

30 November 2023

Rare Inflammatory Disorders

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**
- **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 Melvonte 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.

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

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)**
- **Juvenile Arthritis with Systemic Onset (SJIA)**
- **Periodic Fever Syndromes (FMF, TRAPS or MKD)**
- **Cryoprin-associated Periodic Syndromes (CAPS)**

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)**

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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)

Adults

Response for Rheumatology and Dermatology, this includes Paediatrics Outpatients.

We are unable to provide a response to the number of patients admitted. The information requested is not collated centrally and an extensive trawl of patient notes would be required.

We estimate that compliance with this request for information would exceed the appropriate costs limit. Under Section 12 of the Freedom of Information 2000, the limit has been specified as £450 and represents the estimated cost of one or more persons spending 18 hours in determining whether we hold the information, locating, retrieving and extracting this information.

Drug	Condition	Rheumatology	Dermatology
Anakinra	Any medical condition	<5	<5
	Rheumatoid Arthritis	<5	<5
	Adult Onset Stills Disease (AOSD)	<5	<5
	Juvenile Arthritis with Systemic Onset (SJIA)	<5	<5
	Periodic Fever Syndromes (FMF, TRAPS or MKD)	<5	<5
	Cryoprin-associated Periodic Syndromes (CAPS)	<5	<5
Canakinumab (Ilaris)	Any medical condition	<5	<5
	Adult Onset Stills Disease (AOSD)	<5	<5

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	Juvenile Arthritis with Systemic Onset (SJIA)	<5	<5
	Periodic Fever Syndromes (FMF, TRAPS or MKD)	<5	<5
	Cryoprin-associated Periodic Syndromes (CAPS)	<5	<5
Tocilizumab	Any medical condition	195	<5
	Adult Onset Stills Disease (AOSD)	<5	<5
	Juvenile Arthritis with Systemic Onset (SJIA)	<5	<5
	Periodic Fever Syndromes (FMF, TRAPS or MKD)	<5	<5
	Cryoprin-associated Periodic Syndromes (CAPS)	<5	<5
Etanercept	Any medical condition	120	9
	Adult Onset Stills Disease (AOSD)	<5	<5
	Juvenile Arthritis with Systemic Onset (SJIA)	<5	<5
	Periodic Fever Syndromes (FMF, TRAPS or MKD)		<5
	Cryoprin-associated Periodic Syndromes (CAPS)	<5	<5

Use of < 5 (less than five): We are unable to provide an exact figure - exempt from release under section 40(2) of the FOI Act - as this could make patients personally identifiable. Disclosure would constitute a breach of the principles of the General Data Protection Regulations 2018.

Paediatrics

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**
- **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 Melvonte Kinase Deficiency (MKD) – ICD10 code E85.0**
- **Cryoprin-associated Periodic Syndromes (CAPS) – ICD10 code not available**

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Adult Onset Stills Disease (AOSD) – ICD10 code M06.1	< 5 patients were admitted during the period August 22 – July 2023
Juvenile Arthritis with Systemic Onset (SJIA) – ICD10 code M08.2	9 patients were admitted during the period August 22 – July 2023
Periodic Fever Syndromes including Familial Mediterranean Fever (FMF), Tumor Necrosis factor Associated Periodic Syndromes (TRAPS) or Melvonte Kinase Deficiency (MKD) – ICD10 code E85.0	< 5 patients were admitted during the period August 22 – July 2023
Cryoprin-associated Periodic Syndromes (CAPS) – ICD10 code not available	We are unable to identify these patients as there is no diagnosis code for this disease

Please note: Data supplied relates to the 12 month period between August 2022 and July 2023 as data from August 2023 to current is not yet available.

Use of < 5 (less than five): We are unable to provide an exact figure - exempt from release under section 40(2) of the FOI Act - as this could make patients personally identifiable. Disclosure would constitute a breach of the principles of the General Data Protection Regulations 2018