

Ref: FOIA Reference 2020/21-144

Royal Stoke University Hospital
Data, Security and Protection
Newcastle Road
Stoke-on-Trent
Staffordshire
ST4 6QG

Date: 11th August 2020

Email foi@uhnm.nhs.uk

Dear

I am writing in response to your email dated 27th July 2020 (received into our office 28th July) requesting information under the Freedom of Information Act (2000) regarding haemophilia

On our acknowledgment we added the following statement:

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 We would greatly appreciate it if you could provide answers to the following questions.

Q1. How many adult and paediatric patients registered with your Haemophilia Centre suffer from the following conditions?

- Haemophilia A
- Haemophilia B
- Von Willebrand Disease

A1 Please see below:

- Haemophilia A=64
- Haemophilia B= 6
- Von Willebrand Disease =104

Q2 In the last three months, how many patients have been treated with the following?

- Advate
- Adynovi
- Elocta
- Esperoct
- Factor Eight Inhibitor Bypass Activity (FEIBA)
- Hemlibra
- Jivi
- NovoEight
- NovoSeven RT
- Obizur
- Refacto AF
- Alprolix
- BeneFIX
- Idelvion
- Refixia
- Rixubis
- Gene therapy (for Haemophilia B)
- DDAVP (desmopressin)
- Tranexamic acid
- Veyvondi
- Voncento
- Wilate

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, see below.

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

- Advate=5
- Adynovi=0
- Elocta=0
- Esperoct=0
- Factor Eight Inhibitor Bypass Activity (FEIBA) =<5
- Hemlibra=0
- Jivi=0
- NovoEight =0
- NovoSeven RT=<5
- Obizur=0
- Refacto AF=0
- Alprolix=<5
- BeneFIX=0
- Idelvion=0
- Refixia=0
- Rixubis=0

- Gene therapy (for Haemophilia B) = 0
- DDAVP (desmopressin) = 0
- Tranexamic acid= 5
- Veyvondi = 0
- Voncento =<5
- Wilate = 0

Q3 Of the Haemophilia A patients treated in the last three months, could you please tell us the number of?

- **Mild**
- **Moderate**
- **Severe patients.**

A3 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, see below.

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

- Mild=<5
- Moderate =0
- Severe patients. =<5

Q4 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.

A4 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, see below.

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

- With = <5
- Without=5

Q5 Of the Haemophilia B patients treated in the last three months, could you please tell us the number of?

- **Mild**
- **Moderate**
- **Severe patients**

A5 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, see below.

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

- Mild=<5
- Moderate=0
- Severe patients=<5

*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.

Yours,

A handwritten signature in black ink on a light grey background. The signature reads "Jean Lehnert" in a cursive, slightly slanted script.

Jean Lehnert
Data, Security & Protection Manager