

NHS Foundation Trust Information Governance Robert Dolan House 9 Alie Street London

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4 June 2025

E18DE

Our reference: FOI DA6078

I am responding to your request for information received 28 May 2025. This has been treated as a request under the Freedom of Information Act 2000.

I am now enclosing a response which is attached to the end of this letter. Please do not hesitate to contact me on the contact details above if you have any further queries.

Yours sincerely,

Information Rights Coordinator

If you are dissatisfied with the Trust's response to your FOIA request then you should contact us and we will arrange for an internal review of this decision.

If you remain dissatisfied with the decision following our response to your complaint, you may write to the Information Commissioner for a decision under Section 50 of the Freedom of Information Act 2000. The Information Commissioner can be contacted at:

Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

Tel: 0303 123 1113 Web: <u>www.ico.org.uk</u>

Please note that the data supplied is not allowed to be re-used and/or published without the explicit consent of East London NHS Foundation Trust. Please contact the signatory to request permission if this is your intention

Chief Executive Officer: Lorraine Sunduza

Chair: Eileen Taylor

Request:

Question 1: 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+

Answer:

The Trust has reviewed question 1 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled—
(a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and

(b) if that is the case, to have that information communicated to them.

East London NHS Foundation Trust is primarily a Mental Health and Community Health Trust and as such does not provide services for the treatment of epilepsy. The Trust is therefore unable to provide a response.

Question 2: 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+

Answer:

The Trust has reviewed question 2 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

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(b) if that is the case, to have that information communicated to them.

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Question 3: 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+

Answer:

The Trust has reviewed question 3 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled—
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Chief Executive Officer: Lorraine Sunduza Chair: Eileen Taylor (b) if that is the case, to have that information communicated to them.

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The number of patients treated for Lennox-Gastaut syndrome in 2025, Question 4: 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+

Answer:

The Trust has reviewed question 4 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled— (a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and

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Question 5: The above data separated by treatment, focusing on the following treatments:

- o fenfluramine
- o sodium valproate
- stiripentol
- o clobazam
- o cannabidiol
- levetiracetam
- topiramate
- o potassium bromide
- Other treatments
 - carbamazepine
 - gabapentin
 - lacosamide
 - lamotrigine
 - oxcarbazepine
 - phenobarbital
 - pregabalin
 - tiagabine
 - vigabatrin
 - rufinamide

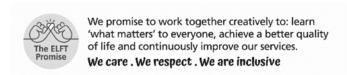
Answer:

The Trust has reviewed question 5 of your request for information under the Freedom of Information Act (FOI) 2000.

Section 1(1) of the Freedom of Information Act 2000 states:

Any person making a request for information to a public authority is entitled— (a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and

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Question 6: Numbers of patients moving from one specific treatment to another e.g. fenfluramide gains from cannabidiol, sodium valproate losses to cannabidiol

Answer: The Trust has reviewed question 6 of your request for information under the Freedom of Information Act (FOI) 2000.

> Section 1(1) of the Freedom of Information Act 2000 states: Any person making a request for information to a public authority is entitled— (a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and (b) if that is the case, to have that information communicated to them.

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Question 7: 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

The Trust has reviewed question 7 of your request for information under the Answer: Freedom of Information Act (FOI) 2000.

> Section 1(1) of the Freedom of Information Act 2000 states: Any person making a request for information to a public authority is entitled— (a) to be informed in writing by the public authority whether it holds information of the description specified in the request, and (b) if that is the case, to have that information communicated to them.

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