



Ref: FOIA Reference 2023/24-215

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

Date: 21st July 2023

Email foi@uhn.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 5th July 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 I have a freedom of information query regarding the treatment for Myelofibrosis. Could you please answer the following questions?

Does your Trust treat myeloproliferative neoplasms? If not, which other Trust do you refer these patients to?

A1 Yes

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

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

A2 I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in this question is not held centrally, but may be recorded in health records. In order to confirm whether this information is held we would therefore have to individually access all health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: *cost of compliance is excessive*. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all health records and then extracting relevant information would take longer than the 18 hours allowed for. In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: *oppressive burden on the authority*

Under section 16 of the FOI Act we are required to provide requestors with advice and assistance where possible. We would therefore like to advise you that your request is shortened to just the questions that we are able to comply within the 18 hour time frame. In order to avoid delay to your response we have provided this below.

Note: There is no correlation on Careflow between procedures and diagnoses. Depending on what methods are used to treat the above condition will depend if the data is available. If the patient is treated in an outpatient setting we do not record ICD10 or OPCS coding on the Careflow outpatient record therefore we are unable to identify this cohort. If the patient is treated in an inpatient setting as the above codes can be classed as co-morbidities someone would have to look at all those patients who have a diagnosis of the above and review the notes to ascertain if the reason for the admission was to treat the above condition or not.

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

- **Ruxolitinib**
- **Fedratinib**

A3 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 Trust's 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 = 23
- Fedratinib = <5

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)**

A4 See below:

- Polycythaemia Vera (ICD10 code D45) = 6
- Myelofibrosis (ICD10 code D47.4) = 17

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?**

A5 We do not record on Careflow a person's diagnosis

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 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.

MITHRIDATE: A phase III, randomised, open-label, Multicenter International Trial comparing ruxolitinib with either HydRoxycarbamide or interferon Alpha as first line Therapy for high risk polycythemia vera

<5 patients recruited

Published Papers

1. CPX-351 for Acute Myeloid Leukaemia: Real World Results Are Comparable to Trial Outcomes and Exceeds Them in Non-Adverse Risk Patients- a Multicentre Experience from West Midlands Hospitals on Behalf of West Midlands Research Consortium (WMRC) UK Murthy V., Whitmill R., Lodwick C., Dyer P., Ahmed M., Khan R., Paneesha S., Pemberton N., Raghavan M. Blood 2021;138(Supplement 1): 4416.
2. Radioactive phosphorous (P32) leukomogenic and oncogenic risk stratification Fullagar A., Sodhi L., Pillai S., Brunt M. British Journal of Haematology 2018;181(Supplement 1): 166-167.

*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.

If following review of the responses I can be of any further assistance please contact my secretary on 01782 671612.

Yours,



Rachel Montinaro
Data Security and Protection Manager - Records