from the Lived Experience Advisory Group.

Feedback

Gender

The biggest area of concern around inequalities was around women and girls. Respondents highlighted that women, girls, and people with inattentive-type ADHD are at risk of being overlooked. Concern is mainly due to criteria and assessment tools focusing on hyperactivity and impulsiveness, which are more typical in boys/men and more visible presentations. Feedback also relates to a lack of understanding about the differences in presentation from women and girls and associated misdiagnoses, particularly in relation to depression or anxiety.

> *"…many women who don't fit the standards for hyperactive will be overlooked"*

Masking and coping strategies are frequently mentioned as reasons why people may not appear to meet criteria or may not recognise their own symptoms. Many pointed out that this is a particular issue for women and high-functioning individuals who are more likely to be diagnosed with mental health conditions.

> *"Women mask and have different traits. It doesn't mean they shouldn't be a priority for testing. The system has always been set up for boys/ men it's needs to be made more equal."*

> *"I understand the need for reduction in assessments/diagnosis but unless I misunderstood, the new strategy does feel as though there will be a gender bias alongside reduced access to support for those who internalise and/or mask their symptoms – particularly women."*

> *"As women/high masking has been a repeated theme throughout our LEAG, alongside the public consultation element, I just wonder how this fits and how it will be addressed?"*

People who identify as non-binary or gender queer are more likely to raise concerns about ADHD services and diagnostic criteria often not being inclusive of non-binary experiences. They highlight issues such as male-focused criteria, masking, intersectionality with other neurodivergence, and the risk of being overlooked or dismissed by services. There is a call for more inclusive assessment processes, better staff training on gender diversity, and a wider range of support options that are accessible to non-binary people.

One non-binary respondent explicitly states that option B would negatively impact gender minorities, who are already often dismissed because their experiences do not fit typical ADHD profiles. There is an implicit concern that trans and nonbinary people may be overlooked or deprioritised due to atypical symptom presentation or because of intersectional barriers (e.g. being less likely to advocate for themselves in a system designed around cisgender norms).

“Option B I feel would affect gender minorities significantly, as their experiences often do not align with what is considered typical ADHD and are often dismissed already, and I feel these people with more internal, psychologically distressing experiences of their ADHD would be deprioritised”

In contrast to females or non-binary respondents, men are much less likely to have comments about the criteria being exclusionary or problematic instead, they sometimes mentioned general issues with the criteria being too rigid or not inclusive of all presentations.

There were only a handful of comments about specific barriers faced by men; most comments about men were in the context of comparing their experiences to those of women or discussing the male bias in diagnostic tools and no significant or unique disadvantages for men were identified in these responses.

Co-occurring conditions

Many respondents stressed that ADHD often co-occurs with other neurodevelopmental or mental health conditions such as autism, anxiety or depression and that assessments should be holistic and trauma-informed to avoid misdiagnosis or exclusion.

There was widespread concern and criticism of criteria that require ‘other severe mental or physical health problems’ for referral or assessment. Many felt this would unfairly exclude people with “just” ADHD from accessing diagnosis and support.

During a one-to-one engagement session, a gentleman shared a very personal story about being misdiagnosed with schizophrenia and psychosis for many years and had made several attempts to take his life.

“It took one person to recognise that my mental health diagnosis could have been ADHD and this changed my life completely. I can now be a parent again and have a responsible job that I am thriving in”.

Respondents were concerned about overshadowing and stress that ADHD often co-occurs with other conditions and that ruling out ADHD because of another diagnosis is inappropriate and risks missing those most in need.

Some respondents, particularly in focus groups talked about the difficulty of being referred for ADHD due to other co-occurring conditions they were being supported for, especially Autism with many people saying they believe support is much better for people with Autism.

Caring responsibilities

Parents and carers were more likely to express concerns about option B being a disadvantage to those with ADHD. Carers' responses are more focused on the practical barriers faced by people with ADHD in accessing help, and they are less likely to support options that involve additional steps or signposting before assessment.

Many carers describe negative impacts of long waits on their loved ones and want to see support for carers/families as well as the person with ADHD.

Carers are also more likely to express the need for joined up services and better transition from child to adult services.

Barriers to accessing services were highlighted in focus groups for parents and particularly young, single parents or parents of babies and young children living in difficult circumstances. Some people said that without early recognition, support and help for parents with ADHD there is a much higher risk of children being placed in care or difficulties with bonding and parenting leading to relationship breakdowns.

People said that ADHD is linked to difficulties such as attachment or drug and alcohol dependency and without proper interventions parents will struggle to adequately look after children.

There were many reports of professionals in the wider system e.g. supporting people with drug and alcohol difficulties or parenting not recognising or knowing how to refer someone for ADHD support.

> *"We now have many services involved at a massive cost to the NHS/local authority and if ADHD is a factor, nothing is likely to change for this family until his assessment/medication/strategies are in place."*

> *"A significant number of dads I support are on the waiting list for diagnosis. ADHD symptoms are not always recognised by the dad's or professionals meaning that some are undiagnosed and struggle with parenting often leading to mental health or other problems that impact on their ability to parent."*

Financial hardship

People said that those with less money are more affected by long waiting lists because they cannot just decide to go private while they wait, either for private assessment and medication, or for aids to help mitigate the wait such as counselling, coaching, apps, etc.

Some people had paid for initial private assessments due to desperation but had found themselves in financial hardship, facing monthly bills which they were unable to afford but not being accepted into the NHS system due to shared care issues. Some people told us this was costing hundreds of pounds per month.

The cost of attending appointments (transport, taxis) was also mentioned as a barrier, especially for those with disabilities or who live far from services.

People also highlighted the link between ADHD and unemployment and the high prevalence of unemployed people needing support.

> *“People with lower incomes are already more highly impacted by ADHD as it is, because they usually have less secure/supportive employment, less childcare, less disposable cash to buffer the additional “ADHD tax” you end up paying. And similarly, people with worse ADHD are more likely to be un(der)employed, unable to work full time, less able to manage their finances, like me.”*

Delays in diagnosis were linked to increased financial hardship due to inability to access work-related support (such as Access to Work), reasonable adjustments, or benefits. Some noted that without a formal diagnosis, it is not possible to get reasonable adjustments at work or claim relevant benefits. One participant in a focus group described losing his job as a nurse due to lack of support and recognition.

Disability

A significant number of respondents were concerned about option B presenting a barrier for people with disabilities, particularly for people with ADHD due to executive function and organisation and being able to follow through. They felt that Option B would result in people ‘falling through cracks’, being left without a diagnosis or meaningful support.

People with disabilities were also more likely to express concerns about the referral criteria due to co-occurring conditions and the potential of being overlooked.

Barriers to accessing services and support for some people with disabilities was also mentioned and people called for services to offer a range of ways for people to access and receive support.

Ethnicity

Respondents expressed significant concern that adult ADHD services do not adequately account for cultural and ethnic diversity from minority ethnic backgrounds.

Several respondents highlighted that ADHD is often underdiagnosed or misdiagnosed in certain ethnic groups, particularly women and people from Black, Asian, or minority ethnic backgrounds. This is attributed to cultural differences in symptom presentation, masking, and lack of awareness among both patients and professionals.

For example, some respondents from minority backgrounds (e.g. Black British, Asian British, Pakistani, Jewish, African, Latin American, Romany) expressed concern that their cultural background or ethnicity may affect how their symptoms are perceived or whether they are taken seriously by professionals. This was also echoed in focus groups and one participant shared a personal story about her son who went undiagnosed into adulthood but had been expelled from school due to bad behaviour.

There was concern that current diagnostic criteria and assessment tools are based on white, male, hyperactive presentations of ADHD and do not account for cultural or gender differences in symptom expression. Respondents noted that inattentive-type

ADHD (more common in women and some ethnic groups) is often missed because it does not fit the stereotypical profile.

> *“Cultural perspectives need to be addressed."*

> *“Women typically present differently from men, and not everyone exhibits hyperactivity. Additionally, cultural factors may lead to different presentations of symptoms among different ethnic groups.”*

Language barriers, lack of culturally appropriate information/resources, and stigma within some communities were cited as obstacles to accessing ADHD assessment and support. People want to see, better training for professionals on diversity in ADHD presentation, and more inclusive resources. They also wanted to see more information and resources in multiple languages. They believe this will support better access to services including diagnostics and support and an improved service user experience.

> *"Materials need to be in a huge amount of languages if materials are written. If they aren't, lots of communities won't be able to benefit”*

Some respondents in the survey highlighted that cultural expectations (e.g. masking in women, different family structures) can make it harder for people from certain backgrounds to be recognised as having ADHD. This was echoed in the focus group held with an ESOL class in Rochdale attended by Pakistani women.

LGB

People who identified as gay, lesbian, bi-sexual or queer in these responses mainly discussed ADHD service issues that affect all users. A small number mentioned wanting LGBT+ inclusive support groups or noted that generic services may not always meet their needs as gay men/women. There were no reports of discrimination or negative experiences specifically due to being gay or lesbian in relation to ADHD services. Some respondents highlighted intersectionality and the importance of inclusive, person-centred care.

Drug and Alcohol users

People told us that there is a strong link between ADHD and alcohol or drug use, often due to stimulants being used to help manage symptoms. This includes people undiagnosed. For example, a small number of university students when they spoke to us commented that they use alcohol and drugs to help them to cope and reduce symptoms.

Drug and alcohol misuse were frequently identified as important areas where support is needed for people with ADHD. Many groups, when asked to prioritise support needs, included drugs and alcohol alongside mental health, anxiety, sleep, and gambling. For example, in Oldham, drugs and sleep were the top priorities for support among Pakistani women; in Bury, alcohol misuse and drug misuse were both selected as support needs during engagement with a mental health support group; and, in Trafford, drug misuse was among the most useful supports identified.

People using the drug and alcohol support services at Achieve in Salford told us that impulsive behaviours meant it was more likely that they would use stimulants and that support in relation to this is crucial. However, they reported barriers to accessing support due to being told they needed to decrease use before being referred.

"I self medicate with alcohol and I know it's not good but it's the only time my brain relaxes."

The need to ensure professionals understood the link between drug and alcohol use and ADHD came across strongly. There were some reports of professionals not taking into ADHD into account when supporting people with drug use making it difficult for individuals to manage their addiction.

"When I enquired with drug worker about ADHD and advised that his substance misuse was unlikely to be managed well without ADHD being considered – it was clear that they were not factoring this into his care planning which surprised me given what we know about ADHD and addiction."

Age

Some respondents said that both options risk missing people who have "managed" for years (often older adults) but are now struggling, as well as those who do not fit the stereotypical profile of ADHD (often younger women or high-functioning individuals).

There was a sense that the current and proposed systems do not adequately account for the lifelong impact of undiagnosed ADHD, particularly for those diagnosed later in life.

One respondent explicitly listed "older people" as a group likely to be negatively impacted by the proposed changes.

"Because I'm older I can now cope much better in certain situations, having taught myself some practical things, so maybe don't meet the strict criteria. There are still massive gaps in my life that I can't get help with, and my symptoms are inconsistent."

A strong and recurring them was around transition from children to adult services. There were many reports throughout the consultation and particularly in one-to-one conversations in the community, around the gap between children and adults and some reported having been on the children's waiting list for a number of years, only to pass the age threshold and to then be placed at the bottom of the waiting list for adult services.

Specific issues were highlighted for university students who require support and reasonable adjustments whilst studying. This included accessing support at convenient times due to their schedules.

“University students (due to being away sometimes) may struggle with accessing support at convenient time. This is why we feel like the best avenue for students accessing ADHD support and diagnosis is through the GM Mental Health Student Hub.”

Offenders and ex-offenders

People raised significant concerns about prisoners with ADHD, particularly regarding, prisoners struggling to get access to medication after release due to the issues with shared care. People working in the criminal justice system said that this was a huge problem, particularly given the disproportionality of offenders with ADHD and gave lots of examples of people waiting years to be re-prescribed ADHD making reoffending much more likely.

“…prisoners are diagnosed with ADHD by the prison psychiatrist but when they are released they cannot access NHS services due to lack of shared care agreements and have to be placed back on a waiting list so their symptoms aren’t managed and they are more likely to reoffend.”

“There is the possibility of being fast tracked for diagnosis if individuals complain to the GP and MP. However, this is a barrier for ex offenders who are much more likely to have other priorities such as getting benefits sorted and a fixed abode. Literacy levels are also low in this population making it difficult to write complaint letters to GPs, etc.”

They said that these prisoners were much more likely to reoffend potentially to get quicker access to ADHD drugs. Other issues cited included:

- difficulties accessing ongoing medication and support after release from prison
- the risk of reoffending linked to lack of access to ADHD treatment
- barriers to assessment for those with substance misuse issues
- the need for better training for criminal justice staff
- the high prevalence of ADHD among prisoners and the potential societal benefits of better diagnosis and support

These points were raised repeatedly across both professional and lived experience groups, highlighting this as a key area of concern within the consultation. Of specific concern was the high prevalence of ADHD among prisoners and the potential societal benefits of better diagnosis and support.

There is the possibility of being fast tracked for diagnosis if individuals complain to the GP and MP. However, this is a barrier for ex-offenders who are much more likely to have other priorities such as getting benefits sorted and a fixed abode. Literacy levels are also low in this population making it difficult to write complaint letters to GPs, etc.

Section 8: Alternative proposals

A small number of alternative proposals were submitted through the consultation for consideration. Some of these were quite detailed, whilst others were more general.

These proposals will all need to be considered and assessed by the commissioners.

Alternative proposal 1: more money and staff

The most suggested alternative was to put more funding into the existing service, employ more skilled staff, so that the services are able to meet the increasing demand.

Alternative proposal 2: combine options

A number of people suggested combining the strengths of both options.

This included following the pathway for Option A, including triaging need and moving forward with assessment, but including the early support offer from Option B in parallel.

One specific blended approach came from a collective of people in Manchester who suggested that people with severe comorbidities would follow Option A, while those with significant functional impairment but without severe health problems would initially be supported through Option B. If self-help and signposting do not reduce impairments, they would then progress to assessment and treatment. This would ensure that those struggling most, even without additional diagnoses, are not excluded from care.

Alternative proposal 3: redesigned triage and pathway with oversight panel

Healthwatch Bury also submitted a list of recommendations that could be seen to amount to an alternative proposal. This included:

- Designing triage tools and pathways that account for co-morbidities and explicitly meet the NICE guidelines
- Provide clear, written outcomes of decisions to patients
- Establish an independent oversight panel for appeals, or a clinical oversight panel to review borderline or complex triage cases
- Make sure the pathway is accessible with multiple pathways in, inclusive and easy read formats, and a multi-disciplinary oversight board

Further information on the Healthwatch Bury proposals can be found in Appendix 4.

Alternative proposal 4: stepped approach to triage

One respondent who works within Primary Care and supports GP practices and public services with the ADHD referral process, as well as being diagnosed in adulthood, felt that the process could be further simplified.

The respondent suggests following a model for referral similar to the one used for Talking Therapies:

- Patient completes ASRS questionnaire and self-refer into triage.
- People who meet the criteria are triaged.
- People who need support completing ASRS are supported by social prescribers or Mental health wellbeing practitioners

Once referred, they recommend:

- A stepped approach to triage with people receiving coping strategies for support whilst waiting, e.g. emotional regulation, task management, organisational skills.

Alternative Proposal 5: holistic affirming service

A respondent with lived experience who attended the Bury focus group and is an accredited CBT therapist provided a comprehensive response (appendix 5) and suggested an alternative model.

In summary, the model shifts ADHD services from a narrow diagnostic focus toward a holistic, accessible, neurodiversity-affirming system. It emphasises early supportive interventions, transparent communication, multi-disciplinary integration, fair waiting list management, and long-term systemic benefits, aiming to reduce harm from delays while building trust with the Neurodivergent community. Key principles of this model include:

- **Early, evidence-based triage**: All referrals (via GP or self-referral) undergo structured triage using validated tools (e.g., ASRS), including checks for co-occurring conditions and quality of life.

- **Transparency**: Patients are clearly informed whether they are likely to meet ADHD diagnostic criteria and guided to either assessment or alternative support.

- **Holistic support before diagnosis**: Services should provide wellbeing plans, crisis support, and access to ADHD-specific resources *before* formal diagnosis, reducing harm from long waiting times.

The full proposal and commentary can be found in appendix 5 (mental health professional).

Section 9: Wider feedback

In the process of engaging and getting feedback on the service and the proposals, we have heard lots of wider comments of importance or for consideration, but that don't naturally have a home within this report. It is important that they are acknowledged.

The feedback will be sent to the relevant team within the organisation for review and held on file should it be relevant to future reviews.

Children and young people

Within the feedback there were experiences of children and young people ADHD services and the need to improve them. We have recently held engagement on these services and much of the feedback was similar to what had previously been heard. The report for this engagement can be found on our website.

There were also concerns raised about the transition between children and young people and adult services. This feedback is relevant to the consultation and is picked up within this report.

National change

There was a call from some for changes to be made at a national level. There is a national taskforce working on this and considering what can be achieved nationally. The work in Greater Manchester aligns with the national taskforce and we continue to be active contributors.

Find out more about the taskforce on the NHS England website.

Employment

Some of the respondents referenced the need for more support in employment – both getting it and keeping it. This is outside the reach of the NHS, but it will be considered whether there is any information or advice that can be offered to employers to help them understand and support employees who experience symptoms of ADHD.

Process and consultation

A number of points were raised by a small number of people about the process of arriving at the options and the delivery of the consultation. These included:

- **The need for people with lived experience and Healthwatches to be involved in the process of reviewing the options and preparing for the consultation**

To reduce any concerns about this, we can confirm that before developing firm options, we engaged with people across Greater Manchester about the current services and what can be done to improve them. The engagement report can be found on our website.

After the engagement, we recruited to a lived experience advisory group which had over 50 members who were involved to varying degrees. Members of this group were involved in developing criteria and reviewing the options. They also helped us to design and develop the materials for the consultation, including offering feedback on the survey.

A member of Healthwatch was involved in the lived experience advisory group.

- **The consultation was not accessible as the survey was too long for people with ADHD**

  The survey was not the main component of the consultation. We spoke to more people outside of the survey than through it, with focus groups (online and face-to-face), visits to community groups, phone calls, WhatsApps/texts, community pop-up stalls, and social media engagement all offered and encouraged.

  We worked with the lived experience advisory to make the consultation and survey as accessible as possible, but we recognise that it was long to make sure that we captured as much feedback on the different elements we were consulting on as possible.

  We therefore offered everyone who entered the survey the option to get help to complete the survey, request a phonecall or email, send us a file (including voicenotes) instead, or come to a focus group.

  We also offered the survey and supporting information in easy read – a simpler version.

  Further to this, all the information in the consultation was provided in large print and easy read. The web information, including the survey, could be completed in the top 10 most common languages. We offered other translations on request and posted out information to people who wanted hard copies.

  However, whilst we did try to make sure that the consultation was accessible, we are very sorry if anyone felt excluded and therefore was unable to take part.

- **The terminology in the consultation was deficit-based, rather than positive, and ADHD is a neurodevelopmental condition, not a mental-health one.**

  We are sorry if you felt that we were negative about ADHD in anyway. That was never our intention. We agree that ADHD is not a mental health condition and it is important that it is appropriately framed.

Information about ADHD for people, family and employers

There needs to be more information or a marketing campaign explaining about ADHD to help people who don’t have it better understand.

Thank you for the suggestion for this. It is something we will consider and will take forward if we can.

Section 10: Key points to consider and next steps

Key points for commissioners to consider

From the engagement, there are a number of key points that have emerged for the commissioners to consider.

Overall:

- The service needs to be designed to be ADHD by involving people with ADHD in the process.
- Waiting times are the biggest priority problem for people with experience of the service.

Model:

- When reviewing the model, consider the needs of diverse and at-risk groups to ensure inequalities are not widened.
- Not everyone wants or needs to access services in the same way, and consideration needs to be given to a range of ways to access them.
- Consider how we ensure that professionals such as GPs, triage teams and those working with people with potential ADHD, particularly those who are also vulnerable, are supported and trained to have the skills, knowledge and expertise to recognise, support and refer individuals for appropriate help.

Preferred option:

- Option A is the preferred option, but there are still some concerns raised about it that need to be reviewed and considered carefully.
- Carefully review all the alternative proposals put forward against the evidence to see whether they would be appropriate for implementation and preferred against the options consulted on.

Referral criteria:

- Consider the feedback on the referral criteria and review whether it needs updating in light of the feedback given on both the process and the individual criteria, particularly with regards to the health inequalities and the needs of identified ‘at risk’ groups.

Support:

- When reviewing the support package, consider the suggestions and feedback on support across the whole pathway – including both when the support is accessed, how it is accessed, how long it is available, and what is offered.

- People felt very strongly about support being tailored to individual needs and not ‘one size fits all’; allow for flexible, needs based and culturally sensitive support.
- When designing support options consider how you can work with the VCFSE sector to understand capacity and whether further funding would be required.

Wider points:

- Consider how to incorporate the feedback into the Equality Impact Assessment and including any mitigations that need to be implemented.
- Stigma and misinformation impact negatively on people with ADHD and we should consider how the NHS could help with this.

Next steps

This report will be shared with the people responsible for commissioning and delivering services. We will also update the equality impact assessment (EIA) using the feedback and the things we have learnt.

Commissioners will give the feedback and updated EIA careful consideration. They will use the information to check their proposals and help them come to a final recommendation for what the future model of Adult ADHD services should look like.

The recommendation will go through our governance process with this report and the equality impact assessment, along with any other relevant evidence. The NHS Greater Manchester Board will take a final decision.

The report will be published on our website and shared with those directly involved through focus groups etc, along with regular updates on what has changed as a result of the engagement.

If you would like to be kept up-to-date, or get involved in the next steps, please contact us:

Email: gmhscp.engagement@nhs.net

Ring, text or WhatsApp: 07786 673762

Section 11: Glossary and Accessibility

Glossary

ADHD

Attention Deficit Hyperactivity Disorder (ADHD) is a condition that affects people's behaviour. People with ADHD can seem restless, may have trouble concentrating and may act on impulse.

ASRS Assessment

The adult ADHD Self-Report Scale assessment is a commonly used assessment tool used to diagnose people with ADHD. It is a list of questions based on the diagnostic criteria for ADHD.

Assessment

An assessment is a way of understanding or judging something. In this case it would assessing whether someone has ADHD and the impact on their life.

Case Study

A case study is an in -depth, detailed account of someone's experiences. this would include their experiences, both the good and the bad, and how people might feel things could have been improved.

Clinicians

Doctors, nurses, consultants, or any other health care worker who treats patients directly.

Commissioner

Someone who works for NHS Greater Manchester reviewing services to help improve them, improve patient care and outcomes, and make the services more efficient.

Consultation

A public consultation offers patients, people and communities a formal opportunity to comment and influence plans to change services in the NHS. This consultation was about Adult ADHD Services.

Co-occurring condition

Health conditions that can sometimes occur together, for example, ADHD and autism (Autism Spectrum Disorder).

Criteria

Usually, a list of guidelines or conditions that help a clinician determine a patients' diagnosis or needs.

Diagnosis

The identification of an illness or other problem by examination of the symptoms.

Equality impact assessment

A review of how different communities might be affected by any change, and what can be done to reduce any negative impacts. It focuses on characteristics that are protected by equality law (e.g. age, gender, ethnicity), plus other locally identified communities (e.g. carers, veterans, low income).

Health inequalities

Health inequalities are avoidable differences in health across the population, and between different groups within society. These include how long people are likely to live, the health conditions they may experience and the care that is available to them.

Impulsiveness

Impulsivity is a symptom of ADHD. People who are impulsive have trouble waiting their turn, may act without thinking, and may interrupt others. Impulsivity can appear in a variety of ways, such as talking out of turn, reckless spending, and risk-taking behaviours. People with ADHD tend to react first and think afterward. ADHD treatments, such as medication and therapy, can help people manage their impulsivity.

Inattentiveness

Inattentiveness is a symptom of ADHD. People with inattentive ADHD may struggle with paying attention to details, following instructions, and managing time, leading to careless mistakes, forgetfulness, and difficulty with sustained mental effort.

Lived experience group

This is a group of people who have experiencing of living with a condition or illness (in this instance, ADHD) that come together to help the system improve the services by helping us better understand peoples' thoughts and needs. This group meet regularly and we learn through sharing experiences, constructive challenge and understanding the different ways we might need to work.

Masking

Masking is when people try to hide their symptoms of ADHD to help them fit in with what is expected of them. It is more common in girls and women and can make it more difficult to diagnose ADHD.

NHS Greater Manchester

NHS Greater Manchester are responsible for commissioning most health services across Greater Manchester, including hospital, community and mental health services, GP practices, dentists, optometrists, and pharmacists. This means that they are responsible for managing the contracts, making sure they deliver good quality care, and paying for the NHS services that they deliver.

NICE

The National Institute for Health and Clinical Excellence (NICE) provides national guidance and advice to improve health and social care.

Option

For the consultation, an option is a suggested way forward for ADHD services. In this process, we asked people to share their views on 2 options that had been reviewed and shortlisted following a review of the evidence.

Peer support

This is a way of relating to someone through similar and shared experiences, the goal is that people offer each other support.

Referral

Directing someone to a different person, team or organisation for further information, advice and support.

Right to choose

Right to choose is the legal right of patients to choose which hospital or service provider they are referred to for certain types of care, particularly for mental health services like ADHD assessments. This includes the right to choose qualified private providers who are then paid by the NHS for the service. This means that when a GP refers a patient for an assessment, they can choose from a list of different providers – both NHS and private.

Signpost

Pointing people in the direction of information, advice or support from a different service or organisation.

Symptoms

A physical or mental feature which is regarded as indicating a condition of illness or disease, for example, impulsivity is a symptom of ADHD. Clinicians use symptoms to help them to diagnose people or decide what tests are needed.

Transition

The point when someone becomes too old for children and young people's services and moves to adult services.

Treatment

Management of a condition by the giving of medicines, surgery, counselling, advice etc.

Triage

The first assessment of patients in order to determine the urgency of their need for treatment and the nature of treatment required.

VCFSE

The voluntary, community, faith and social enterprise sector, made up of organisations, charities, religious groups and community groups who support other people in their community.

Accessibility and translation

If you would like this information in another format, or translated into a different language, please email gmhscp.engagement@nhs.net

如果您希望以其他格式获得此信息， 或将其翻译成其他语言， 请发送电子邮 件至 gmhscp.engagement@nhs.net

Jeżeli chciał(a)byś otrzymać te informacje w innym formacie lub w innej wersji językowej, prześlij wiadomość na adres gmhscp.engagement@nhs.net

Pour obtenir ces informations dans un autre format ou dans une autre langue, veuillez adresser un e-mail à gmhscp.engagement@nhs.net

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إرسال رسالة بالبريد الإلكتروني إلى gmhscp.engagement@nhs.net

ਜੇਕਰ ਤੁਸੀਂ ਇਸ ਜਾਣਕਾਰੀ ਨੂੰ ਕਿਸੇ ਹੋਰ ਫਾਰਮੈਟ ਵਿੱਚ, ਜਾਂ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿੱਚ ਅਨੁਵਾਦ ਕਰਨਾ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ gmhscp.engagement@nhs.net ‘ਤੇ ਈਮੇਲ ਕਰੋ

اگر کسی اور فارمیٹ میں، یا کسی اور زبان میں ترجمہ شدہ آپ کو یہ معلومات چاہیئے تو براہ
کرم ای میل gmhscp.engagement@nhs.net

Haddii aad rabto in aad macluumaadkan ku hesho qaab kale, ama lagu soo turjumo luqad kale, fadlan farriin iimayl u dir gmhscp.engagement@nhs.net

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Section 12: Appendices

Appendix 1: Survey Equality Monitoring Data

Chart 1: Age

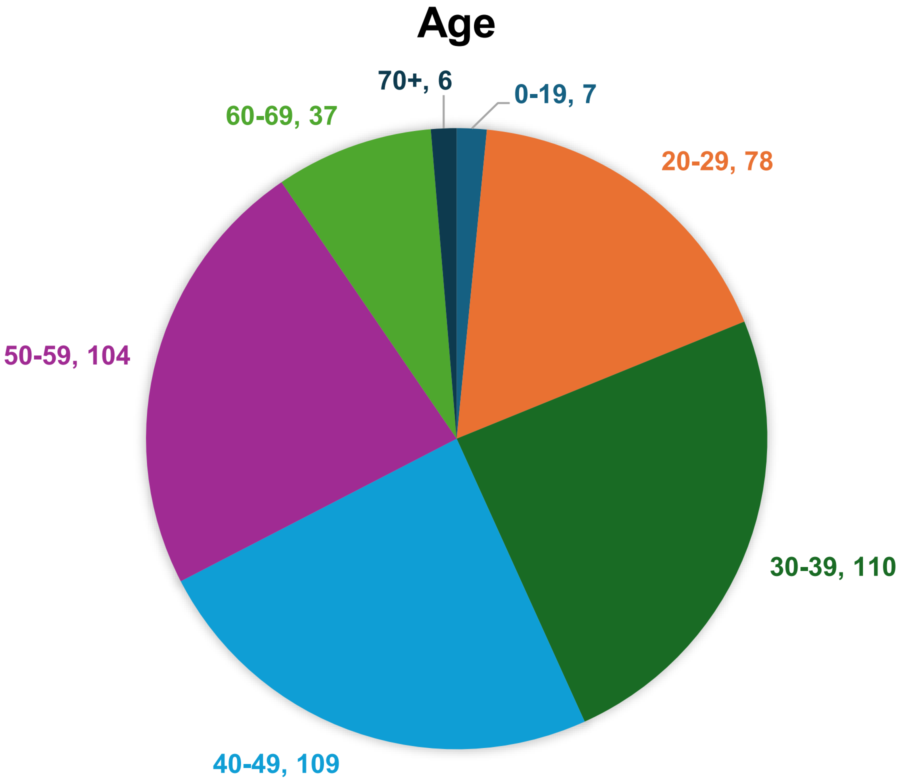


Chart 2: Ethnicity

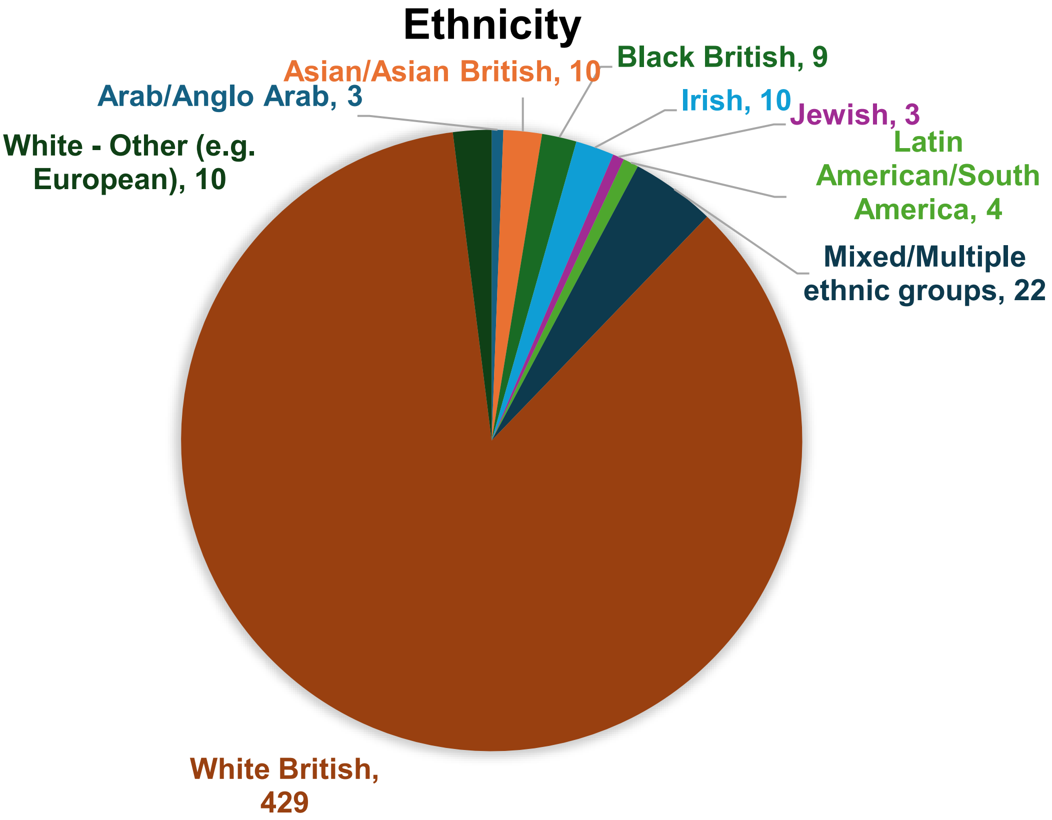


Chart 3: Gender

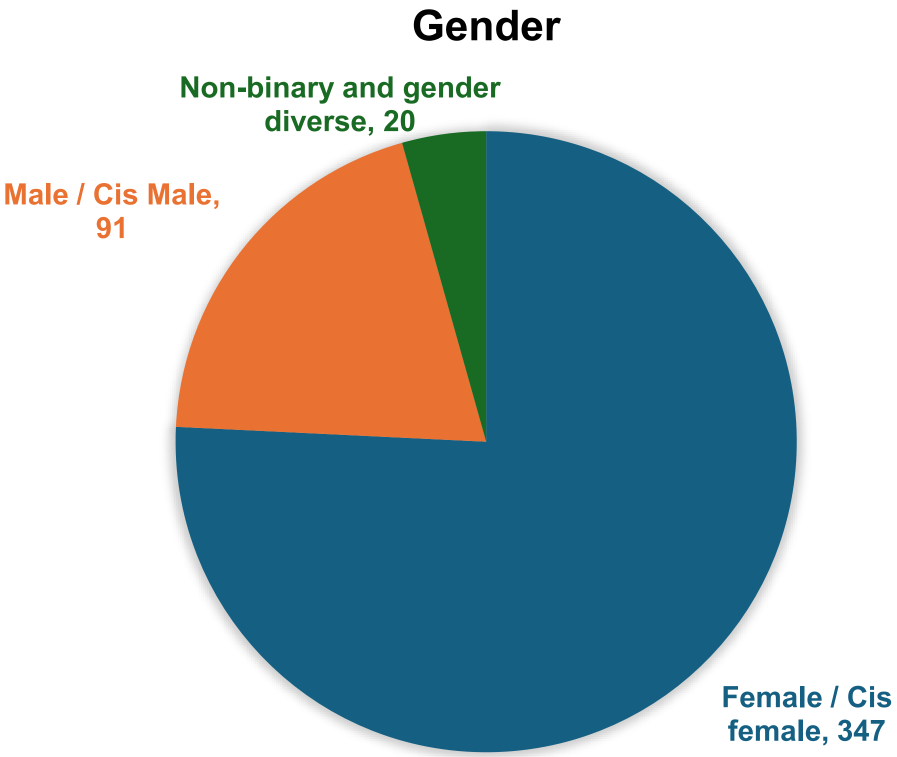


Chart 4: Gender the same as described at birth

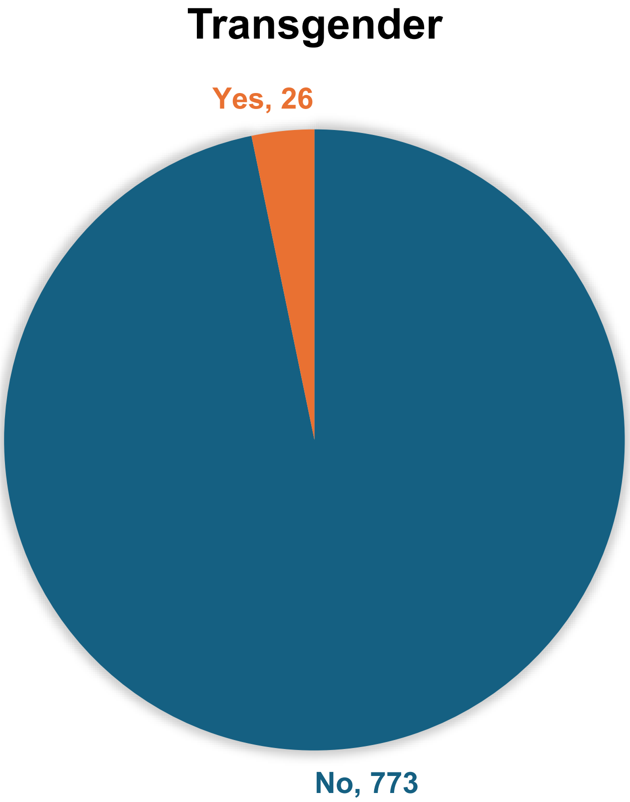


Chart 5: Relationship status

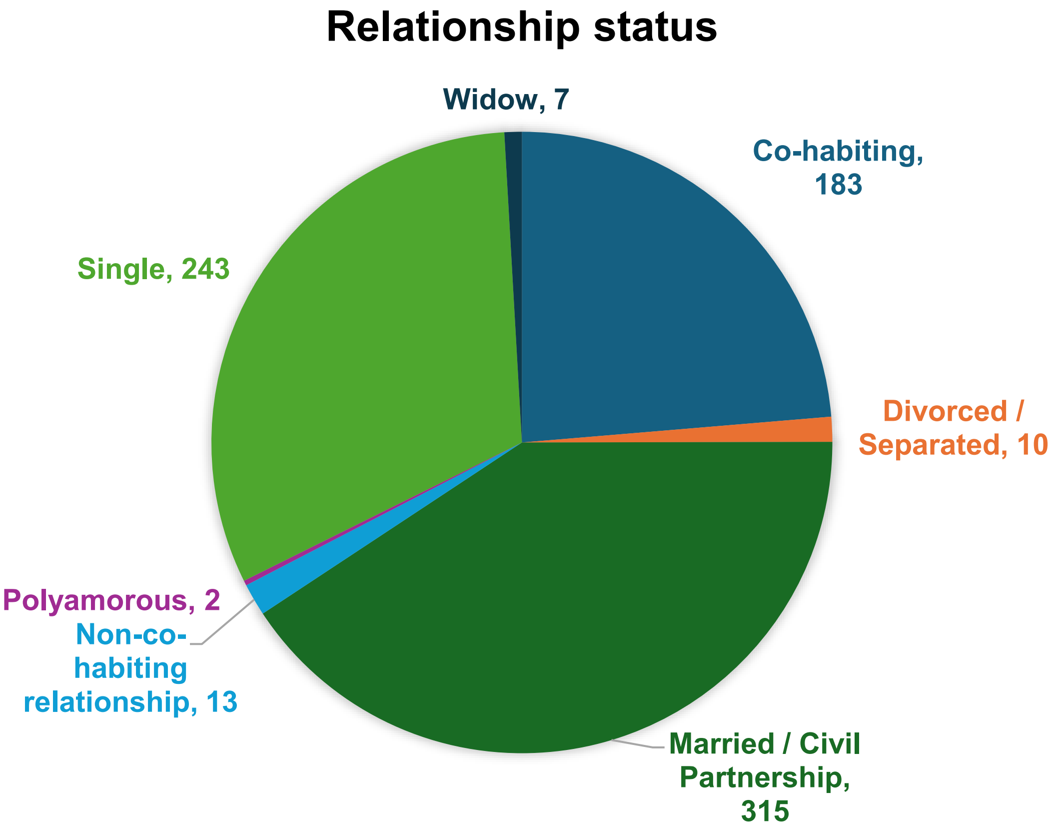


Chart 6: Religion

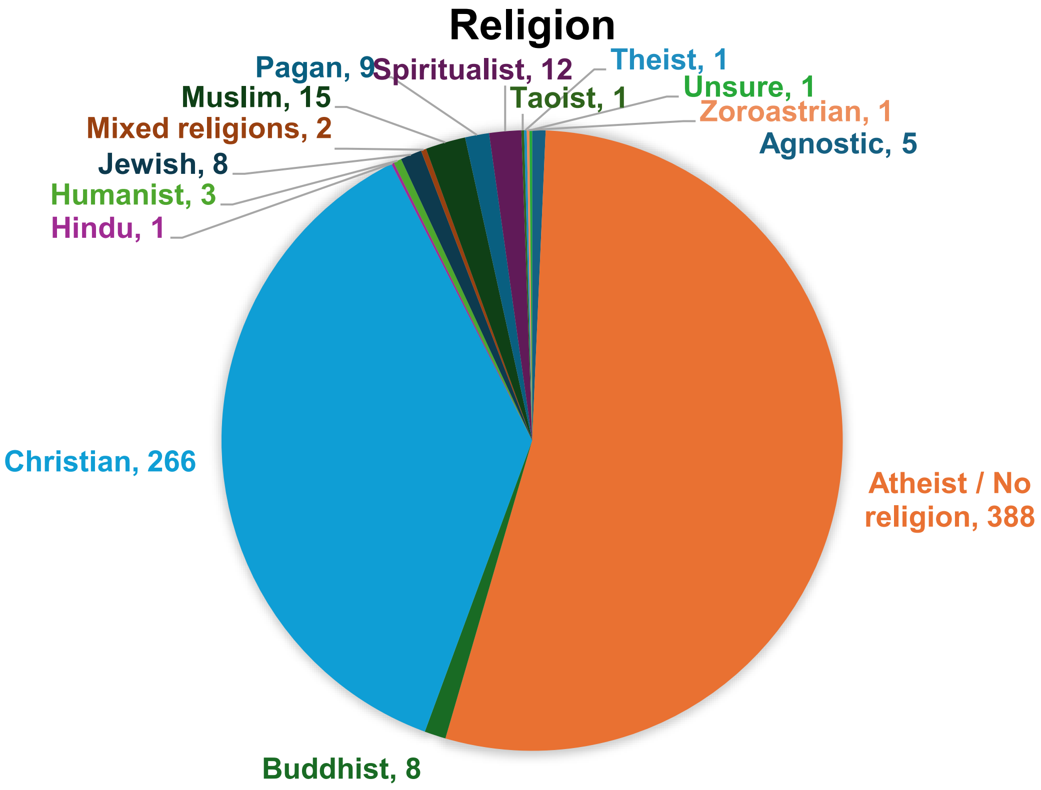


Chart 7: Sexual orientation

Chart 8: Employment status

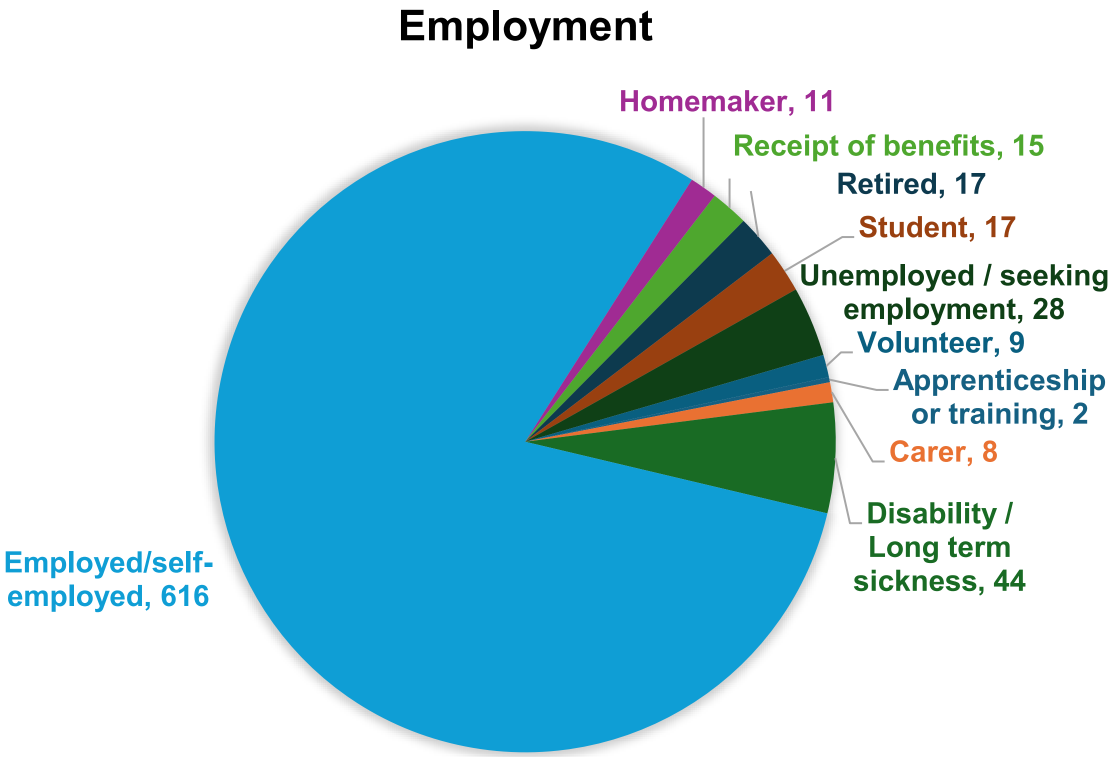


Chart 9: Disability

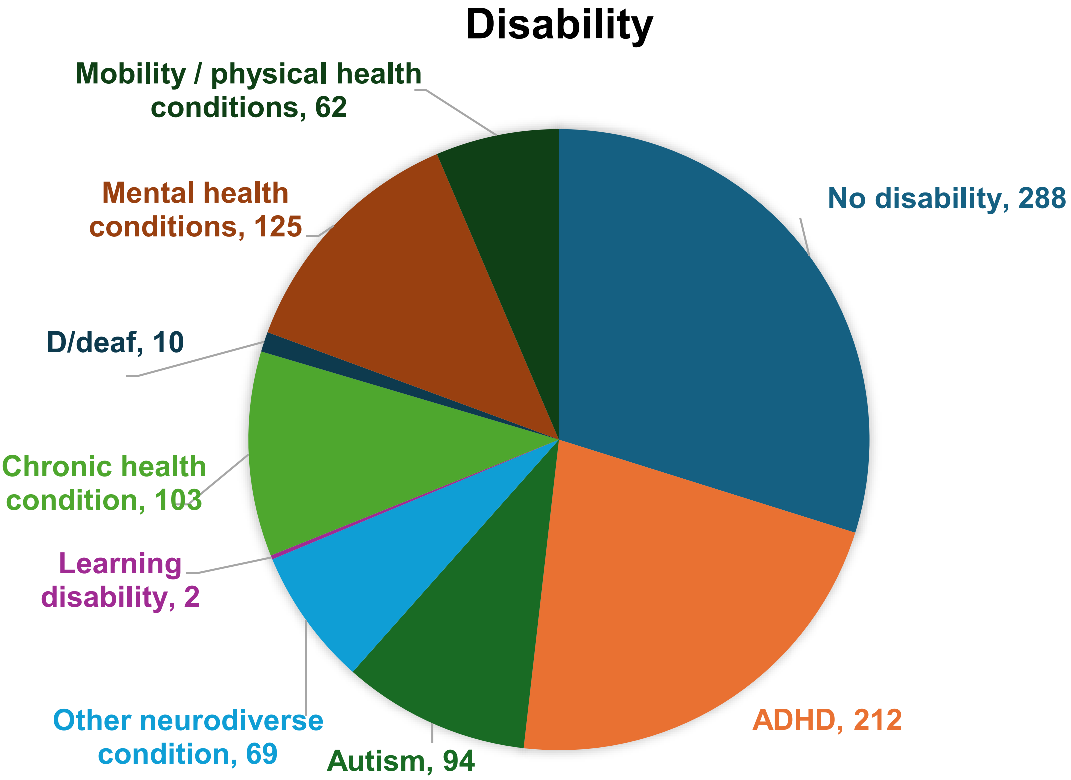


Chart 10: Armed forces (currently serving and veterans)

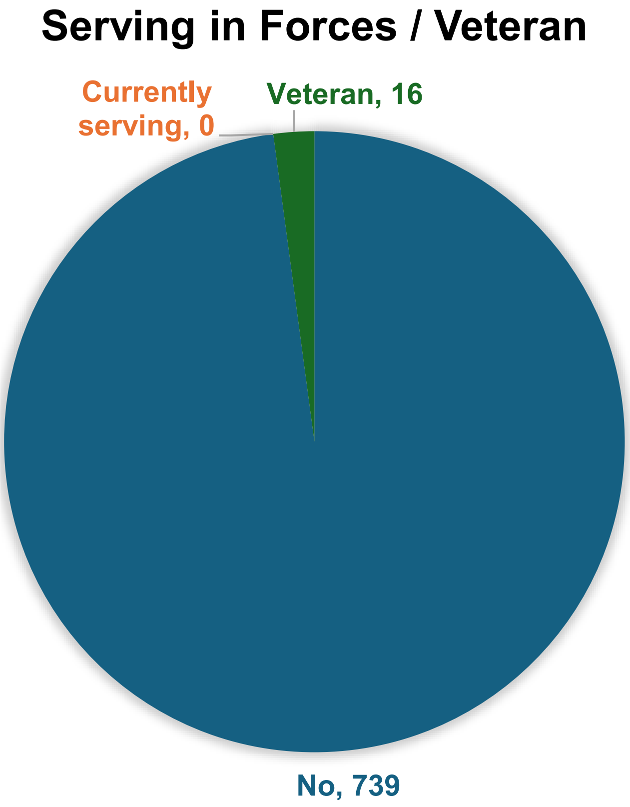
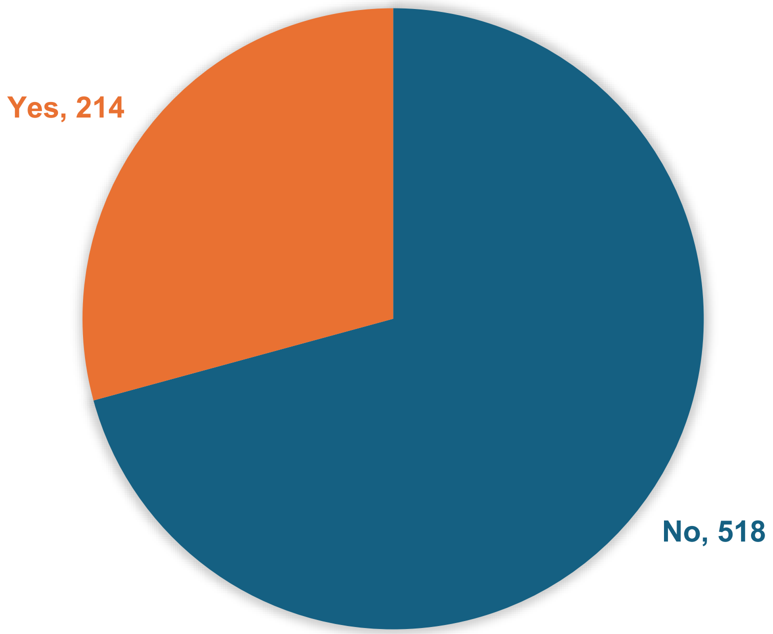


Chart 11: Carers

Carer



Appendix 2: Focus groups

NB the online focus groups are included as full transcripts due to the tools within Microsoft Teams. The face-to-face focus groups are included as summaries.

15th May 2025, Community Health Champions/Action Together Focus Group

Summary notes from Adult ADHD Consultation focus group with Community Health Champions/Action Together (Oldham) via MS Teams on 15 March 2025, 10am-11am.

Outline

NHS GM were invited to attend the CHC meeting and run the ADHD focus group. The group is led by Action Together, Oldham's Local Infrastructure Organisation. This is a group who work in different services across Oldham (including health, faith and education).

Number of attendees engaged with: 10 women

Resources used: Adult ADHD Focus Group presentation, links put in chat to the Adult ADHD web page and survey link.

Facilitators: Scott Williams, Tracy Clarke (notes)

Focus group session findings

Topic 1: Support - What are your thoughts on these? Anything missing?

People suggested the following would be useful to signpost to:

- Help with cleaning
- Time management
- Parenting support (for both those with ADHD symptoms and not)
- Menopause and pregnancy (both which can affect ADHD symptoms)
- Information about services/tips that can assist those with ADHD symptoms without need for signposting
- Information regarding how to access credible forms of ADHD assessments
- Workplace training/awareness/tips for reasonable adjustments
- Strategies for managing ADHD in the workplace
- Strategies for managing ADHD in education

"People with ADHD want help with things like cleaning house, which is less visible to measure and impacts life of those with ADHD"

"I see parents with ADHD who may struggle and they'd really welcome help to support caring for children"

“Parents often recognise their own ADHD symptoms when their own child is diagnosed – so support for parents with symptoms will be needed”

“When adults who were diagnosed with ADHD become parents – they may need extra support, as they may not have been linked into ADHD services/ support for some time”

“As waiting lists are very long, people are arranging ADHD assessments privately online, ending up with diagnosis which is not recognised by the NHS. It would be good to have information available outlining credible ways of accessing ADHD assessments (NHS and privately).

ADHD training/awareness – including reasonable adjustments

Several people told us there was a big gap in ADHD training/awareness in workplaces, education, faith and criminal justice.

Workplace: Several people told us that better workplace awareness around ADHD would be welcomed. They told us it would help to increase understanding about signs, symptoms, reduce stigma and build knowledge about reasonable adjustments.

“My workplace knows I’ve been recently diagnosed and they are supportive. I’m happy to self-manage my symptoms but would like to know what is out there to support me, with tips etc (like an information sheet). I’m not sure all organisations would be as supportive.”

“When I told my colleagues and friends I was recently diagnosed with ADHD they were shocked, as they thought it was usually badly behaved boys that were diagnosed, I was female and I never got into trouble at school. People don’t understand how females mask their symptoms”.

Education:

We were told some schools may not put reasonable adjustments in place for those with ADHD symptoms without a formal ADHD diagnosis – which may take some time to receive.

“Parents are coming to me saying school won’t put reasonable adjustments in place for their child without a formal diagnosis. This puts extra pressure on them to seek a formal diagnosis”

Faith:

Someone who works in a Faith organisation felt guidance and support to improve their governance of staff and volunteers re ADHD would be welcome, which could also be linked to their Safeguarding and Health and Safety policies.

Criminal justice Services:

It was suggested that training and information is needed for those working in the criminal justice services, especially custody sergeants.

Questions to NHS GM from a participant: signposting to support doesn’t necessarily mean people will access/use the support. How will it be monitored? Will signposting just move people from waiting list to yet another for support for mental health or say gambling?

Topic 2 Referral criteria – suggested criteria was outlined by facilitator

Participants were asked what their thoughts were on these and is there anything else NHS need to consider?

People told us:

"Symptoms aren't caused by MH illness" criteria – how would those assessing know?

"Problems from being a child" – participants wanted further clarity on what this meant

"It seems to cover more things than what I had for my ADHD assessment" (person recently diagnosed).

Topic 3 Improving access to services (options)

NHS GM provided an update re the different options being considered. Participants were asked what their thoughts were on the two options and their preference.

General views:

Option A

People will get a response and feel heard and seen

Option B

This could be a waste of resources, waiting for people to see if the signposting works.

Unsure how long people could be waiting for assessment in option b as this delays access to assessment.

One person likes offer of support in this option, but worries whether there is capacity in the system to support everyone.

Other suggestion: Have an Option C

Option C would be a mix of option A and B – where people are seen face to face and are provided with an information sheet of all the support available/tips to help those with ADHD symptoms live a normal live at home/education/work straight away (covering all the topics mentioned in the support question, plus more). They would choose if they needed support and contact the support organisation themselves/or be advised about tips to help support them, rather than have to be referred. "For example, I bought loop ear buds which have made a massive difference to me working in an office. I bought them and wouldn't want to get that support from a professional. I just need an info sheet to help me know that if I'm experiencing challenges I can get tip or information to make like easier" Woman recently diagnosed with ADHD

All asked to put a preference of a or b, or c just blended in the chat.

Option A: 8 people preferred

Option C: 2 people preferred

Comments:

“If that the idea that we would expect someone to have been experiencing problems since being a child and they come forward for support and then we just signpost and people struggle for longer before their experience is heard really difficult”

“not everyone will access support as they just want the diagnosis”

Participants were advised of upcoming opportunities to get involved and were asked to share the information and links with colleagues and people they work with.

Actions by NHS GM

Scott to send presentation and Oldham focus group post to Karen for further circulation.

28th May 25: The Mosses Centre, Bury

Adult ADHD Consultation Workshop

Date: Wednesday, 28th May 2025

Time: 1pm – 2.30pm

Venue: Mosses Centre, Cecil St, Bury, BL9 0SB

In attendance: *Amanda Rafferty, Head of Locality Engagement, Scott Williams, Engagement Manager, Ian Trafford, Head of Programmes, Bury Integrated Delivery Collaborative and seven members of the public*

Background

Greater Manchester is consulting on two proposed options for improving Adults ADHD services. This event was to share further information with the public and to understand their views in relation to:

- Proposed support options
- Proposed referral criteria
- Pathway Option A and B

Notes of the discussion

Discussion one – support

Other support options suggested included;

- Neurodivergent support services
- Receiving therapy/support with ADHD professionals
- Networking/support groups
- Online training sessions
- ADHD webinars
- ADHD coaching, helping to navigate day to day living and understand what ADHD is and how to cope
- Green therapy
- Yoga
- Mental health must be specific to ADHD. General will not work.

Further comments and queries around support:

The need to account for co-occurring conditions such as autism, learning disabilities, or mental health disorders (e.g., anxiety or depression). Individuals with multiple or complex needs may risk being deprioritised, leading to further delays in appropriate support and potential misdiagnosis.

The need to ensure accessibility across socio-economic and geographic boundaries. Support without diagnosis. Concerns that triage may inadvertently gatekeep essential services for those who still need support but may not receive a formal diagnosis.

Need to consider appropriate funding. The current proposal lacks clarity on how services will be funded and whether budget constraints may limit availability or create unequal access.

Consider including a parallel support pathway for individuals on the waiting list, regardless of diagnostic outcome.

Discussion two – referral criteria

There is a need to inform patients and families. Patients and families may not understand how or why decisions are made regarding their place in the diagnostic queue.

Equity of access must remain a priority, in line with the NHS commitment to reducing health inequalities. There is concern that vulnerable individuals, particularly those from disadvantaged backgrounds or those with communication difficulties, could be disproportionately affected if the system relies heavily on digital self-referral or complex pre-assessment forms.

Design triage tools and pathways that account for comorbid conditions and intersectional health needs.

Include multidisciplinary input at triage stages to avoid exclusion or misclassification.

Concerns that the triage system doesn't align with NICE guidelines e.g. NICE NG87.

Consider implementing an appeals mechanism or clinical oversight panel to review borderline or complex triage cases. Introduce an appeals or second-opinion process for those declined assessment.

Ensure continuous auditing to identify and rectify any unintended consequences or systemic bias.

Option A and B

The group expressed concerns around both option A and B and were not in favour of either:

It was unclear what the GP interaction was at the beginning of the pathway including whether the GP would continue to use the ASRS assessment tool. Participants felt this needed clarifying and could result in duplication and multiple steps in the pathway.

The group were concerned about the predicted 70% of people not receiving an assessment.

Concerns around Duty of Candor and adherence to NICE guidelines were raised.

Healthwatch feedback

Healthwatch member reported issues with;

- ADHD management and burnout

- Lack of timely reassessment and medication access, anxiety around changes to mental health medication without adequate consultation
- Poor communication between services and patients
- Difficulty navigating healthcare systems, especially for vulnerable or neurodiverse individuals
- Lack of clarity and communication gaps in service processes and follow ups, leading to confusion and distress

Following the meeting two participants submitted further comments which will be include as part of the overall consultation findings.

Next steps

Findings from this workshop will be submitted as part of the AADHD consultation, analysed and presented to commissioners in the consultation report. The consultation report will be shared with all participants.

20th May 25, Medtia Centre, Oldham

Adult ADHD Consultation Workshop

Date: Tuesday, 20th May 2025

Time: 10:30am – 12pm

Venue: Medtia Centre, 80 Union Street, Oldham, OL1 1DJ

In attendance: *Amanda Rafferty, Head of Locality Engagement, Scott Williams, Engagement Manager, Greg Vaughan, Head of Strategic Commissioning, Mental Health and Learning Disability (Bolton) and 25 members of the public.*

Background

Greater Manchester is consulting on two proposed options for improving Adults ADHD services. This event was to share further information with the public and to understand their views in relation to:

- Proposed support options
- Proposed referral criteria
- Pathway Option A and B

The event was attended by 25 members of the public. Two participants took part on behalf of a VCSE organisation and 23 Asian ladies attending an early ESOL class also participated.

Notes of the discussion

Discussion one – support

The group discussed support options and participated in an exercise to identify priorities for ADHD support. Results of the exercise were:

- drugs (9)
- sleep (9)
- mental health (7)
- anxiety (8)
- alcohol (4)
- gambling (4)
- sexual health (2)
- eating (1)

Additional to the above, employment support and understanding from employers were also suggested and there was a strong desire for peer support, better information for families/carers, more accessible and culturally sensitive services with improved communication.

Discussion two – referral criteria

Whilst most people agreed with the referral criteria in principle, there were significant concerns about barriers created by childhood requirements, distinguishing ADHD from other mental health conditions, inflexible or unclear criteria, and the risk of stigma. Suggestions included making the process more flexible, adding relevant symptoms to the checklist, and ensuring assessments are conducted by knowledgeable professionals.

Participants specifically mentioned the below.

Childhood requirement: Some participants expressed worries that requiring evidence of symptoms from childhood could be a barrier, especially for those who cannot recall or prove childhood difficulties, or for those whose symptoms became apparent later in life

Difficulty distinguishing ADHD from mental health symptoms: Several people noted it can be hard to judge whether symptoms are due to ADHD or another mental health condition, especially for those with co-occurring conditions like depression, anxiety, or bipolar disorder. There was concern that people may not know the cause of their symptoms and that only a qualified doctor could make this distinction.

Concerns about the number and type of criteria: Some people questioned the rationale behind specific numbers (e.g., why six months, why five criteria) and felt the criteria did not allow for flexibility or account for severity. There were suggestions to use severity scales or allow self-definition of what is problematic.

Masking and gender differences: Some people noted that women and girls may mask symptoms or internalise struggles, making it harder to meet strict criteria.

Stigma and gatekeeping: Some raised concerns that strict criteria and GP gatekeeping could prevent people from accessing support or medication, and that being labelled with a mental health condition could be stigmatising to the Pakistani community.

People also suggested additional criteria including emotional regulation difficulties, problems with organisation, day-to-day management, family history, other neurodiversity or co-morbidities, and sleep problems.

Discussion three – Options

Participants discussed the preferred option. All participants preferred option A. They believe that people would be seen and supported more quickly, triage would happen sooner, and immediate support would be available without having to return to the GP or experience delays.

Other feedback

Participants also reported stigma around ADHD and mental health in their communities, a preference for female-only support groups, and a lack of culturally sensitive information and resources. They face barriers accessing GP appointments and want materials in their own languages. There is interest in further engagement and collaboration to improve awareness and support tailored to cultural needs.

Next steps

Findings from this workshop will be submitted as part of the AADHD consultation, analysed and presented to commissioners in the consultation report. The consultation report will be shared with all participants.

6th June 2025, Online Focus Group, MS Teams

Transcript

6 June 2025, 09:32am

Person 1 started transcription

Person 1 0:04
And I'll sort it in on.
OK, Person 2, you want to run through the slides, please?

Person 2 0:16
What is this lobby keeps?

Person 1 0:21
OK. In the next one.
OK, so who are we? That's important, isn't it? So you know who he's been. You can sue in the room today. So we're from an organisation called NHS Greater Manchester and that formed a couple of years ago when the former clinical commissioning groups came together across the 10 localities in Greater Manchester. So we have the budget for health and care across Greater Manchester. So we're made-up mostly of commissioners and service improvement type people.
I'm from the engagement and consultation team, as is Person 4, as is Person 2, Person 3 is in the room here as your expert around ADHD today.
In terms of commissioning, so he can answer any kind of technical questions that you might have. So we have approximately 8 1/2 billion that we spend on health and care in Greater Manchester and we need to make sure that that's spent in the right places on the right things. And that's why we have an engagement team who speaks people like yourselves today and make sure that services are shaped in accordance with people's needs. So we're also part of this thing called the Greater Manchester Integrated Care Partnership and that's where we.
With other partners who have a remit for health and well-being, so people like the combined authority, so the the 10 local authorities that come together into one combined authority, also the voluntary community and social enterprise sector. So we work with voluntary sector organisations, community groups etcetera to understand what is needed in terms of neighbourhood type.
Services and we hope with that work with our providers as well such as hospitals and GP practises.
So I think I've said a little bit about myself and Person 4 and also the other few people have introduced themselves. So we'll move on to the next slide please, Person 2.
OK, so what's this all about?
I think we missed the housekeeping one. Do you want to just?
We'll check we've got that one there somewhere.

Person 2 2:24
I think it's included in this one.

Person 1 2:27
OK, don't worry. We've done a little bit of housekeeping, so I'll just reiterate. So we've got an agenda. So we want to make sure that we keep to time with that agenda.
I'll be facilitating so moving people on if we need to. So the way that it's going to work is that we'll have a little bit of a presentation, then we'll move into breakout discussions and then we'll come back to the main room. We've got two discussion rooms and then at the end, we've got a a chance for us to all look at the options that are on the table.
So what we're consulting on today is option A and option B. So we'll talk about that a little bit further down the line. As I've said, if you'd meet your mics during the presentations, that would be amazing. When we're in the main rooms, we'll have chance for discussion.
We're not taking questions in this arena. However, if you've got a question, please pop it in the chat and we can we can get round to it. We will do. There is a chance for questions around the referral criteria when we get to it a little bit later in the agenda.
So if we'd move on then to the next slide.

Person 2 3:50
This lady looking for.

Person 1 4:00
You to do. Oh, go on. I'm sorry. We're talking a little bit about what ADHD is and as a system we have a little bit of a definition that we've created and put forward through our consultation documents. There is an opportunity to share your thoughts and feelings on this in the chat, if if you would please.
But we're here today to talk about attention deficit hyperactivity disorder, and that's the condition that affects people's behaviour. People with ADHD can seem restless. May have trouble concentrating and may act on impulse. The exact cause of ADHD is unknown, but the condition has been shown to run in families and research is also identified. A number of possible differences in the brains of people with ADHD when compared with those without the condition.
In previous focus groups, we have had a little bit of a conversation about this, but for the purpose of this online conversation, if you have thoughts or feelings about that definition or commentary about that, please feel free to add that narrative in the chat and we can come back to it.
And and pull out the bits are important to you. Next slide please, Person 2.
So the consultation period has been running since the 23rd of April and will run till the 17th of June, which is 11 days from today.
This consultation is about improving adult ADHD services across Greater Manchester.
This is not about children and young people's services, and there has been some

work carried out by the system to review how children's services do work and those reports.
I've on our website.
Today we're talking about two potential options. So in option A and an option B, we want to walk through our process and hear your thoughts and views on the elements that we're going to be talking about today. But in particular, how you feel about option A and option B, which we'll talk about later in the presentation. Your feedback helps us make sure that we understand what is important to people who may be affected may be affected.
By the proposed changes and what your needs are, it is important that we consider this when we make the final decision on the best option for changes to adult ADHD services. What I need to stress is this is not a vote between A or B. It is about understanding your thoughts and feelings about those and anything that we have missed or any thoughts that you have that we should consider as assistant.
Next slide please, Person 2.
This I'm handing over to yourself, Person 3 anti for the one of things needs to change. Thank you.

Person 3 6:55
OK, so we've reviewed the ADHD process because the number of people being referred is not that way above what was originally designed for. So if we look at some of the boroughs, a lot of them were commissioned for roundabout 11:50 people a month to come in.
That was back in 2016, and that was based on the actual.
Presentation that we saw at that point and at the moment those same services are getting between 150 and 350 each per month.
So we do estimate there are around 25,000 people who are waiting for a diagnosis of ADHD. And this, as I've just said, it's it's growing each month and the currently awaiting is about 7 years for assessment diagnosis in some parts.
System.
Most of the NHS systems, if you're referring to it, you just go on the bottom. There's no prioritised stations. Nobody looks at anything about your referral, you just join it at the bottom and the majority of NHS services are provided are not provided like that, they're they're based on need, risk, demand and people tend to get prioritised and going quicker the higher their need is. So if it did carry on at the current levels, this would cost us around about £10 million a year to fund.
An assessment service capable of meeting the demand, and that that's just the assessment service that doesn't also pick up the support that's required outside of that, including the ongoing monitoring for for medication.
So.
Again, it's the reasons above that we we do need to change the services, how we do it and how we look after people with ADHD and Greater Manchester.
Is this as well? Sorry.
The support, diagnosing treatment for your HD and we want this to be equitable and consistent across Greater Manchester, doesn't matter where you live or which services you came into, you would get the offer.

So it's going to be responding to and needs of individuals and not literally just A1 size fits all, which is realistically what we have at the moment.
So it won't says understand the.
To individuals, so I just said that one time.
So it's an offer support for everybody and a diagnosis for those who need it most.
I have to do this by.

Person 1 9:37
Yeah. I think Person 3 is having some it issues.

Person 3 9:39
A new triage hub.

Person 4 9:46
Thank you for that part. Way through and delivering that.

Person 1 10:03
I think we lost, Person 3.
So these are things that he was talking about in terms of the vision that we're trying to achieve at NHSGM. So Person 3 mentioned, didn't see that there's approximately 25,000 people on the waiting list at the moment and there's no prioritisation of those people. So clearly that's not something that we want to continue. So one of the things that Commissioners have once put in place is prioritising those that are on the list in terms of who needs to be seen more quickly.
There will be a new team that's been commissioned, so this hasn't started yet, but this team is a triage team of people health experts. It was brought the triage process to ADHD diagnostics so that team, as I say, is brand new. And Person 3 can maybe talk a little bit more about that if you have any questions when he comes back on.
The other thing to make sure is that there's a broken support service in place for people who meet the criteria for diagnosis, but also those who perhaps just need support and not diagnosis.
So at the moment, we know when people have told us throughout the consultation as well that very few are getting the support that they need so.
The the third priority here is making sure that everybody receives report supports regardless of whether they're on the waiting list or whether or not they've been to see the GP they've been triaged and the triage team have have decided that.
Think how we support.
Diagnostic. So it's those three things that we're trying to achieve. I do think that we've probably lost. Person 3, do you want to move on to the next slide?
So Person 3 was also going to talk about the model of care. Again, this is something that's proposed. So some of these things will absolutely go ahead and some other things that we want to talk to you about today, which you can influence in terms of how they're shaped. So what we're wanting to achieve is 1 consistent service across GM. It's varied at the moment. So some localities will have an NHS service, some won't, for example.
We do know that there are huge waiting times that Person 3 has spoken about.

So one of the things that we absolutely want to achieve is shorter waiting times. It's not safe at the moment for some people who are having to wait years and years and years without any intervention. So that is an absolute priority. We've talked about the assessment. So prioritising those who are most at need, which is what the triage team will do once the GP has referred on to that team.
And all the way to support on offer. So we'll talk about that in a moment. In the workshop, what that's about ensuring that everybody gets the support that they need once their need has been determined by the GP.
And that everybody gets the support. So it's a nice, less approach, it's it's quite different from the one that's in in place at the moment. Do you want to move on to the next slide?
Is Person 3 back in the room yet?
OK, So what we're asking today, so obviously we've alluded to the fact that some of these things will go ahead and some are for you to shape. So these are the things that absolutely can be influenced, which is why we're having the consultation. So it's these three areas that we want to hear from you about. One is around what support should be in place to help people manage their diagnose their symptoms. So we'll have a chat about that in discussion spaces in a moment.
So we have some ideas about what they might be, and that's from engagement that we've been doing over the years and what people have told us, but you might think there's something missing and you might also think that.
We need to be aware of some of the kind of implications of how these support offers are offered or managed, or how people access them. So that's something that we need to check back with you. We're also going to talk about the criteria or the checklists that the new ADHD triage team will use to determine whether or not someone's signposted for diagnostics. So that's something that.
We really, really need your views around it's brand new.
It's something that's not happened before.
And we've had lots of views from people across the the consultation period so far, so we've allowed for a 20 minute discussion on that. And then at the very end, we want to talk about to you about the option A or option B pathway. So we we need to understand which is the one that we should be going forward with in GM, so.
I want to split you into breakout rooms now, so we've got.
Until 11:10 to focus on the the support question.
So each of the facilitators one will be in in each of your rooms. We'll talk about the plans so far. So what those support packages might entail, but we really need to understand from you what you think is needed, what might be missing, and what we need to consider when we're developing and offering those support packages. So Person 4, you're going to put people in rooms now, aren't you in? Yeah. So you'd be randomly selected. So in a moment, you'll probably disappear off to a different room. Some people will stay in the main room, but you'll.
Particularly come back to this main room at 11:10. Thank you.

Person 4 15:57
Hello and good afternoon. Can everybody see me? OK. Can everybody hear me? OK. Wonderful. At this point, if you want to unmute your mic's, feel free to do so

because this is a little bit more about a conversation.
And or if you'd rather use a chat to share your thoughts and your feelings, that is also absolutely OK. I'm going to share the screen that that we've got because I think it's important that you see the question that we're discussing. Please feel free to use the chat. Sorry, I am in the same room as Person 1 because we're we're working.
Together, hybridly.
Elsewhere, so you might hear some some crossover conversation, but it's not, it's not a problem. If anybody has any challenges with that, please let me know, but you'll see here that we have a question.
So are we happy? Can you see that on your screen? OK, I will. I will make it larger. There we go. That will take up our our whole screen now.
Can everybody see that OK now?
So thank you very much for joining us.
It'd be great to kind of understand who we've got in the room. Obviously I can see names and you can see each other's names, but it'd be great for us as we start to have this conversation to understand kind of, not necessarily the reason that you're sat here having this conversation, but certainly what you bring in regards to lived experience or professional experience etcetera.
So the questions we are looking at is as part of the new process that is being looked at in both options.
Support will be offered, so for those that have not had the opportunity to look through the documents we've put online etcetera, we are looking or what is being suggested by the system is that people joining a waiting list and waiting 7 to 10 years across Greater Manchester cannot continue. The current process is you will attend your GP surgery, they will give you a very brief conversation. You will then end up.
In.
Being referred to a waiting list and that waiting list currently stands. It's between 7 and 10 years.
Recognise that that's not OK. So we're looking at a triage process, which we will come on to again shortly. But as part of that, we're also looking at a support system and organisations that we may work with to best support.
Patients with ADHD and their families. So we're asking what are your thoughts on the types of services that we're that we've listed and what is missing or what do you feel we should be looking to prioritise?
As part of this programme of work, so please feel free to unmute coming in conversation or to continue to converse and share your thoughts via the chat.
Person 6, you were muted first or I think, and then I'll go to Person 7 and Person 5 because they are muted too, I think.

Person 5 19:03
None.

Person 6 19:12
OK, personal experience, I would say spending and that's I have absolutely no control over what I spend and just like live payday to pay day and often run out of money before the end of the month.

Probably not as bad now I've got diagnosed as they've got Pip and all that. But yeah, pre diagnosis that will be one of my biggest issues.
Things like going through like a bankruptcy just because it was easiest thing to do and I had loads of debt spells up.
Just forgetting stuff up there, things like direct debits and just figure out if it's the file coming up for us. Even bank balance go. Oh, got lots of money to spend it. Go on.
I mean, look at that list.
I'm not really. That was never really addicted to alcohol, anything like that, but didn't know my limits.
Barely drink now, but when I do, and if I do drink a lot, I just keep drinking, drinking, drinking. Just, I'm bored. So carry on. Have something else.
Yeah, maybe that and anxiety or sexual health.
Yeah, that was my other experience anyway.

Person 4 20:27
No, no, thank you. Thank you for for starting the the conversation.
I I I don't. I think somebody else muted with it yourself, Person 7 first. Or was it Person 5? Person 7, do you want to do you want to come in and share your thoughts please.

Person 7 20:41
That soon.

Person 5 20:42
So.

Person 7 20:44
I was curious about a couple of points. One work.

Person 5 20:47
042 medication.

Person 7 20:50
2.
Medication.
My concern is if the wait list is 7 to 10 years.

Person 5 20:57
I mean.

Person 7 21:02
Does that mean that'll be how long it'll be before I can get methotre?
X.

Person 4 21:11
Some of that if you want me to come in. So if you're currently on the waiting list, what

we're looking to do or what is being suggested as the options is that you will join a triage process.

Person 7 21:17
Yeah.

Person 4 21:25
And that triage process will look at whether you meet a criteria which we'll discuss in the next workshop.
Whether you meet a criteria to go forward for assessment and diagnosis, what the recommendation is in the paperwork is that only 20 to 30%.
Of all referrals will go through that process.
Some of that is because.
There is a recognition that with support and with other interventions, people are telling us through the engagement programme that we ran in 2024 that.
With that, they feel that they can live.
Kind of fulfilled or supported lives and therefore what we recognise is across the world the world globally, there is a shortage of medication.
And there are also people who are going private, who are being diagnosed and therefore medicated, who in in, in real terms may not need that level of intervention.
And there are people who significantly need or would need that to function in everyday life. And there is significant differences between that. So there will be a process of GP speaking to you triage process speaking to you if you meet that criteria, which we'll discuss in the second workshop.
You would then go forward to an assessment.
And diagnosis process, which then would lead to a medication route because that is the only treatment pathway post diagnosis. What we're saying in in the proposals is with support, would that make a difference? What could that look like and what should we be prioritising? And for some people that that's a very different experience. So I'm really keen to hear how that would impact you Person 7.

Person 7 23:10
Well, I think I'm. I think there's a good chance I'm wasting my time.
To be blunt.
Like.

Person 4 23:27
Is that is that from what I've just said, Person 7, in respects of what the system could look like, OK.

Person 7 23:30
Yes, specifically from what you've just said, yes.

Person 4 23:34
And what I need to be really clear about is consultation is not about a vault, it is about us understanding the impacts on people.
Because.

We have to make.
This conversation as an engagement person, I'm here to talk to people to establish, and I will write the report with my colleague Person 1. We will write the report and lived experience, your thoughts and feelings form the basis of that report. It is written without discrimination, without lenses.
It's written in the rawest of approaches to enable the system to understand.
What it would mean for people?
So this question in particular is about what support can help people live and and feel supported and enable and engaged the next process around referral criteria and then the options. There's lots of opportunities for people to be honest about if this wouldn't work for you, Person 7, and you think, wow, what could that look like that that's why we're here? Because we're not telling you that this is what it's going to look like. We're asking for your thoughts and things about what could it look like.
And if we if we were to think about this, what what would that mean for you and how would that impact on you because that's what's important to us.
If you if you want to take a moment and and just yeah absorb that because I I appreciate that when people join these calls, they might not have seen some of the information. I will put our web page in the chat by the end. So you can read through some of that information or or we can have follow up conversations from this. But I do wonder whether I can bring just for the moment because you look obviously that it's been quite a shock if I if I just move on to somebody else.

Person 7 25:23
It's not shocked, it's just to be honest, but.

Person 4 25:25
Well.
And that OK, I mean that's fair. Then obviously I'm, I'm, I'm.
It would be great to understand your thoughts and feelings about that, but I want to give you a bit of time to kind of get to that point maybe.
So I think you've unmuted, but Person 5 had a muted too. So I don't know which one of you would like to go first. Person 5, did you want to come in on any of that? And then I'll go to Person 8. Is that OK? Trying to remember an order of unmuting.

Person 5 25:58
OK, OK.
Well, hello. Hello. So.
The experience with the, with the, with the ADHD is what kind of standard of it makes everything very, very difficult. It costs me a lot of money. I need to, when any I keep, I keep losing things for getting them. Maybe I need to and then and and then I need to rebuy them.
It's that's the ADHD talks, it's it's it's it's cost me a lot and I and I can not afford that kind of thing. There's.
Other problems?
And the.
Anxiety is terrible for me. Eating is.

Basically, outsource my my hunger and association mechanism to a spreadsheet.
Drugs as well. Yes, they're fun.
I don't think that that they are much of a problem for me as well. Sleep, however well sleep. I'm not sure exactly how much sleep I still.
With ADHD, so there's some there are some things I will also.
Also have sleep apnea, but that's a. That's one. But that one is also decades long waiting list to get sleep study.
And there's also the part where I actually I had. I was sent a a tiny little questionnaire.
Years ago now by my GP.
To and I'm pretty sure that that one for us was for ADHD assessment and.
I think that that happened before they registered that I had changed my gender and that they may give me a new number and promptly lost my entire file and archives.
Absolutely. That was not that much because.
I've I've moved to England.
Recently so.
Oh well.
Yeah, my thing is that, look, it's I don't think this is going to work. What is? I think that's what is what is necessary is a giant funnel where where, where people can be seen really, really quick. There's there's there's been a change, but the build up of backlog.
So I think you need a lot, a lot of rings to do there to to do a tonne of assessments in the in over something like 10 months or something possibly and then and then have a provision to.

Person 4 29:00
We lost Sofia. I think we may have had some technical difficulties there, Person 5. We will come back to you if you can still hear us.
Person 8, let me just let me just let me just make sure that I'll bring you in, Person 8. And when Person 5's back, we'll, we'll, we'll allow them to come back into the conversation. So would you like to. To.
Share your thoughts please.

Person 8 29:22
And so I will diagnose dignity with add. It was normal and dyspraxia, but then I was all right. I never needed support in my life. But then, well, looking back, I really did. But I didn't think I did. And then as I've reached perimenopause, I've got a job as a new job, as a social worker, which is in adult localities. So. And I really, really struggled. I've had a very difficult two years and it's had a huge impact on my psychological health and well-being. And I've had multiple. I'm still on the waiting list, but I ended up getting a private diagnosis.
That's my brief summary with regards to the support the services offered, I think they focused way too much on like the individualised negative symptoms. The problem with health and social care is it is a system and you want to put all these systems in place. But people with ADHD, we don't really think like that with one person. We don't fall into these like neat processes and as well. Furthermore, a lot of these

services are already in place.
So what the? I feel money would be better spent on is ensuring that all staff across health and social care are appropriately trained and have the knowledge to ensure new inclusivity because it's ultimately been beneficial for everyone. It's not just us, it's benefiting and I just think it would be better off.
But I understand it because according to the statistics and the numbers, that's what people need support with. Hope that helps.

Person 4 30:45
Thank you so much, Person 8 and I realise I've put two to wiganas in the same room. Haven't had Person 6 in so well, actually three because I'm actually from Wigan. I actually spent 20 years working in children's services for Wigan Council, so it's good. Yeah, well, OK. Yeah. Sorry. Sorry, Person 6, I understand there the politics there. Thank you, Sir, for sharing those sorts. Person 9. Your your hands up. So I would like to bring you into the conversation.

Person 6 30:58
Weird.

Person 4 31:10
And then I don't if Person 10's unmuted. So I'm just looking at who's got a mute and sign so Person 9, can I bring you in and then I'll, I'll go to Person 10 to give Person 10 an option to to speak and then I'll go back to Person 5 because it looked like the back of the room, which is great, Person 9.

Person 9 31:24
Hi, thanks for calling me in. Yeah, I just I I wanted to 2nd, someone had mentioned financial support and I think that's something that is from most people that I've spoken to who are on the journey. That's been a real struggle. So I think any kind of support along those paths but again.
Neuro affirming support because not like you're not just going to be able to print off a budget sheet and fill in the boxes and stick to it every month, it's going to look very different. Financial support for people who are potentially ADHD. So I think it needs to be targeted just like all of the other.
Support systems.
The other thing that and I know this could be tricky because at this point you're dealing with people who who may have ADHD symptoms but may not have ADHD. But I think something that's missing is a kind of centralised support and information resource space for people to understand more about ADHD. Because at the start of this journey, a lot of the information is coming from.
All over the place and it's not, it's not information that you can necessarily rely on at face value.
Because everyone's personal experience and bias can be fed into the information that you're receiving. So I feel like at this point supporting understanding, ADHD and understanding the impact that it can have would be really crucial for people to

understand their own journey at this early point. And to do that in a Safeway where it's kind of, yeah, an official viewpoint of ADHD, not just whatever TikTok says today.

Person 4 33:09
You so much for that, Person 9. Thank you for your your input. I'm there. Person 10, you are muted. So I'm going to come to you. I don't know if you have anything to say or input.

Person 10 33:21
Yeah. Yeah. Thank you.

Person 4 33:22
You do. Wonderful. And I'll go to Person 5. We have 5 minutes left of this workshop, so thank you.

Person 10 33:27
So I'll try and just kind of be as brief as possible. It feels like I could talk for an hour and so I'm in the position where around 20 years ago had kind of problems, the usual kind of thing. Where did well at school? All clever. But Daydream, he doesn't pay attention. So.

Person 4 33:31
No, please. Please take some time. Yeah, please.

Person 10 33:52
Nothing was picked up at the time, struggling when it got more towards college, getting more complex job life choices. The usual kind of thing that like everybody struggles with with ADHD.
That just led to diagnosis of depression and then anxiety. Despite medication for that support therapist that just don't help and not tailored towards what would actually support me, it feels like chasing doctors and then five years ago, starting to look at it could be ADHD from other people who've been through.
The process and have diagnosis and relating to the kind of struggles I have.
My experience around here is.
It just kind of been brushed off by the GP because they're so rushed they don't have experience of it where you go and see it's a different reaction to every single time where it's kind of not believed and it's just well, this is your diagnosis from years ago. This is what should work despite the fact that medication hasn't ever helped me. So I've been on various.
Antidepressants.
And it's more just negative side effects than anything positive at all, but not getting any further with any support of investigating in right in our massive lists of what I struggle with and being promised that I'd be put on to referrals.
I don't know whether it was last year, when there were letters sent out around kind of the stopping of any further referrals for ADHD.
My partner who?
Six months after me went and asked at the GP as well, got a letter, so I assume is

on sort of waiting list. I've never had anything. There's no updates. There's no knowing where we're up to, which just adds to everything at the moment, so I don't know if my GP just popped me off, whether there's any kind of process there support and it just makes me feel like I'm a hassle.
Unwanted and that it it's just something that's too much work.
That's ended up with my workers luckily added kind of on the private medical and you're a diverse pathway which has led now to me getting a diagnosis for both ADHD and autism at the end of last year starting medication in January this year.
Then kind of going through that, my worries now are like shared care just doesn't seem to be like a thing accepted anywhere. I'm paying a fortune for medication and for my private medical cover.
The company alone would keep me on for so long as a private cover. They don't support it indefinitely. I don't know whether I go to the back of A7, year to 10 year wait list that I assumed I was on several years ago and restart. I don't know if my diagnostic.
From a private place is even going to be accepted, or whether the kind of feel that I get is that if you go for private.
Needs to look down on because some companies are looked as just making money and putting everybody on it.
It feels like when you go private, you're already very sure when you pay in the cost that it costs to go private.
To the extent that at work I'm working like benefits and everything kind of team. So I know that 83% of people who like took up private medical cover gone through it, have added a diagnosis for ADHD, which is way more than kind of this triage for 20 to 30% of referrals.
I guess going in through AGP, it's not gonna be as kind of high as that because there will be some other people who it's not gonna be that far. But 20 to 30% for the triage seems really low from when my experience. I've had all these other support things they they haven't benefited me in any way, but I've been pushed back time and time again.
To all these kind of things and like, I'm really worried that.
I'm coming up to the end of my 3 yard process and I have nowhere to turn or I'm gonna have to look at what my assessment even means for me and what it means, kind of.
Am I just doomed now where I'm stuck with this?

Person 4 38:48
No, thank you for that, Person 10. So, yeah, everybody's come back, but let's continue that conversation when we go back into the OR let's give you more opportunity. Sorry at 10 past everybody used to automatically comes back in so, so. So thank you for for sharing and thank you to the workshop. I've just been in for, for all your contributions. And we'll give you time and space to share more. Thank you.

Person 1 38:48
Hey, we're back in the main room now.
OK. Thank you.

OK. I think everybody's back in the room. Person 2, would you mind going back to the slide set, please?

Person 2 39:17
Person 4, are you presenting this? Do you want to just continue? I can open it.

Person 4 39:21
Oh, can you. Can you see? Oh, can you see my PowerPoint now? Of course you can.

Person 2 39:23
Yeah, yeah, your slide's still on. Still on support.

Person 4 39:27
Oh, wicked. So yes, I can. Now I can take over again.
Adopting back to my role. Thank you.

Person 1 39:39
OK. Thanks, Person 4. So Person 3 is going to talk about the referral criteria next. We had some questions in our room. If we get time at the end of this session, Person 3, I'll, I'll put them to you. So would you mind just describing what the new kind of referral pathway and criteria is that the triage team are going to use because they we then want to go back into the rooms and look at this criteria in more detail and check whether.
We're looking at the right things or do things need to change. So Person 3, if you wouldn't mind just describing what it is that we're proposing.

Person 3 40:13
Yeah. So that obviously we've we've got a slide there that's presented which kind of covers it realistically.
The way that GPS refer at the moment into whichever service they're referring to won't change, so there'll be most likely continuing to use the ASRS as a screening tool. But instead of referring off to individual services, then I'll go into a hub. The hub will then complete an hour face to face assessment and that will be a comprehensive mental health assessment looking at.
ADHD, mental health, and everything realistically, those that are deemed.
Appropriate for onward assessment for a a funded NHS assessment for ADHD will mostly be those with comorbid mental health or significant physical health issues. Some other things that we're looking at considering as well is for example, where people might be transitioning kind of at that 17 plus age. There's a few other things, but they're they're open consideration, but the the priority.
And the main people that would be going on to treatment as those with Co existing mental health.
And physical health challenges and expected to be round about 20 percent, 30% of the current people who are referred through were basing that off a similar offer that's in Cheshire and Wirral. So it's not putting our fingers in the air. We've seen another service. We've already done this and that's what they're reporting back in terms of

numbers.
OK. Can we go on to the next?

Person 7 41:44
What about disabilities? Does that count?

Person 3 41:47
So disabilities will fall under the physical health. So yeah, it is very much the other comorbid mental health or physical health.
So we've got some.

Person 7 41:58
There's something like autism, for example.

Person 5 41:59
There's something.

Person 3 42:02
Yeah, autism is probably quite likely to be there, but again, it it does depend on severity. I I wouldn't want to rule anything out, but I wouldn't want to be over inclusive of everything as well, but it's very likely that somebody who's got comorbid autism will qualify for an ADHD assessment, but some quite specific criteria. Here is where they had five symptoms or more for over six months had problems since they were a child. We see quite a few of those where.
People have had difficulties for a long time but weren't picked up through the education system, so they're coming into the services newly as an adult.
And again, that we've seen problems in in more than one part of a life where so the school you have to have it in in the two different areas, which is why we use the school sencos. But for adults it would be you know if you were having difficulties in education or higher education work, something like that, finding it really hard to cope.
And then the two also the one at the bottom again where symptoms aren't cause purely and only by mental health. So we've got some.
Information to do on this area and we'll be working with colleagues across the Northwest when we're looking at this as well. Learning from the work that they've already done.

Person 1 43:16
OK, so we've got another 10 minutes or so. If people have any other questions about the referral process and criteria, if you wouldn't mind putting your hand up if you do have a question, it'll be easier for us to monitor who wants to speak any questions before we go into the workshops. Any points of clarification, anything you're not sure about?

Person 9 43:39
Hi there I just wondered for the team. He'll be doing the initial triage, how how kind of trained up on ADHD and its symptoms and supporting people specifically with ADHD. Will that team be?

Person 3 43:55
Don't need to be specialists.

Person 9 44:00
And not gonna be specialist.

Person 3 44:00
So no, that they will need to be specialist. We we yeah, yeah, absolutely.

Person 9 44:03
Yeah, need to be sorry. Yeah, great. Thank you.
Yeah, great. Just because one of the concerns that I had was like the, the first interaction that I had with my GP when I first went was quite, I mean it's a strong word, but there was quite a lot of lasting trauma about it because there were a lot of things that were downplayed and it triggered quite a lot of things for me.

Person 3 44:24
Yeah. No, absolutely. I mean it. It's really key to what we're doing. And not only did there have to be specialists in ADHD, we'll have to have really good knowledge around comprehensive mental health assessments as well.

Person 2 44:37
Thank you, Person 9. Person 8.

Person 8 44:40
Oh yeah, I just wanted to ask about regarding the mental health illness. Like, I didn't really know what was happening to me when I was going through it all. I've never needed support with my addict historically, so.
I went to the doctors and I spoke about mental health, and I've reached a very, very dark period in my life because I didn't know that it was my ADHD. So as much as you can tell, the symptoms are caused by a mental health illness. But I wasn't able to differentiate what was going on. And it's only with hindsight and learning about neurodiversity that I can say, you know what, that's what it was. So I just, I just wanted to talk that please.

Person 3 45:16
Not too thank you.

Person 2 45:17
Thank you. Thank you, Person 11.
Person 11, did you want to has other hands gone down?

Person 11 45:34
Hi. Sorry, I'm sorry I didn't realise I was on meet there. I wanted to make some points very quickly so everyone has a chance to speak. First of all, we still don't have the strengths in there because a lot of people with ADHD are already feeling crappy about themselves. So some strengths.

Person 2 45:35
Yeah.

Person 11 45:49
Some of the strengths based traits in that criteria would be really useful, so they realise you know they come to a point where then they realise it's not just a deficit or a disorder, but it's actually something that can be positive and those are really useful symptoms as well. Things like hyper focus.
Speed of work. Creativity, stuff like that would be I think quite helpful as part of the process.
Having the you, somebody else asked about who is doing the assessment, people who have ADHD make really good assessors because we're so much quick. We can see it straight away. And also I know this might be challenging, but having people from different backgrounds because the experience of somebody from a different culture or someone from the global majority, IE who isn't Mike, is going to be different. And those people aren't getting diagnosed at the same rate.
As the majority of women as well are another one because we know women present differently, we don't have enough female assessors or enough consideration of the way women present. And my last point was just tying into the point about mental health that a couple of other people have made. I think there should be a space for a diagnosis that you can have ADHD and a mental health condition. Not if you have a mental health condition. You can't have ADHD, but a recognition that you can have both. Thank you.

Person 2 47:03
Thank you, Person 4. I've seen your message. I'll just bring Person 12 in and then Person 5.

Person 12 47:10
Hi so pretty much someone already mentioned it.
Oh yeah. So yeah. Same with the GP kind of thing. Like when I got first told to the GP said that I can't have it because I've got anxiety, depression and then it turns out it's actually untreated ADHD which is, you know, made my anxiety depression really bad. And now since I've been diagnosed, I'm not. My depression's gone and my anxiety, it's not anxiety. It's just they just described it as anxiety. So one of my things was kind of like the threshold.
You mentioned about two two problems, part of two difficulties like work and school and things like that or personal life because I got told you can't have ADHD because you went to uni and got you got a job. That's what my GP told me and I just thought that was, you know, horrific and then it wasn't until another GP said no, I think it is ADHD. Anyway, what I was going to say is is that going to be the case like if someone does have a job or is in a relationship, would they not meet that threshold because I just don't want it to end up.
In terms of what the GP, how that GP affected me, obviously you can still have a job and have issues at work and you know have a relationship and still have issues or

find it difficult to manage a relationship. I just want to make sure that that wasn't going to happen.

Person 3 48:24
People can be very, very high functioning and still have significant issues with either ADHD mental health. So know that there's there's not something because you're doing there, you don't qualify. This is a list of trying to look at actually, who do we need to prioritise our services for. So there's nothing that if you do that, you're off the list or if you got a mental health problem you can't have ADHD that that's just not accurate at all. As I think a couple of people have pointed out.

Person 12 48:29
Yeah.
Yeah.
OK.
Yeah.
That's great. Thank you so much.

Person 2 48:51
Thank you, Person 5.

Person 5 48:55
Yes. So my main question is where is our open of? At least when's when's that 20 to 30% number, is that is that is it where? How was that that number determined is is, is, is there is it, is it we already had someone to talking about how they were they were.
Basically classified as a false negative or not or or not or not meetings or or or not. They think enough. I don't know points or or something to get a better to get properly diagnosed and treated so.
Well, it's it's all like it's.
What? What? What is?

Person 3 49:40
Has come the 2030% has come from the work that's already undertaken in Cheshire and Mersey, Merseyside, who have moved to a model similar to this earlier than we did it. It's a guess, we don't know.

Person 2 49:40
Which OK.

Person 5 49:41
What's?

Person 3 49:54
We're not Cheshire and Merseyside we're Greater Manchester. We've got a slightly different population. It's an estimate. That's what we've seen over there. We'll have to see what happens here. So it's not this is we're limiting it 20 percent, 30% of

people. It's just clinically that where we've seen this happening elsewhere, that's what's happened.

Person 5 50:16
Right.

Person 2 50:18
Thank you any.

Person 1 50:18
Are there any other questions?
Sorry to ask, can't see anybody else hand up.
Is there anything in the chat, Person 2, that you've picked up pertinent to this topic?

Person 2 50:30
Yeah, thank you to those that have shared links and resources in there. I just wanted to pick up on the on the point around, could we say symptoms rather than problems being presented in childhood and that's got that's got four likes and in some work that I've done that's been raised as well. So that the language and the terminology. Is really important.
Not sure about the mental health bit. We've we've discussed as well because they could be interlinked, one could cause the other, etcetera.
Comments around how people have you know their experience of of going to the GP and things is comment around females and masking.
And some useful links. So thank you for that.

Person 1 51:18
OK. Thank you everybody. We had a question from our room, Person 3 as well, but it was linked to people that had been offered support and not been sent for diagnosis and maybe they were still struggling.
But hadn't gone back to GP to ask for a referral, but you know, perhaps how do we pick those people up? So if people are continuing with support and not being sent, fold for diagnosis, but clearly things aren't helping them then then what happens? How do we, how do we make sure it's safe for those people?

Person 3 51:52
I mean quite clearly we need to and I think this is this has been brought up on the same a similar group, but we're at Person 1, that's something we need to make sure that people have been forward for the offer, not got an NHS assessment and continue to deteriorate or not do better. We've got to make sure that there's an easy way back into the system or an easy way to highlight that things have got worse. So it's something we definitely need to plan for and understand and make sure that people have got an easy and quick way to highlight where things have got worse.

Person 4 52:24
Yeah, we've just had another question presented in the chat around with the right to choose service be included in this, not just an NHS referral.

Person 3 52:33
So, but to choose our NHS referrals, it's just you choose where you you get those from. So you would go into the triage hub 1st to see whether you qualified for NHS funded treatment and then at the point where it's decided that you did, you would have a choice then about whether you go to local services or to right to choose services at that point.

Person 1 52:54
Thank you. Person 3. If there are no further questions for the time being, then we'll go into our workshops. We have 10 minutes in the workshop and and really it's just for anything that you've not been able to bring up in this session or to have a think if there's anything that we need to change about that list or add to it.
I think that's all I need to say. We've been through the chat, haven't we? OK. So Person 4 will put us in the rooms in a moment.

Person 4 53:25
Thank you.

Person 2 53:27
In 10 minutes.

Person 4 53:29
Yes, you will. Don't forget to record please if you're a facilitator.

Person 2 53:31
Oh, I did first time, so that'll work this time.

Person 4 53:34
Thank you.
You will be in the same room, yes.
Unless I've ended up with, I've ended up with. Oh, I've ended up with more people. I'm lucky we automatically record because we're still in the main room, so this space really is for people who might not have the facilities on their phone or or device to go into a room. So, so welcome all for people who've recently joined us. So obviously on the screen, you can see the suggested criteria. And I think there's been some comments.
Already around some of the narrative and and language we're using against the problems.
But it's really an opportunity to share your thoughts on where these fit for you, whether you feel that these are quantifiable as in can they be marked upon, what would that look like? But also if you feel like there's anything that we shouldn't consider that's in that list or anything that we should consider that's not in that list. So again, it's it's an opportunity to unmake come in if you can raise your hand, if you want to, great. If not, and we want to have a conversation that that's also.
Harry, I'm worried that you've just unmuted, so I'm going to spotlight you if that's OK.

Person 10 54:50
Yeah. Thank you.
It's a really complicated one, this one, and I hear about it from a lot of other people, and it was an experience for me, but the problems from being a child, that is a really, really difficult one. And I think this is where like a lot of push back from the GP was and it's hard for myself as well. It took me a lot of planning to kind of.
Detail stuff.
My memory is horrific.
It's constantly flowing with just other stuff trying to remember what happened as a child is really bad.
It seems to me that all the people that I know with ADHD, they're in the same situation where parents haven't picked it up. They just thought, well, you were clever at school, you were doing OK, you were quiet, you kept to yourself.
They just don't agree with it or seem with my parents. They seemed to be scared, frightened or offended, but I could have ADHD and were really unsupportive.
Through the process, it feels like that one's like a really big sticking point potentially for where it might not be picked up right at that very first GP stage and where it ends up being identified as just a general mental health issue.
And I'll just got to be that evidence of it. But sometimes it's kind of like if you've had the struggles for so long as an adult, you've got that history of the mental health issues that.
They've been ongoing. Stuff isn't helping with it that.
I don't know if it'd be beneficial for GPS to bring it up. There's a possibility rather than people suggest it, like some people might not have heard of the possibility of having ADHD. Could that initial checklist that everybody fills in as part of the process be something that GPS look at for people who aren't having any benefit?
Where they've got an ongoing mental health issue and don't realise that they could have ADHD.
Looking down a different route could pick that up. That's something that would have benefited me so, so long ago. And he's kind of like one of the really upsetting points to me. If I think back at how many years ago, I kind of fallen through and then didn't miss it. It's it's something that could help so many people.

Person 4 57:40
No, I mean thank you so much for that, Person 10. And for the feedback, it's all really helpful to understand kind of how that process works for for different people. So thank you for that Person 13e, welcome.
To the online focus group and I welcome you to come in and share your thoughts.

Person 13 58:01
Sorry, I know I've just jumped in. I've literally just received an e-mail saying it was on and sorry it was on now so I thought and I can't make the next one. So I thought, do you know what, I'll just jump on, but I can very much resonate with what's just been shared at 15 year old. I was taken to the doctors by my mum and put on antidepressants and told that I had depression and anxiety now.

Person 4 58:11
Grateful. Thank you.

Person 13 58:24
Looking back, a very much masked all the ADX G symptoms and I think a lot of the issue is that.
There's a a stereotype as to what ADHD is and how it presents, and it doesn't always present like that. As we know now. But I think back then I didn't present as ADHD. I did well at school, I was quite good, kind of with my focus to a degree. Yeah, I talked too much and all that kind of thing. But on the surface I was OK and at 28, I got diagnosed with PMDD.
I was on and off antidepressants for about 10 years, but I still didn't quite feel like things fitted.
And it was only about five years ago someone said ADHD to me. And I looked and kind of thought, Nah, and that was because of that stereotype of the naughty little boy kind of thing. And having now gone through that process, I'm actually an ADHD coach now. But having gone through that process, it's made me realise how detrimental it's been on my life for all this time. And it's such a shame that.
GPS are so resistant because of the waiting lists are huge and I understand that obviously they have to.
Part of B to a degree. But there should be something for in the middle part, and that's actually something that I want to do as a coach and someone that has workshops. I kind of want to run a course for those people who are dropping in the middle as adults who know they've got it, but it's going to be years till they actually get the proper support. But yeah, I just wanted to share my kind of journey in brief because it's very, very similar and I think it had my daughter's got ADHD.
As as my son and I saw it in my son really early at three years old.
And my daughter then when I realised I had it, I can see it in her because I now know that she's very similar to me. But it's funny how when my son had it, actually it is a genetic condition, so it should be made aware to parents that if a child is presenting like that, potentially look at the parents too. Are they masking? Have they got ADHD? Is it presenting differently?

Person 4 1:00:28
So it just to just to pull in on that point, 'cause, we actually mention it in the presentation, don't we that it it runs in families, we actually set this research that suggests that however, that's not one of the referral criteria or suggested criteria.

Person 13 1:00:38
Yeah.
And it's funny because both my children have, they're not diagnosed, but I'd better life on it. The dad also had a diagnosis. Ironically the same week as me, and I now know my brother's going through the diagnosis process and my mum and my dad both have got ADHD but undiagnosed. But without doubt. So it shows that genetic kind of links there.

Person 4 1:01:03
Yeah. So maybe that needs to be to be put into a referral criteria in respects of family or you know that that genogram that holistic approach to you know is there somebody, you know, a spouse or sibling or parent that has ADHD diagnosis because therefore you're linking it. Right. OK. Well, thank you for going through.

Person 13 1:01:16
Yes.
Yeah. The amount of people, the amount of people I coach that say I only realised I had it when my son or daughter was going through the diagnosis process, because then you start to look at the symptoms and think, hang on, that reflects me as well and I think that's a really important thing for to bear in mind.

Person 4 1:01:43
Thank you so much Person 13seph for sharing that, Person 6. I'm going to bring you in now. I think we've got probably a couple of minutes left and I'll try and get you into Person 5.

Person 13 1:01:45
No worries.

Person 6 1:01:51
That's so quick. And then just echoing basically all that really.
I've went to the doctor several times.
Over the years.
With the symptoms and it's just like, oh, it's it's it'll give you a smatty depressants or like, later when it was CBT and just don't feel like it's it's been a few times and nothing's working or whatever. I actually went to a doctor when I after I'd moved down. I think The Simpsons must have been.

Person 5 1:02:16
Yeah.

Person 6 1:02:24
Lifting on my Elms, it's must've like got worse.
I saw some kind of doctor and it and I remember him saying you don't have a mental illness or anything and then looking on me, you should be relieved. And I'm just like, but it's not really answering the question. There's something wrong there.
Something's up. And it was. It wasn't until after my stepdad got diagnosed.
And I looked his symptoms. And because we're kind of similar characters anyway, and I'm like, this is me.
And he asked. It's got to the point where a child has to be diagnosed for adults to be recognised. It's never picked up at all.
Yeah. And the economy toll is crashing here anyway.
Yeah, that's that's it. Kind of summed up.

Person 4 1:03:09
No, thank you. Thank you so much for sharing that with us. Person 6. Person 5, your your hand went up, so I'd like to bring you in for for the last couple of minutes.

Person 6 1:03:11
Nice.

Person 5 1:03:20
Yeah. Oh yeah, that's so.
And it is when you when you get, when you, when you came up. I know this is that that here.
Family history of ADHD is not under diagnostic criteria with and, and that is an. That is. That seems to me to be an A giant oversight when it when when I just found the three or four sources right now saying that, it reminded me that the heritability of ADHD is 80%, please put it on the list.

Person 4 1:03:56
No, thank you. I think it's something that we we we have to take forward. This isn't our only focus group. We've done quite a few of these. We've actually been on face to face stalls and spoken to over 1000 people and we've had 700 people complete our survey. So we are heaving a lot about this. So. So thank you for kind of validating and for for for sharing your experience of that. I'm going to pull it back into the main room now and then.
There will be further opportunities for you to share. Thank you.

Person 2 1:04:40
Hello.

Person 1 1:04:46
Just wait for everybody to get back into the main room.

Person 4 1:04:52
Not hacking? Let us know. It kind of feels.

Person 2 1:04:55
End up if you're not here.

Person 4 1:04:56
Yeah, I think we've got 18 back in the room.

Person 1 1:05:01
Amazing.

Person 4 1:05:01
So that looks that looks promising.
So we're moving into the discussion about the options, which again we'll invite Person 3 in to do some of that. But as part of our engagement, because this is an online process and you know I think we need to acknowledge that for some people.

Communicating on an online focus group.
And may not be the most appropriate for people are sharing their thoughts, feelings and experiences in open forum like this can be a challenge. We have set up a mentee in the background and we're bringing it to the forefront now because we are going to leave this open all day, so it will be open and and we will review it probably Monday morning.
But there is AQR code Dave if you could scan that and use it a device or if you have an electrical device in front of you that you're able to utilise or take a screenshot of this.
It is www.mently.com and that is the access code 42420188. If you use AQR code it will take you straight to the questions and it's a survey type approach very similar to. You know, you'll see the the questions that you've already been asked in respects of the support and in respects of the triage and we're going to move into now kind of some of the final part of Fiona's back.
There.
Into the final part of of discussing the options, and we'll discuss or certainly Person 3, we'll be discussing some of the our preferred option. So if people would like to take that, I'll take a screenshot.
I'll leave it up as Person 3 starts to talk and then we'll move on to the the next slide.

Person 1 1:06:56
OK. Person 3, do you want to cover this next session? So this is the the last discussion that we're going to have around options at the end of this, we're going to be asking you to use a mentimeter to think about which option you prefer. So Person 4's, sorry, Person 3 is going to talk through each of these options in turn and describe how the pathway might look. And then if we've got any questions of clarification before we move into that kind of voting exercise or choice exercise, that would be welcome. OK, over to you, Person 3.

Person 3 1:07:25
OK, so current referral from GP or how people access it not changing at all. Asrs a screening tool, so an option A what would happen is that would go straight into the triage system.
And they would use the referral criteria that we were talking about earlier to identify whether people were appropriate for an ongoing NHS assessment or not. If they did, they would go on then either to right to choose or to one of the Greater Manchester Commission services for an ADHD assessment plus post diagnostic support. If they didn't, they go into a more generic offer, which is where.
That there's a lot more options around.
Things that that can help.
To be hopefully that the digital programme to provide additional support.
But you go through that triage 1st Ed rather than you went off and had your assessment or you went into that, that kind of very much open general offer which provides that the more general support self self help realistically.

Person 5 1:08:21
I.

Person 3 1:08:28
That's our preferred option. The option B is that when you go into your GP.
Go into that open air of support 1st and it's only if you find that that's not enough for you. Would you then look to go back to have that face to face assessment through the triage team and then either back into the self help support which you are accessing earlier or through to the NHS funded support the option be that the the risks around that are that people who really need help might be delayed from getting it by going through that Open Access first which is why.
With recommended option A as the preferred option that that the ICB are recommending, but again really good to hear from you what your thoughts on that are.

Person 1 1:09:17
Thanks, Person 3. Are there any questions about those options? Because I realise that they are quite complex, but the the main difference between each of them is that in option B people nobody will be triaged in the first instance, only those that are offered support that isn't working and come back.
May be triaged whereas in option a everybody is offered support and some will be triaged. So I suppose option B present to delay. I'm trying to understand it myself Person 3, but is that correct?

Person 3 1:09:52
Yeah.

Person 1 1:09:52
Yeah. Are there any questions?
We've got one lady with a hand up. I think it's Person 9. Yeah.
Embody first, actually and then Person 9. Person 9. OK.

Person 9 1:10:05
7.

Person 14 1:10:07
Hello.
So with option A, would it be possible to?
Do an I apartment approach where patients could self refer into the triage rather than going to the GP first because I think going to the GP about it already.
Creates quite a large barrier currently because GPS there's quite a lot of stigma around ADHD because of the amount of referrals that are going to.
With the GP practises so I think they get frustrated and don't really listen.
And I think if a patient could complete the form themselves and self referring to.
The triaging service that would remove a barrier for them.

Person 3 1:11:00
It's something that that we need to consider the the difficulty is there's so much information that the GP holds that we need with the referral it. It's really critical that we get background, especially around any cardiac or significant health issues along with that referral.

Person 14 1:11:15
Yeah.

Person 3 1:11:16
Again, I mean, we've heard this from GPS as well that that they're asking us to look at that kind of model as well and.
I I come from talking therapies, I'm an absolute advocate of self referral, so we'll definitely look at it, but it won't be something that we're doing be doing to start off with. And I think there was a question in the chat. Is it just GPS, it's from healthcare clinicians, so it it could, if you are seeing a a different person in secondary care for an acute.
Physical health they they potentially could refer you in there as well, but primarily it will be from the GP or practise nurse.

Person 1 1:11:57
Questions Person 2.

Person 2 1:11:58
And sorry, I was going to say, yeah, there's a question in the chat from Fiona about whether there's a target in terms of time, whether it could be 30 days or nine months to assessment, if there's any sort of timeline around, you know, when people will be seen in the new service.

Person 3 1:12:17
Yes, there is. There's very much timelines because I've just written our spec and I can't remember what they are, but it it will be following that the NHS standard of 18 weeks, we're a long way off that we think it will probably take us about two years to try and catch up. But the idea is that everybody would be seen and those who require an assessment would be having that assessment within 18 weeks.

Person 2 1:12:41
Thank you. And Matthew had said about having both options.
Option here for risky or high priority people and option B for someone who hasn't tried anything else before and correct me if I'm wrong Person 3, but I imagine that the waiting list at present we don't know who is high risk and who is not on that list, so everybody will need to go through that process to find out who is more high risk than others.

Person 3 1:13:03
Yep.

Person 2 1:13:09
Fiona's put whilst waiting lists are high. Can't there be an option B when someone can find self help for the meantime?
And I think that is the way the option. It works. Yeah. So whilst you're waiting or anyone can access that support that will be available.

Person 3 1:13:18
It will, Yep.

Person 2 1:13:26
On that.
Matthew said can NHS services all pulled together like we did with COVID? Looking at staff from all areas for this service?

Person 3 1:13:37
I see if I'm being really honest. I think all of our areas are overstretched. That is already we're we're going through some significant changes at the moment and I I can't think of any area where realistically we would be able to identify staff from.

Person 2 1:13:42
Yeah.

Person 3 1:13:53
I mean, even with our triage scenes with, they're going to be taken to a certain extent from existing offers and because we need the experience and the expertise there. But the yeah, I understand the question, I understand the thing, but.
Difficulty was when we had COVID is. There's other things we said, right? Well, we're not going to do any of those now. We we put a lot of operations on hold. We can't do that anymore. But we can't pull things from other areas because we've got to keep those. We've got to keep everything up and running now. Whereas in COVID there's certain things we determined and said we're not going to do those for for the next six or nine months.

Person 2 1:14:08
Move.
Yeah.
I've seen that. Yeah. And before I bring Person 14 in as well, Person 8 is asked. How long does it typically take from this console test consultation stage to implement in the new way of working?

Person 3 1:14:41
Is that for me to answer?

Person 2 1:14:43
I'm not sure.

Person 3 1:14:45
I can't honestly say I know and and and the reason I don't know is because we are going to have to do what's called procurement and having done a lot of procurement it it can be very quick and it can be very lengthy. We we want to get this going the day after what we want. We want to study and look at everything that we've we've had put in place, but we want to get this model up and running as quickly as we possibly can.
We may encounter some delays in doing that, but.

Person 2 1:15:09
Mm hmm mm hmm.

Person 3 1:15:13
Certainly from us as literally as soon as we can get things started, we will.

Person 2 1:15:18
Thank you.

Person 3 1:15:18
People can't keep waiting.

Person 2 1:15:21
Person 14.

Person 14 1:15:24
What social prescribers be able to refer into the service 'cause? I think that would take some of the pressure off the GPS.

Person 3 1:15:34
Not at this point, knowing that that's again because of the history of the physical health, it would need to come from the GP with that information.
Certainly something we can look at in the future though.

Person 14 1:15:43
It they would, they'd be able to access the same information.
Because they have access to e-mail. Sorry I work as a social prescriber.

Person 3 1:15:56
So you would want, you would want that understanding. So although you can access the system, are you gonna be able to pull off there potential results which haven't been moved into any formal diagnosis at the moment we need the GPS understanding or or GP or practise nurse understanding of actually other things that sit behind the the referral that they're making. But as I say, you know, I think you're in a great position going forwards, but it's not something we can look at at the start.

Person 1 1:16:27
Thanks, Person 3. We've got time for maybe the last two questions. I think two more people have got their hands up and anyone else, if you've got any further questions,

pop them in the chats and we'll answer them as part of the reporting process. Thank you.

Person 9 1:16:44
Hi. Just a quick question, I think I just to agree with you that my preferred option is option A as I think the undiagnosed ADHD adults particularly have probably tried self help quite a lot through their lives and the failure of that is really really devastating and has a devastating impact to the quality of your life.
My my my concern is with the statistics being so low at the point of triage in terms of who will go on for the assessment and they're needing to be some kind of comorbid thing.
What's the safeguarding around the people who are referred into that self help pool to ensure that they're not coming to any further harm whilst in that and checking back in to see if they have developed any signs of any additional comorbid mental health issues or struggles that could be put in them at risk of I finally asked for help. I've been I've hit a failure of what I thought was happening to me.
And now I'm trying again to support myself and trying all these things but failing at them.
Which could trigger a mental health crisis.

Person 3 1:17:55
That should be picked up during the the hour face to face assessment. There won't be any ongoing checking of people who have gone through that. There's not the capacity to do that, but I'm hoping that within that there'll be a discussion around if things changed or if people needed to do something differently and also routes back into the system.

Person 2 1:18:15
Thank you and Person 15?

Person 15 1:18:23
I was just wondering if it would be helpful or kind of quicker if there was an option to self refer but with maybe a quicker kind of GP appointment than would be needed if there wasn't that to kind of go over.
Other kind of conditions and take blood pressure.
And stuff like that.

Person 3 1:18:48
As I say, I mean if it where we are at the moment, we need to to look at maintaining the existing referral routes that we've got.
We absolutely can look at that in the future, but it it's just not something we're going to be able to do at the moment. We've got to get this system configured and set up properly and to do that, we need comprehensive records from from people's GP primary care episodes, because it's not just the GP, they also hold information from any other services that people have been. So that may be a history of mental health. It may be a history of other physical health.

And and we do need that consolidated.
History behind the referral to start off with. I'm not saying it it it's never going to be there, but it is something we're going to need to look at down the line.

Person 1 1:19:34
OK. Thanks everybody. Person 4's just going to remind everybody about the mentimeter before I go into the next steps.

Person 4 1:19:41
Yeah, please do participate in showing your thoughts and feelings on this. There will be the options. Questions. So you'll see the picture of option A. The illustration of option A. The illustration of option B, and then it will ask you to have a sliding scale and the sliding scale is 1 to 5 S, one being I prefer. I definitely prefer option A to. I mostly prefer option A to sit in the middle is I. I don't prefer either option A or B.
And then four is, I mostly prefer option B or I definitely prefer option B, so we're using a sliding scale.
To do that, there is then a supplemental question about why have you chosen that cause what's really important to us is why do you like that? Or why do you dislike that? Or why do you sit in differently? Because it's really important to how that might impact you and that will help us understand some of the direct lived experience. And then there is the last question is anything else you'd like to share with any thoughts, feelings or contributions that you would like?
To have as part of the ongoing consultation in the chat as well, and I will read it, we'll we'll add our e-mail. So if anybody would like to share their own lived experience in any way or anything that they didn't feel that they've been able to ask or get out today, please feel free to to e-mail us that. So we are going to move on through the slides if anybody needs the QR code, it is at the end as well.

Person 1 1:21:11
Thanks. Person 4. You want to keep moving through the slides to next steps, please.
OK, so a huge thank you from us. We've had a whole load of information that some things that I've not heard before and the diversity in the room I think has helped with that as well. So we've had people who've lived experience, we've had people who are providing services, whether that be through the NHS or the vcse sector. So we've got a massive amount of feedback, very, very useful so.
Everything that you've told us today will come together into a report and will be presented with the rest of the consultation that we're doing to Commissioners.
The consultation closes at midnight on the 17th of June, so there's just over a week away. At the moment we've got almost 1000 survey responses. I think there's 825 at the last account, so we're really encouraging, if you haven't taken part in that survey, please do so or spread the news so we can get as many views as possible. We have also what are you putting that on for nesca?
Person 4 gets running away, runs away with himself on the slides, go back to where we were. Yeah, I will mention that. Thank you.
So and I need to see what's in front of me so I can present it just the way I work.

So as I was saying, we've got until the 17th of June midnight so that some people can give their views, we'll bring everything together in a report. It'll be published on our website too. The other thing that we've been doing is going out to localities with pop up styles and speaking to people that wouldn't necessarily come to this space. So for example, we were at Manmet University yesterday speaking to students because we know that there are.
Particular issues for people that are studying, if they're not being supported, for example, and we've been to other places too. So we've been to achieve drug and alcohol services in Salford. I've spoken to people in the criminal justice system. So we are trying to get into as many places as possible, but please do encourage people to get involved if there are people that you think need to have the say, you can move on to the next slide now. Thank you.
Yeah. So finally, we just wanted to share with you how to give further thoughts. So the QR code is said it leads you to our website where you'll find further information. Our e-mail address is there too. I know a couple of you wanted to e-mail me with certain things, so that's fine. Please do so. And we have our mobile phone as well if anybody wants to call us or send us a text. So hopefully you've said everything that you want to.
If not, as I say, they're meant to, metre is still open and will be for the rest of the day. And we will pull all this together and feed it back to you. So we'll let you know where the report will be. So is there anything anybody else wants to say? Person 4. Person 2. Person 3.

Person 4 1:24:16
I I just think it's been a really well attended, really diverse and I just would like to thank everybody for sharing and being so open with us today because without that feedback we can't, you know, record and promote the the best service moving forward. So thank you.

Person 1 1:24:36
Great. Thank you, Person 4.

Person 2 1:24:36
Thank you. And to continue to share the you know the link to the web page and the information on the survey with anyone who you think might be relevant to continue to give us that feedback up until the 17th of June or whenever it is.

Person 1 1:24:52
OK, great. Thank you everybody. I'm going to close the meeting. If there's anything that you've not been able to say. And I feel that you want to please use the QR code 01 person with a hand up before we leave. Person 14, I think it is.

Person 14 1:25:06
You able to share the slide so that they can be shared with our team? Thank you.

Person 1 1:25:10
Yeah. Yes, we'll definitely do that, Person 14. Thank you.

OK everyone, I'll close the meeting. So thank you so much. Enjoy the rest of your day and your weekends. Thank you. Bye bye.

10th June 2025, Online Focus Group, MS Teams

Transcript

10 June 2025, 05:05pm

Person 1 started transcription

Person 2 0:03
Remember, a couple of years ago there were clinical commissioning groups in each locality, so each of the 10 localities in Greater Manchester and they all came together a few years ago to form the Integrated Care Board. So we have the budget for health and care across Greater Manchester, which is approximately 8.5 billion. So it's a, it's a big chunk of money, but it doesn't go very far when we break it down in terms of what we're having to provide, including hospital services, etc.
So some of that money is obviously spent on ADHD adults, ADHD, and we want to make sure that it's spent in the right way.
So that's who we are. We work together with Grace, managed to integrated Care Partnership, which is the Combined Authority, GP practises, hospitals and the Council and the wider voluntary and community and social enterprise sector. And that's just to make sure that we're all doing as much as we can to support people's well-being because it isn't just about offering NHS services. Obviously. Next slide please.
Person 1.
So in terms of the aims today, then we really want to inform you of our plans. So to let you know what's proposed in terms of adults, ADHD services in Greater Manchester and we want to talk to you about some of the challenges that we're facing. So Person 3 will do that, but we really want you to understand from our perspective and we need to understand from your perspective what the issues are and what the challenges are around ADHD services.
And primarily it's about obtaining your input and thoughts on those plans so that we can make sure that they feed into the consultation.
Person 1 will talk about the consultation in a moment in terms of when that's ending and how we're collecting other people's views. Next slide please, Person 1.
So this is the agenda.
In a moment, I'll pass over to Person 1, who will introduce the consultation and Person 3, who will talk from a technical perspective about what the plans are around changes to adults, ADHD services. Then at 6:20 we'll go into a discussion. So we'll put people into breakout rooms. Actually, I don't know how many people are on today, Person 1, but if it's less than 8, then we might want to stay in one room.

Person 1 2:23
I've been so far, but 66 so far, sorry.

Person 2 2:27
So let's break out into two rooms. Then I think the Person 1, you will assign people automatically, won't you? And there'll be a facilitator in each room. So we'll have 20 minutes to talk about the discussion points, and then we'll come back to the main room.
Then we're going to be talking about triage and referral specifically. So Person 3 will go into detail about how the proposed and that's a really important word triage process might look and in particular around the referral criteria, really want your views on those.
At the moment they're not set in stone, therefore discussion, so really important that you you know about them and you're able to input and there will be a chance for Q&A as well. If there's anything that you're not sure about. And then finally, we'll go into voting on option A and B and by then hopefully you'll have enough information to be able to take part in that exercise, which will do via the chat or mentimeter. And then we'll aim to close around 7:25.
Thank you, Person 1. Next slide please.
She's got.

Person 1 3:32
It is off to me. Thank you so much. So we are currently working up a working towards a definition. Now. We recognise that this does have a deficit model and we are aware that through this process we will be reevaluating our terminology and our definitions. But as it stands, this is where we are at as a system. We welcome your thoughts and feelings as I've put in the chat on this. If you'd like to say your thoughts or your feelings or your definition.
We do welcome that to enable us to develop something that's a little bit more meaningful interactive with by patients and members of the public. As it stands, when we talk about ADHD, we talk about an attention deficit hyperactivity disorder, which is a condition that affects people's behaviour. People with ADHD can't seem restless. They may have trouble concentrating and may act on impulse.
The exact cause of ADHD is unknown, but the condition has been shown to running families.
Researchers also identified a number of possible differences in the brains of people with ADHD when compared with those without the condition.
When we talk about the consultation, we are running an 8 week consultation which started on the 23rd of April and will conclude next Tuesday on the 17th of June. The consultation is about improving ADHD services in Greater Manchester and it's about two potential options which will showcase through conversations today.
We want to hear your views not just on those two options, but some other elements, including.
Support and refill criteria.

The consultation is not about ADHD services for children and young people. We did carry out a piece of engagement last year and there is an e-mail at the end on our website which you can go on to find more information and we we do work in thoughts but through the duration of today's conversation, we will be focusing our attentions on adult ADHD services. Your feedback, which is really important to us, will help make sure that we understand what is important to the people who may be affected by.
Changes and what your needs are. It is important that we consider this when we make the final decision on the best option for changes to adult ADHD services.
Whilst we talk about two options, consultation is not about a vote, so we will be considerate about everybody's views, thoughts and feelings and compile recommendations which will be taken forward to Commissioners to ensure that they can make informed decisions on the service.
Implementation moving forward.
I'll hand over to Person 3 now to talk a little bit further. Thank you.

Person 3 6:35
All these years and I'm still not taking myself off mute. OK, so why things need to change.
Essentially, we're reviewing the service because when we originally designed these and a lot of them were commissioned round about 2014 through to 2016.
At that point, I can talk specifically in time, so I'll be commissioned the service for 73 people a year and we get more than that a week now and it's very similar in a lot of other areas.
Estimate at the moment that we've got round about 25,000 people waiting for a diagnosis and we get round about 1000 new referrals every month.
So the demand really, really outstrips what we can supply.
At the moment it's not consistently, but on average all people could wait over seven years for an assessment and diagnosis within our our core offer.
As well, at the moment it doesn't matter who you are. What's going on? How how bad you are if you come in, you go at the bottom of the list and we have very, very few NHS services that we provide that way.
Normally people are seen based on on their risk, their needs.
So for example, you go to A&E if you're really, really unwell. You seem very, very quickly if you're not as unwell and and you can wait for a little bit, you do wait for a little bit.
So if the demand carries on rising at the current levels, says here it will cost the NHS Greater Manchester 10 million a year. We've just reviewed that actually and it's considerably higher than that already. So we're looking at between 12 and 15,000,000 a year to fund assessment services capable of meeting the demand. And it's For these reasons that the Greater Manchester needs to change.
We need to better support the people who really, really do need the service.

Can we go to the next slide?

So what do we want to do? So we want it to be equitable and consistent. We don't want somebody in Wigan being seen in six months and somebody in Manchester being seen seven years. It's got to be a consistent offer and we want a service that understands and responds to needs of individuals, not just the one-size-fits-all model.

And again the assessment.

Diagnosis for those who really need it. But I know for a open offer of support for everybody. So how are we going to do this? So we will prioritise people on waiting lists in most clinical need.

We'll be looking at what's called a newly formed triage team, which is where the referral into triage team so the way people are referred at the moment is you go to GP.

I think just about everybody does the arsr screening form and that wouldn't change, but instead of going directly to a service, you go into a triage team.

You'd sit down with somebody face to face and have an hour long assessment to to really look at everything, including anything else that you might be presenting with and where you might get some additional support through other areas. And then we're going to be using some triage criteria which we are going to be talking about later on about who then qualifies to go through.

For an NHS funded assessment for ADHD.

So the new model of care, so it's one consistent offer across everywhere. There'll be shorter waiting times based on those qualifying for the assessment. There will be an Open Access to support for anybody who needs it. So whether somebody's gone through a service being diagnosed, whether they choose to choose medication or not, there will be a much more what's called post diagnostic support. But that's also open diagnostic support. So people don't need to have a diagnosis to learn about things that might help them.

Strategies. They can use things that can help them. Lots of information about say for example, if you go into access to work to get some support things you can ask for because quite often people are just referred there without too much information on that and also lots of information about your legal rights as well. A lot of people are barred from accessing things because they don't have an official diagnosis which is not actually correct. So all that kind of information and sharing that everywhere.

So.

It becomes a needs led approach. It's not based on a medical model and it's not based on a diagnostic model, so the assessments will be prioritised, though those who really need them and need them quickly will be seen much higher in the queue and much quicker as well.

The next slide, please, Person 1.

Person 2 11:03
That's me, Person 3. Yeah. So the three things that we're asking people in the consultation and here today.
Our bullet pointed here so one is around support and checking back with you in terms of what support should be in place and we've got some ideas already, but we've already heard from over 2000 people about what they think needs to be in that package. So we wanted to break into discussion in a moment so we can have a chat a little bit more about that.
Then the criteria are checklists. That's going to be used by the new triage team when they're assessing people in terms of whether they should go forward for diagnosis or not. So again, the Commissioners have some ideas we want to share those with you and pick up if you think there's anything missing or you've any concerns about what they might be. And then finally, the option. So we prefer option A and we'll describe that in a moment. But there is an option B2. So we want want you to have a say in terms of which.
I think should go forward and the reasons why. So those are the three things that can be influenced. Obviously Person 3 has talked a lot about the wider package and the things that we're putting in place, but these are the three things that we really need to shape and hear from you about.
South next slide, please, Person 1.
So we'll break out in two discussions then and we'll have a chat about the support package and get your views in terms of what you think needs to be done. So you're automatically going to the breakout room. Some of you will stay here.
And others will be placed in a room and you've got 20 minutes. For this discussion, I'm just checking the time. Yes, we meant to start at 6:20. So we're dead on time. Really. And then we'll come back into the main room at 6:40. Thank you.

Person 1 12:59
You start to be moved into rooms now.
There we go. Person 3 and Person 10 are leaving, so there should be 5 in that space and five in this space, which is wonderful.
Can everybody still see the support question on the screen?

Person 4 13:16
Yeah.

Person 1 13:17
This is a place to unmute and for us to have a really open.
Fluid conversation, which aids us in kind of answering this questions, which is very much going to be up and on and over to you yourselves. So we're talking about in, in both options.
Support services being available for people now that will be relevant to different times and spaces, but we are asking.
About what help and support do you feel people with ADHD, their families, support

systems need and where should we be prioritising our focus in regards to working with these sort of questions are what are your thoughts on this list and is there anything missing and where do you think we should be prioritising our focus?
So it's really much very much over to to to the three of you that have joined us to to participate in this workshop around what your thoughts are.

Person 5 14:19
Oh, Megan.

Person 1 14:20
Hi, Person 5.

Person 2 14:21
So Person 5, nice to be here.

Person 5 14:22
That's hello.

Person 1 14:22
Please welcome.

Person 5 14:25
I think something that's really missing off this, that's something I think that in service as you see a lot of is relationships and family like relationships and parenting. If you are ADHD, you're up to five times more likely to be in an abusive relationship.
And what we see within our services parents and in, do you know what you and your local children's services and kind of?
Social care and stuff like that. A lot of the families in your divergent. What? What? What we realising now is a lot of menu divergent and they might struggle with a lot of the tasks of parenting, prioritising parenting, you know.
Dealing with kinds of children when they're feeling dysregulated, so I think that's something that's really relationship as well as parents and I think is really, really important. And I think because people might not understand when they.
When they when they fill the forms in that that could be an option.
But I think what we're seeing in services is it's very distinct. The people are really struggling in relation to parent and in relation to like intimate relationships and family relationships.

Person 1 15:39
Thank you so much for that feedback, Person 5. And can I just ask in regards to that statistic that you mentioned, any respects of those people with diagnosed ADHD being more at risk of kind of domestic abuse or violent relationship, is that across a piece in regards to heterosexual same sex relationships across across that or is it it's not?

Person 5 15:54
It doesn't. It doesn't. It was it was. It was at the Nhsi went to an NHS England

conference in November, October and it was put on because of Neurodivergence in the perinatal period, and they identified that part of I don't know, who was it, who was, but that was brought to it. That up. You're up to five times more likely it was women with ADHD. But again, I don't know where the stats have come from.
Are up to, yeah.

Person 1 16:22
Really interesting information. So we'll look into that. Thank you for that. I think it's just it's just important for us to understand as well dynamically around.

Person 5 16:24
Yeah.
Yeah.

Person 1 16:30
Different people's circumstances and sort of thank you for that Reds. I saw your your space light up there. I don't know if you're going to come in and say something or whether it was more of a of just a. Yeah, I don't know. Were you going to come in say something? Yeah, you were brilliant.

Person 6 16:42
Yep, yeah, yeah. Sorry, I haven't got a camera on this computer. I completely forgot. That's not a bad thing for you guys.
Yeah, a lot of the assessments we did, we we don't actually do that many assessments. It's something we're trying to explore doing more of. But the adult ones that we've done definitely see relationship difficulties there. You can talk about Person 5, but a big one for us is work.
A lot of people have come to us with difficulties at work. I work with someone who's got ADHD and I see the day-to-day struggle that she does have, which and it links him with all mental health anxiety.
Eating.
All those things that kind of encompasses a lot of people need that support with work and how to manage their, their work life balance with ADHD. That's an absolute massive one that we see.
And yeah, and the relationship side of it, I think all these on the list are definitely. Important because it's linked to, obviously, of impulsivity stuff as well, isn't it? And as well, but work is an absolute massive area that that needs to be addressed. We've had a few referrals from Occupational health, health departments or HR for people who.
Need an ADHD or even an autism assessment as well because they've been struggling in the workplace.
So that's a massive area that we're seeing.

Person 1 18:01
Thank you for that. I'm going to bring Nicola in and I might come back and reflect on

some of that because I'd love to unpick a bit more of that. Nicola, would you, would you like to come in?

Person 4 18:10
Yeah. I just wanted to say I'm looking sort of at the list there and.
Before that.
Looking at supporting people when they're diagnosed because it's like you're diagnosed and then off, you pop and everything seems to make sense and it's great. And then all of a sudden, it's. Oh, and that's when some of these things come in, your anxiety, your mental health. So I think there needs to be.
Some sort of support of how to cope and deal with.
When you've been diagnosed and I don't, I don't mind saying I've I've been diagnosed. I have autism.
And ADHD.
And it 55 and my life was really hard, but not as hard as getting my diagnosis and then trying to.
Carry on, yeah.

Person 1 19:07
Thank you for sharing that. It's always really kind of a bit of a privilege to kind of hear people's lived experience and stories and how how this has impacted them. And I think we are hearing quite a lot about work reflecting back on a new and we are hearing lots about pre diagnostic support and post diagnostic support and that actually there are lots of.
Life events that might change how your ADHD manifests itself or symptomatically kind of, you know, you might have highs and lows, etcetera and all those things that, those things that life happened really would like to understand from a work perspective. Obviously, you mentioned there about OT doing referrals etcetera.

Person 4 19:34
Yeah.

Person 6 19:35
Hmm.

Person 1 19:48
What? What would that look like if we were to look at work as a subject matter? What might that look like? Would it be about employers? Would it be about employees? Would it be how? What are you thinking there?

Person 5 20:01
I've just sorry, sorry. Go on. Can I get you gone?

Person 6 20:01
That mate. Oh Person 4s, alright.
So sorry. Person 5, you go.

Person 1 20:05
Yeah, feeding. And I'll go. I'll go to you, Person 5.

Person 5 20:06
I'm just. I'm going to sorry.
So we'll just, we'll just, I'll just keep interrupting. Sorry, I'm going through. So at the moment, I'm having workplace coaching through the DWP. I've just started this week and I'm in burnout at the moment and I think possibly what Nicola was describing then is I'm also I'm having a Norton assessment soon. So one of the things on there that's not on there is that like the source of the Co occurrence of that, the research shows it's really highly Co occurren now so.
So we should be starting to think about them together a bit, because what quite often happens is when you medicate a for ADHD, the autistic traits kind of become more obvious because the ADHD is not masking it anymore, and that that has caused me like a whole wealth of other issues that I hadn't realised. The realisation of those traits. Sensory sensitivities.

Person 6 20:35
Hmm.

Person 5 21:00
At the moment, because I'm in burnout, there's lots of foods that I could normally eat that I can't eat because I cannot tolerate them. I can't tolerate the texture. I can't tolerate the smell, the taste.
But also in relation to the work stuff, it's that it's that OverDrive I think to to prove yourself like if you've gone through school thinking you've not done good enough, you will work 110% all of the time with or without the accommodations. And I'm really lucky I work with the tip. My, my team is all we work in mental health saturns. And so we've got two psychologists on the team and I'm really lucky. But even I find it hard with that level of support.
And the safety that I've got because.
Is this internal thing that tells me that I'm still not doing good enough no matter what I do, and I think it's it's. It's really tricky to navigate that. But yes, I think I think having autism is something that's explored that but also.
My workplace will get a session from the DWP around raising their awareness of neurodivergent and the impact so it can be things like RSD, so someone might give you some constructive feedback and you might internalise that as something that you've got you experiencing 10 shame about.
And then might struggle to regulate yourself. For me, it's it equipment. If the IT equipment doesn't work, I can deal with complex families and I can deal with things chaotic things. But if the IT systems don't work or I've forgotten my password because it's a fluctuating disability, I can get onto things one day. The next day. I can't and I and I can't work out why. And then I'm. I'm anxious about asking for help because I know that people may think, well, you could do it yesterday. Like, what's

wrong with you?
That's my internal narrative, then.

Person 2 22:46
Can I ask a question linked to that because I've had a lot of feedback in terms of people being supported at work and surprisingly in the NHS as well, so we went to Manchester Royal Infirmary with a pop up stall and lots of staff were saying that they didn't feel supported and one of the reasons they thought it was an issue was that they didn't think it was given equal parity to other conditions. So say for example yeah if it's called disability or maybe something like Ms for example.

Person 5 23:08
The question of physical disability, especially not.

Person 2 23:14
They were saying that staff would be supported through that.
And, you know, people would respect that. But when they mentioned ADHD, then there's still a bit of a taboo around it. And it was almost as if, like it was just.
Ignored to an extent though.

Person 5 23:28
I think that I think people think once you've got the things in place as well that that's solved, that you can also. You can then can then you can work at the same pace or harder than everyone else because you've got these accommodations and it just doesn't work like that. My brain will never function the same as others. So there's certain circumstances where it will excel, but then there's other circumstances where it just won't or it cannot access that bit of my brain and the memory is of how to do things.
So it's it's and that's what I think people don't understand because they they see you and and it's fluctuating.
You see, you're on a good day. But what they don't realise is then you go home and there's intense shame and like criticism of maybe Blair and things out in a meeting or taking too much time in a meeting, for example.
So there's there's all of that that goes alongside her.

Person 1 24:15
Thank you. Thank you for that, Reg. What? What, what? What was your kind of? Was it similar? It'd be great to hear kind of your perspective.

Person 6 24:16
I go. Yeah, sorry.
Yeah, I was gonna say a couple things. I wanted to touch what Person 4s said on there about the diagnosis and the support and things like that, if any. We do autism assessments as well. So if people come to us for autism, ADHD diagnosis, I always say to them, why do you want it?
Are you doing it for the label or are you doing it so it's going to open doors of support

for you and we only do it if it's going to further.
Make a difference in life and things like that. We don't want people just get label and be stuck without any support.
What what we think about the workplace that.
And with the private service I used to work in the NHS, I've got OCD, so I know full well how it's delivered mental health condition. So been really lucky to be able to create a company that is neurofirming mental health friendly, that people can be themselves and then we use that approach in our assessments and our work as well. And what you're saying about the ADHD assessments and crossover with autism, it is huge.
I was doing ADHD assessment today and the answers I was getting to the questions I was thinking wow, I could. I could do an autism assessment on.
On this person as well, so that there's such a crossover there, but it's trying to work out what's ADHD, what's autism, what's mental health, as you know, it's really, really complex, isn't it? To work it all out?
And then from the tease perspective is supporting in the workplace, I'm hoping to maybe create a bit of a an OT occupational health neurofirming Occupational Health service where we do functional assessments and find those reasonable adjustments for people in work.
And see how we can develop that side of things as well, because I think OT is key in in that area.
I woke in the functional assessments, workplace assessments and how.
Your activity analysis and break everything down. I don't have you ever just asking you, Person 5, if you don't mind me asking, have you ever had an OT assessment or anything around your ADHD?

Person 5 26:08
So I had.
The oh gosh, what have I had? I've I had when I when I got. You're going to get the origin story now because I can't just get the actual. The bit that you want. So not an OT assessment. I had the DWP kind of where you talk with them over the phone.
But I've not had an OT assessment. I've got, I've got some equipment.
But yeah, and I've got some guidelines.
But that's it really. I've not had a like a proper, I would say, assessment assessment.

Person 6 26:40
OK, now. But we did had the referral for guy in work has got autism and he's got support work with him. He's retiring. So our role in that was to find what tasks he can do, functional assessment, everything like that, the regional adjustments he'll need. Once his support workers finished and the additional support and things. So that's an area we kind of want to tap into on more of a neurodivergent people as well and mental health side of things as well to hopefully make the workplace a better place for people with sort of hidden disabilities and different conditions.

Person 5 27:10
No. Yeah. And I do think what you said. What what you were saying before, Nick, I think it was, I think it was Nicola.
Around it's not. Given this, it's almost like right. You wouldn't say to it to a person with a wheelchair like you've got a ramp now, that's all you need, that you're done. And I think it's that. It's that kind of overwhelming thing. This is not going away. This is never going to go away. It's always going to be something that's part of me. But but.

Person 6 27:25
Me.

Person 5 27:36
Constantly having to you feel like you're constantly justifying why you need support so.

Person 6 27:41
Mm hmm.

Person 5 27:41
Because I'm in burnouts at the moment, my son, through sensitivities, have just, they're off the scale. So being around people is really overwhelming. And that what that looks like for me is in work. It's completely fine. No one else would know. But I'm I'm when I come home, I cannot do the things that I need to do within the house. Like I can't cook meals. I can't do any admin tasks of my life. I'm quite tearful all the time. I've withdrawn from people. But.
The effort of.
Who I can't change who I present. As in work, I will always present as the same way, even if I'm on my knees and years ago when I first experienced burnout, I thought it was depression and the only way I could convey to people how how I felt was to go on with and without makeup on. And I never. I never go in without makeup on, but that it was like I couldn't because I would always like, laugh and joke the same. I would always present as the same and that's what masking is, isn't it? It's kind of. People go well. She didn't seem like that. We'll know because.
You but what it does is it. It reduces your life quality and your quality of life at home and it impacts on relationships. You know, I'm really lucky. I've got a very supportive partner.
But it impacts on friendships and stuff and relationships, and I get really upset because other people are not so lucky. I'm really lucky and within work and within my friends and family and partner that I'm supported, but not everyone has that experience and that's that's the people I worry for.
The people who don't have that support because it's really hard when you have.

Person 6 29:16
It's happening. I've got that support. Definitely. It's it, yeah.

Person 5 29:18
You know.

Person 1 29:21
I have 5 minutes left in this space for this conversation. Welcome server to the to the conversation. I have put a hello in the chat and feel free. Please feel free to contribute and get stuck in wherever you feel most appropriate.
We've spoke quite a lot though in regards to some support elements and there seems to be an agreement that these on the screen have a place.
And are important to people.
And I think from what I'm hearing, what I'm hearing is it's important to have pre diagnostic support around this.
Certainly as well post and to continue that openness of access to support.
I'm also hearing that work plays a really work support in in multiple approaches, whether that be work supporting their employees or the systems supporting employers to understand how to support their employees, we need to get a bit of a cycle around what that looks like. Have I captured some of that?
That nuance or care, or is there something else that I've missed that you think let's focus on that for a couple of minutes?

Person 5 30:35
Hmm.

Person 6 30:35
If you can manage to needs better than one person, then you can focus a bit better. But if you're in, if you are struggling with that then a lot of employers don't understand really what sentry needs are now to put those accommodations in place. I'd say 90% of our referrals are for century assessments. It's just such a an unmet area. And then when you start looking at the sensory elements of people's lives and things like that and you put strategies in place, then it makes a massive difference. We've one of my colleagues have recently started working with the 65 year old lady who.
All their life is supported by a husband. He died and then it became. She then became aware that she's got autism and ADHD and sensory needs. So she's going through some sentry sessions now. So which is amazing because it's meeting her need. But I think with workplace and just in barely general life, really we need to be making people aware of sensory needs and and how to put accommodations in place.

Person 5 31:29
It's for me. What? What it looks like for me is I can work up from home a little bit more.
And you know, it might not be always that way, but if there's stuff that I can do at home and it's not, you know, I can't do it every day, but enough for me massively

helps because going into that office environment and then masking with people being the way I normally am, really struggling with the sensory issues, but also it's depleting what little energy I've got.
So I think the sensory issues are really and it's scary when suddenly you can't eat the foods that you would normally eat. And you know, there's a lot of eating disorders within neurodivergence and it makes sense, like I wouldn't have had that understanding in the past that that, oh, something's changed. But it's very distinct now to me, it's very obvious what it is, what's going on. And it's it's really scary. When it happens.

Person 6 32:20
Yeah. Is when you're in it, it's really hard to come out of it as well, isn't it, Person 5?

Person 1 32:23
Thank you. Thank you so much for sharing. We've got 2 minutes left in the room. And, Person 7, I wonder if you you wanted to add anything quickly or?

Person 7 32:30
Yeah.
Hi yeah, I would love to. Hi, just introduce myself. I'm Person 7 stuns thought I'm actually a CAMS consultant working in the adolescent team with 1617 year olds and also an adult with ADHD.
So I've got kind of two hats on, I suppose this my concern like big area that we have is like transition and we've been having loads of problems. So I just I I don't know if you've thought about this already.
But.
Just that kind of getting people from young people services into adult services because at the moment a lot of the GP practises across Manchester, not all of them but quite a number are not agreeing to carry on with medications for people who are already on medication.
Because they're not having. Because there's such a long wait for a review by the adult services.
And so people who are on established medication treatments that help for helping them are then being stopped.
And at A at a really crucial point in young people's lives. And I just like, really have been wanting a forum to be able to talk about this with someone. And then I've only just found out about your thing last minute. So sorry, I've got the children screaming in the background and things, but yeah.

Person 1 33:49
Well, welcome. Welcome to it.
So, so sorry, it's a it's a great opportunity. We we do have a Commissioner as part of this conversation who's actually supporting the other room because there are another five people in a different space. So when we come together and we talk

about the referral criteria, maybe that's a question we can look at in regards to or we might have an opportunity at the end to look at some of these questions and certainly in regards to transition because it is certainly being thought about.
It's certainly part of our emphasis.

Person 7 34:25
Because no one's assessed anything.

Person 1 34:28
We well, we've been able to speak to lots of students. We've been able to talk to lots of different people and and and transition is, is is because, well, you see well, I would say that all Commission services have been made aware of this, whether they have shared it and cascaded that information. I think it would be a really great point to make in front of Person 3 as a Commissioner who sits on part of the Neuro developmental service because if you don't know about it then then that's a problem.
I'm going to bring everybody else back into the room.

Person 2 34:28
Yeah.

Person 7 34:32
Right, but not many times there's farmers on my web, but.
Yeah, yeah. Brilliant.

Person 1 34:57
But I think it's a really pertinent point, because if you've not heard about it as a clinician, then yeah, that's that's a challenge, isn't it?

Person 7 35:06
I mean, I've told everyone about it now, but I had to find out about it on social media, so.

Person 1 35:12
Well, I'm glad that works. Our digit team will love that.
But yeah, I think it from a provider's perspective. Maybe. Maybe you should have found out about that differently. So we're just closing off the the final bit that go on.
Sorry.

Person 7 35:22
Yeah, I mean, but I'll answer your question on that slide. I mean, I would say there's other kind of things like debt to housing.
You know, other kind of social access to things like that might need also need to be thinking about signposting people too.

Person 1 35:39
Thank you. Thank you so much. We're going to close that conversation now, but thank you.

Person 2 35:39
OK. Thank you, Person 7.
Is everybody back in the room?

Person 1 35:47
If you put your hand up.

Person 2 35:51
I think we're all here. There's definitely 2 rooms here. OK. Thanks very much for your input there. We're going to Passover. To Person 3, who's going to talk a little bit more about referral criteria and then we'll have space of about 10 minutes for any questions. Thank you. Over to you, Person 3.

Person 1 35:52
Thank you. Yeah, there's eleven you.

Person 3 36:08
OK, so the referral criteria that we're looking at is predominantly based around.
People who present with comorbid mental health or physical health difficulties.
Will be a number of criteria we're looking at and we'll come on in a moment. There's a different slide which talks about some of those.
Again, some groups will automatically get referred due to increased risk of harm.
That includes veterans and young people transitioning to adult services.
We've got a figure here where it's expected that 20 to 30% of people will meet the criteria and go for assessment. It's not something, it's not a figure we've set. It's a figure that Cheshire and Wirral partnership have already moved to this model and that's the numbers that they've seen following the introduction of their criteria are the number of people who qualify for an NHS funded assessment at that point.

Person 2 37:06
Thanks, Person 3. So for those of you that joined us a little bit later because you'll have missed the introduction to this. So this is in relation to the brand new ADHD triage team which the GP will refer people on to and that triage team will assess people against set criteria and the criteria is what we want to talk to you about to make sure that we're asking the right questions. So as Person 3 said, it's expected that between 20 and 30% of people who meet the criteria.
Will go forward for an assessment, but everybody will be offered some sort of support.
Person 7, I think you've got your hand up and and anyone else that wants to ask a question, this is a good time.

Person 7 37:41
Yeah. So.
Sorry, just to be clear. So what's going to happen to people who are presenting with clear ADHD, but they don't also have a severe physical or mental health problem?

Person 3 37:54
I will get the triage full assessment.
If it if the outcome for them, I mean they may go off to other services as well people can access.

Person 7 38:03
Which other, which other services and how will they access an ADHD assessment if they if the presentation is ADHD but not they wouldn't, right? So they they right So what should they do?

Person 3 38:05
So for example the.
They wouldn't that they wouldn't qualify for at night. They wouldn't.
So there's still the open offer of of the I don't wanna call it post diagnostic support, but the kind of the the self help.

Person 7 38:33
This is not gonna be a service for adults with ADHD unless they have physical or mental health.
Significant physical or mental health comorbidities. Is that what you're saying?

Person 3 38:45
I I wouldn't want to use the significant because I think you're creating a layer there. That's not necessarily there. We've we've got a number of other criteria that we're going to look at in a moment and that's what we specifically want to talk to you about is what criteria should be, should we be looking at. I think we talked earlier about the fact that with the demand we have, we we can't meet that demand. So we need to prioritise the service for those that most need it.
But that's very specifically what we want to talk about too. Who should be qualifying for that assessment?

Person 7 39:16
Fine, OK, as long as we're clear.

Person 2 39:18
Thanks, Person 3. Yeah, we we mentioned, yeah, I think there's a little bit at the beginning that Person 3 talked about in terms of the case for change and the fact that we've got a seven-year waiting list and approximately 25,000 people on it. And the way things are happening at the moment, the process is that anybody that wants to can be referred for an ADHD diagnosis and that's clearly not safe because that waiting list is growing and growing and we're not getting to see the people who are a priority. So everybody will be assessed is what Person 3 is saying, some will be.
For diagnosis, but everybody will get support. Are there any other questions?
Any questions come up in rooms? Oh, sorry.

Person 8 39:55
Is that?

Person 1 39:57
Sorry Stevens speaking.

Person 8 39:58
Sorry, the support the support that you're talking about that everybody's gonna get the support is the support that we've just been looking at previously on the previous group, the signposting, so there's no support really then because it's just been signposted to other services.

Person 3 40:05
Yeah.
There's some very ADHD specific digital programmes.

Person 7 40:14
Yeah.

Person 3 40:19
So I wouldn't.

Person 8 40:19
The tool's not gonna be for everyone. Silver Cloud's not gonna be for everyone, though.

Person 7 40:19
Then is there any evidence for them in helping with ADHD symptoms?

Person 2 40:31
I think you moved it.

Person 3 40:32
I mean.
It doesn't, sorry. I think what you're talking about is, will there be an assessment and a medical pathway because we've got two pathways and we've one will be that medication and the people that won't qualify for that. The other one, which anybody, whether they have a diagnosis or not, will be the non medical pathway and it's the non medical pathway. And that's not just signposting, it's things around peer support. There's lots of other things that have been put in there. There's lots of things people have told us that they want in there.
But there will be a number of people that do not qualify going forwards for an NHS funded assessment.

Person 2 41:13
This is your opportunity, as is the rest of the consultation to feed in any concerns about that. So if there is something that you think is an issue.

Person 5 41:19
Can I? Can I just ask one thing around?
So so if that's the case, I don't know that we've had discussions about this before. So if that's the case that, that if people do not meet the criteria and there's some people that won't for the for the medical pathway.
What about the people who are willing to pay for their assessment? I'm not, and I know that's like a privilege to be able to do that. Will they be able to access shared care via the GP so they're not paying for the medication forever because there's some people who will, you know, will feel actually, do you know what?
I don't want to take that place away from someone else. They might manage their condition through private therapy. They might do that for a number of years. It might then become apparent that actually, what's causing the difficulty is is related to ADHD. But none of that information is going to be because it's done through the private kind of sector. None of that information will be on the medical records. What about those people like?

Person 3 42:19
That that there is already provision for that and that there's quite specific guidance set out in what's called the G triple MG guidance that the issue that that complicates that at the moment is the GPS action on shared care.
We did actually talk about that in our group. I'm hoping that's going to be resolved in the next three to four months because it doesn't just affect ADHD medication, it effects all what are called amber drugs, where they require a specialist review every 12 months. But there, there's an awful lot of work being going on for quite some time and and hopefully that will be resolved soon. I can't give you a definite time. I'm saying I think three to four months.
I've been involved in the work and and it's almost over the line, but not quite there.

Person 1 43:02
I'm gonna come straight in. Yeah, we've got Person 9 and then we've got a comment in the chat that probably links to this and then I think we need to close off because we're going into the the next workshop. Sorry, Person 9.

Person 2 43:02
You've got your hand up, sorry.

Person 9 43:11
OK. Hi.
So the referrers will be consistent. There'll be people who need it. OK, I I get that. What? What are the what do you consider symptoms? That would make a difference to life, for example.
You know, one one of us is struggling to get a job job because of ADHD. The other one is struggling to keep up at work because of burnout with ADHD, I'm probably the milder of the two. I'll probably fall in that category in that category of not.

And making enough of a difference in life. But it does make a massive difference to my life, but I suspect I won't meet the criteria. Where's the line? What? What? What is enough of a difference in life for the criteria you're proposing?

Person 3 44:00
I bet that's what we intend to go on and talk about next.

Person 9 44:04
OK.

Person 1 44:06
And yeah, just at the fan point. Thank you. Thank you, Person 9. A really great point. Stevens asked. Is this for new referral starting from now or is this for people who are currently on the waiting list? Where is the cut off point? I think is kind of where people are looking for.

Person 3 44:23
In time, it will be for both, so it'll definitely be for new assessments.
Some people, before we get to them, will have been seen. We will ask people to prioritise those. We will ask people to look at the waiting list and those who are really unwell, potentially to see them earlier. We need to look at that. We need to look through it.
It will probably take us at least two years to get through that waiting list of of people who are who are there. I think that's around the time frame we're looking at. There'll be a number of people who in that case will go through.
And have the assessment without going through the triage.
Process within that time frame so it will pick up some people on waiting list. It will pick up all new referrals.

Person 1 45:06
Thank you. I'm going to move us on if that's OK, because we've still got some time to discuss. We failed criteria and beyond that we've got some, we've got some opportunities.

Person 2 45:15
OK. We are ahead of ourselves. So we have got plenty of time for the next session and in this we'll put you into breakout rooms in a moment, there'll be a facilitator in each room. As before, the session will be recorded. This is particularly about the referral criteria. And Please remember that these are just a proposed set of questions for the time being, it's really important that you import and you tell us where you think these might not work or any other kind of impact that these questions might have or even if you want to talk to us about how they might be deployed.
It's really, really useful. So we'll put you into breakout sessions in a couple of seconds.

Person 1 45:59
Sorry it's, it's for Person 3. Sorry, could you could you walk us through the refill criteria and then I'll put us into breakout rooms if that's OK. Thank you.

Person 3 46:07
So yeah, it's I.

Person 2 46:08
Oh, OK. Yeah. My fault. Yeah. If one's described them first. Person 3. Thank you.

Person 3 46:10
So this is the criteria that kind of things that we're thinking about.
So it's potentially for people. I've had five symptoms for more than six months.
We've had problems from being a child where it wasn't picked up within school.
Potentially they've got problems in two parts of their life, so for example, it's not just a home, it's also in work or it's in school.
I'm say school that would for adults that would be secondary education, finding it really hard to cope.
But the symptoms aren't caused directly by mental health illness.
But as I said earlier, if they have a comorbid mental health illness as well, then there will be priorities there.
And as I said, where they have other severe mental or physical health problems.

Person 2 46:58
Reg, you've got your hand up. Do you want to quickly come in before we go into the discussion groups?

Person 6 47:03
Yeah. Sorry. I was gonna ask the IT says the that's the referral criteria used elsewhere in the country that considering using what is it that you're using at the moment?

Person 3 47:12
I think everybody, everybody who screens on the arsr goes through for a full assessment.

Person 6 47:13
Ah, right, OK.
Right. OK, cool. Thank you.

Person 2 47:25
OK. Person 1, do you want to work your magic and put us into groups, please?
Thank you.

Person 1 47:32
Occurring as we speak.
We should be left with six if I've done my math right.
Although we've lost Person 7.

She seems to go after that room, which is strange because I had. Oh, no, they should be in here unless I've dropped off the car, unfortunately. But anyway, that's that's by the bye. If they have dropped off the car, they'll leave. You know? I'd hope so. You've just heard that from. From Person 3 in regards to the referral criteria.
The process is that you will still attend your GP surgery and they will give you a very quick.
Conversation around what you're presenting symptoms and they will make that decision as they do now to send you off for referral for triage.
A point of being seen at triage, these are the thematic elements that will be discussed and identified to move you from that triage process.
Through to for the assessment process and formal diagnosis. So we really would like your thoughts and feelings on regards to these elements, but also what are we not considering that should be on this list. So again I I welcome.
Nicola, you, you, you sound like you're going to speak. So, so coming in.

Person 4 49:02
Yeah, I was just gonna say, do the doctors have to do an initial assessment?
Do doctors have to be involved?

Person 1 49:12
So yeah, as it currently stands, so I think Person 3 would would in the previous one suggested that for now the system will follow its same footprint and they will look in in the coming you know year two years etcetera around what are the professional routes might there be. But yes, as it stands, as we move through this process, the GP will be the initial point of contact. So you would have to speak to your doctor.
They would then people have used the term QB test or that kind of.
Looking up the severity of your symptoms to to then push you through to that referral to the triage team.

Person 2 49:51
Somebody else had this question last week. Person 1 and Person 3 confirmed that at the moment they're using the ARASRS, you'll know more than many people on this call. Yeah, and they'll probably continue to use that. But he was also saying that virtually everyone that's assessed through that method gets put forward. So they're not expecting that people will be ruled out at that stage. It's just so that the Triage team have the information in front of them when they are doing the triage.

Person 1 49:54
Yep.
SCA.

Person 4 50:19
Yeah, because I sorry just to continue because I I think that's like one of the hold ups because it you know it's like just to get a doctor's appointment anyway and if there was a team of people that could do like a quick triage and signpost people for

support while they're waiting to go and have an assessment, it's like putting the triage before.

Person 2 50:39
Yeah, I think it's because of the way it's the way the NHS works on the the GP is the gateway to all services. I don't know whether that can change in the future. I know Person 3 was thinking about opening up the gates to other people being able to refer. I don't think he mentioned self referral, but so for example, social prescribers or people like Person 5, that might be able to transfer refer people that they're worried about. But I don't think we're ready for that yet.

Person 4 50:39
If that does that make sense?

Person 2 51:05
And I think it's partly to do with the funding as well. And he also mentioned about having the medical records so that you know, people had the history. So whoever was being preferred would also have the history, medical history of the person that needs the assessment. So I think there's a bigger picture, but I know it's something that they're looking at.

Person 5 51:24
I'd like to understand.
What does severe mental or physical health problems look like? What? What is that? Because you know, you're talking about kind of the really severe enduring like bipolar schizophrenia or you're talking about, like recurring depression. I think it's really unclear what does that look like?
Because I think that for me is a big blocker. If you're talking about people who are struggling with anxiety but are kind of when I say function, I mean like, you know, they're they're not bedbound and they're able to get on about.
But actually it's having a massive impact on the life. That's one thing, isn't it? But if you're talking about those people who have got some of these, like more challenging diagnosis and maybe have a lot of services involved already, then I just feel like that there's a big gap there around. What does that mean? We know that neurodivergent people struggle a lot more with chronic health problems.
But they might not be able to advocate for themselves, so they might not have a diagnosis, but they might be struggling with, like fibromyalgia or autoimmune conditions.
So, but the amount struggle to advocate for themselves, so they might not have the diagnosis, but doesn't mean they've not got it. I don't know. I just. I feel like it's it's it's very vague and I think one of the things I came away from the meeting from recently when I was when I came to the last meeting and you know we expressed concerns about actually there's lots of women on high masking individuals that will be missed with this is the fact that communication is so important for neurodivergent people and

being clear because I think it was asked at one of the meetings when we've I don't think it I think it was Sunday.
I mean not not Person 3. And it was asked basically is this a way to reduce access to?
Diagnosis and the response was it's a way to increase access to support, but what I've reflected on since is that wasn't a no. It was a very political answer. But you can't do that when you're a divergent people. You can't. You can't give like you can't expect us to read between the lines because then we're not going to do that. So. So it can't be political answers that you're given if we're asking questions we need.
We need a direct response, so we need to know yes or no because it might change our views on things.
So I think it's important to impact.

Person 2 53:42
It's coming, Person 1.

Person 1 53:44
Yeah, I'm going to bring Reds in shortly, but the challenge for consultation is we we consultation very much sits in the grey and the reason for that is because if we came it was asked us in a focus group that we did in Bury. You need to tell us what you're planning and we'll tell you when I get we can't. Because if we came and told you this is what we think, which is why we've got two options, option A and option B.

Person 5 54:06
Yeah.

Person 1 54:11
One's a preferred option. This is what we would like it to look like. How might this happen and the reason for that is because if we came out with an option as a system, as a function, as NHS organisation said, this is what we're doing. Like at lumpet. What do you want it to look like?
That's predetermined. We can't. You can't run an official form of consultation on that.
So it's I understand what you're saying and This is why we're trying to have these nuances of conversations around. Well, if if that's your view on that, why would that be a problem? Or why would that be good? Because what we can then do is pull all that feedback in from everybody.

Person 5 54:44
MMM.

Person 1 54:45
Get some themes, get some similarities, some commonalities, some some total differences, and and give that to Commissioners so they can make an informed choice about OK, what are we missed here? What do we need to consider? What do people think? So I appreciate that because it's very difficult and we we also would love as as engagement to have to say what do you what do you want? We're stuck.

Person 5 54:55
Yeah, yeah.
Yeah.
Suppose yeah.
And it's not. I suppose it's not about that. I suppose it's about then feeling like the response from the last meeting was different and the the response was actually.

Person 1 55:18
None.

Person 5 55:20
That is what's happening, and I suppose it's it's that mismatch then because there's frustration with that then. So I think it's more around actual it being quite.

Person 1 55:24
Yeah. OK.

Person 2 55:26
Yeah.

Person 5 55:31
I suppose.
The response that we got one time then versus the response we got another time now that is what's happened that there is that is happening and I suppose then it.

Person 2 55:39
Yeah, yeah.
I think people are beginning to ask questions, aren't they about the sorry to jump in. But I think there is some black and whiteness to this. And I think what you were saying was that the response you had last time was that this was about increasing access to support, but it also was about it is about.

Person 5 55:44
Yeah.
Yeah.

Person 2 55:59
Making sure the right people go forward for diagnosis and that doesn't mean any everybody. So yeah, it will decrease access because it will be some people will be offered support.

Person 5 56:06
And it just needs to be real clarity. I think that there needs to be real clarity and I think otherwise people feel like they're investing this time in it. And actually it's a bit of lip service. I've been involved in loads of NHS consultations, staff consultations and actually they're not, they're not really. They've got the plan, they're going to do what they want to do. It's just a way to say they've had people involved and I think

that's my worry. Do you know, like, if if it's something like that and people have invested a lot of time and energy into it, I think that's really important.

Person 2 56:09
No. Yeah.

Person 1 56:14
Yeah.

Person 2 56:15
Yeah.
Yeah.

Person 1 56:28
Yeah, yeah.

Person 5 56:34
That we listen to the feedback.

Person 2 56:36
Yeah, yeah. And absolutely, we will and certainly the referral criteria is going to significantly change. I think given the responses that we've had so far from the other 2000 people that have been involved. So for example, that question is it #5 on the list there, Simpsons aren't caused by a mental health illness. So a lot of people have said, well, how would we know that? That's something that it would be very difficult for an individual to answer and surely that needs a bit of a a doctor's sort of perspective on it. And so yeah.

Person 1 56:43
Yeah.

Person 2 57:05
It absolutely isn't going to be set in stone in terms of referral criteria and the other thing around support that is up for shaping. But what will happen is there will be a triage team and the triage team will decide who goes forward for diagnosis and who is offered support. So.

Person 1 57:07
Yeah.

Person 2 57:23
That will stay. That's not up for consultation. Maybe that's something that we need to be a little bit clearer about and. And as Person 3 said, the reason being that at the moment everybody goes through for diagnosis. But because of that, the waiting list is just growing and growing and there's not enough people to see those individuals. So it has to change in some way. And I think one of the things that Sandy has said in the past, so sorry, Sandy Berry is the lead Commissioner, but he's also an expert around neurodiversity.

One of the things that he said in the past is that people.
When they access healthcare and certainly secondary services, they don't just get referred. If they go to the GP, usually the GP will do some sorts of a referral. So our assessment. So for example, if you went to GP with a headache and you asked for an MRI scan, they wouldn't automatically send everybody that asks for an MRI scan, that there needs to be some sort of assessment and some sort of triage to make sure the right people are going through.
So that is what will happen, but maybe we've not been clear about that in the past, Clare and I agree. Actually I think we've talked very much about the positives of.
And people's support. But we maybe haven't really highlighted the fact that it will be between 20 and 30% of people that will go forward for diagnosis.

Person 1 58:41
We're going to bring Reds in if that's OK, because Reds did have their hand up and then put it down so I don't know if you wanted to make a comment out whether it was already made, but I don't want to dismiss that opportunity.

Person 6 58:50
No, no worries. Thank you. Yeah, I'm just a bit confused because it said that the symptoms aren't caused by mental health illness, but then it says they they have other severe mental or physical health problems. If someone presented to me with a mental health problem, maybe an undiagnosed one, I'd, I'd always refer him back to mental health services before addressing sort of an ADHD diagnosis or any symptoms like that just to the crossover with different things. I don't have different services do that, but.
I think obviously having a condition like OCD, there's a lot of crossover for ADHD and OCD for me, so.
I can't see see that mental health kind of the the primary need there. So I always refer that back. But again as we know with mental health services there, they're struggling. So what they can get diagnosed or support for that, that's a tricky one as well.
Also, they're just thinking about the referral criteria. They find it hard to cope is obviously quite a broad term. I suppose that I feel that needs to be narrowed down to find it hard to cope is that because of the symptoms of ADHD, anything else I think that needs to be written in a more specific way.
To understand what what the finding how to cope with. Because yeah, that could. That could be anything.

Person 1 1:00:03
Thank you. Thank you for a few feedback. Nicola, you had your hand up and knocking down. So I'd like to come to you and give you the chance.

Person 4 1:00:11
I was just. I was just going to say we need to take all that money and reinvent the

wheel because.
It I feel like the those sort of suggested criteria on there, if I read that I.
Probably don't even fit in them and.
There's just so much more about it.
Yeah, there's just so much more. And I know that's not what we're here for.
Yeah.
It just don't seem any different than.
Anything that's already been done.

Person 5 1:00:52
I think I can hear. I can hear you feel quite. You sound quite sad and I think I think it's made me sad. The prospect of this because I was looking forward to being something exciting. But it's made me feel really sad about the people who are not going to be able to access that and I know our life changing the diagnosis has been for me.
Hey, but yeah, there's something in it in it for me that makes me feel that you're going to have to be on your knees. Basically, before you're able to access support. Yeah. And I just think I think for a lot of people who are involved in it, I think there's going to be a bit of a sadness to to kind of realising that they probably wouldn't meet the criteria. But knowing how how hard life has been for them and how.
Difficult things are.

Person 4 1:01:38
Yeah.

Person 1 1:01:38
No, thank. Thank you, Person 5. Thank you Nicola, for for sharing that it reads your hands up.

Person 6 1:01:45
Yeah, I I I completely get with Nicola and and Clare coming from because we I know we're a provider. But I mean we see people have been so disillusioned with the with the waiting lists and how long they take and they just as you say there Person 5 diagnosis can be absolutely life changing, can't they? And people have come to us. I was going to say something Boston Trainer thought completely that was going to ask. So obviously this new consultation is happening and is this is the plan to still have this long right to choose for private providers to scrap that completely, to bring everything back in House.

Person 1 1:02:20
It's it's a great question and it's it's something that we wouldn't be able to answer that from an engagement perspective, but it's certainly something that we can raise with Person 3 as I think right to choose shared care, private providers have have been a point of question concerning query throughout this consultation. So we will raise it again with Person 3 when we go back into the room.

Person 2 1:02:42
And maybe bring it when we go back in the room because it has come up before, hasn't it? And I think Person 3 has said that rights choose will stay. It has to because we don't have enough NHS services. Yeah, yeah, yeah.

Person 6 1:02:49
OK.

Person 1 1:02:50
It's an NHS given in to.
To choose, I think it's the private provider question linking into that would be really interesting to understand Reds it's it's a great question.

Person 6 1:02:53
Yeah, I have it. Yeah.
No, we've. Yeah, that's something we've explored going down the right to choose pathway, but finding out how to be a provider of it is nigh on impossible. So any but yeah, that's just part of the process.

Person 1 1:03:08
Yeah.
No, fair enough. We'll ask Person 3. I will give you opportunity to ask Person 3. Person 7, would you like to come in?
Got probably a minute 2 minutes left I think.

Person 7 1:03:21
Yeah. I just wanted to ask on the subject of the borough criteria on one second. So no, sorry, sorry, sorry, go.
So on the online questionnaire, it said they have to have symptoms of.
Impulsivity and hyperactivity, but it didn't mention like inattention in an executive dysfunction. Was that just a typo or?
Are you only taking people with hyperactivity and impulsivity problems?

Person 1 1:03:53
So so that criteria was given to us by the commissioning team and we were specifically asked to ask those questions. However, what we have found throughout this whole process, Person 7, is that there is a gender bias and when you talk about attention deficit hyperactivity disorder, what we are hearing is lots of biologically.

Person 7 1:03:58
My name.
Let me let me.
Let me let me oh.

Person 1 1:04:13
You know, born females do not identify with any of that. Can you hear me? Because I can hear you. OK. Can you hear me? OK. Through your earbuds. Wicked.

Person 7 1:04:18
Yeah, yeah, I can hear you. I'm sorry about the silence.

Person 1 1:04:22
Don't worry about it, honestly. Don't worry about it. It's the giant having children.

Person 7 1:04:26
Yeah, I can.

Person 1 1:04:26
So yeah, so we are looking at that and I think you are right, what we recognise is the presentations are very, very different and certainly for women who have masked for a long time.

Person 7 1:04:30
Honey.
Yeah, I mean, it is for women, but I think even for young men who I see like, often by the time they're getting to approaching adulthood, a lot of the impairment comes from the inattention. And, you know, organisation difficulties.
That's often what's causing difficulties in education and work, and so for me, that's a primary deficit in adulthood, and it seems a bit crazy for that not to be the primary referral criteria.
Around the main symptoms, obviously you know it's different for different people.
But yeah, that thing is completely wrong in my mind. If that's if that wasn't an actual that was the referral criteria.

Person 1 1:05:18
Thank you. It's it's something that we can note and and it will be considered when we when we pull that together. So yeah, again thank you for for everybody's contributions to kind of that conversation. I am pulling people back into the room. So you will start to see the rest of them join.

Person 2 1:05:32
Well, you mentioned you asked the question of Person 3 Person 1 about the right to choose and whether it's it will stay.

Person 1 1:05:32
And there will be opportunity to feedback.
And private providers and outer private providers become magnitudes or become an option. Absolutely.

Person 2 1:05:39
Yeah.

Person 6 1:05:42
Be good.

Person 1 1:05:50
Hello everybody and welcome back into the main space.
So we have probably a couple minutes before we move into the at least a minute to move in before we move into the next element. Person 3, we've just had a really interesting conversation. I think it's been raised on multiple occasions through these workshops.
Around right to choose and private providers and also how private provider organisations could be considered under right to choose and how to become eligible to become a right to choose organisation.

Person 3 1:06:13
Yep.

Person 1 1:06:22
Wondered if we could have a synopsis on rather you know how the right to choose process private providers and and how that might become something that we we work on moving forward.

Person 3 1:06:29
Yep. OK, so that's it's really important to differentiate between a private provider and a right to choose provider. A private provider is someone you go to, you pay for an assessment, you then pay for the medication and pay for the review. So everything sits outside the NHS, a right to choose provider is any provider, whether it be a trust or somebody with a different name, for example psychiatry UK or something like that.
And they hold an NHS standard contract.
Which means they're providing same NHS services as anybody else and you can see that in physical health quite often you'll you'll go off, especially cataracts is a really good example is provided by what would be seen as as not a standard. You don't go to a hospital, you go to a specific organisation to do that. And it's the same thing with ADHD. So in terms of right to choose people's rights.
At the point of referral, anybody can go to right to choose. I think somebody talked earlier about 40 weeks.
If you can expect to wait longer than 18 weeks, not if you have waited 18 weeks, or if you've waited 40 weeks. If you can expect to wait longer than 18 weeks, then you can choose to go to some other to a right to choose provider, and you can do that the day after you've been referred. If you turn around and say how long am I going to wait? And they say two years go right. I'd like to go to a right to choose provider please. The difficulty is is that some GPS don't want to do that because they don't have faith in who you're going to.
We have no control over that.
It's what I spend a lot of my day doing is is talking to GPS and talking to them about what they can and can't do that are some providers. There are genuinely symptom genuine concerns about and G PS don't want to refer to those.

There are some very new providers where G, PS are a little bit reluctant because if they refer them then the organisation doesn't exist in a year, then they're kind of left in the lurch around the share care prescribing. We we have no say over that as an ICB, but.
If, if anybody's experiencing difficulties in that, I'd urge you to contact patient services at Greater Manchester integrated care. They normally come through to me, I speak to the GPS to make sure that they're not doing things that they shouldn't be and sometimes they are, but that that's more of an education in terms of organisations who are wanting to provide service and I think red, some might have responded to this earlier today for you.
We have to wait till this consultation is finished.
We we then will have a a Greater Manchester service specification and people can ask to be benchmarked against that to see in terms of delivery.
And the one thing we do want, which will be central in that is that people can be seen face to face. We don't particularly want people who are getting a service down in Southampton being seen very briefly with no robust and proper physical health check. But I think you've got my e-mail anyway. So happy to pick it up outside if you want a further conversation.

Person 6 1:09:38
Thank you.

Person 2 1:09:41
OK. Thank you, Person 3. Should we move into the options please, Person 1?
Slide. Thank you.

Person 1 1:10:01
Sorry, no, it was it was. It seems to be running away with me again.
Bear with me. It needs to go back. Do you want to discuss from here or would you rather see the slide before Person 3?

Person 3 1:10:13
So we can go from here. I forgot this was me. I got a bit lost. So we have two options. The the options are relatively similar. The main difference between them is what happens first. So option A is where the GP does. The screening tool thinks this ADHD refers into the triage team. The triage team then do their face to face assessment.
And then either people go through for the NHS funded assessment or they go into that open offer that that we were talking about earlier.
Option B is that the 2nd and 3rd element of it is the other way round, so the GP the 1st place you go to is the open offer and it's only people where that doesn't work for them. They would then go into the triage service so that they're the other way round.
So option A is our preferred.
Option taking forwards one of the main reasons for that is again just a concern about

the people who really need help is this just puts a further delay into them getting that. But again, I think you get to have your own say on this. We've we've put the options forward. We're saying what, what the ICB preferred option is and it is mainly around that, it's around people who really need support getting it as quickly as they possibly can.

Person 2 1:11:44
It might be worth going back to the first slide that describes those options. Again, before we go into the the kind of voting or discussion exercise. So if you flick back up, Person 1.
Two or three.

Person 1 1:12:02
Yeah, I'm. I'm trying to. It's it's going the wrong way. It's.

Person 2 1:12:04
Yeah, sure, Internet isn't so.

Person 1 1:12:08
So if I go back a couple of slides.

Person 2 1:12:10
So just for clarity then obviously Person 3 has described those two options. We will be taking one of those forward. So they have been through NHS England's gate, what we call gateway process. So they've been signed off. The preference for NHSGM is option A. However, we welcome your thoughts on both of those options. And Person 1 will talk us through in a moment when we've had the opportunity to ask questions, how you can choose which option you prefer or make comments on both of these options.
Are there any questions in relation to these two pathways or options?

Person 10 1:12:48
Yeah, we've got Steven.

Person 1 1:12:48
Steven has her hand up. Sorry, Person 10.

Person 2 1:12:49
My Steven.

Person 8 1:12:51
And I don't know if it's probably a question to Person 3. Anyone feel free to answer. So we know that kind of resourcing and recruitment of staff, especially within the mental health sector and funding of that's of the staff within the mental health sector is a is a struggle. How do we intend to resource the triage team? Is that going to be NHS recruited staff or is it going to be private providers and what type of staff is it that's going to be doing that triage in?

Person 3 1:13:18
OK, it would be more about the skills that people need to have specific skills in ADHD and mental health assessments. We have to go out. We've just been told we have to go out to an open procurement for that. So anybody can bid for it. We have a lot of people interested in in doing this and delivering it for us.
So yeah, normally if we stand in your mental health service up we we really struggle to get it off the ground, but it that's not going to be the case with this. I think it is just trying to get that procurement done quickly because we've already had a number of people both from public and private stepping forward saying they'd like to do it.

Person 2 1:13:58
Any other questions?

Person 1 1:13:59
Are there any other questions? Sorry, Person 2.
Doesn't look to be.

Person 2 1:14:08
We're moving to the meantim metre. She wants to describe how this works.

Person 1 1:14:11
So as part of our evidence collection, I know this has been recorded.
We're using Mente, which is an online kind of engagement tool that we use within our system. This can be accessed through any mobile or Internet ready device. You can either go on your web browser and type in www.ment.com and type in that code and.
This.
Mentally, we'll be open for the next 24 hours. So if you would like to take a picture of that, you can do and access that at a time that's more convenient to you. Or scan the QR code. What you will find if there are a couple of questions on that, it actually looks at the the questions we've covered in the room. So we just talk a little bit about the support elements. It talks about the referral criteria and it walks you through the options with the visuals that you've just seen.
What you can then do is post post answering some of those questions is share anything that we've not considered or any concerns that you've got as well as anything that you would like us to think about moving forward.
Well, there is some space that you have open text, ability to share, anything that you've not felt able to share it during tonight's kind of focus group conversation.
There will this slide will repeat at the end. We're just going to talk through the what next steps and then this slide will come back up and we'll just open up for any further or final thoughts and questions.

Person 2 1:15:44
Next one.
OK, So what will happen next? As we've said, the consultation closes at midnight on

the 17th of June, which is next Wednesday.
Myself and the team will be bringing together all of the comments that we've had so far. We've had almost 1000 survey responses and we've done almost 1000 face to face engagement sessions. And I know there's still some more to happen in the next couple of days. They're all on our website. If you want to share those with anybody that you know that you think might be interested.
And we'll produce a report which will be presented to Commissioners, which will have the main themes, people's concerns, people, people's comments and the results of the option A or B exercise that will be published on the website. So everybody, we will be able to see what's happened, what the results have been and what will happen next in terms of decision making. It will be a little while before things are put in place because there is a little bit of a process that we have to go through in terms.
Signing off the final report, making a decision as a board in terms of option A or Option B and then as Person 3 mentioned, going through the procurement process for the new team and putting things in place. So it will be at least another three or four months I think after the consultation has completed. Next slide please Person 1.
So in terms of getting involved further, the website link is here and I'll make sure that this presentation is shared with you. Do you want to just go back? Yeah.
And you have our e-mail address. If there's anything else that you've thought of, or any other comments that you want to make. And there's also a telephone number there if you prefer to WhatsApp or call us.
Are there any other final comments before I close the meeting? I think somebody's got the hand up, Person 7. Yeah.

Person 10 1:17:39
Yeah, there's a few questions. Yeah, we've got Person 7 with that and then we've got some questions in the chat as well.

Person 2 1:17:44
OK, so a couple of minutes for questions then. Thank you.

Person 7 1:17:53
Hi. I just wanted to ask.
So there's gonna be the plan is potentially for there to be a new triage team and these kind of support services. But is there a plan for an expansion in the capacity of the like medical, you know, the assessments and the medical treatment aspect of of AD of the service or is that going to stay the same?

Person 3 1:18:19
Longer term, Greater Manchester. Yes, we don't have anywhere near the Commission capacity we need, but at the moment we're we're spending an awful, awful lot of money on the right to choose. So what we'd rather do is to to re channel

the money we're spending there into being people being able to access it where they live realistically and face to face.

Person 7 1:18:38
Then it's brilliant. Thank you.

Person 10 1:18:45
Your question, Person 7, yeah.

Person 7 1:18:48
Yeah, yeah.

Person 10 1:18:48
Brilliant. Thanks. And then we've got a question about the website. When will the report you're findings be published on the website?

Person 2 1:18:49
Can't see. Oh, I'm sorry. Go on.
OK, so I don't mind Person 1, it depends how long it takes to pull the analysis together and report it, doesn't it? We've allowed. Was it 4 weeks, Person 1 or six? I can't remember. Yeah, yeah, yeah. It really does take that much time. We've got this really sophisticated system that analyses qualitative feedback. It's a bit like the WeChat facility, but we will have to go through it all and just make sure that it makes sense and that it's valid. So it'll take a little while, I would imagine.

Person 1 1:18:58
I wanna cover that.
Six, six weeks to develop the report.

Person 2 1:19:28
Take at least four weeks and but please keep your eye on the website and if there's anything in the meantime that you're not sure about, you've got our emails, so don't hesitate to contact us.

Person 1 1:19:38
Yeah. If you follow that project on our get involved platform, you will automatically be alerted when anything changes on there. So anything that we publish or populate on there, you'll you'll get an alert that says something's changed on there. So. So please feel free to to do that. It's a great way of being kept informed on next steps.

Person 10 1:20:00
Because that then we've got two questions from Kira. I've got one about shared care. So what's changing about shared care? That'll improve our chances of GPS supporting it.

Person 2 1:20:01
OK.

Person 3 1:20:11
A number of things. So first of all, a lot of the share care documentation isn't completed properly by the secondary care practitioners and and that's really important from a legal aspect. But then more resources to help them actually be able to do it because that's the biggest issue is that GPS don't have time to do it. So it's actually putting a bit more resource into primary care to help them to do that across the whole patch and say shared care is not just about ADHD. It covers so many medications both in.
Mental and physical health that that primary care is really struggling with.
And more access again to when things aren't quite going right, where they can quickly seek support and advice from specialists.

Person 2 1:20:50
Thanks, Person 3. I think we've got time for one more question.

Person 10 1:20:55
We have a lot. We will. The presentation also include more information about perimenopause being a comorbidity due to an increase in symptom severity.

Person 3 1:21:06
Oh, this this is not the first time this has been brought up. So we absolutely as as I said earlier, we need to look at that. We need, we need to do some more work on it. I I can't see it not being included there personally.
But it's something we need to look at and and I'm saying that because we we have a limited evidence base for it at the moment and we'd like to be guided by evidence, but I would be really, really surprised if it's not something that's included within the comorbid physical health presentations.

Person 10 1:21:35
Thank you so much, Person 3.

Person 2 1:21:35
Thank you, Person 3. Still time to ask questions if you want to in the chat and we'll respond to them after the meeting, I'm going to close the meeting now because it's 27 minutes past and we did say we'd be finished before half past. So thank you so much for your time and contributions and we've got tonnes there that are going to be really, really helpful for Commissioners and some things that have been said that we haven't heard before in, in the rest of the consultation that's been happening so. Really, really pleased about that. Thanks so much for your contributions. Enjoy the rest of your evening. And don't forget we've got the mensimeter.
For you to choose your options and the preference. OK, so have a great evening everybody.

12th June 2025: WCWA women’s Group, Oldham

What support would people find helpful?

Help to understand the symptoms of ADHD Help to understand the difference between pubity in girls (age 9 - 15) and symptoms of ADHD Support for someone caring with ADHD Support to manage the symptoms of ADHD Teachers don't recognise the symptoms and are not supportive Issues with limited time to discuss concerns with a GP - 10 minutes in not enough

Is there anything else that the group shared that you would like to add?

This group of over 30 women were very interested in understanding more about ADHD. Many recognised some of the symptoms in themselves but were concerned that they can't get an appointment with a GP and in the 10 minute appointment they don't have time to have a discussion. Lots of the women indicated that they would feel confident to discuss their symptoms with a GP. One lady referred to prayer helping her to manage any mental health difficulties she experiences and prayer helps her to stay mentally well. The group have invited us back to discuss more about support needed and we have agreed that we would take a clinician with us.

As a facilitator of the discussion would you like to share anything?

The group were a Bengali speaking ladies group and we had booked an interpreter. We had to change the approach in delivery as we were not sure that the ladies would know what ADHD was, in fact they thought they were attending a session to understand about ADHD. Some of the words of the symptoms of ADHD don't translate well into Bengali but the group were very engaged with one of the participants helping the interpreter. We have agreed to return to the group to discuss support services and possibly primary care issues in July. There is also an opportunity to visit the group and talk about the Interpretation and Translation engagement that is taking place.

12th June 2025: Friends Meeting House, Manchester

Adult ADHD Consultation Workshop

Date: 12th June 2025

Time: 6pm – 7:30pm

Venue: Friends Meeting House, Manchester

In attendance: *Amanda Rafferty, Head of Locality Engagement, Scott Williams, Engagement Manager, Greg Vaughan, Head of Strategic Commissioning, Mental Health and Learning Disability (Bolton), Sandy Bering, Strategic Lead Clinical Commissioner / Consultant (Mental Health & Disabilities) and 9 members of the public*

Background

Greater Manchester is consulting on two proposed options for improving Adults ADHD services. This event was to share further information with the public and to understand their views in relation to:

- Proposed support options
- Proposed referral criteria
- Pathway Option A and B

Notes of the discussion

Discussion one – support

Need to include employment and support for people to understand where they can get help and what their rights are. This also needs to extend to employees. People do not generally feel supported in work.

Support around 'loss' where people feel that they have missed opportunities due to their late diagnosis.

Should include support around understanding the condition, what this means, how to manage and cope on a daily basis.

Support should be offered ASAP to everyone even is they haven't had a diagnosis.

Social prescribing for people like gardening, crafts etc is good for having an outlet and silencing the mind.

It was discussed that there are a lot of interdependence on support systems

List of support services needed:

- Support for work: this would include employer and employee support. Ideas were discussed about the need to empower
- Financial management
- Practical Support: groups like Maddchester and @neurowavy (Levenshulme)

- Coaching and peer support, this role would be interwoven in tot other themes such as Work, financial management
- Trauma support services
- Webpage/website with useful links and NHS branded evidence led practice included, this should include link with GM library (Useful audio books)
- Post pregnancy support – MNVP's and pregnancy support via midwifery
- NHS understanding of missed appointments, applying reasonable adjustments for neurodiversity patients

All the support service need to be collaborative

Discussion two – referral criteria

The group thought that there were certain demographics more at risk including; people who had been through the care system, people with caring responsibilities, females due to masking, parents involved in child protection, people in the criminal justice system. The triage team need to be adequately trained and knowledgeable to be able to identify and prioritise those at risk as part of the triage process.

The ability to answer if problems were around in childhood may be hindered by those who are not knowledgeable about their childhood, masked during childhood or do not have the executive function to recall this.

Include problems with concentration and organisational in the criteria for getting an ADHD diagnosis. This is often the main the main issue which causes problems in the lives of people with ADHD as adults. If this is excluded it will make your service discriminatory against women who often don't have problems such as high activity levels and impulsivity.

The group felt the referral criteria in its broadest sense was ok, they had some challenges with the inference of Mental Health illness

- It was felt the MH issues needed further consideration and MH history i.e accessing wider support services should be considered, the group wanted Dual diagnosis considered
- Lots of people (women) mask more and often get diagnosed with depression/anxiety or BPD but underlying they have ADHD

List of groups people felt should be considered for prioritisation:

- People with experience of care
- Acutely Struggling
  - Homelessness or at risk of homelessness
  - People involved or at risk of being involved in the Criminal Justice system,
  - Unemployed due to challenges around symptoms
- Single Parents
  - Those thinking of family planning – post pregnancy impacts including medication, need to consider working within system with midwifery, supply advise and guidance
- Existing condition such as those who are imunno suppressed

- It weas suggested that research would suggest different criterion be applied to different genders (Men, Women and Trans) this is due to the presentation and some bias
- Factors such as Educational Attainment should be considered, one delegate was told by their GP “because you have a masters I can’t have ADHD”

Next steps

Findings from this workshop will be submitted as part of the AADHD consultation, analysed and presented to commissioners in the consultation report. The consultation report will be shared with all participants.

NHS Greater Manchester Neurodiversity Staff Group

Recap of the Meeting

1. Person 1’s Presentation on Neurodiversity Coaching

- Person 1 discussed their experience and the importance of neurodiversity coaching.
- Outlined areas covered in their slides: definition of neurodiversity, significance, challenges, and strengths.
- Emphasised creating a supportive environment and using appropriate language.
- Mentioned the use of visual aids, technology, and flexibility in coaching sessions.

Feedback and Questions on Person 1’s Presentation:

- Person 2 asked if Person 1 would share the script and slides.
- Person 3 emphasised the importance of language in creating an inclusive environment.
- Person 3 mentioned the social model of disability and the need for managers to understand environmental factors.
- Person 4 suggested including a section on handling situations where coaches are uncomfortable supporting neurodiverse individuals.

2. Person 5’s Presentation on ADHD Services Consultation

- Person 5 presented the current state and challenges of adult ADHD services, including high referral numbers and long waiting times.
- Discussed introducing a triage process to prioritise individuals based on clinical need.
- Highlighted the vision to improve access to support and reduce waiting times.

Feedback and Questions on ADHD Services:

- Person 4 raised concerns about triage criteria and the impact of age and changing clinical needs.
- Person 6 questioned the practicality of the triage process and the potential for people to manipulate the system.
- Person 6 pointed out the irony of a lengthy feedback form for individuals with ADHD.

3. Discussion on Support Options

- Participants discussed various ADHD support options, including managing emotions and financial independence.

- Person 4 emphasised communication and support for understanding and managing ADHD symptoms.

4. Referral Criteria and Options

- Person 5 explained referral criteria and expected that 20–30% of people would meet diagnostic criteria.
- Participants discussed support mechanisms and challenges in identifying ADHD symptoms in childhood, particularly for women.
- Persons 4 and 3 expressed concerns about childhood-related criteria and the need for a holistic approach.

5. Next Steps

- Person 5 noted the consultation would close next Tuesday, with a report in six weeks.
- Encouraged participants to share further feedback via email.

Key Links Shared:

- GM=EqAl Inclusive Language Guidance

Action Items:

- Person 1 to send out revised slides for feedback.
- Person 5 to share the engagement report on children’s services with Person 8.
- Person 5 to send the targeted equality engagement matrix to Person 9 for feedback.

Summary of Comments in the Chat

- Person 7 asked if the current diagnosis rate was representative.
- Person 8 suggested including support for managing emotions and stresses.
- Person 9 suggested budgeting and financial independence.
- Person 8 suggested practical support for task planning, organisation, and time management.
- Person 10 emphasised considering dual diagnoses and multiple neurodiversities.
- Person 9 shared GP experience regarding ADHD referral and antidepressant prescriptions.
- Persons 10 and 7 discussed challenges recognising childhood problems, especially in women.
- Person 8 asked if safeguarding should be part of criteria.
- Person 9 described viewing their condition as a superpower.
- Persons 10 and 8 preferred **Option A** for the ADHD services model.

- Person 7 emphasised the importance of context.

Appendix 3: Face-to-face engagement

Dates and locations

- 24 April 2025, One Riverside, Rochdale (joint with Healthwatch Rochdale)
- 24 April 2025, Stockport Public Involvement Network, Stockport
- 28 April 2025, Riveredge Public Event, Wigan
- 29 April 2025, Phoenix Centre, Heywood
- 29 April 2025, Lived Experience Advisory Group
- 1 May 2025, Tesco Superstore, Bury
- 1 May 2025, Millenium Cultural Centre, Oldham
- 3 May 2025, Bolton Wanderers Wellbeing Centre, Bolton
- 7 May 2025, Millgate Shopping Centre, Bury
- 7 May 2025, Better Together Event, Stretford Public Hall, Trafford
- 8 May 2025, Nye Bevan House, Rochdale
- 13 May 2025, Wigan Arcade Shopping Centre, Wigan
- 13 May 2025, Lived Experience Advisory Group
- 14 May 2025, Pendleton Gateway, Salford
- 14 May 2025, Oldham Youth Council, Oldham
- 14 May 2025, Wigan Primary Care Network, Wigan
- 15 May 2025, Talk English Health Fair, Rochdale Town Hall, Rochdale
- 15 May 2025, Achieve Recovery Group, Orchard, Salford
- 15 May 2025, Oldham Community Health Champions, Oldham
- 19 May 2025, Manchester Royal Infirmary, Manchester
- 20 May 2025, Rochdale Royal Infirmary, Rochdale
- 20 May 2025, Medtia Centre ESOL class and VCSE focus group, Oldham
- 22 May 2025, Wythenshawe Hospital, Manchester
- 27 May 2025, Limelight Wellbeing Centre, Trafford
- 27 May 2025, Lived Experience Advisory Group
- 28 May 2025, Focus Group, The Mosses Centre, Bury
- 28 May 2025, Emmeaus, Salford
- 28 May 2025, Breakthrough UK
- 2 June 2025, Leigh Shopping Centre, Wigan
- 4 June 2025, Manchester Metropolitan University
- 4 June 2025, Sainsburys, Hazel Grove, Wigan
- 4 June 2025, Anthony Seddon Centre, Tameside
- 6 June 2025, Croft Shifa Health Centre, Rochdale
- 6 June 2025, Online Focus Group
- 10 June 2025, Online Focus Group
- 10 June 2025, St Martin’s Community Hall, Rochdale
- 12 June 2025, Focus Group, Friends Meeting House, Manchester
- 12 June 2025, Family Action Centre, Bolton
- 12 June 2025, Harpurhey Shopping Centre, Manchester
- 12 June 2025, Oldham Womens’ Group, Oldham
- 18 June 2025, Merseyway Shopping Centre, Stockport

Appendix 4: Communications

Key partners and colleagues

- NHS GM Chief officers
- NHS GM Chief medical officer
- NHS GM clinical lead
- NHS GM project lead
- NHS GM Equalities lead
- Greater Manchester Mental Health NHS Foundation Trust (GMMH) service leads
- GMMH communications lead
- Pennine Care NHS Foundation Trust service leads
- Pennine Care NHS Foundation Trust communications lead
- GM ICP Board members and officers
- NHS England

Public/service users and VCFSE groups

- NHS GM Adult Lived Experience Advisory Group
- Greater Manchester Healthwatch organisations
- Patient and user groups connected with NHS Foundation Trusts and wider health and wellbeing system (via the System Participation Group members)
- 10GM
- GM Equality Alliance
- GM Equality Panels (via GMCA)
- VCFSE organisations representing equality groups (via NHS GM Engagement Team); First Point Family Support Services, St Andrew's Community hub, Food Pantry – Whitefield, Food Pantry – Parkhills, Brandlesholme Community Centre & Foodbank, Halal Fusion Food Ban/ Bury Active Womans Centre, The Attic Project, African and Caribbean Women's Centre, Heaton Park Food Pantry, African and Caribbean Women's Centre, Prestwich Social Prescribers, Whitefield Social Prescribers, North Bury Community Hub, West Bury Community Hub, East Bury Community Hub, Whitefield Community Hub, Prestwich Community Hub, Oldham & Rochdale Maternity Voice Partnership, Womens' Diverse Community Café, Caring and Sharing Rochdale, Oldham & Rochdale Maternity Voice Partnership, Support and Action Womens' Network (SAWN), Action together CIC, Pennine Mencap, Positive Steps, Scope, Bolton Maternity Voices, The Flowhesion Foundation, Anna Sukoon Womens' Group, Arising Futures CIO, Baby Basics Bolton and Bury, Barbodhan Muslim Welfare Society, Base X, Total Fitness Womens Only Gym, Wigan Maternity Voices, Home Start, Salford Angels WI, Women with Wings, Salford Disability Forum, The Salford Poverty Truth Commission, Autistic Society Greater Manchester, North Manchester Maternity Voices Partnership, Europia, Caribbean African Health Network (CAHN), Can Survive UK, African Caribbean Care Group, BHA for Equality, Ananna - previously Manchester Bangladeshi Women's Organisation, Mustafia Sharif Charity, Manchester BME Network, Women's Voices, LGBT Foundation, Rainbow Noir, Black Beetle Health, 422 Community Hub, Autizma, Inclusive Choice, Manchester

People First, Better Things, Lifted, Trafford community collective (collective of VCFSE orgs in Trafford), Collaborative Women (housing and support), Maternity Voices Greater Manchester & Eastern Cheshire Community Explorer Forum, MADDchester, Food banks, Fact - Autism support group, Sendiass Service – Tameside, Tameside Women and Families Support Services, Tameside Womens' Community Cycling Group, The National Association of Womens' Groups, The Studio Womens Gym, Tameside College, Great Places Housing Group (Service Managers), Minkin ADHD Group, BAND Bolton, MHiST Bolton, Manchester LGBT Foundation, Bury Neurokinetics Club, Peter Hill Place, Manchester Community Explorers, Wai Yin Society, We are Better Things, Survivors Manchester, Booth Centre, Mustard Tree, Lifted Carers Centre, Rainbow Haven, Manchester City of Sanctuary, Boaz Trust, Manchester Settlement, Coffee 4 Craig, Revive, Red Cross, Migrant Support, Street Support, Big Life Company, Shelter, Back on Track, Black Mental Health, Age UK, Mood Swings, Manchester Home Birth, Homestart, Barnados, Rochdale Community Influencers, Centre of Wellbeing Training and Culture, Manchester Community Explorers, Women's Empowerment through Art

- NHS GM Fit for the Future Panel
- Stockport Patient Engagement Network

Organisations and system wide boards, committees groups and individuals

- NHS GM Involvement and Assurance Group
- NHS GM Clinical effectiveness committee
- NHS GM Executive Committee
- NHS GM Board
- Greater Manchester ICP board
- NHS GM Clinical Effectiveness Committee
- NHS GM Executive Committee
- NHS GM Primary Care Blueprint Delivery Group
- GM Trust Provider Collaborative
- GM Primary Care Provider Board
- GM Locality Boards
- NHS GM Extended Leadership Team
- NHS Trust Boards
- Equalities Lead for Greater Manchester Combined Authority
- GM SEND Oversight Board
- GM Mental Health Partnership Board
- NHS GM Associate Programme Director Children & Young people
- NHS GM Programme Director for Commissioning Development
- NHS GM Deputy Chief Medical Officer
- NHS GM Programme Director Mental Health
- Salford Safeguarding Children Partnership/Chair of a peer support network for neurodiversity
- NHS GM Adult ADHD Steering Group
- NHS GM Neurodiversity Staff Peer Support Group
- NHS GM AADHD Steering Group

- NHS GM Head of MH Strategic Commissioning
- NHS GM Clinical Director for Mental Health
- NHS GM Assistant Director of Mental Health Strategic Commissioning Children and Young People
- NHS GM Head of Mental Health Clinical Effectiveness
- NHS GM Director of Contract Management
- Ancoats Urban Village Medical Practice
- GMMH Associate Director of Strategic Development and Performance
- NHS GM Integrated Commissioning Manager (Learning Disabilities/Complex Needs) Salford
- NHS GM Head of Mental Health, Learning Disabilities, Autism & Neuro-Rehabilitation (Manchester)
- NHS GM Head of Mental Health and Learning Disability
- NHS GM Head of Programmes - Bury Integrated Delivery Collaborative
- NHS GM Assistant Director of Delivery & Transformation (Wigan)
- Pennine Care Foundation Trust, Network Director of Operations
- NHS GM Associate Director of Transformation and Delivery (Heywood, Middleton and Rochdale)
- NHS GM Adults Mental Health Transformation & Delivery Commissioning Manager (Heywood, Middleton and Rochdale)
- NHS GM Programme Management Officer – Mental Health, Learning Disabilities & Autism Strategic Mental Health Commissioning Team
- NHS System Participation Group
- GM Placed Based Leads
- GM Deputy Place Based Leads
- Directors of Adult Social Services (via NHS Trust communications leads)
- GM Councils; Chief executives, Directors of Education, Directors of Public Health, Exec Leads for Health, Council Chief Execs and Communication Leads
- Locality Participation Groups; Manchester Equality and Engagement Network, Trafford Locality Participation Group, Salford Engagement Practitioners, Stockport Locality Participation Group, Bolton Voice and Influence Group, Oldham Engagement and Insight Group, Wigan Participation Group, Tameside Participation Group, Bury Engagement Community of Practice Forum, Rochdale Engagement and Insight Group
- GM VCSE Leadership Group
- Transport for Greater Manchester

Providers

- Chief Executive Officers; engagement and communications leads; Wrightington, Wigan and Leigh NHS FT, Manchester University NHS FT, Tameside and Glossop Integrated Care NHS FT, GM Diagnostics Network, Greater Manchester Mental Health NHS FT, Pennine Care NHS FT, The Christie NHS FT, Northern Care Alliance NHS FT, Stockport NHS FT, Bolton NHS Foundation Trust
- Pharmacists, optometrists and dentists (via NHS GM Primary Care Team)

- GPs
- Student mental health services (all GM Universities)
- Private providers located in GM and with an NHS ICB contract; Edgerton GP Practice (DR Leach), Jacobs Clinic, Optimise

External boards

- GM Joint Health Overview and Scrutiny Committee
- Local Health and Overview and Scrutiny Committee chairs
- Local Pharmaceutical Committees
- Local Medical Council (LMC)

Political

- GM Mayor and deputy mayor
- Lead members for health
- MPs in Greater Manchester

Staff

- NHS Greater Manchester staff
- ICP partner staff (via comms teams)
- Council staff (via communications teams)
- Provider staff (via communications teams)
- Wider ICP system staff (via communications and engagement teams)

Other key partners

- Greater Manchester Combined Authority
- NHS Lancashire and South Cumbria Integrated Care Board
- North West Ambulance Service NHS Trust
- Primary care clinicians (via primary care networks)
- Secondary care clinicians (via secondary care communications teams)
- Health Innovation Manchester
- Greater Manchester Universities

Other external

- Media – North West and GM wide
- Specialist media

Appendix 5: Clinical and organisational full responses

Healthwatch Bury full response

Event: NHS GM ADHD Diagnostic Pathway Consultation, Moses Centre Bury

Healthwatch Bury – Observations and Recommendations:

Healthwatch Bury attended the recent consultation session regarding proposed changes to the ADHD diagnostic pathway, specifically the introduction of a new triage system. While we welcome efforts to improve efficiency and access, several critical considerations were observed that require attention to ensure patient safety, fairness, and legal compliance.

Lack of Holistic Consideration for Comorbidities:

The proposed triage system appears to focus narrowly on ADHD symptoms without sufficiently accounting for co-occurring conditions such as autism, learning disabilities, or mental health disorders (e.g., anxiety or depression).

Individuals with multiple or complex needs may risk being deprioritised, leading to further delays in appropriate support and potential misdiagnosis.

Transparency and Informed Decision-Making:

There is currently insufficient clarity regarding the criteria and process underpinning the triage system. Patients and families may not understand how or why decisions are made regarding their place in the diagnostic queue.

This raise concerns related to the **Duty of Candour**, which requires providers to be open and transparent when things go wrong or when care falls below an expected standard.

Alignment with NICE Guidelines:

Any proposed system must align with the **NICE Guidelines (NG87)** for ADHD, which recommend timely access to diagnosis and assessment, multidisciplinary involvement, and clear communication with patients and carers.

Triage should not lead to prolonged waiting times or limit access based on arbitrary thresholds not supported by evidence.

Right to choose Pathway (RTC):

During the consultation on the ADHD pathway to diagnosis, attendees highlighted the **'Right to Choose' (RTC) pathway** as a **positive and effective route**, noting it provided an **easier experience and faster access to diagnosis**.

There was strong feedback emphasising the importance of **making the RTC pathway more widely accessible**, especially in contrast to the potential introduction of a **triage system**, which some participants expressed concern could create additional delays or barriers. The discussion suggested that **enhancing access to**

RTC might be a more patient-centred solution than adding another layer of assessment before referral.

Risk of Exacerbating Inequality:

There is concern that vulnerable individuals, particularly those from disadvantaged backgrounds or those with communication difficulties, could be disproportionately affected if the system relies heavily on digital self-referral or complex pre-assessment forms.

Equity of access must remain a priority, in line with the NHS commitment to reducing health inequalities.

Limited Patient and Public Involvement:

Service users and community stakeholders, including local Healthwatch groups, were not sufficiently involved at the formative stage of the proposal.

This limits the system's ability to reflect real-world user experiences and may reduce public trust in its outcomes.

Feedback has been provided in regard to the complexity of the online survey and the barriers regarding completion of this by neuro divergent users.

Recommendations:

Ensure Comprehensive Assessment of Multiple Disabilities:

Design triage tools and pathways that account for comorbid conditions and intersectional health needs.

Include multidisciplinary input at triage stages to avoid exclusion or misclassification.

Embed NICE Guidelines and Duty of Candour:

Confirm that all aspects of the triage system explicitly align with relevant NICE guidelines.

Align service redesign with NICE NG87 and other relevant guidelines.

Include citations and references to evidence that justify each stage of the triage process.

Provide clear, written communication to patients explaining decisions, their options, and expected timelines, in line with transparency obligations.

Establish an Independent Oversight Process:

Consider implementing an appeals mechanism or clinical oversight panel to review borderline or complex triage cases. Introduce an appeals or second-opinion process for those declined assessment.

Ensure continuous auditing to identify and rectify any unintended consequences or systemic bias.

Strengthen Equity and Accessibility:

Offer multiple pathways into the diagnostic system (e.g., GP referral, school referral, paper-based forms, in-person assessments).

Use inclusive, easy-read formats and translated materials to support broader access.

Publish a clear plan to develop an ADHD diagnostic service that is fully accessible to all patients, regardless of background or co-occurring needs.

Establish a multidisciplinary oversight board to ensure fairness, consistency, and equity.

Consult Healthwatch and Service Users Early and Often:

Healthwatch Bury recommends that **local Healthwatch bodies be consulted before final decisions are made** on the design and implementation of any changes to ADHD services.

Early involvement will ensure that the voices of service users, carers, and underserved communities are embedded into service development.

Reframe and Relaunch the Consultation Process:

Include co-facilitation with Neurodivergent representatives and advocacy groups.

Ensure all future sessions are designed with inclusivity, accessibility, and trauma-informed practices at the core.

Include Healthwatch in Service Co-Design:

We strongly recommend that **Healthwatch Bury and other local Healthwatch organisations be consulted before final decisions are made.** Our role is to represent the patient voice and ensure services are designed around real-world needs and experiences.

Unanswered questions:

However, several key areas were left unaddressed, and I would like to raise the following questions, concerns, and suggestions for further consideration:

Accessibility and Funding of Support Services

Questions:

- **What specific support services (e.g., educational support, therapy, coaching, family support) will be available for individuals awaiting diagnosis and those who do not meet the diagnostic threshold?**
- **How will accessibility be ensured across socio-economic and geographic boundaries?**

Concerns:

There is a risk that triage may inadvertently gatekeep essential services for those who still need support but may not receive a formal diagnosis.

The current proposal lacks clarity on how services will be funded and whether budget constraints may limit availability or create unequal access.

Suggestions:

Consider including a parallel support pathway for individuals on the waiting list, regardless of diagnostic outcome.

Provide a transparent budget overview or funding model to reassure the public of the plan’s viability.

Transition from Child to Adult Services

Questions:

- **What happens to children who are on the ADHD diagnosis waiting list when they transition to adulthood before being seen?**
- **Is there a transitional policy in place to ensure continuity of care and assessment?**

Concerns:

There appears to be a gap in care for individuals who age out of child services while waiting for assessment.

Young adults may face additional barriers if required to restart the referral process in adult services.

Suggestions:

Develop an integrated child-to-adult service transition protocol, ensuring individuals do not lose their place in line or access to interim support.

Consider a "bridging service" for late teens and young adults to mitigate disruptions in care.

General Observations:

Transparency: A detailed breakdown of how decisions are made during the triage process would be beneficial.

Engagement: Continued consultation with service users, families, and professionals will be key to ensuring the triage model meets real-world needs.

Outcomes Monitoring: Clear metrics should be established to evaluate the effectiveness of the triage system and ensure it reduces delays without compromising quality.

Conclusion:

Healthwatch Bury supports the intention to improve the ADHD diagnostic pathway but urges decision-makers to proceed with care, ensuring that reforms are evidence-based, inclusive, and transparent. We look forward to further engagement on this matter and remain available to assist in co-designing services that reflect the needs of our local population.

References: https://www.healthwatch.co.uk/news/2025-05-28/ADHD-diagnosis-life-changing-long-waits-nhs-need-urgent-action

Mental health clinical lead and colleagues, Trafford Locality full response

Full submission

Re: Adult ADHD consultation launch

Submitted on behalf of Trafford Locality ICB

Neither option A nor option B is acceptable for the following reasons

1. **Both are designed to restrict access to diagnosis and evidence-based medications** as an option for individuals who would benefit from them based on internationally accepted diagnostic criteria.

2. **These proposals create an entirely separate system for diagnosing ADHD, isolating it from other mental health conditions**. **This is short-sighted thinking** **and will continue to perpetuate damage to individuals, in particular the most needy and is the wrong approach.** Single tract diagnostic pathways are more likely to lead to inaccurate diagnoses.

Many individuals with more severe ADHD are likely to already have had contact with mental health services, where a comprehensive approach to diagnosis is crucial. Before determining an ADHD diagnosis, other mental health conditions must be considered—just as, when assessing other mental health diagnoses, ADHD must also be considered. By running ADHD assessments/services separately from broader mental health assessments/services these proposals undermine a patient centred approach. If mental health services are equipped to diagnose and manage conditions such as bipolar disorder and psychosis, they should equally be capable of diagnosing and managing ADHD (and ASC). Historically, many individuals with ADHD have been misdiagnosed within mental health services.

A fundamental priority for GM should be ensuring its mental health professionals are capable of accurately diagnosing the full spectrum of conditions they encounter, both mental health and neurodiversity because the overlap can be significant (and it may well be that some' SMI diagnoses' now are actually neurodivergent in origin). This is what the ICB System in GM should be supporting the MH Trusts to deliver. **We need to stop duplication of assessments and duplication of payment.** The Royal College of Psychiatrists requires all psychiatrists to be competent in neurodevelopmental assessment (Royal College of Psychiatrists, 2010). Professional barriers to this approach need to be considered and addressed as a priority.

3. **They reduce access to diagnosis to only the most severely affected**--Under these proposals, individuals with ADHD who do not fall into the 20-30% deemed eligible for diagnosis but who compensate for their neurodivergence to some degree would be denied both recognition of their difficulties and access to medication that could significantly improve their well-being and prevent other deteriorations in their mental and physical health. A diagnosis not only provides clarity and understanding for those affected, but it also opens the door to evidence-based treatment. **Need in**

an individual is inherently subjective and **influenced by factors and co-morbidities beyond ADHD itself.** By contrast, an ADHD diagnosis is an objective measurement backed by recognized, evidence-based treatments. Failing to provide a formal diagnosis when key criteria are met reduces the prevalence and individuals to disappear from the system, it removes system accountability (which is likely the purpose of the exercise) and leaves a vulnerable cohort without appropriate care. It also reduces perceived need for further services and hinders the development of further evidence-based interventions and systems.

If we were to apply this same logic as these options propose elsewhere, would we change the diagnostic threshold of Type 2 diabetes to 60 mmol/mol (instead of 48mmol/mol—merely labelling these individuals below 60 mmol/mol as having "dietary blood sugar related needs" thus limiting medication options to only the most severely affected? Such an approach would be both unjust, medically irresponsible and increase long term complications for individuals and expense for the system.

4. **They widen health inequities** --those who can afford a private diagnosis will receive this, and they should; individuals who cannot self-fund will continue to revolve around existing primary care services. Such individuals can be excluded from secondary care services, but they cannot be excluded from GP services, talking therapies, drug and alcohol services, or living well where (under these proposals) their unmet needs will continue in some cases to be inappropriately addressed.

Beyond this, a separate ADHD diagnostic service should exist to serve those outside the traditional mental health system for individuals with ADHD without complexity. Avoiding duplication of assessments and double paying for individuals already with access to MH practitioners with the skills to make the diagnosis and prescribe treatment would free resources which could be put towards such a service.

Why do we have the influx in individuals seeking an ADHD diagnosis? –it is not for spurious reasons as some suggest-it is because historically such difficulties in the main were brushed under the carpet -there was a failure to recognise the pattern in girls (thus there is an increase in 50% of the population to which such a diagnosis can be applied), secondly awareness means those not previously diagnosed in childhood (the majority of cases in adults) have not been dealt with. The numbers are therefore not surprising at this time.

In addition it may be that societal changes are pushing numbers with ADHD symptoms such as social media as the fast food business has pushed up the prevalence of diabetes but that does not mean we do not deal with the symptoms, while developing a long term Public Health strategy to make our society an better place to live in (perhaps by reducing social media) –if that were possible.

Poorly directed or inadequate investment in ADHD now not just impacts individuals but systems and society --untreated it is associated with multiple adverse health and societal outcomes, including increased mortality, increased family, relationship and parenting problems (perpetuating intergenerational difficulties in a highly hereditable condition), more accidents,

poorer educational attainment, career and financial struggles for more, higher rates of criminality, substance misuse & risks of homelessness.

All of the above represent significant economic burden to the wider GM system

There is no real choice in these options they are largely the same and will only make the current situation for individuals suffering with mental ill health and neurodiversity worse.

Mental Health Therapist full response

Full submission

Response to Consultation - Adult ADHD Diagnostic Service:

To whom it may concern, My name is Icarus Williams, I am an accredited CBT Therapist with specialties in Neurodiversity Affirming Therapy, ACT, and Long-Term Health Conditions. I work in NHS Talking Therapies Services, and I have delivered CPD on Neurodiversity Affirming Therapy and Long-Term Health Conditions for NHS Talking Therapies staff. I am also in the early stages of seeking funding for research focusing on the development of Neurodiversity Affirming Therapy within NHS Talking Therapies services. I am AuDHD myself, which is something I choose to discuss this openly. Given my particular experience in the field of Neurodivergence and Pathway Development, I believe I am well placed to highlight some specific concerns that may have gone unnoticed and offer significant solutions for both the initial and subsequent phases of the development of the Adult ADHD Diagnosis Service. I attended the Adult ADHD Consultation Focus Group on 28th May 2025. I'd like to extend my thanks to the group of passionate and empathic people who brought their professional and lived experiences of ADHD with them to the meeting. It should be noted that people came to contribute despite the fact they were not awaiting diagnosis themselves, and that part of their reason for attendance was to selflessly advocate for the wider Neurodivergent community. I'd also like to thank Scott Williams , Sandra Lindsay, and Ian Trafford for facilitating the engagement on a topic that is not a common area of a knowledge. Following the session, I was asked to summarise my concerns and any potential solutions. I have broken this information down into 4 sections:

1 – Acknowledgement of Current Challenges

2 – Cultural Competency Concerns within Consultations and Proposals A & B

3 – Clinical and Logistical Concerns within Proposals A & B

4 – Considerations for an Alternative Service Structure I can assure you that both my response, and the time taken to complete it, are being offered in good faith. I hope this contribution is taken in the spirit it is intended, and that further progress can be made towards identifying a successful service design. Yours sincerely, Icarus Williams

1 – Acknowledgement of Current Challenges:

1.1: I fully appreciate the scale of the current waiting lists, both with regards to the number of people awaiting diagnostic assessments and the length of time they have been waiting. This is a significant challenge, and these contributions are in no way intended to diminish the enormity of the task faced in establishing a new diagnostic service. While I fully acknowledge the scale of the challenges faced, I am also of the belief that these challenges should not compromise the creation of an exceptional and inclusive evidence-based service.

1.2: The current situation has been attributed to rising referral rates and inconsistencies across Regional services. This was described at the consultation on 28/05/2025 as services designed in good faith being rendered unsustainable. Whilst a new service is a rare opportunity for a reset, this new service will need to be able to present itself from the outset as both sustainable and designed in good faith.

1.3: In order to provide a service that can be held in high regard by both patients and commissioners, the task of establishing a service in a time of crisis is better understood as the task of establishing an exceptional service. The current proposals appear to focus on short-term crisis navigation, which may have resulted in consideration not being given to other relevant guidance and information available. This risks misrepresenting the local ADHD community as a burden.

1.4: It is not the responsibility of public need to shape itself to meet services, but the responsibility of services to shape ourselves to meet public need. Should either proposal be put into practice in its current form, I have genuine concerns about the functionality and acceptability of the service it will produce. I hope that by identifying concerns in this way, resolutions can be found. If, however, necessary adjustments are not made and these concerns are not addressed, it may become challenging to overlook the fact that these concerns were identified during the consultation stage.

1.5: It should be understood that this contribution is intended to increase hopefulness for the new service. I appreciate this contribution is longer than may be expected and does not sit within the boundaries of traditional contributions to consultations. I appreciate the concerns identified in this contribution may be uncomfortable reading at times, and that it may be felt that it is too early or late for input on this scale.

1.6: I am of the opinion that the current scale of public need can be met by a well-structured service, and identifying detailed concerns is something that allows for the identification of effective solutions. As I have given both my personal time and professional experience to offer proposals for solutions, I gently request that the genuine nature of the concerns identified will be taken on board and alternatives will be carefully considered by those with the influence to do so.

2 – Cultural Competency Concerns within Consultations and Proposals A & B:

2.1: During the consultation meeting on 28/05/2025, the 3 facilitators present openly discussed their own uncertainty regarding language around ADHD, with negative reactions to terminology noted throughout the session. Facilitators attempted humour at times, and there was an instance where a facilitator struggled to acknowledge guidance on some unwelcome language. This is not a criticism of the individual facilitators on the day, who I have already expressed my thanks to. It does however highlight a lack of cultural awareness in designing services for the Neurodivergent community as a marginalized group.

2.2: There are currently bridges that need to be built between diagnostic services and the Neurodivergent community. There is a longstanding sense that Neurodivergent people are the acceptable victims for gaps in services. This is exacerbated by a current trope that the increased demand for diagnosis can be dismissed as a social trend, rather than progress towards inclusivity.

2.3: The premise that marginalised individuals would have to seek assessment from a service that intends to decline the responsibility to help others from the same marginalised group is unthinkable for the Neurodivergent community. Creating an ADHD assessment service that openly aims to reject referrals is creating a service based in perpetuating one of the most painful experiences for the Neurodivergent community. There is a longstanding narrative that Neurodivergent people are “oversensitive to perceived rejection”. There is a similar narrative that Neurodivergent people are demanding or that they are seeking special treatment. These often occur when the Neurodivergent community advocates for itself around equitable access to services and Parity of Esteem. It should be noted that Parity of Esteem is something the NHS is committed to on a National scale. As with all marginalized groups, Neurodivergent people experience the impact of minority stress, and the Neurodivergent community understandably wishes to advocate for itself within this consultation process.

2.4: The current proposals reflect a cultural misunderstanding of what is acceptable to the Neurodivergent community, including what is acceptable to those who have already accessed diagnosis. All stakeholders want to see shorter wait times and better support. It is contradictory to suggest to the Neurodivergent community that the solution to a 7 year wait for diagnosis is to make diagnostic waiting lists less accessible to the majority of the community in the first place. In this instance, the differentiations between proposal A and proposal B are academic, as both proposals would result in a service that is less accessible to the community it is intended to assist. It raises an underlying question as to whether these types of proposals would be acceptable in any other service.

2.5: Wider society is still in the early stages of building bridges with the Neurodivergent community, which also experiences disproportionately high rates of physical ableism and anti-LGBTQIA+ prejudice. Consultations can harm a services relationship with minority groups when they are not delivered in a culturally competent way. Embracing Neurodivergent culture will be as essential to a successful consultation process as it will be to the service itself.

2.6: The current proposals also lead to concerns around staffing. The Neurodivergent community is well represented amongst healthcare staff. Whilst the presence of Neurodivergent staff greatly benefits services for Neurodivergent people, these staff members are unlikely to stay in working environments that perpetuate inaccessible care for their community. Staff working in the service will repeatedly experience declining access to diagnosis as achieving the goal of the service, sending a harmful message about how minority communities should be treated. This is likely to contribute to a high rate of complaints within the service.

2.7: Caution is also needed regarding potential legal challenges related to service accessibility, similar to those seen elsewhere in the country. Any concerns identified by the Neurodivergent community during the consultation process, that are not suitably accounted for in the final service proposal, could significantly increase the likelihood of a legal challenge. This runs the risk of affecting the public perception of a new regional service. Given the potential cost in both time and money stemming from any potential legal challenges, enforced changes, delays to services, and loss of public confidence, it is my professional opinion that alternative pathway structures should be considered at the earliest opportunity.

3 – Clinical and Logistical Concerns within Proposals A & B:

3.1: Establishing a diagnostic service amid large legacy waiting lists presents significant challenges. New services have the benefit of being able to review successful models used by other services.

3.2: Limiting access to diagnostic assessment has already been identified as an ineffective method of waiting list management in these services. The repeated pausing of access to waiting lists has been the primary tactic of managing the increase in referral rates across services in the region. Given that that unsuccessful nature of this approach is a contributing factor to the need for the establishment of a new service, it is unclear why this method is central to both proposals for the new service.

3.3: Figures presented within the current proposals do not identify how they are informed by research into the current prevalence of ADHD in the adult population, nor do they acknowledge the changing rate of that prevalence. The absence of references to this information, or its application to the population of the area the service intends to provide for, raises understandable questions about what evidence-base has been used to inform this element of the service design.

3.4: Concerns about the role of the current evidence-base within the service design are significant. No reference was made to evidence-based care during the 28/06/2025 consultation meeting, including during discussions relating to diagnosis, triage, and discharge. Whilst it would be unreasonable to expect engagement professionals to provide clinical expertise outside their field, it is essential to communicate in what way proposals for the service are informed by the clinical evidence base.

3.5: During the 28/05/2025 consultation, a facilitator stated that NICE Guidelines are not legal documents. It should be noted that NICE guidelines are admissible as evidence of best practice, and that services are required to justify deviations from guidelines by presenting evidence-based rationales. Regardless of service pressures, appropriate regard should be shown for NICE guidelines relating to ADHD, along with other recent relevant guidance and public literature.

3.6: During the 28/05/2025 consultation, there were mentions of both the DSM-V and the Adult Self Report Scale (ASRS) potentially informing questions at triage within the current proposals. This overlooks the status of the DSM-V and the ASRS as reliable and valid clinical resources rooted in an evidence base. A reliable clinical measure will provide reliable clinical results and cannot be adapted to suit a service structure with a predetermined rate of access to diagnostic assessment. Arbitrary adaptation of such resources detaches them from the clinical evidence base on which they are founded. While specialist knowledge of Neurodivergence may not always be immediately available whilst developing proposals, adherence to clinical standards is fundamental to both the service design and commissioning processes.

3.7: Under the proposed “need”-based access system, a patient may be identified as likely to meet the diagnostic criteria for ADHD but could still be discharged without being offered access to an assessment. Failing to offer diagnostic assessment without an evidence-based clinical rationale to do so risks breaching the NHS Duty of Candour. This duty mandates transparency in healthcare, something which qualified triage professionals in adult ADHD services would be professionally obliged to uphold. Attempts to read the Duty of Candour as only relating to transparency in the context of errors within a patient’s care are not within the spirit of transparent practice, and also do not preclude the concerns relating to this which have been identified in the current proposals.

3.8: There is a concern that the “need”-based structure of triage will result in patients being discharged whilst clinically indicated for diagnostic assessment, or discharged before proper attempts to identify clinical indicators for assessment have been made. Diagnostic services must make intentional and transparent efforts to both identify and share clinical indicators with patients, and to provide assessments when clinically indicated, regardless of the community they are seeking to serve. Alongside concerns relating to the NHS Duty of Candour, this also raises previously mentioned concerns relating to NHS Parity of Esteem. Increased prevalence within a minority community is not grounds to reduce access to services for this community.

3.9: A key concern is the lack of support for patients denied diagnosis. The proposal’s vague details on support contrast sharply with clear information about the number of individuals excluded from diagnostic assessments. ADHD-focused support cannot serve as a safety net for patients discharged at triage under the current proposals, as this support will not be clinically indicated for those without diagnosis. Under the current proposals, it would be an acceptable patient journey through the service, for someone who is clinically indicated as requiring a diagnostic assessment to be knowingly discharged to support services that are not designed to meet their needs.

3.10: A further concern is that a lack of consideration given to the current clinical understanding of ADHD. ADHD has been identified as having a high rate of genetic heritability, and to deny access to a clinically indicated diagnostic assessment to an individual, is to deny access to relevant healthcare information to a whole family. It is worth noting that this could contribute to reduced identifications of ADHD in childhood, and risks maintaining pressure on adult diagnostic services. Actions that may knowingly reduce the accuracy of a family medical history are a serious concern for both patients and professionals alike.

3.11: There are also concerns relating to the lack of consideration of the impact reduced access to ADHD assessments could have on NHS physical health services. Sussex Partnership NHS Foundation Trust's successful Integrated Neurodivergence and Brain-Body Medicine service is well-documented in media and clinical circles. They highlight the disproportionate impact of some co-occurring physical health conditions on Neurodivergent people. A non-exhaustive list would still include Postural Orthostatic Tachycardia Syndrome (POTS), Chronic Fatigue, Long-COVID, Endometriosis/PCOS, Mast Cell Activation, Fibromyalgia, Irritable Bowel Syndrome, Inflammatory Bowel Disease, Hypermobile Ehlers-Danlos Syndrome (HEDS), and other differences in Connective Tissue. The current proposals fail to acknowledge the wider clinical relevance of ADHD and presents an avoidable a risk relating to its role in informed evidence-based care for the discharged patients in Cardiac, Musculoskeletal, Reproductive Health, and Gastroenterology services.

3.12: An understandable concern is possible the frequency of clinical incidents for patients on long waiting lists. Reducing incidents that occur within a service is not equivalent to reducing the number of incidents which take place. Incidents which take place after a patient is rejected from services continue to reflect on the operational processes of those services. Declining access to an assessment is an active decision, leading to a potentially lifelong risk of reduced access. This differs from the passive and temporary risk of waiting for an assessment. Dismissing requests for assessment based on “need” has already been identified a likely source of distress for Neurodivergent people, increasing incidents that could be attributed to the service. Incidents occurring for patients whilst in services are more reliably identified and addressed. Any logic equating reduced accessibility with reduced frequency or culpability for clinical incidents must be thoroughly reviewed.

3.13: Staffing concerns have been previously discussed from a cultural standpoint. High discharge and rejection rates are linked to poor staff retention in NHS services, jeopardising the goal of reduced waiting lists due to staffing difficulties. Low satisfaction among patients and staff also increases the likelihood for complaints against the service. Issues such as these can lead to difficulties in meeting performance targets and could jeopardise future commissioning outcomes.

3.14: It is worth noting that the outlines of proposal A and proposal B acknowledge their high level of similarity. Ultimately, the differences between the 2 currently proposed service structures do not mitigate the concerns identified. It is not in the spirit of public consultation to offer such narrow choice. This also places inequitable demand on the Neurodivergent community to advocate for itself on the specific topic of healthcare policy. An alternative service structure should be included in consultation at the earliest opportunity.

4 – Considerations for an Alternative Service Structure:

4.1: This section of the response should not be seen as an attempt to propose a final design of services. It is an attempt to present an example of an alternative structure which would mitigate current cultural and logistical concerns, allowing for alternate service designs to be included in discussions in a way they have not been to date.

4.2: This section will outline an initial suggestion for the service, where managing waiting lists, evidencing care, and rebuilding community relationships will be essential. This structure will allow for decisions to be made based on immediate need alongside the provision of appropriate support for those without priority access to a diagnosis.

4.3: This section will also outline further suggestions for the service, including inter-service relationships, the identification and presentation of data that will aid future commissioning, and long-term goals for the pathway.

4.4: NHS responsibilities to provide care aligned with guidelines, best practices, and the current evidence must be upheld despite logistical hurdles.

4.5: Identifying concerns during consultation allows for timely restructuring of the pathway, before the launch of the service. Failure to do so may undermine the service's credibility and could prompt questions as to why these issues were not resolved at an earlier opportunity when identified during consultation. Referral Procedure:

4.6: A referral avenue via the GP or via self-referral can be considered. Self-referral may increase accessibility and help improve service relationships with GP surgeries, which will be important when discussing issues relating to accepting diagnoses and providing prescriptions. A self-referral option may also present an opportunity for some clinical measures to be completed independently by the patient in advance of triage. There may be costs associated with establishing a self-referral system that contains a patient portal for the completion of clinical measures, and considerations should be given to ensure that the service is accessible to those without access to technology. Triage:

4.7: Clinical indicators for assessment should be considered at triage, before a decision to discharge is made. This should be done using evidence-based outcome measures, such as the Adult Self-Report Scale (ASRS).

4.8: Triage should include the use of other evidence-based outcome measures to identify co-occurring physical health problems and gain a measure of the patient's quality of life. This information will contribute to evidencing the work of the service to stakeholders, including commissioners.

4.9: Patients not clinically indicated as likely to meet the diagnostic criteria for ADHD should be transparently advised of this and referred to alternative services which may meet the needs that brought them to the service.

4.10: All patients clinically indicated as likely to meet the diagnostic criteria for ADHD should be transparently advised of this and be offered the opportunity to access a diagnostic assessment with the service.

4.11: Wellbeing plans and Risk management plans should be completed with every patient at triage, and the patient should be provided with a written copy of these in their triage outcome letter.

4.12: Patients should be made aware of the relevant support available for them whilst awaiting assessment.

4.13: Careful consideration should be given to where the service is placed in relation to other NHS services to ensure that patients are not denied access to other services whilst awaiting assessment.

4.14: Patients attending triage may be in crisis, however this should not prevent access to the service. Referrals to the local single point of access team should be completed at triage, or at any other stage if required.

4.15: Access to suitable clinical skills and case management supervision should be available to triage staff. Waiting List Structure:

4.16: Waiting lists should be structured to include both the patient's referral date, and the date the patient last had contact with the service. This ensures that any support engaged with can be presented within service data via the date of last contact. The wait for an assessment should be measured from the patient's referral date, to ensure patients are not penalised for engaging in other support. This can help reduce an emphasis on lower numbers in services being represented as better numbers.

4.17: A priority assessment waiting list measured on need can be made available. Considerations for what constitutes need for a priority assessment could include instances where access to an assessment would: - Reduce a current likelihood of adverse life events to the patient or their household. - Reduce a current risk of suicide or self-harm. - Benefit the patient due to a need to prioritise medication titration for mental or physical health reasons. - Benefit the patient as they have a newborn under the age of 1 year old, have recently adopted, are pregnant, or are currently expecting a child to enter into their care. - Benefit the patient and the wider public by enabling a staff member of essential public services to remain in/return to work.

4.18: A non-priority waiting list should be structured based on the patient's referral date and should be presented as one element of the patient's contact with services. Page 10 of 12 Support whilst awaiting non-priority assessment:

4.19: As part of a multi-disciplinary approach, learning should be taken from the establishment of other more integrated services.

4.20: Support whilst awaiting a non-priority assessment should be seen as an opportunity to mitigate the impact of the wait for diagnosis, by providing genuinely useful content at the earliest opportunity.

4.21: Once accepted into the service for assessment, all patients should receive a letter confirming they are clinically indicated for an assessment for ADHD and outlining that the impact of accessing individualised adaptations is a useful indicator in the diagnostic process. This will allow patients to immediately begin to trial adaptations at work or in other areas of their life, without having to wait for a final assessment.

4.22: As part of a multi-disciplinary working approach, the service should establish formal working relationships with relevant physical and mental health teams in the area. Multi-disciplinary meetings help build service relationships, share responsibility, share workload, and ensure every effort is made for issues identified at triage to receive assistance whilst the patient is awaiting assessment. This should include links with NHS Talking Therapies, Musculoskeletal, Perinatal, and Primary/Secondary care risk management services.

4.23: As part of a multi-disciplinary working approach, accessible, ADHD specific resources should be made available to the patient, with an emphasis on living a rewarding life with ADHD. This can include written resources, pre-recorded presentations on specific topics, group sessions, and Q&A sessions on ADHD. These could be delivered as part of a shared workload across formal inter-service relationships, providing a mutual benefit to services seeking to meet the increased demand for ADHD specific resources.

4.24: An emphasis should be placed on the quality and suitability of the resources and support available.

4.25: A conscious effort should be made to measure and present the holistic benefits of this way of working to commissioners. Following engagement with resources, measures taken at triage should be taken again, alongside effective Patient Experience Questionnaires. This patient feedback cab be used to both demonstrate benefits and highlight areas for resource improvement.

4.26: Patients should be reassured that they will not be denied access to an assessment if their measures improve.

4.27: Patients opting not to pursue assessment after benefitting from resources should be provided with a new letter outlining this, to ensure they do not lose access to beneficial adaptations. Opting not to wait for assessment should not be classified as the absence or presence of a diagnosis. Discharge after Diagnostic Assessment:

4.28: Patients should be given clear and accessible documentation of their diagnosis, with a pathway for this to be accepted by all GPs in the region already in place. This will help address a historical issue of patients having to re-access assessment as their diagnosis was either not accepted or not properly recorded.

4.29: A regional medication titration pathway should be established, including access to accurate information regarding both stimulant and non-stimulant medication, with clear and equitable prescribing plans in place.

4.30: Patients who accessed a priority assessment should be given the opportunity to access the same support made available to those who accessed resources whilst awaiting a non-priority assessment. Cultural Competence:

4.31: The service should actively present and follow through on a commitment to an affirming understanding of Neurodivergence.

4.32: Staff should receive high-quality training on Neurodiversity Affirming Culture and Practice.

4.33: Support offered whilst awaiting treatment should include an acknowledgement that the service has been designed in a way that intends to avoid the repeat of previous hurtful experiences for the Neurodivergent community.

4.34: The service should build bridges with the Neurodivergent community through consistent, reliable and genuine engagement, including engaging with those who are already diagnosed.

4.35: The service should be receptive to communication and feedback from the Neurodivergent community, even if this contains challenging learning for the service in the early stages of this relationship. Staffing:

4.36: Staffing structures should consider the essential role of a diagnostic service, with a priority focus on diagnostic staff.

4.37: Diagnostic staff roles should be structured to minimise time spent on tasks that do not require this skillset.

4.38: The service should actively acknowledge that both staff and their loved ones may also be Neurodivergent. Any such crossover between staff members and the Neurodivergent community should be seen as welcome. Affirming support should be available to staff having their own experiences connected to ADHD.

4.39: The service should maximise the use of trainee placements to cover develop skillsets specific to the service, such as those covered by Assistant Practitioner's on their training course. This will reduce the non-diagnostic workload for diagnostic staff, present training opportunities to the local community, and increase access to work in the field of Neurodivergence.

4.40: The potential shared benefits for services, regarding staffing when using multi-disciplinary working, should be investigated at the earliest possible stage in service design. Long-Term Considerations:

4.41: Increased identification of ADHD in a generation of adults could assist in the identification of ADHD for generations of children. This could reduce the risk of some adverse childhood events, contribute to Neurodivergent children accessing affirming content as early as possible, and lead to a long-term reduction in pressure on adult diagnostic services.

4.42: Increased multi-disciplinary working can contribute to improved physical health outcomes and the accuracy of wider family medical histories.

4.43: Beneficial patient experiences of community relationships, affirming resources, and a culturally competent service will assist in the development of an exceptional and inclusive service. The inclusion of measures properly acknowledging patient's lived experiences throughout their time with the service will allow for this to be fully evidenced.

4.44: A reduction in pausing waiting lists/declining assessment to those clinically indicated for assessment will reduce the impact of rereferrals for assessment from those previously denied access.

4.45: The current prevalence of ADHD in the adult population, the changing rate of that prevalence, and the application of this to the population of the area the service intends to serve should be considered in all future commissioning and service capacity discussions.

4.46: Long-term plans for full integration with other assessment and brain-body medicine services should be considered. These can be evidenced by considering the progress of other such services (E.g. Sussex Partnership NHS Foundation Trust). The success of integrated services responses to legacy waiting lists, such as the founding of the Bury Integrated Pain Service in the wake of the change in NICE guidance on persistent pain, can also be considered.

Manchester community collective full response

ADHD Consultation Response Letter (GM ICB Adult ADHD Consultation) 22/06/2025

To whom it may concern, This letter is a collective response to proposed changes to the adult ADHD assessment pathway set out in the consultation. It is important to recognise that whilst this letter may give feedback against certain elements of the proposed changes, the following is clearly recognised and appreciated: - The proposed changes are well thought out, highly researched, and have many elements that would be beneficial to service provision changes. - The need to change current service provision to ensure neurodivergent people do not wait excessively long. - The need to ensure that service provision is cost-effective, realistic, and able to be funded. - The implementation of service provision needs to be able to respond to risk through prioritisation. - That not everyone presenting with ADHD traits will need medication, and that over-medicalising and over-prescribing for neurodiversity is a key issue with serious negative impact. Referral Criteria - Needing Additional Mental/Physical Health Problems. Firstly, the proposed referral criteria for the ADHD assessment pathway, notably the last point pertaining to having ‘other severe physical or mental health problems’ may lead to significant inequalities in clinical care, and the potential for those who have moderate-severe impairment related to ADHD traits not being able to access diagnosis and treatment. The primary feedback and critique on this referral criteria is that this criterion could exclude a significant proportion of neurodivergent people with severe traits and severe functional impairment from accessing the evidence-based treatment recommended by NICE guidance. There will be many people without severe mental health or physical health problems who may not be able to carry out work, access education, access their GPs (due to inaccessible pathways), get reasonable adjustments at work, maintain meaningful relationships and friendships and overall are unable to function in the world that has been built for neurotypical people, and people that do not have an ADHD brain. The costs of lack of ADHD-care, lack of diagnosis and lack of support can be extreme distress, trauma, and burnout. Whilst there are proposed signposting for those that do not meet that criterion, what happens to the individuals that this signposting does not help ameliorate their ADHD traits or their impact, who also do not have mental health difficulties.

Additionally, there is no real acknowledgement on some of the greatest impacts of ADHD, such as those on estimated life expectancy, where the reduction in life expectancy for adults with diagnosed ADHD relative to the general population was 6.78 years for males, and 8.64 years for females (O’nions et al., 2025). This criteria essentially relies on an assumption that ADHD symptom severity and its impact is significantly, positively, and strongly correlated with mental health severity, in order for this criteria to mean that the most severe cases of ADHD are seen for assessment and diagnosis. However, several studies may provide evidence against this. For example, Gjervan et al. (2014) showed that only the hyperactivity domain, and not inattention, was a strong predictor of mental health quality of life, however, women are less likely to present with hyperactivity/impulsivity traits (Fraticelli et al., 2022), therefore this could amount to indirect discrimination of a protected characteristic. Additionally, Garcia et al. (2012) showed that “the negative life events experienced by these patients are associated with the severity of ADHD independently from comorbid psychiatric disorders.” On the consultation form, there is no clear guidance on how the criterion of severe mental / physical health problems would be measured or categorised, whether this would require a diagnosis of mental health problems, and where the boundary of moderate to severe lies. If meeting this criteria would involve being open to other services, or having mental / physical health diagnoses, then a paradox may occur. Mainstream physical and mental health services are known to be inaccessible to a degree of people with ADHD, through extensive form filling, needing to remember appointments and strict DNA policies, requirement to focus for appointments/therapy, etc. Therefore, people with more severe ADHD may not be able to access ADHD assessment and potential treatment, not because they don’t meet the criteria, but because they are unable to access the services they need to prove they meet the criteria. Additionally, a significantly well-known and established issue in receiving mental health support is diagnostic overshadowing, for example having most mental health needs being seen as just someone’s learning disability or autism. It is asked – as a result of diagnostic overshadowing for those more likely to have ADHD (people with other neurotypes), Often, ADHDers can present with significant mental health needs, but in the context of ‘emotional impermanence’ (Emotional Permanence in ADHD: Why It’s Challenging and What to Do) and ‘emotional dysregulation’, and neither of which are diagnoses. Therefore, a large subsection of those struggling with their mental health related to ADHD may not be able to meet this criterion. Additionally, professionals working in ADHD services have found many of the more severe ADHD cases did not also have mental health problems, but had severe

functional impairment related to education, occupation, relational and home life functioning. An alternative - merging elements of option A and option B Finally, it is proposed that a change to the options layed out could be one that aggregates parts of option A and option B. Firstly, that option A works as it is, however for the subgroup of people who do not meet the threshold for ‘severe mental/physical health problems’ they go through similar proposals to option B. Where this group of people who have ADHD symptoms, functional impairment in several areas of life, and this was present from childhood, will be signposted to self-help, services and support groups initially, and if this does not make an impact and functional impairment/symptoms continue to be significant, they then get referred onto the Assessment, Diagnosis and potential Treatment pathway. What is ‘signposting to support and services’ Secondly, the pathway for those who do not meet the referral criteria is not clear, detailed or sufficient to make this consultation informed and meaningful. Although there is some detail stating “self-help tools, apps, peer support groups, and other relevant services for their symptoms”, considering this is the proposed pathway for 70-80% of referrals, it simply is not sufficient to give feedback on. Several queries arise from this proposed pathway. What are these self-help tools and apps, are they evidence-based, are they safe, efficacious and effective, are they acceptable and feasible to those with ADHD? In general, do the proposed signposting offer and other intervention offers have any evidence to show that they may support in reducing the functional impairment or severity of ADHD? Regarding the peer support groups, who are these being run and funded by? Currently there are very few third-sector organisations around adult ADHD in greater Manchester, and would this therefore need to be a service offer funded by GMMH or the GM ICB? Regarding the signposting/referral to primary care talking therapies services, this is assumed to amount to CBT-based self-help and talking therapy interventions. However, research has shown that “Overall, participants [adults with ADHD] found non-adapted, generic CBT in the UK to be unhelpful, overwhelming, and at times harmful to their mental well-being.” (William et al., 2024). Therefore, whilst this may be helpful for those referred that do not have the ADHD neurotype, this could be harmful and ineffective for those with ADHD who do not meet the criteria related to severe mental/physical health problems.

The impact of gatekeeping diagnosis – What does diagnosis change? As clearly identified in the previous public consultation document, the public and patients clearly express that diagnosis is a gateway to further support regardless of medication options, and therefore the reduction of diagnostic assessment to 20-30% of current referrals appears to ignore the impact of diagnosis on various domains – ability to seek support, reasonable adjustments, making sense of own life, being believed by others in power (such as employers or educators). There are no details on any campaigns that are aiming to reduce the need to diagnose in order to access support. Without strong collaborative campaigns with the intention of creating a more accessible society, for example in education, workplaces, access to healthcare, then the costs to the individuals of gatekeeping the opportunity to receive a diagnosis is not balanced with the needs of creating a realistic and cost-effective service provision. Further, as described by many people with lived experience, diagnosis can be extremely important for people to make sense of their own life, their difficulties, their differences and their needs. Whilst diagnosis should not be done solely for people’s validation, is there any way that a new proposed model could have an informal ‘balance of probability’ identification so that people are able to understand their difficulties (without medication) as suggestive of ADHD. This is not to say handing out the ADHD label immediately and without thorough assessment, but of giving people an understanding or idea of the probability that ADHD may describe the way their brain works, in order for them to understand themselves better and do their own guided and informed research themselves (e.g. there is a mild/moderate/high probability that ADHD may describe your presentation and needs).

Person 1 Lived experience as an Adult diagnosed with ADHD (in adulthood) and Professional experience of over 3 years an Assistant Psychologist in neurodiversity services. This included a substantial post in an ADHD service - no longer in work there.

Person 2 Lived experience as an adult diagnosed with ADHD (in adulthood) with negative experiences of diagnoses that resulted in formal complaints. Clinical Psychology Master’s student undertaking research exploring how gender minorities experience ADHD and their perceptions of barriers to diagnosis and support.

Person 3 Lived experience as an adult diagnosed with ADHD in adulthood, and with insight into the impact of a late and difficult to obtain diagnosis.

Person 4 Lived experience as an Adult diagnosed with ADHD (in adulthood) and with insight on the consequences of late diagnosis and lack of ADHD awareness.

Person 5 Lived experience as an Adult diagnosed with ADHD (in childhood) and with insight into the struggles of getting support from specialist ADHD teams in adulthood, and the impact of lack of ADHD support.

Person 6 Lived experience as an Adult diagnosed with ADHD (in adulthood) and with insight on the consequences of late diagnosis and lack of ADHD awareness.

Person 7 Lived experience of traits suspected to be ADHD, however with experience of struggling to get an assessment or needed support.

Person 8 (Surname not provided) Lived experience as an Adult diagnosed with ADHD (in childhood) and with insight into the struggles of getting support from specialist ADHD teams in adulthood, and the impact of lack of ADHD support.

Person 9 Lived experience of traits suspected to be ADHD, however with experience of struggling to get an assessment or needed support.

Person 10 Lived experience of supporting adults with ADHD, and experience of several loved ones with diagnosed ADHD and undiagnosed traits resembling ADHD.

Person 11 Lived experience of supporting adults with ADHD, and experience of several loved ones with diagnosed ADHD and undiagnosed traits resembling ADHD.

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Appendix 6: Case studies and stories

Maisie's Story

Maisie was diagnosed with ADHD by a psychiatrist while on maternity leave, following a referral from their GP. However, they couldn't start the prescribed medication immediately due to breastfeeding. When Maisie was ready to begin treatment, the ADHD clinic had shut down, and their GP had no record of the diagnosis, placing Maisie on a long NHS waiting list. Meanwhile, Maisie was struggling with the demands of new parenthood and returning to work.

"I was facing a mental health crisis and couldn't wait any longer, so I used my employer-provided health insurance to see a private psychiatrist. They confirmed my ADHD diagnosis and started me on Elvanse, which was absolutely lifechanging. But I couldn't afford to keep paying privately – it just wasn't sustainable.

"When I went back to my GP, they initially refused a shared care agreement (a written agreement between a patient, their GP, and a hospital consultant that allows for the sharing of care for a specific health condition) *because I wasn't connected to an NHS clinic. I had to really push and advocate for myself to finally get that shared care, which stopped me from being abruptly cut off from my medication.*

"My GP then referred me to ADHD 360, where I had to go through a third diagnosis just to keep accessing treatment through the NHS. But then ADHD 360 lost its NHS contract, and I had to start the whole process again – having to start with yet another clinic just to stay on my medication safely."

NHS Not Private

Maisie really believes in the importance of patient-led changes being made to the adult ADHD service because of how much people rely on the NHS and not private health insurance. Although Maisie was able to initially access private healthcare through their job, it was not a long-term option.

"I feel for the people who are on waiting lists for years and years, who weren't as lucky as me to have the private help that I had…especially because the medication and support changed my life.

"I don't feel alone as much anymore because I have a community of other people after setting up the neurodiversity group at my work about two years ago. We've got 400 people in it, and it's amazing the community we've created [providing] the space to understand each other."

Reflecting On Their Diagnosis Experience

Maisie describes their experience of the ADHD service as the most difficult they've had of any medical service in their whole life – due to the combination of long waits and numerous clinic changes because of clinics closing and ending their partnership with the NHS:

“I'm autistic as well and I struggle a lot with so much change, as well as advocating for myself and understanding when I can stand up for myself. But I do also know a lot about this stuff through peer connections, lived experience, as well as taking a keen interest in conferences and scholarly articles – so I wish I was listened to more when I say what might work better for me.

“GPs need more training on ADHD – truly understanding Neurodiversity, and shared care needs better management. There needs to be a strong and meaningful push for more consistent services to keep people well and safe…People don't even check-up on you properly. There is already so much misunderstanding about adults with ADHD, we just want to be accepted instead of judged, and our GPs are supposed to be who we go to for support.”

The Holistic Approach

Maisie believes that when it comes to treatment, medication alone is not enough even though it helped them. It was a combination of the government’s Access To Work and Workplace Strategy Coaching, paired with the right medication that has worked for them:

“Every person is different and deserves to be treated with care, respect, and consideration for their individual needs.

“A lot of ADHD treatment needs to be more well-rounded and varied, because at the moment all that seems to be offered is medication. I’ve done access to work and coaching for access to work - which a lot of people don’t even know about, even though part of ADHD treatment should be coaching.

“Although I have found some therapy very helpful, a lot of traditional therapies don’t always work well for Neurodivergent people, whereas coaching seems to be more impactful because it accepts how our minds already function – and that is incredibly validating. Take coaching for work, for example, that's the best thing that I've ever done for work and for life. It's meant that I'm working my full-time job and I'm able to actually take part in society more. If I wasn't being listened to and learning how to better advocate for myself, I wouldn't have got that.”

“I think improving all these things would improve people's lives. It would help with a lot of the crisis we're having in mental health in the UK.”

The Importance Of Having A Voice

Maisie explains that the reason why it is so important for adults who are affected by ADHD to have a say on what is and isn’t working is: *“…because nothing should be decided about us without us.*

“A lot of the time our experiences are poor because decisions are being made by people who do not always have the ways of thinking that we have. There can be a lot of misunderstanding or biased thinking due to unfortunate and inaccurate stereotypes. We need to inform because if we’re not listened to, it’s not going to be

shaped in the right way – then what's the point? It's a waste of the service and money if it's not effective!"

A Positive Outcome

Although it has been a struggle to get to this point, and can still be very hard sometimes, Maisie now feels in a much better place than a few years ago and credits speaking up for themself, a recognised diagnosis with medication, getting the right support at work for helping them to excel both in their career and at home:

"I've developed more at work since getting treatment for ADHD. I've been able to better use my strengths, I can organise myself more effectively, understand my mind better and I feel empowered knowing more about myself and how to explain my thought process to other people to get the best from what I can do.

"The most impactful thing for me has been accepting myself as I am and learning to be kind to my own mind."

Audio submission Summary

Challenges in Accessing Treatment

Respondent described serious barriers to getting the treatment and support they need. They identified long waits or inaccessible services to losing jobs and experiencing depression. They felt their life could have been very different if help had been available earlier.

Reflections on Education and Access

School experiences had both positives and negatives, but education was seen as vital. There was a strong belief that everyone should have equal access to opportunities, regardless of their background or circumstances.

Decline in Healthcare Services

The respondent felt mistreated or let down by the system. They reported that NHS services have been underfunded for 10–20 years, with charities increasingly filling the gap. Healthcare staff were described as unable to provide the level of care expected, they called the situation “barbaric.”

Perspectives on Mental Health and Contribution

It was their belief that with the right medication, people with mental health conditions could contribute more to society. Cuts to services were seen as harmful, lowering quality of life. They rejected the idea that ADHD and other conditions are “modern trends,” pointing out that many have gone undiagnosed for decades.

Normalisation and the Mental Health Crisis

Concerns were raised about the normalisation of unmet need, meaning more people go without help. Funding without proper diagnosis was described as fuelling a mental health crisis. Misinformation about lived experience was said to affect all areas of life.

Plea for Timely and Quality Treatment

The respondent expressed frustration with long waiting times and called for healthcare that is both accessible and high quality. They hoped for a future where support comes quickly, enabling individuals to live productive and fulfilling lives.