

FOI 3213

14th August 2025

FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST

ENC: FOI 3213

Question 1. Please provide the total number of patients treated in the last 6 months for:

- **Polycythaemia Vera (ICD10 code D45)**
- **Myelofibrosis (ICD10 code D47.4)**
- **Myelofibrosis (ICD10 code D47.4) patients aged 65 and older**

Response:

Please see attachment.

Question 2. How many patients were treated in the past 6 months (for any disease) with:

- **Ruxolitinib**
- **Fedratinib**
- **Momelotinib**

Response:

- Ruxolitinib 22
- Fedratinib <5
- Momelotinib 5

The Trust has a legal duty to protect patient confidentiality and, in line with this duty, the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves and the sensitivity of the information requested. In addition the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

S 40 (2) (third party information) of the Freedom of Information Act 2000 has been applied to exempt the redacted information from disclosure. The Trust does not consider the disclosure of the redacted information to be fair to the individuals

concerned as there is the potential risk of identification of an individual(s) which they would not expect, and which would therefore breach the fairness element of the first principle of the Data Protection Act 2018.

Question 3. 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**

Response:

This information is not recorded centrally. Data currently held cannot be linked to a single diagnosis and therefore retrieving it would involve a manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

Under section 12 of the Freedom of Information Act 2000, Public Authorities are not obliged to comply with an information request where to do so would exceed the cost limit.

In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

Question 4. 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?**

Response:

This information is not recorded centrally. Data currently held cannot be linked to a single diagnosis and therefore retrieving it would involve a manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

Under section 12 of the Freedom of Information Act 2000, Public Authorities are not obliged to comply with an information request where to do so would exceed the cost limit.

In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

Question 5. 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.

Response:

SHSCT is not participating in any clinical trials for the treatment of myelofibrosis.

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