

Reference:	FOI.14890.24
Subject:	Dravet Syndrome (DS) and Lennox-Gasteau Syndrome (LGS)
Date of Request:	18 July 2024

Requested:

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

1. How many patient's does the trust have with a recorded diagnosis of Dravet Syndrome (DS)
2. Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?
3. Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?
4. How many patient's does the trust have with a recorded diagnosis of Lennox-Gasteau Syndrome (LGS)
5. Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?
6. Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

Response:

Hywel Dda University Health Board (UHB) does not record the information exactly as requested. The Welsh Patient Administration System (WPAS) does not have a code for exclusively for Dravet Syndrome (DS) or Lennox-Gasteau Syndrome (LGS). These conditions are recorded as part of other generalised epilepsy and epileptic syndromes on WPAS.

The UHB is unable to provide you with all of the requested information (questions 2, 4 and 5), as there is a potential risk of identifying individuals if this information was disclosed, due to the low number of cases (5 and under), as there is a potential risk of identifying individuals if this was disclosed. This decision has been made as it is not within the reasonable expectations of these individuals that their personal data would be put into the public domain. This information is classed as personal data of a third party.

Therefore, these details are being withheld in accordance with the exemptions set out in section 40(2) of the Freedom of Information Act 2000 (FoIA), and by virtue of section 40(3)(a) of the FoIA, which permits a public authority to withhold details pertaining to identifiable information and personal data other than the requestor's where the disclosure would breach Data Protection principles.

This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations, as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles of the UK GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

In reaching this decision, the DPA and UK GDPR define personal data as data that relates to a living individual who can be identified solely from that data or from that data and other information, which is in the possession of the data controller.

However, whilst operating in accordance with the Section 45 Freedom of Information Code of Practice, the UHB has a duty to provide advice and assistance and provides the accessible information it holds as follows.

1. The UHB can inform you that there are seven patients (7) recoded on the WPAS as having the condition of Dravet Syndrome (DS), as recorded as part of the generalised code on WPAS covering other epilepsies and epileptic syndromes undetermined as to whether they are focal or generalised.
2. The UHB has applied a Section 40 to this information request.
3. The UHB can inform you that there are zero patients (0) recorded to have been treated with Fintepla (Fenfluramine) in the last six months.
4. & 5. The UHB has applied a Section 40 to this information request.
6. See question 3 for response.