

Ref: FOI/2023/8603

Date Received: 12th January 2023

Response Due: 9th February 2023

Date: 13th February 2023

Dear Sir/Madam

You asked:

I would like to please request the following information, with regards to treatment of Epilepsy in your trust/ board.

In the last 12 months of available data:

1a. What number of unique patients have been treated for Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex? Please give answers for each condition separately.

Lennox-Gastaut syndrome - <5

Dravet syndrome - <5

Tuberous Sclerosis Complex - <5

Refusal Notice: Sec 40(2) Personal Information

The Trust has a policy of not releasing information when the data involved is less than 5. This is because we feel that such low numbers could make the individuals involved identifiable and therefore may cause undue harm and distress.

To disclose this information would:

- a) Contravene the Data Protection Act principles in that it would amount to unfair and possibly unlawful processing, as there was a legitimate expectation by the third parties that this information would remain confidential, and
- b) Disclosure may cause damage or distress to the individual(s) involved, and that damage or distress would be unwarranted (section 10 of the DPA).

1b. For each indication (Lennox-Gastaut syndrome, Dravet Syndrome and Tuberous Sclerosis Complex), what number of these have been treated in a paediatric environment?

All patients above are treated and monitored in a paediatric environment in the Epilepsy Clinic at the Thomas Linacre Centre and on Rainbow Ward at Wigan Infirmary, as needed locally also in the Tertiary Epilepsy Clinics at the Royal Manchester Children's Hospital (RMCH) and Alderhey Children's Hospital, Liverpool.

2a. How many patients have been treated with Epidyolex in a paediatric environment?

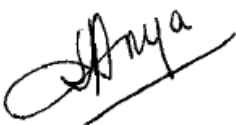
All the above patients are treated with Epidyolex in a paediatric environment. Epidyolex is initiated and prescribed in the Tertiary Epilepsy Clinics at Royal Manchester Children's Hospital (RMCH) and Alderhey Children's Hospital, Liverpool. They are monitored in our local Paediatric Epilepsy clinics here at our Wigan site.

3a. Can you please detail which NHS Trusts/ Health Boards these patients have been referred from?

All the patients live within the Wigan Borough and have been seen in local Epilepsy clinics. We have referred them from my local Epilepsy clinics to the Tertiary Epilepsy clinics appropriately via our Joint Neurology clinics (attended by Visiting Paediatric Neurologist from the Royal Manchester Children's Hospital (RMCH)).

If you are not entirely satisfied with this response, please do not hesitate to contact the Information Governance Department via the email address provided. If we do not hear from you within 28 days, we will assume that we have been able to accommodate your request under the Freedom of Information Act 2000.

Yours sincerely,



Sanjay Arya
Medical Director

PLEASE NOTE:

If you are unhappy with the service you have received in relation to your request and wish to make a complaint or request a review of our decision, you should write to: Information Governance Department, Wrightington, Wigan and Leigh NHS Foundation Trust, Suite 9, Buckingham Row, Brick Kiln Lane, Wigan, WN1 1XX.

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner for a decision at:

The Information Commissioner's Office
Wycliffe House

Water Lane
Wilmslow
Cheshire, SK9 5AF

Helpline number: 0303 123 111