

Name:

Date: 02/03/2020

Ref: 19-20 517

Dear

### **Freedom of Information request**

Thank you for your request for information under the Freedom of Information Act 2000, which was received by our Freedom of Information team on 20/01/2020.

- 1. How many patients with Haemophilia A are registered with your centre?**  
Less than 90 patients with Haemophilia A.
- 2. Of these how many are mild, moderate or severe? If unknown, please state unknown.**  
Unknown.
- 3. How many patients with Haemophilia B are registered with your centre?**  
Less than 90 patients with Haemophilia B.
- 4. Of these how many are mild, moderate or severe? If unknown, please state unknown.**  
Unknown.
- 5. How many patients with Von Willebrand disease are registered with your centre?**  
100 with Von Willebrand Disease
- 6. In the last 3 months, how many patients have been treated with the following:**
  - *Advate*
  - *Afstyla*
  - *Elocta*
  - *Emicizumab (Hemlibra)*
  - *Helixate*
  - *Kogenate*
  - *NovoEight*
  - *Nuwiq*
  - *Refacto AF*
  - *Factor Eight Inhibitor Bypass Activity (FEIBA)*
  - *NovoSeven RT*
  - *Alphanate*
  - *DDAVP (desmopressin)*
  - *Haemate P*

- *Trabexamic acid*
- *Veyvondi*
- *Voncento*
- *Willate*
- *Willfact*
- *Willfactin*
- *Alprolix*
- *BeneFIX*
- *Idelvion*
- *Refixia*
- *Rixubis*

Monthly datasets are provided to commissioners quarterly and annual reports are submitted the National Haemophilia Database and NHS England for their statistics which are then made available on the website. This annual report includes the numbers of patients per treatment centre, the numbers of patients on regular (prophylaxis) treatment, and market share of different products across the UK. Data which is concatenated at this level does not compromise patient confidentiality or commercially sensitive information.

The website is [www.ukhcdo.org](http://www.ukhcdo.org) and national haemophilia database statistics can be found there for the year.

Please accept this letter as completion of your request. Please note that copies of this request will be held on file for three years before being confidentially destroyed.

If you are dissatisfied with the outcome of your request, please contact our Head of Information Governance on [Information.Governance@porthosp.nhs.uk](mailto:Information.Governance@porthosp.nhs.uk) or write to the above address and we will conduct an internal review. Upon review, if you are still dissatisfied, you may appeal our decision by contacting the Information Commissioner's Office; for more information please visit the [ICO's website](#).

Please be aware, if we do not receive an appeal within 30 days of you receiving this letter, we will assume that you are satisfied with our response. If you have any further queries, please do not hesitate to contact us.

Yours sincerely

Freedom of Information Team