

Freedom of Information Act 2000 - Request Reference Fol/20/273

Paediatric Patients

Request details

1. How many adult and paediatric patients registered with your Haemophilia Centre suffer from the following conditions:

- Haemophilia A - **210**
- Haemophilia B - **53**
- Von Willebrand Disease - **241**

2. In the last three months, how many patients have been treated with the following:

- Advate - **23**
- Adynovi - *
- Elocta - **17**
- Esperoct - *
- Factor Eight Inhibitor Bypass Activity (FEIBA) - *
- Hemlibra - **11**
- Jivi - *
- NovoEight - **8**
- NovoSeven RT - *
- Obizur - *
- Refacto AF - **13**
- Alprolix - *
- BeneFIX - **6**
- Idelvion - *
- Refixia - *
- Rixubis - *
- Gene therapy (for Haemophilia B) - **0**
- DDAVP (desmopressin) – **10**
- Tranexamic acid – **145**
- Veyvondi - *
- Voncento - **9**
- Wilate - *

3. Of the Haemophilia A patients treated in the last three months, could you please tell us the number of mild, moderate and severe patients.

- Mild – **9**
- Moderate – **6**
- Severe – **52**

4. Of the Haemophilia A patients treated in the last three months, could you please tell us the number of patients with and without Factor VIII Inhibitors.

- With inhibitors – **10**
- Without inhibitors - **57**

5. Of the Haemophilia B patients treated in the last three months, could you please tell us the number of mild, moderate and severe patients.

- Mild – *
- Moderate – *
- Severe – **8**

Please note that Section 40 of the Freedom of Information Act 2000 has been applied where the information above has been replaced with an asterisk. The UHB will not provide these exact numbers due to the low numbers of individuals involved (5 or less). The UHB believes there is a potential risk of individuals being able to be identified, when considered with other information already available within the public domain, if this was disclosed. Therefore, the data is classed as personal data as defined under the General Data Protection Regulation (GDPR) and Data Protection Act 2018 and its disclosure would be contrary to the data protection principles and constitute unfair and unlawful processing in regard to Articles 5, 6, and 9 of GDPR. We are therefore withholding this detail under Section 40(2) of the Freedom of Information Act 2000. This exemption is absolute and therefore there is no requirement to apply the public interest test.