

Reference:	FOI.20357.26
Subject:	Epilepsy
Date of Request:	5 May 2026

Requested:

Under the Freedom of Information Act, I would like to request the following information and documentation on the below. Please provide a breakdown of the years 2022, 2023, 2024, 2025, Q1 2026.

1. How many patients with epilepsy are there in your Health Board (please provide a breakdown of gender.)
2. Of those, how many would be considered at high risk of SUDEP?
3. How many patients with epilepsy have died during pregnancy? Please give a breakdown of how many of these were due to SUDEP.
4. Any local risk assessment completed by the Health Board on the implementation of MHRA regulations on Valporate
5. Any inclusion of MHRA regulations on Valproate on the Health Board risk register and reports of action taken
6. Any Health Board reports on stakeholder involvement on epilepsy or epilepsy and maternity and whether SUDEP Action included

Response:

Hywel Dda University Health Board (UHB) is unable to provide you with all the information requested, as it is estimated that the cost of answering your request would exceed the “appropriate limit” as stated in the Freedom of Information Act 2000 (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2 ½ 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 for question 1 broken down by gender, the UHB would need to undertake a manual search of all epilepsy patients’ medical records, for the 2022 to 2025 calendar years and the period 1 January to 5 May 2026, to identify any information that would fulfil this part of your request.

Additionally, to provide you with the information requested for question 2, a further manual trawl of patient medical records would be required, to identify any information relating to Sudden Unexpected Death in Epilepsy (SUDEP), that may fulfil this part of your request, as it is not recorded centrally.

It is estimated that three thousand, eight hundred and fifty-six (3,856) patients across the UHB have epilepsy and a manual search of these records would exceed the 18 hours stipulated within the Freedom of Information Act 2000 (FoIA). Based on the number of records identified, conducting a search of digital records taking a minimum of five (5) minutes per digital record, would far exceed the ‘appropriate limit’, costing the UHB the following:

3,856 @ 5 minutes per record = 321 hours and 20 minutes
321 hours and 20 minutes @ £25 per hour = £8,033.33

The UHB is therefore applying an exemption under Section 12 of the 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, this can include assisting a requestor to further refine their request.

Unfortunately, the UHB is unable to provide advice on how you can refine your request further. This is due to the UHB still requiring a manual trawl of patient medical records to be undertaken to identify information that may fulfil your request.

1. The estimated number of patients recorded across the UHB as having epilepsy is currently three thousand, eight hundred and fifty-six (3,856).

An exemption under Section 12 of the FoIA has been applied to the breakdown by gender. However, under Section 16, as recorded on the Epilepsy Action (2025) Seizing Change: A review of epilepsy in Wales, the gender split recorded for the period 20 October 2025 to 13 May 2026 is as follows:

Male – 43%
Female – 57%

2. An exemption under Section 12 of the FoIA has been applied.
3. The UHB does not hold the requested information, as the cause of death and any contributing factors is determined by the Coroner, who is appointed by the Local Authority (LA). We therefore recommend that you redirect this part of your request to the Freedom of Information Teams within each LA in the UHB's footprint, who may be able to help you with your enquiry. Their contact details are set out below:

- Information & Data Protection Officer, Carmarthenshire County Council, County Hall, Carmarthen, SA31 1JP or by email foia@carmarthenshire.gov.uk
- Complaints & Freedom of Information Team, Ceredigion County Council, Canolfan Rheidol, Rhodfa Padarn, Llanbadarn Fawr, Aberystwyth, Ceredigion, SY23 3UE or by email foi@ceredigion.gov.uk
- Information Governance Team, Pembrokeshire County Council, County Hall, Haverfordwest, Pembrokeshire, SA61 1TP or by email FOI@pembrokeshire.gov.uk

4. The UHB does not hold the requested information. However, the UHB provides a copy of the Valporate Compliance Action Form supporting the implementation of Medicines and Healthcare products Regulatory Agency (MHRA) regulations, at Attachment 1.

Additionally, the UHB provides a copy of the Audit of Valproate use in women of childbearing potential undertaken, at Attachment 2.

5. The UHB does not hold the requested information. However, the UHB has implemented the following mitigating actions:
 - The UHBs formulary has been updated to include details of the MHRA safety alert for Valproate.
 - Paediatric patients prescribed Valproate have been identified, with a central register established. A plan is in place to ensure Annual Risk Acknowledgement Forms (ARAFs) are completed annually.
 - Patients within Mental Health and Learning Disabilities services have been identified, with a central register reviewed and updated quarterly, with ARAF completed annually.
 - Adult Neurology (epilepsy) patients have been identified. Responsibility for review and completion of ARAF documentation sits with the tertiary neurology service, based in Swansea Bay University Health Board (SBUHB).
 - The Medicines Management Operational Group (MMOG) identified that Valproate was identified as an area requiring further work and a working group has recently been established with the first meeting due to take place by the end of June 2026.
6. The UHB does not hold the requested information.