

Date 26/02/2026
Your Ref
Our Ref 11103

Enquiries to Richard Mutch
Extension 35687
Direct Line 0131 465 5687
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Dear

FREEDOM OF INFORMATION – PRESCRIBING

I write in response to your request for information in relation to prescribing.

Question:

1. The number of patients under the trust's care with a recorded diagnosis of Dravet syndrome in each month of 2025 (January–December). Patients may be counted in more than one month. Likely coded as ICD-10 code G40.3 or SNOMED code 230437002.
 - a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
2. The number of patients under the trust's care with a recorded diagnosis of Lennox-Gastaut syndrome in each month of 2025 (January-December). Patients may be counted in more than one month. Likely coded as ICD-10 code G40.4 or SNOMED code of 230418006.
 - a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+

Answer:

I am advised that we do not have this information in a centrally extractable format as you are asking for the number of patients with a condition rather than discharges with that diagnosis.

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.

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. The number of patients under the trust's care who have been treated with **fenfluramine** in 2025 (January-December), separated by month
 - a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.

4. The number of patients under the trust's care who have been treated with **cannabidiol** in 2025 (January-December), separated by month
 - a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.

5. The number of patients under the trust's care who have been treated with **cenobamate** in in 2025 (January-December), separated by month

- a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.
6. The number of patients under the trust’s care who have been treated with **rufinamide** in 2025 (January-December), separated by month
- a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.
7. The number of patients under the trust’s care who have been treated with **stiripentol** in 2025 (January-December), separated by month
- a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for

these patients during the year, and the number of patients associated with each medication

- d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.

Good to know questions:

8. The number of patients under the trust’s care who have been treated with **clobazam** in 2025 (January-December), separated by month
 - a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.

9. The number of patients under the trust’s care who have been treated with **sodium valproate** in 2025 (January-December), separated by month
 - a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were

recorded for these patients during the year, and the number of patients associated with each medication.

10. The number of patients under the trust's care who have been treated with **topiramate** in 2025 (January-December), separated by month
 - a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002
 - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For patients with a recorded diagnosis of Dravet syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication
 - d. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.

11. The number of patients under the trust's care who have been treated with **lamotrigine** in 2025 (January-December), separated by month
 - a. Patient numbers segmented by age:
 - i. <2 years old
 - ii. 2-8 years old
 - iii. 9-17 years old
 - iv. 18 years+
 - b. For these patients, how many of them had a diagnosis of:
 - i. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - c. For patients with a recorded diagnosis of Lennox–Gastaut syndrome treated with fenfluramine during 2025, please indicate which other anti-seizure medications were recorded for these patients during the year, and the number of patients associated with each medication.

Answer:

Please see enclosed spreadsheet.

To protect the identity of the individuals involved any figure of 5 or less has not been shown in the enclosed spreadsheet. 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.nhslothian.scot/FOI/Pages/default.aspx>

Yours sincerely

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

<2 years old								X				
2-8 years old	X	X	X	X	X	X	X	X	X	X	X	
9-17 years old	14	9	9	7	15	9	14	9	11	10	6	
18+ years old	547	548	558	534	534	500	562	504	541	496	510	

11A. The number of individual patients with a prescription for lamotrigine from January 2025 to November 2025 is shown in the table below.

Age/Month	Jan-25	Feb-25	Mar-25	Apr-25	May-25	Jun-25	Jul-25	Aug-25	Sep-25	Oct-25	Nov-25	Dec-25
<2 years old				X	X	X	X	X	X	X		
2-8 years old	X	X	X	X	6	7	X	8	7	7	9	
9-17 years old	43	52	50	56	42	53	50	48	54	51	43	
18+ years old	2456	2296	2396	2458	2524	2362	2636	2489	2571	2519	2474	