

Reference Number: FOIAH2425/215
From: Commercial
Date: 18 July 2024
Subject: Numbers of Patients with Diagnosis of Dravet Syndrome and Lennox-Gastaut Syndrome (LGS) and Associated Treatments

- Q1 a) How many patient's does the trust have with a recorded diagnosis of Dravet Syndrome (DS) within the last 6 months?
- b) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?
- c) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

A1 a) 12

b-c) Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to confirm treatment following medication being dispensed, the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.

- Q2 a) How many patient's does the trust have with a recorded diagnosis of Lennox-Gastaut Syndrome (LGS) within the last 6 months?
- b) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?
- c) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

A2 a) 32

b-c) Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to confirm treatment following medication being dispensed, the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.