

## **The Dutch MS Patient Voice Survey: impact of disease on daily life**

C.C. Schouten<sup>(1)</sup>, E.M. de Wolf<sup>(1)</sup>, L. Avis<sup>(2)</sup>, L. Hoeijmakers<sup>(3)</sup>, A. Buurman<sup>(3)</sup>, J. Muis<sup>(3)</sup>

*(1) MS Association Netherlands (MSVN); (2) DVJ insights, (4) employees of Novartis Pharma.*

**Background:** Shared decision-making is a key aspect in healthcare and patients are motivated to take ownership of their own lifestyle changes. Informing patients with multiple sclerosis (MS), sharing knowledge, and coaching are some key objectives of patient advocacy organizations. Gathering patient insights on disease burden and interests will help patient organizations and other stakeholders to support MS patients in the Netherlands.

**Objective:** This survey aimed at gathering insights on the symptom development, the impact of MS on activities of daily living (ADL) in relation to (co) medication use and MS phenotype.

**Method:** From June until August 2019, 1029 MS patients participated in this on-line survey. Dutch patient advocacy organizations, MS association Netherlands and the National MS Foundation, invited participants to fill in the survey. The survey consist of three parts: 1. characteristics of disease phenotype and activity, 2. influence of the disease on daily life, and 3. information gathering and needs. The results of part two are shown.

**Results:** Of the 1029 participants, 75% were female. The participants split by phenotype: clinically isolated syndrome/Benign (CIS/B) 4%, relapsing-remitting MS (RRMS) 45%, primary-progressive MS (PPMS) 18%, secondary-progressive MS (SPMS) 23%, and not reported 10%. The most frequently reported symptoms were; difficulties walking (85%), decline in overall condition (79%) and sensory problems (74%). The kind of symptoms and how they change over time differed between MS phenotypes. The impact on ADL showed a decline in meeting family (27%), ability to perform household tasks (34%) and an increased in family dependence (41%) for SPMS patients. Most PPMS (64%) and SPMS (68%) patients did not use disease-modifying therapies (DMTs) but use more other types of medication. A higher EDSS score correlates with a higher number of doctor's appointments.

**Conclusion:** There is a range of MS symptoms that affect ADL and social life. The burden of disease and progression of specific symptoms differ strongly per phenotype, with the PPMS and SPMS patients reporting a higher burden of disease and impact on ADL. The majority of the PPMS and SPMS patients do not use DMTs. Importantly, both PPMS and SPMS groups reported a decline in functionality and increase in symptomatic treatment, which highlights the burden of disease and a potential medical need in these patients.

**Disclosure:** C.C. Schouten nothing to disclose, E.M. de Wolf nothing to disclose, L. Avis employee of DVJ insights, L. Hoeijmakers, A. Buurman & J. Muis are employees of Novartis Pharma The Netherlands.