



Ref: FOIA Reference 2023/24-469

Royal Stoke University Hospital
Data, Security and Protection
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

Date: 30th October 2023

Email foi@uhnm.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 17th October 2023 requesting information under the Freedom of Information Act (2000) regarding rare diseases

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

Q1 I have a freedom of information request about rare inflammatory disorders. Could you please answer the following questions:

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.**

A1 We do not record on Careflow the reason for the admission, therefore in order to answer this request all patient records would need to be viewed, also note that these conditions are classed a comorbidities and may not have been treated for that condition whilst an inpatient - section 12 exemption as detailed below:

I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in this question is not held centrally, but may be recorded in health records. In order to confirm whether this information is held we

would therefore have to individually access all health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: *cost of compliance is excessive*. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all health records and then extracting relevant information would take longer than the 18 hours allowed for. In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: *oppressive burden on the authority*

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)**

A2 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5 This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.

- Any medical condition - <5
- Rheumatoid Arthritis - 0
- Adult Onset Stills Disease (AOSD) - 0
- Juvenile Arthritis with Systemic Onset (SJIA) - 0
- Periodic Fever Syndromes (FMF, TRAPS or MKD) - 0
- Cryoprin-associated Periodic Syndromes (CAPS) - 0

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)**

A3 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5 This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.

- Any medical condition -0
- Adult Onset Stills Disease (AOSD) - 0
- Juvenile Arthritis with Systemic Onset (SJIA) - 0
- Periodic Fever Syndromes (FMF, TRAPS or MKD) - 0
- Cryoprin-associated Periodic Syndromes (CAPS) - 0

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)**

A4 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5

This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.

- Any medical condition - 86
- Adult Onset Stills Disease (AOSD) - 0
- Juvenile Arthritis with Systemic Onset (SJIA) - <5
- Periodic Fever Syndromes (FMF, TRAPS or MKD) - 0
- Cryoprin-associated Periodic Syndromes (CAPS) - 0

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)**

A5 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5

This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.

- Any medical condition - <5
- Adult Onset Stills Disease (AOSD) - 0
- Juvenile Arthritis with Systemic Onset (SJIA) - 0
- Periodic Fever Syndromes (FMF, TRAPS or MKD) - 0
- Cryoprin-associated Periodic Syndromes (CAPS) - 0

*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

Yours,



Rachel Montinaro
Data Security and Protection Manager - Records



University Hospitals
of North Midlands
NHS Trust

