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Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Freedom of Information Act 2000 - Request Reference FoI/22/395

Myelofibrosis Treatment

Information Requested:

1. Does your trust treat myelofibrosis? If not, which other trust do you refer these patients to?

Yes – we see patients with myelofibrosis – both local patients from our immediate area but also (as a regional centre of expertise) also see patients from around South Wales and sometimes South West England, both for routine review / 2nd opinions and for clinical trials.

2. Please provide the total number of patients treated in the last 6 months (or the latest 6 months data you have available) for myelofibrosis (ICD10 code D47.4)? How many of these patients were above age 65?

In completing a search for the information requested, Cardiff and Vale University Health Board (the UHB) has confirmed that this information is not centrally recorded or collated. To retrieve the information requested would require a manual search through individual records and the UHB considers that this would exceed the limit set within regulations for responding to a request. The UHB has therefore relied upon the Section 12 exemption ('Exemption where cost of compliance exceeds appropriate limit') of the Freedom of Information Act 2000 and is refusing your request.

The UHB has estimated that to complete the work needed to respond to this request would exceed the time limit as set within regulations to respond to a Freedom of Information Act request. Under the Act there is an allowance of two and a half days, or 18 hours, to comply with a request and the cost limit set within the fees' regulations for this amount of work (18 hours) is £450 for the UHB. The fees regulations specify that the cost of complying with a request must be calculated at the rate of £25 per hour.

3. How many myelofibrosis patients were treated in the past 6 months with Ruxolitinib?

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





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4 a. Of these patients, how many were treated in the past 6 months (or the latest 6 months data you have available) with:

- Hydroxyurea
- Fedratinib
- Received No Treatment

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5. 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.

Yes. Currently open are MANIFEST-1 (2 patients treated to date), MANIFEST-2 (2), PROMISE (3). We are generally active in myelofibrosis studies and have a portfolio that evolves from year to year.

