



Ymddiriedolaeth GIG  
Prifysgol Felindre  
Velindre University  
NHS Trust



Pencadlys Ymddiriedolaeth GIG Prifysgol Felindre  
Velindre University NHS Trust Headquarters  
2 Cwrt Charnwood  
Heol Billingsley  
Parc Nantgarw  
Caerdydd/Cardiff  
CF15 7QZ  
Ffôn/Phone : (029) 20196161  
<https://velindre.nhs.wales>

Date: 23<sup>rd</sup> August 2024  
Ref: CORP 2024 - 147

Dear xxx

**Freedom of Information request: Treatment of haematology (CORP 2024 – 147)**

Thank you for your request for information which the Trust received on 6<sup>th</sup> August 2024.

Your Request:

**MYELOPROLIFERATIVE DISEASES**

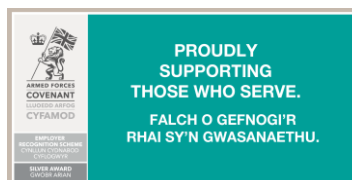
Q1. How many patients were treated in total, regardless of diagnosis, with the following medicines in the 3 months between the start of April 2024 and end of June 2024, or latest 3-month period available?

Name of medicine	Number patients treated
1.1 Fedratinib (Inrebic)	
1.2 Momelotinib (Omjjara)	
1.3 Ruxolitinib (Jakavi)	
1.4 Hydroxycarbamide	

Q2 How many patients were treated for the following myeloproliferative diseases in the 3 months between the start of April 2024 and end of June 2024, or latest 3-month period available?

Diagnosis with ICD10 codes	Number patients treated
2.1 Polycythaemia vera ICD10 codes = D45, D450, D45.0, D45X OR morphology code = 9950/3	
2.2 Myelofibrosis ICD10 codes = C944, C94.4 or D474, D47.4; OR morphology codes = 9931/3 or 9961/3	
2.3 Essential thrombocythemia ICD10 code = D473, D47.3 OR morphology code = 9962/3	
2.4 Myeloproliferative Disease, Chronic ICD10 code = D471, D47.1	

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**Q3. How many patients with *Myelofibrosis* (ICD10 codes = C944 or D474; OR morphology codes = 9931/3 or 9961/3) were treated with the following medicines in the 3 months between the start of April 2024 and end of June 2024, or latest 3-month period available?**

Name of medicine	Number patients treated
3.1 Fedratinib (Inrebic)	
3.2 Momelotinib (Omjjara)	
3.3 Ruxolitinib (Jakavi)	
3.4 Hydroxycarbamide	
3.5 Peginterferon Alfa-2a (Pegasys)	
3.6 Ropeginterferon Alfa-2b (Besremi)	
3.7 Epoetin alfa (Eprex, Binocrit)	
3.8 Epoetin beta (NeoRecormon, Mircera)	
3.9 Epoetin zeta (Retacrit)	
3.10 Darbepoetin (Aranesp)	
3.11 No active treatment	
3.12 Allogeneic stem cell transplant	

**Q4. How many patients were treated with *ruxolitinib (Jakavi)* in combination with *epoetin* in the 3 months between the start of April 2024 and end of June 2024, or latest 3-month period available?**

Please include all types of epoetin – epoetin alfa, epoetin beta, epoetin zeta, darbepoetin alfa

Name of medicine	Number patients treated
4.0 Ruxolitinib (Jakavi) + epoetin	

### **NON HODGKIN LYMPHOMA (NHL) AND CHRONIC LYMPHOCYTIC LEUKAEMIA (CLL)**

**Q5. How many patients were treated in total, regardless of diagnosis, with the following medicines in the**

**3 months between the start of April 2024 and end of June 2024, or latest 3-month period available?**

Name of medicine	Number patients treated
5.1 Acalabrutinib (Calquence)	
5.2 Ibrutinib (Imbruvica)	
5.3 Pirtobrutinib (Jaypirca)	
5.4 Venetoclax (Venclyxto)	
5.5 Zanubrutinib (Brukinsa)	

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Q6. How many patients with **Chronic Lymphocytic Leukaemia OR Small B-Cell Lymphoma** – ICD10 codes = C911, C91.1 OR C830, C83.0 - were treated with the following medicines in the 3 months between the start of April 2024 and end of June 2024, or latest 3-month period available?

Name of medicine	Number patients treated
6.1 Acalabrutinib (Calquence)	
6.2 Ibrutinib (Imbruvica)	
6.3 Pirtobrutinib (Jaypirca)	
6.4 Venetoclax (Venclyxto)	
6.5 Zanubrutinib (Brukinsa)	

Q7. How many patients with **Chronic Lymphocytic Leukaemia OR Small B-Cell Lymphoma** were treated with the following medicines as monotherapy, or in combination, in the 3 months between the start of April 2024 and end of June 2024, or latest 3-month period available?

Name of monotherapy or combination	Number patients treated
7.1 Ibrutinib + venetoclax	
7.2 Obinutuzumab + venetoclax	
7.3 Acalabrutinib monotherapy / maintenance	
7.4 Zanubrutinib monotherapy / maintenance	
7.5 Ibrutinib monotherapy / maintenance	
7.6 Venetoclax monotherapy	
7.7 Venetoclax + rituximab	

### MANTLE CELL LYMPHOMA

Q8. How many patients with **Mantle Cell Lymphoma** – ICD10 code = C831, C83.1 - were treated in the 3 months between the start of April 2024 and end of June 2024, or latest 3-month period available?

	Number patients treated
8.0 Treated for Mantle Cell Lymphoma	

Q8.1 How many patients with **Mantle Cell Lymphoma** were treated with the following medicines as monotherapy, or in combination, in the 3 months between the start of April 2024 and end of June 2024, or latest 3-month period available?

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Name of medicine	No. patients treated
8.1 MaxiCHOP + rituximab + high dose Cytarabine or NORDIC protocol	
8.2 Stem Cell Transplant	
8.3 Rituximab + bendamustine + cytarabine	
8.4 Rituximab + bendamustine	
8.5 Ibrutinib	
8.6 Rituximab + CHOP, Rituximab + CVP or rituximab + other chemo	
8.7 Acalabrutinib + rituximab + bendamustine	

Please find the Trust's response below:

In relation to **Question 1** the Trust's Pharmacy do not use any of these regimens.

In relation to **Questions 2-8**, the Trust does not record the data requested in a format that enables the information to be easily retrieved to the level of detail required to specifically answer your request. This would involve a manual review of patient notes.

In reaching this decision we estimate that it would take a minimum of 22 hours or £550 an amount of £100 over the core amount of £450 extra to obtain the data. The amount would require payment in full prior to the Trust undertaking the work.

As result, the Trust is applying an exemption under Section 12 Freedom of Information Act (Exemption where cost of compliance exceeds appropriate limit), the legislation in this instance states:

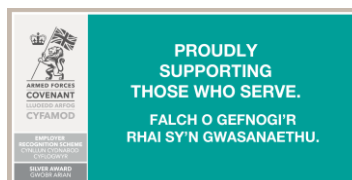
**12 Exemption where cost of compliance exceeds appropriate limit.**

*(1) Section 1(1) does not oblige a public authority to comply with a request for information if the authority estimates that the cost of complying with the request would exceed the appropriate limit.*

The Trust has a duty to advise and assist you under Section 16 of the Act and therefore may I suggest that you consider the option to revise your request so that it falls below the prescribed appropriate limit.

I trust this answers your request for information, however, should you not be satisfied with the information supplied or the process of supplying it, you have a right to complain and request a

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review. Please note that you must submit a request for a review within 40 days of the date of this letter.

You should forward your complaint to:

Mr Ian Bevan via [FOI.VUNHST@wales.nhs.uk](mailto:FOI.VUNHST@wales.nhs.uk)  
Head of Information Governance  
Velindre University NHS Trust  
2, Charnwood Court  
Heol Billingsley  
Parc Nantgarw  
Cardiff  
CF15 7QZ

Should you wish to take your complaint further, if you are still unhappy with the decision after review, you can contact the:

Information Commissioner's Office - Wales  
2nd Floor  
Churchill House  
Churchill Way  
Cardiff  
CF10 2HH  
Telephone: 0330 414 6421  
email: [wales@ico.org.uk](mailto:wales@ico.org.uk)

Yours sincerely

**Non Gwilym**  
**Interim Director of Corporate Governance**  
Velindre University NHS Trust  
2 Charnwood Court  
Heol Billingsley  
Parc Nantgarw  
Cardiff  
CF15 7QZ

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