

<b>Reference:</b>	FOI.13073.23
<b>Subject:</b>	Rare inflammatory disorders
<b>Date of Request:</b>	7 November 2023

**Requested:**

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

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 Melvonnate 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.

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)
  - Periodic Fever Syndromes (FMF, TRAPS or MKD)
  - Cryoprin-associated Periodic Syndromes (CAPS)
3. 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)
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
  - Adult Onset Stills Disease (AOSD)
  - Juvenile Arthritis with Systemic Onset (SJIA)
  - Periodic Fever Syndromes (FMF, TRAPS or MKD)
  - Cryoprin-associated Periodic Syndromes (CAPS)
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

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

**Response:**

Hywel Dda University Health Board (UHB) is unable to provide you with all of the information requested, as it is estimated that the cost of answering your request would exceed the “appropriate limit” as stated in the Freedom of Information Act 2000 and the Data Protection (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

In order to provide you with the data for the specific conditions requested, the UHB would need to undertake a manual trawl of all identified prescriptions and cross reference with the patient’s medical record to identify the reason for treatment, as this information is not recorded centrally.

The UHB is therefore applying an exemption under Section 12 of the Freedom of Information Act 2000 (FoIA), which provides an exemption from a public authority’s obligation to comply with a request for information where the cost of compliance is estimated to exceed the appropriate limit.

However, under section 16 of the FoIA, the UHB has a duty to provide advice and assistance and therefore, provides the accessible information it holds below.

1. The UHB provides, within the table below, the number of patients that have been admitted for the conditions requested, as recorded on the Welsh Patient Administration System (WPAS), during the period 1 September 2022 to 31 August 2023. (The date range provided is the most up to date period available; this is due to a standard clinical coding backlog of up to three (3) months)

Condition	Number
Adult Onset Stills Disease (AOSD)	*
Juvenile Arthritis with Systemic Onset (SJIA)	*
Periodic Fever Syndromes including Familial Mediterranean Fever (FMF), Tumor Necrosis factor Associated Periodic Syndromes (TRAPS) or Melvonnate Kinase Deficiency (MKD)	13
Cryoprin-associated Periodic Syndromes (CAPS)	0

2. to 5. The UHB provides, within the table below, the number of patients treated with the medications requested for any medical condition, as recorded on the UHB’s Pharmacy system, during the period 1 November 2022 to 31 October 2023.

Medication (all conditions)	Number
Anakinra (Kineret)	*
Canakinumab (Ilaris)	0
Tocilizumab	126
Etanercept	280

Where the figures in the tables above have been replaced with an asterisk (\*), the UHB is unable to provide you with the exact number of patients, due to the low number of cases (less than 8), as there is a potential risk of identifying individuals if this was disclosed. The UHB is therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000 (FoIA). This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations (GDPR), as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles of the UK GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

In reaching this decision, the DPA and UK GDPR define personal data as data that relates to a living individual who can be identified solely from that data or from that data and other information, which is in the possession of the data controller.

Please note:- the variation in timeframes provided in the response is due to the information being held on different systems and recorded in a different manner.