

FOI 3153

2<sup>nd</sup> July 2025

## FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST

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+

**Response:**

Year of Admission	Month of Admission	Age Bands			
		0-3yrs	4-8yrs	9-17yrs	18+ yrs
2024	April	<5	0	0	<5
	May	0	0	0	<5
	June	0	<5	<5	<5
	July	0	<5	0	<5
	August	0	0	<5	<5
	September	0	0	0	<5
	October	0	0	0	<5
	November	0	0	<5	<5
	December	0	<5	0	<5
2025	January	0	0	<5	<5
	February	<5	0	<5	<5

The Trust has a legal duty to protect patient confidentiality and, in line with this duty, the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves and the sensitivity of the information requested. In addition, the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

S 40 (2) (third party information) of the Freedom of Information Act 2000 has been applied to exempt the exact figures from disclosure. The Trust does not consider the disclosure of the information to be fair to the individuals concerned as there is the potential risk of identification of an individual(s) which they would not expect, and which would therefore breach the fairness element of the first principle of the Data Protection Act 2018

**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+**

**Response:**

Year of Admission	Month of Admission	Age Bands			
		0-3yrs	4-8yrs	9-17yrs	18+ yrs
2024	April	0	0	0	<5
	May	<5	0	<5	0
	June	0	0	0	0
	July	0	0	0	<5
	August	0	0	0	0
	September	<5	0	0	0
	October	0	0	0	<5
	November	<5	0	0	0
	December	<5	0	0	0
2025	January	0	0	0	0
	February	0	0	<5	0

The Trust has a legal duty to protect patient confidentiality and, in line with this duty, the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves and the sensitivity of the information requested. In addition, the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

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

**Response:**

Zero

**a. Patient numbers segmented by age:**

- i. 0-3 years old**

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

**Response:**  
N/A

- 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

**Response:**  
N/A

- 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

**Response:**  
N/A

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

**Response:**  
Five

June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May
<5		<5	<5	<5	<5	<5	<5		<5	<5	

- a. Patient numbers segmented by age:

- Response:**
- i. 0-3 years old            0
  - ii. 4-8 years old            0
  - iii. 9-18 years old        0
  - iv. 18 years+                5

- 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

**Response:**  
This information is not recorded centrally and therefore retrieving it would involve a significant manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

Under section 12 of the Freedom of Information Act 2000, Public Authorities are not obliged to comply with an information request where to do so would exceed the cost limit.

In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

- 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**

**Response:**

This information is not recorded centrally and therefore retrieving it would involve a significant manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

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In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

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

**Response:**

Age/Month	J	F	M	A	M	J	J	A	S	O	N	D
0-3 years old												
4-8 years old												
9-18 years old												
18+ years old						<5		<5				

The Trust has a legal duty to protect patient confidentiality and, in line with this duty, the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves and the sensitivity of the

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- a. 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**

**Response:**

This information is not recorded centrally and therefore retrieving it would involve a significant manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the "appropriate limit" as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

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In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

- b. 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.**

**Response:**

This information is not recorded centrally and therefore retrieving it would involve a significant manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the "appropriate limit" as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

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In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

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

**Response:**

Zero

**a. Patient numbers segmented by age:**

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

**Response:**

N/A

**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**

**Response:**

N/A

**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**

**Response:**

N/A

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

**Response:**

Zero

**a. Patient numbers segmented by age:**

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

**Response:**

N/A

- 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

**Response:**  
N/A

- 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

**Response:**  
N/A

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

**Response:**  
Zero

- a. Patient numbers segmented by age:
  - i. 0-3 years old
  - ii. 4-8 years old
  - iii. 9-18 years old
  - iv. 18 years+

**Response:**  
N/A

- 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

**Response:**  
N/A

- 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

**Response:**  
N/A

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

Age/Month	J	F	M	A	M	J	J	A	S	O	N	D
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0-3 years old					<5							
4-8 years old			<5	<5			<5					
9-18 years old						<5	<5			<5		
18+ years old	<5	7	8	15	<5	8	<5	8	7	9	5	<5

The Trust has a legal duty to protect patient confidentiality and, in line with this duty, the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves and the sensitivity of the information requested. In addition, the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

S 40 (2) (third party information) of the Freedom of Information Act 2000 has been applied to exempt the exact figures from disclosure. The Trust does not consider the disclosure of the information to be fair to the individuals concerned as there is the potential risk of identification of an individual(s) which they would not expect, and which would therefore breach the fairness element of the first principle of the Data Protection Act 2018

- a. 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**

**Response:**

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In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

- b. 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 –**

**Response:**

This information is not recorded centrally and therefore retrieving it would involve a significant manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

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In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

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

**Response:**

Age/Month	J	F	M	A	M	J	J	A	S	O	N	D
0-3 years old		<5	<5	<5						<5	<5	
4-8 years old		<5				<5						
9-18 years old	<5			<5	<5	<5				<5		
18+ years old	9	13	7	11	13	11	11	12	15	9	6	9

The Trust has a legal duty to protect patient confidentiality and, in line with this duty, the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves and the sensitivity of the information requested. In addition, the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the ‘world at large’ and is published on the Trust website.

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



4-8 years old												
9-18 years old												
18+ years old	<5	<5		<5	<5	<5		<5				<5

The Trust has a legal duty to protect patient confidentiality and, in line with this duty, the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves and the sensitivity of the information requested. In addition, the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

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- a. **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**

**Response:**

This information is not recorded centrally and therefore retrieving it would involve a significant manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the "appropriate limit" as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

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In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

- b. **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 –**

**Response:**

This information is not recorded centrally and therefore retrieving it would involve a significant manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

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**Email:** [foi.team@southerntrust.hscni.net](mailto:foi.team@southerntrust.hscni.net)

