



Ref: FOIA Reference 2024/25-625

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

Date: 12<sup>th</sup> December 2024

Email [foi@uhnm.nhs.uk](mailto:foi@uhnm.nhs.uk)

Dear Sir/Madam

I am writing to acknowledge receipt of your email dated 6th December 2024 requesting information under the Freedom of Information Act (2000) regarding Haemophilia A

**Q1 I am researching the incidence and treatment of Haemophilia A across the UK. I would greatly appreciate if you could answer to the following questions.**

**How many haemophilia A patients are registered with your centre, and how many of these patients are classified as exhibiting mild, moderate, or severe disease.**

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 <5  
*This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.*

<5 severe

< 5 moderate

78 mild

**Q2 In the last three months, how many Haemophilia A patients, including on-demand patients, have been treated with the following products?**

- Altuvoct
- Advate
- Adynovi
- Elocta
- Esperoct
- Factor Eight Inhibitor Bypass Activity (FEIBA)
- Hemlibra (standalone)
- Hemlibra in combination with any Factor VIII
- NovoEight
- NovoSeven RT

- Nuwiq
- Obizur
- Refacto AF
- Any other products

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.*

• Altuvoct	0
• Advate	<5
• Adynovi	0
• Elocta	6
• Esperoct	0
• Factor Eight Inhibitor Bypass Activity (FEIBA)	0
• Hemlibra (standalone)	<5
• Hemlibra in combination with any Factor VIII	0
• NovoEight	0
• NovoSeven RT	0
• Nuwiq	0
• Obizur	0
• Refacto AF	0
• Any other products	0

**Q3 For patients treated with Advate in the last three months, please provide:**

- the number of haemophilia A patients treated prophylactically
- the number of haemophilia A patients treated for any other reason (e.g. surgery, on-demand, breakthrough bleeds)

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 patients treated prophylactically and nil for haemophilia A patients treated for any other reason.

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

**Q4 In the last three months, how many patients were treated with the following products for severe Haemophila A ONLY?**

- Altuvoct

- Advate
- Adynovi
- Elocta
- Esperoct
- Factor Eight Inhibitor Bypass Activity (FEIBA)
- Hemlibra (standalone)
- Hemlibra in combination with any Factor VIII
- NovoEight
- NovoSeven RT
- Nuwiq
- Obizur
- Refacto AF
- Any other products

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.*

Altuvoct	0
Advate	<5
Adynovi	0
Elocta	0
Esperoct	0
Factor Eight Inhibitor Bypass Activity (FEIBA)	0
Hemlibra (standalone)	<5
Hemlibra in combination with any Factor VIII	0
NovoEight	0
NovoSeven RT	0
Nuwiq	0
Obizur	0
Refacto AF	0
Any other products	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.***

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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](http://www.ico.org.uk).

Yours,



**Leah Carlisle**  
Head of Data, Security & Protection and Health Records  
Data Protection Officer