

Information Governance Department

Suite 9 Buckingham Row Brick Kiln Lane Wigan WN1 1XX

Email: foi@wwl.nhs.uk Web: www.wwl.nhs.uk

Ref: FOI/2024/9310

Date Received: 17th October 2023

Response Due: 14th November 2023

Date: 23rd April 2024

Dear Sir/Madam

With reference to your request for information received on 17th October 2023, I can confirm in accordance with Section 1 (1) of the Freedom of Information Act 2000 that we do hold the information you have requested. A response to each part of your request is provided below.

In your request you asked:

- 1. 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
- Juvenile Arthritis with Systemic Onset (SJIA) ICD10 code M08.2
- Periodic Fever Syndromes including Familial Mediterranean Fever (FMF), Tumor Necrosis factor Associated Periodic Syndromes (TRAPS) or Melvonate Kinase Deficiency (MKD) – ICD10 code E85.0
- Cryoprin-associated Periodic Syndromes (CAPS) ICD10 code not available

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

The answers have been answered based upon the period of 01/10/22 – 30/09/23.

- 2. 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
- Rheumatoid Arthritis

Adult Onset Stills Disease (AOSD)

Juvenile Arthritis with Systemic Onset (SJIA)

0

Periodic Fever Syndromes (FMF, TRAPS or MKD)

Cryoprin-associated Periodic Syndromes (CAPS)

3. How many patients has your trust/health board treated with Canakinumab (llaris) 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)

Periodic Fever Syndromes (FMF, TRAPS or MKD)

0

Cryoprin-associated Periodic Syndromes (CAPS)

0

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

86 (28 Acute Trust and 48 Homecare – however the Trust only records indication data for homecare)

Adult Onset Stills Disease (AOSD)

0

Juvenile Arthritis with Systemic Onset (SJIA)

<5 (of the 48 Homeware patients, the Trust cannot identify if the 38 Acute patients were SJIA)

Periodic Fever Syndromes (FMF, TRAPS or MKD)

0

Cryoprin-associated Periodic Syndromes (CAPS)

0

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

246 (all Homecare)

Adult Onset Stills Disease (AOSD)

(

Juvenile Arthritis with Systemic Onset (SJIA)

_

Periodic Fever Syndromes (FMF, TRAPS or MKD)

0

Cryoprin-associated Periodic Syndromes (CAPS)

0

The Trust has a policy of not releasing information when the data involved is less than 5. This is because we feel that such low numbers could make the individuals involved identifiable and therefore may cause undue harm and distress.

To disclose this information would:

- a) Contravene the Data Protection Act principles in that it would amount to unfair and possibly unlawful processing, as there was a legitimate expectation by the third parties that this information would remain confidential, and
- b) Disclosure may cause damage or distress to the individual(s) involved, and that damage or distress would be unwarranted (section 10 of the DPA).

If you are not entirely satisfied with this response, please do not hesitate to contact the Information Governance Department via the email address provided. If we do not hear from you within 40 days, we will assume that we have been able to accommodate your request under the Freedom of Information Act 2000.

Yours sincerely,

Gary Masterman

Deputy Chief Pharmacist

PLEASE NOTE:

If you are unhappy with the service you have received in relation to your request and wish to make a complaint or request a review of our decision, you should write to: Information Governance Department, Wrightington, Wigan and Leigh NHS Foundation Trust, Suite 9, Buckingham Row, Brick Kiln Lane, Wigan, WN1 1XX.

If you are not content with the outcome of your complaint, you may apply directly to the Information Commissioner for a decision at:

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

Helpline number: 0303 123 111