

Ref: FOIA Reference 2022/23-575

Date: 9<sup>th</sup> February 2023

Email [foi@uhn.nhs.uk](mailto:foi@uhn.nhs.uk)

Dear

I am writing to acknowledge receipt of your email dated 11th January 2023 requesting information under the Freedom of Information Act (2000) regarding Multiple sclerosis

On the same day we contacted you via email as we require the following clarification:

'What are you meaning by "how many hospital patients (inpatients or outpatients) currently have a diagnosis of..." Are you looking over a period of time, for example 6 months like in Q1 and FOI 350-2223 or how many patients are under the care of the hospital that have a diagnosis of... or as of today how inpatients and outpatients are currently in hospital for the conditions stated?'

On 30<sup>th</sup> January 2023 you replied via email with:

*'Yes we are happy to have the information for "how many patients are under the care of the hospital that have a diagnosis of... or as of today how inpatients and outpatients are currently in hospital for the conditions stated".'*

As of 1<sup>st</sup> 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 have a Freedom of information query. How many patients has your Trust/health board treated in the past 6 months (for any disease) with the following 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)**
- **Kesimpta (ofatumumab)**
- **Mavenclad (cladribine)**
- **Mayzent (siponimod)**
- **Ocrevus (ocrelizumab)**
- **Plegridy (peginterferon beta-1a)**
- **Ponvory (ponesimod)**
- **Rebif (beta interferon-1a)**

- **Tecfidera (dimethyl fumarate)**
- **Tysabri (natalizumab)**
- **Tysabri (natalizumab) pre-filled syringes ONLY**
- **Vumerity (diroximel fumarate)**
- **Zeposia (ozanimod)**

A1 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 as being <5  
*This exemption is an absolute exemption and therefore no consideration of the public interest test is needed.*

- Aubagio (teriflunomide) = 13
- Avonex (interferon beta-1a) = 18
- Betaferon (interferon beta-1b) = <5
- Brabio (glatiramer acetate) = 0
- Copaxone (glatiramer acetate) = 72
- Extavia (beta interferon-1b) = <5
- Gilenya (fingolimod) = 60
- Lemtrada (alemtuzumab) = 8
- Kesimpta (ofatumumab) = 8
- Mavenclad (cladribine) = 0
- Mayzent (siponimod) = 26
- Ocrevus (ocrelizumab) = 364
- Plegridy (peginterferon beta-1a) = 20
- Ponvory (ponesimod) = 0
- Rebif (beta interferon-1a) = 27
- Tecfidera (dimethyl fumarate) = 164
- Tysabri (natalizumab) = 229
- Tysabri (natalizumab) pre-filled syringes ONLY = 0
- Vumerity (diroximel fumarate) = 0
- Zeposia (ozanimod) = 0

**Q2 It would also be very helpful if you could advise how many hospital patients (inpatients or outpatients) currently have a diagnosis for the following conditions:**

- **Multiple sclerosis (any type)**
- **Relapsing remitting multiple sclerosis (RRMS)**
- **Primary progressive multiple sclerosis (PPMS)**
- **Secondary progressive multiple sclerosis (SPMS)**

A2 Unfortunately we are not able to identify those who are currently in hospital as we require the clinical coding, which is applied to a patient's record following discharge, to identify what conditions /treatments a patient has. Therefore to answer this question we have given the information for the last 6 month as per Q1. As we are still applying clinical coding to January's data so we have supplied the information for the period Jul-22 to Dec-22

We are not able to distinguish between the difference types of multiple sclerosis - Taken from clinical coding's response "*We only have one code for multiple sclerosis which is G35.X Multiple sclerosis, this code covers all the different types listed.*"

Therefore the below answer is for all stated conditions as we are unable to distinguish between the 4. This information may be held in the patient notes however to obtain this level of information would require some to review each patient manually. – section 12 exemption as detailed below:

For Outpatients we do not apply clinical coding to the outpatient record nor do we record the reason for appointment

For Inpatients as we do not record the on a patients records current medical conditions can only identify if a patient has a condition by the clinical coding that has been applied to their inpatient stay. As per the guidance from the Clinical coding team we have used the above clinical coding (G35.X) to identify any patients who have been an inpatient within the trust who have been identified as having MS.

Applying the above logic for the period 01/07/2022 to 31/12/2022 (6 months as stated in Q1) – the number of inpatients who have the MS clinical coding applied to their inpatient stay is 2434.

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 this question 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*

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

***UHNM NHS Trust is a public sector body and governed by EU law. FOI requestors should note that any new Trust requirements over the EU threshold will be subject to these regulations and will be advertised for open competition accordingly.***

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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:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via [www.ico.org.uk](http://www.ico.org.uk).

If following review of the responses I can be of any further assistance please contact my secretary on 01782 671612.

Yours,



**Rachel Montinaro**  
Data Security and Protection Manager - Records