

Reference:	FOI.19448.26
Subject:	Treatment of Waldenström Macroglobulinaemia (WM) and Marginal Zone Lymphoma (MZL),
Date of Request:	30 January 2026

Requested:

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)

If yes:

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

Waldenström macroglobulinaemia (WM)

Marginal zone lymphoma (MZL)

b. 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)
- Marginal zone lymphoma (MZL)

Please skip 1c to question 2 and 3.

If no:

c. 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		
Ibrutinib in combination with rituximab		
Zanubrutinib		
Acalabrutinib		
Chemotherapy (Other than the listed regimens)		
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.

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)		
Chlorambucil in combination with rituximab (Known as CR)		
R CVP (Rituximab + cyclophosphamide + vincristine + prednisolone)		
R CHOP (Rituximab + cyclophosphamide + doxorubicin + vincristine + prednisolone)		
Zanubrutinib		
Stem Cell Transplant		
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.

Response:

Hywel Dda University Health Board (UHB) is unable to provide you with all the information requested for questions 2 and 3, as it is estimated that the cost of answering your request would exceed the “appropriate limit” as stated in the Freedom of Information Act 2000 and the Data Protection (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

In order to provide you with the data requested for wait and watch or Stem Cell Transplant treatments, the UHB would need to undertake a manual trawl of medical records of those diagnosed with WM and MZL, to identify any information that would fulfil these parts of your request, as this is not recorded centrally.

The UHB is therefore applying an exemption under Section 12 of the Freedom of Information Act 2000 (FoIA), which provides an exemption from a public authority’s obligation to comply with a request for information where the cost of compliance is estimated to exceed the appropriate limit.

However, under Section 16 of the FoIA, we are required as a public authority, to provide advice and assistance so far as it is reasonable to individuals who have made a request under the FoIA, this can include assisting a requestor to further refine their request.

Unfortunately, the UHB is unable to provide advice on how you can refine your request further. This is due to the UHB still requiring a manual trawl of all WM and MZL patient records to be undertaken to identify their diagnosis and treatments.

Where the figures in the tables have been replaced with an asterisk (*), the UHB is unable to provide you with the exact number of patients due to the low number of cases (less than 5), as there is a potential risk of identifying individuals if this was disclosed. The UHB has also replaced the total which could be used to calculate the redacted figure with a double asterisk (**). The UHB is therefore withholding this detail under Section 40(2) of the FoIA. This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations (UK GDPR), as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles of

the UK GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

In reaching this decision, the DPA and UK GDPR define personal data as data that relates to a living individual who can be identified solely from that data or from that data and other information, which is in the possession of the data controller.

1. The UHB confirms that it does treat patients for WM and MZL.

1a. The UHB confirms that twenty-three (23) patients received treatment for WM or MZL, during the 2025 calendar year.

1b. The UHB confirms that it is not currently participating in any clinical trials for WM or MZL.

1c. Not applicable.

2. The UHB provides within the table below, the number of patients that received the listed treatments for WM, during the period 1 July to 31 December 2025.

Treatment	Total patients	New patients
Fludarabine, cyclophosphamide and rituximab (Known as FCR)	0	0
Bendamustine in combination with rituximab (Known as BR)	*	0
Ibrutinib	*	0
Ibrutinib in combination with rituximab	0	0
Zanubrutinib	*	*
Acalabrutinib	0	0
Chemotherapy (Other than the listed regimens)	*	0
Wait and watch - no active treatment and monitoring only	Section 12 exemption applied	
Any other treatment (Other than the listed regimens)	0	0
Total	6	**

3. The UHB provides within the table below, the number of patients that received the listed treatments for MZL, during the period 1 July to 31 December 2025.

Treatment	Total patients	New patients
Bendamustine in combination with rituximab (Known as BR)	*	*
Chlorambucil in combination with rituximab (Known as CR)	0	0
R CVP (Rituximab + cyclophosphamide + vincristine + prednisolone)	5	*
R CHOP (Rituximab + cyclophosphamide + doxorubicin + vincristine + prednisolone)	*	*
Zanubrutinib	*	*
Stem Cell Transplant	Section 12 exemption applied	
Wait and watch - no active treatment and monitoring only	Section 12 exemption applied	
Any other treatment (Other than the listed regimens)	*	*
Total	17	10

