

Reference:	FOI.11207.23
Subject:	Myelofibrosis treatment
Date of Request:	7 March 2023

Requested:

1. How many patients were treated in the past 6 months (for any disease) with:
 - Ruxolitinib
 - Fedratinib
2. Does your trust treat myeloproliferative neoplasms? If not, which other trust do you refer these patients to?
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
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)
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?

Response:

Hywel Dda University Health Board (UHB) is unable to provide you with all of the information requested, as it is estimated that the cost of answering your request would exceed the “appropriate limit” as stated in the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

In order to provide you with the data requested, the UHB would need to undertake a manual search of all Haematology patient medical records which are located across the UHB, to identify those patients diagnosed with myelofibrosis and scrutinise those patients’ records, to identify any information that would fulfil your request, as this is not recorded centrally.

The UHB is therefore applying an exemption under Section 12 of the Freedom of Information Act 2000 (FoIA), which provides an exemption from a public authority’s obligation to comply with a request for information where the cost of compliance is estimated to exceed the appropriate limit.

However, under section 16 of the FoIA, the UHB has a duty to provide advice and assistance. Therefore, the UHB has provided the accessible information it holds, for all diseases, for question 1 below.

1. The table below provides the number of patients treated with the named medications, for any disease, during the period 1 September 2022 and 28 February 2023.

Medication	Number
Ruxolitinib	21
Fedratinib	0