

Ref. No: 2330  
Date: 30/01/26  
Subject: Recorded diagnosis of Dravet syndrome

## REQUEST & RESPONSE

**Please note there is no indexable ICD-10 code for Dravet Syndrome. The data below has been pulled using the ICD-10 codes G40.3 (Generalized idiopathic epilepsy & epileptic syndromes) and G40.4 (Other Generalized idiopathic epilepsy & epileptic syndromes incl Lennox-Gastaut Syndrome) as requested.**

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+

### **G40.3 Generalized idiopathic epilepsy & epileptic syndromes**

	2025									
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct
<2 years old			<5	<5	<5	<5	<5	<5	<5	<5
2-8 years old				<5	<5	<5		<5	<5	
9-17 years old		<5	<5			<5	<5	<5	<5	
18+ years old	22	<5	13	7	10	14	17	20	21	8

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+

**G40.4 Other Generalized idiopathic epilepsy & epileptic syndromes  
incl Lennox-Gastaut Syndrome**

	2025										
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	
<2 years old		<5		<5							
2-8 years old											
9-17 years old											
18+ years old				<5	<5			<5	<5	<5	

Q3 = 0

Q4 = 0

**Q5** 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+ <5
- b. For these patients, how many of them had a diagnosis of:
  - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 <5
  - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006

**Q6** 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+ <5
- b. For these patients, how many of them had a diagnosis of:
  - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 <5

ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006

**Q7** 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 **<5**
- iv. 18 years+ 1

b. For these patients, how many of them had a diagnosis of:

- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 **<5**
- ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006 0

**Q8** 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 **<5**
- ii. 2-8 years old **10**
- iii. 9-17 years old **23**
- iv. 18 years+ **178**

b. For these patients, how many of them had a diagnosis of:

- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 **30**
- ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006

**Q9** 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 **<5**
- ii. 2-8 years old **<5**
- iii. 9-17 years old **16**
- iv. 18 years+ **275**

b. For these patients, how many of them had a diagnosis of:

- i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 **22**
- ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006

**Q10.** 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 **0**
    - ii. 2-8 years old **0**
    - iii. 9-17 years old **13**
    - iv. 18 years+ **90**
  - b. For these patients, how many of them had a diagnosis of:
    - i. Dravet Syndrome (ICD10 Code: G40.3) SCTID: 230437002 **0**
    - ii. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
- For patients with a recorded diagnosis **0**

**Q11.** 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 **0**
  - ii. 2-8 years old **9**
  - iii. 9-17 years old **52**
  - iv. 18 years+ **453**
- b. For these patients, how many of them had a diagnosis of:
  - i. Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006