

FOI REF: 23/706

21st November 2023

FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

I have a freedom of information request about rare inflammatory disorders. Could you please answer the following questions:

Q1. In the past 12 months, how many patients have been admitted as inpatients for each of the following conditions* (primary or secondary diagnosis)?

- **Adult Onset Stills Disease (AOSD) – ICD10 code M06.1**

1

- **Juvenile Arthritis with Systemic Onset (SJIA) – ICD10 code M08.2**

0

- **Periodic Fever Syndromes including Familial Mediterranean Fever (FMF), Tumor Necrosis factor Associated Periodic Syndromes (TRAPS) or Melvonte Kinase Deficiency (MKD) – ICD10 code E85.0**

0

- **Cryoprin-associated Periodic Syndromes (CAPS) – ICD10 code not available**

0

***In case you do not treat any condition, please provide the name of the trust you refer these patients to.**

Not applicable.

Cont.../

Q2. How many patients has your trust/health board treated with Anakinra (Kineret) in the past 12 months, for each of the following:

- Any medical condition 0
- Rheumatoid Arthritis 0
- Adult Onset Stills Disease (AOSD) 0
- Juvenile Arthritis with Systemic Onset (SJIA) 0
- Periodic Fever Syndromes (FMF, TRAPS or MKD) 0
- Cryoprin-associated Periodic Syndromes (CAPS) 0

Q3. How many patients has your trust/health board treated with Canakinumab (Ilaris) in the past 12 months, for each of the following:

- Any medical condition 0
- Adult Onset Stills Disease (AOSD) 0
- Juvenile Arthritis with Systemic Onset (SJIA) 0
- Periodic Fever Syndromes (FMF, TRAPS or MKD) 0
- Cryoprin-associated Periodic Syndromes (CAPS) 0

Q4. How many patients has your trust/health board treated with Tocilizumab in the past 12 months, for each of the following:

- Any medical condition
- Adult Onset Stills Disease (AOSD)
- Juvenile Arthritis with Systemic Onset (SJIA)
- Periodic Fever Syndromes (FMF, TRAPS or MKD)
- Cryoprin-associated Periodic Syndromes (CAPS)

East Sussex Healthcare NHS Trust does not centrally record the breakdown as requested. To enable the Trust to provide this information would require a manual review of all patients records that are treated with Tocilizumab which we estimate would take in excess of 18 hours. We are therefore applying Section 12(1) to this part of your request.

Section 12(1) of the Act allows a public authority to refuse to comply with a request for information if the authority estimates that the cost of compliance would exceed the 'appropriate limit', as defined by the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004 (the Regulations). These state that this cost limit is £450 for public authorities which are not part of central government or the armed forces. The costs are calculated at £25 per hour per person regardless of the rate of pay, which means that the limit will be exceeded if the work involved would exceed 18 hours. The Trust estimates that the cost of complying with this request would significantly exceed the above limit.

However, we can confirm that the Trust have a total of 110 patients treated with Tocilizumab.

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Q5. How many patients has your trust/health board treated with Etanercept in the past 12 months, for each of the following:

- **Any medical condition**
- **Adult Onset Stills Disease (AOSD)**
- **Juvenile Arthritis with Systemic Onset (SJIA)**
- **Periodic Fever Syndromes (FMF, TRAPS or MKD)**
- **Cryoprin-associated Periodic Syndromes (CAPS)**

East Sussex Healthcare NHS Trust does not centrally record the breakdown as requested. To enable the Trust to provide this information would require a manual review of all patients records that are treated with Etanercept which we estimate would take in excess of 18 hours. We are therefore applying Section 12(1) to this part of your request.

Section 12(1) of the Act allows a public authority to refuse to comply with a request for information if the authority estimates that the cost of compliance would exceed the 'appropriate limit', as defined by the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004 (the Regulations). These state that this cost limit is £450 for public authorities which are not part of central government or the armed forces. The costs are calculated at £25 per hour per person regardless of the rate of pay, which means that the limit will be exceeded if the work involved would exceed 18 hours. The Trust estimates that the cost of complying with this request would significantly exceed the above limit.

However, we can confirm that the Trust have a total of 436 patients treated with Etanercept.

If I can be of any further assistance, please do not hesitate to contact me.

Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department (esh-tr.foi@nhs.net), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

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Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF

Telephone: 0303 123 1113

Yours sincerely

Linda Thornhill (Mrs)
Corporate Governance Manager
esh-tr.foi@nhs.net