

Reference: FOI.ICB-2526/198

Subject: Cushing's Disease/Syndrome Pharmacy Management

I can confirm that the ICB does hold some of the information requested; please see responses below:

QUESTION	RESPONSE
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.	<p>It is not possible for the ICB to confirm how many people are currently diagnosed with endogenous Cushing's disease or syndrome as the ICB does not have access to full medical diagnoses records for the patients in our area.</p> <p>We can only confirm the number of patients who have had a diagnosis recorded where the diagnosis is relevant to the care activity for which the data has been collected.</p> <p>In commissioning datasets¹ held by the ICB where a diagnosis of Cushing's Disease or Syndrome has been recorded in any diagnosis position for the combined financial years 22/23, 23/24 & 24/25, fewer than 8 patients² were identified.</p>
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	<ul style="list-style-type: none"> · 24/25 - financial year – <5 patients · 23/24 - financial year – <5 patients

¹ [Datasets in support of statutory duties - NHS England Digital](#)

² Data governance rules relating to data held by the ICB require that small figure suppression is applied to any aggregated data where the figure is between 1 and 7.

<p>number of patients over the last three years will be adequate)</p> <ul style="list-style-type: none"> 24/25 - financial year 23/24 - financial year 22/23 - financial year 	<ul style="list-style-type: none"> 22/23 - financial year – <5 patients <p>Please note that '<5' has been used where the numbers are under 5 as this could make the data identifiable.</p> <p>This data is GP data and so may not be complete as some prescribing of metyrapone is from hospital and retained by hospital e.g. for children. The ICB does not hold the data for hospital prescribing of metyrapone for Cushing's.</p>
<p>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)</p> <ul style="list-style-type: none"> 24/25 - financial year 23/24 - financial year 22/23 - financial year 	<p>The ICB does not hold this data</p>
<p>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)</p> <ul style="list-style-type: none"> 24/25 - financial year 	<p>The ICB does not hold this data</p>

<ul style="list-style-type: none"> 23/24 - financial year 22/23 - 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	The ICB does not hold this data
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.	Joint Formulary Paperwork (Remedy BNSSG ICB)
7. Can you send the individual patient request form for medications that are not currently on formulary	Exceptional funding - BNSSG Healthier Together
8. Can you provide the Name and/or contact details of the Meds Management lead for Cushing Syndrome treatments	Please contact Medicines Optimisation Team via email with any questions/queries: bnssg.medicines-optimisation@nhs.net

The information provided in this response is accurate as of 2 October 2025 and has been approved for release by Dr Geeta Iyer, Deputy Chief Medical Officer for NHS Bristol, North Somerset and South Gloucestershire ICB.