



Ref: FOIA Reference 2018/19-677

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

Date: 25th March 2019

Email foi@uhnm.nhs.uk

Dear

I am writing in response to your email dated 11th February 2019 requesting information under the Freedom of Information Act (2000) regarding Haemophilia A and B and Von Willebrand Disease. I apologise for the delay to your response.

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHM) 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 Haemophilia A patients are registered?

A1 There are sixty three (63) Haemophilia A patients are registered

Q2 How many Haemophilia A patients with active Factor 8 Inhibitors do you have registered?

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 of being less than 5. Please note that although these patients are registered with UHM, we don't treat them at UHM.

Q3 How many Haemophilia B patients are registered?

A3 There are seven (7) Haemophilia B patients registered

Q4 In the last 3 months of data that you have, how many patients with Haemophilia A have been treated with?

Drug Name	Total
Advate	
Afstyla	
Elocta	
NovoEight	
Kogenate	

Helixate	
Nuwiq	
Refacto AF	
Emicizumab	
Factor Eight Inhibitor Bypass Activity (FEIBA)	
NovoSeven RT	
Immune Tolerance Induction	
Any trial drug (please state drug name)	
Any other treatment for Haemophilia A	

A4 Please see below: 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.

Drug Name	Total
Advate	Less than 5
Afstyla	0
Elocta	0
NovoEight	0
Kogenate	0
Helixate	0
Nuwiq	0
Refacto AF	0
Emicizumab	0
Factor Eight Inhibitor Bypass Activity (FEIBA)	Less than 5
NovoSeven RT	0
Immune Tolerance Induction	0
Any trial drug (please state drug name)	0
Any other treatment for Haemophilia A	0

Q5 In the last 3 months of data that you have, how many patients with Haemophilia B have been treated with:

Drug Name	Total
Alprolix	
BeneFix	
Idelvion	
Rixubis	
Any other treatment for Haemophilia B	

A5 Please see below; Please see below: 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.

Drug Name	Total
Alprolix	Less than 5
BeneFix	Less than 5
Idelvion	0
Rixubis	0
Any other treatment for Haemophilia B	0

Q6 How many Von Willebrand Disease patients do you have registered?

A6 89

Q7 How many are paediatric (18 years old and under)

A7 39

Q8 How many Von Willebrand Disease patients were treated with the following products in the year of 2018?

Drug Name	Total
Veyvondi	
Willfact	
Alphanate	
Willate	
HaemateP	
Voncento	
Other	

A8 Please see below: Please see below: 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.

Drug Name	Total
Veyvondi	0
Willfact	0
Alphanate	0
Willate	0
HaemateP	0
Voncento	Less than 5
Other	

*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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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,



Leah Carlisle
Deputy Head of Quality, Safety & Compliance