

Freedom of Information Act 2000 – Request Reference FoI/24/427
Patient Treatment

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

Please find below a table reflecting the number of distinct patients admitted between 1 January 2024 and 30 June 2024 for Dravet syndrome.

Month	Dravet Syndrome
January	7
February	7
March	5
April	1
May	2
June	6
Total	28

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

Cardiff and Vale University Health Board (the UHB) has estimated that to complete the work needed to respond to this request would exceed the time limit as outlined in the Appropriate Limit and Fees Regulations 2004. When estimating the cost of complying with a request for information under the applicable legislation, the UHB must calculate this cost at a rate of £25 per person per hour to a maximum of £450, with the appropriate time limit for complying therefore being 18 hours.

In completing a search for the information requested, 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 which the UHB considers would exceed the appropriate limit for the purposes of the 2004 Regulations. The UHB has therefore relied upon the exemption set out in section 12 of the Freedom of Information Act 2000 ('Exemption where cost of compliance exceeds appropriate limit') and is refusing your request.

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

The UHB believes the exemption as outlined in section 12 of the 2000 Act to apply in this instance and is therefore refusing your request.

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

Please find below a table reflecting the number of distinct patients admitted between 1 January 2024 and 30 June 2024 for Lennox-Gastaut syndrome.

Month	Lennox-Gastaut syndrome
January	2
February	1
March	3
April	4
May	1
June	0
Total	11

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

The UHB believes the exemption as outlined in section 12 of the 2000 Act to apply in this instance and is therefore refusing your request.

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

The UHB believes the exemption as outlined in section 12 of the 2000 Act to apply in this instance and is therefore refusing your request.