

Cross-Sector Attention Deficit Hyperactivity Disorder (ADHD) Taskforce

Terms of Reference

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Project/Programme Manager (PM)	Dan St John		
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1. Document Management

1.1. Revision history

Version	Date	Summary of changes
1.0	29 November 2024	Final draft for Taskforce Working Groups

1.2. Approved by

This document must be approved by the following people:

Name	Signature	Title	Date	Version
Catherine Hinwood		Attention Deficit Hyperactivity Disorder Programme Director		
Anita Thapar		Clinical Professor, Cardiff University, Chair of the ADHD Cross - Sector Taskforce		

1.3. Document control

The controlled copy of this document is maintained by NHS England. Any copies of this document held outside of that area, in whatever format (e.g., paper, email attachment), are considered to have passed out of control and should be checked for accuracy and validity.

2. Purpose

2.1. Background

In recent years, multiple challenges relating to the pathways and provision of services for Attention Deficit Hyperactivity Disorder (ADHD) have been reported by individuals, systems, regions and other key stakeholders. This includes a significant rise in referral to specialist services and reported poor experience for those living with ADHD and their parents/carers (whether diagnosed, awaiting assessment or considered subthreshold for diagnosis). Poor experience and long waits span across age groups and pathways, including early support/waiting well.

The NHS England ADHD Programme was stood up in December 2023 to consider issues related to ADHD service provision. Initial engagement undertaken by the programme, including with those with lived experience, has confirmed that the impact of ADHD is not limited to an individual's health, but is felt across all aspects of their life, including education, employment, relationships and in wider health behaviours and outcomes. This cross-cutting impact is also felt at a societal level; affecting the nation's health and economic outcomes and creating additional pressure within a strained health system. Health focused work alone will not improve access, experience, and outcomes for people with ADHD; a joined up cross-sectoral and multi-agency approach is needed.

2.2. Purpose

NHS England has convened an independent, cross-sector ADHD Taskforce to bring together expertise across the whole of society to lead public engagement and make recommendations to government on a whole system approach to managing ADHD. The focus is not limited to those with formal diagnoses but is inclusive of all those experiencing symptoms, as well as their families and caregivers.

The Taskforce, led by an independent chair, will comprise individuals with lived experience and those working in health, education, justice and employment sectors. They will be supported by additional working groups that convene experts by experience and experts in evidence to build consensus around the evidence base. The Taskforce will also have access to NHS England's ADHD Clinical Reference Group (CRG) where relevant clinical expertise is required.

3. Duties and responsibilities

3.1. Role

The work of the Taskforce will facilitate transformation across systems to improve the lives of people with ADHD, via the NHS England ADHD Programme. The Taskforce will:

- Bring together lived experience, clinical, scientific, education and other professional sectors and insight to understand the root causes of current and emerging challenges
Identify priorities and potential solutions via active engagement with stakeholders
- Support identification, development and sharing of evidence-based opportunities for innovation which progress the transformation of ADHD and neurodevelopmental pathways and services across sectors.
- Deliver a report outlining recommendations for NHS England, government and cross-sector partner organisations to consider in terms of implementation.

3.2. Scope

The Taskforce will consider how services and supports across health, education, justice and the whole of society need to be transformed to ensure those with ADHD are able to access timely, appropriate, effective and high quality support and live to their full potential.

Discussions will be oriented around key priorities outlined by experts by experience, and include:

- Tackling stigma and ensuring people with ADHD are treated with empathy, respect and understanding across society
- Training professionals about ADHD, challenging stigma within the health and care sector, and increasing awareness of the different ways that ADHD can present
- Supporting people to access joined-up care, centred around their needs as a whole person, as well as continuity of care as individuals transition from childhood to adult life

- Earlier identification and support across different sectors, including waiting well and reducing the burden on those with suspected ADHD; waiting times across the person's journey and easier access to support across the pathway

Specific topics for review are to be identified and agreed by the Taskforce. Scope is expected to include the following topics:

- Understanding the reasons for seeking referrals and diagnosis for individuals, families and society, and considering options to address needs.
- Exploring the true costs of ADHD to society, taking into consideration the impact of recognised and unrecognised ADHD on life outcomes, educational engagement and achievement, employment and involvement in society, to support identification of cost effect and sustainable support offers for the future.
- Recognising the benefits and limitations of adopting a broader neurodivergence model of support, the significant co-occurrence of ADHD with other neurodevelopmental conditions and mental health and the opportunities to shape pathways and service delivery across conditions.
- Defining components for an integrated, system-wide support offer that is needs led and easily accessed and understood, to empower early support-seeking behaviours. It is critical that opportunities be comprehensively identified to maximise the holistic offer of support, that these consider evolving needs, including at different life stages, and that these consider the full range of available interventions across pharmacological and non-pharmacological pathways, across sectors and including tools to empower self-management where appropriate.
- Exploring quality improvement in ADHD services and supports, including approaches to measuring and monitoring performance and outcomes.
- Considering opportunities to establish a more neuro-inclusive society that maximises the opportunities for individuals with ADHD and their families to live well.

The Taskforce is also expected to consider broader learnings from work already undertaken on the provision of services for both ADHD and other neurodevelopmental conditions, both in the UK and internationally. The appointment of a joint member across the Taskforce and the

Department of Education's Neurodivergence Task and Finish Group will support alignment across multidisciplinary portfolios.

The scale of potential change to be considered by the Taskforce is significant. The Taskforce may choose to consider interim solutions that can be implemented quickly alongside a longer term plan to deliver wider transformation.

4. Working groups

Members will be supported by additional working groups that convene (a) experts by experience, and (b) experts in evidence to build consensus around the evidence base; these groups will be chaired by Taskforce members. This document applies to members of those working groups.

5. Ways of working

4.1 Stakeholder engagement

The Taskforce includes those with ADHD, their families and carers, and third sector organisations to understand the impact of ADHD, and their experience of using or providing ADHD pathways and services so that Taskforce recommendations are co-produced with lived experience.

The Taskforce will consider relevant evidence to inform its recommendations. It will draw on academic publications, grey literature, professional expertise, examples of good practice, and lived experience, working with its experts by experience and experts by evidence working groups to commission, collate and consider findings and co-develop recommendations. Ongoing insight from stakeholders will be sought through the working groups, as well as through surveys and listening exercises supported by the working groups and NHS England.

The Taskforce will work with NHS England teams to align work with the ADHD Programme and other internal directorates and programmes where relevant and appropriate. Similar work with external partner organisations will ensure cross-sectoral alignment to system-wide aims. Cross-governmental alignment will be supported through a joint appointment to the

Taskforce and the Department for Education's Neurodivergence Task and Finish group, and through a cross-governmental working group convened by NHS England.

6. Membership

5.1 Membership

The Taskforce will be chaired by Professor Anita Thapar, Clinical Professor, Cardiff University.

The Experts by Experience Working Group will be chaired by Char Bailey.

The Experts in Evidence Working Group will be chaired by Tamsin Ford.

Taskforce and working group members are appointed by NHS England at the discretion of the Taskforce Chair.

All members will have equal and fair opportunity to input into the Taskforce's discussions.

Breaches of the ToR may result in removal from the Taskforce and/or its Working Groups.

5.2 Secretariat

The NHS England ADHD Programme will provide secretariate support. The secretariat can be contacted via email at england.adhdtaskforce@nhs.net.

7. Timing

The Taskforce is expected to run from November 2024 for a minimum of six months. The Taskforce will meet monthly for 1.5 hours. Working group schedules to be determined based on need but will likely be once a month to feed into Taskforce meetings.

The Taskforce will report findings and recommendations in summer 2025, or a timescale otherwise agreed with the NHS England Board.

8. Confidentiality

All materials and information shared with the ADHD Taskforce and its Working Groups are confidential, unless otherwise stated. Members can discuss broad, non-attributable meeting outcomes once minutes have been shared.

Members will not disclose information or written material (including agendas, minutes, discussion papers or other documents) to other parties, unless directed by the Chair of the Taskforce.

9. Declaration of interest

A conflict of interest is a set of circumstances by which a reasonable person would consider that an individual's ability to apply judgement or act, in the context of delivering, commissioning, or assuring taxpayer funded health and care services is, or could be, impaired or influenced by another interest they hold.

Taskforce and Workgroup members must ensure that they are not placed in a position that risks, or appears to risk, compromising their role or the NHS or equivalent organisation public and statutory duties or reputation. Members must also not accept gifts or hospitality by virtue of their role on the Taskforce

Taskforce and Working Group members are required to declare conflicts of interest and the receipt of gifts, hospitality, and/or sponsorship, in line with the national guidance to the NHS or equivalent bodies. Conflicts of interest should be declared in writing to the Taskforce secretariat and specific conflicts should be raised at the start of any agenda item or discussion for which that conflict arises. A conflict of interest and a hospitality register will be maintained by the secretariat.

10. Media and communications

Whilst 'independent', the Taskforce and its work has been commissioned by and for NHS England. Social media posts and other forms of media engagement undertaken by Taskforce and Working Group members, both in the context of their role on the Taskforce, and personally, may impact upon NHS England both materially and reputationally.

- a) You may of course comment on such matters as you wish as individuals but should avoid giving the impression that your personal view represents the view of NHS England, or the Taskforce where they differ.
- b) You must make it clear that you are speaking for yourself and not on behalf of NHS England.

- c) You must not use the organisation's logo/identifier on personal web pages or social media accounts. The NHS logo is a protected brand and cannot be used without permission.
- d) You should obtain the consent of other members of the Taskforce, including members of Taskforce Working Groups, and employees of NHS England, before referring to them in social media posts.
- e) Post relating to the Taskforce should not be linked to the work of the organisation you represent – it should not appear that the Taskforce is endorsing any organisations or commercial interests.
- f) Please flag any requests for media made by journalists with both the Chair of the Taskforce and the Taskforce Secretariat so they can inform the NHS England media and communications team can assist with preparation for media appearances.
- g) If you have any concerns or questions about social media interactions, please do contact the Taskforce Secretariat. NHS England's communications team can provide advice and guidance.

11. Location of meetings

Meetings will last 90 minutes and be held virtually via Microsoft Teams.

12. Quorum

Meetings will require a minimum the Chair and a minimum of (50%+1) members to be present. If quorum is not met, the meeting will be rescheduled.

13. Governance and Administration

An updated action log will be circulated to all colleagues via meeting invitations by the secretariat. This will be circulated within three working days of the meeting being held.