

Reference:	FOI.17143.25
Subject:	Treatment of Dravet Syndrome (DS) and Lennox-Gastaut Syndrome (LGS)
Date of Request:	22 April 2025

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:

The UHB is unable to provide you with the information requested for questions 1, 4, 5, 7 and 8, as there is a potential risk of identifying individuals if this information was disclosed, due to the low number of cases (5 and under). 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.

2. The UHB can inform you that no DS patients are recorded as having been treated with Epidyolex (Cannabidiol) between 1 May 2024 to 30 April 2025.
3. The UHB can inform you that no DS patients are recorded as having been treated with Fintepla (Fenfluramine) between 1 May 2024 to 30 April 2025.
6. The UHB can inform you that no LGS patients are recorded as having been treated with Fintepla (Fenfluramine) between 1 May 2024 to 30 April 2025.