

The Dutch MS Patient Voice Survey: The search for information

C. Schouten ⁽¹⁾, E.M. de Wolf⁽¹⁾, [L. Avis](#)⁽²⁾,
L. Hoeijmakers⁽³⁾, A. Buurman⁽³⁾, J. Muis⁽³⁾

ePoster Session: P0667

⁽¹⁾ MS Association Netherlands (MSVN); ⁽²⁾ DVJ insights,
⁽³⁾ Novartis Pharma The Netherlands

ePoster presentation at the 8th Joint ACTRIMS-ECTRIMS Meeting, MSVirtual 2020, September 11–13, 2020

Copyright © 2020 Novartis Pharma AG. All rights reserved



Scan to download
information

Disclosures

- C.C. Schouten, Dutch MS association - nothing to disclose
- E.M. de Wolf, Dutch MS association - nothing to disclose
- L. Avis, DVJ Insights - nothing to disclose
- L. Hoeijmakers, employee of Novartis Pharma The Netherlands
- A. Buurman, employee of Novartis Pharma The Netherlands
- J. Muis, employee of Novartis Pharma The Netherlands

The MS Patient Voice research collaboration group consists of:

- Dutch MS association
- National MS foundation
- DVJ insights
- Novartis pharma

Background and objective

- Shared decision-making is a key aspect in healthcare and patients are motivated to take ownership of their own lifestyle changes. Informing, coaching, and sharing knowledge with patients with multiple sclerosis (MS) are some of the key objectives of patient advocacy organizations. Therefore, gathering patient insights on disease burden and interests will help patient organizations and other stakeholders to support MS patients in the Netherlands. Moreover they will be able to reach out to the MS community in an effective way

Objective

The Dutch MS Patient Voice Survey aims to investigate the opinions and perception of MS patients for each phenotype. Part 3 of 3 of this survey focuses on how patients with MS gather disease information, which topics are of interest to them and whether this depends on phenotype or age

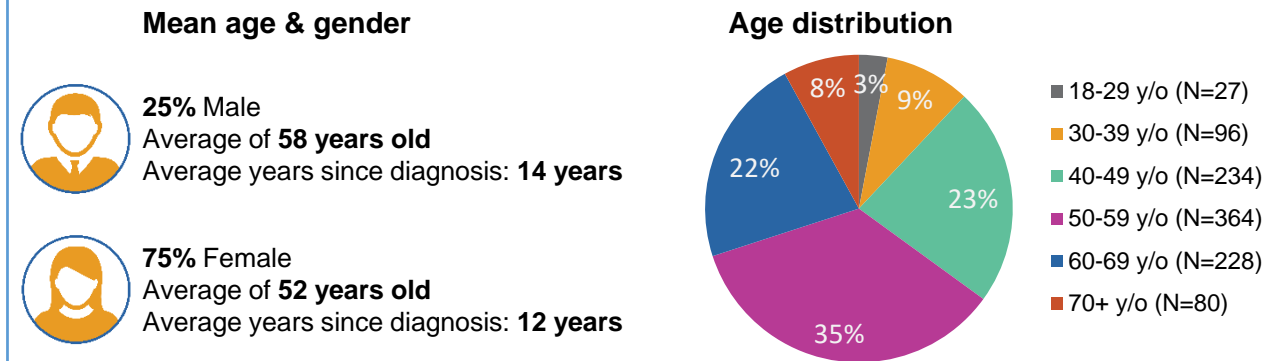
Methods: Patient voice: online patient survey

- From June until August 2019, 1029 MS patients participated in this (20 minute) online 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 sections:
 1. Characteristics of disease phenotype and activity
 2. Influence of the disease on daily life and
 3. Information gathering and needs
- Data presented here is the third part of the survey:

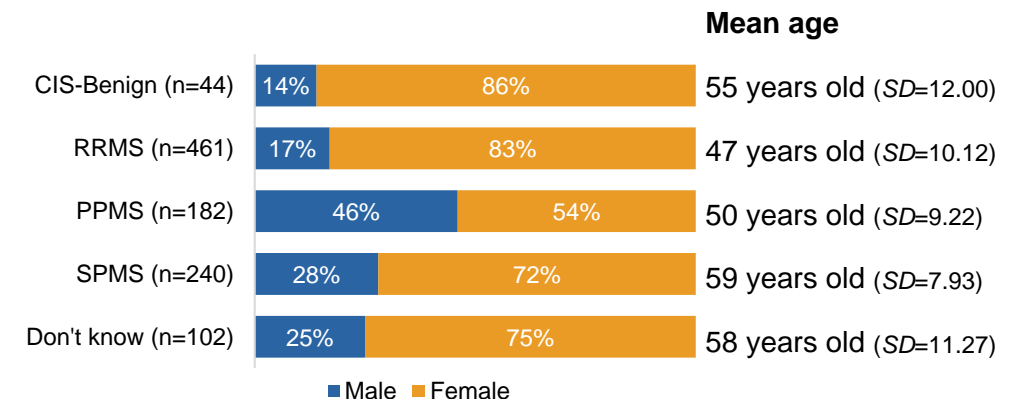
Profile of the study population

- This Patient survey is the largest MS patient survey ever conducted in the Netherlands
- More than half of the 1,029 participants were older than 50 years (65%) and a large proportion of participants were female (75%)
- The average years till diagnosis was 12 years for the female patients and 14 years for the Male survey group
- 10% of all participants could not report their MS phenotype
- The study population of MS patients may bias some of the results of this study

Characteristics (age, gender & disease duration)



Characteristics (age & phenotype)



Results: Topic of interest to MS patients

- Of the 1029 participants, 75% were female, 25% male

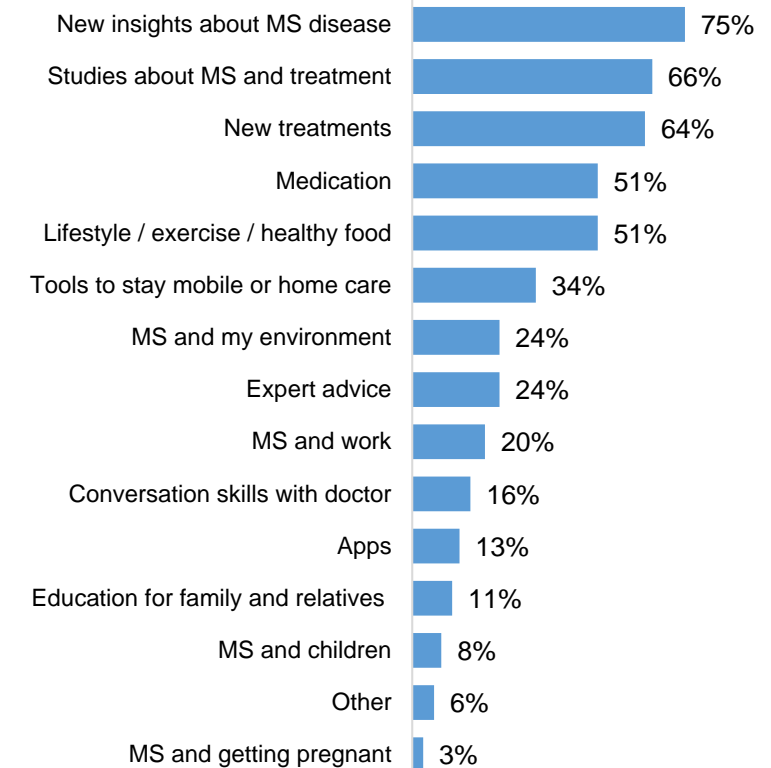
Study participants by age, EDSS* & phenotype.

	CIS-Benign	RRMS	SPMS	PPMS	Not reported
Total N	44	461	240	182	102
Mean age	55	47	59	58	58
Average EDSS	2,8	3,8	6,4	6,2	4,6

* Expanded Disability Status Scale

- The patients show the highest interest in new treatment developments and in insights in MS as a disease, accounting for 75% and 64%, respectively
- Information about medication and lifestyle rank third with 51%
- There is a difference in topics of interest by age, not by phenotype. Younger patient search for information about lifestyle, pregnancy, children and MS and work. More senior patients tend to search for information about how to stay mobile

Overall topics of interest of MS patients

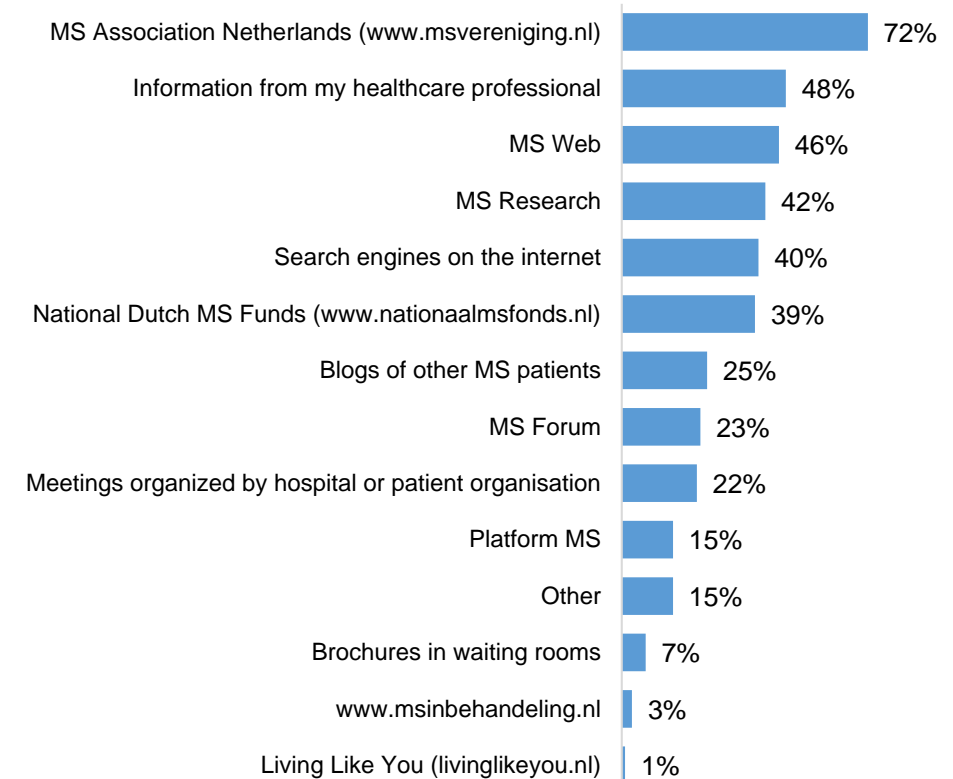


Total N=1,029

Results: Sources consulted for gathering information about MS

- When patients have questions about MS, the information from the patient association (MSVN) is consulted in 72% of the cases, followed by the information given by health care professionals
- Waiting room brochures are less popular as information source
- Younger patients more often use various online platforms to find the information they are looking for
- An in depth analysis showed no significant difference in the information sources by phenotype

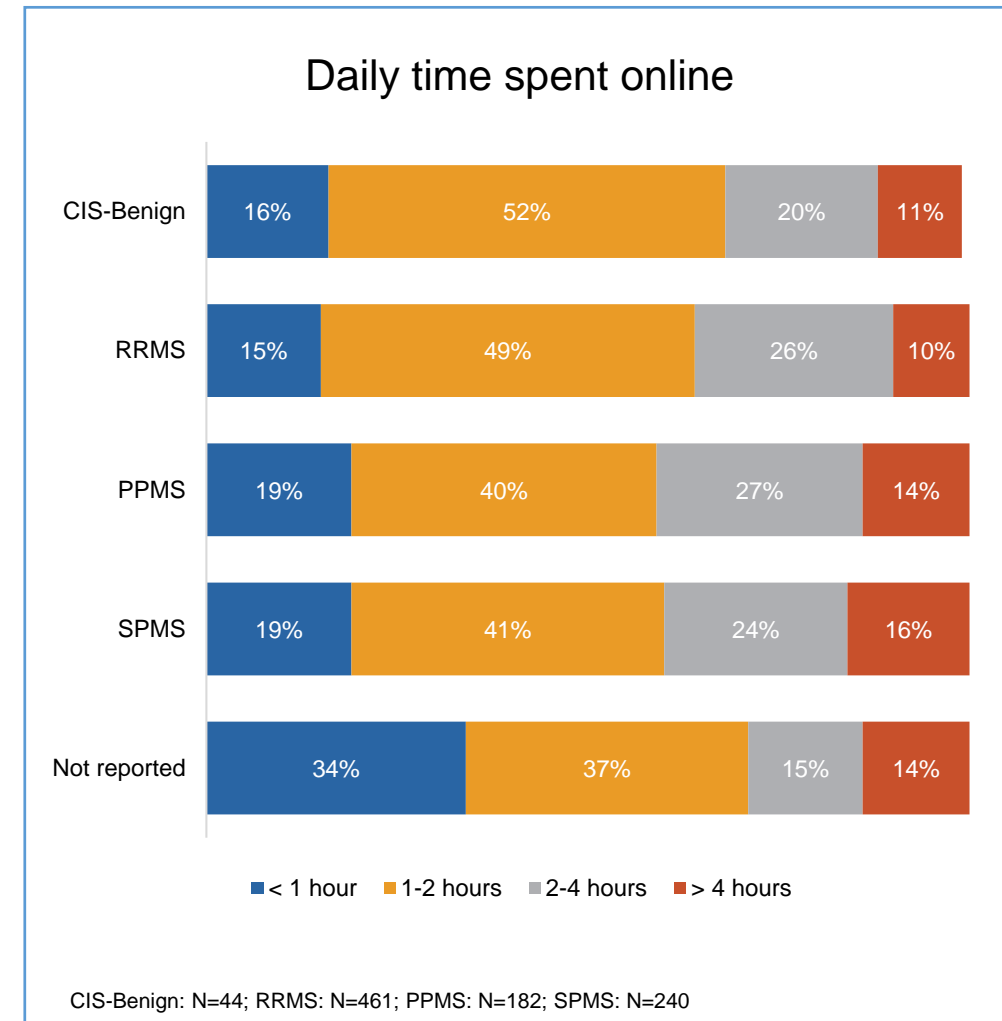
Sources for gathering information about MS



Total N=1,029

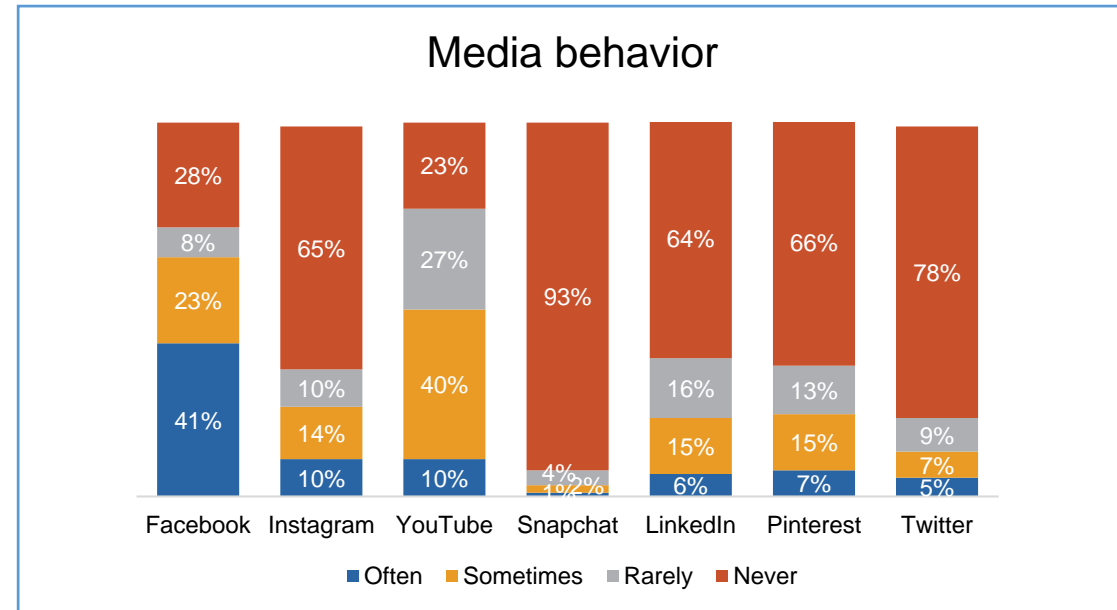
Results: Time spent online by phenotype per day

- 80% to 85% of the MS patients spent more than one hour a day online
- There is no significant difference between phenotype and time spent online
- Age was found to be a differentiating factor; more senior patients (60+) spent less time online than younger patients
- We should note that the survey was filled in online and the participant recruitment was conducted by the patient associations using their social media contacts. This may bias the results



Results: The use of sources of information

- Younger patients (<60 year) use Facebook most frequent and this medium is most often used by 41% of the respondents
- Daily newspapers are read by 78% of the MS patients and 39% of them read magazines (weeklies or monthlies)
- Snapchat and twitter are hardly used by this study population
- There is a significant correlation between age (groups) and time spent online



Times spent online by age group

	18-29 year (A)	30-39 year (B)	40-49 jaar (C)	50-59 year (D)	60-69 year (E)	> 70 years (F)
Time a day	N=27	N=96	N=234	N=364	N=228	N=80
< 1 hour	4%	15%	14%	17% A	26% ACDE	28% ABCD
1 - 2 hours	37%	42%	46%	48% E	39%	44%
3 - 4 hours	37% DF	29%	27%	23%	23%	20%
> 4hours	22% F	15%	13%	13%	12%	9%

A/B/C/D: significantly different from column with corresponding letter

Conclusions

- Online platforms and social media play an important role for MS patients in gathering information about MS. Patients and HCPs should be aware that not all of the available information online is fact-checked and might misinform patients and could, subsequently, influence their treatment behavior
- The patients indicated that they mainly use the information given by their health care professional and MS patient association websites to obtain information about MS. Waiting room brochures are less often used
- The most interesting topics are new insights in the MS in general and information about new treatments. Although the subjects such as MS and pregnancy, MS and work, and MS and life-style are more of interest to the younger patients. The older patient are more interested in how to stay mobile. These findings suggest that information should be tailored by age and not necessarily by MS phenotype solely
- Facebook is the most frequently used platform. There are special (closed) MS Facebook communities that are used by patients to ask questions or discuss subject with fellow MS patients
- Most MS patients read the local newspapers, to keep in touch with the local news