

Reference Number: FOI202223/253
From: Commercial
Date: 23 August 2022
Subject: Haemophilia treatments

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

- a. Alphanate
- b. Alprolix
- c. BeneFIX
- d. HaemateP
- e. Idelvion
- f. Refixia
- g. Rixubis
- h. Veyvondi
- i. Voncento
- j. Wilate
- k. Willfact

A1

- a. 0
- b. Information exempted under Section 40: Personal data. Providing this information would likely identify individuals involved.
- c. 0
- d. 0
- e. Information exempted under Section 40: Personal data. Providing this information would likely identify individuals involved.
- f. 0
- g. 0
- h. 0
- i. 0
- j. 0
- k. Information exempted under Section 40: Personal data. Providing this information would likely identify individuals involved.

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

- a. Gene therapy for Haemophilia B ONLY
- b. Desmopressin for Von Willebrand Disease ONLY
- c. Tranexamic Acid for Von Willebrand Disease ONLY

A2

- a. 0
- b. 0
- c. 0

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

- a. During surgery
- b. On demand to treat bleeding episodes

A3 Not applicable, as per A1h above

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

- Information not held - Alder Hey Children's NHS Foundation Trust is a specialist children's hospital and does not provide services to adult patients
- 64
- 5

The Trust is unable to respond to all or specific elements of your request where the response would indicate five or less individuals. The Trust is withholding this information under Section 40 (Personal Information) of the Freedom of Information Act (FOIA) 2000 to reduce the risk of any individuals being identified. The Trust is of the view that disclosure of such information would significantly increase the risk of individuals being identified and as such would constitute a breach of their personal data.

The Trust has applied exemption Section 40(2) of the FOIA and is therefore withholding the information as disclosure which may identify an individual would breach their rights under the Data Protection Act 2018. The grounds for application of this exemption include:

- Any data relating to patients or staff is third party data, furthermore health data is classified as sensitive personal data within the Data Protection Act 2018. As such, Section 40 (2) of the FOIA applies along with the Trusts duty of confidentiality. Therefore under s.2 (3) (f) (ii) of the FOIA, there is an absolute exemption from disclosure on the grounds that it would contravene the First Data Protection Principle.
- The Trust has a duty under the Data Protection Act 2018 and specifically the First Data Protection Principle to ensure personal data regarding staff and patients is processed fairly and lawfully. Disclosure of such data which may identify an individual, either through the data alone or other data in conjunction with that data which may identify an individual would therefore breach this principle.
- The Data Protection Act 2018 defines sensitive personal data to include data relating to the "physical or mental health or condition" of a person. Any such information about specific individuals falls within this category and disclosure of such data including statistical data, with any potential likelihood of identification would breach the Data Protection Act 2018.