

Freedom of Information Act 2000 - Request Reference Fol/22/189

Epilepsy

Information Requested:

Under the Freedom of Information Act 2000, please can you tell us the number of unique patients since January 2020 with a recorded diagnosis of: -

1. Epilepsy. Likely coded as ICD G40
2. Dravet syndrome. Likely coded as ICD10 code G40.3, or SNOMED code (SCTID) of 230437002 (if applicable)
3. Lennox Gastaut Syndrome. Likely coded as ICD10 code G40.4 or SNOMED code (SCTID) of 230418006
4. Tuberous Sclerosis Complex. Likely coded as ICD10 code Q85.1 or SNOMED code (SCTID) of 7199000
5. How many patients have been treated with Cannabidiol (Epidyolex) in the latest 3 months?
 - a. For these patients, how many of them had a diagnosis of: -
 - Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006
 - b. Or how many of them had a diagnosis of
 - Dravet Syndrome (ICD10 Code: G40.8) SCTID: 230437002

Please provide information on how each number was calculated (Using SNOMED CT, using ICD10, using both, another means.)

Please provide the data in tabular format, a simple example of which is shown below.

| Metric | Patients | Method/Comments |
|-------------------------------------|----------|-----------------|
| Epilepsy | | |
| Dravet syndrome | | |
| Lennox Gastaut Syndrome | | |
| Tuberous Sclerosis Complex | | |
| | | |
| Epidyolex patients | | |
| Epidyolex & Lennox-Gastaut syndrome | | |
| Epidyolex & Dravet Syndrome | | |



Response details:

| Distinct Patients in period* | | |
|------------------------------------|-----------------|--------|
| | CRN Count Total | Method |
| 1. Epilepsy G40 | 2,202 | ICD10 |
| 2. Dravet Syndrome G403 | 145 | ICD10 |
| 3. Lennox Gastaut Syndrome G404 | 54 | ICD10 |
| 4. Tuberous Sclerosis Complex Q851 | 11 | ICD10 |

*1st January 2020 to 30th April 2022.

