

3 April 2023

Treatment of Myelofibrosis

I have a Freedom of Information query regarding the treatment for Myelofibrosis. Could you please answer the following questions?

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

- Ruxolitinib 27
- Fedratinib <5

Use of <5 (less than five): We are unable to provide an exact figure - exempt from release under Section 40(2) of the Freedom of Information Act - as this could make patients personally identifiable. Disclosure would constitute a breach of the principles of the General Data Protection Regulation 2018.

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

Yes.

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

- Polycythaemia Vera (ICD10 code D45) <5
- Myelofibrosis (ICD10 code D47.4) 34 (June 2022 – Nov 2022)
- Myelofibrosis (ICD10 code D47.4) 13
Patients aged 65 and older

As per Question 1, where the figure is <5, we are unable to provide an exact figure - exempt from release under Section 40(2) of the Freedom of Information Act.

4. 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)
- Myelofibrosis – low risk*
- Myelofibrosis – Intermediate Risk I*
- Myelofibrosis – Intermediate Risk II or High Risk*

*Risk assessment as based on DIPSS scores if available

Belfast Trust does not hold this information centrally.

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To retrieve it would require a manual trawl of individual patient records, which would take more than 18 hours.

The Trust considers that the cost of retrieving the information would be above the 'Appropriate Limit', as defined by the Freedom of Information Act under Section 12. Section 12 of the Freedom of Information Act makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit. The limit has been specified as £450 for public authorities such as Belfast Trust. This represents the cost of one or more persons spending 18 hours in determining whether we hold the information, locating, retrieving and extracting this information.

5. How many Myelofibrosis (ICD10 code D47.4) patients has your Trust diagnosed in the past 3 years?

	2020	2021	2022	2023 (Jan - March)
Myelofibrosis Diagnoses	8	7	15	<5

Note: 3-month lag in clinical coding - no patients coded December 2022.

- **Of the patients diagnosed with Myelofibrosis in the past 3 years, how many were treated in the past 6 months with Hydroxycarbamide?**

<5

- **Of the patients diagnosed with Myelofibrosis in the past 3 years, how many were treated in the past 6 months with Interferon therapy?**

<5

- **Of the patients diagnosed with Myelofibrosis in the past 3 years, how many have received no active treatment in the past 6 months?**

<5

All other patients have been treated with Ruxolitinib and Fedratinib.

Where the figure is <5, we are unable to provide an exact figure - exempt from release under Section 40(2) of the Freedom of Information Act.