

FOI 2246

21st March 2024**FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST**

Q1. How many patient's does the trust have with a recorded diagnosis of Dravet Syndrome (DS)?

There is no specific ICD-10 code for this and this information is not centrally collated. We consider that the cost of retrieving the information would be above the 'appropriate limit' as defined by the FOI Act under Section 12. Section 12 makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit. The limit has been specified as £450 for public authorities such as the Southern Trust. This represents the cost of one or more person spending 18 hours or more in determining whether we hold the information locating retrieving and extracting the information.

a) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?

One

b) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

None

Q2. How many patient's does the trust have with a recorded diagnosis of Lennox-Gastaut Syndrome (LGS)?

28

a) Of these, how many have been treated with Epidyolex (Canabidiol) in the last 6 months?

One

b) Of these, how many have been treated with Fintepla (Fenfluramine) in the last 6 months?

None

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