

<b>Reference:</b>	FOI.10688.23
<b>Subject:</b>	Epilepsy treatment
<b>Date of Request:</b>	12 January 2023

**Requested:**

I would like to please request the following information, with regards to treatment of Epilepsy in your trust/ board.

In the last 12 months of available data:

- 1a. 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.
- 1b. For each indication (Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex), what number of these have been treated in a paediatric environment?
2. How many patients have been treated with Epidyolex in a paediatric environment?
3. Can you please detail which NHS Trusts/ Health Boards these patients have been referred from?

**Response:**

Hywel Dda University Health Board (UHB) is unable to provide you with of the information requested for questions 1a and 1b, as it is estimated that the cost of answering your request would exceed the "appropriate limit" as stated in the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004. The "appropriate limit" represents the estimated cost of one person spending 18 hours (or 2½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

In order to provide you with the information being requested, the UHB would need to undertake a manual search of all epilepsy patient records, for a twelve (12) month period, to identify those diagnosed with Lennox-Gastaut syndrome and Dravet Syndrome, as the UHB's Welsh Patient Administration System (WPAS) is unable to identify these conditions, as they are not coded separately or centrally.

The UHB is therefore applying an exemption under Section 12 of the Freedom of Information Act 2000 (FoIA), which provides an exemption from a public authority's obligation to comply with a request for information where the cost of compliance is estimated to exceed the appropriate limit.

However, under Section 16 of the FoIA, we are required as a public authority, to provide advice and assistance so far as it is reasonable, to individuals who have made a request under the FoIA. Therefore, the UHB provides the information it holds and is accessible for questions 1, 2 and 3 below.

The UHB can identify those patients treated for Tuberous Sclerosis for question 1 and those that have been treated with Epidyolex in a paediatric environment in response to question 2. However, the UHB is unable to provide you with the exact numbers for both questions, due to the low number

of cases (5 and under), as there is a potential risk of identifying individuals if this was disclosed. The UHB is therefore withholding this detail under Section 40(2) of the FoIA.

This information is protected by the Data Protection Act 2018 and the UK General Data Protection Regulations (UK GDPR), as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles 6 and 9 of the UK GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

3. The UHB confirms that the patients in relation to question 2 are UHB patients. However, the prescribing was undertaken by the Tertiary Care Neurology Department in Swansea Bay University Health Board and the medication dispensed locally.