

**Freedom of Information Act 2000 – Request Reference FoI/24/405**  
**Myeloproliferative Neoplasms**

**Q1. Please provide the total number of patients treated in the last 6 months for:**

- Polycythaemia Vera (ICD10 code D45)

Cardiff and Vale University Health Board (the UHB) has estimated that to complete the work needed to respond to this request would exceed the time limit as outlined in the Appropriate Limit and Fees Regulations 2004. When estimating the cost of complying with a request for information under the applicable legislation, the UHB must calculate this cost at a rate of £25 per person per hour to a maximum of £450, with the appropriate time limit for complying therefore being 18 hours.

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 which the UHB considers would exceed the appropriate limit for the purposes of the 2004 Regulations. The UHB has therefore relied upon the exemption set out in section 12 of the Freedom of Information Act 2000 ('Exemption where cost of compliance exceeds appropriate limit') and is refusing your request.

- Myelofibrosis (ICD10 code D47.4) – 19
- Myelofibrosis (ICD10 code D47.4) patients aged 65 and older – 11

**Q2. How many patients were treated in the past 6 months (for any disease) with:**

- Ruxolitinib – 34
- Fedratinib – 1
- Momelotinib – 3

**Q3. How many patients were treated in the past 6 months for Myelofibrosis (ICD10 code D47.4) with:**

- Ruxolitinib
- Fedratinib
- Momelotinib

The UHB believes the exemption as outlined in section 12 of the 2000 Act applies here and is therefore refusing your request.

**Q4. How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years?**

- Of these patients, how many were treated in the past 6 months with Hydroxycarbamide?
- Of these patients, how many were treated in the past 6 months with Interferon therapy?
- Of these patients, how many have received no active treatment in the past 6 months?

The UHB believes the exemption as outlined in section 12 of the 2000 Act applies here and is therefore refusing your request.

**Q5. Does your trust participate in any clinical trials for the treatment of myelofibrosis? If so, can you please provide the name of each trial along with the number of patients taking part.**

- Incyte INCB 00928-104 (commercial study) – opened to recruitment, one patient currently in screening.
- FEDORA (investigator-led study – part of TAP, trials acceleration programme) – open until 31 August 2024, one patient recruited and on treatment.
- PROMISE (investigator-led study, CRUK funded) – open, four patients recruited to date.
- MANIFEST-2 (commercial study) – closed to recruitment, two patients recruited and one remains on treatment, one has stopped.
- MANIFEST-1 (commercial study) – closed to recruitment, three patients recruited, one remains on treatment, two in follow-up. Patients in this trial are soon to be transferred to a commercial follow-on study to ensure continuing drug supply.
- Gilead GS-352-0101 (commercial study) – closed to recruitment, one patient remains on treatment.
- MOSAICC – an epidemiological study covering a range of patients with different myeloproliferative neoplasms, including polycythaemia vera, essential thrombocythaemia and myelofibrosis. Nine patients have been entered into the study so far. And a further two patients are currently screening for this study.
- Kartos KRT-115 study (commercial study) – recently approved and in set up, scheduled to open in either the third or fourth quarter of 2024.