

Freedom of Information request 421-22

Request

The following questions are being asked for on behalf of Novartis. 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?

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:

- Hydroxyurea
- Fedratinib
- 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.

Response

1. NHS Borders does treat myelofibrosis patients.
2. a) There have been 12 patients treated in the last 6 months.
b) Of those patients 10 were over 65 years of age.
3. Of these patients 10 were treated with Ruxolitinib.
4. a) NHS Borders do record diagnosis data electronically therefore under Section 17 of the FOI(S)A 2002 this data is not held.
b) In the last 6 months <5 patients were treated with Hydroxyuera and no patients were treated with Fedratinib.
5. NHS Borders do not participate in any clinical trials for myelofibrosis.

If you are not satisfied with the way your request has been handled or the decision given, you may ask NHS Borders to review its actions and the decision. If you would like to request a review please apply in writing to,

Freedom of Information Review, NHS Borders, Room 2EC3, Education Centre, Borders General Hospital, Melrose, TD6 9BS or foi.enquiries@borders.scot.nhs.uk.

The request for a review should include your name and address for correspondence, the request for information to which the request relates and the issue which you wish to be reviewed. Please state the reference number **421-22** on this request. Your request should be made within 40 working days from receipt of this letter.

If following this review, you remain dissatisfied with the outcome, you may appeal to the Scottish Information Commissioner and request an investigation of your complaint. Your request to the Scottish Information Commissioner should be in writing (or other permanent form), stating your name and an address for correspondence. You should provide the details of the request and your reasons for dissatisfaction with both the original response by NHS Borders and your reasons for dissatisfaction with the outcome of the internal review. Your application for an investigation by the Scottish Information Commissioner must be made within six months of your receipt of the response with which you are dissatisfied. The address for the Office of the Scottish Information Commissioner is, Office of the Scottish Information Commissioner, Kinburn Castle, Doubledykes Road, St Andrews, Fife.