

Freedom of Information Request

Ref: 23-490

24 July 2023

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we do hold the information you are requesting

Q1. Does your trust treat myeloproliferative neoplasms?

Yes

If not, which other trust do you refer these patients to?

Not applicable

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

- Polycythaemia Vera (ICD10 code D45) 41
- Myelofibrosis (ICD10 code D47.4) 28
- Myelofibrosis (ICD10 code D47.4) patients aged 65 and older 21

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

- Ruxolitinib 26
- Fedratinib *

Please note: Where the figures are between 1 and 5, this has been denoted by *. Due to the low numbers, we have considered that there is the potential for individuals to be identified from the information provided, when considered with other information that may also be in the public domain. In our view disclosure of these low figures would breach one of the Data Protection Principles set out in Schedule 1 of the Data Protection Act, namely Principle 1. The Trust therefore finds that the Section 40(2) exemption contained within the Freedom of information Act 2000 is engaged. (Section 40 is the exemption for personal information).

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) 11

Please note: Where the figures are between 1 and 5, this has been denoted by *. Due to the

low numbers, we have considered that there is the potential for individuals to be identified from the information provided, when considered with other information that may also be in the public domain. In our view disclosure of these low figures would breach one of the Data Protection Principles set out in Schedule 1 of the Data Protection Act, namely Principle 1. The Trust therefore finds that the Section 40(2) exemption contained within the Freedom of information Act 2000 is engaged. (Section 40 is the exemption for personal information).

Q5. How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years?

We cannot provide this information - our systems cannot break down the information.

• Of these patients, how many were treated in the past 6 months with Hydroxycarbamide?

We cannot provide this information - our systems cannot break down the information.

• Of these patients, how many were treated in the past 6 months with Interferon therapy?

We cannot provide this information - our systems cannot break down the information.

• Of these patients, how many have received no active treatment in the past 6 months?

We cannot provide this information - our systems cannot break down the 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.

Currently no studies are open for treating Myelofibrosis.

Momentum 4365 extension study * (now closed for recruitment)

Please note: Where the figures are between 1 and 5, this has been denoted by *. Due to the low numbers, we have considered that there is the potential for individuals to be identified from the information provided, when considered with other information that may also be in the public domain. In our view disclosure of these low figures would breach one of the Data Protection Principles set out in Schedule 1 of the Data Protection Act, namely Principle 1. The Trust therefore finds that the Section 40(2) exemption contained within the Freedom of information Act 2000 is engaged. (Section 40 is the exemption for personal information).

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Data Protection Officer
University Hospitals Bristol and Weston NHS Foundation Trust
Trust Headquarters

Marlborough Street
Bristol
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

Freedom of Information Team
University Hospitals Bristol and Weston NHS Foundation Trust