

Dear

FREEDOM OF INFORMATION – ADULT NEURODEVELOPMENTAL SERVICES

I write in response to your request for information in relation to adult neurodevelopmental services in NHS Lothian.

Question:

1. Please describe your adult neurodevelopmental service and what you offer (e.g. autism diagnostic service; neurodevelopmental support service).

Answer:

The adult community mental health services in each of the Health and Social Care Partnerships with NHS Lothian provide diagnosis and support for ADHD and ASC. For those diagnosed with ADHD, the services offer specialist initiation and titration of medication, with ongoing mental health input during the first year and periodic review thereafter. The services also aim to signpost individuals who do not meet the threshold for specialist assessment, or who are waiting, to digital resources and third-sector or community supports.

Question:

2. Please describe your triage process (e.g. separate referrals management team, paper screening of referrals by core team, initial screening assessments offered to clients).

Answer:

Referrals are received and triaged by the Community Mental Health Teams.

Question:

3. How many people are currently awaiting diagnostic assessment (as of April 2026)?

Answer:

As of 12 May 2026, there are 14,160 patients on the adult neurodevelopment waiting list across NHS Lothian.

Question:

4. What is the maximum waiting time for diagnostic assessment?

Answer:

I am not able to give the longest waiting time, as this may need to the identification of the individual patient involved. 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.

Question:

5.What percentage of referral were declined between April 2023-April 2026 and for what reason (common themes)?

Answer:

This information is not collected centrally. Information may be held in individual patient records, but in order to provide the information you request it would be necessary to review each patient record over the period you have specified, requiring significant resources. Under section 12 of the Freedom of Information (Scotland) Act 2002, NHS Lothian is not required to respond to your request if the resources required to do so equate to more than £600 in cost.

Question:

6.How many complaints were received between April 2023-April 2026 (please describe common themes)?

Answer:

NHS Lothian has received 13 complaints about neurodevelopmental services during this period.

The themes are detailed in the table below. Some complaints referred to more than one of these themes. I have not released numbers of 5 or fewer in the table, as this information could lead to the identification of the individuals involved. 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.

Complaints themes, Neurodevelopmental Services, NHS Lothian, 1 April 2023 – 30 April 2026	
Theme	Number of complaints
Waiting times / delays in assessment or treatment	9
Access / appointment issues	≤5
Communication concerns	≤5
Treatment concerns / inappropriate treatment	≤5
Neurodevelopmental / mental health support delays	≤5
Medication-related concerns	≤5
Staff clinical judgement concerns	≤5
Child-friendly complaints process concerns	≤5

Question:

7. What framework do you use for diagnostic assessment? (e.g. following NICE and/or AQAS guidelines).

Answer:

NICE guidelines are followed.

Question:

8. Do you offer pre and/or post diagnostic interventions (if so which)?

Answer:

Medication may be offered post diagnosis, and patients are signposted to third sector organisations for support. Patients on the waiting list or post diagnosis can access mental health pathways for intervention via primary or secondary care services.

Question:

9. If ADHD medication treatments (initiation and titration) are offered, what local arrangements do you have in place for shared care?

Answer:

In NHS Lothian, sharing the care of patients who require medicines as part of their treatment is based on national guidance and involves the application of general principles as well as a select number of specific Shared Care Agreements (SCAs) for medicines and conditions that benefit from having additional information provided.

The Scottish Executive Circular (1992) establishes that prescribing responsibility lies with the clinician in charge and requires clear handover arrangements between specialists and general practice. <https://www.publications.scot.nhs.uk/files/gen1992-11.pdf>

At a local level, there is a NHS Lothian Procedure for the Shared Care of Medicines and the Prescribing and Monitoring following a Private Consultation guideline which align with the General Medical Council's Good Practice guide:

- Procedure for the shared care of medicines - <https://policyonline.nhslothian.scot/wp-content/uploads/2023/03/Shared%20Care%20of%20Medicines.pdf>
- Prescribing and monitoring after a private consultation - <https://policyonline.nhslothian.scot/wp-content/uploads/2025/05/Prescribing-following-private-consultation-guideline.pdf>
- Good practice in prescribing and managing medicines and devices - <https://www.gmc-uk.org/professional-standards/the-professional-standards/good-practice-in-prescribing-and-managing-medicines-and-devices/shared-care>

For the treatment of attention deficit hyperactivity disorder, the following shared care agreements have been written by specialists, agreed as clinically appropriate at a primary care prescribing advisory group and then published for routine use:

- Atomoxetine - https://www.formulary.nhs.scot/media/ozcb2waj/shared-care-agreement-atomoxetine-v4-final_wc.pdf
- Dexamfetamine and lisdexamfetamine – https://www.formulary.nhs.scot/media/hpugzx0l/shared-care-agreement-lisdexamfetamine-v4-final_wc.pdf
- Guanfacine - https://www.formulary.nhs.scot/media/bx5dh0tp/shared-care-agreement-guanfacine-v4-final_wc.pdf
- Methylphenidate - https://www.formulary.nhs.scot/media/h4qemmfe/shared-care-agreement-methylphenidate-v4-final_wc.pdf

In summary, the shared care agreements cover:

- Requirement for specialist initiation and stabilisation
- Clear allocation of responsibility and monitoring
- Define explicit roles for specialists and those delivering care in general practice
- Ensure effective communication and monitoring systems
- Require GP agreement and patient consent before transfer
- Decisions being made in the patient's best interests
- GPs are not obliged to accept prescribing responsibility for privately initiated ADHD medicines
 - Before accepting, the GP must ensure:
 - Adequate clinical information is provided
 - Treatment aligns with local formularies and shared care protocols
 - If these criteria are not met:
The GP may decline prescribing and request specialist NHS review

Question:

10.What is your staffing model? (mdt members, admin)

Answer:

The neurodevelopmental services teams include Mental Health Occupational Therapists, Community Psychiatric Nurses, Consultant Psychiatrists and Psychologists.

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 <https://www.foi.scot/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 reviewer at the address at the top 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>

Yours sincerely

ALISON MACDONALD
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Cc: Chief Executive