

gofalu am ein gilydd, cydweithio, gwella bob amser caring for each other, working together, always improving

Rydym yn croesawu gohebiaeth yn y Gymraeg ac yn y Saesneg. We welcome correspondence in Welsh or English.

Dyddiad/Date: 26th October 2021 Ein Cyf / Our Ref: 21-H-028



Corporate Services
Headquarters
1 Talbot Gateway
Baglan
Port Talbot, SA12 7BR

I refer to your Freedom of Information Act Request acknowledged by ourselves on 20th August 2021. Your request sought information relating to blood disorder treatments.

Please note that we have provided the information for the period 01.01.21 to 30.06.21.

1. How many patients has your Health Board treated (for any disease) in the last 6 months with the following treatments:

Please note that the figures we have provided are patient numbers for Secondary Care. The numbers in brackets represent prescription numbers in Primary Care – we do not hold patient numbers for this data.

- Doptelet (avatrombopag) 0
- Jakavi (ruxolitinib) 9
- Nplate (romiplostim) <5
- **Revolade (eltrombopag)** 17 (12 prescriptions in Primary Care)
- Tavlesse (fostamatinib) 0
- **Hydroxycarbamide** 140 (326 prescriptions in Primary Care)
- 2. You clarified on the 30th September 2021, that you required those patients admitted with the specific diagnosis below.

In the last 6 months, how many patients has your Health Board treated for:



Pencadlys BIP Bae Abertawe, Un Porthfa Talbot, Port Talbot, SA12 7BR / Swansea Bay UHB Headquarters, One Talbot Gateway, Port Talbot, SA12 7BR

- Immune thrombocytopenia (ICD10 code D69.3) 25
- Myelofibrosis (ICD10 code D47.4) <5
- Myelofibrosis (ICD10 code D47.4) patients over the age 65 <5
- 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)

I can confirm that this information is not held centrally – our Pharmacy systems do not hold medication data down to diagnosis level. To obtain this information would involve a manual trawl and search of patient records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. Section 12 of the FOI Act and The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulation 2004 provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

- 4. How many myelofibrosis (ICD10 code D47.4) patients has your Health Board 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?

I can confirm that this information is not held centrally. To obtain this information would involve a manual trawl and search of patient records which we have estimated would significantly exceed the 18 hours limit set down by the FOI Act as the reasonable limit. Section 12 of the FOI Act and The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulation 2004 provides that we are not obliged to spend in excess of 18 hours in any sixty day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

- 5. Does you Health Board 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?
 No
- 6. Does you Health Board 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?

Where fewer than 5 has been indicated we are unable to provide you with the exact number of patients as due to the low numbers, there is a potential risk of identifying individuals if this was disclosed. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This information is protected

by the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute as unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. This exemption is absolute and therefore there is no requirement to apply the public interest test.

I hope this information is helpful. If you require anything further please contact us at FOIA.Requests@wales.nhs.uk.

Under the terms of the Health Board's Freedom of Information policy, individuals seeking access to recorded information held by the Health Board are entitled to request internal review of the handling of their requests. If you would like to complain about the Health Board's handling of your request please contact me directly at the address below or register your complaint via FOIA.Requests@wales.nhs.uk.

If after Internal Review you remain dissatisfied you are also entitled to refer the matter to the information commissioner at the Information Commissioner's Office (Wales), 2nd Floor, Churchill House, Churchill Way, Cardiff, CF10 2HH. Telephone Number: 029 2067 8400.

Yours sincerely

Pam Wenger

Director of Corporate Governance

P. a. wenger