

Ref: FOIA Reference 2019/20-103

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

Date: 29th May 2019

Email foi@uhn.nhs.uk

Dear

I am writing in response to your email dated 23rd May 2019 requesting information under the Freedom of Information Act (2000) regarding Haemophilia patients.

On 24th May 2019 you contacted us via email as you had omitted to add Refixia to the list.

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 Would you be able to help with the following information request?

I would like to know:

How many Haemophilia A patients are registered at your hospital or treatment centre

A1 Sixty Three (63) Haemophilia A patients are registered at our hospital or treatment centre

Q2 How many Haemophilia B patients are registered with you?

A2 Six (6) Haemophilia B patients are registered with us.

Q3 In the last three months of data that you can supply, how many Haemophilia A patients have been treated with:

- Advate
- Elocta
- Novo Eight
- Kogenate
- Nuwiq
- Refacto
- Hemlibra
- Factor eight inhibitor bypass activity
- Novo Seven
- Afstyla

A3 We are unable to provide some of 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:

Advate	6
Elocta	0
Novo Eight	0
Kogenate	0
Nuwiq	0
Refacto	<5
Hemlibra	<5
Factor eight inhibitor bypass activity	<5
Novo Seven	0
Afstyla	0

Q4 Finally, have any been treated with Immune Tolerance Induction?

A4 None

Q5 And similarly for Haemophilia B, in the last three months, how many patients treated with:

- **Benefix**
- **Idelvion**
- **Rixubis**
- **Alprolix**
- **Refixia (late addition as per your email above)**

A5 We are unable to provide some of 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:

Benefix	<5
Idelvion	0
Rixubis	0
Alprolix	<5
Refixia	0

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

UHNM NHS Trust is a public sector body and governed by EU law. FOI requestors should note that any new Trust requirements over the EU threshold will be subject to these regulations and will be advertised for open competition accordingly.

Where the Trust owns the copyright in information provided, you may re-use the information in line with the conditions set out in the Open Government Licence v3 which is available at

<http://www.nationalarchives.gov.uk/doc/open-government-licence/version/3/>. Where information was created by third parties, you should contact them directly for permission to re-use the information.

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.

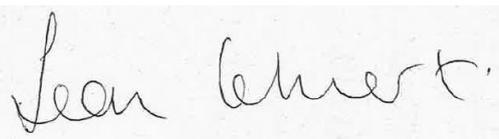
Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and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