

Date 11/02/2026
Your Ref
Our Ref 11043

Enquiries to Richard Mutch
Extension 35687
Direct Line 0131 465 5687
loth.freedomofinformation@nhs.scot
richard.mutch@nhs.scot

Dear

FREEDOM OF INFORMATION – ACUTE MYELOID LEUKAEMIA

I write in response to your request for information in relation to Acute Myeloid Leukaemia prescribing.

Question:

1. How many patients have been diagnosed with Acute Myeloid Leukaemia (AML) at your Trust in the last 12 months
 - a. Of these patients how many are refractory/relapsed (R/R)?
 - b. How many of the R/R patients were FLT3 positive?

Answer:

I am advised that this information is not held in a centrally extractable format. Under the Freedom of Information Act NHS Lothian is not required to create new records to enable it to respond to your enquiry. This information is not collated or held in aggregate form and it would be necessary to review all case files relating to patients over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

Question:

2. How many patients have been treated for AML in the latest 12 months with the following treatments
 - a. Venetoclax with azacitidine
 - b. Midostaurin
 - c. Quizartinib
 - d. Gemtuzumab
 - e. Ivosidenib with azacitidine
 - f. Liposomal cytarabine–daunorubicin
 - g. Oral azacitidine
 - h. Gilteritinib
 - i. Palliative care
 - j. Enrolled in a clinical trial

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

Answer:

a.	18
b.	5<
c.	Nil
d.	5<
e.	Nil
f.	8
g.	5<
h.	5<
i.	NA
j.	5<

To protect the identity of the individuals involved any figure of 5 or less has not been shown in the table 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).

Question:

3. How many relapsed/refractory patients have been treated for AML in the last 12 months with the following treatments (This question relates to treatments administered to relapsed/refractory AML patients in clinical practice, regardless of licence status or funding route (including any off-label use).
- Venetoclax with azacitidine
 - Midostaurin
 - Quizartinib
 - Gemtuzumab
 - Ivosidenib with azacitidine
 - Liposomal cytarabine–daunorubicin
 - Oral azacitidine
 - Gilteritinib
 - Palliative care
 - Enrolled in a clinical trial

Answer:

I am advised that this information is not held in a centrally extractable format.

Question:

4. Of your AML patient how many were tested as below in the last 12 months
- Received an FLT3 mutation test when they were diagnosed
 - Received an FLT3 mutation test when their disease relapsed
 - Received an FLT3 mutation test when their disease became refractory

Answer:

I am advised that this information is not held in a centrally extractable format.

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. 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