

19 August 2025

The treatment for Myelofibrosis

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

- **Polycythaemia Vera (ICD10 code D45) = 127**
- **Myelofibrosis (ICD10 code D47.4) = 45**
- **Myelofibrosis (ICD10 code D47.4) patients aged 65 and older =27**

The above figures are for the six-month period of 1st September 2024 to 28th February 2025. These are the number of patients treated as an outpatient available from our new Encompass system – Cogito.

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

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

Belfast Trust does not hold this information centrally as electronic prescribing is not in place for Haematology. To retrieve it would require a manual trawl of individual patient records, which would take more than 18 hours.

Belfast 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.

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**

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

Belfast Trust cannot answer this question, as the date of diagnosis is not recorded.

The numbers of individuals admitted to hospital as a day case or elective with a Primary Diagnosis as listed below for the time period 1st December 2021 to 31st May 2024 is the last information available, due to validation issues and a backlog in coding due to the introduction of our new Encompass system.

Individuals 36, Admissions 165.

Note:- The number of admissions may be higher than the number of individuals as patients may be admitted to hospital a number of times during the time period.

- **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?**

Belfast Trust does not hold this information centrally as electronic prescribing is not in place for haematology. To retrieve it would require a manual trawl of individual patient records, which would take more than 18 hours.

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?

FEDORA- A Phase II Study to Evaluate the Tolerability, Safety and Activity of Fedratinib combined with Ropeginterferon alfa-2b in Patients with Myelofibrosis.
– <5 patients recruited
NB. Fedora is now closed to recruitment.

PROMise - Investigation into the Combination of PLX2853 with Ruxolitinib in Patients with Intermediate-2 Or High Risk Myelofibrosis Not Receiving An Adequate Response With Ruxolitinib Alone.
– <5 patients recruited