

Date: Wednesday, 04th December 2019
Our Ref: MB/SS FOI 4112

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Re: Freedom of Information Request FOI 4112

We are writing in response to your request submitted under the Freedom of Information Act, received in this office on 12th November 2019.

Your request was as follows:

I am writing to request information under the Freedom of Information Act 2000 on the pharmacological treatment of

1. How many patients with NDM are currently treated in your organisation?

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2. How many of your organisation's NDM patients receive pharmacological treatment for symptoms of myotonia?

Here at The Walton Centre Foundation Trust we can only provide the number of patients receiving mexiletine for NDM, We have 7 patients currently on mexiletine for NDM. We cannot provide the treatment for those not receiving mexiletine for NDM as they are used for many other indications.

3. Which pharmacological product(s) are currently used for the treatment of symptoms of myotonia in NDM patients within your organisation?

Treatments include nothing, carbamazepine, and mexilitine.

4. What proportion of your NDM patient population receive each of the pharmacological product(s) mentioned in your response to the above question?


I can confirm in accordance with Section 1 (1) of the Freedom of Information Act 2000 (FOIA) that we do not collate information regarding the proportion of your NDM patient population receive each of the pharmacological product. Under the FOI Act, we are not required to create this information in order to answer your request. I should explain that the FOI Act is to do with transparency of information held by public authorities. It gives an individual the right to access recorded information held by public authorities. The FOI Act does not require public authorities to generate information, or to answer questions, provide explanations or give opinions, unless this is recorded information that they already hold.

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.



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Further information can be found at 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

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 4112 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