

# Discordance Between Neurologists and People Living With Multiple Sclerosis on the Perception of the Presence and Burden of Cognitive Impairment

Iris-Katharina Penner<sup>1</sup>, Virginia De Las Heras<sup>2</sup>, Eddie Jones<sup>3</sup>, Suzannah Ryan<sup>4</sup>, Patricia Dominguez Castro<sup>4</sup>, Emma Houchen<sup>4</sup>, Shruti Narasimham<sup>4</sup>, Himanshu Karu<sup>5</sup>, Rahul Chetlangia<sup>5</sup>, Sourav Biswas<sup>5</sup>, Vladimir Bezlyak<sup>2</sup>, Daniela Piani Meier<sup>2</sup>, Carol Lines<sup>2</sup>

<sup>1</sup>COGITO Center for Applied Neurocognition and Neuropsychological Research, Merowingerplatz 1, 40225 Düsseldorf, Germany; Heinrich Heine University Düsseldorf, Medical Faculty, Department of Neurology, Moorenstr. 5, 40225 Düsseldorf, Germany; <sup>2</sup>Novartis Pharma AG, Basel, Switzerland; <sup>3</sup>Adelphi Real World, Manchester, UK; <sup>4</sup>Novartis Ireland Limited, Dublin, Ireland, <sup>5</sup>Novartis Healthcare Private Limited, Hyderabad, India.

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Author Name	Disclosures
<b>Iris-Katharina Penner</b>	Received fees for speaking at scientific meetings, serving at scientific advisory boards and consulting activities from Adamas Pharma, Almirall, Bayer Pharma, Biogen, BMS, Celgene, Desitin, Genzyme, Janssen, Merck, Novartis, Roche and Teva. She has received research support from the German MS Society, Celgene, Novartis, Roche and Teva.
<b>Eddie Jones</b>	Employee of Adelphi Real World and his organization has received a subscription fee from Novartis to access some of the data reported in this study.
<b>Virginia de las Heras, Suzannah Ryan, Patricia Dominguez Castro, Emma Houchen, Shruti Narasimham, Himanshu Karu, Rahul Chetlangia, Sourav Biswas, Vladimir Bezlyak, Daniela Piani Meier, Carol Lines</b>	Employees of Novartis.

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## Introduction

- Approximately 34%-65% of people living with multiple sclerosis (pwMS) develop cognitive impairment (CI)
- CI can occur from the early stages of multiple sclerosis (MS), although it is more common in secondary progressive MS (SPMS). CI has a negative impact on quality of life for pwMS<sup>1</sup>
- CI often encompasses different domains such as information processing speed, memory problems, difficulty concentrating, and problems using executive functions effectively<sup>2-5</sup>
- Cognitive status relates to working ability of pwMS and may be predictive of a more severe disease course and disability progression<sup>6-8</sup>
- CI is not routinely assessed in clinical consultations, and therefore can remain undetected<sup>9</sup>

## Objective

- This study explores the level of agreement on the perception of the presence of CI between pwMS and neurologists

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Introduction

Methods

Results

Conclusions



- Retrospective cross-sectional analysis of data from neurologists and plwMS from the US, UK and EU (France, Germany, Italy and Spain) from the 2011-2019 Adelphi Multiple Sclerosis Disease Specific Programme (MS-DSP)
- The Adelphi MS-DSP is a study based in the real-world clinical setting which describes MS management, burden and associated impacts
- Participating neurologists provide data on the next 10 plwMS to have a consultation, patient record form (PRF), with the same plwMS invited to voluntarily complete a patient self-completion form (PSC)
- Both plwMS and neurologists were asked about the presence of problems concentrating around the time of consultation (two weeks prior, or at the consultation, respectively)
- Kappa analysis was used to calculate the level of agreement between neurologists and plwMS. Agreement results were derived from matched PRF-PSC pairs

MS, multiple sclerosis; plwMS, people living with multiple sclerosis; SPMS, secondary progressive MS.

Introduction

Methods

Results

Conclusions



- Surveyed neurologists provided data for 25,374 plwMS, of which 11,220 completed a PSC. Of the 11,220 plwMS with a PSC 4,817 provided information on cognitive and mood symptoms
- The majority of plwMS were female (67%) with an average age of 38.9 yrs for RRMS and 49.4 yrs for SPMS
- Fewer SPMS patients were in full/part time employment (36% vs 67%) vs RRMS

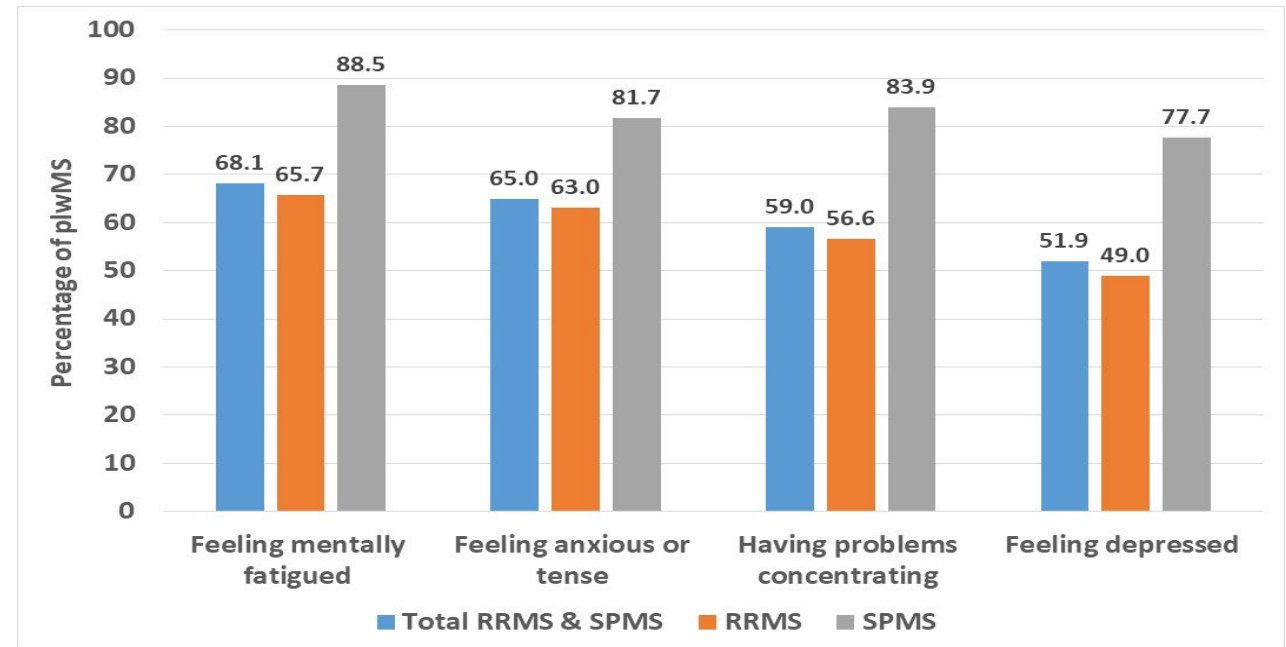
MS patients (n=4817)		
<b>Age</b>	40.0 (SD=11.77)	
<b>Gender</b>	67% Female, 33% Male	
	RRMS (n=4320)	SPMS (n=497)
<b>Age</b>	38.9 (SD=11.52)	49.4 (SD=9.49)
<b>Gender</b>	67% Female, 33% Male	64% Female, 36% Male
<b>Working full-time</b>	53%	21%
<b>Working part-time</b>	14%	15%
<b>Student</b>	8%	0%

MS, multiple sclerosis; plwMS, people living with multiple sclerosis; PRF, patient record form; PSC, patient self-completion form; RRMS, relapsing-remitting MS; SPMS, secondary progressive MS.

# Results: Proportion of RRMS and SPMS participants reporting cognitive and mood symptoms

- 59% reporting having problems concentrating, and 68% reporting feeling mentally fatigued
- A higher percentage of SPMS participants reported suffering from cognitive or mood symptoms compared to RRMS participants

Cognitive and mood symptoms

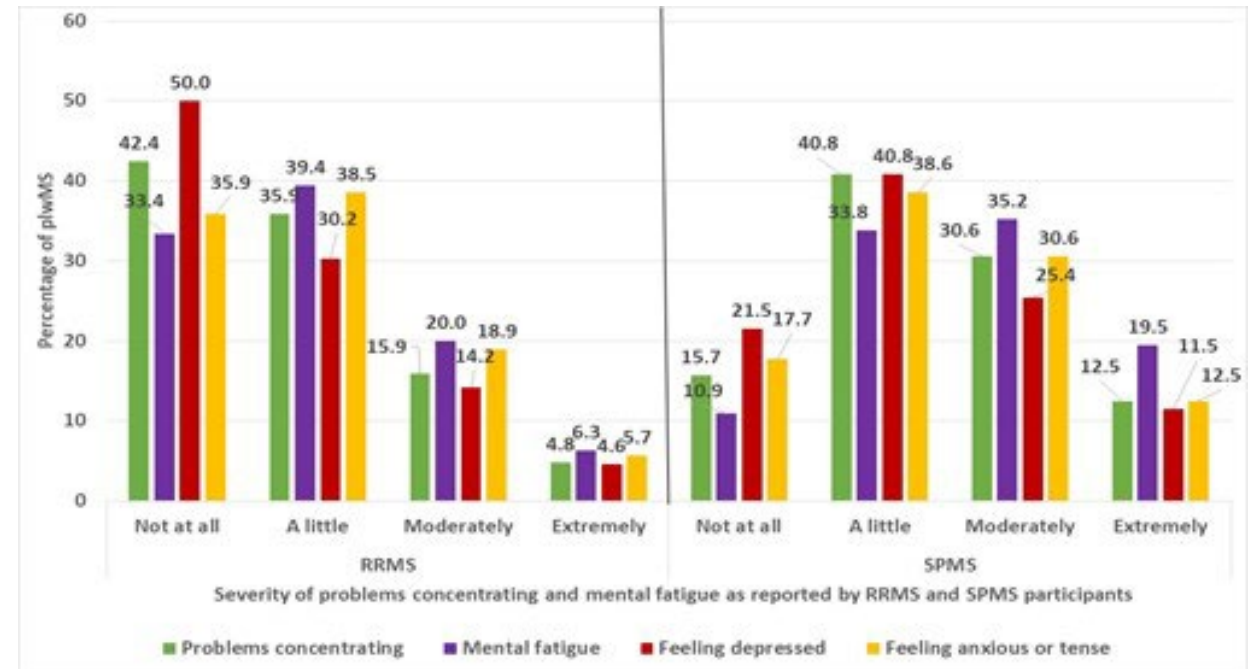


RRMS, relapsing-remitting multiple sclerosis; SPMS, secondary progressive multiple sclerosis.

# Results: Proportion of RRMS and SPMS participants reporting cognitive and mood symptoms classified by severity

- 59% reporting having problems concentrating, and 68% reporting feeling mentally fatigued
- A higher percentage of SPMS participants reported suffering from cognitive or mood symptoms compared to RRMS participants
- A higher percentage of SPMS participants reported moderate or extreme cognitive and mood symptoms compared to RRMS participants

Cognitive and mood symptoms classified by severity



RRMS, relapsing-remitting multiple sclerosis; SPMS, secondary progressive multiple sclerosis.

Introduction

Methods

Results

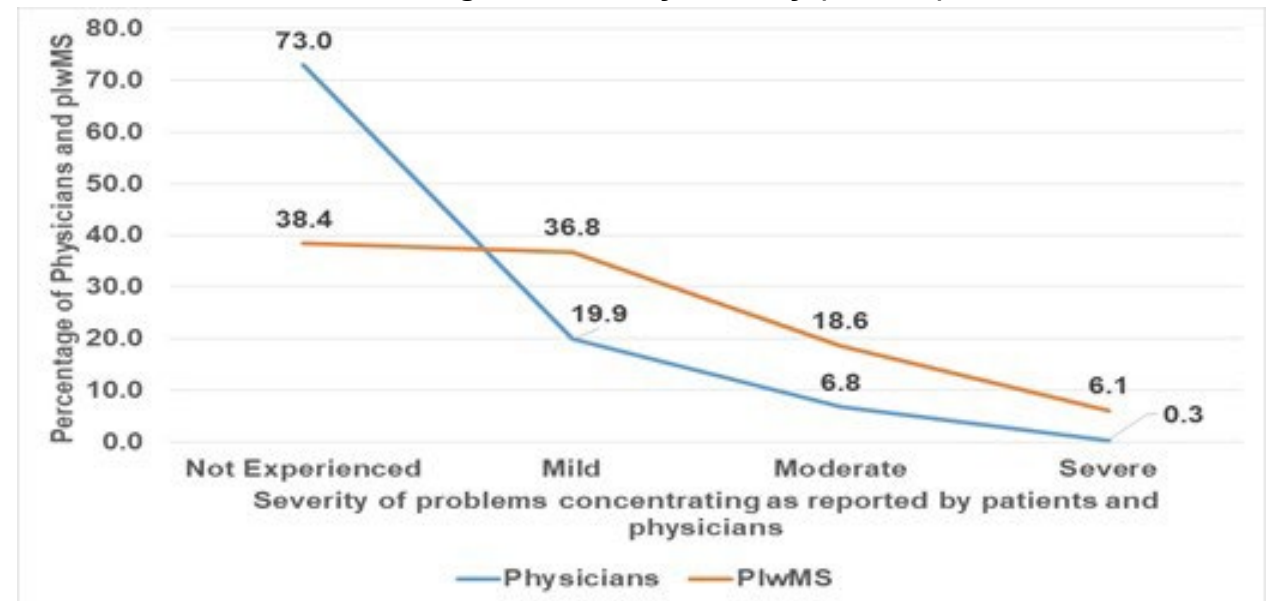
Conclusions



# Results: Proportion of physicians and plwMS reporting problems concentrating classified by severity

- 59% reporting having problems concentrating, and 68% reporting feeling mentally fatigued
- A higher percentage of SPMS participants reported suffering from cognitive or mood symptoms compared to RRMS participants
- A higher percentage of SPMS participants reported moderate or extreme cognitive and mood symptoms compared to RRMS participants
- 62% of plwMS reported problems concentrating in the past two weeks. For the same plwMS, neurologists reported 27% currently having problems concentrating, showing a discordance on the perception of the presence of CI between neurologists and plwMS (Kappa=0.162)

Proportion of physicians and plwMS reporting problems concentrating classified by severity (n=4294)



plwMS, people living with multiple sclerosis; RRMS, relapsing-remitting multiple sclerosis; SPMS, secondary progressive multiple sclerosis.



- A large proportion of plwMS reported cognitive and mood symptoms, participants with SPMS reporting these symptoms with higher frequency and severity
- A clear discordance is observed between neurologists and plwMS when reporting their perception of the presence and severity of CI with neurologists underestimating their existence
- This might be responsible for cognition not being discussed at the time of consultation and clearly indicates an unmet need

CI, cognitive impairment; plwMS, people living with multiple sclerosis; SPMS, secondary progressive MS.

Introduction

Methods

Results

Conclusions

