



GIG
CYMRU
NHS
WALES

Ymddiriedolaeth GIG
Prifysgol Felindre
Velindre University
NHS Trust



Gwasanaeth Gwaed Cymru
Welsh Blood Service

Pencadlys Ymddiriedolaeth GIG Prifysgol Felindre
Velindre University NHS Trust Headquarters
2 Cwrt Charnwood
Heol Billingsley
Parc Nantgarw
Caerdydd/Cardiff
CF15 7QZ



Canolfan Ganser Felindre
Velindre Cancer Centre

Ffôn/Phone : (029) 20196161

<https://velindre.nhs.wales>

Date: 31st July 2023

Ref: CORP 2023 - 109

Dear *****,

Freedom of Information request: Treatment for Myelofibrosis (CORP 2023-109)

Thank you for your request for the following information which the Trust received on 5th July 2023.

Your Request:

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

Q1. Does your trust treat myeloproliferative neoplasms? If not, which other trust do you refer these patients to?

Q2. 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*

Q3. How many patients were treated in the past 6 months (for any disease) with:

- Ruxolitinib*
- Fedratinib*

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)*

Q5. 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?*

Mae Ymddiriedolaeth GIG Prifysgol Felindre yn hapus i dderbyn gohebiaeth yn y Gymraeg neu'r Saesneg.
Velindre University NHS Trust is happy to receive communication in Welsh or English.





**GIG
CYMRU
NHS
WALES**

Ymddiriedolaeth GIG
Prifysgol Felindre
Velindre University
NHS Trust



Gwasanaeth Gwaed Cymru
Welsh Blood Service

Pencadlys Ymddiriedolaeth GIG Prifysgol Felindre
Velindre University NHS Trust Headquarters
2 Cwrt Charnwood
Heol Billingsley
Parc Nantgarw
Caerdydd/Cardiff
CF15 7QZ



Canolfan Ganser Felindre
Velindre Cancer Centre

Ffôn/Phone : (029) 20196161

<https://velindre.nhs.wales>

- *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?*

Q6. 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.

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

Our response to Question 1- 5 is as follows:

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.

The Trust estimates that to carry out this task. the cost of complying would exceed the appropriate limit of 18 hours of work at a rate of £25 per hour or £450.

As result, the Trust is applying a Qualified Exemption under Section 12 (Exemption where cost of compliance exceeds appropriate limit) In particular the legislation 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, therefore may I suggest that you consider the option to revise your request so that it falls below the prescribed appropriate limit.

Mae Ymddiriedolaeth GIG Prifysgol Felindre yn hapus i dderbyn gohebiaeth yn y Gymraeg neu'r Saesneg.
Velindre University NHS Trust is happy to receive communication in Welsh or English.





**GIG
CYMRU
NHS
WALES**

Ymddiriedolaeth GIG
Prifysgol Felindre
Velindre University
NHS Trust



**Gwasanaeth Gwaed Cymru
Welsh Blood Service**

Pencadlys Ymddiriedolaeth GIG Prifysgol Felindre
Velindre University NHS Trust Headquarters
2 Cwrt Charnwood
Heol Billingsley
Parc Nantgarw
Caerdydd/Cardiff
CF15 7QZ



**Canolfan Ganser Felindre
Velindre Cancer Centre**

Ffôn/Phone : (029) 20196161

<https://velindre.nhs.wales>

To provide you with the necessary guidance, Page 23, paragraph 6.9 of [Section 45 \(Code of Practice\) on Request Handling under FOI](#) states:

6.9 Where a request is refused under section 12, public authorities should consider what advice and assistance can be provided to help the applicant reframe or refocus their request with a view to bringing it within the cost limit. This may include suggesting that the subject or timespan of the request is narrowed. Any refined request should be treated as a new request for the purposes of the Act.

In reaching this decision we estimate that it would take a minimum of 20 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.

However, under Section 16 of the Act (duty to provide advice and assistance), the Trust suggests that you revise your request so that it falls below the prescribed appropriate limit. In order to provide more information, Page 23, paragraph 6.9 of [Section 45 \(Code of Practice\) on Request Handling under FOI](#) states:

6.9 Where a request is refused under section 12, public authorities should consider what advice and assistance can be provided to help the applicant reframe or refocus their request with a view to bringing it within the cost limit. This may include suggesting that the subject or timespan of the request is narrowed. Any refined request should be treated as a new request for the purposes of the Act.

The Trust's response to Question 6 is as follows:

The Trust does not participate in any clinical trials for the treatment of myelofibrosis.

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

Mae Ymddiriedolaeth GIG Prifysgol Felindre yn hapus i dderbyn gohebiaeth yn y Gymraeg neu'r Saesneg.
Velindre University NHS Trust is happy to receive communication in Welsh or English.





**GIG
CYMRU
NHS
WALES**

Ymddiriedolaeth GIG
Prifysgol Felindre
Velindre University
NHS Trust



Gwasanaeth Gwaed Cymru
Welsh Blood Service

Pencadlys Ymddiriedolaeth GIG Prifysgol Felindre
Velindre University NHS Trust Headquarters
2 Cwrt Charnwood
Heol Billingsley
Parc Nantgarw
Caerdydd/Cardiff
CF15 7QZ



Canolfan Ganser Felindre
Velindre Cancer Centre

Ffôn/Phone : (029) 20196161

<https://velindre.nhs.wales>

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,
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

Mae Ymddiriedolaeth GIG Prifysgol Felindre yn hapus i dderbyn gohebiaeth yn y Gymraeg neu'r Saesneg.
Velindre University NHS Trust is happy to receive communication in Welsh or English.

