

Date 8 September 2026
Your Ref
Our Ref 11818R

Enquiries to Richard Mutch
Extension 35687
Direct Line 0131 465 5687
loth.freedomofinformation@nhs.scot
richard.mutch@nhs.scot

Dear

FREEDOM OF INFORMATION REVIEW - ADHD AND ASD

I write in response to your request for review of NHS Lothian's response to your Freedom of Information request about ADHD and ASD. Having discussed your request and our response of 19 June 2026 I can respond as follows:

Original Request and Response:
Question:

- Under the Freedom of Information (Scotland) Act 2002, I would like to request the following information relating to referrals for ADHD and Autism Spectrum Disorder (ASD) assessments within your Health Board area.

Please provide the data separately for:

- Children and young people services
- Adult services

Please also provide the data separately for:

- ADHD assessments
- ASD assessments

For each calendar year:

- 2024
- 2025 (to date, if full-year data are not yet available)

Please provide the following information:

Referral pathway data

- The total number of referrals received from General Practitioners (GPs) requesting assessment for ADHD and ASD.
- Of these referrals, the number that:
 - Were rejected without further screening/triage
 - Were accepted for screening/triage
 - Progressed to a full diagnostic assessment

Waiting time data

3. The average waiting time from referral receipt to initial response regarding the referral outcome (for example, acknowledgement, rejection, or acceptance).
4. The average waiting time from referral receipt to screening/triage appointment.
5. The average waiting time from referral receipt to full diagnostic assessment.

If available, please provide waiting times in:

- Mean average days/weeks
and/or
- Median waiting time

Answer:

It should be noted that the majority of adult patients are not on a specific ADHD / ASD waiting list. The majority of patients are on a non-specific “Neurodevelopmental Assessment” list and without reviewing each patient’s clinical notes, we are unable to say whether these patients are waiting for an ADHD, ASD or other neurodevelopmental assessment.

For children and young people, there are no ADHD / ASD specific waiting lists. All patients are on non-specific “Neurodevelopmental Assessment” lists. We are therefore unable to provide an accurate figure for wait times to assessment or number of children currently waiting specifically for an ADHD, ASD assessment.

Referral Pathway - screening and triage - assessment waiting list - assessment appointment.

Under the Freedom of Information Act NHS Lothian is not required to create new records to enable it to respond to your enquiry. This information is not collated or held in aggregate form and it would be necessary to review all case files relating to patients over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

Review Request:

We are dissatisfied with the decision to withhold this information on the basis that the data is combined within your Neurodevelopmental Assessment service and separate data cannot be obtained without exceeding the cost limit.

While we understand that the data is not categorised by individual conditions, the health board still holds the overall neurodevelopmental datasets.

Five other NHS health boards have a similar setup, yet they successfully fulfilled this identical request by providing their combined neurodevelopmental service data rather than no data at all.

Under Section 15 of the Freedom of Information (Scotland) Act 2002, public authorities have a duty to provide advice and assistance. Where specific separation of data is not possible, the board should have offered the combined neurodevelopmental service data as the closest available alternative to satisfy the request.

Please review this decision and provide the combined neurodevelopmental service referral and waiting time data for both adults and children for the requested periods as in the original request (copy attached). If available, please also provide a list of the conditions which are part of your Neurodevelopmental Assessment service.

Review Response:

1. The total number of referrals received from General Practitioners (GPs) requesting assessment for ADHD and ASD.

The number of GP referrals to neurodevelopmental waiting lists for children and young people may be considerably higher than shown below. The reported figures include only referrals made directly to neurodevelopmental services.

Many neurodevelopmental referrals first enter the CAMHS pathway through a CHOICE appointment wait list and are then referred on to a neurodevelopmental service after the initial appointment. At this point the referral source will no longer appear as GP referral. Because the system does not distinguish between neurodevelopmental and non-neurodevelopmental CHOICE appointments, these referrals cannot be identified and are excluded from the figures below.

	ADHD	ASD	ND Total
2024 Children & young people	NA	NA	198
2025 Children & young people	NA	NA	504
2024 Adults	NA	NA	3,801
2025 Adults	NA	NA	3,365

2. Of these referrals, the number that:

2a: Were rejected without further screening/triage
NHS Lothian does not hold the information requested.

2b: Were accepted for screening/triage

These figures are the same as those reported for Question 1. It should be noted that referrals rejected before reaching the screening or triage stage may not have been recorded on a waiting list. As a result, such referrals would not be reflected in the total referral numbers presented.

	ADHD	ASD	ND Total
2024 Children & young people	NA	NA	198
2025 Children & young people	NA	NA	504
2024 Adults	NA	NA	3,801
2025 Adults	NA	NA	3,365

2c: Progressed to a full diagnostic assessment

	ADHD	ASD	ND Total
2024 Children & young people	NA	NA	10
2025 Children & young people	NA	NA	5
2024 Adults	NA	NA	330
2025 Adults	NA	NA	107

3. The average waiting time from referral receipt to initial response regarding the referral outcome (for example, acknowledgement, rejection, or acceptance).

*NHS Lothian does not hold the information requested.

4. The average waiting time from referral receipt to screening/triage appointment.

*NHS Lothian does not hold the information requested.

5. The average waiting time from referral receipt to full diagnostic assessment.

NHS Lothian does not hold the information requested. We can provide waiting time to first assessment appointment. Assessments can require multiple appointments and it is not possible to tell from the data when an assessment was completed.

	ADHD	ASD	Adjusted mean wait (days)	Adjusted median wait (days)
2024 Children & young people	NA	NA	472	402
2025 Children & young people	NA	NA	551	369
2024 Adults	NA	NA	568	321
2025 Adults	NA	NA	790	778

Completed True waits in 2024 & 2025, not limiting referral source to GP for this section.

Methodology

The analysis was undertaken using routinely collected outpatient waiting list appointment data held within NHS Lothian's electronic patient information system.

Waiting lists related to the Assessment pathway and unattributed pathway were included in the analysis. The assessment pathway classification was derived using a pathway filter variable based on service naming conventions, whereby services containing the terms "ADOS", or "Assessment" were classified as Assessment-related waits; however, a number of service names could not be attributed to any pathway category (and were not classified as Titration or Review).

If you are not satisfied with this response you still have the right to make a formal complaint to the Scottish Information Commissioner who you can contact at the address below or 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.

Scottish Information Commissioner
Kinburn Castle
Doubledykes Road
St Andrews, Fife
KY16 9DS
Telephone: 01334 464610
Fax: 01334 464611
e-mail: enquiries@foi.scot

Yours sincerely

Freedom of Information Reviewer/
NHS Lothian
cc: Executive Nurse Director