

Ref: FOIA Reference 2022/23-582

Date: 27th February 2023

Email foi@uhnm.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 12th January 2023 requesting information under the Freedom of Information Act (2000) regarding Epilepsy Treatment.

On 13th January 2023 we contacted you via email as we required the following clarification: What do you mean by "...have been treated for..." – is this, they have received inpatient treatment for their condition following a seizure or treatment to manage the condition?

On 8th February 2023 you replied via email with:
'Treatment for either inpatient or to manage, would be gratefully received'

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 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.

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

A1 Outpatients - We are unable to distinguish between the different types of epilepsy as patients are seen in a generic epilepsy clinic, to ascertain the information requested would require a manual audit of all the patients who attended the epilepsy clinics.

Inpatients - As epilepsy is classed as a comorbidity the ICD10 clinical coding will be applied to the inpatient stay whether the patient was treated for the stated conditions or not. After speaking with the clinical coding team there is no specific ICD10 codes for the stated conditions therefore we are unable with doing a manual audit to identify the cohort of patients stated in the question.

Section 12 exemption as detailed below:

I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in this question is not held centrally, but may be recorded in individual health records. In order to confirm whether this information is held we would therefore have to individually access all individual health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: *cost of compliance is excessive*. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all individual health records and then extracting relevant information would take longer than the 18 hours allowed for.

In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: *oppressive burden on the authority*

Q2 How many patients have been treated with Epidyolex in a paediatric environment?

A2 None

Q3 Can you please detail which NHS Trusts/ Health Boards these patients have been referred from?

A3 Not applicable, see above

*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

UHNM NHS Trust is a public sector body and governed by EU law. FOI requestors should note that any new Trust requirements over the EU threshold will be subject to these regulations and will be advertised for open competition accordingly.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

If following review of the responses I can be of any further assistance please contact my secretary on 01782 671612.

Yours,



Rachel Montinaro
Data Security and Protection Manager - Records