

Date: Wednesday, 26th October 2022  
Our Ref: MB/CM FOI 5385

Sid Watkins Building  
Lower Lane  
Fazakerley  
Liverpool L9 7BB  
Tel: 01515253611  
Fax: 01515295500  
Direct Line: 01515563038

**Re: Freedom of Information Request FOI 5385**

We are writing in response to your request submitted under the Freedom of Information Act, received in this office on 10th October 2022.

Your request was as follows:

1. How many patients with any Ehlers Danlos Syndrome variant have any of your spinal or neurosurgeons operated on in the last five years?

[16 operations on 11 unique patients with Ehlers Danlos Syndrome](#)

2. How many of your neuro surgeons and how many of your spinal surgeons have operated on any patient with any Ehlers Danlos Syndrome variant in the last five years?

[7 spinal neurosurgeons and 5 neurosurgeons have operated on patients with Ehlers Danlos Syndrome](#)

3. How many patients had cervical stabilisation surgeries has the health board performed in the last five years? How many of these were for patients with craniocervical and for patients with atlantoaxial instability (or both)? How many of these patients had any Ehlers Danlos Syndrome variant? Did any of the patients also have a documented PMP 22 deletion?

[I confirm that The Walton Centre NHS Foundation Trust holds the information you have requested. However, I am unable to provide you with that information as I consider that the following exemptions apply to it:](#)

**Section 40 (2) - Third Party Data**

[This information is exempt from disclosure under Section 40\(2\) of the Freedom of Information Act 2000 \(FOIA\), due to the minimal number of patients identified as data requested is relating to 1-5 patients. In answering your query may lead to the undue stress of families and patients/staff as this information may still lead to patients being identified. Therefore, this information has not been released for reasons of confidentiality.](#)

[This exemption is not subject to the public interest test. This response therefore acts as a refusal notice under section 17 of the FOIA.](#)

Please see our response above in [blue](#).

**Re-Use of Public Sector Information**

All information supplied by the Trust in answering a request for information (RFI) under the Freedom of Information Act 2000 will be subject to the terms of the Re-use of Public Sector Information Regulations 2005, Statutory Instrument 2005 No. 1515 which came into effect on 1st July 2005.

Under the terms of the Regulations, the Trust will licence the re-use of any or all information supplied if being used in a form and for the purpose other than which it was originally supplied. This license for re-use will be in line with the requirements of the Regulations and the licensing terms and fees as laid down by the Office of Public Sector Information (OPSI). Most licenses will be free; however the Trust reserves the right, in certain circumstances, to charge a fee for the re-use of some information which it deems to be of commercial value.

Further information can be found at [www.opsi.gov.uk](http://www.opsi.gov.uk) where a sample license terms and fees can be found with guidance on copyright and publishing notes and a Guide to Best Practice and regulated advice and case studies, at [www.opsi.gov.uk/advice/psi-regulations/index.htm](http://www.opsi.gov.uk/advice/psi-regulations/index.htm)

If you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to the Freedom of Information Office at the address above.

**Please remember to quote the reference number, FOI 5385 in any future communications.**

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at: Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

Yours sincerely

*Mike Burns*

**Mr. Mike Burns, Executive Lead for Freedom of Information**