

Freedom of Information Act 2000 - Request Reference FoI/23/125

Myelofibrosis

Information Requested:

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 - 37

Fedratinib - 1

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)

Myelofibrosis (ICD10 code D47.4)

Myelofibrosis (ICD10 code D47.4) patients aged 65 and older

Number of Admissions as values		6 Months
D45 - Polycythaemia vera	All Ages	45
D474 - Osteomyelofibrosis	18-64	68
	65+	79
	All Ages	147
Total		192

Please note: Cardiff and Vale University Health Board (the UHB) have supplied the numbers of Patients admitted with either of the conditions as their Primary Diagnosis during the most recent 6 months from July to December to allow for a delay in coding.

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)

In completing a search for the information requested, the UHB has confirmed that this information is not centrally recorded or collated. To retrieve the information requested would require a manual search 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.

- 5. How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years?
Of the patients diagnosed with myelofibrosis in the past 3 years, how many were treated in the past 6 months with Hydroxycarbamide?
Of the patients diagnosed with myelofibrosis in the past 3 years, how many were treated in the past 6 months with Interferon therapy?
Of the patients diagnosed with myelofibrosis in the past 3 years, how many have received no active treatment in the past 6 months?**

The UHB believes that Section 12 applies here, please see the exemption set out above.