Freedom of Information Act 2000 – Request Reference FoI/23/579
Myeloproliferative Neoplasms Treatment

Information Requested:

Q1. How many patients were treated in the past 6 months (for any disease) with:

- Ruxolitinib
- Fedratinib
- Interferon (any type)

Q2. 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)

Q3. 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?

Q4. How many Polycythaemia Vera (ICD10 code D45) 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?

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.

Response Details:

In response to Q1:

- Ruxolitinib: 31
- Fedratinib: 2
- Interferon (any type): 0

In response to Q2:

In completing a search for the information requested, Cardiff and Vale University Health Board (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 of the Freedom of Information Act 2000 ('Exemption where cost of compliance exceeds appropriate limit') 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.

In response to Q3 and Q4:

Please see the response to Q2.

In accordance with our duty to advise and assist under section 16 of the Act, the UHB can confirm that it is unable to identify the date of diagnosis from the available data.

In response to Q5:

Yes, the UHB participates in clinical trials for patients with myelofibrosis.

Current trials that include myelofibrosis patients include:

- FEDORA (investigator-led study – part of TAP, trials acceleration programme) – open, 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 remain on treatment.
- MANIFEST-1 (commercial study) – closed to recruitment, three patients recruited, one remains on treatment, two in follow-up.
- 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.