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Date: 31 May 2022  
Our ref: K: FOI/Ref: 2022-000102  
Direct Line: 0131 275 6807  
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Dear [REDACTED],

**Freedom of Information Reference: FOI-2022-000102 – Scottish HSCT Network**

I refer to your Freedom of Information request that we received on 3 May 2022. The information is detailed below in response to each question asked.

We feel that it would be beneficial to structure the response beginning with some contextual background.

**We are requesting the NSD provides specific information in order to disseminate the correct information to our membership.**

**Who are NSD and what do they do?**

In their role as the commissioners of Highly Specialised Healthcare for the population of Scotland, NHS National Services Scotland (NSS), National Services Division (NSD) undertake a continual process of planning, agreeing, and monitoring specific services on behalf of the Scottish Government and Board Chief Executives.

In addition, NSD work closely with their colleagues in NHS England to provide access for Scottish patients to highly specialised services which require specific facilities, innovations or clinical expertise which is not available in Scotland. It is often the case that the numbers of patients needing such treatments for rare disease is very small and concentrating the skills and expertise in either a single or a few centres has been shown to provide the greatest assurance of quality and patient safety.

NSD manage financial resources via a risk share agreement on behalf of the 14 Health Boards in Scotland to allow patients to access highly specialised HSCT in England where their clinical team feel that such expertise is not available. An example of where this would be the case is for MS patients going to Sheffield as NHS England recommend that there is the need for specific neurological, haematological and critical care expertise to deliver this treatment. Another example is where patients suffer from a condition called Severe Combined Immunodeficiency who access care in Newcastle as this requires particular immunology input as well as haematology and critical care.

In general, the provision in Scotland of autologous stem cell transplantation which could potentially be used in the treatment of multiple sclerosis does not sit with NSD as this is delivered regionally across Scotland.



**Headquarters**

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Chairperson Keith Redpath  
Chief Executive Mary Morgan

The way in which healthcare is planned and delivered in Scotland is complex and NSD contributes a very small but specific role in regard to Haematopoietic Stem Cell Transplantation services in Scotland, they are responsible only for the commissioning of the National Allogeneic service in Glasgow for both adults and children which is used to treat haematological malignancy.

### **Clinical Elements of HSCT for Multiple Sclerosis**

NSD has no specific role in defining the clinical eligibility for treatment for individual patients nor any role in defining the overarching clinical criteria which is used to define the eligibility for treatment in providers in England. Such criteria are defined by NHS England within their clinical commissioning policies and more widely by the British Society of Blood and Bone Marrow Transplantation (BSBMT).

The NHS England Treatment Algorithm for Multiple Sclerosis Disease-Modifying Therapies places autologous haematopoietic stem cell transplant as a rescue therapy for continued inflammatory activity whilst on second-line therapy. In the text, they state that autologous haematopoietic stem treatment for autoimmunity is commissioned at specialised centres and is currently being offered to some people with MS in some parts of the UK.

They further comment that there is not yet adequate controlled trial of its efficacy relative to other potent therapies and therefore recommend that it is made available equitably to all people with MS, but that it should only be considered for people with relapsing disease (not progressive) who have failed high-activity licensed disease modifying therapies and are prepared to accept the significant risks of the procedure.

In addition, they recommend that this treatment is offered only by units with expertise both in the management of aggressive multiple sclerosis and the use of autologous haematopoietic stem treatment.

I can advise you that we have now completed the search of our records and from this search we have identified some specific areas which we can answer under the Freedom of Information policies however a number of these unfortunately we cannot. Our response to your questions is as follows:

#### **1. "RRMS"**

**Relapsing Remitting MS is now not a classification all Neurologists use.**

**How long would a patient be classified as having RRMS to be eligible?**

**Also, who would classify them as having RRMS? For example, one Neurologist may classify a patient as RRMS where a second opinion from a different Neurologist may classify SPMS.**

Under Section 17 of the Freedom of Information Scotland Act an organisation does not require to provide information if it does not hold that information. NSS does not hold this information. NSD do not have the specific neurological clinical expertise required to comment on this question.

#### **2. "Evidence of significant inflammatory disease"**

**How this is decided? Is this based on a patient's presenting symptoms or a clinical measure such as MRI? What are the accepted timescales between identification of inflammation and accessing HSCT treatment? Some of our members started their HSCT referral process with 'significant inflammation' but due to delays in accessing treatment, due to no fault of their own, subsequent MRI scans have not identified the same level of inflammation. Can you please state that strength of MRI scanner to be used as the benchmark? For example, different hospitals across Scotland have different strengths of MRI machines e.g. 1T, 1.5T, 3T.**

Under Section 17 of the Freedom of Information Scotland Act an organisation does not require to provide information if it does not hold that information. NSS does not hold this information. NSD do not have the specific neurological or neuroradiological clinical expertise required to comment on this question.

**Also, the majority of patients receive a brain MRI scan. This will not identify active lesions present in cervical, thoracic or lumbar areas.**

**Therefore, a patient may have “significant inflammatory disease “and active lesions and be considered for HSCT funded treatment. What are the criteria for patients to receive both a brain and full spine MRI?**

Under Section 17 of the Freedom of Information Scotland Act an organisation does not require to provide information if it does not hold that information. NSS does not hold this information. NSD do not have the specific neurological or neuroradiological clinical expertise required to comment on this question.

**3. “Not responded to adequate treatment”**

**We require clarification on what exactly adequate means. Ambiguity exists here as some Neurologists consider this as the length of time a patient has been prescribed medication, while others consider this to be new or existing MS lesion activity on MRI.**

Under Section 17 of the Freedom of Information Scotland Act an organisation does not require to provide information if it does not hold that information. NSS does not hold this information. NSD do not have the specific neurological or neuroradiological clinical expertise required to comment on this question.

**4. “High Efficacy DMD’s”**

**Can you please provide a current list of DMD’s the NSD considers as High Efficacy. New drugs have been made available to MS patients in Scotland since October 2019 and an up-to-date list which we can circulate would be appreciated.**

Under Section 17 of the Freedom of Information Scotland Act an organisation does not require to provide information if it does not hold that information. NSS does not hold this information. NSD has no defined role in relation to policy in relation to the use of medications for the treatment of Multiple Sclerosis. Medicines for use in Scotland are reviewed by Scottish Medicines Consortium who make recommendations for consideration by the local Health Boards across Scotland who will then decide via local governance processes which treatments to make available for their local population.

**In addition, can the NSD please clarify**

**5. The specific criteria patients must meet in order to be considered for NHS Scotland funded HSCT.**

Under Section 17 of the Freedom of Information Scotland Act an organisation does not require to provide information if it does not hold that information. NSS does not hold this information. The specific criteria that individual patients are required to meet are not defined by NSD. Each patient is a unique individual and therefore the decision as to eligibility is clinical and there is an expectation that they reviewed by their consultant and wider team to determine the most appropriate treatment.

For funding to be provided by NSD there is the requirement that the patient’s Consultant make a formal request via the Out of Area Team of the Health Board where the patient resides. Such requests are considered locally or regionally prior to submission to NSD for consideration.

**6. Whether all NHS Scotland Neurologists are aware of the criteria for MS patients to be considered for NHS Scotland funded HSCT? Our membership continue to experience inconsistency in advice and information between different Health Boards in Scotland and even different Neurologists within the same Health Board.**

Under Section 17 of the Freedom of Information Scotland Act an organisation does not require to provide information if it does not hold that information. NSS does not hold this information. NSD cannot confirm that all neurologists working within the NHS in Scotland are aware of the referral criteria for eligibility for funded HSCT for the treatment of multiple sclerosis. Each individual Health Board is responsible for the commissioning +/- delivery of haematological and neurological services on behalf of their resident population. Each service will have their own protocols and ways of working which are supported by evidenced guidelines. There are often local or regional multi-disciplinary team

meetings which take place to discuss specific patients with a view to gaining clinical consensus on diagnostic or therapeutic challenges.

**7. How many patients in Scotland have been considered for funded HSCT and then gone on to receive funded HSCT since October 2019? Also, for which Health Boards? To our knowledge, all patients who have received HSCT in treatment facilities in England since October 2019 have self-funded and none have received HSCT in Scotland.**

Under Section 17 of the Freedom of Information Scotland Act an organisation does not require to provide information if it does not hold that information. NSS does not hold this information.

NSD does not have any oversight as to the number of patients who have been considered locally or regionally for potential treatment for their MS with HSCT. NSD have received no funding requests nor funded any patients for treatment since the SHTG recommendations were made.

The Covid-19 pandemic has presented unique challenges in both service delivery, capacity, and patient prioritisation as well as a differing profile as to how to accept risk and therefore this period may not be reflective of what would have been expected under normal circumstances. Funding requests to NSD more generally for treatments for all conditions in NHS England fell significantly during this time.

Local Health Boards may have funded patient treatment for patients who are participating in a clinical trial.

We suggest that where individual members of your organisation have queries about their own health and eligibility for treatment that they discuss these with their own Consultant or Clinical Nurse Specialist at their next clinical appointment who would be best placed to answer these with full awareness of their clinical situation. NHS National Services Scotland do not have the clinical expertise specific to this disease process and treatment strategies to make comment about individual patient circumstances and treatment plans.

**We would like to arrange a meeting with a representative from NSD to discuss HSCT further and some of the challenges and barriers our membership experience when accessing HSCT in Scotland via the NHS?**

NSD does not have a role in the governance for clinical eligibility of HSCT, nor the patient pathway to access HSCT and therefore we recommend that if you wish to arrange a meeting we would suggest you contact your local neurology service teams.

I trust you will find the information of assistance and if you require any further information, please do not hesitate to contact me.

If you are unhappy with any aspect of how we have dealt with your request, you can make representations to us asking us to review the handling of your request. Please write to the

Head of Information and Cyber Security  
Digital and Security  
NHS National Services Scotland  
Headquarters  
Gyle Square  
1 South Gyle Crescent  
Edinburgh  
EH12 9EB

or at the email address [nss.foi@nhs.scot](mailto:nss.foi@nhs.scot) within 40 working days of the date of this correspondence.

If after a review you are still unhappy, you also have the right to apply to the Scottish Information Commissioner, who can be contacted at Kinburn Castle, St Andrews, Fife, KY16 9DS, or via their [online application form](#).

If you have any queries about this letter, please contact me at the above address.

Yours sincerely

[Redacted signature]

[Redacted contact information]