

Dear

### FREEDOM OF INFORMATION – PRESCRIBING

I write in response to your request for information in relation to

Question:

1. Does your Trust treat patients for the two following conditions? Yes/No  
Waldenström macroglobulinaemia (WM) (ICD-10 C88.0)  
Marginal zone lymphoma (MZL) (ICD-10 C83.0 & C88.4)

Answer:

Yes

Question:

2. How many patients did the Trust treat in calendar year 2025 (January to December) for each of the below conditions?

Answer:

Waldenström macroglobulinaemia (WM)	48
Marginal zone lymphoma (MZL)	20

Question:

3. Are there any ongoing clinical trials running at the Trust for each of the below conditions? Please can you advise on any details available on the clinical trials.

Answer:

Waldenström macroglobulinaemia (WM)	Nil
Marginal zone lymphoma (MZL)	Nil

Question:

4. How many patients (and new patients\* if possible) received treatment for Waldenström macroglobulinaemia (WM) in the period 1st July 2025 to 31st December 2025?

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

Answer:

Waldenström macroglobulinaemia (WM) (ICD-10 C88.0)		
Regimen	Total Patients	New Patients*
Fludarabine, cyclophosphamide and rituximab (Known as FCR)	Nil	Nil
Bendamustine in combination with rituximab (Known as BR)	≤5	≤5
Ibrutinib	10	Nil
Ibrutinib in combination with rituximab	Nil	Nil
Zanubrutinib	21	18
Acalabrutinib	Nil	Nil
Chemotherapy (Other than the listed regimens)	15	14
Wait and watch - no active treatment and monitoring only		
Any other treatment (Other than the listed regimens)		

\*Please define a new patient as a new patient to treatment, receiving the specified treatment for the first time since December 2024.

Question:

5. How many patients (and new patients\* if possible) received treatment for Marginal zone lymphoma (MZL) in the period 1st July 2025 to 31st December 2025?

Answer:

Marginal zone lymphoma (MZL) (ICD-10 C83.0 & C88.4)		
Regimen	Total Patients	New Patients*
Bendamustine in combination with rituximab (Known as BR)	≤5	≤5
Chlorambucil in combination with rituximab (Known as CR)	Nil	Nil
R CVP (Rituximab + cyclophosphamide + vincristine + prednisolone)	7	6
R CHOP (Rituximab + cyclophosphamide + doxorubicin + vincristine + prednisolone)	≤5	≤5
Zanubrutinib	≤5	≤5
Stem Cell Transplant	Nil	Nil
Wait and watch - no active treatment and monitoring only		
Any other treatment (Other than the listed regimens)	7**	≤5**

\*Please define a new patient as a new patient to treatment, receiving the specified treatment for the first time since December 2024.



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