

Freedom of Information Request

Ref: 24-306

18 April 2024

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we hold some of the information you are requesting

Could you please provide answers to the following five questions related to the incidence and treatment of Haemophilia B and Von Willebrand Disease?

Q1. How many patients has your Trust treated (for any medical condition) in the past 3 months with the following drugs:

- **Alphanate** - 0
- **Alprolix** - 9
- **BeneFIX** - *
- **HaemateP** - 0
- **Idelvion** - 0
- **Refixia** - 0
- **Rixubis** - 0
- **Veyvondi** - 0
- **Voncento** - 8
- **Wilate** - 10
- **Willfact** - 0

Please note: Where the figures are between 1 and 5, this has been denoted by *. Due to the low numbers, we have considered that there is the potential for individuals to be identified from the information provided, when considered with other information that may also be in the public domain. In our view disclosure of these low figures would breach one of the Data Protection Principles set out in Schedule 1 of the Data Protection Act, namely Principle 1. The Trust therefore finds that the Section 40(2) exemption contained within the Freedom of information Act 2000 is engaged. This follows NHS Digital (formerly HSCIC) analysis guidance (2014) which states that small numbers within local authorities, wards, postcode districts, providers and Trusts may allow identification of patients and should not be published.

Q2. How many patients have been treated in the past 3 months with:

- **Gene therapy for Haemophilia B ONLY - 0**
- **Desmopressin for Von Willebrand Disease ONLY - ***
- **Tranexamic Acid for Von Willebrand Disease ONLY**

We do not hold this information. All patients are issued tranexamic acid to work concurrently for a bleed/surgical event and mild bleeds issued tranexamic as stand alone treatment

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Q3. Of the patients that were treated with Veyvondi in the past 3 months, how many patients received treatment:

- **During surgery - 0**
- **On demand to treat bleeding episodes - 0**

Q4. Of the patients that were treated with Voncento in the past 3 months, how many patients received treatment:

- **During surgery - ***
- **On demand to treat bleeding episodes - ***

Please note: Where the figures are between 1 and 5, this has been denoted by *. Due to the low numbers, we have considered that there is the potential for individuals to be identified from the information provided, when considered with other information that may also be in the public domain. In our view disclosure of these low figures would breach one of the Data Protection Principles set out in Schedule 1 of the Data Protection Act, namely Principle 1. The Trust therefore finds that the Section 40(2) exemption contained within the Freedom of information Act 2000 is engaged. This follows NHS Digital (formerly HSCIC) analysis guidance (2014) which states that small numbers within local authorities, wards, postcode districts, providers and Trusts may allow identification of patients and should not be published.

Q5. How many patients are registered with your trust for the following diseases:

- **Haemophilia B - 42**
- **Von Willebrand Disease - 268**

• **Von Willebrand Disease - paediatric patients (age 17 or under) - 52**

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Data Protection Officer
University Hospitals Bristol and Weston NHS Foundation Trust
Trust Headquarters
Marlborough Street
Bristol
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

Freedom of Information Team
University Hospitals Bristol and Weston NHS Foundation Trust