

Ref: FOI/GS/ID 7641

Please reply to:
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28 October 2022

Freedom of Information Act 2000

I am writing in response to your request for information made under the Freedom of Information Act 2000 in relation to Myelofibrosis Treatment.

You asked:

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

Q2.

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?

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

Q4.

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:

i. Hydroxyurea

ii. Fedratinib

iii. Received No 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.

Trust response:

Please note: The Trust does not record diagnosis details at an outpatient level and patients diagnosed with myelofibrosis often do not have any active treatment and are wholly monitored through outpatients. We are not able to

report on these patients as the diagnosis is not recorded electronically to be able to extract.

Q1. We treat very few cases of myelofibrosis at the Trust. We sometimes refer cases onto Kings or Guys but very few.

Q2.

a. One patient has had active treatment between April 2022 and September 2022

b. Due to the very small number of cases and in order to protect patient confidentiality the Trust has decided that further information be refused using the limitations available under Section 10 and Section 11 of the Data Protection Act 1998.

Q3. Due to the very small number of cases and in order to protect patient confidentiality the Trust has decided that further information be refused using the limitations available under Section 10 and Section 11 of the Data Protection Act 1998.

Q4.

a. One

b. Due to the very small number of cases and in order to protect patient confidentiality the Trust has decided that further information be refused using the limitations available under Section 10 and Section 11 of the Data Protection Act 1998.

Q5. The only trial the Trust has is: "A Randomized Open-Label, Phase 3 Study to Evaluate Imetelstat (GRN163L) Versus Best Available Therapy (BAT) in Patients with Intermediate-2 or High-risk Myelofibrosis (MF) Refractory to Janus Kinase (JAK)-Inhibitor" (IRAS 1003434), which is open to recruitment.