

Our Ref: NG/RM/25200
Date: 19th June 2025

Nicola Griffiths
Deputy Director of Governance
North Staffordshire Combined Healthcare NHS Trust
Lawton House
Bellringer Road
Trentham
ST4 8HH

Reception: 0300 123 1535

Dear

Freedom of Information Act Request

I am writing in response to your e-mail of the 28th May 2025. Your request has been processed using the Trust's procedures for the disclosure of information under the Freedom of Information Act (2000).

Requested information:

I would like to submit an FOI request for the following data for North Staffordshire Combined Healthcare NHS Trust:

- 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+
- 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+
- 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+
- 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+

- 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.

As North Staffordshire Combined Healthcare NHS Trust is a Mental Health Trust and does not provide Neurology Services, Dravet syndrome and Lennox-Gastaut syndrome may not be recorded as the primary diagnosis.

A search of primary diagnosis shows that we have coding recording <5* patients recorded with these syndromes in 2024-2025, <5* with Dravet syndrome and <5* with Lennox-Gastaut syndrome, due to the small numbers we are unable to break this number down further into categories due to the risk of identification.

***As numbers are smaller than five we have replaced the number with <5, again to reduce the risk of patient identification.**

After due consideration we believe we are unable to provide a reliable response without manual trawl through patients records. We believe that the cost of collating the information in order to respond to your request would exceed the threshold of £450 as defined by the Freedom of Information and Data Protection (Appropriate limit Fees) Regulations 2004.

As a result, we are refusing your request under Section 12 of the Freedom of Information 2000 however we have included the outcome of our initial search as part of our Duty to Assist under Section 16 of the Freedom of Information Act 2000.

If you are dissatisfied with the handling of your request, you have the right to ask for an internal review of the management of your request. 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: Dr Buki Adeyemo, Chief Executive, North Staffordshire Combined Healthcare Trust, Trust Headquarters, Lawton House, Bellringer Road, Trentham, ST4 8HH. 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.

Yours sincerely



Nicola Griffiths
Deputy Director of Governance