

Reference:	FOI.20898.26
Subject:	Treatment for Myelofibrosis
Date of Request:	1 July 2026

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:
 - Ruxolitinib
 - Fedratinib
 - 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 ninety-seven (97) patients were diagnosed with Myelofibrosis (ICD10 code D47.4), during the three-year period from 1 July 2023 to 30 June 2026. 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 fifteen (15) minutes per digital record, would exceed the ‘appropriate limit’, costing the UHB the following:

97 @ 15 minutes per record = 24 hours and 15 minutes
 24 hours and 15 minutes @ £25 per hour = £606.25

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 patient records to be undertaken to identify any of the information requested.

Additionally, the UHB is unable to provide you with the exact number of patients, due to the low number (less than 5) and have therefore, replaced the figures in the tables with an asterisk (*), as there is a potential risk of identifying individuals if this was disclosed. The UHB is therefore withholding this detail under Section 40(2) of the FoIA. This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations (UK GDPR) 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 January to 30 June 2026.

Condition	Number
Polycythaemia Vera (ICD10 code D45)	70
Myelofibrosis (ICD10 code D47.4)	12
Myelofibrosis (ICD10 code D47.4) patients aged 65 and over	12

2. The UHB provides within the table below, the number of patients treated with the listed medications, for any disease, during the period 1 January to 30 June 2026.

Medication	Number
Ruxolitinib	10
Fedratinib	*
Momelotinib	*

3. The UHB provides within the table below, the number of patients treated with Ruxolitinib for the listed conditions, during the period 1 January to 30 June 2026.

Medication	Number
Myelofibrosis (ICD10 code D47.4)	8
Polycythaemia Vera (ICD10 code D45)	*
Other/Unknown	0

4. The UHB confirms that ninety-seven (97) inpatients were discharged with a recorded diagnosis of Myelofibrosis (ICD10 code D47.4), during the three-year period from 1 July 2023 to 30 June 2026.
 - a. Of the patients identified in response to question 4, none were treated with Hydroxycarbamide, during the period 1 January to 30 June 2026.
 - b. Of the patients identified in response to question 4, none were treated with Interferon therapy, during the period 1 January to 30 June 2026.
 - c. An exemption under Section 12 of the FoIA has been applied.