Reference:	FOI.13083.23
Subject:	Treatments for myelofibrosis and polycythaemia vera
Date of Request:	8 November 2023

Requested:

1. How many patients were treated in the past 6 months (for any disease) with:
   - Ruxolitinib
   - Fedratinib
   - Interferon (any type)

2. 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)

3. 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?

4. 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?

5. 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:

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 Act 2000 and the 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 for questions 3 and 4, the UHB would need to undertake a manual trawl of all patient records and liaise with the Primary Care Team, to identify any information that may fulfil these parts of your request, as this information 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 provides the accessible information it holds overleaf.

Additionally, where the figures in the tables below have been replaced with an asterisk (*), the UHB is unable to provide you with the exact number of patients due to the low numbers of cases (less than 5), 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 Freedom of Information Act 2000 (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 with the listed medications, for all conditions, during the period 1 May to 31 October 2023.

Medication	Number
Ruxolitinib	16
Fedratinib	*
Interferon (any type)	0

2. 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 2023.

Medication	Number
Polycythaemia Vera (ICD10 code D45)	*
Myelofibrosis (ICD10 code D47.4)	14

3. & 4. Section 12 exemption applied.

5. The UHB confirms that it is not currently participating in any clinical trials for the treatment of myelofibrosis.