

Royal Stoke University Hospital

Quality, Safety and Compliance Department

Newcastle Road Stoke-on-Trent Staffordshire ST4 6QG

Date: 13th February 2020

Ref: FOIA Reference 2019/20-651

Email foi@uhnm.nhs.uk

Dear

I am writing in response to your emails dated 5th February 2020 requesting information under the Freedom of Information Act (2000) regarding test for test and prescribing in neuroscience.

On the same day we contacted you via email to inform you that these requests were identical apart from the heading and that under section 14 of the FOI Act we would be responding once.

Section 14 (2) of the FOI Act states, where a public authority has previously complied with a request for information which was made by any person, it is not obliged to comply with a subsequent identical or substantially similar request from that person unless a reasonable interval has elapsed between compliance with the previous request and the making of the current request.

I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in questions 1 to 4 is not held centrally, but may be recorded in individual health records. In order to confirm whether this information is held we would therefore have to individually access all individual health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: cost of compliance is excessive. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all individual health records and then extracting relevant information would take longer than the 18 hours allowed for.

In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: *oppressive* burden on the authority

Under section 16 of the FOI Act we are required to provide requestors with advice and assistance where possible. We would therefore like to advise you that if your request is shortened to just question 5 then we are able to comply within the 18 hour time frame. In order to avoid delay to your response we have provided this below.

As of 1st November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

- Q1 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?







- A1 Section 12 and 14 exemptions as detailed above
- Q2 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
- A2 As answer 1
- 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
- A3 As answer 1
- Q4 Of the patients who are receiving Ocrevus (Ocrelizumab), how many are primary progressive (PPMS)? If unknown, please state unknown.
- A4 As answer 1
- Q5 How many patients have been treated with these drugs in the past 6 months, <u>regardless</u> of diagnosis.



- 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
- We are unable to provide the information you require in the requested format as to release this data could lead to the identification of the person(s) involved due to the low numbers involved, and would breach the Trusts obligations under Data Protection Act 2018. Accordingly, this aspect of your request is exempt from disclosure under the terms of Section 40(2) of the FOI Act. *Personal information*. However as the Trust is committed to openness and transparency we can band the numbers, please see below.

This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.

Aubagio (teriflunomide)	16
Avonex (interferon beta-1a)	25
Betaferon (interferon beta-1b)	<5
Brabio (glatiramer acetate)	0
Copaxone (glatiramer acetate)	61
Extavia (beta interferon-1b)	0
Gilenya (fingolimod)	76
Lemtrada (alemtuzumab)	17
Mavenclad (cladribine)	0
Mayzent (siponimod)	0
Ocrevus (ocrelizumab)	133
Plegridy (peginterferon beta-1a)	30
Rebif (beta interferon-1a)	39
Tecfidera (dimethyl fumarate)	155
Tysabri (natalizumab)	249
Vumerity (diroximel fumarate)	0
Zinbryta (daclizumab)	0
Ampyra (fampyra)	0







*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

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Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via www.ico.org.uk.

If following review of the responses I can be of any further assistance please contact my secretary on 01782 676474.

Yours,









Information Governance Manager



