The Walton Centre NHS
NHS Foundation Trust
Excellence in Neuroscience

Date: Friday, 13th March 2020
Our Ref: MB/SS FOI 4239

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Re: Freedom of Information Request FOI 4239

We are writing in response to your request submitted under the Freedom of Information Act, received in this office on 05th February 2020.
Your request was as follows:

Could you please provide us with the numbers of patients in relation to the questions mentioned below, for a period of last 12 months:

1. In your trust how many patients have a diagnosis of Multiple Sclerosis (MS), regardless of whether they are currently on treatment?

Between 01/03/2019 and 29/02/2020 there were 5904 outpatient attends for patients with MS, comprised of 2992 unique patients. Also 1266 inpatient stays (including daycases) for patients with MS, comprised of 346 unique patients.

2. Of these MS patients, how many have been diagnosed with relapsing (RRMS), primary progressive (PPMS) or secondary progressive (SPMS) MS;

If you do not code your MS patients in this way, do you have plans to do this?

RRMS

PPMS

SPMS

Not known

I can confirm in accordance with Section1 (1) of the Freedom of Information Act 2000 (FOIA) that we do not collate information as our data sets do not differentiate types of MS in diagnosis coding. Therefore we have provided an overall figure below for all migraine diagnosis:

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.

3. How many patients with Multiple Sclerosis have been treated with disease modifying drugs in the past 6 months. Please include all patients whose treatment is ongoing, even those with infrequent dosing schedules (e.g. Lemtrada, Mavenclad, Ocrevus). Please provide the total number of patients by treatment for the following disease modifying drugs:

Aubagio (teriflunomide)

Avonex (interferon beta-1a)

Betaferon (interferon beta-1b)

Brabio (glatiramer acetate)

Copaxone (glatiramer acetate)

Extavia (beta interferon-1b)

Gilenya (fingolimod)

Lemtrada (alemtuzumab)

Mavenclad (cladribine)

Mayzent (siponimod)

Ocrevus (ocrelizumab)

Plegridy (peginterferon beta-1a)

Rebif (beta interferon-1a)

Tecfidera (dimethyl fumarate)

Tysabri (natalizumab)

Vumerity (diroximel fumarate)

Zinbryta (daclizumab)

Ampyra (fampyra)

Ozanimod

I can confirm in accordance with Section1 (1) of the Freedom of Information Act 2000 (FOIA) that we do not collate isease modifying drugs usage by indication/ condition therefore we cannot provide this.

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.

4. Of the patients who are receiving Ocrevus (Ocrelizumab) , how many are primary progressive (PPMS)? If unknown, please state unknown.

We do not collate this data - as above.

5. How many patients have been treated with these drugs in the past 6 months, regardless of diagnosis.

Aubagio (teriflunomide)

Avonex (interferon beta-1a)

Betaferon (interferon beta-1b)

Brabio (glatiramer acetate)

Copaxone (glatiramer acetate)

Extavia (beta interferon-1b)

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Plegridy (peginterferon beta-1a)

Rebif (beta interferon-1a)

Tecfidera (dimethyl fumarate)

Tysabri (natalizumab)

Vumerity (diroximel fumarate)

Zinbryta (daclizumab)

Ampyra (fampyra)

Ozanimod

The data captured is for the past 10 month period

TERIFLUNOMIDE (HOMECARE) 14 mg tablets 53

Interferon beta-1a (Avonex) 28
INTERFERON Beta 1b HOMECARE (BETAFERON) 250 micrograms in 1ml injection 3
Glatiramer acetate (Brabio) 0
Glatiramer acetate (Copaxone) 331
Beta interferon-1b (Extavia) 0
FINGOLIMOD (HOMECARE) 500 micrograms capsules 130
ALEMTUZUMAB 12 mg in 1.2ml injection 23
CLADRIBINE (HOMECARE) 10 mg tablets 11
Siponimod (Mayzent) 0
OCRELIZUMAB 300 mg in 10ml injection 38
Peginterferon beta-1a (Plegridy) 22
Beta interferon-1a (Rebif) 88
Dimethyl fumarate (Tecfidera) 250
Natalizumab (Tysabri) 46
Diroximel fumarate (Vumerity) 0
Daclizumab (Zinbryta) 0
Fampyra (Ampyra) 4
Ozanimod 0

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 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 4239 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