

Freedom of Information Request

Ref: 22-210

3 May 2022

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we do hold the information you are requesting

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

3282

2. Dravet syndrome. Likely coded as ICD10 code G40.3, or SNOMED code (SCTID) of 230437002 (if applicable)

434

3. Lennox Gastaut Syndrome. Likely coded as ICD10 code G40.4 or SNOMED code (SCTID) of 230418006

118

4. Tuberous Sclerosis Complex. Likely coded as ICD10 code Q85.1 or SNOMED code (SCTID) of 7199000

42

How many patients have been treated with Cannabidiol (Epidyolex) in the latest 3 months?

19

For these patients, how many of them had a diagnosis of:-

- **Lennox-Gastaut syndrome (ICD10 Code: G40.4) SCTID: 230418006**

*

Please note: Where the figures are between 1 and 5, this has been denoted by *. Due to the low numbers, we have considered that there is the potential for individuals to be identified from

the information provided, when considered with other information that may also be in the public domain. In our view disclosure of these low figures would breach one of the Data Protection Principles set out in Schedule 1 of the Data Protection Act, namely Principle 1. The Trust therefore finds that the Section 40(2) exemption contained within the Freedom of information Act 2000 is engaged. (Section 40 is the exemption for personal information).

Or how many of them had a diagnosis of

- **Dravet Syndrome (ICD10 Code: G40.8) SCTID: 230437002**

*

Please note: Where the figures are between 1 and 5, this has been denoted by *. Due to the low numbers, we have considered that there is the potential for individuals to be identified from the information provided, when considered with other information that may also be in the public domain. In our view disclosure of these low figures would breach one of the Data Protection Principles set out in Schedule 1 of the Data Protection Act, namely Principle 1. The Trust therefore finds that the Section 40(2) exemption contained within the Freedom of information Act 2000 is engaged. (Section 40 is the exemption for personal information).

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

These numbers were identified using ICD-10 diagnosis code.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Data Protection Officer
University Hospitals Bristol and Weston NHS Foundation Trust
Trust Headquarters
Marlborough Street
Bristol
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because

information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

Freedom of Information Team
University Hospitals Bristol and Weston NHS Foundation Trust