

Reference:	FOI.7187.21
Subject:	Lupus
Date of Request:	18 October 2021

Requested:

1. What guidelines or protocols do you refer to regarding the management of patients with:
 - a. Systemic lupus erythematosus (SLE)
 - b. Lupus nephritis (LN)
2. Please detail the number of patients that were admitted as an inpatient or day case in the last 12 months for the following primary diagnosis:

	Diagnosis (ICD10 code)
Patient number and care setting	Systemic lupus erythematosus with organ or system involvement (M321)
Inpatient admission	
Day case	

3. Do you refer patients within the ICD10 code M321 to another Trust?
If you answered 'Yes', please detail which Trusts you refer patients to.
4. Is there a specific clinic for LN patients at your Trust?
5. Please complete the number of patients prescribed with the following products in the last 12 months within the ICD10 code Systemic lupus erythematosus with organ or system involvement (M321):

	Diagnosis (ICD10 code)
Product	Systemic lupus erythematosus with organ or system involvement (M321)
Azathioprine	
Belimumab	
Ciclosporin	
Cyclophosphamide	
Mycophenolate mofetil	
Oral tacrolimus	

6. Has a shared care agreement/arrangement been established between your institution and primary care for the treatment of lupus nephritis?
If you answered 'Yes', which of the following medicines can be prescribed within the shared care agreement?

	Azathioprine	Ciclosporin	Cyclophosphamide	Mycophenolate mofetil (MMF)	Oral tacrolimus
Yes/No					

7. Has a shared care agreement/arrangement been established between your institution and a tertiary centre for the treatment of lupus nephritis? If so, please specify what medicines can be prescribed in secondary care within these shared care agreements.

8. What is the name of your local integrated care system?

9. For the LN patient pathway, is care commissioned by:

	Activity	Block contract	Blended payment
Yes			
No			

Response:

Hywel Dda University Health Board (UHB) is unable to provide you with the information requested for question 5, as it is estimated that the cost of answering your request would exceed the “appropriate limit” as stated in the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2 ½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

In order to provide you with the information requested, the UHB would need to undertake a manual trawl of all Lupus patient records, to identify the information that fulfils your request. Whilst the UHB could identify the number of patients prescribed the named medications from the pharmacy databases, it is not possible to identify the condition these were used to treat without cross referencing against the medical records.

The UHB is therefore applying an exemption under Section 12 of the Freedom of Information Act 2000 (FoIA), for question 5, 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 FoIA. Therefore, the UHB provides the information it holds below.

1a. Hywel Dda University Health Board (UHB) confirms that it refers to the British Society for Rheumatology (BSR) guidance for the management of cases of Systemic Lupus Erythematosus (SLE). A link to the guidance is provided:

[British Society for Rheumatology guideline for the management of systemic lupus erythematosus in adults | Rheumatology | Oxford Academic \(oup.com\)](https://www.bsr.org.uk/guidelines/guideline-for-the-management-of-systemic-lupus-erythematosus-in-adults)

1b. The UHB does not hold specific guidance for Lupus Nephritis (LN).

2. The UHB confirms that there were no admissions with a primary diagnosis code of ICD10 recorded in the UHB’s Welsh Patient Administration System (WPAS), during the last twelve (12) months).

3. The UHB confirms that patients within the ICD10 code M321 have occasionally been referred to The Louise Coote Lupus Unit at Guy’s Hospital, London.

4. The UHB confirms that it does not have specific clinics for LN patients.

5. Under Section 16 of the FoIA as stated above, the UHB provides, within the table below, the number of patients treated for any condition within the scope of this request, with the listed medications provided, during the period 1 November 2020 to 31 October 2021.

Medication	Number
Azathioprine	127
Belimumab	1
Ciclosporin	59
Cyclophosphamide	218
Mycophenolate mofetil	70
Oral tacrolimus	48

6. The UHB confirms that there are shared care arrangements in place for Mycophenolate and Mixed Connective Tissue Disorders, which includes LN.
7. The UHB confirms that it does not have a shared care agreement/arrangement with a tertiary centre for the treatment of LN.
8. The UHB confirms that the system used to record patient community health records is the Welsh Clinical Community Information System (WCCIS).
9. The UHB confirms that LN patients are initially referred to the Renal Team in Swansea Bay University Health Board (SBUHB). The UHB has a block contract Service Level Agreement (SLA) with SBUHB.