

Dear

FREEDOM OF INFORMATION – ADHD

I write in response to your request for information in relation to ADHD within NHS Lothian.

Question:

- How many people in the Lothians have been referred for an ADHD diagnosis through the NHS in each of the last 10 years, year by year. And please if possible a breakdown of each local authority.

Answer:

The data for adult neurodevelopmental referrals and assessments is very incomplete. Prior to 2023 Neurodevelopmental cases were added to General Adult Mental Health Waiting lists. We are therefore unable to provide historical data from our electronic patient information system for patients who were referred and have been seen for assessment.

Also note that we can't differentiate between condition (ADHD or ADD) The Adult Team Neurodevelopmental (ND) Lists are for any Neurodiverse disorder.

Adult Teams	Locality	2018	2019	2020	2021	2022	2023
Adult Mental Health East Lothian Neurodevelopmental	East Lothian	0	5<	14	152	350	709
Adult Mental Health West Lothian - Neurodevelopmental	West Lothian	0	0	5<	199	725	1028
Neurodevelopmental Adult NE	Edinburgh NE	0	0	5<<	302	618	491
Neurodevelopmental Adult NW	Edinburgh NW	13	64	71	107	175	377
Neurodevelopmental Adult SE	Edinburgh SE	5<	11	154	368	478	468
Neurodevelopmental Adult SW	Edinburgh SW	0	7	129	283	370	344
Adult Mental Health Midlothian	Midlothian						224

Notes:

a. Excluded Services:

*General Psychiatry NDD Return Patient
New Near Me Neurodevelopmental Review - AMH WL ND
Neurodevelopmental Review*

*Neurodevelopmental Titration
AMH Edinburgh SE – OPD Neurocog Return Patient*

b. Locality is based on Team

The service included for AMH Midlothian team is: *ADHD Assessment New - AMH Mid Community*

We cannot separate out ADHD from ASD and thus present data for number of referrals to a CAMHS Neurodevelopmental (ND) team by GP Locality.

	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
City of Edinburgh	190	274	268	325	306	467	365	595	957	1297
East Lothian	60	74	57	46	98	112	117	141	473	872
Midlothian	80	81	102	91	103	146	150	206	389	501
West Lothian	125	121	161	158	211	259	276	375	550	1061

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:

- What is the number of people who have been diagnosed with ADHD in each of the last 10 years? And please if possible a breakdown of each local authority.

Answer:

We cannot provide this information as Diagnostic coding is not routinely added to Outpatient episode.

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.

Question:

- What is the number of people who have been prescribed medication for ADHD in each of the last 10 years? And please if possible a breakdown of each local authority.

Answer:

Paid Calendar Year	Number of Patients by Health and Social Care Partnership					Unknown HSPC / NA
	NHS Lothian Total	East Lothian	Edinburgh	Midlothian	West Lothian	
2013	1400	108	718	178	286	198
2014	1567	120	839	192	307	307
2015	1775	135	949	207	352	389
2016	2015	152	1044	222	398	490
2017	2234	155	1185	251	433	602
2018	2531	195	1356	251	503	760
2019	3022	262	1577	279	598	1003
2020	3270	327	1703	316	662	850
2021	3824	377	2039	370	726	1045
2022	4576	458	2478	473	834	1208
2023 ^p	5455	553	2841	664	999	1598

Notes:

- 2023p - Indicates that the data for 2023 is partial. Currently data is only complete until the end of November 2023. Validated Data for 2024 is not yet available.
- Data includes items prescribed in NHS Lothian and dispensed both within and outwith NHS Lothian.
- Data captured from Paid Items.
- Data shown is for that dispensed within the community only.
- Data presented are based on Legacy British National Formulary Hierarchy and not clinical usage. It is not possible to determine for what purpose these drugs were prescribed.
- Medication for ADHD is defined as medicines in BNF Section 4.4. (CNS Stimulants and drugs used for attention deficit hyperactivity disorder) excluding 'MODAFINIL'
- A person can be counted in more than one Health and Social Care Partnership
- Patient count is only possible when a valid Community Health Index (CHI) number is recorded. This means that the data presented is a small underestimate of the total patient number. The CHI Capture rate for drugs used for attention deficit hyperactivity disorder in NHS Lothian is as follows:

CHI Capture

Paid Calendar Year	CHI Capture					Unknown HSPC / NA
	NHS Lothian Total	East Lothian	Edinburgh	Midlothian	West Lothian	
2013	84.8%	99.5%	98.0%	98.4%	98.9%	19.9%
2014	86.2%	99.3%	99.2%	99.7%	99.5%	27.0%
2015	89.3%	99.4%	99.5%	99.8%	99.0%	37.7%

2016	88.4%	99.8%	99.3%	99.7%	99.7%	40.5%
2017	86.7%	98.8%	99.2%	99.8%	99.6%	37.3%
2018	86.9%	98.7%	99.5%	99.7%	99.9%	37.9%
2019	88.6%	99.4%	99.2%	100.0%	99.6%	45.2%
2020	90.6%	99.7%	99.0%	99.7%	99.6%	43.4%
2021	90.4%	99.7%	99.2%	99.9%	99.6%	44.8%
2022	90.5%	99.8%	99.3%	99.9%	99.5%	43.3%
2023 ^P	93.2%	99.7%	99.4%	99.6%	99.4%	58.6%

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
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Cc: Chief Executive