

Date 05/08/2025  
Your Ref  
Our Ref 10311

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Dear

## FREEDOM OF INFORMATION – MYELOFIBROSIS

I write in response to your request for information in relation to Myelofibrosis prescribing.

Question:

1. Please provide the total number of patients treated in the last 6 months for:
  - a. Polycythaemia Vera (ICD10 code D45)
  - b. Myelofibrosis (ICD10 code D47.4)
  - c. Myelofibrosis (ICD10 code D47.4) patients aged 65 and older

Answer:

a.	42
b.	15
c.	7

Question:

2. How many patients were treated in the past 6 months (for any disease) with:
  - a. Ruxolitinib
  - b. Fedratinib
  - c. Momelotinib

Answer:

a.	38
b.	5<
c.	7

Question:

3. How many patients were treated with Ruxolitinib in the past 6 months for the following diseases?

Headquarters  
Mainpoint  
102 West Port  
Edinburgh EH3 9DN

Chair Professor John Connaghan CBE  
Chief Executive Professor Caroline Hiscox  
*Lothian NHS Board is the common  
name of Lothian Health Board*

- a. Myelofibrosis (ICD10 code D47.4)
- b. Polycythaemia Vera (ICD10 code D45)
- c. Other/Unknown

Answer:

a.	16
b.	19
c.	5<

Question:

4. How many myelofibrosis (ICD10 code D47.4) patients has your trust diagnosed in the past 3 years?
- a. Of these patients, how many were treated in the past 6 months with Hydroxycarbamide?
  - b. Of these patients, how many were treated in the past 6 months with Interferon therapy?
  - c. Of these patients, how many have received no active treatment in the past 6 months?

Answer:

4.	103
a.	12
b.	35
c.	23

Question:

5. 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.

Answer:

Currently NHS Lothian are not participating in any clinical trials for the treatment of myelofibrosis.

To protect the identity of the individuals involved any figure of 5 or less has not been shown in the tables above. Since we do not have their consent to release this data from their records, the information is exempt under section 38(1)(b) of the Freedom of Information (Scotland) Act i.e. to provide it would breach the Data Protection Act (2018).

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain

dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at [www.itspublicknowledge.info/Appeal](http://www.itspublicknowledge.info/Appeal). If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhslothian.scot/FOI/Pages/default.aspx>

Yours sincerely

**ALISON MACDONALD**  
**Executive Director, Nursing**  
Cc: Chief Executive