Reference:	FOI.3940.20
Subject:	Lupus
Date of Request:	4 September 2020

Requested:

- 1. We ask, following your job advertisement on social media dated 6th February 2020, for 6 Consultant Ophthalmology positions for Pembrokeshire, Carmarthenshire and Ceredigion – have you now filled any of these positions?
- 2. How are you complying with the BSR NICE Guidelines for adults with lupus, with the required eye checks for retinal toxicity?
- 3. What is the current waiting list for the Rheumatology Department, for new potential lupus referrals?
- 4. Can you please confirm that all our Pembrokeshire Lupus Support Group have been referred to Dermatology for annual checks, following our reviews with Consultant Rheumatologist, Dr Jayne Evans, Consultant Rheumatologist at the start of 2019?
- 5. Many of the group who were reviewed in January and February 2019 have not had Rheumatology appointments since then. Please confirm how long the waiting lists are currently for follow-up appointments with Rheumatology in general? How far behind are the lupus patient reviews? (We believe at least 18 months in between some lupus patients monitoring now).
- 6. Other monitoring to comply with BSR NICE Guidelines & multidisciplinary teams including nurse specialists and physiotherapists, rheumatologists, nephrologists, dermatologists, haematologists, cardiologists, chest physicians, neurologists, obstetrics, podiatrists and occupational therapists working together is recommended by the Guidelines.

Can you please confirm how many multidisciplinary appointments are offered with Rheumatology and these specialisms?

7. Considering all your answers above, how is Hywel Dda UHB complying with the BSR NICE Guidelines for the Management of Adults with Systemic Lupus Erythematosus?

Response:

1. Hywel Dda University Health Board (UHB) confirms that following the job vacancy advertisement on social media on 6 February 2020, four (4) locum ophthalmology consultants were successfully appointed across Carmarthenshire and Pembrokeshire. In addition, the contracts of two (2) locum ophthalmology consultants in Ceredigion have been extended.

The UHB continues to advertise for substantive ophthalmology consultant roles; however, the UHB is aware of a national shortage of ophthalmologists.

2. The UHB confirms that based on the COVID-19 situation and the management of patients with irreversible sight loss, the service have been clinically prioritising patients based on guidelines from the Royal College of Ophthalmologists. Planning work is ongoing to re-instate these clinics and is being monitored the clinical team. Therefore, patients should continue to visit their community optometrists whilst awaiting specialist care during the pandemic. Should a patient show signs of urgent disease they would be referred to the UHB for an urgent assessment.

- 3. The UHB confirms that the average waiting time for urgent outpatients is currently thirty-six (36) weeks; all Lupus referrals are urgent.
- 4. The UHB is unable to answer your questions as to do so would reveal personal information of third parties and is not an admissible Freedom of Information request under the Freedom of Information Act 2000.
- 5. The UHB confirms that the rheumatology follow up lists are validated clinically, with the longest follow up appointment recorded as taking thirteen (13) months.
- 6. The UHB is unable to provide you with the information requested as it is estimated that the cost of answering your request would exceed the "appropriate level" as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004.

The "appropriate level" represents the estimated cost of one person spending 18 hours or (2 $\frac{1}{2}$ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

In order to provide you with all of the information being requested, the UHB would need to undertake a manual search of all rheumatology patient records to identify any information that fulfils your request.

Therefore, the UHB is applying an exemption under Section 12 of the Freedom of Information Act 2000 (FOI), 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.

 The UHB participated in the All Wales BSR Systemic Lupus Erythematosus (SLE) audit and its compliance is above average for most standards for both the Welsh and UK averages. The audit used standards derived from BSR National Institute for Health and Care Excellence (NICE) Guidelines for the Management of Adults with SLE.