



Ref: FOIA Reference 2019/20-596

Royal Stoke University Hospital
Quality, Safety and Compliance Department
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

Date: 27th January 2020

Email foi@uhnm.nhs.uk

Dear

I am writing in response to your email dated 17th January 2020 requesting information under the Freedom of Information Act (2000) regarding Haemophilia A

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 How many patients with Haemophilia A are registered with your centre?

A1 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 between 60 and 70 with the majority being mild.

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

Q2 Of these how many are mild, moderate or severe? If unknown, please state unknown.

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 and have provided this below;

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

Please see below:

- Mild= 55-70
- Moderate = 0-5
- Severe= 0- 5

Q3 How many patients with Haemophilia B are registered with your centre?

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 less than 10

Q4 Of these how many are mild, moderate or severe? If unknown, please state unknown

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 and have provided this below;

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

- Mild <5
- Moderate =0
- Severe= <5

Q5 How many patients with Von Willebrand disease are registered with your centre?

A5 101

Q6 In the last 3 months, how many patients have been treated with the following?

- Advate
- Afstyla
- Elocta
- Emicizumab (Hemlibra)
- Helixate
- Kogenate
- NovoEight
- Nuwiq
- Refacto AF
- Factor Eight Inhibitor Bypass Activity (FEIBA)
- NovoSeven RT
- Alphanate
- DDAVP (desmopressin)
- Haemate P
- Trabexamic acid
- Veyvondi
- Voncento
- Willate
- Willfact
- Willfactin
- Alprolix
- BeneFIX

- **Idelvion**
- **Refixia**
- **Rixubis**

A6 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 and have provided this below;

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

- Advate= <5
- Afstyla 0
- Elocta 0
- Emicizumab (Hemlibra) 0
- Helixate 0
- Kogenate 0
- NovoEight 0
- Nuwiq 0
- Refacto AF 0
- Factor Eight Inhibitor Bypass Activity (FEIBA) <5
- NovoSeven RT 0
- Alphanate
- DDAVP (desmopressin) 6
- Haemate P 0
- Trabexamic acid >10
- Veyvondi 0
- Voncento <5
- Willate 0
- Willfact 0
- Willfactin 0
- Alprolix <5
- BeneFIX <5
- Idelvion 0
- Refixia 0
- Rixubis 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.

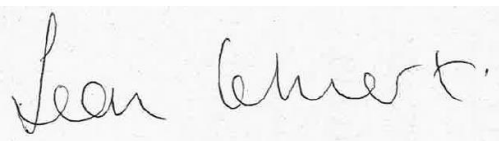
Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and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

If following review of the responses I can be of any further assistance please contact my secretary on 01782 676474.

Yours,



Jean Lehnert
Information Governance Manager