

Dear

FREEDOM OF INFORMATION – MULTIPLE MYELOMA

I write in response to your request for information in relation to multiple myeloma.

Question:

As of 1 Jan 2024:

- Total population size served by Regional Board
- Number of hospitals providing oncology services
- Total number of consultant haematologists employees; specialist haematology registrars employed; consultant haematologists specialising in multiple myeloma; haematology clinical nurse specialists employed and multiple myeloma clinical nurse specialists.

Answer:

1.	Approximately 900,000
2.	2
3.	<ul style="list-style-type: none"> ○ consultant haematologists employees - 10 (Western General Hospital only) ○ specialist haematology registrars employed - 7 ○ consultant haematologists specialising in multiple myeloma - 2 ○ haematology clinical nurse specialists employed - 5 ○ multiple myeloma clinical nurse specialists - 1

Question:

During 2023 (1 Jan – 31 Dec), please provide the:

- Total number of multiple myeloma (MM) cases diagnosed (Please state which code(s) were used)
- If known, how many people were diagnosed with smouldering multiple myeloma?
- How many in-person haematology-based consultation/telephone haematology-based consultations/ video haematology-based consultation took place for people diagnosed with MM?

During 2023 (1 Jan – 31 Dec):

- Were multiple myeloma (MM) patients discussed/reviewed at a MM specific MDT or general haematology MDT?
- How frequently did MDT meetings meet?

- What percentage of MM patients diagnosed in 2023 were reviewed/discussed at a MDT?
- Which professionals/disciplines are represented on MDT meetings for MM?
- What supportive and palliative care services are available for MM patients?

Answer:

I am advised that we do not currently or have data available for the requested time period due to there being a 1-year lag in its collection.

To assist with other parts of the query complex linkage and clinical input is required. Therefore, the data is not readily available.

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.

The data we do hold is extracted from *all the myeloma cases discussed at MDM in 2023*. This will only be as correct as recorded for the MDM outcomes.

- *Lothian - 64 (54 WGH and 10 SJH)*
- *Borders General Hospital - 7*

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.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing, Midwifery and AHPs
Cc: Chief Executive