NHS
Greater Manchester
Integrated Care

# Adult ADHD options paper

**NHS Greater Manchester Integrated Care**

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| **WHICH GROUP HAS PRODUCED THIS PAPER (IF APPLICABLE):** | ADHD Task and Finish Group |
| **PRESENTED BY:** | Sandy Bering |
| **PURPOSE OF PAPER:**<br>**Decision Requested:**<br>**For Discussion:**<br>**For Noting/Information:**<br>**Financial Implication:** | <br>**Yes ☒ No ☐**<br>**Yes ☒ No ☐**<br>**Yes ☒ No ☐**<br>**Yes ☒ No ☐** |



**PURPOSE OF REPORT:**

This paper addresses the urgent need to redesign adult Attention Deficit Hyperactivity Disorder (ADHD) services in Greater Manchester (GM). The demand for neurodevelopmental disorder services has surged, with an estimated 60,000 adults eligible for NHS funded diagnostic assessments and treatment for ADHD in GM alone in the context of currently undefined clinical prioritisation criteria. This surge, intensified through the pandemic with increased public expectations following celebrity endorsements, has led to prolonged waiting times, inadequate quality assurance, and increasing reliance on private providers through the "Right to Choose" arrangement as well as more recently reduced availability of medication supplies for those most in need.

This purpose of this paper is twofold – to present a proposal for reconfiguring the adult ADHD pathway and suggest this as one of three potential options:

- Option 1: Do Nothing
- Option 2: Implement Proposed Changes
- Option 3: Seek Alternative Solutions

Each option is assessed based on its impact on GM's ADHD services, alignment with National Institute for Health and Care Excellence (NICE) guidelines, and its ability to manage escalating demand effectively.

**KEY MESSAGES:**

- The current adult ADHD pathway is financially unsustainable. Addressing the waiting list backlog of 15,000 will cost at least £15m, with a further £8m needed annually to manage future demand.
- Patients joining the waiting list today face a wait of up to 7 years. This is clearly unacceptable from a patient experience and safety perspective.
- A task & finish group was set up to consider how the pathway could be reconfigured to address increased demand and long waits, whilst ensuring those who most need care can receive it more promptly.
- A proposal to reconfigure the pathway includes establishing triage support systems for GPs to assess and prioritise adult ADHD patients, building specialist primary care shared care prescribing support capacity and implementing a universal support offer for anyone experiencing symptoms of ADHD enabling better pre and post diagnostic support options.
- Implementing this proposal is expected to reduce costs by £12m for the existing waiting list backlog and £6.4m annually.
- Other options include *do nothing* and *seek alternative solutions*.

**RECOMMENDATIONS:**

Option 2 - Implement proposed changes is recommended and we ask the Board to consider:

- Agreeing that option 2 should be taken forwards.

If agreeing to endorse option 2, we also ask for:

- Advice on whether formal consultation and/or any other assessment activity (e.g., equality impact assessment) would be required.
- Support in taking forwards the development of detailed mobilisation plans with lead commissioners and providers, taking into account all the points noted in this paper.
- A steer on where in the system this work should sit for further development and implementation.

If not agreeing to endorse option 2, we ask for:

- Advice on what alternative actions we can take to mitigate the significant financial and patient safety risks of doing nothing or delaying any alternative actions.

## 1. Background

ADHD is a complex neurodevelopmental condition that can have a considerable impact on a person's daily life. Nationally, demand for adult ADHD services has increased five-fold since the pandemic, with an estimated prevalence of around 2.5-4% of the adult population. Applying this to GM indicates there could be ~60,000 adults potentially wanting access to ADHD assessments and, if diagnosed, treatment.

The reasons for this increase are not clear but are likely to include increased awareness of the symptoms of ADHD following campaigns on social media involving a number of high-profile celebrities sharing their experience of ADHD and reported impact of access to prescribed medication.

The sharp increase in demand for ADHD assessments has outstripped capacity to carry out those assessments, leading to longer waiting times, not only in GM but across the country. Recent media attention has focused on poor quality services, with CQC inspections also noting serious quality concerns. Yet despite this, there remains no clear national policy direction from NHSE on how to manage this situation.

NHS GM ICB established a Task and Finish Group, including leads from Mental Health Trusts, GPs, Pharmacists and NHS commissioners, to look at possible solutions to the issues highlighted above. Adopting their proposal is option 2 in this paper.

## 2. Current levels of demand and the case for change

GM faces a growing backlog of over 15,000 adults awaiting ADHD assessment, despite significant past investments into waiting list initiatives. It is estimated that addressing this backlog would cost at least £15 million. Additionally, we expect annual costs of £8 million to meet future demand. Despite efforts to reduce waiting times, the backlog persists, with some individuals facing an approximate 7-year wait for assessment.

The financial implications of this are clear, with GM ICB unable to make or sustain the level of investment needed to service demand for the current ADHD pathway. From a patient perspective, a lengthy waiting period for an ADHD assessment can have detrimental effects on individuals' overall well-being and quality of life. It often exacerbates the challenges and symptoms associated with ADHD, such as difficulties in concentration, impulsivity, and emotional regulation. This delay can hinder academic and professional achievements, strain personal relationships, and lead to feelings of frustration and helplessness. Moreover, extended waiting times can contribute to a sense of uncertainty and anxiety, as individuals and their families grapple with the unknown while seeking support and treatment. Timely assessments are crucial to provide timely interventions and support, mitigating the potential negative impacts of ADHD and enabling individuals to access the appropriate care they need to thrive.

## 3. Proposal

The Task and Finish Group's proposal recommends that the adult ADHD pathway is reconfigured to support people with ADHD whilst managing the current risks to enable priority to be given to those people most in need of specialist assessments, medication and treatment. There are two elements to this:

- Establishing triage support systems for General Practitioners (GPs) to assess and prioritise individuals, and building specialist primary care shared care prescribing support capacity.
- Implementing a universal support offer for adults with ADHD symptoms.

Instead of continuing with the routine commissioning of assessment, diagnosis, and treatment for all adult ADHD referrals, we suggest implementing a refined approach. This involves establishing triage support systems for GPs to assess and prioritise individuals**.** This prioritisation would be conducted using

standardised tools and assessments, ensuring that those with the highest clinical need receive prompt attention (see Appendix A for details).

The existing commissioning pathway allows all adults displaying symptoms of ADHD to access assessment, diagnosis, and treatment on the NHS. However, given the limited capacity and resources available, we believe it is necessary to revise this approach. Our goal is to target specialist assessments and support for individuals with complex mental health issues, aligning with NICE guidelines[1]. Additionally, we propose implementing a universal broader social prescribing and psychoeducation support service offer, which could be based on the North West Coast AHSN work[2].

For those individuals who experience some of the symptoms of ADHD but do not meet the criteria for prioritisation, we would offer the following to support them to manage and reduce the impact of the symptoms of ADHD that they are experiencing.:

- Online self-help support, for example ORCHA.
- Referral into Living Well primary Care MH services.
- Referral to NHS Talking Therapies.
- Referral to VCSE support services.

Similar pathways are in place in Lancashire and being developed across Cheshire and Merseyside – and so this offer would be refined/aligned with these developments so that a coherent and consistent approach is in place across the North West ICBs and providers footprints should this proposal be supported.

This adjustment to the ADHD pathway is vital for effective resource management and to address the current risks associated with the utilisation of private providers via the Right to Choose mechanism. Our approach has undergone testing with NHSE Legal and Choice Team leads and aligns with national guidelines. We considered factors such as quality and experience comparable to NHS standards, CQC registration (or demonstration of non-detriment to patients if not registered), multi-disciplinary input into the assessment pathway with mental health professional involvement, adherence to good clinical assessment guidelines, consideration of conversion rates, and the provision of post-diagnostic support equivalent to services in the area.

In order to implement this across GM we are proposing that two clinical teams would need to be created (i.e., in the West at GMMH and in the East at PCFT). These teams of mental health specialists (not ADHD clinicians) would apply the above criteria and needs stratification to all existing waiters and any new referrals across GM. Our understanding from similar work at CWP is that approximately 20% of current adult ADHD referrals will subsequently meet the criteria outlined in Appendix A.

Those people that are prioritised will then be supported to access GM ICB funded assessment, diagnosis and treatment via commissioned NHS or Private Providers in the 10 localities across GM or identify an eligible provider meeting agreed GM, NICE and CQC provider criteria themselves via Right to Choose arrangements.

As part of the proposal, we would develop a list of qualified providers across GM to support this work in a proactive way. This will also help provider assurance around the quality of service offered and ensure that these providers follow a service model which enables shared care arrangements to be agreed with GPs to be established once a stable dose of medication is achieved.

If accepted as an appropriate direction of travel for future GM ADHD pathways, we would welcome the opportunity for further clinical engagement on the final prioritisation criteria if the proposal were progressed

[1] Recommendations | Attention deficit hyperactivity disorder: diagnosis and management | Guidance | NICE
[2] Service Model for ADHD Integrated Care.pdf

(including building from reactive work developed in Stockport and the NE GM Sector).
The issues highlighted already include:

- Questions about how the information is gathered and potential for reliance on self-declaration.
- Young people who are 'transitioning to adult care' from children's ADHD services – is it appropriate for these young people to go through this pathway? Should these diagnosed young people not have a seamless transition to adult ADHD services?
- Which patients would need to be and remain under shared care arrangements with a specialist provider and have routine medication reviews.
- Grading of some of the criteria above. For example, there is a case for saying that current presenting risks to self, others, neglect, forensic etc and current drug / alcohol misuse should be classified as Red.
- Where patients ought to have a general mental health assessment prior to any referral for an ADHD assessment.
- Further consideration around the support available to those who do not meet the criteria for assessment. If these people are going to be directed or signposted into the talking therapies, Living Well teams and VCSE organisations - this could pose some capacity challenges and there may be a need for investment in training and development for staff. Also, in relation to VCSE services that may offer advice and support to people presenting with ADHD type symptoms, these organisations may not available in all localities leading to inequitable provision.

## 4. Options

### Option 1: Do nothing

The do-nothing option means we would accept that demand outstrips supply and adults are going to have very long waits for an ADHD assessment. Assessments would continue to be offered on a first come first served basis.

Pros:

- Minimal immediate change.
- No financial investment required.

Cons:

- Continuing escalation of waiting times.
- Unmet demand leading to potential risks for patients.
- Ongoing reliance on private providers under the "Right to Choose" arrangement.
- Non-compliance with NICE guidelines and a potential deterioration in service quality with GPs refusing to treat individuals using Amber drugs without access to specialist clinical support and reviews.

### Option 2: Implement proposed changes

The proposal is to reconfigure the commissioning pathway for adult ADHD services in GM. This change aims to optimise resource allocation while ensuring that individuals with ADHD receive the support they need based on clinical need and risk factors.

The proposal, if implemented would help in managing demand but not all patient expectations. There will be a need to support the implementation with a robust communications plan including clear information to support GPs who are currently on the front line of managing the message to patients around waiting times, Right to Choose, etc.

Should this proposal be supported and based upon the experience in Cheshire and Wirral, we estimate that we are likely to see targeted ADHD assessment and support work possible for the 20% of individuals likely to qualify through formal triage assessments. At the same time, it is suggested that there will be an 80% reduction in the number of adults progressing to GM ICB commissioned specialist assessments, diagnosis and treatment.

This option aims to reduce the costs associated with existing care pathways significantly. The estimated direct cost reduction models is substantial:

- For current waiters: A reduction of £12 million from the £15 million cost[3].
- For annual referrals: A reduction of £6.4 million from the £8 million cost.
- Investment to establish two triage teams is estimated at approximately £1.5 million, funded through GM 2024/25 Mental Health Investment Standard (MHIS) funding and reallocation of existing ADHD investments.

Pros:

- Prioritisation of those in greatest clinical need.
- Alignment with NICE guidelines and improved service quality.
- Reduction in long waiting times and risks associated with unmanaged demand.
- Enhanced clarity in commissioning pathways.

Cons:

- Financial investment required for implementation.
- Potential media scrutiny and controversy.
- Adjustment period for patients and healthcare providers.

**Option 3: Seek alternative solutions**

The task & finish group were unable to identify any other options to address the growing demand for adult ADHD diagnosis that will limit the number of people eligible for NHS funded treatment and, at the same time, ensure those most in need can actually access the limited diagnostic assessment and treatment available in GM. However, we recognise that stakeholders may have other ideas for how to address the increasing demand and long waiting times for adult ADHD services and so include the option to explore this further.

Pros:

- Exploration of innovative approaches.
- Flexibility to consider other strategies to manage demand and improve service quality.
- Potential to learn from successful practices in other regions.

Cons:

- May lead to delays in addressing the current crisis with continuing escalation of waiting times.
- Unmet demand leading to potential risks for patients with ongoing reliance on private providers under the "Right to Choose" arrangement.
- Non-compliance with NICE guidelines and a potential deterioration in service quality with GPs refusing to treat individuals using Amber drugs without access to specialist clinical support and

[3] Based on an ADHD assessment costing £1,000

reviews.
- Uncertainty about the effectiveness of alternative solutions.
- Possible resource allocation challenges.

## 5. Recommendation

We recommend option 2 – implement proposed changes.

We acknowledge that this change may be perceived as controversial and could attract media scrutiny. Therefore, it is imperative that the Board recognises and supports this approach. This decision is necessitated by the significant surge in demand, recent controversies surrounding ADHD assessments and treatment, challenges in recruiting sufficient specialists despite funding availability, and the imperative to redesign the commissioning model. Evidence indicates that long waiting times persist despite NHS commissioners willingness to substantially increase resources for this service area in Greater Manchester.

## 6. Summary

This paper presents three alternatives to address the escalating demand for adult ADHD services in GM.

- Option 1 (Do nothing) entails maintaining the status quo, risking continued escalation of waiting times and potential quality issues.
- Option 2 (Implement proposed changes) involves prioritising those in greatest clinical need, aligning with NICE guidelines, and managing demand effectively.
- Option 3 (Seek alternative solutions) allows for exploration of innovative approaches but may lead to delays in addressing the current crisis.

The decision will have profound implications for GM's adult ADHD services, its patients, and its ability to meet national standards and guidelines.

**Appendix A: Proposed clinical criteria to prioritise patients**

We are planning to establish triage support arrangements for GPs to prioritise support for individuals on the basis of clinical need and risk using a standardised set of tools and assessments with the following criteria adapted from a similar pathway used effectively by the Cheshire and Wirral Partnership NHS Trust. These suggest that the Minimum Criteria for agreeing the need for a GM ICB funded specialist ADHD assessment would be as follows:

- The symptoms of hyperactivity/impulsivity can be covered in the ADHD self-reporting questionnaire (ARS's form below). Five or more symptoms of inattention and/or 5 or more symptoms of hyperactivity/impulsivity must have persisted for 6 months or more to a degree that is inconsistent with the developmental level and negatively impacts social and academic/occupational activities.

- Several symptoms (inattentive or hyperactive/impulsive) were present before the age of 12 years.

- Several symptoms (inattentive or hyperactive/impulsive) must be present in at least 2 settings e.g., at home, college/Uni or work, with friends or relatives, in other activities.

- There is clear evidence that the symptoms interfere with or reduce the quality of social, academic or occupational functioning.

- Symptoms do not occur exclusively during schizophrenia or another psychotic disorder and are not better explained by another mental disorder e.g., mood disorder, anxiety disorder, dissociative disorder, personality disorder, substance intoxication or withdrawal.

*If the person fulfils the criteria above, then we would proceed with the rest of the needs stratification. If they do not, the person does not meet the criteria for an ADHD assessment.*

The following needs stratification will then be applied to identify those most in need of referral for full assessment, diagnosis and treatment:

General information. This section relates to priority groups within the service completed by clinician.

1. An active or ex-military veteran including Territorial Army (**Red** if yes)
2. A young person who is 'transitioning to adult care' from children's ADHD services (**Red** if yes)
3. A person being transferred from another service who is currently receiving treatment for ADHD (**Red** if yes)
4. Has a Formal diagnosis (does not score). It is important to identify if the patient has a 'formal' diagnosis of ADHD and if so, who confirmed the diagnosis and when the diagnosis was confirmed.
5. Already Prescribed ADHD medication being reviewed by GP only (**Green**). If the patient is taking medications for ADHD, ask them if it is working well and identify if they feel they would benefit from a review of medication and why they believe this to be the case.

Clinical information (completed by clinician)

6. Details of Psychiatric history
   - unstable/untreated mental health (**Amber**)
   - stable and treated mental health (**Green**)
   - past episodes of mental health (**Green**)
   - none reported (**Green**)
7. Current presenting risks to self, others, neglect, forensic etc (**Amber**)
8. Past presenting risks to self, others, neglect, forensic etc (**Green**)
9. Details of any current substance misuse or excessive alcohol use (Yes **Amber**)

10. Is it safe for lone working? If not, state why (does not score)
11. Are there any current Safeguarding concerns? If yes detail (Yes **Amber**)
12. Details of physical health history (**Green**)
13. Details of current medication (does not score)
14. History of recurrent mental health hospital admissions? If so when and why? Were these formal/ informal admissions? (**Amber** within the last 2 years/**Green** over 2 years/or none)
15. Provide information suggestive of ADHD symptoms (early and longstanding with attention or self-control. Some significant symptoms should have been present in childhood under 12 years of age; indicate how this is impacting on the person's functioning e.g.
    - **Red** significant impact (some indications of **Red**)
        - University/college student struggling meeting deadlines, attending lectures, organisation of work etc
        - A person who may lose their job imminently. e.g., under HR, capability or sickness management due to unmanaged symptoms of ADHD.
        - Impulsivity say the wrong things that causes me to get into trouble. e.g., work or education in 2 or more domains (expelled/ suspended)
        - Extremely agitated and restless (no switching off due to internal hyperactivity of ADHD)
        - MEDICATION NOT WORKING BUT THE IMPACT IS AS ABOVE.
    - **Green** is low impact/no impact (some indications of **Green**)
        - Impulsivity on relationships
        - Agitation and restlessness intermittent
        - MANAGING their job, attending college etc but are managing their symptoms to a degree, with coping strategies or family/carer support.
        - Not having a major impact on relationships.
        - Managing their bills adequately.
        - Already on prescribed medication by GP, symptoms managed or symptoms not qualifying for uncontrolled symptoms of ADHD and is the significant section

**RAG Outcome Scoring Sheet**

- **Red** 1, 2, 3,15 significant risk
- **Amber** 6 unstable/untreated, 7, 9, 11, 12, 14 within 2 years of admission or revolving door at A/E
    - Mental health concerns, past risks, substance use, forensic history, safeguarding, mental health hospital admissions. Has other concerns related to comorbidities. SIGNPOST to relevant service.
- **Green** 6 stable and treated, past episodes, none. 8, 12 Physical health concerns. Consider signpost to relevant service. 14 over 2 years & 15 low/or no impact.

Only those referrals identified as meeting one or more of the RED indicators will in the future be prioritised for assessment, diagnosis and treatment funded by the NHS.