



Ref: FOIA Reference 2022/23-318

Date: 24th October 2022

Email foi@uhnm.nhs.uk

Dear

I am writing to acknowledge receipt of your email dated 12th September 2022 requesting information under the Freedom of Information Act (2000) regarding Von Willebrand Disease.

The University Hospitals of North Midlands Trust is committed to the Freedom of Information Act 2000.

However, the NHS is facing unprecedented challenges relating to the coronavirus (COVID-19) pandemic at the current time. Understandably, our resources have been diverted to support our front-line colleagues who are working tremendously hard to provide care for our patients, and to those in need of our services.

We strive to be transparent and to work with an open culture. But at this time, whilst care of our patients and the safety of our staff takes precedent, it is likely that responses to some requests for information will be delayed. We apologise for this position in advance, and will endeavour to provide you with as much information as we can, as soon as we are able.

The Information Commissioners Office has recognised the current situation in the NHS.

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

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

- **Alphanate**
- **Alprolix**
- **BeneFIX**
- **HaemateP**
- **Idelvion**
- **Refixia**
- **Rixubis**
- **Veyvondi**
- **Voncento**
- **Wilate**
- **Willfact**

A1 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5

This exemption is an absolute exemption and therefore no consideration of the public interest test is needed. See below:

- Alphanate - 0
- Alprolix - <5
- BeneFIX - 0
- HaemateP - 0
- Idelvion - 0
- Refixia - 0
- Rixubis - 0
- Veyvondi - 0
- Voncento - <5
- Wilate - 0
- Willfact - 0

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

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

A2 We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers as being <5

This exemption is an absolute exemption and therefore no consideration of the public interest test is needed. See below:

- Gene therapy for Haemophilia B ONLY= 0
- Desmopressin for Von Willebrand Disease ONLY= <5
- Tranexamic Acid for Von Willebrand Disease ONLY= <5

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

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

A3 See below:

- During surgery = N/A not used
- On demand to treat bleeding episodes = N/A not used

- Q4 How many patients are registered with your Haemophilia Centre For?**
- **Von Willebrand Disease – adult patients (age 18 or above)**
 - **Von Willebrand Disease – paediatric patients (age 17 or under)**
 - **Haemophilia B (any age)**

- A4 See below:**
- Von Willebrand Disease – adult patients (age 18 or above) =102
 - Von Willebrand Disease – paediatric patients (age 17 or under) = 38
 - Haemophilia B (any age) = 7

*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

UHNM NHS Trust is a public sector body and governed by EU law. FOI requestors should note that any new Trust requirements over the EU threshold will be subject to these regulations and will be advertised for open competition accordingly.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

If following review of the responses I can be of any further assistance please contact my secretary on 01782 671612.



University Hospitals
of North Midlands
NHS Trust

Yours,

L Carlisle

Leah Carlisle
Head of Data, Security & Protection/ Data Protection Officer

