

FOI REF: 24/821

11<sup>th</sup> December 2024

Tel: 0300 131 4500  
Website: [www.esht.nhs.uk](http://www.esht.nhs.uk)

## FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

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

[1<sup>st</sup> May 2024 – 31<sup>st</sup> October 2024](#)

- Polycythaemia Vera (ICD10 code D45) 18
- Myelofibrosis (ICD10 code D47.4) 37
- Myelofibrosis (ICD10 code D47.4) patients aged 65 and older 36

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

- Ruxolitinib 30
- Fedratinib 0
- Momelotinib 4

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

- Myelofibrosis (ICD10 code D47.4) 27
- Polycythaemia Vera (ICD10 code D45) 1
- Other/Unknown 2

**Q4. How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years? [November 2021 – November 2024](#)** 36

- Of these patients, how many were treated in the past 6 months with Hydroxycarbamide? 2
- Of these patients, how many were treated in the past 6 months with Interferon therapy? 0

- **Of these patients, how many have received no active treatment in the past 6 months?**

East Sussex Healthcare NHS Trust does not centrally record this information. To enable the Trust to provide this information would require a manual review of all 34 patient records which we estimate would take over 22 hours. This is because each record would have to be completely reviewed to be able to confirm that no added treatment was given at any point during the past 6 months, and we estimate that this would take approximately 40 minutes per record. We are therefore applying Section 12(1) to this part of your request.

Section 12(1) of the Act allows a public authority to refuse to comply with a request for information if the authority estimates that the cost of compliance would exceed the 'appropriate limit', as defined by the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004 (the Regulations). These state that this cost limit is £450 for public authorities which are not part of central government or the armed forces. The costs are calculated at £25 per hour per person regardless of the rate of pay, which means that the limit will be exceeded if the work involved would exceed 18 hours. The Trust estimates that the cost of complying with this request would significantly exceed the above limit.

**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.**

We do not have any clinical trials open to recruitment for myelofibrosis.

If I can be of any further assistance, please do not hesitate to contact me.

Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department ([esh-tr.foi@nhs.net](mailto:esh-tr.foi@nhs.net)), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

The Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire SK9 5AF

Telephone: 0303 123 1113

Yours sincerely

Freedom of Information Department  
[esh-tr.foi@nhs.net](mailto:esh-tr.foi@nhs.net)