

Freedom of Information Act Request

Under the Freedom of Information Act, I would like to request the following information:

- The number of patients treated for Dravet syndrome in 2024, ideally separated by month, or quarter
 - Patient numbers segmented by age:
 - 0-3 years old
 - 4-8 years old
 - 9-18 years old
 - 18 years+
- # number under 5

Age Group	2024
0-3 Years Old	#
18 Years+	15
4-8 Years Old	0
9-18 Years Old	#

- The number of patients treated for Dravet syndrome in 2025, ideally separated by month, or quarter
 - Patient numbers segmented by age:
 - 0-3 years old
 - 4-8 years old
 - 9-18 years old
 - 18 years+
- # number under 5

Age Group	2025
0-3 Years Old	0
18 Years+	7
4-8 Years Old	#
9-18 Years Old	#

- The number of patients treated for Lennox-Gastaut syndrome in 2024, ideally separated by month, or quarter
 - Patient numbers segmented by age:
 - 0-3 years old
 - 4-8 years old
 - 9-18 years old
 - 18 years+
- # number under 5

Age Group	2024
0-3 Years Old	6
18 Years+	6
4-8 Years Old	#
9-18 Years Old	5

- The number of patients treated for Lennox-Gastaut syndrome in 2025, ideally separated by month, or quarter
 - Patient numbers segmented by age:
 - 0-3 years old
 - 4-8 years old
 - 9-18 years old
 - 18 years+

ANS: We Can't provide as the count is less than 5

After careful consideration, we are unable to provide specific numerical data where the count is fewer than five. This decision is made to protect the privacy of individuals and is consistent with our obligations under the Freedom of Information Act 2000 (FOIA) and the Data Protection Act 2018.

Explanation of Exemption:

Section 40(2) of the FOIA exempts the release of personal data if it would contravene any of the data protection principles set out in the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018.

- ****Personal Data****: The numbers requested pertain to very small groups, which could potentially lead to the identification of individuals, thereby constituting personal data.
- ****Data Protection Principles****: Disclosing this information would breach the first data protection principle, which requires that personal data is processed lawfully, fairly, and in a transparent manner. Releasing data where the numbers are fewer than five could inadvertently disclose personal information about identifiable individuals.

Public Interest Test:

Section 40(2) is an absolute exemption and does not require a public interest test. The need to protect personal data and the privacy of individuals outweighs the interest in disclosure in these cases.

Summary:

In conclusion, while we strive to be as transparent as possible, the information you requested includes counts fewer than five, and releasing such detailed data could lead to the identification of individuals. Therefore, we are unable to disclose this information under Section 40(2) of the FOIA.

- The above data separated by treatment, focusing on the following treatments:
 - fenfluramine

- sodium valproate
- stiripentol
- clobazam
- cannabidiol
- levetiracetam
- topiramate
- potassium bromide
- Other treatments
 - carbamazepine
 - gabapentin
 - lacosamide
 - lamotrigine
 - oxcarbazepine
 - phenobarbital
 - pregabalin
 - tiagabine
 - vigabatrin
 - rufinamide
- Numbers of patients moving from one specific treatment to another e.g. fenfluramide gains from cannabidiol, sodium valproate losses to cannabidiol
- Alternatively, just the numbers of patients on each treatment for each month/quarter will be able to show how the numbers on each treatment are changing

I am writing to confirm that DBTH holds the information on the subject you have requested. However, I advise you that we will not be able to answer your request without exceeding the appropriate limit. This is because our pharmacy system doesn't store diagnosis data, so we're unable to determine this against the prescribed treatment. To ascertain this data, the Trust would need to perform an audit of each individual patient record, which wouldn't be achievable within the s.12 timescale of the Freedom of Information Act 2000.

. Section 12 of the Act makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit, We have estimated that it would take more than 18 hours to carry out a manual search to locate, retrieve, and extract all the information you have requested. In this situation the associated cost would therefore exceed the appropriate fee limit of £450 set out under Freedom of Information & Data Protection (Appropriate Limit and Fees) Regulations 2007.

The fee limit specified in regulations for NHS trusts represents the cost of one person spending 2½ working days at a rate of £25 per hour determining whether the Trust holds the information sought and then locating, retrieving and extracting that information.

If you are not satisfied with the handling of your request, you have the right to request an internal review. Requests for an internal review should be submitted within 40 working days from the date of this response, and should be addressed to d.wraith@nhs.net.

Our Ref: 345
May 2025

If you remain dissatisfied after the internal review, you have the right to appeal to the Information Commissioner's Office (ICO). The ICO can be contacted at:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
Tel: 0303 123 1113
Website: <https://ico.org.uk/make-a-complaint/>