

Our ref: IG/FOI/FOI.302.25

6 May 2025

Sent via email to: [REDACTED]

Dear [REDACTED]

Request under the Freedom of Information Act 2000

I write further to your request for information, which was received on 22 April 2025, to confirm, in accordance with S.1(1)(a) of the Freedom of Information Act 2000, that Powys Teaching Health Board (PTHB) does not hold the information that you require.

For ease of reference your request is set out below and my response follows.

Your Freedom of Information (FOI) Request:

I am writing to submit an FOI request with the following questions:

- Q1. How many total patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Dravet Syndrome (DS)
- Q2. Of total DS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months?
- Q3. Of total DS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months?
- Q4. How many total patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Lennox-Gastaut Syndrome (LGS).
- Q5. Of total LGS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months?
- Q6. Of total LGS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months?

Pencadlys
Tŷ Glasbury, Ysbyty Bronllys,
Aberhonddu, Powys LD3 0LU
Ffôn: 01874 711661



Headquarters
Glasbury House, Bronllys Hospital
Brecon, Powys LD3 0LU
Tel: 01874 711661

Q7. How many adult (aged 18+) patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Dravet Syndrome (DS).

Q8. How many adult (aged 18+) patients has the trust seen within the latest 24 months of available data (for any reason), with a recorded diagnosis of Lennox-Gasteau Syndrome (LGS).

Powys Response:

Q1, Q4, Q7 & Q8. I can confirm Powys Teaching Health Board (PTHB) does not hold this data. The diagnosis would only be recorded if the patient was admitted, therefore we cannot give an accurate total number of patients seen with either of the conditions mentioned.

Q2, Q3, Q5 & Q6. PTHB does not initiate treatment with any of the medicines listed; patients are treated by providers outside of Powys. PTHB commissions services from a number of Welsh health boards and English provider organisations.

Due to the complex nature of PTHB's commissioning arrangements, not all of our providers indicate the indication for use for each episode of care where these drugs are used. For this reason, PTHB does not hold the data relating to your request, however, the health board is working closely with providers to ensure that this information can be provided in the future. We therefore recommend that you approach our providers for this information directly:

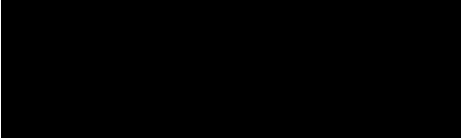
English NHS Trust	FOI Contact Details
Gloucestershire Hospitals NHS Foundation Trust	ghn-tr.foi@nhs.net
Sandwell and West Birmingham NHS Trust	swb-tr.SWBH-GM-FOIRequests@nhs.net
The Shrewsbury and Telford Hospital NHS Trust	sath.foi@nhs.net
The Royal Wolverhampton NHS Trust	rwh-tr.foi@nhs.net
Worcestershire Acute Hospitals NHS Trust	wah-tr.FOI@nhs.net
Wye Valley NHS trust	Freedom.Information@wvt.nhs.uk

Welsh Health Board	FOI Contact Details
Aneurin Bevan University Health Board	FOI.ABB@wales.nhs.uk
Betsi Cadwaladr University Health Board	bcu.foi@wales.nhs.uk
Cardiff & Vale University Health Board	FOI.Requests@wales.nhs.uk
Cwm Taf Morgannwg University Health Board	Freedomofinformation@wales.nhs.uk
Hywel Dda University Health Board	FOI.hyweldda@wales.nhs.uk
Swansea Bay University Health Board	FOIA.Requests@wales.nhs.uk

Under the terms of the Health Board's Freedom of Information procedure, individuals seeking access to recorded information held by the Health Board are entitled to request an internal review of the handling of their requests. If you would like to complain about the Health Board's handling of your request, please contact us directly at the address below or register your complaint via Powys.FOI@wales.nhs.uk

If after Internal Review you remain dissatisfied you are also entitled to refer the matter to the information commissioner at the Information Commissioner's Office (Wales), 2nd Floor, Churchill House, Churchill Way, Cardiff, CF10 2HH. Telephone Number: 0330 414 6421.

Yours sincerely



Richard Stratton
Assistant Medical Director-Primary Care

Rydym yn croesawu derbyn gohebiaeth yng Nghymraeg. Byddwn yn ateb y fath ohebiaeth yng Nghymraeg ac ni fydd hyn yn arwain at oedi.

We welcome receiving correspondence in Welsh. We will reply to such correspondence in Welsh and this will not lead to a delay.