Lothian NHS Board

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Date 3 November 2026
Your Ref
Our Ref 11998

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Dear

FREEDOM OF INFORMATION – NEURODEVELOPMENTAL WAITS

I write in response to your request for information in relation to neurodevelopmental waits.

ADHD and ASD waiting lists cannot be reported separately for NHS Lothian. All responses below contain data relating to ADHD and ASD combined. Numbers represent wait list entries, not individual persons. Data was extracted from TrakCare on **7 Oct 2026**. NHS Lothian numbers are not simply a sum of the 4 HSCPs. There is a small team that operates across NHS Lothian which is included in the Lothian wide numbers. Response is after clarification received. The figures provided are based only on true lists, which comprise new assessment appointments only.

Question:
Part A – Current waiting list
1. The number of adults currently waiting for an ADHD assessment, as at the most recent date available (please state the date).

Answer:

	NHS Lothian	Edinburgh	East Lothian	Midlothian	West Lothian
Current number of waits for ND assessment	13,281	6,904	1,877	876	3,620

Question:
2. That number broken down by length of wait from referral: under 12 weeks; 12–52 weeks; 1–2 years; over 2 years.

Answer:

	NHS Lothian	Edinburgh	East Lothian	Midlothian	West Lothian
Under 12 weeks	700	320	130	164	85
12-52 weeks	2,363	1,049	377	371	566
1-2 years	2,947	1,444	396	242	864
Over 2 years	7,271	4,091	974	99	2,105

Question:
3. The median and longest current wait, in weeks.

Answer:
It is not possible to provide detail in relation to single longest waits as this carries a high risk of re-identification. Since we do not have their consent to release their personal data, the information is exempt under section 38 of the Freedom of Information (Scotland) Act 2002 as to provide it would breach the principles of the Data Protection Act 2018.

	NHS Lothian	Edinburgh	East Lothian	Midlothian	West Lothian
Median wait time of current waits	115 weeks	126 weeks	108 weeks	40 weeks	120 weeks
Median wait time of completed waits in the last 12 months	156.5 weeks	227.5 weeks	202 weeks	53 weeks	226 weeks

Question:
Part B – Activity
4. The number of adult ADHD assessments completed in each calendar year 2023, 2024 and 2025.

Answer:

Number of completed ND Assessment waits	NHS Lothian	Edinburgh	East Lothian	Midlothian	West Lothian
2023	406	139	71	191	5<
2024	720	189	115	270	137
2025	713	224	177	225	80

Question:
5. Of those, the number that resulted in an ADHD diagnosis.

Answer:
Diagnostic data is not coded and therefore cannot be extracted without reviewing individual patient records.

Question:
Part C – Referrals and acceptance criteria
6. The number of adult ADHD referrals received, accepted onto the waiting list, and rejected or redirected, in each calendar year 2023, 2024 and 2025.

Answer:
The number of referrals received underestimates the total number of referrals for neurodevelopmental services, as rejected referrals are often never linked to an ND specific

service, meaning they are not captured in the available data. Adult ND referrals are received at a generic triage point which means ND referrals cannot be distinguished from other referrals at this stage. Only when accepted they are then linked to an ND specific service.

As rejected referrals cannot be provided the number of referrals removed (who were not seen for assessment) have been provided instead.

	NHS Lothian	Edinburgh	East Lothian	Midlothian	West Lothian
Referrals Received/Accepted					
2023	4,613	2,162	794	493	1,161
2024	4,719	2,009	661	820	1,215
2025	4,126	1,868	529	727	995
Referrals Removed					
2023	390	247	63	76	5<
2024	2,014	1,591	56	272	94
2025	627	188	95	258	85

Question:

7. For rejected or redirected referrals, the main reasons recorded, with the number for each reason where held.

Answer:

NHS Lothian: As rejection reasons are not routinely coded in Trak, reasons for removal from wait list (when a patient was not seen for assessment) have been provided instead:

- Additional referral received: 36
- Deceased patient: 24
- Declined Reasonable Offer Package: 5<
- Declined Reasonable Offer Package at External Provider: 5<
- Did Not Respond - Central Digital WL Review/Validation: 1216
- Did Not Respond – PFB: 5<
- Did Not Respond - Service WL Review/Validation: 39
- Did Not Respond/Not Contactable: 297
- Did Not Respond/Not Contactable by External Provider: 102
- Inappropriate Referral at Triage: 244
- Incomplete Referral Patient Questionnaire: 85
- Passed to Community Trak or service within Lothian but not on Trak: 9
- Patient Advised Unavailability > 24 weeks: 5<
- Patient could not attend (Multiple Appointments): 5<
- Patient did not attend: 71
- Removal after Clinical Review: 53
- Transferred to another NHS provider (Treat or See & Treat): 8

- Transferred to another NHS provider (Treat or See and Treat): 14
- Treatment Not Currently Required: 472
- W/L Admin Error (Trak comment Required): 350

To protect the identity of the individuals involved any figure of 5 or less has not been shown in the table above. 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).

Question:

8. Whether the board has, or has had at any time since 1 January 2020, criteria limiting which adults are accepted for ADHD assessment (for example a requirement for a co-occurring mental health condition, a level of risk, or a functional impairment threshold). If so, please provide a copy of each version of the criteria and the dates each applied.

Answer:

Referrals are considered against the service's referral criteria of functional impairment to be moderate to severe and are accepted where there is sufficient information to indicate that an ADHD/ ASD assessment is clinically appropriate and where the referral falls within the remit of the service. Referrals may be returned for further information or redirected where insufficient information is provided to determine appropriateness or where another service is better placed to meet the individual's needs. NHS Lothian criteria for referrals to the AD(H)D adult services are set out on our RefHelp pages AD(H)D in Adults - RefHelp.

Question:

Part D – Equality impact assessment

9. Whether an Equality Impact Assessment was carried out for any criteria in question 8 or for decisions on the capacity of the adult ADHD service. If so, please provide a copy.

Answer:

Edinburgh: Edinburgh is developing a recovery plan and will complete an IIA once the plan is clearer.
East Lothian: East have completed an IIA for their recovery plan. The IIA was based on the whole change in model and service delivery.
Midlothian: No, but are planning on completing one.
West Lothian: No but are planning on completing one.

Question:

Part E – Waiting time standards

10. Whether adult ADHD assessment waits are measured against any waiting time standard or target, local or national, and if so which.

Answer:

Adult ADHD assessment waits do not fall under the Scottish Government waiting times standards.

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.nhslothian.scot/FOI/Pages/default.aspx

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive