



Ref: FOIA Reference 2018/19-159

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

Date: 4<sup>th</sup> July 2018

Tel: 01782 676474  
Email [foi@uhn.nhs.uk](mailto:foi@uhn.nhs.uk)

Dear

I am writing in response to your email dated 18<sup>th</sup> June 2018 requesting information under the Freedom of Information Act (2000) regarding patients with Haemophilia A.

As of 1<sup>st</sup> 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 request for information on the treatment of Haemophilia;**

**In the last 6 months [latest 6 months of data you have available], how many patients with Haemophilia A have been treated with:**

<b>Advate</b>	
<b>Afstyla</b>	
<b>Elocta</b>	
<b>Emicizumab</b>	
<b>Factor Eight Inhibitor Bypass Activity (FEIBA)</b>	
<b>NovoEight</b>	
<b>Kogenate</b>	
<b>Helixate</b>	
<b>NovoSeven RT</b>	
<b>Nuwiq</b>	
<b>Refacto AF</b>	
<b>Other [please state]</b>	

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 The General Data Protection Regulation (GDPR) 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, Please see below:

Advate	5
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Afstyla	0
Elocta	0
Emicizumab	Less than 5
Factor Eight Inhibitor Bypass Activity (FEIBA)	Less than 5
NovoEight	0
Kogenate	0
Helixate	0
NovoSeven RT	0
Nuwiq	0
Refacto AF	0
Other [please state]	

**Q2** If possible, could you also supply the above data, but split by severity as follows

	Mild (factor level >5%)	Moderate (factor level 1- 5%)	Severe (factor level <1%)
<b>Advate</b>			
<b>Afstyla</b>			
<b>Elocta</b>			
<b>Emicizumab</b>			
<b>Factor Eight Inhibitor Bypass Activity (FEIBA)</b>			
<b>NovoEight</b>			
<b>Kogenate</b>			
<b>Helixate</b>			
<b>NovoSeven RT</b>			
<b>Nuwiq</b>			
<b>Refacto AF</b>			
<b>Other [please state]</b>			

**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 The General Data Protection Regulation (GDPR) Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers, Please see below:

Mild (factor level >5%)	Moderate (factor level 1- 5%)	Severe (factor level <1%)

Advate	Less than 5		Less than 5
Afstyla			
Elocta			
Emicizumab			Less than 5
Factor Eight Inhibitor Bypass Activity (FEIBA)			Less than 5
NovoEight			
Kogenate			
Helixate			
NovoSeven RT			
Nuwiq			
Refacto AF			
Other [please state]			

**Q3** In the last 6 months [latest 6 months of data you have available], how many patients with Haemophilia B have been treated with:

<b>Alprolix</b>	
<b>Benefix</b>	
<b>Idelvion</b>	
<b>Rixubis</b>	
<b>Other [please state]</b>	

**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 The General Data Protection Regulation (GDPR) Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers, Please see below:

Alprolix	Less than 5
Benefix	Less than 5
Idelvion	0
Rixubis	0
Other [please state]	

**Q4** As with Haemophilia A, if possible please could you split the information by severity?

	<b>Mild (factor level &gt;5%)</b>	<b>Moderate (factor level 1%-5%)</b>	<b>Severe (factor level &lt;1%)</b>
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<b>Alprolix</b>			
<b>Benefix</b>			
<b>Idelvion</b>			
<b>Rixubis</b>			
<b>Other [please state]</b>			

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 The General Data Protection Regulation (GDPR) Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers, Please see below:

	Mild (factor level >5%)	Moderate (factor level 1%- 5%)	Severe (factor level <1%)
Alprolix			Less than 5
Benefix	Less than 5		Less than 5
Idelvion			
Rixubis			
Other [please state]			

**Q5 If you use PK tools, please can you supply the number of patients in the last 6 months using the following?**

- **WAPPS**
- **myPKFIT**
- **Doseme**
- **Optims**

A5 Not applicable, the Trust does not use PK tools

\*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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<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.

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](http://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,

A handwritten signature in black ink, consisting of a large, loopy initial 'M' followed by a horizontal line extending to the right.

Mojgan Casillas  
**Interim Information Governance Manager**



**University Hospitals  
of North Midlands**  
NHS Trust