

OXFORDSHIRE JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE

NHS Adults Autism and Attention Deficit Hyperactivity Disorder (ADHD) services

Summary report from BOB ICB

1. Purpose of Paper

- 1.1. This paper provides an update to the Health Overview and Scrutiny Committee on Adults with Autism and Attention Deficit Hyperactivity Disorder (ADHD) who use autism and ADHD services in Oxfordshire.

2. Executive Summary

- 2.1. Adult Autism and ADHD services in Oxfordshire are experiencing rising demand, long waiting times, and the local NHS service is paused to new referrals due to capacity limits.
- 2.2. Prevalence and Diagnosis: Around 11,778 adults have autism and 27,714 have ADHD in Oxfordshire, but actual diagnoses, especially for ADHD (10,528 adults), are lower reflecting underdiagnosis, particularly among females and older adults.
- 2.3. Service Pressure: Waiting lists are long, with autism assessments capped at 110 per year and over 2,200 people waiting for ADHD assessments. Many GPs (about 50%) are reluctant to prescribe ADHD medication, impacting ongoing care.
- 2.4. Alternative Access: The Right to Choose scheme allows patients to seek assessments from alternative providers when local services are paused, with waits ranging from a few weeks up to 18 months. This does not reflect a financially sustainable model for the ICB
- 2.5. Service Improvements: A five-year autism strategy is in development, and the Adult ADHD Transformation Programme is underway to streamline care pathways, improve medication management, and better engage GPs.
- 2.6. Future Plans: The ICB aims to introduce digital tools, involve community support, and collaborate with service users and partners for more accessible, sustainable services.
- 2.7. This update aims to inform HOSC about the current state of adult autism and ADHD services in Oxfordshire and outline plans to address ongoing challenges.

3. National Policy

- 3.1. There is a National ADHD taskforce, and the interim report findings are set out below we are expecting the final report to be published in September.
 - Better outcomes for everyone: Getting ADHD right isn't just about individuals – it's about reducing school exclusions, easing pressure on mental health services, and helping more people to thrive at home, in work and in society.

- Faster answers for those that need it most: The report calls for a major overhaul of ADHD services, so those that need it most aren't waiting for years for support and diagnosis.
- Support without a diagnosis: The report seeks to reimagine a world that offers practical help (like coaching, classroom tools and parenting advice) to those showing signs of ADHD – even if they're still waiting for diagnosis or don't meet the clinical threshold.
- One joined – up system: The report calls for an end to the confusing patchwork of care, replacing it with clear pathways that work across services and conditions – so no one falls through the cracks.
- Less stress, better lives: The report calls for people to receive quicker support and face fewer barriers, and for families to have to spend less time fighting the system and more time focusing on their child's wellbeing, education, and future.

4. Overview of Population and Prevalence of Autism and ADHD in Oxfordshire

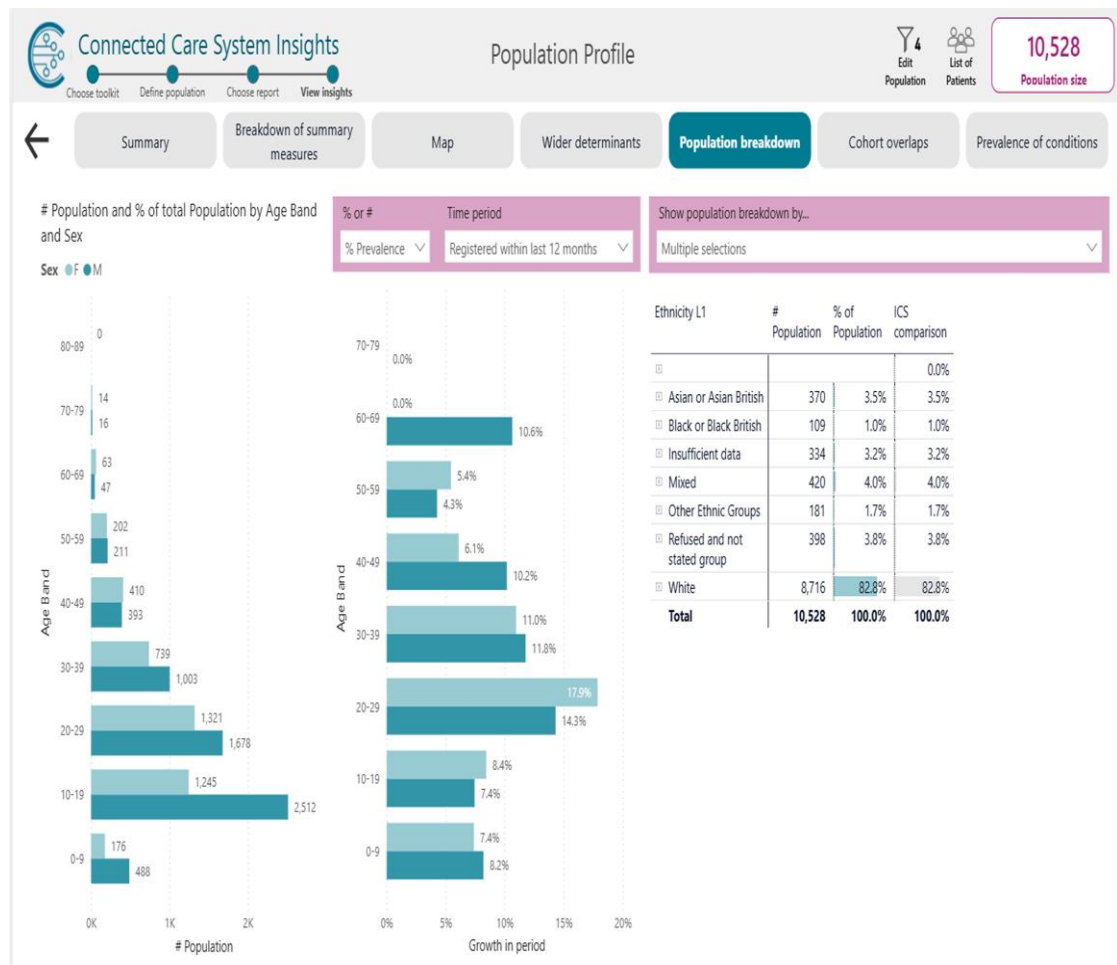
4.1. Population data

- 4.1.1. NHS data ([Patients Registered at a GP Practice, April 2024 - NHS England Digital](#)) shows the population of Oxfordshire in April 2024 was 818,430 based on people registered with a GP. Adults (15+) make up 692,855 of that population.
- 4.1.2. The autism prevalence in the UK is now estimated to be almost double previous estimates at 1.7%, potentially 1.2 million people in the UK. It is noted that 2.94% of 10-14 yrs were diagnosed autistic, it is recognised that adults aged 20 years and over are less likely to be diagnosed and only 10% of autistic adults aged over 50 are diagnosed. ([Getting Real About Autism's Exponential Explosion — NCSA](#)). Based on the data in Paragraph 8 from NHS England Digital, the adult autistic population of Oxfordshire makes up approximately 11,778 calculated using the prevalence figure of 1.7%.
- 4.1.3. The National Institute for Health and Care Excellence (NICE) reports that the prevalence of ADHD in adults is 5% and, which would suggest the population of adults with ADHD living in Oxfordshire is approximately 27,714. This is inclusive of those who are undiagnosed.
- 4.1.4. Statistics from the Electronic Medical Information System (EMIS) (a system used primarily by GP practices) show the number of adults diagnosed with ADHD in Oxfordshire are 10,528, which is much lower than the anticipated population according to prevalence. The average age to receive a diagnosis in Oxfordshire is 24. years old. Diagnosis is most commonly recognised males are in education as they typically present with hyperactivity, whilst for females there is under recognition of ADHD presentation. A study by the United Kingdom ADHD Partnership found that females with ADHD often present with differences in their profile of symptoms, comorbidity, and associated functioning compared with males. Girls may struggle with time management,

daydreaming, or being hyperverbal, and are more likely to be diagnosed with the primarily inattentive type of ADHD over the hyperactive type. This can lead to delays in diagnosis, often until adulthood ([Why Are So Many More Women Being Diagnosed With ADHD? / Females with ADHD: An expert consensus statement taking a lifespan approach providing guidance for the identification and treatment of attention-deficit/ hyperactivity disorder in girls and women | BMC Psychiatry | Full Text](#))

4.1.5. Below is a snapshot of population data (Figure 1). This shows that the highest rates of diagnosed people are males aged 10-19 years old, which is not surprising, given that males are most commonly diagnosed during their time in education. The data shows almost double the number of males to females have a diagnosis during this age range. We can also see that there has been a 17.9% growth of females aged 20-29 years old obtaining a diagnosis which reinforces the study mentioned earlier that females are often diagnosed in adulthood. There are also figures to demonstrate the ethnic percentages of adults diagnosed with ADHD in Oxfordshire and given the diverse population of Oxfordshire, this will need to be considered when commissioning future services to ensure ethnic minority groups are included in co-producing services to ensure they are designed to be easily accessible for all.

Figure 1 – Population Profile for ADHD



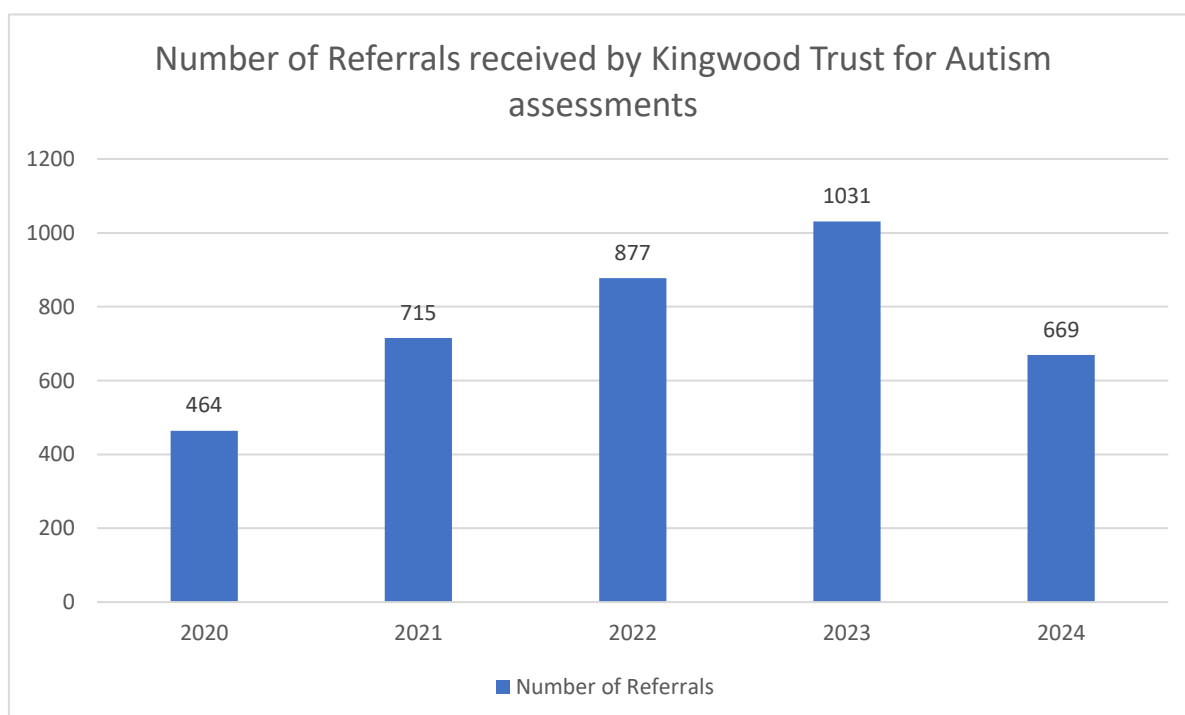
5. Present service provision summary

5.1 Adult ADHD and Autism services have seen significant growth in demand both at a local, region and national level. The waiting list and waiting times in Oxfordshire are not a particular outlier and demonstrate the need for a fundamental review of service provision and pathways to create a sustainable service offer. The ICB is committed to develop these with the Adult ADHD programme already in place and clear commitment to review Autism services driven by the development of a 5 year all age autism strategy. The right to choice model offers an alternative solution where local NHS services are paused and/ or have excessive waiting times but do not reflect a financially sustainable model for the Integrated Care Board.

6. Oxfordshire Autism Diagnostic Services for Adults

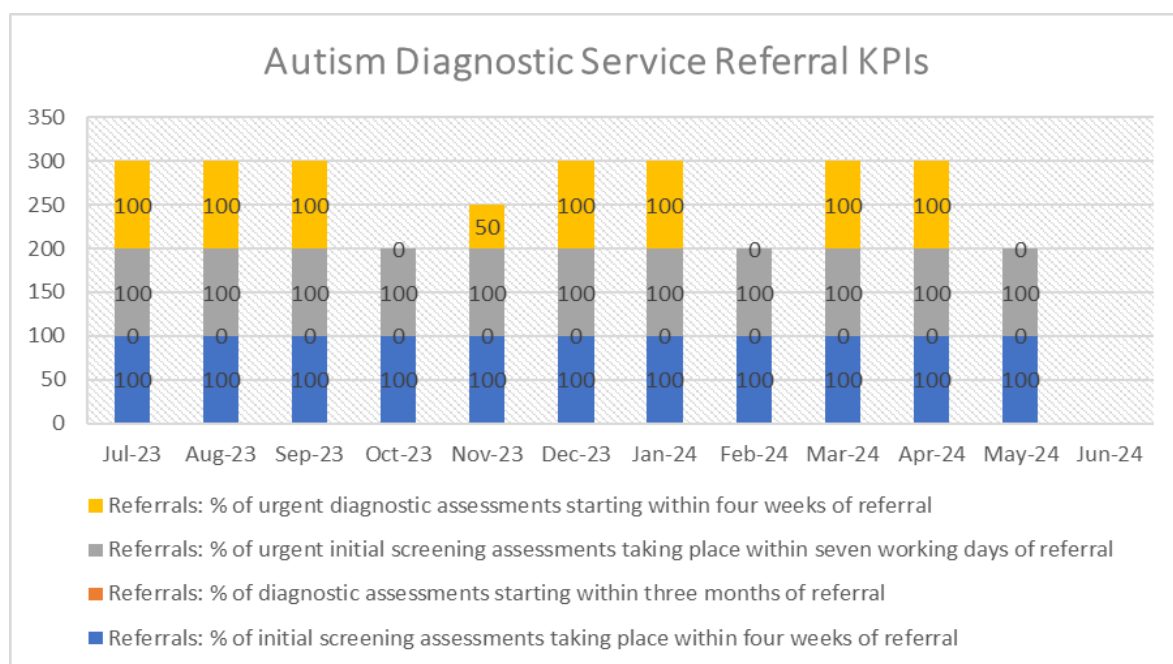
6.1. Kingwood Trust has held a contract with the Integrated Care Board (ICB) for the Adult Autism Diagnostic service and post diagnostic support for 8 years. Awareness of autism has increased nationally, and Kingwood Trust reported that their waiting times had increased year on year with no increase in funding. It was agreed to close the waiting list to new referrals in November 2024 when the waiting time reached 10 years. This decision was made for patient safety and clinical oversight. The demand had exceeded the commissioned capacity of 150 assessments per annum. It was agreed that the contract value would remain at the same and the number of assessments would reduce to 110 per annum and the service was closed to new referrals whilst the backlog of assessments is cleared, however they do continue to deliver services to those that are post diagnosis on what help is available. Table 1 below shows the referrals received by the commissioned Autism assessment service Kingwood Trust. The ICB are committed to continuing dialogue with Kingwood Trust to look at innovation and the contract values to find better solutions than relying on RtC provider. This work will be supported and developed by the action plan for the All-Age Autism Strategy. This action plan will work alongside system partners and community organizations to develop community support provision in Oxfordshire.

Table 1 – Referrals Received by Kingwood Trust 2020 to 2024



6.2. Table 2 below shows the referral Key Performance Indicators (KPIs) for 2023-24 for the Kingwood Trust Adult Autism Diagnostic Contract. The service has consistently delivered above the 95% target for the initial screening assessments; however, they have not reached the 95% target for starting the diagnostic assessment within 3 months, this is due to the high numbers of individuals on the waitlist.

Table 2 – Key Performance Indicators 2023-24 (Adult Autism Diagnostic Contract)



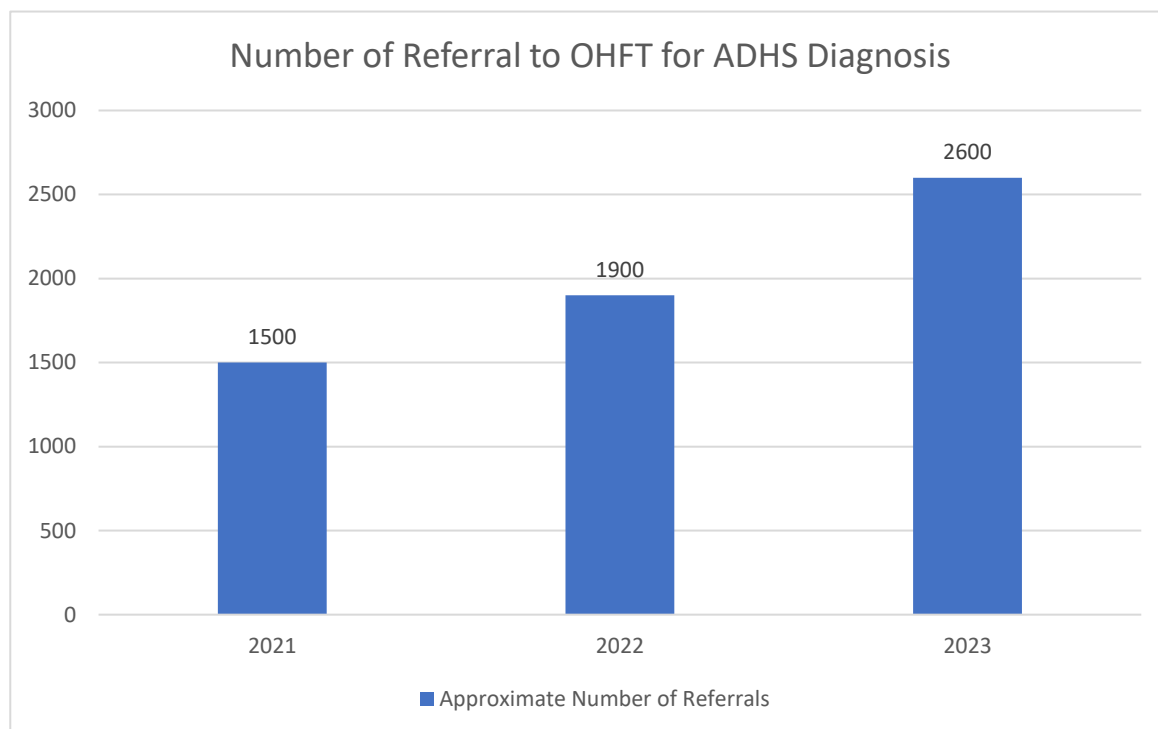
The ICB is establishing a BOB-wide transformation programme for Autism Diagnostic Services for Adults in November 2025. This will address the waiting lists and capacity, and demand issues highlighted above and will continue to assess potential further investment in the service given growth in activity through right to choose providers.

7. Oxfordshire ADHD Diagnostic Services for Adults

7.1. Oxford Health NHS Foundation Trust (OHFT) has held the contract for the Adult ADHD diagnostic service since 2021. With requests for ADHD diagnosis increasing nationally, service waiting times increased to ten years. The service was paused to new patients in February 2024 because patient safety could not be effectively managed. The demand exceeded the commissioned capacity of 200 assessments per annum and the service continues to see patients on the waiting list. Table 3 shows the number of referrals received by Oxford Health NHS Foundation Trust (OHFT) up until February 2024. The 2023 data in the table represents the period

April 2023 to Feb 2024. There is no further data beyond this as referrals are still paused.

Table 3 – Number of Referral received by OHFT up to February 2024



- 7.2. OHFT is assessing people on the waiting list and the current waiting list has 2,229 people on it. OHFT has completed 126 assessments this year and are offering additional support to those that are transitioning into adulthood.
- 7.3. One issue affecting patients is that the Shared Care Protocol for Oxfordshire for Adult ADHD requires secondary care to fully transfer patient responsibility to the general practitioner (GP), however 50% of GPs in Oxfordshire are refusing to issue ADHD drugs because of this. There is a full explanation of what Shared Care is at Paragraphs 7.1 to 7.4.

8. Right to Choose (RtC) Providers

- 8.1. The NHS Right to Choose programme is a legal entitlement in England that allows patients to have more control over where and how they receive care. Patients referred for elective care by a GP, dentist, or optometrist have the legal right to choose the hospital, service provider, and clinical team overseeing their care. This includes private or independent providers with NHS commissioning contracts.
- 8.2. These services offer a pathway to access Adult ADHD and Autism services for the population where local services are paused or experiencing excessive demands.
- 8.2.1. Waiting times for adult autism assessment for (RtC) providers vary from a few weeks to over 12 to 18 months but are shorter than local services.

8.2.2. Waiting times for adult ADHD assessment for (RtC) providers vary from six month to 18 months for diagnosis and further waits for titration support and annual reviews

8.3. The ICB has developed a commissioning framework for Adult ADHD contract for RtC providers. The framework will consist of a list of accredited providers which will support more consistency and quality assurance to ensure patients are able to access high quality services.

8.4. RtC expenditure across the BOB ICB geography on all age autism and ADHD service has grown from approx. £1.7m in 2023/24 to £5m in 2024/25 with a potential forecast spend of £11m in 2025/26. Therefore, whilst the model gives access to these services it is not a financially sustainable service model.

9. Reasonable Adjustment Service (RAS)

9.1. This service provides a case consultation resource and clinical interventions in support of the overall care plan to autistic adults accessing mental services in Oxfordshire. The service contract for RAS has been awarded to and delivered by OHFT, which supports both community and inpatient pathways. The team play an important role in delivering autism clinical training to OHFT staff, improving knowledge, understanding and confidence in supporting autistic adults.

9.2. Following the closure of new referrals to Autism at Kingwood – Oxford Adult Autism and Support Service (OAADSS), the RAS created a document of advice to send to those who were seeking a diagnosis, which contained a list of some of the Right to Choose (RtC) providers for both Autism and ADHD, that have been used by the NHS previously.

9.3. The RAS currently has vacancies within the team and the HESC Commissioning Team is supporting OHFT to ensure the service continues to be delivered whilst the recruitment is in progress.

9.4. The RAS service specification has been reviewed and updated under the new overarching 10-year (7-year plus 3-year) contract with Oxford Health. As part of the RAS specification, OHFT will on an annual basis, identify a service improvement initiative and where appropriate do this in a co-produced way with Experts by Experience.

9.5. To bring the experience to life, below is a compilation of positive feedback received from people who have used the RAS and a professional that has attended their training session:

“The email you sent beforehand with all the info, and I particularly liked the photo of you so I could recognise you and your name as it was hard to hear on the phone. During the appointment I felt listened to and put at ease (I think I was a bit anxious as I knew it was a one-off appointment, and I wanted to make sure I made the most of it) and I appreciated the effort you went to, to make the environment as calm as possible. The 2 documents were quite useful especially the end of the neuro-inclusion passport about when I get overwhelmed and

coming up with ideas of how to respond. The documents you have sent over, look good, I haven't had time to click on all the links yet though."

"Small adaptations can make a big difference!"

"The training was exceptional, my colleague and I have been working in the trust for over 20 years, and this was the best and most engaging training we have ever attended, and we think everyone should do it."

10. The role of Shared Care in ADHD pathways

- 10.1. Shared care protocols (SCP) are mechanisms for GPs to prescribe medications which are initiated within Secondary care, for an area which is thought to be outside a GPs normal knowledge (such as ADHD medication), whereby the GP can prescribe the medication but the decisions about continuing or altering the medication for the condition remains under secondary care consultant. The GP, as they are prescribing, have some responsibility to make sure some elements of physical monitoring is carried out (often but not always including blood test, weight, BP, pulse) and general consideration of side-effects drug interactions etc. An important part of the 'contract' is that secondary care has some overall and ongoing responsibility for the patient, and that they only apply when stable doses are achieved. So, for example, if medication needs to be changed in its entirety or dosage, the consultant will take over responsibility in totality until a stable dose of drug is achieved i.e. the patient is stable on that dose and drug. GPs would not change doses or medication without the say so of the consultant. Therefore, the patient needs to remain open to the consultant. The consultant usually would need to review the patient at least once a year by some mechanism.
- 10.2. The SCP is a tripartite contract among the patient (who could refuse to be part of a SCP and hence the consultant would need to continue to prescribe and monitor the patient long term), the GP (who could refuse to be part of the process if they have reasonable reason), and the consultant (who may want to retain full control in a complicated case). Any one of these members could refuse a SCP and ALL must agree to it for it to be enacted. Patients must also agree to attending for reviews and having necessary tests done.
- 10.3. This has been further exacerbated by the requirement within NICE guidance that the person with ADHD and on medication should have an annual review from a person with expertise in ADHD, which is not regarded as a core skill of GPs. Providing these annual reviews within secondary services has diverted commissioned funds from diagnosis and titration to maintenance dose, to carrying out the annual reviews which are required for Shared Care protocols (SCP) to be possible with General Practice. If the annual reviews are not done, then GPs have argued that terms of the SCPs have been broken and therefore if any changes occur to the patients, they are not covered by the medicolegal protection which the SCP provides.
- 10.4. Currently, GPs are paid for adopting SCPs on prescription for ADHD medication following the general LCS provisions for Near Patient Medicines Management (NPMM) at Level1 [BOB 2023-27 LCS NPMM Revised v.1](#)

- Band 1 – is essentially safely prescribing medication only £24.76 per patient per year
- Band 2 – Prescribing plus one listed additional activity £104 per patient per year.
- Band 3 – prescribing plus multiple additional activities £135 per patient per year.

10.5. The commissioning team via the ICB Patient and Liaison Service (PALS) has received a range of complaints from patients, the public, GPs, Councillors and Members of Parliament around the shared care protocol.

10.6. The ICB is reviewing the present model and may consider increases the annual payment to Band 3, however, further work will need to be undertaken to address the Shared Care protocol issue that is specific to Oxfordshire. This is being addressed through the BOB ICB Adult ADHD Transformation Programme which is described in Paragraphs 10.2 to 10.4.

11. Oxfordshire Autism Strategy

11.1. The HESC Joint Commissioning Team is currently co-producing the Oxfordshire All-Age Autism Strategy with experts by experience, local organisations, strategic partners and professionals. The strategy is a 5-year plan running from 2025 to 2030 for the whole Autism system in Oxfordshire. The vision of that strategy includes:

- Inclusive education and employment – Ensuring that autistic individuals have access to appropriate and supportive access to educational opportunities and support to succeed in the workplace.
- Comprehensive health and social care – When required, provide health and social care services that address and support the unique needs of autistic individuals throughout their lives.
- Community awareness – Promoting understanding of Autism within the community to reduce stigma and create a more inclusive society
- Person centred support – Most autistic people will never need services, however when there is a need for support, then individualised support plans will be used to focus on the strengths and needs of each individual, enabling them to live fulfilling lives.
- Family and caregiver support – Provide resources and support for families and caregivers to help them navigate the challenges and celebrate the successes of living with autistic individuals.
- Accessible services – Moving towards ensuring that services are easily accessible and that there are no barriers to receiving the necessary support in a timely manner.
- Lifelong learning and development – Encouraging continuous learning and personal development opportunities for autistic individuals at every stage of life.

11.2. There will be a delivery plan to follow the strategy, which will see local partners work together with experts by experience to improve the quality of autistic people's lives. Focusing on needs led and based services, making support accessible to those who need it.

12. BOB ICB Adult ADHD Transformation Programme

12.1. The ICB is leading on an Adult ADHD Transformation Programme, and the members of the programme group consist of Providers, Experts by Experience (EbE) and Commissioners. There are seven workstreams, each led by a designated workstream lead. The workstream leads, timeline, and impact of their work are outlined in Table 4 below. The Shared Care Protocol issue is being addressed through this programme of work. The findings from the national taskforce have been incorporated into this programme.

Table 4: Adult ADHD Transformation Programme Workstreams

Workstream	Deliverables	Impact	Status	Date of Completion
Patient Pathway	Produce a document highlighting gaps and challenges in current structures. This needs to include workforce, skillset, investment for inclusion in the business case	Demonstrates current demand and capacity and other key issues and risks for the business case	Completed	
Shared Care	<p>Discussion and agreement with the Local Medical Committee (LMC) around the feasibility of GPs conducting annual health checks and the associated remuneration.</p> <p>A document setting out actions needed to fully implement electronic prescribing and set up teaching sessions for GPs to support Shared Care.</p> <p>Shared Care protocol completed for adult ADHD to be used by RtC providers</p>	<p>GP sign up to the new Shared Care Protocol, which means that patients are offered annual reviews for their ADHD, including medication and ongoing prescribing. This results in the improvement of quality and patients' experience.</p> <p>Frees up capacity in all providers</p>	In progress	October 2025
Primary Care Liaison	<p>workforce and their skillset required in primary care.</p> <p>A document with options appraisal for the model for a single point of access (SPA) for primary care to streamline referrals.</p>	Upskill and give confidence to GPs to offer SCP for ADHD	Completed	
Commissioning Framework	Adult ADHD contract for RtC providers	High quality and affordable services available for patients	In progress	6 weeks process

Workstream	Deliverables	Impact	Status	Date of Completion
	<p>Accredited providers, ensuring consistency and quality across the region.</p> <p>Indicative system-wide activity plans (IAP)</p>	<p>Ensuring that using the IAP will enable the ICB to live within its means</p> <p>Eliminating the waiting list time</p>		culminating in October 2025
Comms and Engagement	Comprehensive and effective Communication and Engagement plan	Managing effective communication with stakeholders and moving from defensive to proactive messaging	In progress	September 2025
Access Criteria	New access criteria across all three places in BOB ICB.	<p>Managing demands and ensuring that complex patients are high priority for our local services.</p> <p>Ability to segment to mild, medium and complex categories</p>	In progress	September 2025

12.2. A Lived Experience Workshop was held in July 2025 to inform pathway redesign.

Key themes identified were:

- Challenges in current pathways and processes.
- Strong demand for pre- and post-diagnosis support.
- Opportunities to scale support using digital tools and VCSE partnerships.

12.3. This was followed by a BOB ICS workshop which brought together Providers, EbEs and Commissioners. A new service model has been established, and a business case is in development and is expected to be finalised in October 2025. The new service model will be dependent on new access criteria which will reduce the over-diagnosis of ADHD, reduce the demand for medication by offering a community support service (learning to live with your ADHD approach) and reduce the need to refer to Right to Choose providers. The new model is likely to be driven using digital and AI systems in line with the NHS 10 Year Plan.

13. Conclusion

13.1. In response to the issues and challenges, the ICB is actively developing and implementing the Adult ADHD Transformation Programme to streamline care, improve medication management, and enhance GP engagement. Future plans include leveraging digital tools, strengthening community support, and co-producing solutions with service users and partners to build a more accessible, equitable, and sustainable service model.

13.2. A county-wide Autism Strategy is in development with the objective of local partners working together with experts by experience to improve the quality of autistic people's lives.

13.3. The initiatives described represent a comprehensive programme to enhance care, support, and equitable access across health and community sectors. The adoption of artificial intelligence and digital platforms is poised to improve diagnostic processes and tailor support to individual needs, benefiting both service users and professionals.

13.4. The focus on reasonable adjustments, targeted diagnostic pathways reflect a commitment to inclusive, patient-centred care and to reducing barriers to effective treatment. Collaboration among healthcare providers, educators, technology developers, and individuals with lived experience remains central to the successful implementation of these approaches.

13.5. Continued evaluation and development will be essential to sustain impact and ensure that services remain responsive to the evolving needs of the population. This report highlights the ongoing importance of investment, partnership, and innovation in enabling improved outcomes, greater autonomy, and fuller participation within the community.

