

9 September 2021

Treatment of Certain Blood Disorders (March 2021 to August 2021): Specifically Immune Thrombocytopenia and Myelofibrosis Information and Clinical Trials

1. How many patients has your Trust treated (for any disease) in the last 6 months with the following treatments:

- Doptelet (avatrombopag) <5
- Jakavi (ruxolitinib) 24
- Nplate (romiplostim) 14
- Revolade (eltrombopag) 26
- Tavlesse (fostamatinib) 0
- Hydroxycarbamide 100

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

2. In the last 6 months, how many patients has your Trust treated for:

- Immune thrombocytopenia (ICD10 code D69.3): 23 patients with Immune thrombocytopenia were admitted for a procedure between 1st December 2020 and 1st May 2021. However, this may not have been related to this diagnosis.
- Myelofibrosis (ICD10 code D47.4): <5
- Myelofibrosis (ICD10 code D47.4) – patients over the age 65: <5

3. Of the patients treated for immune thrombocytopenia (ICD10 code D69.3) in the last 6 months, how many were treated with:

- Mycophenolate mofetil
- Rituximab
- Surgery (splenectomy)

Belfast Trust does not hold this information centrally. 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 FOI 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.

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

	2018	2019	2020	2021 (Jan - July)
Myelofibrosis Diagnoses	6	7	5	<5

5. Of the myelofibrosis patients diagnosed in the last 3 years, how many were treated in the past 6 months with Hydroxycarbamide?

None

6. Of the myelofibrosis patients diagnosed in the last 3 years, how many have received no active treatment in the past 6 months?

As per response to Q3, Belfast Trust does not hold this information centrally. 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 FOI Act under Section 12.

7. Does you trust participate in any ongoing clinical trials for immune thrombocytopenia (ITP)? If so, can you please provide the name of each trial along with the number of patients taking part?

The Trust does not participate in any ongoing trials for immune thrombocytopenia (ITP).

8. Does you trust participate in any ongoing clinical trials for myelofibrosis? If so, can you please provide the name of each trial, along with the number of patients taking part?

The Trust participates in clinical trials for myelofibrosis. Please see details of recruitment below:

Trial name	2021	2020	2019
Manifest	0	0	<5
Mosaicc	0 (currently study suspended)	7	N/A
M16-109	<5	N/A	N/A
Total	<5	7	<5