

Freedom of Information Act 2000 - Request Reference FoI/23/333
Treatment for Myelofibrosis

Information Requested:

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?

The UHB does treat myeloproliferative neoplasms.

Q2. Please provide the total number of patients treated in the last 6 months for:

- Polycythaemia Vera (ICD10 code D45): 23
- Myelofibrosis (ICD10 code D47.4): 12
- Myelofibrosis (ICD10 code D47.4) patients aged 65 and older: 7

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

- Ruxolitinib: 32
- Fedratinib: 1

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)

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.

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?
- 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?

Please see the UHB's response to Q4.

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.

Yes, we do participate in clinical trials in myelofibrosis. These involve both patients diagnosed at our hospital, and also patient from around other parts of South and West Wales (and sometimes Southwest England) who get referred on a tertiary basis in order to access clinical studies.

At the moment we have:

Open

PROMISE (investigator-initiated study funded by CRUK) – 4 patients recruited & treated so far. 2 others failed screening

FEDORA (TAP-sponsored study – IIT) – recently opened, 0 patients recruited yet

Recently closed (in follow-up)

MANIFEST-1 (MF and ET) 3 patients treated

MANIFEST-2 (MF -newly diagnosed) 2 patients treated

ACE-536 (anaemia in MF) 0 patients treated (2 screened)

Several historic trials, including SIMPLIFY, ROBUST.

Soon to open

INCB-00928-104 (Incyte-sponsored ALK2 inhibitor for MF-associated anaemia)