

## FREEDOM OF INFORMATION REQUEST

RF23-441

### Request:

1. How many Haemophilia A patients are registered with your centre?
2. How many of these patients are classified as exhibiting mild, moderate or severe disease?
3. In the last 3 months (April, May, and June 2023), how many Haemophilia A patients were treated with the following coagulation factors:
  - a. Hemlibra (standalone)
  - b. Hemlibra (in combination with any FVIII product)
  - c. Advate
  - d. Adynovi
  - e. Elocta
  - f. Esperoct
  - g. NovoEight
  - h. ReFacto AF
  - i. Nuwiq
  - j. NovoSeven
  - k. FEIBA
  - l. Obizur
4. In the year (January 2022 to June 2023), how many total Hemophilia A inhibitor patients were treated at your centre?
  - a. Of these, how many had major surgery?
  - b. If any, what type of major surgery did they have?
  - c. How many had minor surgeries?
  - d. How many had more than one surgery?
  - e. Which coagulation factor brands (NovoSeven, Hemlibra, Obizur, FEIBA, or other) were they treated with?
5. What **volume** of coagulation factor (in IU or mg) was distributed to East Kent Hospitals University NHS Foundation Trust each month for April, May, and June 2023, broken down by product (see below). If the volume by brand is not available, I would like to request the **number of vials** distributed by brand
  - a. Hemlibra
  - b. Esperoct
  - c. Adynovi
  - d. Elocta
  - e. NovoEight
  - f. Advate
  - g. ReFacto AF
  - h. Nuwiq
  - i. NovoSeven



- j. FEIBA
- k. Obizur
- l. Idelvion
- m. Refixia
- n. Alprolix
- o. BeneFIX
- p. Replenine
- q. Rixubis
- r. Voncento
- s. Veyvondi
- t. Wilate
- u. Willfact

**Response:**

We can confirm East Kent Hospitals University NHS Foundation Trust (EKHUFT) holds the information you have requested

1. 142

2.

Severe	Moderate	Mild
46	12	84

3.

Hemlibra (standalone)	<b>25</b>
Hemlibra (in combination with any FVIII product)	<b>10</b>
Advate	<b>10</b>
Adynovi	<b>0</b>
Elocta	<b>20</b>
Esperoct	<b>&lt;5*</b>
NovoEight	<b>&lt;5*</b>
ReFacto AF	<b>9</b>
Nuwiq	<b>0</b>
NovoSeven	<b>&lt;5*</b>
FEIBA	<b>0</b>
Obizur	<b>0</b>

4. <5\* patients

- a. 0
- b. 0
- c. 0
- d. 0
- e. Advate, Elocta, Hemlibra



5.

	April	May	June
Hemlibra	0	0	0
Esperoct	0	0	34,000
Adynovi	0	0	0
Elocta	0	105,000	40,000
NovoEight	0	0	80,000
Advate	7,500	10,000	0
Refacto AF	55,000	60,000	0
Nuwiq	0	0	0
NovoSeven	0	20,400	0
FEIBA	10,000	0	80,000
Obizur	0	0	0
Idelvion	0	0	0
Refixia	0	0	0
Alprolix	0	0	0
BeneFIX	0	40,500	500
Replenine	0	0	0
Rixubis	0	0	0
Voncento	72,000	180,000	0
Veyvondi	52,000	26,000	78,000
Wilate	0	0	0
Willfact	0	0	0

\* EKHUFT is unable to confirm the exact number where fewer than five patients are recorded. Given the low number, we consider that disclosure of such information, which constitutes personal data, would contravene the first data protection principle under GDPR. This states that personal data should be processed fairly and lawfully. It is the fairness aspect of this principle, which in our view, would be breached by disclosure. We believe that not disclosing this information is in line with Sections 40(2) and 40(3) of the Freedom of Information Act 2000.

**(DATE OF RESPONSE: 04 AUGUST 2023)**

