



Ref: FOIA Reference 2022/23-001

Date: 25th April 2022

Email foi@uhnm.nhs.uk

Dear

I am writing in response to your email dated 1st April 2022 requesting information under the Freedom of Information Act (2000) regarding Jakavi.

The University Hospitals of North Midlands Trust is committed to the Freedom of Information Act 2000.

However, the NHS is facing unprecedented challenges relating to the coronavirus (COVID-19) pandemic at the current time. Understandably, our resources have been diverted to support our front-line colleagues who are working tremendously hard to provide care for our patients, and to those in need of our services.

We strive to be transparent and to work with an open culture. But at this time, whilst care of our patients and the safety of our staff takes precedent, it is likely that responses to some requests for information will be delayed. We apologise for this position in advance, and will endeavour to provide you with as much information as we can, as soon as we are able.

The Information Commissioners Office has recognised the current situation in the NHS.

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHM) 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 would like to request information for the below questions.

The purpose of these questions is to understand the variability of treatment within your trust and in context to the rest of the country.

Q1. Does your Trust treat myelofibrosis? If not, which other trust do you refer these patients to?

A1 Yes, the Trust does treat patients with myelofibrosis, with oral meds or high dose chemotherapy. However, patients that need transplants get referred to the Christie or Queen Elizabeth, Birmingham, depending where they live.

Q2 See below:

A) 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).

b) How many of these patients were above age 65?

A2 As myelofibrosis (ICD10 code D47.4) is a D code and not registerable for cancer waiting times we do not capture this on the Somerset Cancer Register so unable to assist with this request.

Q3 How many myelofibrosis patients were treated in the past 6 months with Ruxolitinib?

A3 See below:

- Royal Stoke: 14
- County: 5

Q4 See below:

A) How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years?

b) 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**

A4 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 question (B) is not held centrally, but may be recorded in individual health records. In order to confirm whether this information is held we would therefore have to individually access all individual 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 individual 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*

A) We are unable to provide total numbers of patients newly diagnosed, see question 2 for details.

B) Section 12 exemption as detailed above

We've had no patients on Fedratinib so far and are unable to provide numbers for patients that have not been started on any treatment.

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?

A5 We do in principle participate in trials for MF, but due to Covid have got a back log of trials to open. A couple of MF trials are in the pipeline, but not open yet.

*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.

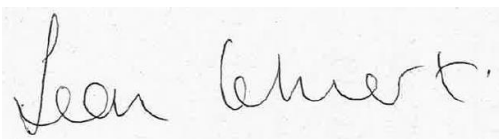
Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and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





**University Hospitals
of North Midlands**
NHS Trust

Jean Lehnert
Data, Security & Protection Manager

