Greater Manchester Joint Health Scrutiny Committee

Date: 16 July 2024

Subject: NHS Greater Manchester – Adult ADHD Service Redesign

Report of: Sandy Bering, Strategic Lead Clinical Commissioner – Mental Health & Disabilities and Claire Connor, Associate Director of Communications & Engagement, NHS Greater Manchester

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Purpose of Report:

To update the Joint Health Scrutiny Committee on NHS Greater Manchester's review of adult ADHD services focusing on addressing unmet need, and for public involvement in support of this work.

Recommendations:

The Greater Manchester Joint Health Scrutiny Committee is asked to:

a) Note the contents of this report

b) Support proceeding to consult on the identified options, on the basis that the proposals constitute 'substantial variation,' and

c) Make any recommendations as to how the consultation should be conducted

Contact Officers:

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Equalities Impact, Carbon, and Sustainability Assessment:

Not applicable.

Risk Management

The programme of work aims to address the risk to patient safety arising from increasing numbers of people being referred to GPs but remaining unassessed for long periods of time.

Legal Considerations

NHS Greater Manchester will meet the statutory duties relating to involvement on service redesign.

Financial Consequences – Revenue

Not applicable

Financial Consequences – Capital

Not applicable

Number of attachments to the report:

1 - Engagement Report

2 – Equality Impact assessment

Comments/recommendations from Overview & Scrutiny Committee

To be gained from this report.

Background Papers

Not applicable

Tracking/ Process

Does this report relate to a major strategic decision, as set out in the GMCA Constitution

No

Exemption from call in

Are there any aspects in this report which means it should be considered to be exempt from call in by the relevant Scrutiny Committee on the grounds of urgency?

No

GM Transport Committee

Not applicable

Overview and Scrutiny Committee

Not applicable

1. Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a complex neurodevelopmental condition that can have a considerable impact on a person’s daily life.

An increasing number of people are seeking diagnosis and treatment for this condition, both in Greater Manchester and nationally. Diagnosis of ADHD in adults is usually undertaken by a psychiatrist after referral by a GP.

2. The national picture

It is estimated that ADHD affects 2.5 - 4% of the adult population nationally. Since the Covid-19 pandemic, the number of adults being referred for assessment, diagnosis and treatment of ADHD has risen exponentially with some estimates suggesting that nationally there has been a five -fold increase in the number of referrals since 2019/20.

The reasons for this increase are not clear but likely to include increased awareness of the symptoms of ADHD following high profile online campaigns of people sharing their experience of living with ADHD and the impact of prescribed medication on this.

As a result, waiting times for adult ADHD assessment services have increased significantly across the country and at the same time there have been increasing concerns through media reports, sudden service closures and CQC inspections noting serious quality concerns (including inadequate record keeping, standards of virtual assessments and clinical reviews or follow-ups.

3. What this means for Greater Manchester

National estimates of the number of people with ADHD would suggest that, in Greater Manchester there are approximately 60,000 adults potentially seeking to access diagnostic assessments and treatment.

As there is no single waiting list in Greater Manchester for adults awaiting ADHD assessment and/or support, it is difficult to precisely say how many people are currently waiting for an assessment.

However, based upon the data we have, it is estimated that there are approximately over 15,000 people waiting across Greater Manchester – with this figure growing daily. This is despite significant additional funding for additional assessments as part of local waiting list reduction programmes. This has made an impact in terms of reducing the number of people waiting for over 2 and 3 years but the actual number of people on waiting lists has continued to increase far more people are continually joining the waiting lists than can be seen.

This figure is growing all the time. In Greater Manchester, approximately 8,000 adults were referred for an ADHD assessment in the last 12 months – most of whom have not yet been seen for specialist assessments so are stuck in the gap between primary and secondary care. Based on the current charges for initial diagnostic assessments (estimated at between £700-£1,400 per assessment), tackling a backlog of 15,000 adults awaiting ADHD assessments would cost at least £15m.

If demand for adult ADHD specialist assessments and treatment continues at current levels, it would also cost approximately £8million a year to fund initial assessment services capable of meeting the demand and avoid lengthy waits. This is both unaffordable and unsustainable given the financial constraints currently in place for the NHS in Greater Manchester and a lack of suitably qualified clinicians.

Greater Manchester Mental Health (GMMH) have recently reported that a person being referred today will face an approximate 7 year wait for their first appointment in their ADHD service if there is no change to the current GM adult ADHD pathways.

The increasing waiting times are leading more people to demanding access to specialist assessment and diagnosis from a variety of private providers via Right to Choose arrangements.

There are significant concerns about the safety of the current situation as a large number of people are being referred to GPs but are then going unassessed for long periods. At present everyone effectively joins a queue and is then seen in order, meaning there is no way to prioritise patients who GPs are particularly concerned about. The extended waits also mean people are not being monitored, so if their condition deteriorates, services will not know about this. This creates real safety issues, with the system not knowing the acuity of the patients on the list and so having no way to prioritise them.

In addition, evidence elsewhere suggests that patients with less severe presentations do not necessarily require a medicalised approached to their care. They are likely to benefit more from access to clinically reviewed self-help materials, talking therapies and peer support groups for example.

In conclusion, demand for adult ADHD diagnosis and treatment has increased far more than the NHS has been able to provide care, and this situation continues to deteriorate. This means people are waiting too long resulting in a poor experience for them and concerns for their safety.

4 Summary Case for Change

4.1 Quality & Safety

- Waiting for help for long periods results in an unacceptably poor patient experience and in can be unsafe. Several cases have come to light recently highlighting how unstable or unmanaged long term physical health conditions such as diabetes have been exacerbated by undiagnosed and untreated ADHD.
- The service needs to be accessible in a timely manner to those who need it, and this means we need to understand the acuity of each patient on the list.
- Our aim is that we stay within the NICE guidelines for ADHD services.

4.2 Accessibility & Patient Needs

- All patients need to be able to access services when they most need them. Currently waiting times and demand are outweighing the service capabilities.
- Patients are currently seen on a ‘first come, first served’ basis, so those with the highest needs are not seen any sooner than other patients.

4.3 Workforce

- With an increased demand on services and a growing waiting list, the impact of staffing ratios is important as we currently cannot meet the demand. We are also seeing a number of referrals that may benefit from other interventions being explored that may help people manage their symptoms/condition.
- Current services do not have the staff capacity to manage the growth in demand, given that approx. 1,500 patients are referred every month for diagnosis.

4.4 Cost & Efficiency

- Financial and demand pressures on the wider NHS in Greater Manchester mean we do not have the money to simply try to do more the same. We need to find ways to save money so we can pay for all the things Greater Manchester patients need.
- The current cost of adult ADHD services is approximately £15million annually and increasing. Driven by growing demand. However, the service is inefficient because, currently, everyone is referred for an expensive clinical diagnosis when we think most would benefit from less medicalised interventions which would cost far less but could be delivered far sooner.

5 Work so far

So far in this review, we have done a lot of work to understand the delivery of ADHD services in Greater Manchester and the views of local people, and service users in particular.

Work to review the adult ADHD service begin in January 2024, gathering together all the previous work done with the public to understand what we did and did not know. An initial Equality Impact Assessment was produced to show us which groups are likely to ‘differentially impacted’ by ADHD (i.e. some more than others) or less likely to be receiving support from the current arrangements.

5.1 Initial public engagement

We then began a six-week period of public engagement, including an online survey and focus groups. We also formed an Adult ADHD Lived Experience Group to help input into the review. This is a group of people, recruited through the engagement, with lived experience of living with ADHD, being a family or friend of someone living with ADHD (both diagnosed or undiagnosed) to act as a critical friend to us and guide us through the review process.

The report from the engagement work can be found in appendix 1. We then refreshed our Equality Impact Assessment to reflect what we had learnt from this exercise.

5.2 Options Appraisal

We worked with the Lived Experience Group to develop a set of criteria or ‘standards’ to assess any proposals by.

It was decided that any proposals must be meet the following gateway standards:

- to be affordable
- to ensure the safety of patients and staff, and
- to deliver equity across GM (i.e. where you live should not affect what you get).

It was also agreed to score proposals for:

- deliverability
- offering support to all
- meeting NICE guidelines, and
- reducing Health inequalities

In May we ran an Options Appraisal workshop of patients, clinicians, and commissioners. The above standards were applied to a ‘long list of options’, which were:

'Long list' of options considered	**Outcome**	
No change to the service which currently exists	This option did not meet the first gateway standard (equity) and therefore was not scored any further and was not considered to be viable.	🟥
Clinical triage: Introducing a clinical threshold, with all patients triaged and prioritised based on their clinical need, and only those who meet the threshold receiving a service and going forward for diagnosis.	This option did not meet the third gateway standard (safety), and therefore was not scored further and was not considered to be viable.	🟥
Clinical triage with wider support offer: Introducing a clinical threshold, with all patients triaged and prioritised based on their clinical need. Patients who do not meet the threshold will get offered support to manage symptoms. Patients who meet the threshold will go forward for diagnosis.	This option met all 3 gateway standards and was scored against all 4 evaluation standards, and therefore was be recommended as an option for consultation.	🟩
Universal offer, followed by clinical triage: Provide everyone who comes forward with an offer of support to help manage symptoms. Patients who then request further support will be triaged against a clinical threshold and prioritised based on their clinical needs, with those who	This option met all 3 gateway standards and was scored against all 4 evaluation standards, and therefore was be recommended as an option for consultation.	🟩

meet the threshold going forward for diagnosis.		🟩
Online triage: Introduce a clinical threshold for patients to access the service, with patients using an online assessment tool which they do by themselves. Only those who meet the criteria will get support and diagnosis.	This option did not meet the first gateway standard (affordability) and therefore was not scored any further and was not considered to be viable.	🟥
Online triage with wider support offer: Introduce a clinical threshold for patients to access the service, with patients using an online assessment tool which they do by themselves. Patients who do not meet the threshold will get offered support to manage symptoms. Patients who meet the threshold will go forward for diagnosis.	This option did not meet the first gateway standard (safety) and therefore was not scored any further and was not considered to be viable.	🟥
Fund a bigger service: Fund additional staff/teams to be able to clear the waiting list and offer diagnosis to everyone going forward.	This option did not meet the first gateway standard (affordability) and therefore was not scored any further and was not considered to be viable.	🟥
Stop the service: No longer fund adult ADHD services.	This option did not meet the first gateway standard (equity) and therefore was not scored any further and was not considered to be viable.	🟥

In summary, **Clinical triage with wider support offer (A)** and **Universal offer, followed by clinical triage (B)** were judged to be viable options because they met the essential criteria and scored sufficiently well against the other criteria.

In June 2024, these options were agreed to be put forward for consultation by our Commissioning Oversight Group, with **Clinical triage with wider support offer** as the preferred option.

Option A is the preferred option because:

- As triage will happen earlier, those in most need will be able to receive the support they need sooner, and
- Providing an additional support offer to those referred but not prioritised, rather than to anyone who wants it, would be less resource intensive and more cost effective

6 The options explained

Both options would involve NHS Greater Manchester establishing triage arrangements to prioritise support for individuals on the basis of clinical need and risk, using a standardised set of tools and assessments.

Triage involves an assessment being made to understand the needs of patients so they can be seen in order of urgency.

Both options would make use of criteria adapted from those used already by the Cheshire and Wirral Partnership NHS Trust and ‘risk stratification’ tools which would assess the impact of the individual’s condition on themselves and others. The criteria and process will be finalised in light of the consultation outcome. We would expect the triage process to result in 20-30% of those referred going forward for assessment, diagnosis and treatment funded by the NHS.

With option A **(Clinical triage with wider support offer)**, people presenting with ADHD-like symptoms would be referred for triaging by their GP, rather than directly to a service provider. Those with the highest priority will be referred to diagnosis, and if necessary, treatment. Those not meeting the criteria for prioritisation would instead be signposted to other support, such as access to an online support package to manage symptoms and help with accessing peer support groups and talking therapies if appropriate.

With option B **(Universal offer, followed by clinical triage)**, anybody would be able to access the same support offer on a “self-service” basis without needing to see a GP. Those feeling they have unresolved issues can then be referred for clinical triage by their GP as above.

So, the key difference between the options is that with option A, the wider support offer would be made available, post-triage, for those not meeting the criteria for prioritisation whereas in option B, the wider support option would be offered to anyone who might think they would benefit, prior to triage taking place.

As part of our options appraisal process, we identified the following pros and cons of the two options:

A. **Clinical triage with wider support offer:** Introducing a clinical threshold, with all patients triaged and prioritised based on their clinical need. Patients who do not meet the threshold will get offered support to manage symptoms. Patients who meet the threshold will go forward for diagnosis.	
Pros	Cons
• Prioritisation of those in greatest clinical need and who need the service most. • Support offered to everyone. • Meeting NICE guidelines and improved service quality. • Safer service with those who urgently need help getting it. • Lower waiting times and reduced risks associated with unmanaged demand.	• This process would take some time to achieve. • The threshold will reduce the number of people who go forward for a potential diagnosis. • The wider support offer will cost money, so this option will be more expensive than triage alone. • Some people who do not meet the threshold following triage may go on to use a private service. • People may choose not to use the support on offer.

• Equal offer for people across Greater Manchester with everyone having access to an NHS triage.	• For those who meet the criteria, different localities will have different providers in place to deliver the assessment and diagnosis service (or the patient would have Right to Choose)

B. Universal offer, followed by clinical triage: Provide everyone who comes forward with an offer of support to help manage symptoms. Patients who then request further support will be triaged against a clinical threshold and prioritised based on their clinical needs, with those who meet the threshold going forward for diagnosis.	
Pros	Cons
• Fast support offered to everyone. • Prioritisation of those in greatest clinical need and who need the service most, although only after trying the initial support offer. • Meeting NICE guidelines and improved service quality. • This could have a positive impact on reducing the size and scale of the waiting list, as some individuals may have got what they need purely from the universal offer of support without proceeding through to assessment for diagnosis. • Equal offer for people across Greater Manchester with everyone having access to an NHS triage.	• This process would take some time to achieve. • This process could make the journey to accessing diagnosis a longer one, therefore increasing risk associated with those who need higher levels of support more quickly. • This option will be more expensive than option A as everyone will access the general, universal offer of support first, before prioritisation. • A small number of people may not want to use the support offer and push for the next stage. • Some people who do not meet the threshold following triage may go on to use a private service.

	- For those who meet the criteria, different localities will have different providers in place to deliver the assessment and diagnosis service (or the patient would have Right to Choose)

7. Next steps

On 24 April 2024, NHS Greater Manchester's Executive Committee received an update on the adult ADHD review and agreed to proceed to consultation. Following the Options Appraisal, the options to be consulted upon were then agreed at the Commissioning Oversight Group on 17 June 2024.

Joint Health Scrutiny Work is therefore asked for their support to consult on the basis that the proposals constitute substantial variation.

The next steps will then be:

- Taking the proposal through the NHS England Service Reconfiguration Gateway process
- Notifying the Secretary of State for Health and Care of the intention to consult

Subject to the agreement of Joint Health Scrutiny and the approval of NHS England, we would then look to start consultation at the earliest opportunity, to run for a period of eight weeks.

Key stakeholders, including the members of the Joint Health Scrutiny Committees, the ten locality Health Scrutiny Committees, other elected representatives and clinical leaders would be briefed immediately prior to the start of consultation and encouraged to share details of the consultation with any other interested parties.

During this consultation period, we would be seeking the views of the public on the options.

A consultation information pack would be published explaining what ADHD is and how current adult ADHD services are run, the case for change, the learning from previous work engagement on this topic, what the options are, how they were decided upon, how they would work and their respective advantages and disadvantages.

The public would be able to be get involved in a number of different ways:

a) Proactively seeking groups to meet with, particularly those should as being potentially differentially impacted by the proposals or who we have the least understanding of that impact
b) Other groups would be able to request our team meet with them to hear their views
c) A printed and online survey would be produced
d) People would be able to ring to complete the survey over the phone or just share their thoughts on the topic if they prefer
e) People would be able to send a voicenote or WhatsApp message
f) People would also be able to share their views via NHS Greater Manchester's social media channels

Surveys and other submissions would be able to be returned via a FREEPOST address.

At the end of the consultation, we would then gather and analyse all the feedback received and produce a feedback report.

This would be considered in a decision-making workshop alongside other information such as financials, workforce data, national guidelines etc. A recommendation would then be made on the future model for the service, which would go through our governance for a decision.

We would ensure the feedback report and the decision are published, so everyone can see what the public told us, what we then did and why.

8. Recommendations

Greater Manchester Joint Health Scrutiny Committee is asked to:

a) note the contents of this report
b) support proceeding to consult on the identified options, on the basis that the proposals constitute ‘substantial variation’, and
c) make any recommendations as to how the consultation should be conducted

NHS
Greater Manchester

Appendix 1

Review of Adult ADHD Services: Engagement Report

April 2024

Part of Greater Manchester Integrated Care Partnership

Table of Contents

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 pre consultation 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 engagement 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 cannot 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 cannot 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 neds 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 have not 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 would not change them as a person.
3) Engagement staff spoke to person 3 on the 12th April and they expressed issues around communication and feedback. They were no longer on ADHD medication and were feeling "all over the place". Person 3's father passed away recently and their son had been diagnosed with ADHD, so was feeling really bad because they think they have passed it on to him. Sadly, he said that if he thought he was going to pass it on to his children he would not have had any. Their experience of the service was interrupted by another health condition and was not picked up after this. They described the member of staff from the provider as very nice but got no feedback from her. She arranged the medication and called maybe once a month to see how

they were getting on but nothing more than that. When they were diagnosed with a heart murmur the provider instructed them to stop taking the medication and get back in touch with hem once the murmur had been sorted out. That was about 18 months later and they got in touch with them who said they were no longer under them their care as too much time had elapsed.

Appendix B

Email Submissions

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

1) Participant A is upset about suggestions from the Adult ADHD team. They do not 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 do not think it is right to deny help to people who need it, especially when they have been referred for help. They compare it to refusing to give medicine to someone with depression. They say it is better to ask for more money to help rather than refusing care. They also think it is wrong to change the rules to stop people from getting help. They want honesty about funding issues and do not 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) Participant 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 is 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:

4) 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 https://www.theguardian.com/society/2024/mar/29/nhs-england-review-adhd-services-concerns-rise-diagnoses.

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.

Best wishes, Paul Baker, CHARM

https://charmmentalhealth.org

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 had not 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 via this link - https://healthierwigan.typeform.com/report/N9dz9VIw/PIBA28P4DIMtCi9v)

1. **How would you describe yourself?**

440 out of 464 participants answered this question.

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 participants described themselves as "Someone Living with ADHD". The second highest response rate came from people describing themselves as Professionals.

85.6% of the Professional participants worked within the NHS. Participants 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 participants answered this question.

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 participants 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 is not 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 participant said they valued **the frequent texts they received to update them** on the waiting list. Similarly in relation to communication, one participant said they always **received a response when sending email enquiries** but that these staff cannot 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. Participants often mentioned the impact of providers such as LancUK closing.

Although this is a review into adult ADHD at present, participants very often spoke generally positively for the children’s service but that this does not translate into adult’s experience. Participants 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 participants 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 time 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. **Participants 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 participants 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. **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).

Participants 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, participants 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.”*

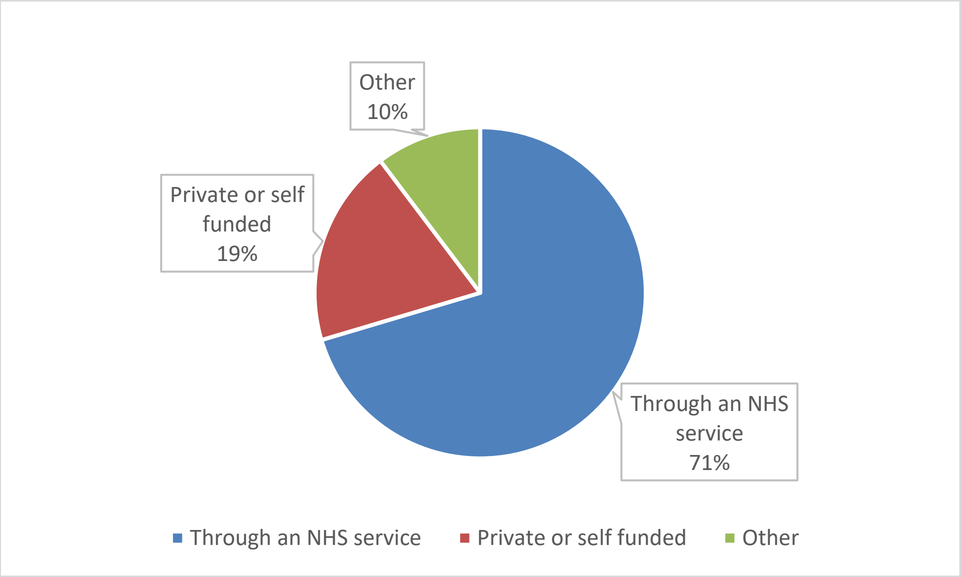
Participants felt that being able to take a family members or friend to appointments as a support would also improve their experience.

Participants wrote about the need for **increased awareness of the RTC pathway for**

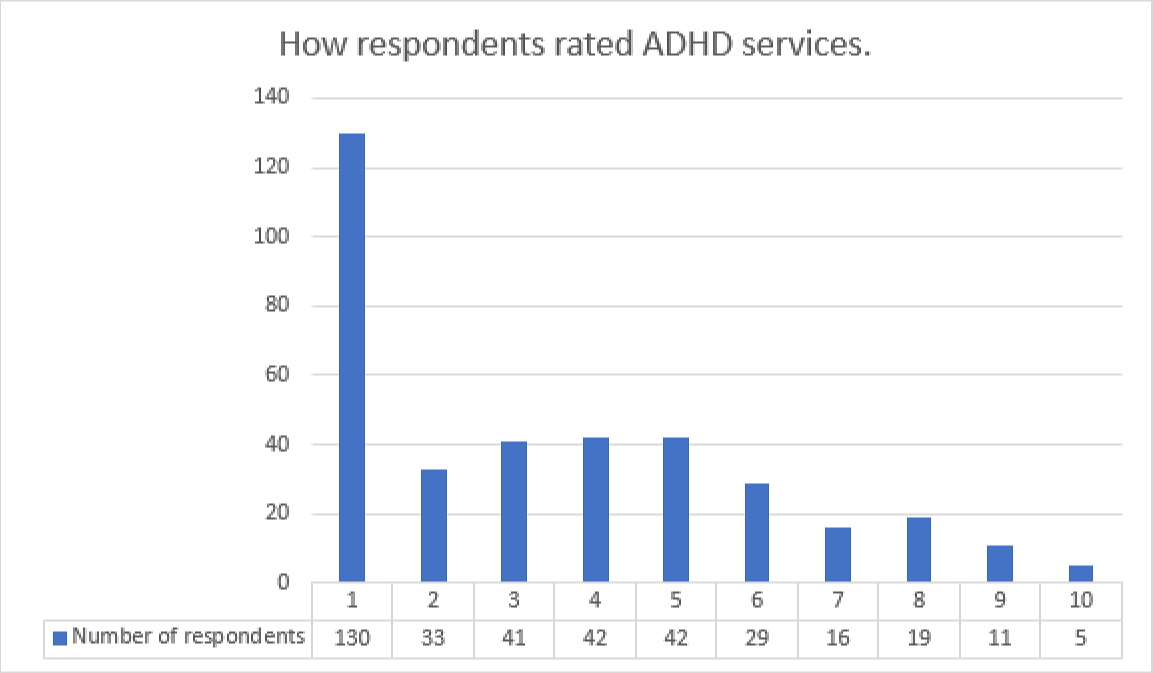
professionals, so patients do not need to explain and/or *'fight for it'.*

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

274 participants 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 participants. Of the 'other' responses, RTC was the most common response followed by listing the name of the private provider such as Physiatry 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 participants who *have previously used* services was rated as 4.3/10.

The average score for participants 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.

Participants 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. **Participants also raised concerns about medication** options, including shortages or delays in accessing medication and limited treatment alternatives beyond medication.

Participants, 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 participants 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 participants 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 **participants 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).

Participants 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 participants 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 participants 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 participants 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 participants 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 participants 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 participants given the challenges this would create for many people with ADHD.

Many participants 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 participants 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 participants 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?

Participants provided a great deal of suggestions for consideration. Below is summary of those which have not 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 participants 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 are not 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 is not 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. Participants 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. Participants 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 participant 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**
Age	
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	
British	**380**
Irish	9
Pakistani	9
Polish	4
Indian	3
White and Black Carribbean	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**

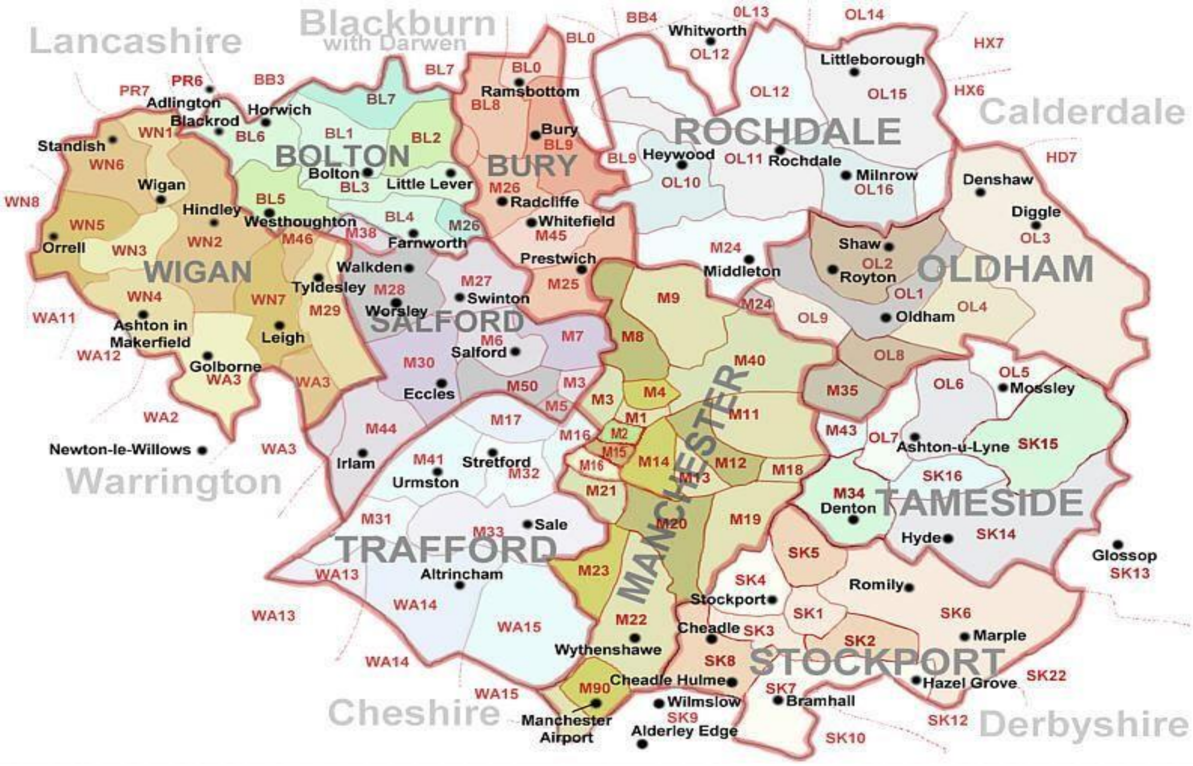
British/UK Citizen	
Yes	429
No	9
Prefer not to say	7
Total	**445**

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

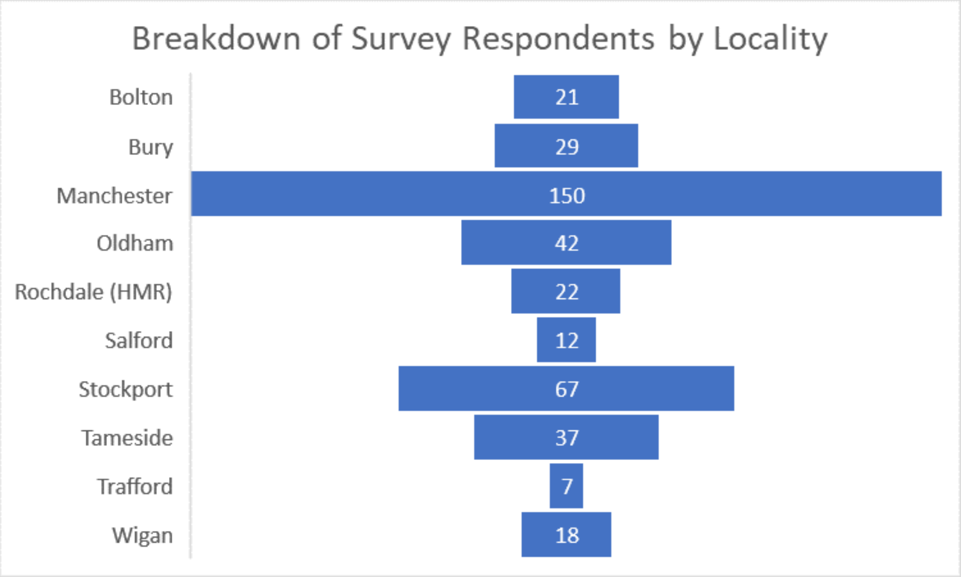
Carers	
Yes	107
No	318
Prefer not to say	18
Total	**443**

Postcode Map

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



418 participants provided us with a partial postcode, 13 of which, were outside of the Greater Manchester area. The greatest response was from participants 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 are 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 could not access anything (or did not 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 do not understand why they feel this way. Thankfully I had a good support network around me but not everyone does.”

“People do not 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 did not 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 do not 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.

Appendix 2 –

Equality Analysis Template Document

Step 1 Evidence
Step 2 Assess
Step 3 Strengthen
Step 4 Monitor
Step 5 Approve

Table of Contents

Step 1 Evidence

If you are unsure about any part of this template, please read the accompanying guidance paper before you complete. ALL sections must be completed – N/A is not applicable in this template as it is used to inform legal compliance. If you need to explain your bespoke approach further, please do so in the text boxes.

This equality analysis is being undertaken to prevent my policy, plan or project from adversely affecting people with different protected characteristics or at known disadvantage.

I am using this template to identify potential discrimination or disadvantage, propose steps to strengthen against those and record and monitor the success of those strengthening actions.

Name of your strategy/policy/plan/project: ADULT ADHD Services

Contact details for the person completing the assessment:

Scott Williams

Scott.williams8@nhs.net,

07388956280

Design date for the plan/project: August 2024

Date your equality analysis is completed: 19/4/2024

Does this template form part of a business case or investment proposal submission? YES

Are you completing this as a result of organisation change? NO

Is there another reason for you completing this template – e.g. renewal of a current service/change to current service – please specify: Change to current service

Initial screening assessment

What are the main aims, purpose of your policy, plan or project?

Service Redesign for ADHD Services and Childrens Autism pathway

What is your expected outcome?

To move through the stages of formal consultation with recommendations for both adult and children's services to lead to service change.

Who will benefit?

Patients

Services

System

Is your project part of a wider programme or strategy (for example, the locality plan)?

No

2. Are there any aspects/activities of the policy, plan or project that are particularly relevant to equality, socio-economic disadvantage, or human rights?

At this stage, you do not have to list possible impacts, just identify the areas. (E.g. we are commencing a new programme of health care aimed at Caribbean men with diabetes)

- We are looking to engage and consult on a service for patients of all ages with ADHD with autism as an additional element for children.

3. What existing sources of information will you use to help you identify the likely impact on different groups of people? (For example, statistics, JSNA's, stakeholder evidence, survey results, complaints analysis, consultation documents, customer feedback, existing briefings, comparative data from local or national external sources).

- Current service evidence
- Comparative data
- Insight through feedback e.g Wigan SEND engagement, Stockport engagement (TBC) further insight following specific service engagement.

Evidence gaps

Are there gaps in information that make it difficult or impossible to form an opinion on how your proposals might affect different groups of people? If so, what are the gaps in the information and how and when do you plan to collect additional information? Note this information will help you to identify potential equality stakeholders and specific issues that affect them - essential information if you are planning to consult as you can raise specific issues with particular groups as part of the consultation process. EIAs often pause at this stage while additional information is obtained.

No: Please go on to question 5. (Be sure to have fully considered all communities and parts of communities – e.g. have you considered the needs of gypsies, travellers and Roma communities, other transient communities, do you need to better understand take up of your service by Muslim women or Orthodox Jewish men, for example.)

Yes: Please explain briefly how you will fill any evidence gaps. You might want to start with contacting research or policy colleagues to see whether they can point you in the right direction. Our third sector colleagues will also be pleased to offer support and direction.

Evidence gap	How will the evidence be collated	Individual or team responsible and timeframe
Lived experiences.	Lived experience panel, Engagement Report	Scott Williams initiated between 12/2-24/3

Family test and provider feedback	Service feedback to be collated and shared to form part of report evidence	Sandy Bering, Scott Williams Throughout Pre-Engagement process
Patient demographics	To be established through provider services , programme leads and task and finish groups	Sandy Bering

Involvement and consultation

Note: You are required to involve and consult stakeholders during your assessment. The extent of the consultation will depend on the nature of the policy, plan, or project.

(Do not forget to involve trade unions and inclusion staff groups if staff are affected and consider socio-economic impact as well as community and third sector groups for different protected characteristics. If there is potential for different impact across different neighbourhoods, consult your neighbourhood leads)

Consultation and involvement that has taken place, who with, when and how?

We are using engagement to date, this is a first draft of this document.

Focus Group Sessions – 21st February 10am and 6pm

Lived experience panel – First meeting – April 2024

Stakeholders – Face to face and online

Key feedback from consultation:

For significant or large strategies and programmes, please provide a link to any written record of the consultation to be published alongside this assessment here:

How engagement with stakeholders will continue Here you need to explain how you continue to engage throughout the course of the delivery to ensure the measures you take to address any disparity are working.		
Involvement group	**Consultation dates**	**Strengthening actions**
Survey Focus Groups	**21st February 10am and 6pm**	
Lived Experience Panel		

Step 2 - Assessing impact and opportunities to promote equality and human rights

4. If you have piloted a project you want to roll out, add here what you learnt about communities not taking up, accessing, or having poorer outcomes from it and what you have done to address those disparities.

N/A

5. What barriers have you identified for the different groups listed by your proposals?

Add the impacts in the box next to the group. (e.g. we have found that working age people are not taking up our services because of our opening hour restrictions)

Complete the identified barriers for each group and identify which group you have identified.
You should complete each category. If you believe there is no adverse impact, you should put an explanation as to why.

Age • Young • Middle age • Older age	However, there is an increase in young people with ADHD or/and autism who are also Emotional School Based Avoiders (EBSA) and this is a factor to consider when assessing wider impact of change It is important to note that Children who have both autism and attention-deficit/hyperactivity disorder (ADHD) are also more likely to experience anxiety, depression, developmental delays, learning disabilities and other mental health conditions than are children with only autism or ADHD. University aged adults and CYP going through exams may be impacted if cannot access service Working age adults seeking employment and other activity can have challenges accessing support during working hours and or evidencing their need without a diagnosis. Increase in adults and children seeking diagnosis. 6x increase in children since 2019. We recognise there are challenges when transitioning between services and also when children transition to adult services given tht the age bracket changes dependant on need and the service being accessed. In Heywood, Middleton, and Rochdale – there has been a rise in referrals at ages where children transition through education settings i.e Early Years to primary and Primary to High school

Disability Types of impairment can be categorised as physical, sensory, psychosocial, and intellectual. There are several types of barrier that cause exclusion including • Physical • Social/attitudinal • Institutional • Communication Complete which *barriers* you will need to consider in your programme.	The potential impact of service change is There may be potential for the programme of work to adversely impact on particular groups within the SEND cohort. This is due to the potential for service change. There is a challenge that change for people with ADHD and Autism leads to confusion, concern and potentially disengagement form services. There are a number of related conditions identified by the autistic society which include: • ADHD • Hearing Impairment: • Some autistic people have sensory differences • Downs Syndrome • Dyspraxia • Dyslexia • Epilepsy • About one in every 100 people have epilepsy. Autistic people are at heightened risk, with between 20% and 40% having epilepsy. This rate increases steadily with age. • Fetal Anti-Convulsant Syndrome (FACS) • Fragile X Syndrome • Hyperlexia • Learning Disabilities • Social Communication Disorder • Visual Impairment • When visual impairment and autism occur together, …the impact is much greater because the difficulties arising from each disability interact with each other

	Further information available: Related conditions - a guide for all audiences (autism.org.uk) We also recognise the challenges partners such as schools face with a growing number of Emotional Based School avoiders. This project will target respondents across GM who currently live with ADHD, and children with Autism.
Sex Identify any potential adverse impact to men or women.	Prevalence of ADHD In adults is estimated at 3 to 4% with a ratio of male to females being 3:1 https://cks.nice.org.uk/topics/attention-deficit-hyperactivity-disorder/background-information/prevalence/ …recent local and national reviews confirm increasing CYP MH inpatients are frequently Autistic females attending services in crisis with comorbid self-harm/disordered eating.

Race Identify any adverse potential impact on different ethnic groups and identify which ethnic groups you may need to specifically consider.	According to gov.uk there is no meaningful difference between ethnic groups when screening positive for ADHD or autism in children. There are barriers to accessing Autism/ADHD services as an ethnic minority, delays in diagnosis, cultural differences impacting experience when interfacing with healthcare services Autism and BAME people Autism and BAME people ; Autism rates have increased and show differences in ethnic minorities and links to social disadvantage | University of Cambridge To consider throughout what the impacts of the service redesign of ethnic minority communities and if their engagement with services is lower than would be anticipated how will that be addressed in service redesign. Certain ethnic groups are more likely to have an education, health, and care plan (EHCP) than others. Based on data published in January 2022, the highest percentage of pupils with an EHCP were Travellers of Irish heritage (5.7%) and the second highest were Black Caribbean pupils (5.4%). Chinese pupils had the lowest percentage of pupils with an EHCP, at 2.3%. The overall percentage of pupils with an EHCP plan was 4% Equalities impact assessment: area SEND framework and handbook - GOV.UK (www.gov.uk)

Religion/ belief Identify any adverse potential impact on different religious groups and identify which you may need to specifically consider.	Through previous engagement activity and working with faith groups across GM we are aware that some religions and belief are less likely to access health services and screening. We are also aware that this is a factor in wider health determinants and choices.
Sexual Orientation Identify any adverse potential impact on different sexual orientations and identify which sexual orientations you may need to specifically consider.	It is not perceived that their will be any undue disadvantage based on sexual orientation. There has been no evidence found of any connections between ADHD and Autism and Sexual Orientation. We do however know from other work that the LGBTQQIA community face challenges in accessing health services.

Transgender Identify any adverse potential impact on transgender or non-binary people.	Autistic children are 4 times more likely to be transgender or gender questioning. Transgender and gender questioning children are 5 times more like to have autism or ADHD (1). Some intersex variations, like Klinefelter Syndrome and Turner's Syndrome, are also linked to higher rates of neurodiversity (2) [1] Thrower, E., et al. Prevalence of Autism Spectrum Disorder and Attention-Deficit Hyperactivity Disorder Amongst Individuals with Gender Dysphoria: A Systematic Review. *J Autism Dev Disord.* 2020; 50: 695–706. [2] de Vries, A. L., et al. Mental Health of a Large Group of Adults With Disorders of Sex Development in Six European Countries. *Psychosomatic Medicine.* 2019; 81(7), 629-640.

Carter status	This project will also look to work with carers and their support in particular projects such as the Parent Carer Forums. We are aware from wider knowledge pools that carers can find it harder to access health services when caring or responding to needs of the cared for. The project acknowledges the impact change of service may have to carers and will review the impact throughout the process and update accordingly. Access to funding and benefits can be diagnosis led.
Socio-economic status Identify any adverse potential impact because of deprived communities and identify which communities you may need to specifically consider.	Financial difficulties, housing tenure, maternal age at birth of child and marital status were significantly associated with an outcome of ADHD, such that families either living in financial difficulty, living in council housing, with younger or single mothers were more likely to have a child with a research diagnosis of ADHD at age 7. Financial difficulties was the strongest predictor of ADHD (OR 2.23 95% CI 1.57-3.16). In the multiple mediation model, involvement in parenting at age 6 and presence of adversity at age 2-4 mediated 27.8% of the association. Socioeconomic Associations with ADHD: Findings from a Mediation Analysis - PMC (nih.gov)

Pregnancy or maternity Identify any adverse potential impact because of pregnancy or maternity.	There would be no adverse potential impact to note within this programme of work
Marriage /civil partnership This category is only required for employment discrimination matters.	It is important to note that: Mothers with children with ADHD were less likely to be married than mothers of children with no ADHD diagnosis. Socioeconomic Associations with ADHD: Findings from a Mediation Analysis - PMC (nih.gov) The socioeconomic impact of single parenthood could impact access to services during pregnancy/maternity.

Other Are there other discriminations or disadvantages that you think you need to address?	Geographical location plays a part in waiting times and diagnostic pathways, across GM there are multiple organisations who are part of the process with no one way for all residents of GM. Tameside also has the largest waiting list for Children. Things we need to consider when reviewing common traits of ADHD. ADHD is more common in people who have: • a sibling or close family member with ADHD • epilepsy • other neurodevelopmental conditions, learning disabilities or learning difficulties. • mental illnesses • a history of alcohol or drug misuse • been involved in the criminal justice system. • an acquired brain injury • been in care. Or who were: • born prematurely • diagnosed with ‘oppositional defiant disorder’ or ‘conduct disorder’ as children. • thought to have a mental illness like anxiety or depression as children.

6. Can the adverse impacts you identified be justified and the original proposals implemented without making any adjustments to them? If so, please set out the basis on which you justify implementing the proposals without adjustments.

Further engagement will be undertaken on the impact and mitigations required

7. Having analysed the initial and additional sources of information including feedback from consultation, is there any evidence that the proposed changes will have a *positive* impact on any of these different groups of people and/or promote equality of opportunity? Please provide details of who will benefit from the positive impacts and the evidence and analysis used to identify them.

Further engagement will be undertaken on the impact and mitigations required.

8. Is there any evidence that the proposed changes have *no* equality impacts? Please provide details of the evidence and analysis used to reach the conclusion that the proposed changes have no impact on any of these different groups of people.

Further engagement will be undertaken on the impact and mitigations required.

9. Please provide details of how you will consult and involve communities on the proposed changes. If you do not plan to consult and involve, please provide the rationale behind that decision.

Engagement Plans: TBC

Step 3 – Strengthening your policy plan or project

Please use the table below to document your strengthening actions.

10. What changes are you planning to make to your original proposals to minimise or eliminate the adverse equality impacts you have found?

Please provide details of the proposed actions, timetable for making the changes and the person(s) responsible for making the changes.

Adverse impact	Proposed action	Person responsible

11. Describe here how you could further promote equality of opportunity. What action/s do you recommend and when?

This is where you are taking the opportunity to advance addressing inequalities beyond the mitigations you are putting in place, for example, your mitigations when moving a service to digital provision will be to ensure alternatives are available for those who

cannot access digital services. Your opportunity to *further promote* equality with a new digital service would be to extend a service to people from their own home where they had previously experienced physical barriers to reaching your surgery.

12. Describe how you could further promote human rights principles. What action/s do you recommend and when? Please provide details.

For example, if you are putting in place improved access to interpreter provision that may enhance the human rights of those that need it to access public services.

13. Describe how you could further reduce socio-economic disadvantage. What action/s do you recommend and when?

For example, if you are undertaking a focused anti-smoking campaign in areas of high deprivation, you can expect to reduce socio-economic disadvantage.

14. Describe here how you could further promote social value. What action/s do you recommend and when?

For example, you might be able to offer new jobs or apprenticeships to people struggling to get employment or offer contracts to community led social enterprises to deliver your services.

Step 4 – Monitoring and review

15. You are legally required to monitor and review the proposed changes after implementation of your strategy or programme to check they work as planned and to screen for unexpected equality impacts. Please provide details of how you will monitor, evaluate, or review your proposals and when the review will take place.

What	When	How

Step 5 – Sign off

Strategy, policy, plan, project or service owner or Work Programme Lead*

Name:

Date:

EIA Lead (the person completing this form)

This equality analysis has been quality-checked and will be passed to the senior responsible officer for final sign off.

Name: Scott Williams

Date:

Director or Senior Responsible Owner *

This equality impact assessment has been completed in a rigorous and robust manner and I agree with the actions identified. It will now be progressed and published where required.

Name:

Date:

*By signing off your EIA you are confirming that you are satisfied that the policy/strategy/project/activity/service has been designed with the needs of different equality groups and communities in mind, and that the groups it is intended to serve will be able to access the service and experience similar outcomes from it.

For records, this EIA will also need to be copied to elaine.mills7@nhs.net to ensure we can evidence our legal duties to undertake equality analysis. However, the original version must be kept with the project documents and pro-actively used to inform the progress of the work, alongside budget, risk and health and safety monitoring.