

Freedom of Information Act Request

I am writing to request information under the Freedom of Information Act 2000.

1. Does your Trust treat patients for the two following conditions?

Yes

Waldenström macroglobulinaemia (WM) (ICD-10 C88.0)

Marginal zone lymphoma (MZL) (ICD-10 C83.0 & C88.4)

If yes:

1a. How many patients did the Trust treat in calendar year 2025 (January to December) for each of the below conditions?

Waldenström macroglobulinaemia (WM) **20**

Marginal zone lymphoma (MZL) **6**

1b. 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.

Waldenström macroglobulinaemia (WM) – No ongoing trials for this condition

Marginal zone lymphoma (MZL) – **No ongoing trials for this condition**

Please skip 1c to question 2 and 3.

If no:

1c. Which Trust(s) does the Trust refer patients onto for treatment for each of the above conditions?

Thank you for answering this survey.

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

Waldenström macroglobulinaemia (WM) (ICD-10 C88.0)		
Regimen	Total Patients	New Patients*
Fludarabine, cyclophosphamide and rituximab (Known as FCR)		
Bendamustine in combination with rituximab (Known as BR)		
Ibrutinib	5	
Ibrutinib in combination with rituximab		
Zanubrutinib	6	
Acalabrutinib		
Chemotherapy (Other than the listed regimens)		
Wait and watch - no active treatment and monitoring only		
Any other treatment (Other than the listed regimens)	5	

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

** The Trust does not routinely record “new patients to treatment” in the manner defined within your request (i.e. first time receiving a specified treatment since December 2024).*

In addition, Waldenström macroglobulinaemia is frequently managed using a prolonged “watch and wait” approach, where patients may be monitored for several years before requiring active treatment, and some patients never require treatment at all. As a result, accurately distinguishing between “new” and “existing” patients starting treatment within a defined period would require detailed manual review of individual clinical histories, which is not held in a readily reportable format.

Under Section 12 of the Freedom of Information Act 2000, the Trust is not obliged to undertake extensive manual searches where this would exceed the appropriate cost limit. Therefore, figures relating specifically to “new patients” as defined in your request are not held in a retrievable format.

3. 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?

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

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

** A “new patient” has been defined in accordance with your request as a patient receiving the specified treatment for the first time since December 2024.*

Marginal Zone Lymphoma is often managed using a prolonged “watch and wait” approach, where patients may be monitored for several years before requiring active treatment, and some patients may never require treatment at all. As a result, distinguishing between “new” and “existing” patients commencing treatment within a defined reporting period can be complex, as treatment history may span several years.

For the period specified, however, no patients received treatment for Marginal Zone Lymphoma at the Trust. Therefore, there were no new patients commencing treatment within this timeframe.

Our Ref: 80
January 2026

If you are not satisfied with the handling of your request, you have the right to request an internal review. Requests for an internal review should be submitted within 40 working days from the date of this response, and should be addressed to d.wraith@nhs.net.

If you remain dissatisfied after the internal review, you have the right to appeal to the Information Commissioner's Office (ICO). The ICO can be contacted at:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
Tel: 0303 123 1113
Website: <https://ico.org.uk/make-a-complaint/>

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