

FOI REF: 25/267

9th May 2025

Tel: 0300 131 4500
Website: www.esht.nhs.uk

FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

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.

- 1. 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.**

East Sussex Healthcare NHS Trust no longer centrally records the number of patients with Haemophilia A. To enable the Trust to provide this information would require a manual review of all Haematology patient records which we estimate would take in excess of 18 hours. We are therefore applying Section 12(1) to this part of your request.

Section 12(1) of the Act allows a public authority to refuse to comply with a request for information if the authority estimates that the cost of compliance would exceed the 'appropriate limit', as defined by the Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004 (the Regulations). These state that this cost limit is £450 for public authorities which are not part of central government or the armed forces. The costs are calculated at £25 per hour per person regardless of the rate of pay, which means that the limit will be exceeded if the work involved would exceed 18 hours. The Trust estimates that the cost of complying with this request would significantly exceed the above limit.

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2. In the last three months, how many Haemophilia A patients, including on-demand patients, have been treated with the following products?
- Altuvoct 0
 - Advate 1
 - Adynovi 0
 - Elocta 0
 - Esperoct 0
 - Factor Eight Inhibitor Bypass Activity (FEIBA) 1
 - Hemlibra (Emicizumab) – Standalone 0
 - Hemlibra (Emicizumab) in combination with any Factor VIII 0
 - NovoEight 0
 - NovoSeven RT 0
 - Nuwiq 0
 - Obizur 0
 - Refacto AF 0
 - Any other products 0
 - Hympavzi (Marstacimab) 0
 - CEVENFACTA 0
3. For patients treated with Advate in the last three months, please provide:
- The number of haemophilia A patients treated prophylactically. 0
 - The number of haemophilia A patients treated for any other reason (e.g. surgery, on-demand, breakthrough bleeds). 1
4. In the last three months, how many patients were treated with the following products for severe Haemophilia A ONLY?
- Altuvoct 0
 - Advate 0
 - Adynovi 0
 - Elocta 0
 - Esperoct 0
 - Factor Eight Inhibitor Bypass Activity (FEIBA) 0
 - Hemlibra (Emicizumab) – Standalone 0
 - Hemlibra (Emicizumab) in combination with any Factor VIII 0
 - NovoEight 0
 - NovoSeven RT 0
 - Nuwiq 0
 - Obizur 0
 - Refacto AF 0
 - Any other products 0
 - Hympavzi (Marstacimab) 0
 - CEVENFACTA 0

If I can be of any further assistance, please do not hesitate to contact me.

Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department (esh-tr.foi@nhs.net), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF

Telephone: 0303 123 1113

Yours sincerely

Freedom of Information Department
esh-tr.foi@nhs.net