

Reference:	FOI.13346, 13358 & 13359.23
Subject:	Lupus
Date of Request:	8 December 2023

Requested:

1. FOI.13346 – Lupus

How many Lupus patients have been referred to specialist lupus clinics, doctors, hospitals or treatment based in England since 2015?

2. FOI.13358 – Specialist Lupus Nurse

In 2018 LUPUS UK offered to fund a Specialist Lupus Nurse for 5 years at £250,000. However, you rejected the offer. As there are currently no Specialist Lupus Nurses in the whole of Wales could you explain why you did this while simultaneously claiming you can provide the same care locally as a specialist lupus clinic in England provides.

3. FOI.13359 – SLE treatment

How many people have been treated for SLE with Rituximab Infusion treatment in your health authority since 2020?

Response:

Hywel Dda University Health Board (UHB) is unable to provide you with all of the information requested, 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 information requested for question 3, the UHB would need to undertake a manual trawl of all Lupus patient records, and cross reference with the Pharmacy systems to identify any information that fulfils your request, as this information is not recorded centrally.

However, the UHB can confirm that it currently has ninety two (92) patients with a confirmed Lupus diagnosis. Therefore, to provide you with the exact information being requested, conducting the search would far exceed the ‘appropriate limit’, costing the UHB the following:

92 @ 15 minutes per item = 23 hours
23 hours @ £25 per hour = £575.00

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, the UHB has a duty to provide advice and assistance. Therefore, the UHB provides the accessible information it holds for requests 1 and 2 below.

1. The UHB confirms that a total of fifteen (15) Lupus patients were approved and referred to hospitals in England, since January 2015 to the date of your request.

However, in line with the Making Decisions On Individual Patient Funding Requests (IPFR) (All Wales) Policy, before any out of area funding request can be considered, the requesting clinician must demonstrate that the patient has exhausted all local options where possible. The patient should first receive a second opinion from a consultant colleague within the same Health Board, and then from a Health Board or English NHS Trust with whom a contractual agreement is held. Patients should not be able to access healthcare services elsewhere unless all treatment options available within locally provided services or those commissioned by Health Boards have been exhausted and it is clinically appropriate to do so. A copy of the IPFR All Wales policy is available on the UHB's website via the link provided below:

[Policies and written control documents - Hywel Dda University Health Board \(nhs.wales\)](#)

2. The UHB confirms that the offer to fund a Specialist Lupus Nurse was not taken up, as the Rheumatology Service was in the process of recruiting new members of staff, and was not in a position to be able to develop and fully support the addition of a Lupus Specialist Nurse to the team.