

Freedom of Information Act 2000 - Request Reference Fol/21/378

Treatment of Blood Disorders

Request Details

I have a freedom of information request related to the treatment of certain blood disorders. I would greatly appreciate if you could answer the following questions.

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

Doptelet (avatrombopag)	4
Jakavi (ruxolitinib)	18
Nplate (romiplostim)	15
Revolade (eltrombopag)	38
Tavlesse (fostamatinib)	0
Hydroxycarbamide	99

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

- Immune thrombocytopenia (ICD10 code D69.3)
- Myelofibrosis (ICD10 code D47.4)
- Myelofibrosis (ICD10 code D47.4) – patients over the age 65

Count of Distinct Patients coded with ICD10 codes D693 or D474 in any position between 1/3/21 and 31/8/21

Count	All Ages
Immune thrombocytopenia	59

Count	Under 65	65+	Summary
Myelofibrosis	7	6	13

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

Mycophenolate mofetil	0
Rituximab	8
Surgery (splenectomy)	0

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

- Of the myelofibrosis patients diagnosed in the last 3 years, how many were treated in the past 6 months with Hydroxycarbamide?
- Of the myelofibrosis patients diagnosed in the last 3 years, how many have received no active treatment in the past 6 months?

In completing a search for the information requested, Cardiff and Vale University Health Board (the UHB) has confirmed that this information is not centrally recorded or collated. To retrieve the information requested would require a manual trawl through individual records and the UHB considers that this would exceed the limit set within regulations for responding to a request. The UHB has therefore relied upon the Section 12 exemption ('Exemption where cost of compliance exceeds appropriate limit') of the Freedom of Information Act 2000 and is refusing your request.

The UHB has estimated that to complete the work needed to respond to this request would exceed the time limit as set within regulations to respond to a Freedom of Information Act request. Under the Act there is an allowance of two and a half days, or 18 hours, to comply with a request and the cost limit set within the fees regulations for this amount of work (18 hours) is £450 for the UHB. The fees regulations specify that the cost of complying with a request must be calculated at the rate of £25 per hour.

However, under our Section 16 obligation to provide advice and assistance, I can inform you that 3 Patients were treated with Hydroxycarbamide in the past 6 months.

5. Does your 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 UHB are not participating in an ongoing ITP study at present.

6. Does your 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?

- PROMISE *
- MANIFEST-1 *
- Celgene ACE-536-MF-001 - 0 Patients enrolled.
- SRA-MMB-4365 (trial closed to recruitment) *

Please note that Section 40 of the Freedom of Information Act 2000 has been applied where information above has been replaced with an asterisk. The UHB will not provide these exact numbers due to the low numbers of individuals involved (5 or less). The UHB believes there is a

potential risk of individuals being able to be identified, when considered with other information already available within the public domain, if this was disclosed. Therefore, the data is classed as personal data as defined under the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This exemption is absolute and therefore there is no requirement to apply the public interest test.

However, under our Section 16 obligation to provide advice and assistance, I can inform you of the clinical trial names.