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

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

ePoster Session: P1085

[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

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 research the opinions and perception of MS patients for each phenotype. This first out of three posters aims at gathering insights in perceived relapse, recovery rate after a relapse and changes in expanded disability status scale (EDSS) score of the respondents in relation to medication use for each phenotype

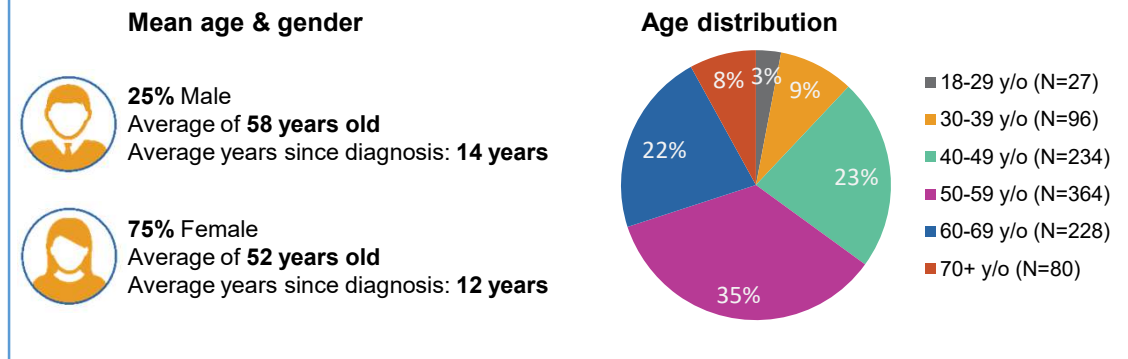Patient voice research collaboration group.

Methods: Patient voice: on-line patient survey

- From June until August 2019, 1029 MS patients participated in this (20 minute) 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 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 section one of the survey:

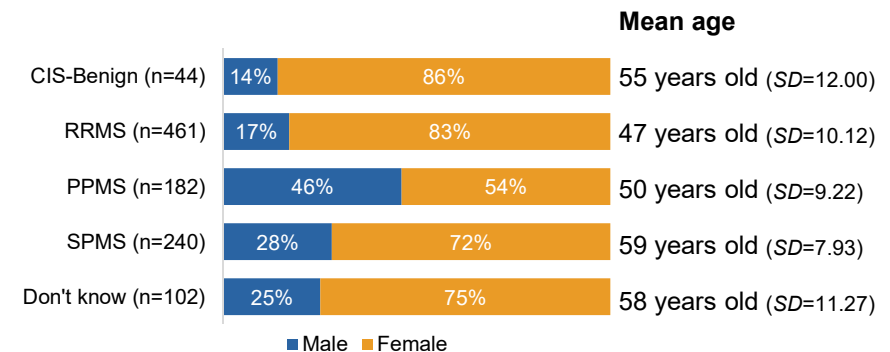Patient voice research collaboration group.

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 population and 14 years for the male population

- 10% of all participants could not report their MS phenotype

- The study population of MS patients may bias the some of the study results

Characteristics (age, gender & disease duration)

Mean age & gender

25% Male
Average of **58 years old**
Average years since diagnosis: **14 years**

75% Female
Average of **52 years old**
Average years since diagnosis: **12 years**

Age distribution

- 8% 3% 9%
- 22%
- 23%
- 35%

- 18-29 y/o (N=27)
- 30-39 y/o (N=96)
- 40-49 y/o (N=234)
- 50-59 y/o (N=364)
- 60-69 y/o (N=228)
- 70+ y/o (N=80)

Characteristics (age & phenotype)

Mean age

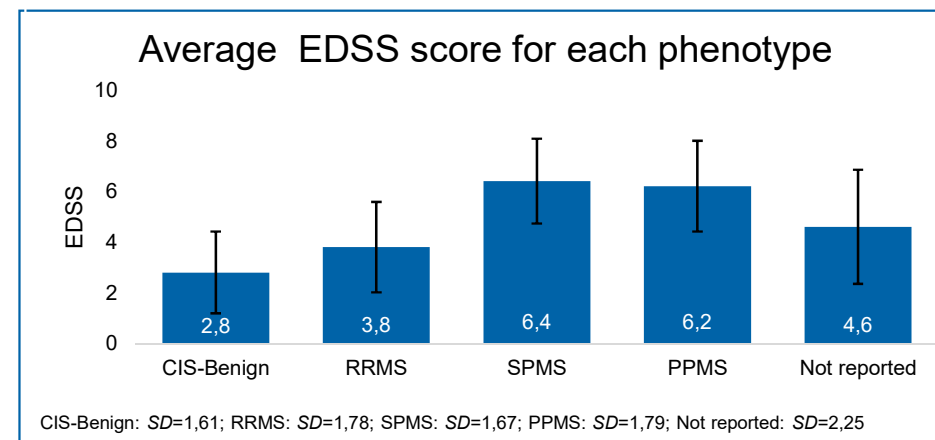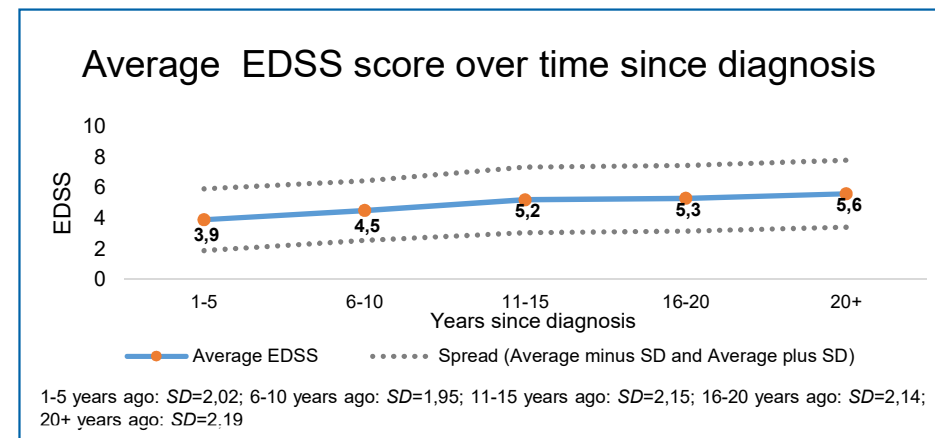| Phenotype	Male	Female	Mean age
CIS-Benign (n=44)	14%	86%	55 years old (SD=12.00)
RRMS (n=461)	17%	83%	47 years old (SD=10.12)
PPMS (n=182)	46%	54%	50 years old (SD=9.22)
SPMS (n=240)	28%	72%	59 years old (SD=7.93)
Don't know (n=102)	25%	75%	58 years old (SD=11.27)

■ Male ■ Female

Results: Demographics, relapses and DMT use

- The SPMS population showed clear differentiating features versus the RRMS population

- The SPMS population was remarkably older with longer disease duration than the RRMS phenotype

- Due to the way in which patient were recruited, the study population may not fully represent the Dutch MS patient population

Demographics, DMT usage an recovery after relapse

Demographics	Total	Cis/B	RRMS	PPMS	SPMS	Not reported
Number of respondents						
Absolute	1029	44	461	182	240	102
% of total	100%	4%	45%	18%	23%	10%
Average Age						
>18	54	55	47	59	58	58
Sex %						
Women	75	86	83	54	72	75
Men%	25	14	17	46	28	25
Patients relapse history %						
Relapse during last 12 months		9	33	7	17	19
Relapse longer than 12 months ago	-	77	62	26	72	56
Never had a relapse		14	5	67	11	25
Use of disease modifying therapies %						
interferon, glatirameeracetaat, dimethyl fumaraat, teriflunomide			40	2	13	8
fingolimod, cladribine			11	3	2	2
alemtuzumab, ocrelizumab	-	-	18	20	6	5
Non DMT medication			5	9	12	11
No medication use			26	64	68	74
Patients with full recovery after relapse during last 12 months %						
Patient with full recovery	-	50	41	35	22	41

Patient voice research collaboration group.

Results: EDSS development over time for each phenotype

- As time passes since diagnosis, EDSS increased from an average of 3,9 (1-5 years since diagnosis) to 5,6 (20+ years since diagnosis)

- The average EDSS score gradually increases with disease progression in a timely matter

- The CIS and Benign patient group had an average EDSS score of 2.8. In contrast, average EDSS score of SPMS patients was 6.4

- The EDSS score for the SPMS and PPMS patients was not significantly different

Patient voice research collaboration group.

Average EDSS score over time since diagnosis

1-5 years ago: *SD*=2,02; 6-10 years ago: *SD*=1,95; 11-15 years ago: *SD*=2,15; 16-20 years ago: *SD*=2,14; 20+ years ago: *SD*=2,19

Average EDSS score for each phenotype

CIS-Benign: *SD*=1,61; RRMS: *SD*=1,78; SPMS: *SD*=1,67; PPMS: *SD*=1,79; Not reported: *SD*=2,25

Results: EDSS development over time for each phenotype

- After diagnosis, the average EDSS score gradually increases with disease progression in a timely matter

- The CIS and Benign patient group had an average EDSS score of 2.8. In contrast, average EDSS score of SPMS patients was 6.4

- The majority (45%) of the SPMS patients were diagnosed with MS more than 20 years ago, this was 22% for PPMS patients

Patient voice research collaboration group.

Average EDSS, phenotype and disease duration
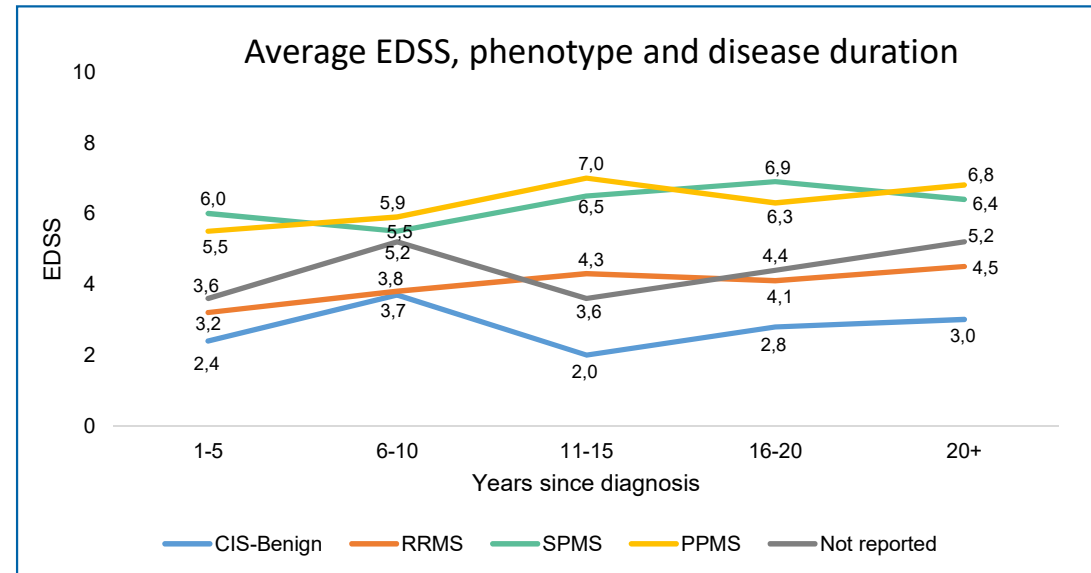
Disease duration for each phenotype					
	CIS-Benign	RRMS	SPMS	PPMS	Not reported
Total N	44	461	240	182	102
1-5 years ago	8	144	10	54	13
6-10 years ago	3	128	32	34	12
11-15 years ago	3	90	47	31	17
16-20 years ago	12	43	44	23	14
20+ years ago	18	56	107	40	46

Results: Relapse of disease and DMT use per phenotype

- Of the RRMS patients, 33% had a relapse in the last 12 months. 5% did not report a relapse

- 74% of the RRMS patients were treated with a disease-modifying therapy (DMT) of which 41% fully recovered after having a relapse over the last 12 months

- In the SPMS group, 17% had a relapse during the last 12 months and 22% fully recovered after relapsing

- 32% of the SPMS group and 36% of the PPMS group were treated with DMTs

- DMT use in the CIS-Benign patient group (11%) led to a 50% fully recovery rate

Patient voice research collaboration group.

Last relapse and DMT use

	CIS-Benign	RRMS	SPMS	PPMS	Not reported
<12 months ago	9%	33%	17%	7%	19%
>12 months ago	77%	62%	72%	26%	56%
Never had relapses	14%	5%	11%	67%	25%
Completely recovered from last relapse*	50%	41%	22%	35%	41%
DMT usage	11%	74%	32%	36%	26%

*Only asked when last a relapse was less than 12 months ago

Disease Modifying Therapies (DMT):
interferon, glatirameeracetaat, dimethyl fumaraat, teriflunomide, fingolimod, cladribine, alemtuzumab, ocrelizumab,

Conclusions

- This large (N=1029) patient survey provides information on the relation between perceived disease status and other relevant joint factors

- The majority (75%) of the 1029 respondents were female. The average age of the survey population was 58 years for the male study population and 52 years of age for the female population

- The EDSS score progresses over time but does not significantly differ between SMPS and PPMS patients

- SPMS and PPMS patients reported the highest EDSS score and lower relapse recovery rates. However, less DMTs are being used compared to RRMS patients, indicating a medical need for effective DMTs in progressive MS

Scan to download information