

Reference:	FOI.6714.21
Subject:	Treatment of certain blood disorders
Date of Request:	19 August 2021

Requested:

I have a freedom of information request related to the treatment of certain blood disorders. I would greatly appreciate if you could answer the following questions.

1. How many patients has your trust treated (for any disease) in the last 6 months with the following treatments:
 - Doptelet (avatrombopag)
 - Jakavi (ruxolitinib)
 - Nplate (romiplostim)
 - Revolade (eltrombopag)
 - Tavlesse (fostamatinib)
 - Hydroxycarbamide

2. In the last 6 months, how many patients has your trust treated for:
 - Immune thrombocytopenia (ICD10 code D69.3)
 - Myelofibrosis (ICD10 code D47.4)
 - Myelofibrosis (ICD10 code D47.4) – patients over the age 65

3. Of the patients treated for immune thrombocytopenia (ICD10 code D69.3) in the last 6 months, how many were treated with:
 - Mycophenolate mofetil
 - Rituximab
 - Surgery (splenectomy)

4. How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years?
 - Of the myelofibrosis patients diagnosed in the last 3 years, how many were treated in the past 6 months with Hydroxycarbamide?
 - Of the myelofibrosis patients diagnosed in the last 3 years, how many have received no active treatment in the past 6 months?

5. Does you trust participate in any ongoing clinical trials for immune thrombocytopenia (ITP)? If so, can you please provide the name of each trial along with the number of patients taking part?

6. Does you trust participate in any ongoing clinical trials for 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 and Data Protection (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 the information requested, the UHB would need to conduct a manual search of all immune thrombocytopenia patient records to identify those treated with Mycophenolate, as the code is not recorded in the UHB’s Welsh Patient Administration System (WPAS). Rituximab is used to treat multiple conditions and therefore the UHB’s WPAS is unable to identify the immune thrombocytopenia patients that are receiving this treatment.

Furthermore, the UHB would need to undertake a manual trawl of patient records to identify those diagnosed with myelofibrosis (ICD10 code D47.4) and identify the treatments administered, 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, 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 FoIA. Therefore, the UHB provides the information it holds below.

1. The UHB provides, within the table below, the number of patients treated with the listed medications, during the period 1 February to 31 July 2021.

Medication	Number of patients
Doptelet (avatrombopag)	*
Jakavi (ruxolitinib)	13
Nplate (romiplostim)	18
Revolade (eltrombopag)	24
Tavlesse (fostamatinib)	*
Hydroxycarbamide	78

Where the figures in the table 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 (5 and under), 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/General Data Protection Regulations 2016 (GDPR), as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles 6 and 9 of the GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

In reaching this decision, the Data Protection Act 2018/General Data Protection Regulations 2016 define personal data as data which 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.

2. The UHB provides, within the table below, the number of patients treated for the listed conditions, during the period 1 March to 31 July 2021.

Condition	Number of patients
Immune thrombocytopenia (ICD10 code D69.3)	158
Myelofibrosis (ICD10 code D47.4)	19
Myelofibrosis (ICD10 code D47.4) – patients over the age 65	19

3. & 4. A Section 12 exemption has been applied to these questions; a full explanation is provided above. However, in accordance with its Section 16 duties, the UHB is able to provide some partial information.

Within the table overleaf, the UHB provides the number of patients that were admitted to hospital with the admission coded as D47.7 on the UHB's WPAS, for the calendar years 2018 to 2020 and 1 January to 31 July 2021.

Calendar year	Number of admissions
2018	103
2019	121
2020	44
1 January to 31 July 2021	27

Additionally, the UHB can also confirm that no patients treated for immune thrombocytopenia (ICD10 code D69.3) were treated with Surgery (splenectomy), during the period 1 March and 31 July 2021.

Please note: Recent figures may be subject to change because of a standard clinical coding backlog of up to three (3) months.

5. The UHB confirms that it is currently participating in a clinical trial for immune thrombocytopenia (ITP), with thirty nine (39) patients participating in the United Kingdom Adult Idiopathic Thrombocytopenic Purpura (ITP) Registry: An Investigation of Disease Progression, Treatment Effectiveness, and Co-morbid Conditions.
6. The UHB confirms that it is not currently participating in any clinical trials for myelofibrosis.