

Dear

FREEDOM OF INFORMATION – NEURODEVELOPMENTAL ASSESSMENTS

I write in response to your request for information in relation to neurodevelopmental assessments for the most recent 24 months.

Question:

1. Waiting Times
 - o Total number of adult referrals for combined ADHD/ASD assessment.

Answer:

East Lothian	570
Edinburgh	1,719
Midlothian	722
West Lothian	909

Table 1: Referrals for ND Assessment from 1st April 2025 to 31st March 2026

Question:

2. Median, average, and longest waiting times from referral to assessment, broken down by HSCP area:
 - Edinburgh City
 - East Lothian
 - Midlothian
 - West Lothian

Answer:

HSCP	Mean (weeks)	Median (weeks)
Edinburgh	164.2	198
Midlothian	47.9	48
East Lothian	132.7	167
West Lothian	177.2	190

Table 2: Wait time from referral to 1st assessment for patients seen between 1st April 2025 & 31st March 2026

Headquarters
Mainpoint
102 West Port
Edinburgh EH3 9DN

Chair Professor John Connaghan CBE
Chief Executive Professor Caroline Hiscox
Lothian NHS Board is the common name of Lothian Health Board

Question:

3. Urgent / Fast-Track Pathways

- o Number of adults assessed via urgent or fast-track pathways, if any.
- o Criteria used for prioritisation.

Answer:

There were five or fewer patients who were seen between 1st April 2025 and 31st March 2026 were prioritised as an urgent referral.

We do not have any documented pathway or fast track criteria.

Question:

4. Community Team Involvement

- a. Number of adults under Community Mental Health Teams (CMHTs) or Community Parental Mental Health Teams while awaiting assessment.
- b. Average length of involvement while waiting.

Answer:

a.	As of 31/03/2026, there were 74 patients being seen who are also on an ND waiting list.
b.	The average (median) length of involvement (at 31/03/2026) was 25 weeks

Question:

4. Shared Care Prescribing Arrangements

- o Number of adults under shared care agreements for ADHD medication initiated or continued in the past 24 months.
- o Any delays in medication initiation attributable to waiting for the combined assessment.

Answer:

This is not recorded centrally as would be a decision made by the individual GP Practices, as independent contractors they are responsible for dealing with there own FOI(S)A requests for information.

Question:

5. Cross-Board Referrals

- a. Number of adult referrals received from or sent to other NHS boards (East, West, Borders, Fife, etc.).
- b. Waiting times for these out-of-board referrals.

Answer:

a.	We have received five or fewer referrals from Aberdeen, Borders and Lanarkshire, but we have not accepted them as the person is a resident in those areas
b.	We are unable to answer this question

Question:

6. Supporting Documentation

- Copies of any internal reports, guidance, or policy documents summarising adult combined ADHD/ASD assessment pathways, waiting lists, or triage procedures in NHS Lothian.

Answer:

We have two pathways for ND however it is only noted in the comments if the person is receiving both on the ADHD wait or ASC wait so the assessment happens at the same time

To protect the identity of the individuals involved any figure of 5 or less has not been shown in this response. Since we do not have their consent to release this data from their records, the information is exempt under section 38(1)(b) of the Freedom of Information (Scotland) Act i.e. to provide it would breach the Data Protection Act (2018).

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhslotian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive
Enc.

ADHD and shared care with private providers

NHS Lothian has shared care agreements for some of the drugs used to treat ADHD in children and young people over 6 and adults. These agreements are between NHS Lothian specialist services and GP practices in Lothian. **These agreements are designed to support GPs and specialist teams in providing safe and accessible care for patients.** The agreements details what part of the care should be provided by specialist/hospital consultant teams and which parts are the responsibility of the General Practitioner and their team and are agreed by representatives of the specialist service, GPs, and pharmacists.

There are no similar agreements between GP practices and private providers. As independent contractors GP practices can choose to share care with private providers but there is no requirement to do so.

If a practice chooses to share care with a private provider, they will normally require the private provider to provide the same level of specialist input as the NHS specialist services; in other words, to follow the NHS Lothian shared care agreement. This is sensible as the shared care agreement is there to support safe and effective care.

Details of the NHS Lothian shared care agreements for AD(H)D medicines:

For patients under 6 years of age

- All of the care would be provided by specialist services including prescribing and they are not part of the shared care arrangements.

For patients over 6 but under 18

- The specialist team (usually CAMHS) is required to undertake, assessment, diagnosis, titration of medicine dosage **and all monitoring including – height, weight, pulse, BP at baseline, 3 monthly, then 6 monthly in the longer term.**
- **Only prescribing is done by GPs** and then only if the CAMHS have confirmed that the ongoing monitoring is in place and supports continued prescribing of the medication.
- When the young person reaches 18 and is transferred to adult services the specialist team are required to facilitate this transfer.

For adult patients

- The specialist team (usually adult mental health teams) is required to undertake, assessment, diagnosis, titration of medicine dosage including - height, weight, and family history of cardiovascular disease at baseline and refer patient for ECG if required, monitor BP and pulse during dose titration.

- The specialist team are also responsible for a re-evaluation of continued need for medication beyond one year.
- The GP is responsible for 6 monthly monitoring of weight, pulse, and blood pressure every 6 months once the patient is stable and for prescribing. The GP would require the 12 months re -evaluation by a specialist to take place to continue the monitoring and prescribing in primary care.

Common issues that arise between GPs and private providers and difficulties for patients:

- Not all private providers are able to offer the monitoring required.
- Not all private providers offer the 12 months re -evaluation.
- It is often extremely expensive for patients and parents who need to pay for the private part of the care.
- There has been doubt cast on the validity of diagnoses made in the private sector. Many private providers are providing a high-quality service, but it is difficult for GP teams to identify concerns of this nature when they have such limited contact with the providers. This has led many GPs and GP practices to decline to enter into shared care arrangements with private providers.
- Recent publicity and some negative local experiences have increased this concern. The BMA, that represents doctors, has advised doctors not to enter into these arrangements and it is likely that the number of practices willing to do so will fall even further if the current difficult situation remains unchanged.
- Often private providers work across a number of regions of Scotland or indeed the UK where subtly different shared care agreements will be in place. This can cause confusion for patients, parents and the clinicians involved.

Waiting times in NHS Lothian for specialist assessment and care in this area are long and this is a pattern seen across the UK. Representatives of both specialist services and General Practitioners have argued that much greater resource is needed, in both sectors, for significant improvements in this situation to be made.

NHS Lothian, and the GP practices we work with, recognise the extreme challenges faced by patients and their families who are concerned about the possibility of an ADHD diagnosis. GP practices work very hard with colleagues in other specialist services using shared care agreements that have been carefully designed to provide high quality care, but do not have the capacity to enter into multiple bespoke arrangements with other providers. NHS Lothian is working hard to continue to improve the quality and accessibility of ADHD care but like other regions of Scotland and the UK is struggling with an unprecedented increase in need in this area.

Dr Jeremy Chowings
Deputy Medical Director Primary Care NHS Lothian
December 2025