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Welsh Blood Service



Canolfan Ganser Felindre
Velindre Cancer Centre

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: 28th March 2023

Ref: CORP 2023-041

Dear *****

Freedom of Information request: Treatment for Myelofibrosis - CORP 2023-041

Thank you for your request for the following information which the Trust received on 8th of March 2023.

Your Request:

I have a freedom of information query regarding the treatment for Myelofibrosis. Could you please answer the following questions:

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

- *Ruxolitinib*
- *Fedratinib*

Q2. Does your trust treat myeloproliferative neoplasms? If not, which other trust do you refer these patients to?

Q3. Please provide the total number of patients treated in the last 6 months for:

- *Polycythaemia Vera (ICD10 code D45)*
- *Myelofibrosis (ICD10 code D47.4)*
- *Myelofibrosis (ICD10 code D47.4) patients aged 65 and older*

Q4. 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)*

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Q5. How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years?

- *Of the patients diagnosed with myelofibrosis in the past 3 years, how many were treated in the past 6 months with Hydroxycarbamide?*
- *Of the patients diagnosed with myelofibrosis in the past 3 years, how many were treated in the past 6 months with Interferon therapy?*
- *Of the patients diagnosed with myelofibrosis in the past 3 years, how many have received no active treatment in the past 6 months?*

The Trust's response:

The Trust has reviewed your request which is correctly formatted and complies with Section 8 of the Freedom of Information Act.

The Information you have requested is below:

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

- Ruxolitinib - Nil
- Fedratinib - Nil

In relation to Questions 2 – 5, the Trust has applied a Qualified Exemption under Section 12 of the Freedom of Information Act (cost of compliance exceeds appropriate limit), which states:

(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.

Section 6 (page 23) of the [Freedom of Information Code of Practice](#) defines the appropriate limit as 18 hours or a cost of £450 at a flat rate of £25 per hour. This is because, the Trust has calculated that it would take 27 hours at a rate of £25 per hour to achieve the extraction of the data task, this in itself would entail a cost of £675.

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Furthermore, it would also require the services of a Consultant to review the results which it is estimated would require at least six weeks work to complete. This would result in the Consultant not being able to deliver other critical services for our patients.

Therefore, the Trust under Section 16 of the Act (Duty to advise and Assist) advises that it only uses IC11 codes, not ICD 10 and that it recommends that you review your request and refine the parameters accordingly.

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 review.

You should forward your complaint to:-

Mr Ian Bevan via FOI.VUNHST@wales.nhs.uk
Head of Information Governance
Velindre University NHS Trust
2, Charnwood Court
Heol Billingsley
Parc Nantgarw
Cardiff / Caerdydd
CF15 7QZ
Tel / Ffon - 029 20196161

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,

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CF10 2HH
Telephone: 0330 414 6421
email: wales@ico.org.uk

Yours sincerely,

Lauren Fear
Director of Corporate Governance and Chief of Staff
Velindre University NHS Trust
2 Charnwood Court
Heol Billingsley
Parc Nantgarw
Cardiff
CF15 7QZ

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