

# A large cohort study evaluating patient reported perspectives on disease burden and early signs of progression in multiple sclerosis in Germany (MSPerspectives) P109

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## Introduction

- Discordant perception of the presence and severity of Multiple Sclerosis (MS) symptoms between healthcare professionals and people with multiple sclerosis (pwMS) may lead to an underestimation of symptom prevalence and relevance. Therefore, determining patients' perspectives is highly relevant for patient counseling and treatment decisions.
- This may also facilitate identifying the transition from RRMS to SPMS as SPMS is usually diagnosed retrospectively, and the transition period is associated with a considerable period of diagnostic uncertainty.

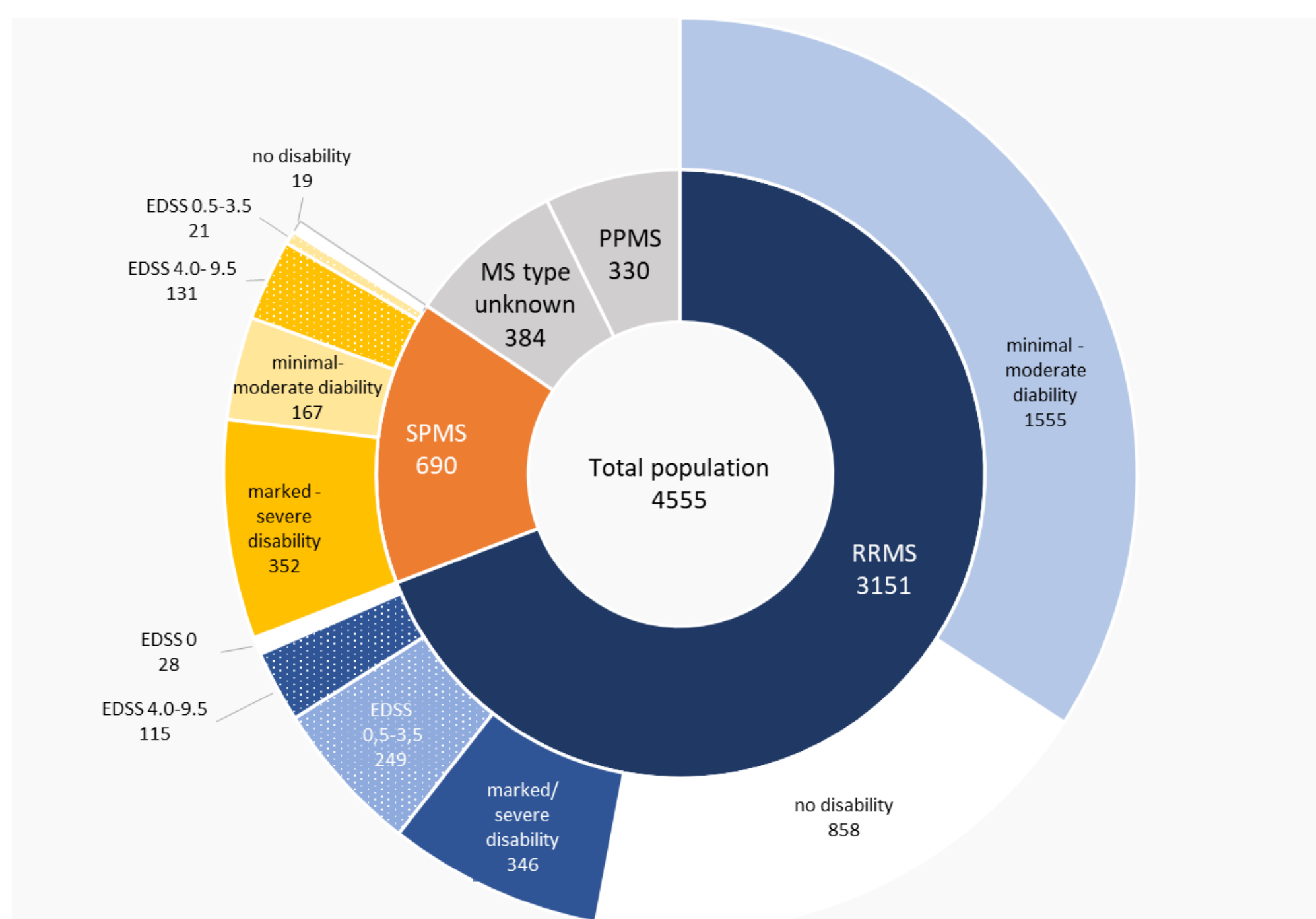
## Objective

- MS Perspectives was designed to collect data on patients' self-assessment of multiple sclerosis (MS) symptoms, relapse-independent progression, and impact on everyday life.

## Methods

- MS Perspectives is a cross-sectional online survey conducted among adult pwMS in Germany between December 2021 and February 2022.
- Participants were identified through newsletters and targeted social media advertising in Germany.
- The questionnaire included 36 items on sociodemographic and clinical characteristics as well as pharmacological and non-pharmacological treatment including pwMS' perceptions regarding MS symptoms, disability progression and impact on daily life.

Figure 1. MS subtypes and EDSS/ disability status



Figures in segments represent absolute patient numbers. Disability not indicated for unknown MS type and PPMS

## Results

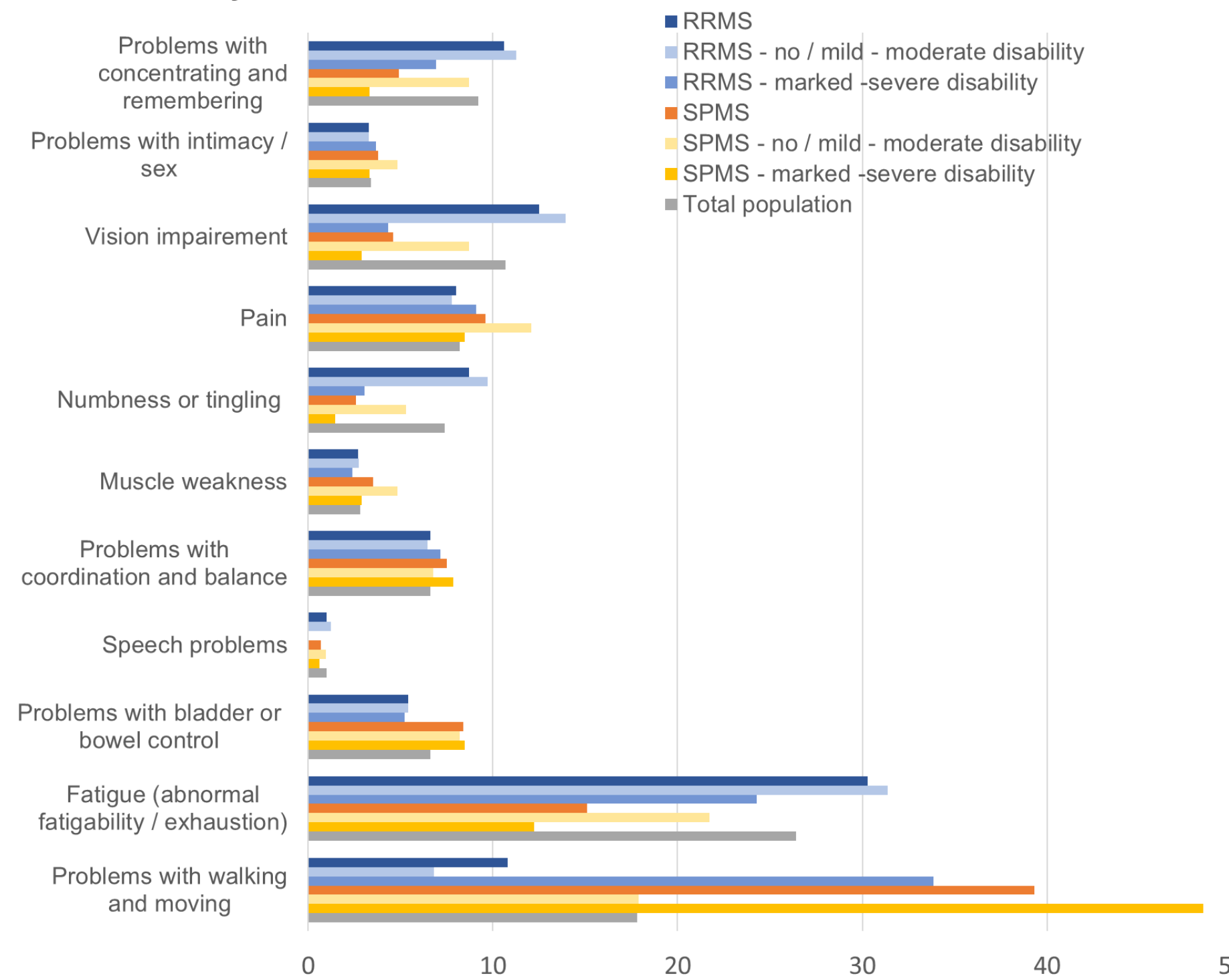
### Demographics

- 4,555 pwMS completed the survey: 3,151 (69.2%) reported to have RRMS, 690 (15.1%) SPMS, 330 (7.2%) PPMS (Fig.1).
- 85.2% were female. Mean age was 41.6 years.
- In 13.5% of participants, EDSS was reported: mean (SD) EDSS was 3.8 (2.2) in the total population, 2.8 (1.8) in RRMS, and 5.7 (1.6) in SPMS.
- 72.3% of the total population had no or mild to moderate disability, and 27.7% of patients marked to severe disability (defined either by EDSS score or self-assessment) (Fig.1).
- Relapse activity in the past 6 months was reported by 26.9% of the total population, 25.6% of RRMS patients, and 35.9% of SPMS patients.

### Most bothersome symptom

- Problems with walking and moving were most bothersome - less pronounced in patients with lower disability status, but in this subgroup more frequent in SPMS (17.9%) than in RRMS (6.8%) (Fig.2).
- Fatigue, cognitive impairment, vision impairment, as well as numbness or tingling were more frequent in RRMS and SPMS patients with lower disability status compared to higher disability status (Fig.2).

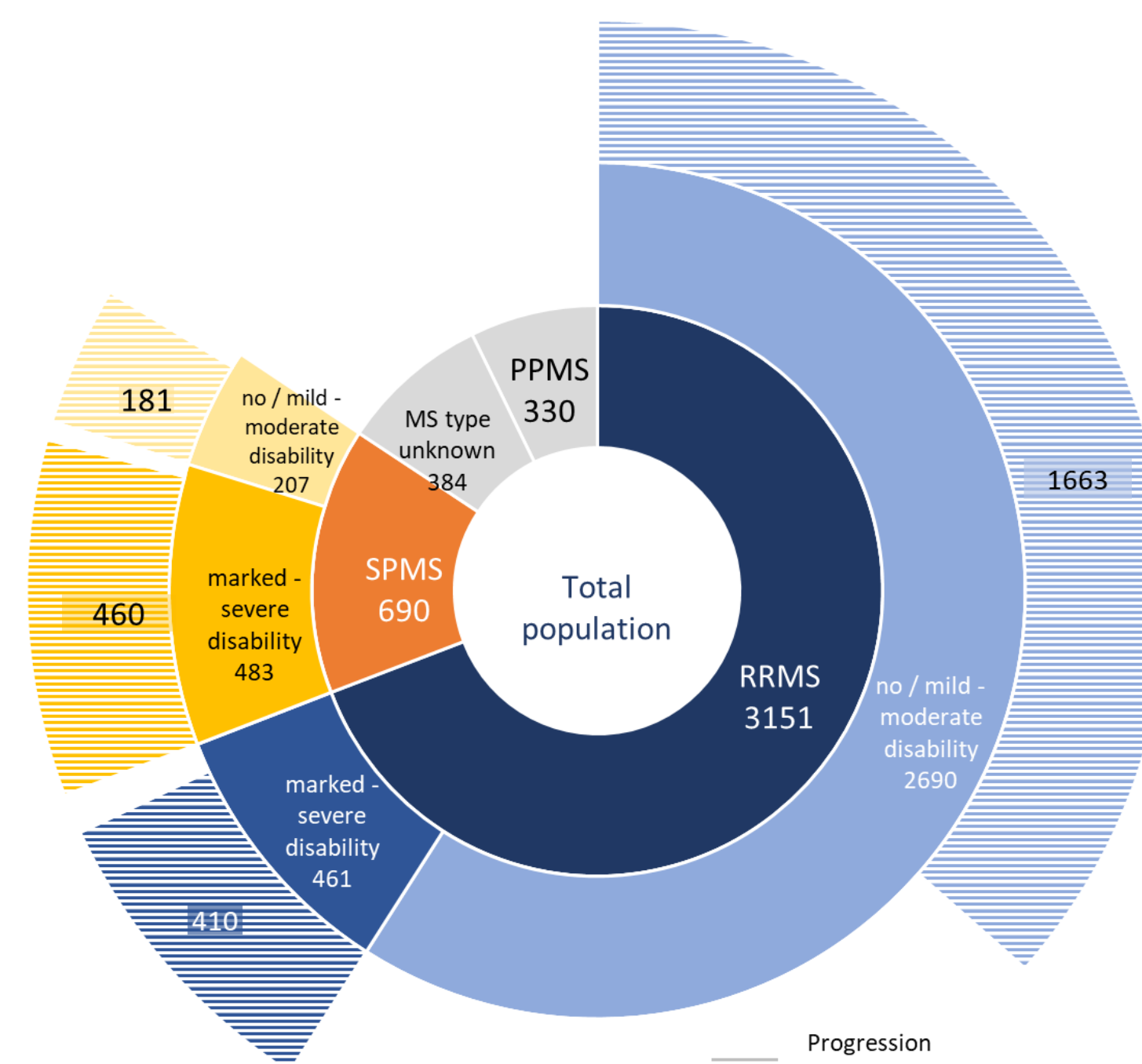
Figure 2. Most bothersome symptom by MS type and disability status



### Progression independent of relapse activity

- 65.8% of all RRMS patients and 92.9% of all SPMS patients reported worsening of symptoms independent of relapses in the previous 12 months (Fig.3).
- Progression independent of relapse activity affected 88.9% of RRMS patients with marked to severe disability, and 61.8% of RRMS patients with no or mild to moderate disability (Fig.3).

Figure 3. Presence of progression independent of relapse activity in last 12 months by MS type and disability status

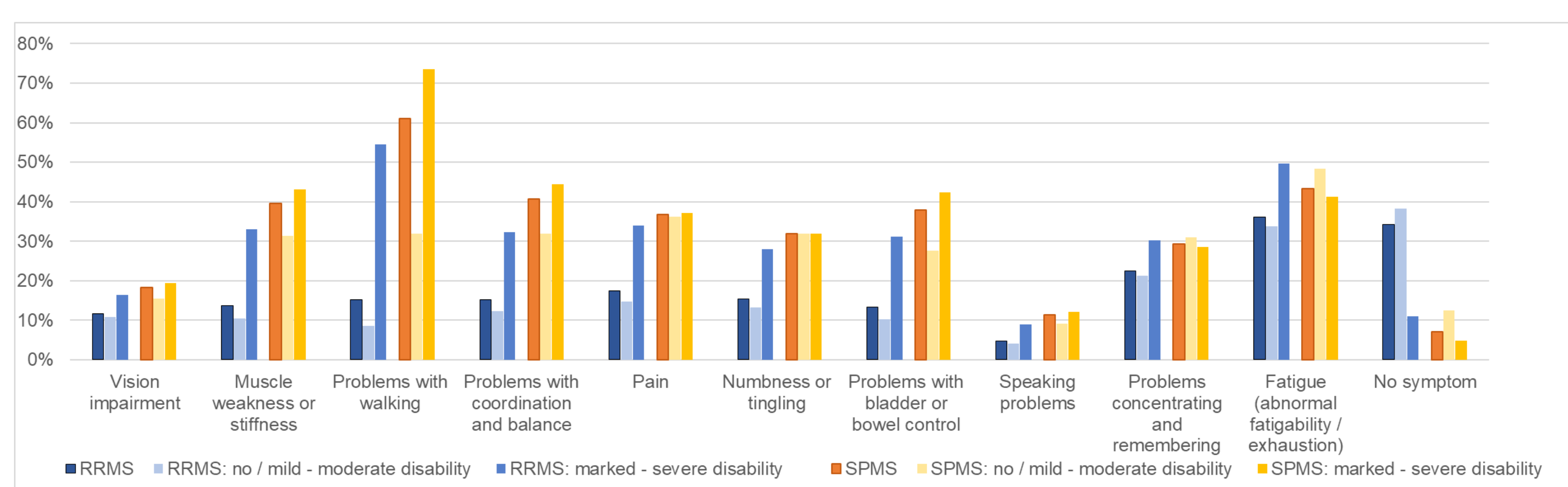


Figures in segments represent absolute patient numbers. Disability not indicated for unknown MS type and PPMS

### Symptom progression independent of relapse activity in the past 12 months

- In RRMS with marked to severe disability, problems with walking (54.4%) and fatigue (49.7%) were affected most by relapse-independent worsening within the last 12 months (Fig.4).
- In RRMS with no or mild to moderate disability, fatigue prevailed in 33.9% and cognitive deficits in 21.3% of pwMS (Fig.4).
- For SPMS patients with marked to severe disability problems with walking (73.5%), and problems with coordination and balance (44.5%) were reported (Fig.4).

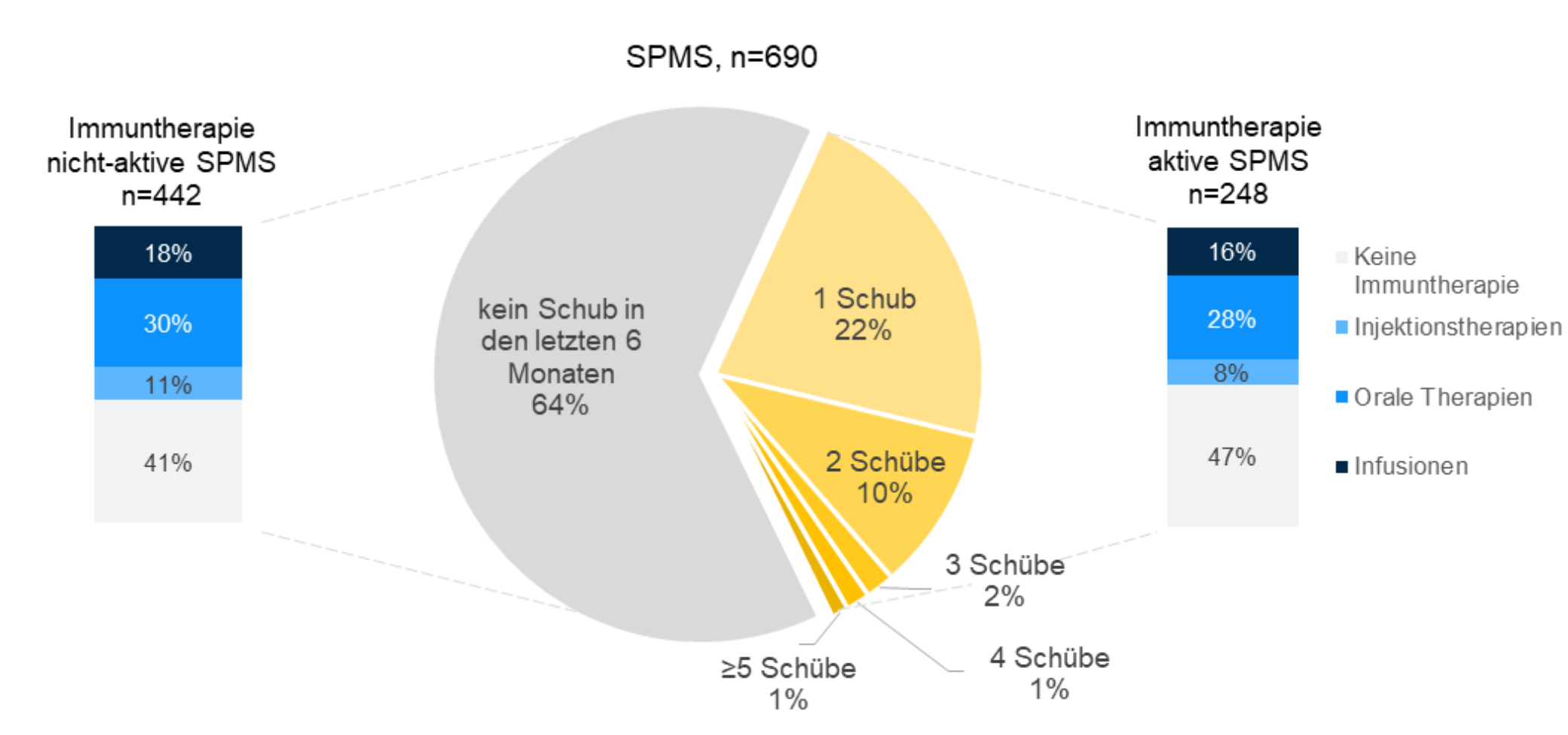
Figure 4. Symptom progression independent of relapse activity in the past 12 months by MS type and disability status



### Immunotherapy and symptomatic therapy

- 24.4% of RRMS and 43.5% of SPMS patients did not receive any disease modifying treatment (DMT) with the proportion of patients without DMT being slightly higher in active SPMS than in non-active SPMS patients (active SPMS 47.2%, non-active SPMS 41.4%) (Fig.5).
- 36.9% of all patients received symptomatic treatment (30.5% of RRMS and 61.7% of SPMS patients). PwMS receiving DMT also had more often symptomatic pharmacological therapy than pwMS without DMT, irrespective of MS subtype and disability status.

Figure 5. Immunotherapy in active (relapse in the last 6 months) versus non-active SPMS



## Conclusions

- MS Perspectives gives an important insight in self-assessed MS symptoms and severity in a large-scale cohort which is highly representative for the MS population in Germany.
- Patients with RRMS were younger, had less disability, and shorter disease duration than SPMS patients.
- However, in RRMS a relevant proportion showed longer disease duration, accumulated disability, worsening of symptoms independent of relapses as well as a symptom pattern and disease burden similar to patients with SPMS.
- This may indicate that SPMS transition is underdiagnosed in clinical practice. This diagnosis of transition is a prerequisite to adapt DMTs accordingly. The results may indicate insufficient treatment modifications regarding disease course and activity in a number of participants.
- Efforts should be made to increase awareness for SPMS transition in clinical practice, also with focus on less visible signs of progression.

## Disclosures

The study was funded by Novartis Pharma GmbH, Germany. Antonios Bayas received personal compensation from Merck Serono, Biogen, Novartis, TEVA, Roche, Sanofi/Genzyme, Celgene/Bristol Myers Squibb, Janssen and Sandoz/Hexal. He received grants for congress travel and participation from Biogen, TEVA, Novartis, Sanofi/Genzyme, Merck Serono, and Celgene. Katrin Schuh is employee of Novartis Pharma GmbH. Monika Christ declares that there is no conflict of interest

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