Diagnosis of Secondary Progressive Multiple Sclerosis in UK Centres: Results from the SPECTRUM project

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Introduction

- Diagnosing secondary progressive multiple sclerosis (SPMS) in clinical practice can be challenging for healthcare professionals (HCPs)[1].
  - SPMS is diagnosed retrospectively and there are no definitive biomarkers or imaging tests that can be used to aid diagnosis[2].
- Consequently, there is thought to be variation in the approach amongst healthcare professionals (HCPs) to diagnosing SPMS, discussing SPMS with patients and allowing diagnosis to influence disease modifying treatment (DMT) decisions.
- As new treatment approaches emerge for progressive forms of multiple sclerosis (MS), it is important to understand the factors underlying current practice.
- SPECTRUM (Secondary Progressive Multiple Sclerosis – Understanding Treatment and Management) was a UK-wide survey of HCPs involved in managing patients with SPMS. The project was designed to capture information about current diagnostic and treatment pathways, with the overall aim to inform future SPMS service review and improvement.

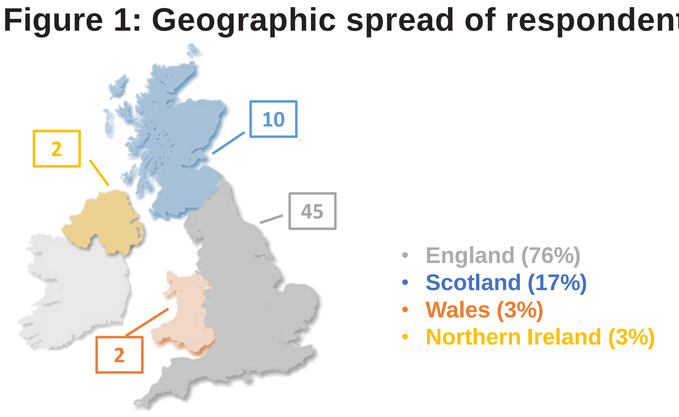
Objectives

- To map the current diagnostic, referral and treatment pathway of patients with SPMS in UK centres.
- To understand the challenges facing clinicians when diagnosing and managing patients with SPMS.

Methods

- Between March and July 2019, interviews were conducted with 59 HCPs involved in managing patients with SPMS. A total of 95 HCPs were initially approached and invited to participate by email.
- The participating HCPs were from 59 centres spread geographically across the UK (**Figure 1**).
- Interviews were conducted face-to-face using a structured questionnaire, which was designed in collaboration with a consultant neurologist and a MS Specialist Nurse. Topics covered included current practices for the definition, diagnosis and management of SPMS, and discussing SPMS with patients. Respondents replied on behalf of their whole centre.
- The survey data were analysed descriptively and results relating to the diagnosis of SPMS in the UK are presented here.

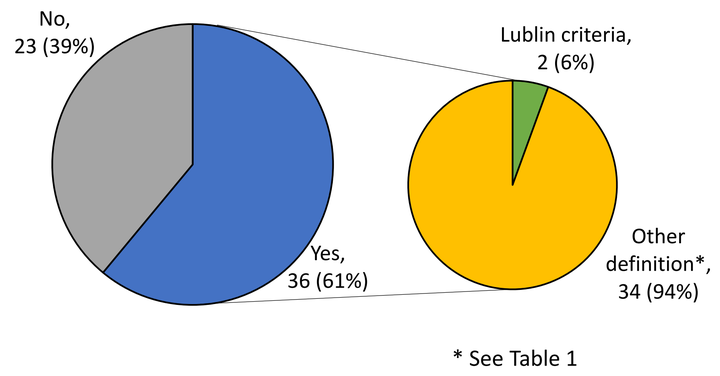
Figure 1: Geographic spread of respondents



Results

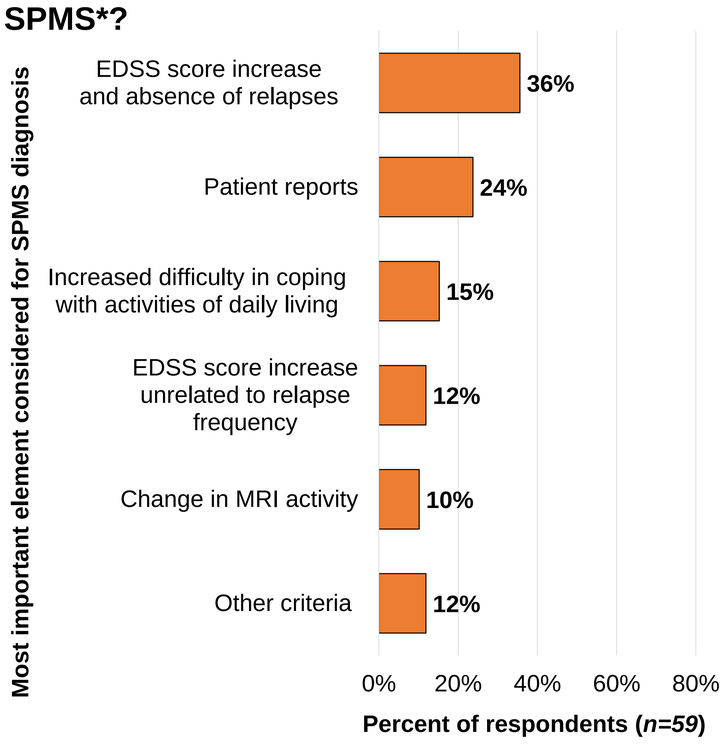
- The respondents comprised 41 MS neurologists, 15 MS specialist nurses and 3 other HCPs.
- The median (interquartile range [IQR]) estimated number of patients with MS under current management was 1,200 (700 to 2000) per centre and of these, the estimated percentage with confirmed SPMS was 30.0% (24.3% to 39.5%).
- Of the HCPs using a specific definition of SPMS (*n*=36/59, 61%), a minority use the Lublin 2014 phenotype criteria (*n*=2/36, 6%); the remainder (*n*=34/36, 94%) use a variety of other definitions (**Figure 2, Table 1**).
- The most important of the elements included in considering a diagnosis of SPMS was expanded disability status scale (EDSS) score increase and absence of relapse (*n*=21/59, 36%) however many other criteria were also used (**Figure 3**).
- At SPMS diagnosis, the median (IQR) estimated percentage of patients with EDSS score ≥5.5 was 90.0% (80.0–100.0, *n*=35) (**Table 2**).
- The median (IQR) estimated time between first suspecting and diagnosing SPMS was 12.0 months (12.0–24.0, *n*=45).
- The most common explanations for reluctance to diagnose SPMS were *concerns over withdrawing DMTs* and *psychological impact on patients* (**Figure 4**).

Figure 2: When diagnosing patients with SPMS in clinical practice, do you use a specific definition of SPMS?



* See Table 1

Figure 3: What is the most important of the elements included in considering a diagnosis of SPMS*?



** Not mutually exclusive (some HCPs selected more than one response)*

Table 1: Other definitions of SPMS

Other definitions of SPMS*	n	% (*n*=34)
Progression of disease/disability and absence of relapse	20	59%
Progression of disease/disability independent of relapses	8	24%
Either of above	3	9%
Absence of relapse (without mention of disease progression)	2	6%
Disease progression or disability (without mention of relapse)	2	6%
Progression or disease/disability based on EDSS score	13	38%
Stable magnetic resonance imaging/reduced signs of inflammation	7	21%
Other	1	3%

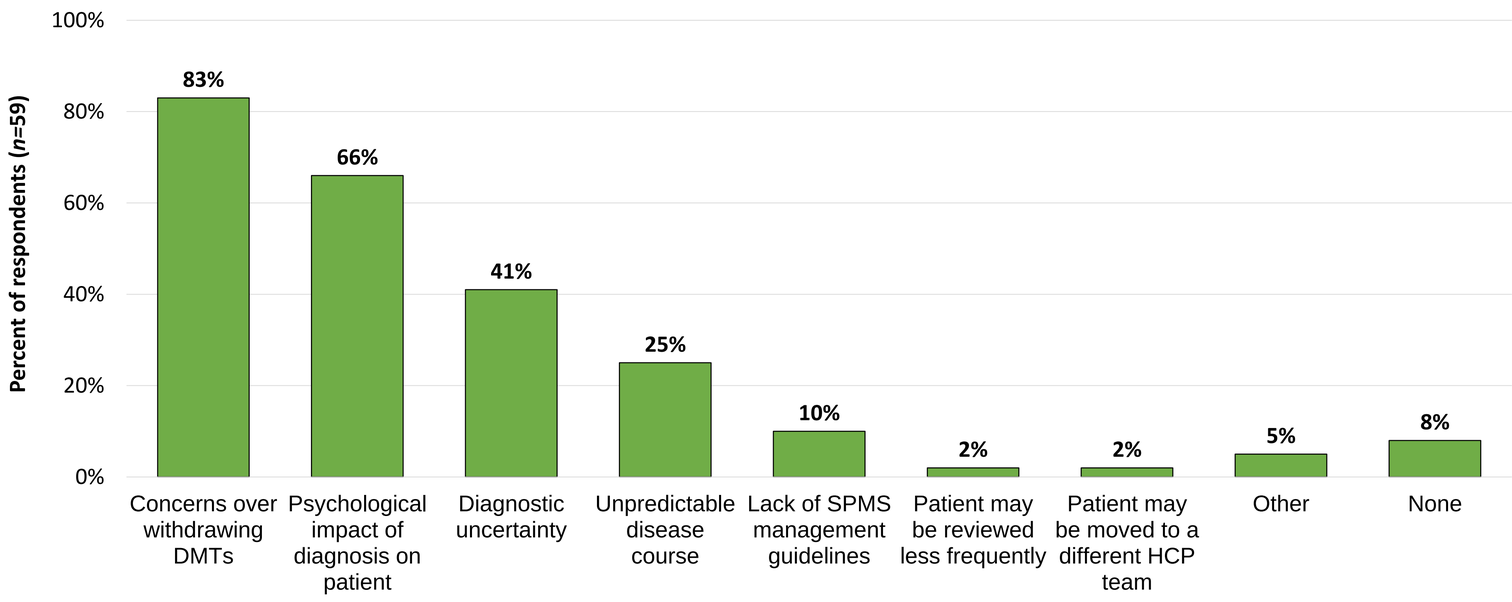
* Not mutually exclusive

Table 2: Estimated percentage of patients in each EDSS score category at SPMS diagnosis

		Estimated % of patients		
EDSS score category	**n***	**Median**	**IQR**	**Range**
EDSS 0.0 to 3.0	40	0.0%	0.0 to 0.0	0.0 to 33.3
EDSS 3.5 to 5.0	37	10.0%	0.0 to 20.0	0.0 to 75.0
EDSS 5.5 to 6.5	38	60.0%	50.0 to 80.0	10.0 to 100.0
EDSS 7.0 to 10.0	35	15.0%	5.0 to 40.0	0.0 to 90.0
EDSS 5.5 to 10.0	35	90.0%	80.0 to 100.0	20.0 to 100.0

** Respondents providing a valid response (remainder answered 'not known')*

Figure 4: If you suspect that a patient has SPMS, are there any reasons that might make you reluctant to give that diagnosis to the patient?



Conclusions

- There is substantial variation in the UK in how HCPs define and diagnose SPMS.
- Diagnosis is often made at advanced levels of disability and can take a year or longer from first suspicion of SPMS.
- HCPs may be reluctant to diagnose SPMS, primarily due to concerns about withdrawing DMTs and the potential psychological impact on patients.

References

1. Davies F, et al. *Int J MS Care*. 2016 Sep-Oct; 18(5): 257–264.
2. Plantone D, et al. CNS Drugs. 2016 Jun; 30(6): 517–26.

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