

Our Reference North East and North Cumbria ICB\
FOI ICB 25–251

North East and North Cumbria ICB
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By Email

2 October 2025

Dear Applicant

Freedom of Information Act 2000 – Request for Information – NHS North East and North Cumbria Integrated Care Board (NENC ICB)

Thank you for your request received on 25 September 2025 for information held by NHS North East and North Cumbria Integrated Care Board (the ICB) under the provisions of the Freedom of Information Act 2000. The ICB covers the areas of County Durham, Newcastle Gateshead, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley.

Please find the information you requested on behalf of the ICB as follows.

Your Request

Under the laws of the freedom of information act 2000, I am writing to you to request the following information.

1. Can you please tell me the number of patients who are currently diagnosed with endogenous Cushing's disease or syndrome (ICD10 CODES – E240 & E243), within your Trust/ICB.
2. Total number of Cushing's patients who received metyrapone, for the following years... (if you are unable to split the patient numbers by year then the total number of patients over the last three years will be adequate)
 - 2024/25 – financial year
 - 2023/24 – financial year
 - 2022/23 – financial year
3. Total number of patients who received a dose of 1.5g or above of metyrapone per day at any point in their treatment, for the following years... (if you are unable to split the patient numbers by year then the total number of patients over the last three years will be adequate)
 - 2024/25 – financial year
 - 2023/24 – financial year
 - 2022/23 – financial year

4. Total number of patients who received a dose of 3g or above of metyrapone per day at any point in their treatment, for the following years... (if you are unable to split the patient numbers by year then the total number of patients over the last three years will be adequate)
 - 2024/25 – financial year
 - 2023/24 – financial year
 - 2022/23 – financial year
5. Directly from your local prescribing data from April 2022 onwards what is the median and maximum duration of treatment in months once a patient has started on metyrapone.
6. Can you send the local formulary submission form for new non-NICE approved and unlisted by CPAG, rare disease medications. If there is a separate local process for these types of medications, please can you send those details.
7. Can you send the individual patient request form for medications that are not currently on formulary.
8. Can you provide the name and/or contact details of the Meds Management lead for Cushing Syndrome treatments.

Thank you in advance for your support in this matter. I look forward to you reply within the designated timelines required by the freedom of information act.

Our Response

We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB holds some of the information you have requested.

1. We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB on this occasion is not able to provide the requested information. In line with your rights under section 1(1)(a) of the Act to be informed whether information is held, we confirm the ICB does not hold any of the information requested. However, we have determined that the information is held by the acute hospital NHS foundation trusts (FTs) within the North East and North Cumbria region.

In accordance with our duty under s.16 of the FOIA to provide reasonable advice and assistance to an individual requesting information, we have provided the FOI email addresses for those foundation trusts to make your request.

NENC Acute Hospital FTs	Email
County Durham and Darlington NHS FT	cdda-tr.cddftfoi@nhs.net
Gateshead Health NHS FT	ghnt.foi.enquiries@nhs.net
North Cumbria Integrated Care NHS FT	foirequest@cumbria.nhs.uk
North Tees and Hartlepool NHS FT	foi@nth.nhs.uk
Northumbria Healthcare NHS FT	foi@northumbria.nhs.uk
South Tees Hospitals NHS FT	foi@stees.nhs.uk
South Tyneside and Sunderland NHS FT	stsft.freedomofinformation@nhs.net
The Newcastle upon Tyne Hospitals NHS FT	nuth.freedom.information@nhs.net

2. Please refer to the response to question 1.
3. Please refer to the response to question 1.
4. Please refer to the response to question 1.

5. We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB holds some of the information you have requested. However, this is publicly available on the NHS Business Services Authority website: <https://www.nhsbsa.nhs.uk/access-our-data-products/open-data-portal-odp> Prescribing data is also publicly available at open prescribing: <https://openprescribing.net/>

In accordance with s.21 of the FOIA, we are not required to provide information in response to a request if it is reasonably accessible to you by other means.

6. The ICB has a region wide formulary and is managed by the Northern Treatment Advisory Group (NTAG) on behalf of the ICB. The link to formulary information is publicly available at: <https://www.northeastnorthcumbriaformulary.nhs.uk/about.asp> Requests for adding to the formulary is available at the following link: <https://www.northeastnorthcumbriaformulary.nhs.uk/>

As stated in the response to question 5, and in accordance with s.21 of the FOIA, we are not required to provide information in response to a request if it is reasonably accessible to you by other means.

7. Patients cannot submit requests for the prescribing of non-formulary medicines. Requests can be made by a patient's doctor or specialist.

Depending on the circumstances this may take the form of an Individual Funding Request (IFR) to the ICB by the patient's specialist. This is the link the ICB IFR Policy: <https://northeastnorthcumbria.nhs.uk/about-us/corporate-information/policies/corporate-policies/individual-funding-request-ifr-policy/>

Individual Foundation Trusts (FT) may also have their own processes for the use of non-formulary drugs. The requester will need to contact each NHS foundation trust for this information. We provided the FOI email addresses for NENC foundation trusts to make your request in the response to question 1.

8. The ICB Medicines Optimisation Team does not have a lead for Cushing Syndrome Treatment. Please direct all telephone queries to NENC ICB Reception on 0191-512-8484 or email nencicb-sun.reception@nhs.net, clearly detailing your request.

In accordance with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the NHS ICB website <https://northeastnorthcumbria.nhs.uk/>.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the service you have received in relation to your request and wish to request a review of our decision, you should write to the Information Governance Manager using the contact details at the top of this letter quoting the appropriate reference number.

If you are not content with the outcome your review, you do have the right of complaint to the Information Commissioner as established by section 50 of the Freedom of Information Act 2000. Generally, the Information Commissioner cannot make a decision unless you have exhausted the ICB's complaints procedure.

The Information Commissioner can be contacted at Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF or www.ico.org.uk.

Any information we provide following your request under the Freedom of Information Act will not confer an automatic right for you to re-use that information, for example to publish it. If you wish to re-use the information that we provide and you do not specify this in your initial application for information then you must make a further request for its re-use as per the Re-Use of Public Sector Information Regulations 2015 www.legislation.gov.uk. This will not affect your initial information request.

Yours faithfully

Information Governance Support Officer

**Information Governance Support Officer
North East and North Cumbria Integrated Care Board**