

The Dutch MS Patient Voice Survey: The search for information

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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 the 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 MS Patient Voice Survey aims to obtain insights in the role and use of different media and topics of interest split by MS phenotype and patients age.

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. Results from the Part 3 is reported in this abstract.

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%. Participants showed the highest interest in information about new treatments (75%), MS as a disease (64%), and lifestyle (51%). Topics of interest were influenced by age and did not vary by phenotype. Younger patient were most interested in MS and work, pregnancy and children while elderly patients have a high interest in how to stay mobile. 80% to 85% of the patients spend more than one hour a day online. There is a significant correlation between age and time spend online. Facebook is most frequent used (41%), mainly by younger patients. Snapchat is only use by 7% of the patients. Of the MS patients, 78% read daily newspapers and 39% read magazines (weekly or monthly).

Conclusion: Online information is an important source of information, especially Facebook. MS patient organizations, healthcare professionals and other stakeholders should keep in mind that some online information is not fact-checked and might misinform patients, which could influence their behavior. Most MS patients read local newspapers. Topics of interest depend mainly on age, suggesting that information should be tailored to patient age groups to fit their specific information needs.

Disclosure: C.C. Schouten, 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