

The Dutch MS Patient Voice Survey: Impact of Multiple Sclerosis on daily life activities; characteristics of disease phenotype and treatment

C.C. Schouten⁽¹⁾, E.M. de Wolf⁽¹⁾, L. Avis⁽²⁾, L. Hoeijmakers⁽³⁾, A. Buurman⁽³⁾, J. Muis⁽³⁾, ⁽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: The Dutch Patient Voice Survey aims to obtain insights in relapses, relapse recovery, changes in Expanded Disability Status Scale (EDSS), and medication use per phenotype through an online patient survey (part 1 out of 3).

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 one are shown.

Results: Of the 1029 participants, 75% were female, 25% male. The participants were split by reported 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%. Average self-reported EDSS score was higher for patients with PPMS and SPMS than for other phenotypes. Average time since diagnose; CIS/B (4.9y), RRMS (3.9y), PPMS (4.5y), SPMS (5.2y), not reported (5.3y). In the past 12 months, 33% of the RRMS patients experienced a relapse and 59% did fully recover after a relapse. Of the SPMS group, 22% fully recovered after a relapse. Disease-modifying therapies (DMT) usage was 74% in the RRMS group, 32% in the SPMS group and 36% in the PPMS group.

Conclusion: Patient-reported disease experiences are an indication of the perceived burden of the disease. A large proportion of participants was female (75%) and 10% of all participants could not report their MS phenotype. SPMS and PPMS patients reported the highest EDSS score and lower relapse recovery rates while they use less DMTs compared to the RRMS patients, potentially indicating a medical need for effective DMTs in progressive disease. This survey provides information on the relation between perceived disease status and other relevant factors.

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