

8 August 2023

Our Ref: RFI 52046

Dear

**Freedom of Information Act 2000
Information in Relation to Treatment for Myelofibrosis.**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to the above which you requested on 5 July 2023. Please accept my apologies for the delay in responding to your request, thank you for your understanding and forbearance.

A response to each of the questions raised has been provided by the Unscheduled Care, Medicine & Cancer Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital (informationgovernance@setrust.hscni.net) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

**Caroline Degans
Information Governance Officer**

Q1. Does your trust treat myeloproliferative neoplasms? If not, which other trust do you refer these patients to?

A1. Yes, the Trust does treat Myeloproliferative Neoplasms.

Q2. 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**

A2. Please see Table 1.

Table 1

Treatment	Number of Patients Treated
Polycythaemia Vera (ICD10 code D45)	Nil
Myelofibrosis (ICD10 code D47.4)	7
Myelofibrosis (ICD10 code D47.4) patients aged 65 and older	Nil

Q3. How many patients were treated in the past 6 months (for any disease) with:

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

A3. Please see Table 2.

Table 2

Treatment	Number of Patients Treated
Ruxolitinib	7
Fedratinib	Nil

- Q4. Of the patients treated in the past 6 months with Ruxolitinib, how many patients had a diagnosis for:**
- **Polycythaemia Vera (ICD10 code D45)**
 - **Myelofibrosis (ICD10 code D47.4)**
- Q5. 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?**

A4&5 The information requested is not held on a central information system. To obtain this information would require a manual review of records.

This would exceed the 'Appropriate Limit' as defined by the Freedom of Information Act 2000. The Trust therefore exempts the release of this information under Section 12(1).

12.-(1) Section 1(1) does not oblige a public authority to comply with a request for information if the authority estimates that the cost of complying with the request would exceed the appropriate limit.

In accordance with the Freedom of Information Act 2000 this letter acts as a Refusal Notice for Questions 4 and 5.

- Q6. 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.**

A6. The Trust does not participate in any clinical trial for the treatment of Myelofibrosis.