

Reference:	FOI.21143.26
Subject:	Dravet Syndrome (DS) and Lennox-Gastaut Syndrome (LGS) patients and treatment
Date of Request:	27 July 2026

Requested:

1. 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)
2. Of total DS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months?
3. Of total DS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months?
4. 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)
5. Of total LGS patients, how many have been treated with Epidyolex (Cannabidiol) in the last 12 months?
6. Of total LGS patients, how many have been treated with Fintepla (Fenfluramine) in the last 12 months?
7. 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)
8. 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-Gastaut Syndrome (LGS)

Response:

1. Hywel Dda University Health Board (UHB) confirms that twenty-three (23) patients with a recorded diagnosis of DS were treated for any reason, during the period 1 August 2024 to 31 July 2026.
2. The UHB confirms that no DS patients are recorded as having been treated with Epidyolex (Cannabidiol), during the period 1 August 2025 to 31 July 2026.
3. The UHB can inform you that no DS patients are recorded as having been treated with Fintepla (Fenfluramine), during the period 1 August 2025 to 31 July 2026.
4. The UHB confirms that eight (8) patients with a recorded diagnosis of LGS were treated, during the period 1 August 2024 to 31 July 2026.
5. The UHB can inform you that no LGS patients are recorded as having been treated with Epidyolex (Cannabidiol), during the period 1 August 2025 to 31 July 2026.
6. The UHB can inform you that no LGS patients are recorded as having been treated with Fintepla (Fenfluramine), during the period 1 August 2025 to 31 July 2026.

7. The UHB confirms that fifteen (15) adults with a recorded diagnosis of DS were treated, for any reason, during the period 1 August 2024 to 31 July 2026.
8. The UHB is unable to provide you with the information requested information, as there is a potential risk of identifying individuals if this information was disclosed, due to the low number of cases (less than 5). 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, the UHB is withholding these details under Section 40(2) of the Freedom of Information Act 2000 (FoIA).

This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations (UK GDPR), 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.