

Date: Monday, 06th September 2021
Our Ref: MB/SS FOI 4847

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Re: Freedom of Information Request FOI 4847

We are writing in response to your request submitted under the Freedom of Information Act, received in this office on 13th August 2021.

Your request was as follows:

1 - Are your patients coded for the different sub types of MS (multiple sclerosis), Relapse remitting, primary progressive and secondary?

Please answer Yes, No, coding planned, partial coding, all patients coded

Here at The Walton Centre NHS Foundation Trust (WCFT) all MS patients coded, however different subtypes can't be identified by coding. There is only code to describe all MS patients.

2 - For secondary progressive MS are your patients coded?

Please answer No coding, coding planned, partial coding, all patients coded

As above.

3 - What proportion of your MS patients have a diagnosis of secondary progressive MS (within all MS diagnosed patients)?

Please answer Unknown, <10%, 10-20%, 21-30%, 31-40%, >50%

As above.

4 - For MS patients requiring an MRI, what is the average waiting time?

Please answer <1 month, 2 - 3 months, 4 - 6 months, >6 months

<1 month

5 - For MS patients requiring an OCT, what is the average waiting time?

Please answer <1 month, 2 - 3 months, 4 - 6 months, >6 months

WCFT does not have an OCT machine.

6 - For MS patients what is the average waiting time for IV MS treatment?

Please answer <1 month, 2 - 3 months, 4 - 6 months, >6 months

WCFT average waiting time from 01/04/2019 is 4.7 weeks.

7 - When a patient has been diagnosed with MS, what is the average time from diagnosis of MS to initiate treatment?

I can confirm in accordance with Section 1 of the Freedom of Information Act 2000 (FOIA) that we do not hold the information you have requested as WCFT do not record time from diagnosis as it's not the diagnosis alone that determines who is eligible for a DMT.

Under the FOIA we are not required to create this information in order to answer your request. I should explain that the FOIA 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 FOIA 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.

8 - How many unscheduled admissions have there been for patients with a diagnosis of MS in any position between April - June 2021?

Please answer with the number of admissions

There have been 2 unscheduled admissions for patients with a diagnosis of MS between April - June 2021.

9 - How many MS patients are being treated in neurology rehab?

Please answer the number of patients

WCFT have had 5 MS patients who have been inpatients in neurology rehab since 2016.

10 - Of the patients in Question 8, how many are being treated with an MS disease modifying drug?

Please answer with the number of patients

Pharmacy do not have the data to answer this question. However, we have provided information on total number of dispensed MS disease modifying drugs in the period April - June 2021 including both homecare and hospital dispensing:

ALEMTUZUMAB 12 mg in 1.2ml injection - 2

FINGOLIMOD (HOMECARE) Packsize 28 (Maintenance) 500 micrograms capsules - 142

FINGOLIMOD 500 micrograms capsules - 2

GLATIRAMER (HOMECARE) 20 mg in 1ml injection - 55

GLATIRAMER (HOMECARE) 40 mg in 1ml injection - 289

INTERFERON BETA 1a HOMECARE (AVONEX) 30 micrograms in 0.5ml injection - 9
INTERFERON BETA 1a HOMECARE (AVONEX) PEN 30 micrograms in 0.5ml injection - 9
INTERFERON BETA 1a HOMECARE (REBIJECT) 22 micrograms in 0.5ml injection - 23
INTERFERON BETA 1a HOMECARE (REBIJECT) 44 micrograms in 0.5ml injection - 11
INTERFERON BETA 1a HOMECARE (REBISMART) 22 micrograms in 0.5ml injection - 18
INTERFERON BETA 1a HOMECARE (REBISMART) 44 micrograms in 0.5ml injection - 22
INTERFERON Beta 1b HOMECARE (BETAFERON) DELIVERY CHARGE Pack - 1
INTERFERON Beta 1b HOMECARE (BETAFERON) 250 micrograms in 1ml injection - 3
OCRELIZUMAB 300 mg in 10ml injection - 30
PEGINTERFERON INITIATION PACK (HOMECARE) injection - 3
PEGINTERFERON beta 1A (HOMECARE) 125 micrograms in 0.5ml injection - 32
TERIFLUNOMIDE (HOMECARE) 14 mg tablets - 53
TOTAL - 704

11 - How many MS patients are in the following EDSS (Expanded Disability Status Scale) groups?

1 - 3.5, 3.5 - 6.5, >7

I can confirm in accordance with Section 1 of the Freedom of Information Act 2000 (FOIA) that we do not hold the information you have requested as WCFT do not systematically record EDSS on a database.

Under the FOIA we are not required to create this information in order to answer your request. I should explain that the FOIA 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 FOIA 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.

12 - How many of your physicians can initiate MS disease modifying drug treatment? If possible please supply the physicians name.

WCFT has Six Neurologists sub-specialising in MS. MS DMTs should only be initiated by a clinician with expertise in MS. In theory, this can be any consultant neurologist but in practice at WCFT (and most other sites in the UK) it is only sub-specialty MS consultants. WCFT does not disclose individual staff members contact details.

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 4847 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