

Freedom of Information Act Request

Under the Freedom of Information Act, I would like to request the following information:

HSJ Information are researching the treatment of myeloproliferative neoplasms. We would greatly appreciate if you could answer the following questions:

Q1. Please provide the total number of patients treated in the last 6 months for:

- Polycythaemia Vera (ICD10 code D45) 39
- Myelofibrosis (ICD10 code D47.4) 20
- Myelofibrosis (ICD10 code D47.4) patients aged 65 and older #

=number under 5

After careful consideration, we are unable to provide specific numerical data where the count is fewer than five. This decision is made to protect the privacy of individuals and is consistent with our obligations under the Freedom of Information Act 2000 (FOIA) and the Data Protection Act 2018.

Q2. How many patients were treated in the past 6 months (for any disease) with:

- Ruxolitinib - 15
- Fedratinib - 1
- Momelotinib - 5

Q3. How many patients were treated with Ruxolitinib in the past 6 months for the following diseases?

- Myelofibrosis (ICD10 code D47.4)
- Polycythaemia Vera (ICD10 code D45)
- Other/Unknown

DBTH holds the information on the subject you have requested. However, I advise you that we will not be able to answer your request without exceeding the appropriate limit. This is because our pharmacy system doesn't store diagnosis data, so we're unable to determine this against the prescribed treatment. To ascertain this

data, the Trust would need to perform an audit of each individual patient record, which wouldn't be achievable within the s.12 timescale of the Freedom of Information Act 2000.

. Section 12 of the Act makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit, We have estimated that it would take more than 18 hours to carry out a manual search to locate, retrieve, and extract all the information you have requested. In this situation the associated cost would therefore exceed the appropriate fee limit of £450 set out under Freedom of Information & Data Protection (Appropriate Limit and Fees) Regulations 2007.

The fee limit specified in regulations for NHS trusts represents the cost of one person spending 2½ working days at a rate of £25 per hour determining whether the Trust holds the information sought and then locating, retrieving and extracting that information.

Q4. 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?

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Q5. 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.

NO

If you are not satisfied with the handling of your request, you have the right to

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request an internal review. Requests for an internal review should be submitted within 40 working days from the date of this response, and should be addressed to d.wraith@nhs.net.

If you remain dissatisfied after the internal review, you have the right to appeal to the Information Commissioner's Office (ICO). The ICO can be contacted at:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
Tel: 0303 123 1113
Website: <https://ico.org.uk/make-a-complaint/>