

Date: 01/09/2021

Ref: 21-22 277

Freedom of Information request

Thank you for your request for information under the Freedom of Information Act 2000, which was received by the Trust on 19/08/2021. Please see responses to your requests below.

Q1. How many patients has your trust treated (for any disease) in the last 6 months with the following treatments:

Medication	Patients Treated
Doptelet (avatrombopag)	0
Jakavi (ruxolitinib)	46
Nplate (romiplostim)	78
Revolade (eltrombopag)	86
Tavlesse (fostamatinib)	0
Hydroxycarbamide	113

Q2. In the last 6 months, how many patients has your trust treated for:

Condition	Patients Treated
Immune thrombocytopenia (ICD10 code D69.3)	55
Myelofibrosis (ICD10 code D47.4)	13
Myelofibrosis (ICD10 code D47.4) – patients over the age 65	11

Q3. Of the patients treated for immune thrombocytopenia (ICD10 code D69.3) in the last 6 months, how many were treated with:

Treatment	Patients Treated
Mycophenolate mofetil	< 5
Rituximab	0
Surgery (splenectomy)	0

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

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

In the last 6 months the Trust has treated < 5 patients with Hydroxycarbamide.

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

The Trust has treated 53 patients who has myelofibrosis in the last three years, to extract this information, we would have to search through a significant amount of patient records. It is estimated that to attempt to retrieve all the information you require would take a considerable amount of retrieval time, which would exceed 18 hours. This would exceed the appropriate limit for dealing with a Freedom of Information Request, in terms of costs and therefore Section 12(1) of the Freedom of Information Act 2000 applies.

Q5. 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 participates in the following trials:

The UK Paediatric ITP Registry

This is a registry for children with acute and chronic immune thrombocytopenia. The primary aim is to relate the long term consequence of a low platelet count to the frequency and severity of bleeding symptoms and to the requirement for treatment. There are 36 participants that are taking part in this study.

The UK Adult ITP Registry

This study seeks to uncover information regarding the aetiology, epidemiology, natural progression, treatment effectiveness and co morbidities of adult ITP in the UK through a multicentre disease registry. There are 97 participants that are taking part in this study.

Q6. 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 is not currently taking part in any clinical trials for myelofibrosis.

Please accept this letter as completion of your request. Please note that copies of this request will be held on file for three years before being confidentially destroyed.

If you are dissatisfied with the outcome of your request, please contact our Head of Information Governance on Information.Governance@porthosp.nhs.uk or write to the above address and we will conduct an internal review. Upon review, if you are still dissatisfied, you may appeal our decision by contacting the Information Commissioner's Office; for more information, please visit the [ICO's website](#).

Please be aware, if we do not receive an appeal within 30 days of you receiving this letter, we will assume that you are satisfied with our response. If you have any further queries, please do not hesitate to contact us.

Yours sincerely

Freedom of Information Team