Transition to secondary progressive multiple sclerosis: When is SPMS identified in the UK and what are the consequences for patients and the National Health Service?

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Introduction

- Two-thirds of people with relapsing-remitting multiple sclerosis (RRMS) eventually transition to secondary progressive multiple sclerosis (SPMS), which involves fewer-to-no relapses but increasing disability.[1]
- SPMS is challenging to identify due to the gradual nature of disease progression and absence of a detectable "transition point" from RRMS.[2,3]
- Compared to patients with RRMS, patients with SPMS have a lower quality of life, increased caregiver dependence, and more limited treatment options.[4–6]
- The identification of SPMS is therefore difficult to accept for both healthcare professionals (HCPs) and patients.

Aim

Our HCP survey sought to:

- Investigate the transition to, and management of, SPMS in UK clinical practice;
- Estimate the NHS resources used for management of SPMS compared to RRMS.

Methods

Recruitment to the survey was based on the following criteria:

- General neurology consultant, MS specialist consultant, or MS specialist nurse;
- Based in an NHS Trust in England, Scotland, or Wales;
- See a minimum of three patients with SPMS per month on average.

We invited eligible respondents to a one-hour telephone interview, scheduled between November 2018 and March 2019.

- All interviews used a pre-defined questionnaire.
- Following the interviews, we identified key emerging themes from qualitative responses.
- Quantitative responses on use of NHS resources were analysed in a simple costing model.
  - We matched the mean values for appointment frequency to Personal Social Services Research Unit (PSSRU) Unit Costs of Health and Social Care 2018[7] or NHS Reference Costs 2017–2018.[8]
- All responses were anonymised. Respondents gave informed consent to participate and could withdraw at any time.

Results

Respondent demographics

- 20 HCPs were successfully recruited and interviewed, including 14 consultants and 6 MS specialist nurses.
- The sample represented several different NHS Trusts across England and Scotland **(Figure 1)**.

Identification of SPMS

- Notable heterogeneity was reported in the approaches used to identify SPMS.
  - Respondents highlighted the unmet need for national bodies to provide diagnostic guidelines for SPMS **(Figure 2)**.
- There is substantial uncertainty in identifying SPMS, with the average time from first suspicion of SPMS to formal identification being 15 months (range 3 months – 5 years).
- As a result of this uncertainty, an average of 12% of patients still recorded as RRMS may in fact have transitioned to progressive disease.
- The limited treatment availability for SPMS was ranked by 11/20 HCPs as the most prominent factor influencing their hesitancy in identifying SPMS **(Figure 3)**.

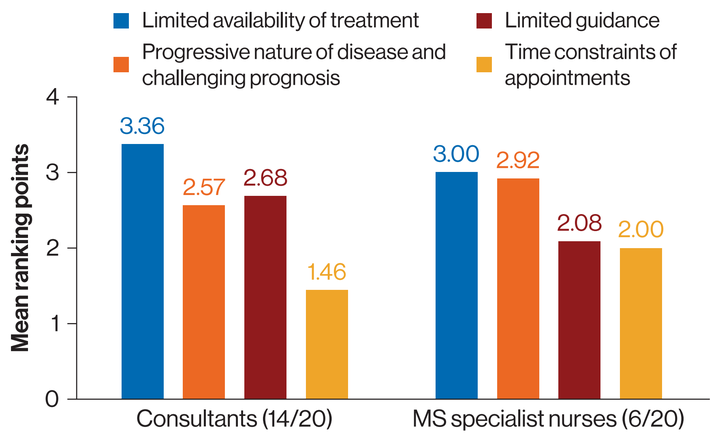
Treatment with disease-modifying therapy

- HCPs are similarly hesitant to discontinue a patient's disease-modifying therapy (DMT).
  - This is due to the lack of alternative treatment options and patients' feeling of loss of control.
- HCPs tend to continue DMTs until absolutely certain that patients are neither RRMS nor benefitting from treatment.
- All 20 respondents indicated DMT availability for SPMS would create a step-change in the approach to identifying transition, providing clinical rationale to confirm SPMS earlier.

Use of NHS resources

- The majority (13/20) of respondents acknowledged that patients with SPMS are seen less in clinic compared to patients with RRMS.
  - Discharge from specialist services is common for patients with SPMS, leading to a sense of abandonment.
  - Patients with SPMS are therefore seen more frequently in primary care, rather than secondary or tertiary care.
- The shifts in healthcare use from RRMS to SPMS result in an estimated increase of ~£106 in NHS costs, per patient (pp) per year (pa) **(Figure 4)**.
  - Much higher costs have been reported in the literature, with a ~£13,000 increase pp pa from RRMS to SPMS.[9]
  - Our survey did not consider DMTs or other drug costs (reported in the literature as RRMS: >£6,000, SPMS: >£3,000 pp pa), social care costs (reported as RRMS: >£5,000, SPMS: >£13,000 pp pa), or indirect costs (e.g. sick leave and early retirement, reported as RRMS: >£4,000, SPMS: >£13,000 pp pa).[9]

Figure 3. Factors influencing the hesitancy towards identifying patients as SPMS

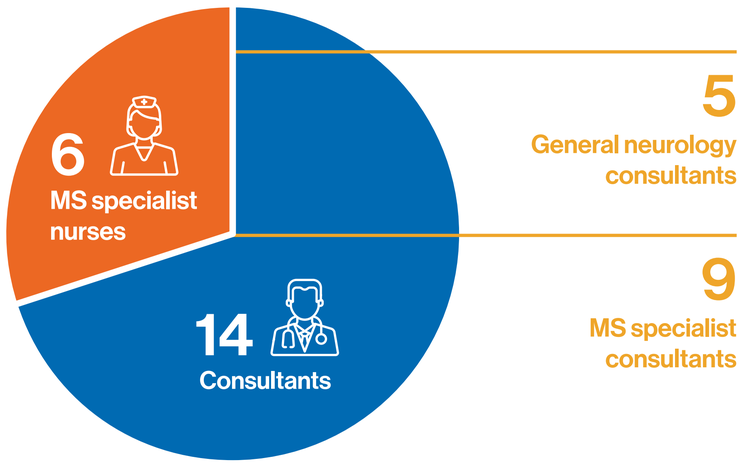


If respondent ranked statement as the 1st most influential factor: 4 points; 2nd most influential factor: 3 points; 3rd most influential factor: 2 points; 4th most influential factor: 1 point.

Figure 4. Mean costs resulting from NHS resource use for RRMS and SPMS, per patient per year

Mean costs are presented. Costs exclude DMTs or other drugs, social care, and indirect costs.

Figure 1. Geographical spread and demographics of respondents



Consultants and nurses are grouped in the UK map to preserve anonymity.

Figure 2. Quotes from respondents highlight the unmet needs in SPMS

"My number one improvement would be for national bodies to provide robust and practical diagnostic guidelines and treatment algorithms for SPMS. Guidelines should ensure that no clinicians feel unduly challenged to give patients a diagnostic label."

MS specialist consultant

"We need a designated care pathway so we know what the care needs are, and how we are going to address those. Transitions need to be as smooth as possible so the patient does not feel they have just been dumped."

MS specialist nurse

Conclusions

- HCPs in our survey highlighted the challenges faced by both HCPs and patients during and following the transition from RRMS to SPMS.
  - Challenges include the limited treatment options, as well as the devasting impact increasing disability has on the lives of patients and their caregivers.
- In order to overcome these challenges, there is a need for SPMS-specific diagnostic guidance, specialised transition clinics, and DMTs proven to be effective in slowing disability progression.
- As reported in our survey and the literature, patients with SPMS incur greater costs per year for NHS services than patients with RRMS.
- Further research should target HCPs in NHS Wales and could use face-to-face interviews to facilitate discussion of more complex topics.

References

1. NICE. Multiple sclerosis in adults: management (CG186). 2014. Available at: https://www.nice.org.uk/guidance/cg186/resources/multiple-sclerosis-in-adults-management-pdf-35109816059077 (Accessed 01 Oct 2019); **2.** Lublin FD. *et al.* Neurology 2014;83(3):278–86; **3.** Katz Sand I. *et al.* Mult Scler 2014;20(12):1654–7; **4.** Davies F. *et al.* BMJ Open 2015;5:e007674; **5.** Montel SR & Bungener C. Mult Scler 2007;13(3):393–401; **6.** Gross HJ & Watson C. Neuropsychiatr Disease Treatment 2017;13:1349–57; **7.** PSSRU. Unit Costs of Health and Social Care. 2018. Available at: https://www.pssru.ac.uk/project-pages/unit-costs/unit-costs-2018 (Accessed 31 May 2019); **8.** NHS Improvement. Reference Costs 2017–2018. Available at: https://improvement.nhs.uk/resources/reference-costs (Accessed 31 May 2019); **9.** Karampampa K. *et al.* Mult Scler 2012;18(2 Suppl):41–5.

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