

Title

Treatment of Haemophilia A

Reference Number: RDF2134-23
Date of Response: 04/01/24

Further to your Freedom of Information Act request, please find the Trust's response(s) below:

Please be aware that the Royal Devon University Healthcare NHS Foundation Trust (Royal Devon) has existed since 1st April 2022 following the integration of the Northern Devon Healthcare NHS Trust (known as Northern Services) and the Royal Devon and Exeter NHS Foundation Trust (known as Eastern Services).

Q1. How many haemophilia A patients are registered with your centre, and how many of these patients are classified as exhibiting mild, moderate, or severe disease?

Classification	Count of Patients
Mild haemophilia A	20
Moderate haemophilia A	* <5
Severe haemophilia A	13
Unknown*	23
Grand Total	59

The Trust is not able to respond fully to the above question. The Trust does not hold all of the requested information. Not all patients are seen in clinic regularly, in particular those with mild and moderate haemophilia A, so the Trust's system (EPR) may not hold up to date information. This information will be stored in the National Haemophilia Database which we do not have access to. The only other data that is held is part of a patient's medical record. As it is personal data, it would not be lawful or transparent to patients to view their records for this purpose as it would be inappropriate use of access to records. As such it is exempt under Section 40(2) of the FOI Act as it is in breach of Principle 1 of the UK GDPR.

Q2. In the last three months, how many Haemophilia A patients, including on-demand patients, have been treated with the following products?

(Note – Answers to Q2 were provided by the Blood Bank rduh.htt@nhs.net)

Advate	* <5
Adynovi	0
Elocta	0
Esperoct	0
Factor Eight Inhibitor Bypass Activity (FEIBA)	* <5
Hemlibra (standalone)	0
Hemlibra in combination with any Factor VIII	0
NovoEight	0

NovoSeven RT	* <5
Nuwig	
Obizur	* <5
Refacto AF	* <5
Any other products	0

Q3. For patients treated with Advate in the last three months, please provide:

- the number of haemophilia A patients treated prophylactically 0.
- the number of haemophilia A patients treated for any other reason (e.g., surgery, on-demand, breakthrough bleeds) - * <5.

Q4. In the last three months, how many patients were treated with the following products for severe Haemophilia A ONLY?

Advate	* <5
Adynovi	0
Elocta	0
Esperoct	0
Factor Eight Inhibitor Bypass Activity (FEIBA)	0
Hemlibra (standalone)	0
Hemlibra in combination with any Factor VIII	0
NovoEight	0
NovoSeven RT	* <5
Nuwig	0
Obizur	0
Refacto AF	* <5
Any other products	0

* <5 - Section 40(2) *

Please note: Where the figures are between 1 and 5, this has been denoted by *5. 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 GDPR, 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.