

Reference:	FOI.18783.25
Subject:	Myelofibrosis
Date of Request:	10 November 2025

Requested:

1. Please provide the total number of patients treated in the last 6 months for:
 - a. Polycythaemia Vera (ICD10 code D45)
 - b. Myelofibrosis (ICD10 code D47.4)
 - c. Myelofibrosis (ICD10 code D47.4) patients aged 65 and older

2. How many patients were treated in the past 6 months (for any disease) with:
 - a. Ruxolitinib
 - b. Fedratinib
 - c. Momelotinib

3. How many patients were treated with Ruxolitinib in the past 6 months for the following diseases?
 - a. Myelofibrosis (ICD10 code D47.4)
 - b. Polycythaemia Vera (ICD10 code D45)
 - c. Other/Unknown

4. How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years?
 - a. Of these patients, how many were treated in the past 6 months with Hydroxycarbamide?
 - b. Of these patients, how many were treated in the past 6 months with Interferon therapy?
 - c. Of these patients, 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 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 Act 2000 (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2 ½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

In order to provide you with all of the data requested for question 4c, the UHB would need to undertake a manual trawl of the medical records for patients receiving treatment for Myelofibrosis, to identify any information that would fulfil this part of your request, as it is not recorded centrally.

The UHB can confirm that one hundred and twenty-three (123) patients were diagnosed with Myelofibrosis (ICD10 code D47.4), during the three-year period from 1 November 2022 to 31 October 2025. It is estimated that a manual search of these records would exceed the 18 hours stipulated within the Freedom of Information Act 2000 (FoIA). Based on the number of records identified, conducting a search of digital records taking a minimum of ten (10) minutes per digital record, would exceed the ‘appropriate limit’, costing the UHB the following:

123 @ 10 minutes per record = 20 hours and 33 minutes
 20 hours and 33 minutes @ £25 per hour = £513.75

The UHB is therefore applying an exemption under Section 12 of the 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, we are required as a public authority, to provide advice and assistance so far as it is reasonable to individuals who have made a request under the FoIA, this can include assisting a requestor to further refine their request.

Unfortunately, the UHB is unable to provide advice on how you can refine your request for question 4c further. This is due to the UHB still requiring a manual trawl of incident records to be undertaken to identify any of the information requested.

Additionally, the UHB is unable to provide you with some of the requested information as there is a potential risk of identifying individuals if this was disclosed. The UHB is therefore withholding the following details under Section 40(2) of the FoIA:

- The figures in the tables for questions 2 and 3 have been replaced with an asterisk (*) due to the low number of cases (less than 5)
- The information requested for question 4a, due to the low number of cases (less than 5).

This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations, as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles of the UK GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

In reaching this decision, the DPA and UK GDPR define personal data as data that relates to a living individual who can be identified solely from that data or from that data and other information, which is in the possession of the data controller.

1. The UHB provides within the table below, the number of patients treated for the listed conditions, and the number treated for Myelofibrosis aged sixty-five (65) and over, during the period 1 May to 31 October 2025.

Condition	Number
Polycythaemia Vera (ICD10 code D45)	6
Myelofibrosis (ICD10 code D47.4)	29
Myelofibrosis (ICD10 code D47.4) patients aged 65 and over	5

2. The UHB provides within the table below, the number of patients treated with the listed medications, for any disease, during the period 1 May to 31 October 2025.

Medication	Number
Ruxolitinib	12
Fedratinib	0
Momelotinib	*

3. The UHB provides within the table below, the number of patients treated with Ruxolitinib for the listed conditions, during the period 1 May to 31 October 2025.

Medication	Number
Myelofibrosis (ICD10 code D47.4)	9
Polycythaemia Vera (ICD10 code D45)	*
Other/Unknown	0

4. The UHB confirms that one hundred and twenty-three (123) patients were diagnosed with Myelofibrosis (ICD10 code D47.4), during the three-year period from 1 November 2022 to 31 October 2025.
- a. Section 40 exemption applied.
 - b. The UHB confirms that of the patients identified in response to question 4, none were treated with Interferon therapy, during the period 1 May to 31 October 2025.
 - c. An exemption under Section 12 of the FoIA applied.