

Your request

You requested the following:

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), Tumour 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)

Our response

1. Our response to question 1 for October 2022 – October 2023 is provided in the table below:

Condition	Inpatient Admissions
Adult Onset Stills Disease (AOSD)	0
Juvenile Arthritis with Systemic Onset (SJIA)	1
Periodic Fever Syndromes including Familial Mediterranean Fever (FMF), Tumour Necrosis factor Associated Periodic Syndromes (TRAPS) or Melvonnate Kinase Deficiency (MKD)	0
Cryopyrin-associated Periodic Syndromes (CAPS)	Unable to identify any admissions as the ICD10 code for this condition is not available.

2. We are not able to provide information on the treatment drugs prescribed to individual patients for specific conditions as it is not recorded centrally. To comply with your request, we would need to review every patient record which we have established would take in excess of 18 hours to undertake and therefore exceeds the appropriate costs limit under Section 12 of the Freedom of Information Act 2000, which is currently £450. This is not an exemption which requires us to consider the application of the public interest test.

3. 0 patients have been treated with Canakinumab in the last 12 months as it is non-formulary and is not recommended for use in Wales.

In response to questions 4 and 5, We are not able to provide information on the treatment drugs prescribed to individual patients for specific conditions as it is not recorded centrally. To comply with your request, we would need to review every patient record which we have established would take in excess of 18 hours to undertake and therefore exceeds the appropriate costs limit under Section 12 of the Freedom of Information Act 2000, which is currently £450. This is not an exemption which requires us to consider the application of the public interest test.