

Freedom of Information Act 2000 - Request Reference FoI/23/405
Haemophilia B and Von Willebrand disease treatment

Information Requested:

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

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

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

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

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

- Haemophilia B

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

Response Details:

After considering your request, Cardiff and Vale University Health Board (the UHB) considers this information to be exempt from disclosure under the Freedom of Information Act 2000 (Section 43) Commercial Interests. This section of the Act sets out an exemption from the right to know if:

- the information requested is a trade secret, or
- release of the information is likely to prejudice the commercial interests of any person. (A person may be an individual, a company, the public authority itself or any other legal entity).

This exemption was considered by the UHB when deciding whether to disclose information because it considered that in doing so there could be a significant risk in prejudicing the commercial interests of both the supplier and the UHB. As this is a qualified exemption, the UHB is required to complete a public interest test in deciding whether it is in the public's interest to withhold or disclose the information.

In favour of disclosure: There is a public interest in transparency and in the accountability of spending of public funds. Furthermore, it is in the public's interest that public funds be used effectively and that public sector bodies obtain the best value for money when contracting for the provision of services.

Against disclosure: The supply and distribution of these products in Wales is maintained using a national approach based on the principle of supply based on plurality of provision. The complex risk of shortage is managed on a national level rather than at HB level. Global shortage also means that there are active supply management techniques in place in Wales. Release of figures pertaining to individual manufacturer's products and the breakdown of individual patient use would be detrimental to the management of the Welsh supply as a whole within a complex and competitive global market. Due to the Product selection guide management, it would also be prejudicial against the individual HB (in this case, C&V) as the number of patients on each product are without meaning and context unless amalgamated with data from all other Welsh HBs.

Decision: It has been established that releasing the information sought under the Freedom of Information Act would affect the supply and distribution of these products. The UHB believes that disclosure of information in a manner which fails to protect the confidential nature of the supply and distribution network in a commercial context could jeopardise the UHB's ability to purchase these products, which would in turn adversely affect the treatment of patients with the relevant conditions. Therefore, the UHB considers that the public interest in withholding the information and protecting patient welfare to be greater than the interest in disclosing data. It was consequently decided that it was not in the public's interest to disclose this information.