

FOI REF: 25/415

27th June 2025

Eastbourne District General Hospital

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FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

1. The number of unique patients with a recorded diagnosis of Dravet syndrome in 2024-2025. Likely coded as ICD-10 code G40.3 or SNOMED code of 230437002, ideally separated by month.

a. Patient numbers segmented by age:

- i. 0-3 years old**
- ii. 4-8 years old**
- iii. 9-18 years old**
- iv. 18 years+**

[Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.](#)

2. The number of unique patients with a recorded diagnosis of Lennox-Gastaut syndrome in 2024-2025. Likely coded as ICD-10 code G40.4 or SNOMED code of 230418006, ideally separated by month.

a. Patient numbers segmented by age:

- i. 0-3 years old**
- ii. 4-8 years old**
- iii. 9-18 years old**
- iv. 18 years+**

[Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.](#)

3. The number of unique patients who have been treated with fenfluramine in 2024-2025, separated by month

a. Patient numbers segmented by age:

- i. 0-3 years old**
- ii. 4-8 years old**
- iii. 9-18 years old**
- iv. 18 years+**

Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.

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**

Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.

c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside fenfluramine, and indicate the number of patients receiving each

East Sussex Healthcare NHS Trust does not centrally record the information requested above. To enable the Trust to provide this information would require a manual review of patients' notes which we estimate would take weeks to review. We are therefore applying Section 12(1) to this part of your request.

Section 12(1) of the Act allows a public authority to refuse to comply with a request for information if the authority estimates that the cost of compliance would exceed the 'appropriate limit', as defined by the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004 (the Regulations). These state that this cost limit is £450 for public authorities which are not part of central government or the armed forces. The costs are calculated at £25 per hour per person regardless of the rate of pay, which means that the limit will be exceeded if the work involved would exceed 18 hours. The Trust estimates that the cost of complying with this request would significantly exceed the above limit.

4. The number of unique patients who have been treated with cannabidiol in 2024-2025, separated by month

a. Patient numbers segmented by age:

- i. 0-3 years old**
- ii. 4-8 years old**
- iii. 9-18 years old**
- iv. 18 years+**

Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.

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**

Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.

c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside cannabidiol, and indicate the number of patients receiving each

Section 12(1) applied, please refer to question 3c.

5. The number of unique patients who have been treated with cenobamate in 2024-2025, separated by month

a. Patient numbers segmented by age:

- i. 0-3 years old**
- ii. 4-8 years old**
- iii. 9-18 years old**
- iv. 18 years+**

Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.

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**

Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.

- c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside cenobamate, and indicate the number of patients receiving each

[Section 12\(1\) applied, please refer to question 3c.](#)

- 6. The number of unique patients who have been treated with rufinamide in 2024-2025, separated by month

- a. Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

[Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.](#)

- 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

[Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.](#)

- c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside rufinamide, and indicate the number of patients receiving each

[Section 12\(1\) applied, please refer to question 3c.](#)

- 7. The number of unique patients who have been treated with stiripentol in 2024-2025, separated by month

- a. Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

[Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.](#)

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**

[Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.](#)

c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside stiripentol, and indicate the number of patients receiving each

[Section 12\(1\) applied, please refer to question 3c.](#)

8. The number of unique patients who have been treated with clobazam in 2024-2025, separated by month

a. Patient numbers segmented by age:

- i. 0-3 years old**
- ii. 4-8 years old**
- iii. 9-18 years old**
- iv. 18 years+**

[Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.](#)

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**

[Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.](#)

c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside clobazam, and indicate the number of patients receiving each

[Section 12\(1\) applied, please refer to question 3c.](#)

9. The number of unique patients who have been treated with sodium valproate in 2024-2025, separated by month

a. Patient numbers segmented by age:

- i. 0-3 years old**
- ii. 4-8 years old**
- iii. 9-18 years old**
- iv. 18 years+**

Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.

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**

Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.

c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside sodium valproate, and indicate the number of patients receiving each

Section 12(1) applied, please refer to question 3c.

10. The number of unique patients who have been treated with levetiracetam in 2024-2025, separated by month

a. Patient numbers segmented by age:

- i. 0-3 years old**
- ii. 4-8 years old**
- iii. 9-18 years old**
- iv. 18 years+**

Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.

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**

Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.

- c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside levetiracetam, and indicate the number of patients receiving each

[Section 12\(1\) applied, please refer to question 3c.](#)

11. The number of unique patients who have been treated with topiramate in 2024-2025, separated by month

a. Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

[Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.](#)

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

[Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.](#)

- c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside topiramate, and indicate the number of patients receiving each

[Section 12\(1\) applied, please refer to question 3c.](#)

12. The number of unique patients who have been treated with lamotrigine in 2024-2025, separated by month

a. Patient numbers segmented by age:

- i. 0-3 years old
- ii. 4-8 years old
- iii. 9-18 years old
- iv. 18 years+

[Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.](#)

- 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**

Please see the attached document - 'FOI 25 415 Dravet Syndrome and Lennox-Gastaut Syndrome'.

- c. For these patients, please provide a detailed breakdown of concurrent treatments. Specifically, list each additional treatment received alongside lamotrigine, and indicate the number of patients receiving each**

Section 12(1) applied, please refer to question 3c.

If I can be of any further assistance, please do not hesitate to contact me.

Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department (esh-tr.foi@nhs.net), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF

Telephone: 0303 123 1113

Yours sincerely

Freedom of Information Department
esh-tr.foi@nhs.net

FOI 25/415 - East Sussex Healthcare NHS Trust

- 1. The number of unique patients with a recorded diagnosis of Dravet syndrome in 2024-2025. Likely coded as ICD-10 code G40.3 or SNOMED code of 230437002, ideally separated by month. Patients segmented by age:**

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	2	0	1	0	0	0	1	0	1	0	0	0
4-8 years old	2	1	1	0	0	1	0	0	0	0	0	1
9-18 years old	0	1	0	1	2	3	3	1	1	0	1	1
18+ years old	14	7	14	12	11	7	7	9	13	8	8	5

- 2. The number of unique patients with a recorded diagnosis of Lennox-Gastaut syndrome in 2024-2025. Likely coded as ICD-10 code G40.4 or SNOMED code of 230418006, ideally separated by month. Patients segmented by age:**

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	1	0	0	0	2	1	0	0	1	0	0
4-8 years old	0	0	1	0	0	0	0	0	0	0	0	0
9-18 years old	0	0	0	0	0	0	0	0	0	0	0	0
18+ years old	0	0	1	1	0	0	2	1	0	0	0	1

4. The number of unique patients who have been treated with cannabidiol in 2024-2025, separated by month. Patients segmented by age:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	0	0	0	0	0	0	0	0	0	0	0
4-8 years old	0	0	0	0	0	0	0	0	0	0	0	0
9-18 years old	0	0	0	0	0	0	0	0	0	0	0	0
18+ years old	0	0	0	1	0	0	0	1	0	1	1	1

B (i) For these patients, how many of them had a diagnosis of: Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	0	0	0	0	0	0	0	0	0	0	0
4-8 years old	0	0	0	0	0	0	0	0	0	0	0	0
9-18 years old	0	0	0	0	0	0	0	0	0	0	1	0
18+ years old	0	0	0	0	0	0	0	0	0	0	0	0

B (ii) For these patients, how many of them had a diagnosis of: Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	0	0	0	0	0	0	0	0	0	0	0
4-8 years old	0	0	0	0	0	0	0	0	0	0	0	0
9-18 years old	0	0	0	0	0	0	0	0	0	0	0	0
18+ years old	0	0	0	1	0	0	0	1	0	0	0	1

5 The number of unique patients who have been treated with cenobamate in 2024-2025, separated by month. Patients segmented by age:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	0	0	0	0	0	0	0	0	0	0	0
4-8 years old	0	0	0	0	0	0	0	0	0	0	0	0
9-18 years old	0	0	0	0	0	0	0	0	0	0	0	0
18+ years old	1	1	0	1	2	0	2	2	2	0	2	2

B (i) For these patients, how many of them had a diagnosis of: Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	0	0	0	0	0	0	0	0	0	0	0
4-8 years old	0	0	0	0	0	0	0	0	0	0	0	0
9-18 years old	0	0	0	0	0	0	0	0	0	0	0	0
18+ years old	0	0	0	0	1	0	0	0	0	0	0	0

B (ii) For these patients, how many of them had a diagnosis of: Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	0	0	0	0	0	0	0	0	0	0	0
4-8 years old	0	0	0	0	0	0	0	0	0	0	0	0
9-18 years old	0	0	0	0	0	0	0	0	0	0	0	0
18+ years old	0	0	0	0	0	0	0	1	1	0	0	0

8. The number of unique patients who have been treated with clobazam in 2024-2025, separated by month. Patients segmented by age:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old		0	0	0	0	0	1	0	0	1	0	0
4-8 years old	0	0	1	0	1	0	0	0	0	1	0	0
9-18 years old	0	1	0	0	0	0	0	0	0	0	0	1
18+ years old	2	9	8	9	10	9	11	10	4	11	6	8

B (i) For these patients, how many of them had a diagnosis of: Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	0	0	0	0	0	0	0	0	0	0	0
4-8 years old	0	0	0	0	0	0	0	0	0	1	0	0
9-18 years old	0	0	0	0	0	0	0	0	0	0	0	0
18+ years old	0	2	1	1	5	1	1	3	1	2	0	0

B (ii) For these patients, how many of them had a diagnosis of: Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	0	0	0	0	0	0	0	0	0	0	0
4-8 years old	0	0	1	0	0	0	0	0	0	0	0	0
9-18 years old	0	0	0	0	0	0	0	0	0	0	0	0
18+ years old	0	0	0	2	0	0	2	2	0	0	0	1

12 The number of unique patients who have been treated with lamotrigine in 2024-2025, separated by month. Patients segmented by age:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	0	0	0	0	0	0	0	0	0	0	0
4-8 years old	0	1	0	0	0	0	0	0	0	0	0	1
9-18 years old	1	1	1	2	2	1	2	2	3	2	3	1
18+ years old	32	31	38	43	35	42	47	44	35	38	33	41

B (i) For these patients, how many of them had a diagnosis of: Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	0	0	0	0	0	0	0	0	0	0	0
4-8 years old	0	0	0	0	0	0	0	0	0	0	0	0
9-18 years old	0	0	0	0	1	0	1	0	0	0	0	0
18+ years old	1	1	0	0	2	1	1	1	0	0	1	0

B (ii) For these patients, how many of them had a diagnosis of: Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006:

Age/Month	Apr-24	May-24	Jun-24	Jul-24	Aug-24	Sep-24	Oct-24	Nov-24	Dec-24	Jan-25	Feb-25	Mar-25
0-3 years old	0	0	0	0	0	0	0	0	0	0	0	0
4-8 years old	0	0	0	0	0	0	0	0	0	0	0	0
9-18 years old	0	0	0	0	0	0	0	0	0	0	0	0
18+ years old	0	0	0	0	0	0	0	1	0	0	0	1