

Reference Number: FOI202223/523
From: Private Individual
Date: 12 January 2023
Subject: Treatment of Epilepsy

I would like to please request the following information, with regards to treatment of Epilepsy in your trust/ board.

In the last 12 months of available data:

- Q1 1a. What number of unique patients have been treated for Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex? Please give answers for each condition separately.
- 1b. For each indication (Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex), what number of these have been treated in a paediatric environment?

A1 a:

	Dravet Syndrome	Lennox-Gastaut Syndrome	Tuberous Sclerosis
2022 Total	12	32	16

b: all patients have been treated in a paediatric environment as Alder Hey Children's Hospital NHS Foundation Trust is a specialists children's hospital and does not treat adults.

- Q2 How many patients have been treated with Epidyolex in a paediatric environment?
- A2 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.
- Q3 Can you please detail which NHS Trusts / Health Boards these patients have been referred from?
- A3 Betsi Cadwaladr University Health Board
 NHS Cheshire and Merseyside Integrated Care Board (ICB)
 NHS Greater Manchester ICB
 NHS Lancashire and South Cumbria ICB
 NHS Leicester, Leicestershire and Rutland ICB
 NHS Nottingham and Nottinghamshire ICB
 NHS Shropshire, Telford and Wrekin ICB
 NHS South Yorkshire ICB
 Isle of Man