

Freedom of Information Request: Our Reference CTMUHB_18_22

You asked:

I write further to my first Freedom of Information request emailed to you on Friday 14th August 2020 and your subsequent response dated 10th September 2020, (Your Reference: CTMUHB_260_20) and my second request dated 14th September 2020 and your response dated 12th October 2020, (Your Reference: CTMUHB_291_20

I have some further questions to clarify the situation further:

- 1) You say, "*Patients who require referral to NHS England are not subject to Individual Patient Funding Requests. Patients will only be referred to specialist centres if their clinical needs cannot be managed in local services and such referrals are simply subject to prior authorisation. We can confirm that there have been zero referrals for patients who have lupus to specialist centres since 2017.*"**

For the sake of transparency and clarity for the lupus patient in Wales, it seems unfair that some Health Boards in Wales are using the IPFR application process for lupus patients to attempt to access a lupus expert / Centre of Excellence in England, whilst some are using this "Prior Approval" system.

1a. Would you please be so kind as to refer me to where I can find the authority for this "Prior Authority" process?

Please see link provided to the [All Wales Prior Approval Policy](#), that ensures a consistent approach to processing prior approval requests. With regards to the 'responsible authority;' each health board in Wales will be responsible for considering prior approval requests for those patients living within their catchment area. Cwm Taf Morgannwg University Health Board (UHB) is therefore responsible for patients living in Merthyr Tydfil, Rhondda Cynon Taf and Bridgend only.

1b. Please also provide the reference for the IPFR procedure.

Please see the link provided to our [IPFR page](#) on the Health Boards website. For ease of access we have also attached is a copy of the All Wales IPFR policy (Attachment 1). Please note that the All Wales IPFR policy is reserved for clinicians who wish to submit an application for an individual patient who requires a service/treatment that is considered new, novel or experimental. Onward referral to a specialist centre for advice/management of lupus does not fall within the IPFR category. Within Cwm Taf Morgannwg UHB, requests are processed via the prior approval process.

WHSSC have previously informed me that this IPFR procedure for lupus patients does not fall within their remit and it has been impossible to obtain any information about how these processes work.

1c. Again, for the sake of clarity, I cannot find out whether a GP can sign an IPFR application, as opposed to a Consultant? It would be very useful to know.

Patients diagnosed with lupus are managed within local secondary care services i.e. they do not fall under the 'specialised service' remit for which the Welsh Health Specialised Services Committee (WHSSC) is responsible. For patients with complex lupus who require specialist opinion/advice/management at a specialist centre, onward referral will be facilitated by the secondary care team and not a patients GP. All referrals outside of NHS Wales are subject to consideration via the All Wales Prior Approval policy.

2) *"Lupus services in Wales do not operate under NHS England Guidelines but do follow NICE guidance where appropriate to Wales."*

"The Lupus Service at CTMUHB is a registered BILAG centre and as such does comply with the NICE and NHS England guidance (although it doesn't have to comply with NHS England guidance) and provides biologic therapy as needed for adult lupus patients attending the service, this includes entering patients into the BILAG Biologics Register."

The NICE approved British Society for Rheumatology Guidelines for the Management of SLE in Adults applies to England, Scotland, Northern Ireland and Wales.

2a. I therefore seek clarification of the NHS England Guidelines term that you used twice. Are the NHS England Guidelines for Biologics different to the NHS Wales Guidelines?

The guidance for treatment of patients with SLE in Wales follows BSR & NICE guidance. There is additional guidance on use of Biologics use in SLE in England as there are additional financial restraints in England relating to access to Biologics. This financial restriction does not apply to Wales however, the NHS England clinical guidance is a useful document and therefore useful in Wales as well.

2b. Also, where would the NICE BSR Guidance not be appropriate to Wales?

NICE BSR guidance applies in Wales.

3) It has become apparent that Dr Ceril Rhys-Dillon undertook an audit of Rheumatology Services in Wales, including lupus care, around 2019. Please provide a link to the report for our reference.

Please find attached a summary of results from the audit.