

Information Governance

4 November 2021

Our Ref: RFI 40391

Dear

**Freedom of Information Act 2000
Information in Relation to patients coded for the different sub types of MS.**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for information relating to the above which you requested on 13 August 2021.

Please accept my apologies for the delay in responding to your correspondence as the Information Governance Department is dealing with a large number of requests for information, including a backlog of requests as a result of the Covid-19 pandemic which had a major impact across services.

A response to each of the questions raised has been provided by the Hospital Services Directorate and is attached in Appendix A.

If you are unhappy as to how this request has been handled, you have the right to seek a review within the Trust in the first instance. You should write to the Information Governance Department, Lough House, Ards Community Hospital (informationgovernance@setrust.hscni.net) within two months of the date of this response and your complaint will be considered and a response provided, within 20 working days of receipt.

If, after receiving a response, you remain unhappy, you can refer your complaint to the Information Commissioner at The Information Commissioner's Office –Northern Ireland, 3rd Floor, 14 Cromac Place, Belfast, BT7 2JB. It is important to note that if you refer any matter to the Information Commissioner, you will need to show evidence of having gone through the Trust's internal review procedure to try to resolve the matter with the Trust in the first instance.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely

Joyce Batch
Information Governance Assistant

Q1. 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

Q2. For secondary progressive MS are your patients coded?

A1&2. No, the Trust does not clinically code outpatient clinic attendances and therefore are unable to provide this level of clinical information at present. To obtain this information would require a manual review of records. This would exceed the 'Appropriate Limit' as defined by the Freedom of Information Act 2000. The Trust therefore exempts the release of this information under Section 12(1)

Q3. What proportion of your MS patients have a diagnosis of secondary progressive MS (within all MS diagnosed patients)?

A3. The requested information is currently unknown. Due to a lack of routine clinical coding for outpatient activity within the Trust we are unable to provide a breakdown of diagnosis for patients attending the MS service.

Q4. For MS patients requiring an MRI, what is the average waiting time?

A4. The Trust is unable to provide a time frame for this question as MRI's are allocated by prioritisation and not by diagnosis.

Q5. For MS patients requiring an OCT, what is the average waiting time?

A5. The MS team have not recently requested an OCT.

Q6. For MS patients what is the average waiting time for IV MS treatment?

A6. The average time for IV MS treatment within the trust is up to 3 months at present.

Q7. When a patient has been diagnosed with MS, what is the average time from diagnosis of MS to initiate treatment?

A7. When a patient has been diagnosed with MS, the average time from diagnosis of MS to initiate treatment is up to 3 months.

Q8. How many unscheduled admissions have there been for patients with a diagnosis of MS in any position between April – June 2021?

A8. Clinical coding as not been verified for this period at present. Therefore we are unable to provide this level of data.

Q9. How many MS patients are being treated in neurology rehab?

A9. The neurology service within the Trust does not provide a dedicated neurological rehabilitation service. This information is therefore not available.

Q10. Of the patients in Question 8, how many are being treated with an MS disease modifying drug?**Q11. How many MS patients are in the following EDSS (Expanded Disability Status Scale) groups?**

A10 &11. To obtain this information would require a manual review of records. This would exceed the 'Appropriate Limit' as defined by the Freedom of Information Act 2000. The Trust therefore exempts the release of this information under Section 12(1).

Q12. How many of your physicians can initiate MS disease modifying drug treatment? If possible please supply the physician's name.

A12. The Trust currently employs one whole time equivalent neurologist with a subspecialty interest in MS.