

Freedom of Information Act 2000 – Request Reference FoI/24/134

Patient Treatment

Information Requested:

Q1. How many patient's does the trust have with a recorded diagnosis of Dravet Syndrome (DS)

a) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?

b) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

Q2. How many patient's does the trust have with a recorded diagnosis of Lennox-Gasteau Syndrome (LGS)

a) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?

b) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

Response Details:

Q 1 & 2

Patient Count	LG Syndrome	Dravet Syndrome
2020	34	75
2021	25	71
2022	24	54
2023	24	48
Total	107	248

In response to Q1 a & b, Q2 a & b, 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 search through individual 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 of the Freedom of Information Act 2000 ('Exemption where cost of compliance exceeds appropriate limit') 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.