

FOI 3603

25th February 2026

FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST

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

Response:

Yes/No

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?

Response:

Waldenström macroglobulinaemia (WM) – 0 newly diagnosed/treated patients in 2025

Marginal zone lymphoma (MZL) – <5 newly diagnosed/treated patient in 2025

The Trust has a legal duty to protect patient confidentiality, in line with this duty the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves. In addition the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

S 40 (2) (third party information) of the Freedom of Information Act 2000 has been applied to exempt the redacted information from disclosure. The Trust does not consider the disclosure of the redacted information to be fair to the individuals concerned as there is the potential risk of identification of an individual(s) which they would not expect, and which would therefore breach the fairness element of the first principle of the Data Protection Act 2018.

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)

Marginal zone lymphoma (MZL)

Response:

No current trials open

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?

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)	Total Patients	New Patients*
Regimen		
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)	Total Patients	New Patients*
Regimen		
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:

This information is not recorded centrally and therefore retrieving it would involve a manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

Under section 12 of the Freedom of Information Act 2000, Public Authorities are not obliged to comply with an information request where to do so would exceed the cost limit.

In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

Furthermore, under Section 16 of the Freedom of Information Act, we can advise that it would require an extensive manual review of individual patient records just to ascertain if information relevant to your request is held. As such, we advise that there is no way to refine this request to bring it within the appropriate limit.

Email: Foi.Team@Southerntrust.hscni.net