



Rydym yn croesawu gohebiaeth yn y Gymraeg neu'r Saesneg. Atebir gohebiaeth Gymraeg yn y Gymraeg, ac ni fydd hyn yn arwain at oedi. We welcome correspondence in Welsh or English. Welsh language correspondence will be replied to in Welsh, and this will not lead to a delay.

**Cais Rhyddid Gwybodaeth / Freedom of Information request**  
**Ein Cyf / Our Ref: 23-A-029**

Please note that we have provided the information for the period November 2021 to October 2022.

**You asked:**

**In the last 12 months of available data:**

**1. What number of unique patients have been treated for Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex? Please give answers for each condition separately.**

You clarified on 8<sup>th</sup> February 2023 that you are looking for patients that have been admitted for any reason and one or more of these conditions appear as their diagnosis at any point in their inpatient stay.

Please note that "Dravet Syndrome" is not a condition that is coded on our systems, therefore we are not able to provide figures for this condition. We have included figures for "Other generalized epilepsy and epileptic syndromes" which covers Lennox-Gastaut Syndrome.

Diagnosis Description	Number of individual patients admitted
Other generalized epilepsy and epileptic syndromes	10
Tuberous sclerosis	5

**b. For each indication (Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex), what number of these have been treated in a paediatric environment?**

You clarified on 8<sup>th</sup> February 2023 that you are looking for all types of patients (inpatient/outpatients/day case).

We have provided the number of admitted patients under the age of 18.



Diagnosis Description	Number of individual patients admitted
Other generalized epilepsy and epileptic syndromes	7
Tuberous sclerosis	<5

Where fewer than 5 has been indicated we are unable to provide you with the exact number of patients as due to the low numbers, there is a potential risk of identifying individuals if this was disclosed. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This information is protected by the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute as unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. This exemption is absolute and therefore there is no requirement to apply the public interest test.

**2. How many patients have been treated with Epidyolex in a paediatric environment?**

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**3. Can you please detail which NHS Health Boards these patients have been referred from?**

SBUHB do not record centrally the health board from which the patients were referred. We can, however, provide you with the area of residence of the patients treated as below;

10 patients were registered as living within SBUHB boundaries at the time of their admission. The remainder were registered as living outside of the Health Board boundary. We are unable to provide you with further detail regarding the area of residence of the remaining patients as due to the low numbers, there is a potential risk of identifying individuals if this was disclosed. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This information is protected by the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute as unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. This exemption is absolute and therefore there is no requirement to apply the public interest test.

