

Reference:	FOI.9698.22
Subject:	Myelofibrosis treatment
Date of Request:	23 August 2022

Requested:

1. Does your trust treat myelofibrosis? If not, which other trust do you refer these patients to?
- 2a. 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).
- 2b. How many of these patients were above age 65?
3. How many myelofibrosis patients were treated in the past 6 months with Ruxolitinib?
- 4a. How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years?
- 4b. 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
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.

Response:

Hywel Dda University Health Board (UHB) is unable to provide you with the information requested, as it is estimated that the cost of answering your request would exceed the “appropriate limit” as stated in the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2 ½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

The ChemoCare Team, which holds a central record of cancer treatments, is based within Swansea Bay University Health Board (SBUHB). In order to provide you with the information requested, the UHB would be required to conduct a manual trawl of all cancer patients’ medical records, to establish the type of cancer diagnosed and therapies used to treat the patients. It is estimated that conducting this search would take longer than the 18 hours ‘appropriate limit’ as stated within the Freedom of Information Act 2000 (FoIA).

The UHB is therefore applying an exemption under Section 12 of the FoIA, which provides an exemption from a public authority’s obligation to comply with a request for information, where the cost of compliance is estimated to exceed the appropriate limit.

However, under Section 16 of the FoIA, we are required as a public authority, to provide advice and assistance so far as it is reasonable, to individuals who have made a request under FoIA. We

therefore recommend that you redirect your request to the Freedom of Information Team in SBUHB, who may be able to help you with your enquiry. The contact details are as follows:-

FOIA.Requests@wales.nhs.uk or alternatively, you can contact: FOIA Team, Swansea Bay University Health Board, Health Board Headquarters, 1 Talbot Gateway, Port Talbot, SA12 7BR.