

Freedom of Information Act 2000 - Request Reference FoI/23/025

Epilepsy

Information 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:

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.

In completing a search for the information requested, Cardiff and Vale University Health Board (the UHB) has confirmed that this information is not centrally recorded or collated. To retrieve the information requested would require a manual trawl through individual patient records and the UHB considers that this would exceed the limit set within regulations for responding to a request. The UHB has therefore relied upon the Section 12 exemption ('Exemption where cost of compliance exceeds appropriate limit') of the Freedom of Information Act 2000 and is refusing your request.

The UHB has estimated that to complete the work needed to respond to this request would exceed the time limit as set within regulations to respond to a Freedom of Information Act request. Under the Act there is an allowance of two and a half days, or 18 hours, to comply with a request and the cost limit set within the fees' regulations for this amount of work (18 hours) is £450 for the UHB. The fees regulations specify that the cost of complying with a request must be calculated at the rate of £25 per hour.

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

The UHB believes that Section 12 applies here, please see the exemption set out above.

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

The UHB believes that Section 12 applies here, please see the exemption set out above.

4. Can you please detail which NHS Trusts/ Health Boards these patients have been referred from?

The UHB believes that Section 12 applies here, please see the exemption set out above.