

Freedom of Information Request: Our Reference CTMUHB_441_21

You asked:

Question 1

What guidelines or protocols do you refer to regarding the management of patients with:

a) Systemic lupus erythematosus (SLE)

Management is in accordance with British Society of Rheumatology (BSR) guidelines and use of biologics in line with NHS England guidance, including entry into BILAG BR register.

b) Lupus nephritis (LN)

The management is shared with the Nephrology Outreach service at the University Hospital of Wales (Cardiff & Vale University Health Board) in accordance with BSR guidance.

Question 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	0
Day case	0

Question 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.

Yes if its lupus nephritis or cerebral lupus, they are referred for an opinion to outreach clinicians (renal and neurology only – not rheumatology) at the University Hospital of Wales (Cardiff & Vale University Health Board), who work on a hub and spoke basis. Inpatient transfer only occurs for renal biopsy, the patient is then relocated back to our Health Board. Treatment is usually decided between teams, in agreement with the patient and delivered locally.

Question 4

Is there a specific clinic for LN patients at your Trust?

No, patients with LN are managed in the Lupus Clinic and at the Renal clinic, on alternate hospital appointments with regular (often on the day) communication between clinical teams as needed.

Question 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):

Please see the table below which has been populated with data that is captured on our Medicines Management system. However, please note the system does not record the condition being treated, so the data provided is for any condition.

Where the figures are less than 5, this has been denoted by **. The exact figures have been withheld due to the low numbers involved.

Where numbers are low we have considered that there is the potential for the individuals to be identified from the information provided, when considered with other information that may also be in the public domain. Also, responses under the Freedom of Information Act are made available to the public at large. The data is classed as personal data as defined under the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute as unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This exemption is absolute and therefore there is no requirement to apply the public interest test.

Product	Any condition
Azathioprine	**
Belimumab	**
Ciclosporin	0
Cyclophosphamide	**
Mycophenolate mofetil	**
Oral tacrolimus	0

Question 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	Yes	Yes	No	Yes	Yes (between renal team and primary care)

Question 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.

No formal shared care needed as treatments are delivered locally on site.

Question 8

What is the name of your local integrated care system?

N/A.

Question 9

For the LN patient pathway, is care commissioned by:

	Activity	Block contract	Blended payment
Yes		Yes	
No	No		No