

Review of Adult ADHD Services Engagement Report

April 2024

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Executive Summary

Throughout the engagement period the NHS Greater Manchester (NHS GM) engagement team interacted with over 500 people across a variety of methods.

Method	Engagement numbers
Online survey	464
Focus groups (2)	23
Emails	3
Phone calls	3
Social media	Reach: 15,860; Engagement: 761

Diagnosis was prioritised as the most important aspect of the pathway to participants, as they described that stage as being crucial to open all other doors of support. Participants commented that, once in pathways, they received positive, individualised care from kind and empathetic healthcare professionals, but this was in comparison to feeling that they were being discouraged or blocked from accessing the referral or pathway to diagnosis. Participants described their experiences of seeking private diagnosis and the implications this then caused when needing to access NHS care, as it ‘didn’t count for anything’.

Participants felt they received a lack of communication about their place on the waiting list, and some participants had fallen off waiting lists due to a change in providers and had not been informed.

They felt there was a lack of support available for individuals whilst they were waiting, which was often over a year. Participants identified the damage this caused them and often resulted in them receiving support from other pathways once reaching mental health crisis point. Needing support whilst waiting was a strong theme throughout this report, as a way to cope whilst on the waiting list. The support needs to be reliable information and tailored to individual needs. Individuals linked this theme back to feeling unsupported whilst on the waiting list and felt that due to the lack of NHS information available, it led them to do their own private research on the internet or social media.

This engagement is expected to be followed up by further engagement or consultation as part of the ongoing process to review the adult ADHD services.

Introduction and Background

NHS GM is reviewing adult ADHD services because a lot more people are now being referred than they were originally designed for. This means that waiting times are getting longer. We think that there are better ways to deliver these services so that they can quickly support the people who need them most.

There is currently no single waiting list in Greater Manchester for adults waiting for ADHD services, so it difficult to say exactly how many people are currently waiting for an assessment. However, our best estimate is that there are over 15,000 people waiting, with that figure growing every day.

If the service continues as it currently is, some people could be waiting over 7 years for diagnosis and treatment, which is not acceptable. So, the service needs to change to better support the people who need it.

Approach

The NHS GM Engagement team ran an online survey between the 12th of February and the 24th of March 2024. The survey received 464 responses over a 6-week period.

We supported people to contribute their thoughts by also booking phone calls, welcoming email, and written submissions, and hosting some online focus groups. Social media posts were issued throughout the engagement period to advertise the opportunity to get involved and to take any comments via social that people may have wanted to share. Our WhatsApp number was promoted throughout the engagement period, should anyone prefer to communicate via messaging. We sought community support groups for adults with ADHD, but whilst we were able to find a number for children, we were unable to locate many for adults. One organisation, CHART, reached out via email and we began a conversation which we hope to develop in future. We will continue to search and would welcome contact from any adult ADHD support groups who we can work together with.

Participants appreciated the opportunities to attend focus groups and speak on the phone, so this style would be something we will take forward into any future engagement or consultation. A summary of each method of engagement has been included in the appendices.

Whilst there were responses from a wide range of people and ages, the most common participant was a British woman aged between 36 – 45 years old. 46% of participants to the online survey described themselves as “Someone Living with ADHD”. 31% of participants were currently on the adult ADHD services waiting list, which is positive in terms of us seeking the views of those currently affected. There were responses from across Greater Manchester, but the highest number was from participants living in the borough of Manchester, which correlates with that of the highest population. The demographic gaps in engagement during this phase included males between the age of 18 – 25.

Findings

Findings from the engagement are as follows:

1. Communication

The main plea was to significantly improve the communication whilst on the waiting list including whether patients are still on the list, and what position they are in.

Overwhelmingly people have had no communication about the waiting list, but one participant said they valued the frequent texts they received to update them on the waiting list, or text reminders for upcoming appointments. Similarly in relation to communication, one participant said they always received a response when sending email enquiries but that these staff can't impact on the waiting list itself.

The lack of communication was also expressed in relation to different NHS departments speaking to each other about the same patient (GP's, mental health, midwifery, gynaecology to name a few). Participants reported having to act as their own care coordinators, navigating between different departments and services.

2. Support whilst waiting

Participants felt strongly about the need to signpost to support services available whilst on the waiting list, (including self-help, websites etc. which are also accessible for family members). Some patients are waiting for long durations of time and described the need for coping mechanisms to support their daily life whilst they were waiting to be appropriately diagnosed. Participants described being pushed to do their own research due to a lack of a webpage or leaflet provided from the NHS. They often found private companies or "untrusted sources" online giving advice around self-help, wellbeing, or medications.

Participants requested support with navigating the system as well such as staff or care coordinators who were able to fully explain options and timescales. Participants spoke of the impact living with ADHD can have on all aspects of their lives including their mental health, careers, relationships, social life, and economic status. An example of some support which has worked well was a letter provided by a person's GP around reasonable adjustments for them to give to their workplace.

3. Diagnosis

Diagnosis was seen as crucial to open the doors to further support a person can receive.

Examples were given around support at university, adjustments in the workplace and perceptions from the wider public of 'being lazy' or being taken seriously. *"Without a medical diagnosis no support is available. My ADHD medication has transformed my life and combined with self-help training my ability to keep on top of tasks has vastly improved."*

Some highlighted a diagnosis as a means to accessing further support. It was suggested that removing diagnosis as a barrier to accessing help could reduce demand for a formal

diagnosis.

70% of participants accessed their diagnosis through an NHS service. We have heard frequently throughout our engagement that people have had to resort to seeking private diagnosis and this makes up 19% of the survey participants. Participants identified the challenges around seeking private diagnosis, including the cost implications and the limitations around the NHS not accepting the private diagnosis.

“I need the NHS to recognise my diagnosis as valid.”

“a private diagnosis of cancer wouldn’t be dismissed with the practice declining medications or care”.

Discussion

Unfortunately, most participants struggled to identify something positive or said that there was nothing positive to note about their experiences. Once people were able to enter the pathway, they commented how positive the healthcare professionals had been, and used words such as knowledgeable, patient, kind and empathetic. When asked what could make their experience better, participants said to reduce the duration of the process including the time taken to be assessed and shorter waiting times.

When asked to rate their experience, the most common response to the survey was 1/10. When analysing the reasons why, the common themes included frustrations with long waiting times which is a strong theme throughout this report. The average score was 3.5/10 which is indicative of a need for change of services.

When asked about a referral criterion to improve the process, there was resistance from some participants to the basic idea that further barriers should be placed between the individual and someone qualified to diagnose their condition. There was a fear that this would make the whole process even harder than it already is, and further barriers would be put in place.

There was some support for prioritisation, especially for those in crisis but a feeling no one should be turned away once they have sought care. There was a minority view that some people may not necessarily need or want the full assessment if they can access self-help strategies, and others will suffer less on waiting lists if they can get some of the help in advance.

Participants felt that pathways should be considerate and accommodating of ADHD traits such as missing appointments, lateness or ensuring text reminders.

“If I miss a phone call, don’t immediately give up on me.”

People who took part in this engagement identified that often people begin seeking diagnosis or support later in life. In particular for women, misdiagnosis was common following involvement in maternity services and entering motherhood.

All participants stated their frustrations with the common stereotypes of ADHD being the condition of a teenage boy who can’t behave in school.

The full analysis of the engagement and is included in the appendices.

Conclusions and Recommendations

These insights could inform improvements in service provision, including:

- **enhancing communication** between healthcare providers and with the patients currently on the waiting list relating to their position
- providing **better support information for individuals throughout their journey**, prior to potential diagnosis and treatment. The support needs to be reliable information and tailored to individual needs such as a focus on women and those who seek diagnosis later in life (over 30)
- Treatment suggestions wider than medication include the **integration of life coaching sessions into healthcare services**, which could potentially save money for the NHS and provide holistic support for individuals facing complex challenges including careers advice and support to navigate things like Access to Work grants.

When considering how the service could be redesigned, we should be particularly mindful of:

- **streamlining administrative processes** and improving access. An example of this could be by having 1 GM wide waiting list or one contact centre to reduce the administrative pressure put on the individual patient
- The support for the idea that people should be first be referred to a **tier 1 service based on talking therapies etc. but then they could be referred to a tier 2 service for diagnosis** and more formal treatment from there.
- Provide regular communication to patients and a mechanism for them to speak to providers

During the next period of engagement, we should **involve the voice of lived experience** and target participants who have been underrepresented in the survey including those from **Trafford, Salford, Wigan, and Bolton** localities as well as targeting **males, those of early adulthood from 18 – 25 and the LGBTQI+ community**.

Appendix A

Phone Call Notes

- 1) Engagement staff spoke to Person 1 on Tuesday 2nd April. They had been referred to ADHD services for diagnosis about 18 months ago and haven't had an update so felt they had no experience of ADHD services to describe to us. They said they have been experiencing symptoms and behaviours for a while now; excitable, acting on impulses and making bad decisions. Because of this, they were now having to face the risk of losing their job and their home. Something which would improve their experience was if they could have access to occupational health for advice and support, as this would also offer help to their employer. They were concerned that they were in a trusted position being a health and social care worker who, without the proper help and support, pose a clinical risk to other people. They felt there should be prioritised as their career impacts other people.
- 2) Engagement staff spoke to Person 2 on Wednesday 3rd April. They did not attend a focus group as they were busy with work but was now on school holidays and keen to have the 121 discussion. They were not on the waiting list and have not used the services but wanted to act on their own mental health and started to explore services in Bury. They have seen my GP and have been prescribed anti-depressants, *"Not a lot of help at all, it has taken me until in my 60's to start to understand myself."* A professional diagnosis would help but they have no confidence in the system. They described having a had a difficult year. They have lost their house and struggled to manage money. Self-help and research have helped but a diagnosis would be helpful to reach some solutions and techniques quicker but wouldn't change them as a person.
- 3) *One further phone call to input from 10th April at 1pm*

Appendix B

Email Submissions

We received 3 email submissions which have been included as follows:

- 1) Respondent A is upset about suggestions from the Adult ADHD team. They don't agree with the idea that medication shortages are because doctors are giving out too much medicine. Instead, they think the problem is with making and approving the medicine. They don't think it's right to deny help to people who need it, especially when they've been referred for help. They compare it to refusing to give medicine to someone with depression. They say it's better to ask for more money to help rather than refusing care. They also think it's wrong to change the rules to stop people from getting help. They want honesty about

funding issues and don't want people in charge to have unfair opinions. They hope their feedback is helpful and understand that everyone is doing their best in a tough situation.

- 2) Respondent B and their husband are both waiting for assessments for their health issues, which is causing problems in their relationship. Urgently needs the assessment for their job but has been told there's too much demand for appointments. They ask to be prioritised because their situation is affecting both their relationship and their work, they are a social worker.

- 3) An organisation emailed in and this was followed up with a phone call from our Engagement team. Please see the email text as follows:

Dear Scott and Engagement Team

I am writing to you on behalf of CHARM (Communities for Holistic Accessible Rights Based Mental Health). We have been made aware that the Greater Manchester Integrated Care Partnership are reviewing adult ADHD services across Greater Manchester.

Also that you are inviting people to have their say on adult ADHD services.

We note that the end of the consultation was 24 March 2024 and that the post advertising the review was put up on the website on the 11th. We have only heard about this review after the closing date.

Whilst the survey asks about experiences, thoughts, and feelings on ADHD services and to share how they could work in the future, the information provided gives a clear lead that you are seeking to introduce a threshold/gateway for access to / and assessment for services.

CHARM believes this is the wrong question as it starts from service and resource availability rather than clinical need.

Further, solutions should be co-produced and the needs of adults with ADHD should be established first from their perspective. This could lead to far more creative solutions and potential support systems. As commissioners it is inappropriate for the Integrated Board to determine without this process being steered by people with ADHD.

You will also be aware that NHS England have this week launched a review of ADHD across England and Wales. What are the implications of this for your review and should it be put on hold?

See the NHS Review information here [Link to a guardian article](#).

We hope you will respond to our concerns and reconsider the way you are engaging with this very large community by extending the review period and holding meetings to bring together people to share their views and concerns.

We would be willing to discuss our concerns further if that would be helpful.

Appendix C

Social Media Analysis

NHS GM Digital Communications team coordinated the promotion of the survey via NHS GM social media accounts.

Throughout the 6-week period they posted 11 times and the interaction received has been included below.

Account	Organic/Paid	Date	Time	Content Type	Reach	Engagement
Facebook ICP	Organic	23/02/2024	13.46pm	image	726	77
Facebook ICP	Organic	05/03/2024	09.14am	image	2500	159
Facebook ICP	Organic	07/03/2024	14.34pm	video	1200	93
Facebook ICP	Organic	15/03/2024	15.24pm	image	883	51
ICP Instagram	Organic	15/03/2024	15.29pm	image	15	8
Facebook ICP	Organic	20/03/2024	07.56am	video	6000	190
ICP X	Organic	23/02/2024	1.40pm	Image	1017	35
ICP X	Organic	05/03/2024	09.10am	Image	2202	110
ICP X	Organic	20/03/2024	07.58am	Video	1195	38

NHS GM Insta	Organic	07/03/2024	14.40pm	Video	83	0
NHS GM Insta	Organic	23/02/2024	13.50pm	Image	39	0

It was highlighted by the team that the post with the highest reach was of video format on the ICP Facebook profile on the 20th of March.

Unfortunately, when some of these posts went live, we did receive some comments which were bots promoting “micro dosing mushrooms” therefore, the digital team had to hide them. There were a few negative replies around how the information was being promoted and that people hadn’t heard the review was taking place until they saw it on social media.

When thinking about the next phase, the digital team have suggested we should focus on producing content which could really draw in some of the audience via Instagram. They would benefit by understanding the wider promotion of the work, and how they can complement this as well as NHS GM providing the digital team with ‘stock’ answers that we could use to respond to any similar comments.

Appendix D

Online Survey

(The full survey results are available by visiting this link t - [Typeform results](#))

1. How would you describe yourself?

440 out of 464 respondents answered this question.

Description	Percentage
Someone living with ADHD (203 resp.)	46.1%
Professional (126 resp.)	28.6%
Family or friend of someone living with ADHD (77 resp.)	17.5%
Other (17 resp.)	3.9%
A member of the public (16 resp.)	3.6%
Carer (1 resp.)	0.2%

Most respondents described themselves as “Someone Living with ADHD”. The second highest response rate came from people describing themselves as Professionals.

85.6% of the Professional respondents worked within the NHS. Respondents often self-identified as social workers within the survey responses.

The ‘other’ category included those who felt they belonged to more than one of the above categories or those who were on the waiting list to be assessed so did not self-define as someone who was living with ADHD.

2. Do you have experience of using or waiting to use ADHD Services?

452 out of 464 respondents answered this question.

Description	Percentage
Yes, currently on a waiting list (142 resp.)	31.4%
No (105 resp.)	23.2%
Yes, currently using services (79 resp.)	17.5%
Yes, previously used services (70 resp.)	15.5%
Other (56 resp.)	12.4%

The majority of respondents were currently on the adult ADHD services waiting list, which is positive in terms of us seeking the views of those currently affected.

Some themes from the ‘other’ category included people who are not being referred by their GP (/other healthcare professional), those who state there isn’t a referral pathway for them or those who have sought private diagnosis. This indicates that the true list of those patients in need within Greater Manchester could be higher than we have at present. Further ‘other’ categories include healthcare professionals who work within the ADHD service or healthcare professionals who try to refer their patients into the service.

3. What has been good about the services and what has worked well for you?

There were 271 responses to this question, **the majority of which stated there was nothing positive to note about their experiences.**

Some of the common themes relating to positive experiences included:

- Once people were able to enter the pathway, they commented **how positive the healthcare professionals had been**, and used words such as knowledgeable, patient, kind and empathetic
- The **Right to Choose (RTC)** method was mentioned frequently as being positive

- Overwhelmingly people have had no communication about the waiting list, but one respondent said they valued **the frequent texts they received to update them** on the waiting list. Similarly in relation to communication, one respondent said they always **received a response when sending email enquiries** but that these staff can't impact on the waiting list itself
- Once people have been through the process and received support, they mentioned the **positive impact this has had on their careers** or workplaces
- Having a **video appointment** instead of needing to travel across Greater Manchester
- The **forms having an autosave function** on the online referrals which was found to be helpful, especially when being asked to resubmit the forms

It needs to be acknowledged the 'postcode lottery' and difference in experience between localities. Salford is often quoted as providing good experiences, and we are aware that some localities have no provision at all. Respondents often mentioned the impact of providers such as LancUK closing.

Although this is a review into adult ADHD at present, respondents very often spoke generally positively for the children's service but that this does not translate into adult's experience. Respondents commented on the difference between children's and adults, either because of their own children having a different experience to themselves or from the transition between children's to adults services once they reached 18.

4. What could make your experience better?

282 respondents answered this question about how to improve their experience.

The most common answer to this question was to reduce the time for the process including the taken to be assessed and shorter waiting times. Some suggestions as to how achieve this included, *"two 'gateways' to get through the waiting list, one for people with a previous diagnosis who may need medication and one for new diagnosis which may need to take longer"*. Another suggestion was to consider the comorbidities which exist, and the suggestion made that ADHD assessments could take place alongside autism assessments as they often coexist. **Respondents felt that creating personalised pathways/specialist services for women, or those who are seeking a late diagnosis (in terms of their age) would improve patient experience.** These audiences were also mentioned in the focus groups as in need of specialised help.

The respondents had suggestions around improving the experience whilst waiting. The main plea was to drastically **improve the communication whilst on the waiting list** including whether they are still on the list, and what position they are in. **Respondents felt strongly about the need to signpost to support services available whilst on the waiting list,** (including self-help, websites etc. which are also accessible for family members).

Respondents requested support with navigating the system such as care coordinators or navigators who were able to fully explain your options and timescales (reminder texts for

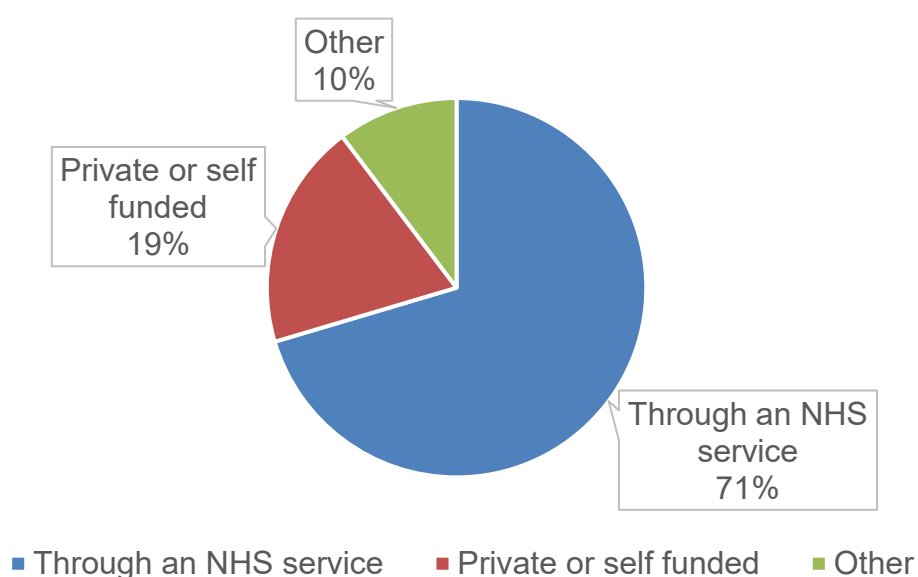
upcoming appointments given as an example). On the theme of making things easier for the patient, respondents asked for the clinic or appointment locations not to be far away from where they live and that the locations have ample parking, as people with ADHD often struggle with time keeping and this exacerbates the problem.

They sought a more personable service via the telephone or in person appointments and said that online systems and forms are difficult for someone with ADHD. *“The process to seek a diagnosis is heavily admin based with strict timeframes. These are notoriously things people with ADHD struggle with. Some people opt to not seek a diagnosis as the process is too hard and overwhelming.”*

Respondents felt that being able to take a family members or friend to appointments as a support would also improve their experience.

Respondents wrote about the need for **increased awareness of the RTC pathway for professionals**, so patients don’t need to explain and/or *‘fight for it’*.

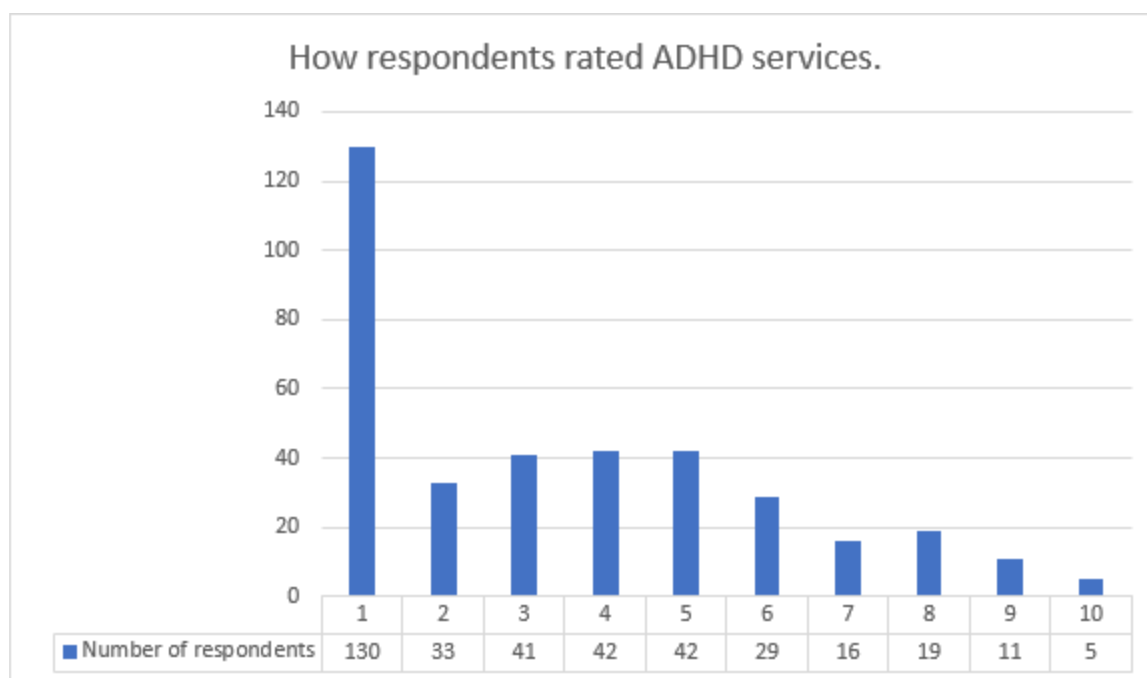
5. Can we ask how you got or will get your diagnosis?



274

respondents answered this question of which **70% accessed through an NHS service**. We have heard frequently throughout our engagement that people have had to resort to seeking private diagnosis and this makes up 19% of the survey respondents. Of the ‘other’ responses, RTC was the most common response followed by listing the name of the private provider such as Psychiatry UK.

6. How would you rate ADHD Services?



The most common response was 1/10. When analysing the reasons why, the common themes included frustrations with long waiting times which is a strong theme throughout this report. **The average score was 3.5/10 which is indicative of a need for change of services.**

Of those who indicated earlier in the report that they *were currently using* services, they rated the ADHD service on as average 4.7/10.

The average score for respondents who *have previously used* services was rated as 4.3/10.

The average score for respondents who said *no, they had not used the service* was 2.9/10 and those who said *they were on the waiting list* rated the service, on average, as 2.7/10.

Respondents also **expressed difficulties in accessing ADHD services**, such as the referral processes, finding new providers and facing barriers such as the distance needed to travel. Similarly, to access, there were concerns raised around online portals being stressful for individuals with ADHD and the need for more face-to-face support.

Communication related challenges were common, including **poor communication about waiting times** which is a theme throughout the report. **Respondents also raised concerns about medication** options, including shortages or delays in accessing medication and limited treatment alternatives beyond medication.

Respondents, who were presume identified as professionals, mentioned **resource challenges within the NHS**, leading to longer waiting times, difficulties in securing appointments and challenges in meeting the demand for services.



7. When thinking about ADHD what are the most important aspects for you?

Nearly all (445 out of 464) the respondents to this survey provided a ranking order of what they felt the most important aspects of the service are.

Diagnosis was ranked first (most important), followed by medication second and strategies / self-help support third.

8. Why did you rank them in that order?

The following question asked respondents why they ranked the answers in that order. The most common themes are highlighted as follows:

Diagnosis was seen as crucial to open the doors to further support a person can receive.

Examples were given around support at university, adjustments in the workplace and perceptions from the wider public of 'being lazy' or being taken seriously. *"Without a medical diagnosis no support is available. My ADHD medication has transformed my life and combined with self-help training my ability to keep on top of tasks has vastly improved."*

"Having a son with ADHD I have seen the significant and life changing importance of diagnosis and medication and how it has positively impacted his daily functioning in respect of his studies, home life and social life development. Therefore, diagnosis and medication along with awareness and functional development are of the highest importance to me."

It was noted though that **respondents often spoke about their struggles with misdiagnosis** before reaching the correct determination of having ADHD (bipolar, anxiety, depression and personality disorders were some of the examples given).

Respondents spoke of the need to understand themselves and their family members (by gaining a diagnosis), including how to support each other and the positive impact this would have on their mental health after searching for answers for a considerable amount of time. *"I mostly want support for myself and those close to me to better manage my needs and help to reduce any strain these may cause on relationships."*

'Validation' was a word often used to describe what a diagnosis would mean to people.

"I've spent my entire life feeling different, feeling like a failure. Feeling like I'm just bad at life, like I don't manage as well as everyone else, like I should be able to cope better and not understanding why I can't. I want to understand myself; I want to be able to live my life without every day feeling difficult."

There were differing views around **medication** as a long-term solution but for those who ranked it highly, they felt it was **imperative for them to be able to move forward**. *"Medication I ranked second most important because it's imperative that people diagnosed with ADHD can access medication as quick as possible so that they can function in life to the best of their ability and intellect. I don't think at this stage in my life, self-help strategies will help me any more than I have already tried or already know, because I have tried to cope on my own for so long that many of them would probably seem patronising to me. I want to be able to concentrate to write an essay long before the deadline, to finish reading a book without abandoning it halfway"*

through, to complete applications for jobs I want to go for but can't, to see tasks through to the end and have that sense of accomplishment. I have never done this properly before and I want to, because I have so much unfulfilled potential. I have tried every coping strategy possible, and nothing works for me."

Some respondents highlighted some gaps in the options given in the survey and stated that **support around employment and careers was important to them.**

"I have struggled to keep a full-time job without medication. This is not acceptable. Work should be accessible to all who want and need it, without relying solely on medication. I was able to access coaching through the access to work scheme which has been so beneficial for both my personal and professional life."

Similarly, to positive employment, finances, accessing benefits such as raising awareness of the Access to Work grant and managing money were highlight as important to people to be able to live a functioning life.

9. We are considering referral criteria for these services. What do we need to think about when considering this?

381 responses were provided for this question, which is important for us to take forward into the consultation. Comments made on the potential for the introduction of referral criteria for accessing ADHD diagnosis and treatment broadly fell into three areas: - **the principle (is it the right approach?), the practicalities (how could this work?) and the offer** (in particular, what sort of support people get who feel they may have ADHD but don't meet the criteria).

Principle of employing referral criteria

There was resistance from some respondents to the basic idea that **further barriers should be placed between the individual and someone qualified to diagnose their condition.** This would support the anxieties noted in question 11 around fearing a review will make the process even harder.

There was a feeling that those who 'put on a brave face' could be disadvantaged, as well as less eloquent people or others who will struggle to voice their experiences or be as assertive in seeking care. It was felt by some respondents that women were particularly likely to be 'fobbed off' as their concerns are less likely to be taken seriously. This concern for women is supported throughout the report findings.

The respondents stated that potentially **denying people support would prove to be a false economy if they subsequently fell out of education or the workforce etc. due to unaddressed issues.** Also, that the treating ADHD in this way would reflect a lack of importance compared to physical health and indicate people with ADHD are not taken seriously by the NHS.

However, there was a minority view that **some people may not necessarily need or want the full assessment if they can access self-help strategies,** and others will suffer less on waiting lists if they can get some of the help in advance.

Some **professionals favoured prioritisation because they have clients with considerable needs who they are unable to have assessed quickly**. There was some support for the idea of access to “emergency assessments”. It was noted that all other NHS services have some kind of threshold for accessing care.

Practicalities of triaging

The comments received emphasised that the process should be started or **consented to by the individual themselves, not done on their behalf**. People need to be given **realistic expectations** about what an assessment and treatment can and can't do for them.

There were **differing views about the importance of clinical severity vs practical impact in determining priority**. Some felt that clinical thresholds based on things like suicide risk would not recognise the impact on people's lives (e.g. work, relationships, mental health). It was felt that impact on day-to-day life would be difficult to evaluate or measure, and some respondents questioned the notion of ‘severity’ and felt that this was inherently subjective.

The limitations of asking people to self-report their condition was raised. The idea of people filling in forms for review was seen as being particularly unhelpful by several respondents given the challenges this would create for many people with ADHD.

Many respondents pointed out that people may be very high functioning and effective at masking. The use of better screening tools (e.g. QB tests) may help, not just the generic ones available online. The same test was mentioned as positive in the focus groups which are detailed later in the report. Several respondents said co-morbidity with other mental health conditions should increase priority for diagnosis and treatment.

There was a feeling that the presentation of ADHD may be similar to other conditions and a triage tool may not recognise this. Broadly there was **scepticism about the ability of simple tools to effectively screen for those who need further help**.

Questions were raised about who would decide the impact on an individual, and what would make them qualified to understand the full impact experienced by them based on a brief consultation and/or questionnaire.

Support to all

There was some support for prioritisation, especially for those in crisis but a feeling no one should be turned away once they have sought support.

Some highlighted a diagnosis as a means to accessing further support. **It was suggested that removing diagnosis as a barrier to accessing help would help reduce demand for a formal diagnosis**. A broader range of support available to all would be appreciated. It was felt by respondents who expressed a view that the focus should be on early intervention and improving quality of life, this includes for people currently on waiting lists. An online toolkit could help people access evidence-based strategies on a symptom by symptom basis as everyone will have a different needs.

There was some support for the idea that people should be first be referred to a tier 1 service based on talking therapies etc. but then they could be referred to a tier 2 service for diagnosis and more formal treatment from there.

10. Is there anything else you would you like us to consider when reviewing how we run these services?

Respondents provided a great deal of suggestions for consideration. Below is summary of those which haven't already been included as a theme earlier in the report.

- Speaking to people with **lived experience** to help shape services
- Acknowledge the impacts on **health inequalities**
- Have **one waiting list which is GM wide** to combat the postcode lottery
- Having a tool to allow people to **self-refer** as well as going through their GP. This was supported by health professionals and patients as it was described as an unnecessary step to lead to specialist advice
- Consider **where and how appointments are offered** (online vs F2F, locality to home) If F2F, is the environment suitable for person with ADHD?
- **Transparency and honesty from services/providers/NHS GM** about what will happen going forward (for this review and for individual assessments) to manage expectations
- Any communications which are produced to **move away from the stereotypical patient** being a 'badly behaved school boy'
- Many people with ADHD are living with co-morbid mental health conditions and respondents asked the review to consider a model which worked jointly with mental health services to **integrate care**
- The **NHS pathway to consider private diagnosis** which has been sought whilst waiting, *"I need the NHS to recognise my diagnosis as valid."*
"a private diagnosis of cancer wouldn't be dismissed with the practice declining medications or care"
- Pathways to be **considerate and accommodating of ADHD traits** such as missing appointments, lateness or ensuring text reminders. *"If I miss a phone call, don't immediately give up on me."*
- In the self-help information **promote the use of the NHS App**, *"The best thing I have done is download the NHS app. It is so hard to remember to fit in requests/paperwork etc in a working day. Often, these things are done at the end of the day & I can now request my prescription at 11pm on my app. When I had to do it through my GP website, which only allows it to be done during working hours, it could take me weeks*

to get it done. Definitely some kind of online portal that can be accessed 24/7 would be great.”

11. Is there any reason why any changes to the current service might have an impact on you more than others?

People thought they would be more affected because they were worried that changes to ADHD services might make it harder for them to get the help they need. They were concerned about things like being treated unfairly because of their age, gender, or where they live. They also shared concerns of not being understood or getting the wrong diagnosis, which could delay them getting better. Some people mentioned other problems they have, like family issues or not having enough services nearby. Many are upset that there aren't enough ADHD services available right now. They want better services that fit the needs of people in the local area.

Overall, they were afraid that changes to ADHD services could make it even harder for them to deal with their ADHD problems.

Not getting help for ADHD can make mental health worse. People want to get support for ADHD as soon as possible to help them feel better.

People said they want services to work together to make ADHD services better. This means doctors, people who make decisions, and community groups coming together to help people with ADHD.

12. Here is space for you to add anything else you feel we need to know, should consider or you want to share with us.

159 comments were made in this question, including for the pathway to be considerate of those **whose first language isn't English.** To be mindful of the **current pressure on the workforce and not to cause further burn out** which will be counterproductive to the waiting lists.

Respondents wished for the staff who work on the pathway to have lived experience or be **specialists in the field** and not described as generic healthcare professionals. Respondents spoke about the need to tackle the waiting list and the impact it is currently having on their lives and those of their family and friends.

Appendix E

Survey Monitoring Data

From analysing the demographic information collected via the online survey, **the most common respondent was a ‘British’ woman between 36 – 45 years old.**

Importantly to note, we mistakenly identified ‘British’ rather than white British in the ethnicity monitoring, which means we may have not captured ethnicity accurately.

Demographic	Responses
Under 16	1
17-25	15
26-35	105
36-45	147
46-55	125
56-65	43
66-75	6
Over 75	1
Prefer not to say	6
Total	449

Ethnicity	Responses
British	380
Irish	9
Pakistani	9
Polish	4

Indian	3
White and Black Carribean	3
Chinese	2
Asian	1
Bangladeshi	1
Gypsy or Traveller	1
White and Black African	1
Other (Mixed White)	3
Other (White European)	5
Prefer not to say	9
Total	443

Gender	
Woman	333
Man	90
Non Binary	6
Prefer not to say	2
Total	428

Is your gender the same as the sex you were assigned at birth?	
Yes	398

No	15
Prefer not to say	7
Total	420

Relationship Status	
Married	182
Single	109
Co-habiting	83
Civil Partnership	9
Widow	5
Divorced	4
Other	10
Prefer not to say	33
Total	435

Disability	
Yes	164
No	239
Prefer not to say	40
Total	443

Sexual Orientation	
---------------------------	--

Heterosexual/Straight	305
Gay	16
Lesbian/Gay Woman	15
Bisexual	46
Pansexual	4
Queer	4
Other	5
Prefer not to say	39
Total	434

Faith	
Atheist	201
Christian	142
Islam	9
Buddhist	3
Jewish	3
Hindu	2
Muslim	2
Sikh	1
Other	10
Prefer not to say	44
Total	417



Employment Status	
Employed / self employed	370
Student	7
Apprenticeship scheme / training	5
Unemployed	11
Other...(Unpaid carer/ carer)	21
Retired	8
Prefer not to say	20
Total	442

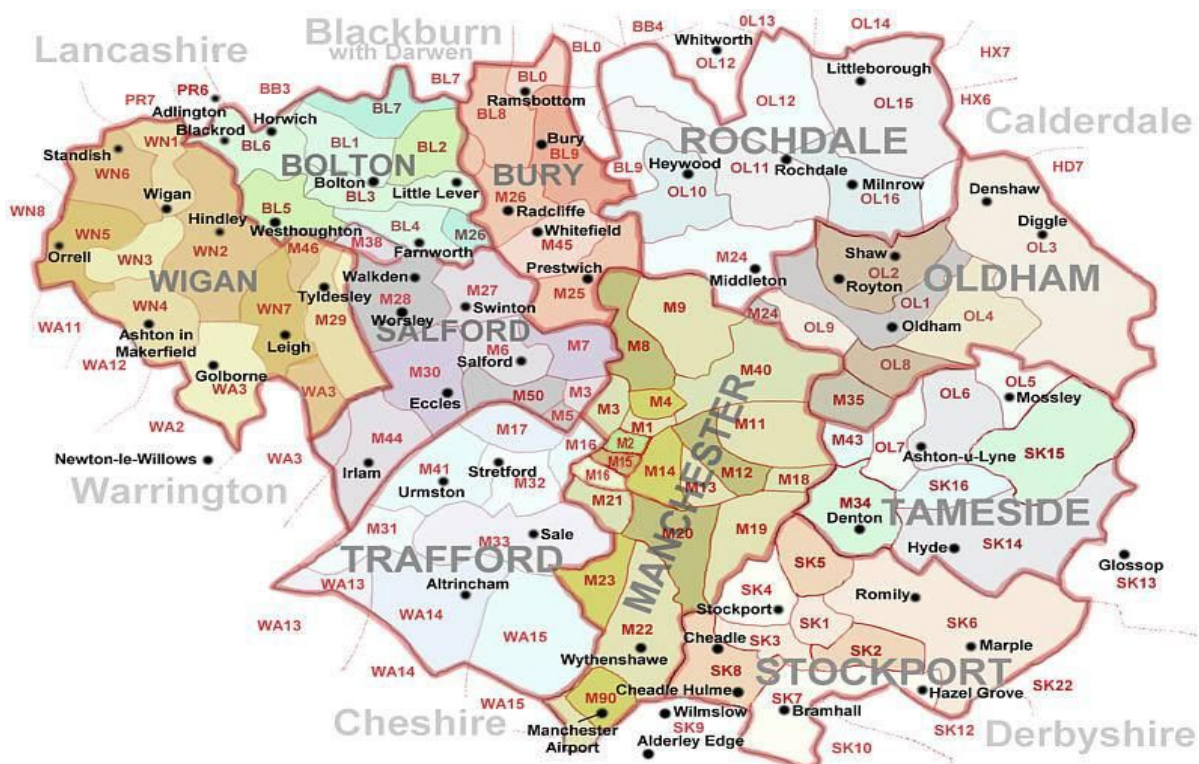
British/UK Citizen	
Yes	429
No	9
Prefer not to say	7
Total	445

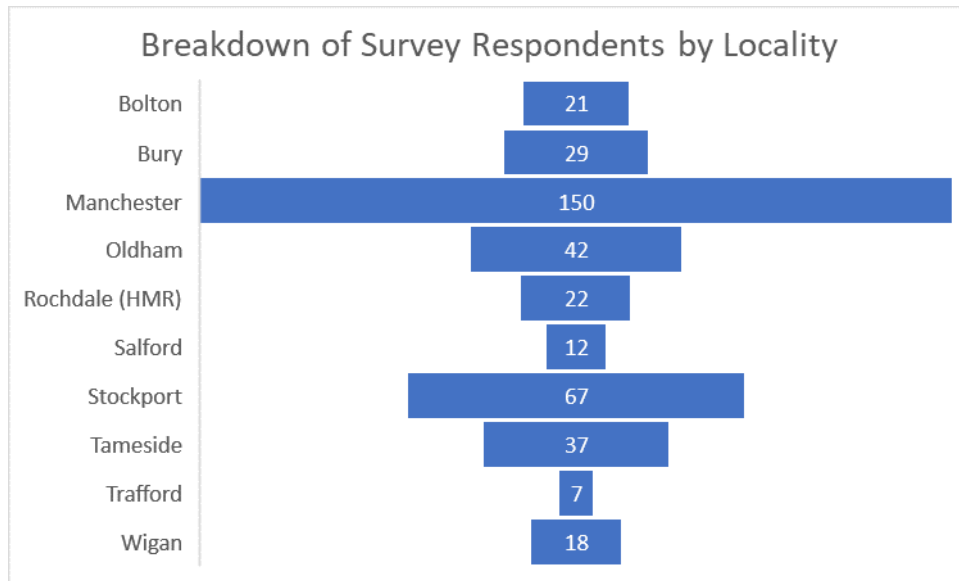
Armed Forces/Veteran	
Yes	10
No	431
Prefer not to say	7
Total	448

Carers	
Yes	107
No	318
Prefer not to say	18
Total	443

Postcode Map

The map below plots the partial postcodes of the survey respondents and table below displays the reach of respondents across Greater Manchester.





418 respondents provided us with a partial postcode, 13 of which, were outside of the Greater Manchester area. The greatest response was from respondents in the borough of Manchester, which correlates with that of the highest population. The lowest response was from Trafford borough.

Appendix F

Focus Groups

NHS GM organised 2 online focus groups on 21st March which welcomed 23 attendees across both groups.

A summary of the questions asked and the discussion which followed is below.

1. **Identify 1 word to describe your experience (either positive or negative) and the explain the reason why you have chosen this word.**

The following is a summary of the words said verbally and, in the chat function.

The **most prominent theme from the discussions on question 1 was waiting times and access** issues. Participants expressed frustration with long waiting times for assessments and lack of clarity about their position on waiting lists. They often referred to being on the waiting list longer than the influx of ‘new’ waiters which had been referred to by NHS GM. The waiting period for assessment and diagnosis was described as emotionally challenging, with individuals feeling unsupported and misunderstood during this time. The lack of support between referral and assessment is highlighted as a particularly difficult aspect of the process.

Access to NHS services was described as challenging, with some resorting to **private diagnosis and treatment due to lengthy waits**. Discussions were also had around the lack of communication between private and NHS colleagues, meaning the private diagnosis was often unhelpful when needing to then seek NHS support.

“Because my diagnosis is private, I don’t have any access to NHS services – it’s meaningless.”

Those who sought private diagnosis to try and overcome waiting times often faced **financial burdens**, with some individuals facing challenges affording medication or private prescriptions.

The second most common theme was communication and coordination problems. This was described initially for those who sought private diagnosis and then needing to seek NHS support, but also between different NHS departments (GP’s, mental health, midwifery, gynaecology to name a few) and participants reported having to act as their own care coordinators, navigating between different departments and services.

“I have had to run around and make sure the departments within the NHS speak to each other”

Participants find the amount of paperwork and forms required burdensome, particularly for individuals with conditions like ADHD, where filling out forms can be challenging.

“The things I struggled with is the amount of forms I had to fill in. Forms for someone like me is not the way to go. How can we capture things in a different way?”

Participants welcomed the opportunity like the focus group where they could verbally describe their experiences.

“It’s great looking at other people on this screen because I’ve often felt on my own like it’s just me and my family.”

Individuals expressed feeling stigmatised when seeking help for ADHD, in particularly from healthcare professionals.

“The stigma of ‘everyone has ADHD now’ you are treated with an eye roll. The staff treat you like you’re trying to take advantage of the system. It is not treated with the dignity and respect it needs, which is the respect of a life changing condition.”

“My GP said to me he has concerns, as everyone in the modern world would benefit from these medications in their life.”

2. Have you or your family member experienced any barriers (in your/their journey)?

Below is a summary of the discussion from the second question around identifying barriers in their ADHD journey.

A lack of information was stated by a large proportion of attendees as a barrier on their journey. Several attendees spoke from both a personal perspective of navigating their ADHD and from working within a healthcare setting and not being able to provide appropriate signposting to their patients/clients.

A supplementary question was also asked around if attendees could rate their access to supportive information which was available from the NHS, with 0 being they couldn’t access anything (or didn’t know how to), and 10 being they knew where to find the supportive information. Every score given for this was below 5/10, indicating a significant gap in knowledge and support systems.

Attendees linked this back to feeling unsupported whilst on the waiting list and felt that **due to the lack of NHS information available, it led them to do their own private research on the internet or social media.** Social media platforms like TikTok are being utilized to disseminate information and support, often filling gaps left by official channels like the NHS. However, there are concerns about reliability and unethical selling practices on these platforms. The abundance of contradictory and confusing information from private companies and non-NHS sources was described as scary by some attendees. A participation also said that the lack of information was hindering their informed decision-making and access to necessary support.

“Heard horror stories from private companies. It is making it very difficult to make informed choices because the information is so contradictory and confusing.”

Gender bias was described as a barrier to diagnosis, and it was identified by both male and female participants that women face significant barriers in accessing proper diagnosis and support, with issues such as misdiagnosis, long waiting times, and lack of transparency in processes.

“Women have to fight so hard to get it. [a diagnosis]”

A discussion followed this around **misdiagnosis and the impact on mental health.** Participants

spoke about entering other services such as maternity or mental health, before ADHD being recognised or considered as a diagnosis.

“I never discovered it until I became a mum. I always managed in life. I found it more difficult than others, but I got by. When I became a mum, I was diagnosed with post-natal depression but then it was discovered that there was something else going on. You have your own ways of coping and then suddenly you become a mum and your whole focus is on someone else and your own strategies of coping go out of the window. It is really upsetting. It is scary how many mums and new mums don’t understand why they feel this way. Thankfully I had a good support network around me but not everyone does.”

“People don’t often discuss the dark side of neurodiversity and the suicidal thoughts and how overwhelming the intrusive thoughts can get. It has a very dark side.”

Participations described the **career implications** of ADHD and the diagnosis-related issues have impacted their careers, leading to job changes or exits when the career or workplace does not accommodate or allow reasonable adjustments for an ADHD diagnosis.

“The main barrier for me over the years has been in my career. I left my job in April because my career did not suit my diagnosis.”

The lack of support services available was raised as having a negative impact on participants journeys. They felt there was a noticeable lack of support services (whilst on the waiting list and thereafter), and the absence of cohesive strategies for addressing various interconnected issues, such as hormonal issues in neurodiverse women.

3. Can you identify any positive experiences or aspects of the service which you have experienced?

In comparison to speaking about barriers, the next question asked was around any positive impacts of their journey which could be supportive for others in the future.

Participants spoke about **positive relationships they had experienced with healthcare professionals such as their GP or psychiatrist, who were supportive and provided personalised care**. Examples were given including supportive letters on reasonable adjustments for workplaces. Many neurodiverse individuals, especially those diagnosed later in life, may struggle to articulate their needs, and understand the impact of their condition on their daily lives. Having support in this area, such as through reasonable adjustments and coaching, can be invaluable.

“I struggle to articulate myself, so having someone else provide this detail was really helpful. I didn’t expect my team at work to find it as helpful as they did.”

Some positive relationships also allowed explorative space for individuals to discuss their thoughts on medication and highlighted the importance of **individualised treatment plans and open dialogue between patients and healthcare professionals**. The positive example given was that the healthcare professional was willing to explore different medication options based on the patient’s needs.

“I was listened to – my consultant supported my research into medication and said you’re onto something here, let’s try it.”

Some participants said they were generally **met with empathy and understanding from healthcare professionals**, despite the challenges they had faced. This contrasts with other feelings of stigmatisation quoted in the question 2.

A participant mentioned the benefit of using **NHS Prepayment** to help manage prescription costs.

4. Do you have an idea or an opportunity to suggest which you feel could improve services? What would you like to see different in the future which NHS GM could take forward into a new service/pathway?

The first idea was around **generating a ‘trusted’ list of support groups, resources and recommendations for further information** which could be provided to people who join the waiting list. It could easily be sent with the referral letter. Support information could cater for specific needs of women or new parents as well.

“The diagnosis is what we’re waiting for, the symptoms are what we’re dealing with and that’s where the signposting can help.”

Participants raised issues around language sensitivity and asked that healthcare professionals **avoid using blaming language and prioritise person first language when discussing neurodiversity**.

“When I was looking at the comms for the survey, we don’t like having a deficit or disorder. People first – people who have ADHD or people first.”

Patients also suggested **repositioning ADHD services within the system** and encouraged collaboration between mental health and neurodiversity services to provide holistic support for individuals.

“If you have ADHD you’ll score really high on the mental health surveys/criteria so there are lots of people on pathways that aren’t appropriate.”

Participants were supportive of trying to promote a culture change around recognising and **supporting individuals based on their traits rather than diagnosis**. The attendees wanted to advocate for organising support services based on individual traits rather than diagnosis.

“Mental health services refused to have anything to do with ADHD/Autism but I try to ask for help for everything as I am one person, not help for just one aspect of my personality.”

Some participants felt that **support should be a life coaching approach**, to help patients make reasonable adjustments and emphasise support for learning strategies to live with neurodiversity beyond medication. This could include advice on nutrition, career support and group therapies (tailored to individuals with neurodiversity).

A participant suggested around **utilising diagnostic tests such as the 'QB Test'** for screening new patients and suggested considering **adjusting review frequency** (for stable patients from every year to every 2 years) and **medication management** protocols to better suit individual

needs (to allow the GP to make one medication change), both of which could save NHS resources. A patient also suggested prioritising non-stimulant medications if there was a shortage and to avoid prescribing medications primarily designed for children to adults.