

**Freedom of Information Request**

**Ref: 23-787**

8 November 2023

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we hold some of the information you are requesting

**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**

14

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

14

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

11

- **Cryopyrin-associated Periodic Syndromes (CAPS) –**

**Please note this does not mean this was the reason for the patient's admission.**

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

We cannot provide this information – our systems do not have a ICD10 code for Cryopyrin-associated Periodic Syndromes

**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** 18

• **Rheumatoid Arthritis** We do not hold this information - our systems do not record information on medication use against indication.

• **Adult Onset Stills Disease (AOSD)** We do not hold this information - our systems do not record information on medication use against indication.

- **Juvenile Arthritis with Systemic Onset (SJIA)** We do not hold this information - our systems do not record information on medication use against indication.
- **Periodic Fever Syndromes (FMF, TRAPS or MKD)** We do not hold this information - our systems do not record information on medication use against indication.
- **Cryoprin-associated Periodic Syndromes (CAPS)** We do not hold this information - our systems do not record information on medication use against indication.

**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 \***
- **Adult Onset Stills Disease (AOSD)** We do not hold this information - our systems do not record information on medication use against indication.
- **Juvenile Arthritis with Systemic Onset (SJIA)** We do not hold this information - our systems do not record information on medication use against indication.
- **Periodic Fever Syndromes (FMF, TRAPS or MKD)** We do not hold this information - our systems do not record information on medication use against indication.
- **Cryoprin-associated Periodic Syndromes (CAPS)** We do not hold this information - our systems do not record information on medication use against indication.

\* Please note: Where the figures are between 1 and 5, this has been denoted by \*. Due to the low numbers, we have considered that there is the potential for individuals to be identified from the information provided, when considered with other information that may also be in the public domain. In our view disclosure of these low figures would breach one of the Data Protection Principles set out in Schedule 1 of the Data Protection Act, namely Principle 1. The Trust therefore finds that the Section 40(2) exemption contained within the Freedom of information Act 2000 is engaged. This follows NHS Digital (formerly HSCIC) analysis guidance (2014) which states that small numbers within local authorities, wards, postcode districts, providers and Trusts may allow identification of patients and should not be published.

**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** 123
- **Adult Onset Stills Disease (AOSD)** We do not hold this information - our systems do not record information on medication use against indication.
- **Juvenile Arthritis with Systemic Onset (SJIA)** We do not hold this information - our systems do not record information on medication use against indication.
- **Periodic Fever Syndromes (FMF, TRAPS or MKD)** We do not hold this information - our systems do not record information on medication use against indication.
- **Cryoprin-associated Periodic Syndromes (CAPS)** We do not hold this information - our systems do not record information on medication use against indication.

**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** 284

- **Adult Onset Stills Disease (AOSD)** We do not hold this information - our systems do not record information on medication use against indication.
- **Juvenile Arthritis with Systemic Onset (SJIA)** We do not hold this information - our systems do not record information on medication use against indication.
- **Periodic Fever Syndromes (FMF, TRAPS or MKD)** We do not hold this information - our systems do not record information on medication use against indication.
- **Cryoprin-associated Periodic Syndromes (CAPS)** We do not hold this information - our systems do not record information on medication use against indication..

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Data Protection Officer  
University Hospitals Bristol and Weston NHS Foundation Trust  
Trust Headquarters  
Marlborough Street  
Bristol  
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

### Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

**Freedom of Information Team**  
**University Hospitals Bristol and Weston NHS Foundation Trust**