

Royal Stoke University Hospital

Data, Security and Protection Newcastle Road Stoke-on-Trent Staffordshire ST4 6QG

Email foi@uhnm.nhs.uk

Ref: FOIA Reference 2023/24-525

Date: 1st December 2023

Dear

I am writing to acknowledge receipt of your email dated 8th September 2023 requesting information under the Freedom of Information Act (2000) regarding Myelofibrosis

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 Wilmington Healthcare are researching the treatment of myeloproliferative neoplasms. We would greatly appreciate if you could answer the following questions:

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

- Polycythaemia Vera (ICD10 code D45)
- Mvelofibrosis (ICD10 code D47.4)
- Myelofibrosis (ICD10 code D47.4) patients aged 65 and older
- A1 We do not capture 'D' codes on the 'Somerset system' therefore we do not hold this information.
- Q2 How many patients were treated in the past 6 months (for any disease) with:
 - Ruxolitinib
 - Fedratinib
 - Interferon (any type)
- We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5

This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.

- Ruxolitinib 20
- Fedratinib <5
- Interferon (any type) 125







- Q3 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)
- A3 See below:
 - Polycythaemia Vera (ICD10 code D45) 5
 - Myelofibrosis (ICD10 code D47.4) 15.
- 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?
- A4 We do not capture 'D' codes on the 'Somerset system' therefore we do not hold this information.
- Q5 How many Polycythaemia Vera (ICD10 code D45) 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?
- A5 We do not capture 'D' codes on the 'Somerset system' therefore we do not hold this information..
- 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.
- A6 No

*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

Yours,

Rachel Montinaro

Data Security and Protection Manager - Records

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