

Date: Wednesday, 03 July 2019 Our Ref: MB/KF FIRM 3879

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## Re: Freedom of Information Request FIRM 3879

We are writing in response to your request submitted under the Freedom of Information Act, received in this office on 10<sup>th</sup> June 2019.

Your request was received as follows:

Can figures be provided in relation to Neuromyelitis Optica (NMO) Can you provide any details based on the UK registry database on the following

- Number of total patients in registry
- Registry coverage of population

The Walton Centre NHS Foundation Trust (WCFT) can confirm we have 144 live AQP4-NMOSD on our database and 95 seronegative NMOSD; these are patients who have come to the trust or are under our care directly or indirectly. As part of UK NMO service we cover north of Birmingham including Scotland, we cannot determine the exact population however we can roughly guess around 25 million.

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 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 above 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 Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

Yours sincerely

Mike Burns

Mr Mike Burns, Executive Lead for Freedom of Information





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