

Freedom of Information Act Request

Q1. Please provide the total number of patients treated in the last 6 months for:

- Polycythaemia Vera (ICD10 code D45)
- Myelofibrosis (ICD10 code D47.4)

Diagnosis Count of D- Number
D45X: Polycythaemia vera 43
D474: Osteomyelofibrosis 100

- Myelofibrosis (ICD10 code D47.4) patients aged 65 and older

Diagnosis Count of D- Number
D474: Osteomyelofibrosis 94

Q2. How many patients were treated in the past 6 months (for any disease) with:

- Ruxolitinib - 22
- Fedratinib – 1
- Momelotinib - 3

Q3. How many patients were treated with Ruxolitinib in the past 6 months for the following diseases?

- Myelofibrosis (ICD10 code D47.4)
- Polycythaemia Vera (ICD10 code D45)
- Other/Unknown

I am writing to confirm that DBTH holds the information on the subject you have requested. However, I advise you that we will not be able to answer your request without exceeding the appropriate limit. This is because our pharmacy system doesn't store diagnosis data, so we're unable to determine this against the prescribed treatment. To ascertain this data, the Trust would need to perform an

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audit of each individual patient record, which wouldn't be achievable within the s.12 timescale of the Freedom of Information Act 2000.

. Section 12 of the Act makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit, We have estimated that it would take more than 18 hours to carry out a manual search to locate, retrieve, and extract all the information you have requested. In this situation the associated cost would therefore exceed the appropriate fee limit of £450 set out under Freedom of Information & Data Protection (Appropriate Limit and Fees) Regulations 2007.

The fee limit specified in regulations for NHS trusts represents the cost of one person spending 2½ working days at a rate of £25 per hour determining whether the Trust holds the information sought and then locating, retrieving and extracting that information.

Q4. How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years?

- Of these patients, how many were treated in the past 6 months with Hydroxycarbamide?
- Of these patients, how many were treated in the past 6 months with Interferon therapy?
- Of these patients, how many have received no active treatment in the past 6 months?

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Trust holds the information sought and then locating, retrieving and extracting that information.

If you are not satisfied with this response or you wish to complain about any aspect of the handling of your request, then you should contact me in the first instance

Please note that any request for an internal review must be made within 40 working days of the date on which the attempt to reach informal resolution has come to an end.

If you remain dissatisfied following an internal review, you may take your complaint to the Information Commissioner under the provisions of Section 50 of the Freedom of Information Act. Please note that the Information Commissioner will not investigate your case until the MOD internal review process has been completed. Further details of the role and powers of the Information Commissioner can be found on the Commissioner's website, <https://ico.org.uk/make-a-complaint/foi-and-eir-complaints/foi-and-eir-complaints/>

Q5. Does your trust participate in any clinical trials for the treatment of myelofibrosis? If so, can you please provide the name of each trial along with the number of patients taking part.

No

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