Freedom of Information request to Public Health Wales

<table>
<thead>
<tr>
<th>FOI Reference:</th>
<th>FOI 427</th>
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<tbody>
<tr>
<td>Date request received</td>
<td>08 September 2020</td>
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<tr>
<td>Date information is due to be sent</td>
<td>06 October 2020</td>
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Information Requested:
I am writing to request some data under the Freedom of Information Act. I am looking for numbers of Haemophilia A, Haemophilia B, and von Willebrand Disease patients on different treatment regimens and treatment types. I do not need any identifiers or information about specific brands or preferences.

I appreciate your help in knowing if this is possible, and what steps I'll need to take next. Please let me know if you have any questions or concerns.

Information provided for the answer:
Thank you for your recent request for information.

Public Health Wales are responsible for the Congenital Anomaly Register & Information Service for Wales and we record overall numbers (and rates in Wales) but the register doesn’t collect any data on treatment regimens or types.

We recommend you contact the individual Health Boards, and the Haematology departments may hold the information you need.
I have included their contact information below for your convenience, as well as some links to web pages that you may find helpful.

Aneurin Bevan University Health Board

http://www.wales.nhs.uk/sitesplus/866/page/39187

Betsi Cadwaladr University Health Board

http://www.wales.nhs.uk/sitesplus/861/page/39134

Cardiff and Vale University Health Board

http://www.cardiffandvaleuhb.wales.nhs.uk/freedom-of-information-new

Cwm Taf Morgannwg University Health Board

https://cwmtafmorgannwg.wales/foi/

Swansea Bay University Health Board

https://sbuhb.nhs.wales/about-us1/foia/

Hywel Dda University Health Board

http://www.wales.nhs.uk/sitesplus/862/page/52085

Powys Teaching Health Board

http://www.powysthb.wales.nhs.uk/freedom-of-information

http://www.caris.wales.nhs.uk/blood-disorders

The national (UK) haemophilia database: http://www.ukhcdo.org/nhd/

If you are unhappy with the service you have received in relation to your request and wish to make a complaint or request a review of the decision, you should write to the Corporate Complaints Manager, Public Health Wales NHS Trust, 3, Number 2, Capital Quarter, Tyndall Street, Cardiff, CF10 4BZ.

If you are not content with the outcome of your complaint or review, you may apply directly to the Information Commissioner for a decision. Generally, the ICO cannot make a decision unless you have exhausted the complaints procedure provided by the Trust. The Information Commissioner can be contacted at:

Information Commissioner for Wales

2nd Floor
Churchill House
Churchill Way
Cardiff
CF10 2HH

Telephone: 029 2067 8400

Email: wales@ico.org.uk