



**TaP MS** Treatment Expectations and  
Priorities of People with MS

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## Abbreviations

<b>TaP-MS</b>	Treatment Expectations and Priorities of People with MS
<b>DMT</b>	Disease Modifying Treatment
<b>PPMS</b>	Primary-Progressive MS
<b>PRMS</b>	Progressive-Relapsing MS
<b>RRMS</b>	Relapsing-Remitting MS
<b>SPMS</b>	Secondary-Progressive MS

# Executive Summary

Multiple sclerosis (MS) is a chronic disease attacking the central nervous system (brain and spinal cord) affecting over 2.3million people worldwide, it is 2-3 times more common in women than in men, and people are usually diagnosed between 20 and 50 years of age . Presently, there is no cure for MS, however disease modifying treatments (DMTs) effectively delay disability for people living with MS.

There is extensive information about how people with MS interact with their neurologists and the MS symptoms that they find most distressing. Fatigue is a widespread concern for patients, the significance of which is not always fully understood by those providing medical care and or social support. There is also evidence that the use of medicines may be delayed or impaired because of fears about factors such as drug side effects and or a lack of belief in their benefits.

## Key Findings

### Barriers

- The availability and uptake of DMTs varies globally and impacts expectations of new treatments .

### Barriers

Treatment concerns pose the greatest barrier to DMT uptake

### Priorities

- Efficacy is of primary importance to patients, followed by concerns around treatments, such as side effects then, to a lesser extent practicalities around treatment taking.
- Reduction of fatigue is a future priority, but is also most expected in new treatments
- Priorities for people with MS are to tackle the disease and its symptoms above minimising treatment harm and practical considerations.

### Priorities

Patients want treatments that combat disease progression

### Perceptions

- There is a degree of coherence throughout between what patients prescribe to treatment and what they prescribe to illness.
- New treatment options for PPMS provides optimism for future curability.

### Perceptions

Patients don't tend to view their disease in terms of brain health, more in terms of how they feel in day to day life

Patients both prioritise and expect treatments that support them in becoming more independent. It is crucial to communicate MS therapeutic advances with patients and instil trust in bio-pharmaceutical innovation, regardless of cultural disparities in attitudes to healthcare.

There were notable differences in response rates from patients that came via a patient organisation group in comparison to being invited individually, demonstrating the power of collective patients voices in information dissemination in MS.

# TaP-MS Introduction

F. Hoffmann-La Roche Ltd (Roche) awarded a grant for Bournemouth University and Spoonful of Sugar (SoS) to examine the treatment expectations and priorities of people living with MS.

Until relatively recently there was no effective treatment for MS other than social support and nursing care, however in the last 20 years there have been a series of therapeutic developments. There is evidence that the use of medicines may be delayed or impaired because of fears about factors such as drug side effects and or a lack of belief in their benefits. Not much is known about how best such problems can be addressed and the priorities that people with MS have for future treatment improvements.

The significance of fatigue is widespread and it is a concern for patients. However, the significant burden it poses to people with MS is not always fully understood by those providing medical care and social support.

## Aims of the research

- To explore MS patient understandings, beliefs and preferences
- To address the gap in present knowledge on expectations and priorities for people with MS
- To improve care standards and health outcomes for people with MS globally

## Methodology

### The SoS Approach

- The Perceptions and Practicalities Approach (PAPA™)
  - Necessity-Concerns Framework (NCF™)
  - Behavioural Insights Research (BIR™)
- 222 papers identified and screened for treatment preferences, satisfaction, and methods previously used.
  - Qualitative interview and social media listening was conducted.
  - Patient organisations and groups were invited to participate.
  - Appendix, Table 1 presents demographic information of participants.



# DMT Uptake

81% RRMS on DMT  
Lower average in the UK (71%) and the US (73%)

UK patients' DMT use reported by TaP-MS were not as low as sources suggest<sup>1</sup>

On average 59% people with SPMS take DMT, the highest in the USA with 96%

Diagnosis	RRMS			SPMS			PPMS+PRMS			Don't Know (DK)		
	On DMT	All	DMT	On DMT	All	DMT	On DMT	All	%DMT	On DMT	All	DMT
Australia	19	20	95.0%	2	3	66.7%	2	4	50.0%	1	1	100.0%
Canada	12	14	85.7%	6	7	85.7%	4	7	57.1%			
France	57	67	85.1%	7	8	87.5%	7	12	58.3%	12	15	80.0%
Germany	46	58	79.3%	3	5	60.0%	6	12	50.0%	6	10	60.0%
Italy	7	9	77.8%		2	0.0%	1	3	33.3%	1	4	25.0%
Spain	36	37	97.3%	9	13	69.2%	2	9	22.2%	2	2	100.0%
Sweden	126	148	85.1%	29	88	33.0%	11	46	23.9%	36	65	65.5%
United Kingdom	76	106	71.7%	9	12	75.0%	9	21	42.9%			
<b>Grand Total (USA not incl.)</b>	<b>379</b>	<b>459</b>	<b>82.6%</b>	<b>65</b>	<b>138</b>	<b>47.1%</b>	<b>42</b>	<b>114</b>	<b>36.8%</b>	<b>58</b>	<b>87</b>	<b>66.7%</b>
United States of America	88	120	73.3%	45	47	95.7%	66	74	89.2%		1	0%
<b>Grand Total</b>	<b>467</b>	<b>579</b>	<b>80.7%</b>	<b>110</b>	<b>185</b>	<b>59.5%</b>	<b>108</b>	<b>188</b>	<b>57.4%</b>	<b>58</b>	<b>88</b>	<b>65.9%</b>

Table 1: Current uptake of DMTs for MS

In the USA the greatest uptake of treatment was seen for PPMS/PRMS at 89.2%, the only market where PPMS treatment licenced

Sweden displays lowest uptake of treatment for SPMS at 33% as well as a high number of patients that don't know classification of their MS

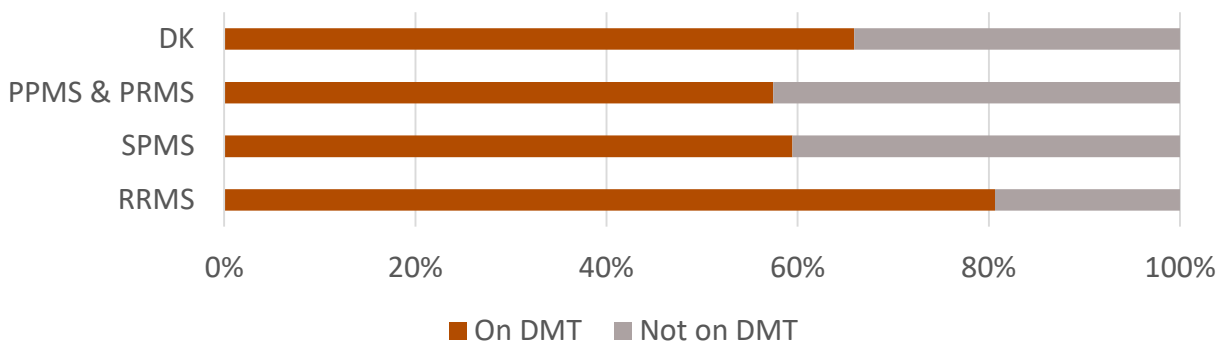


Figure 1: Current uptake of DMTs for MS

During the period of this investigation only the Australian and American pharmaceutical markets contained a DMT officially indicated for PPMS

1. European Burden and Costs of MS study, Kobelt et al, 2017 and Giovannoni et al's Brain report, 2015

# Barriers to DMTs

## Concerns and necessity beliefs

- Even when DMTs are available some patient decided they did not want to take them.
- Concerns about the treatment and necessity beliefs account for 58% of the people surveyed that would not take a DMT.
- Adherence is a major barrier to effective treatment and optimum outcomes for people with MS.

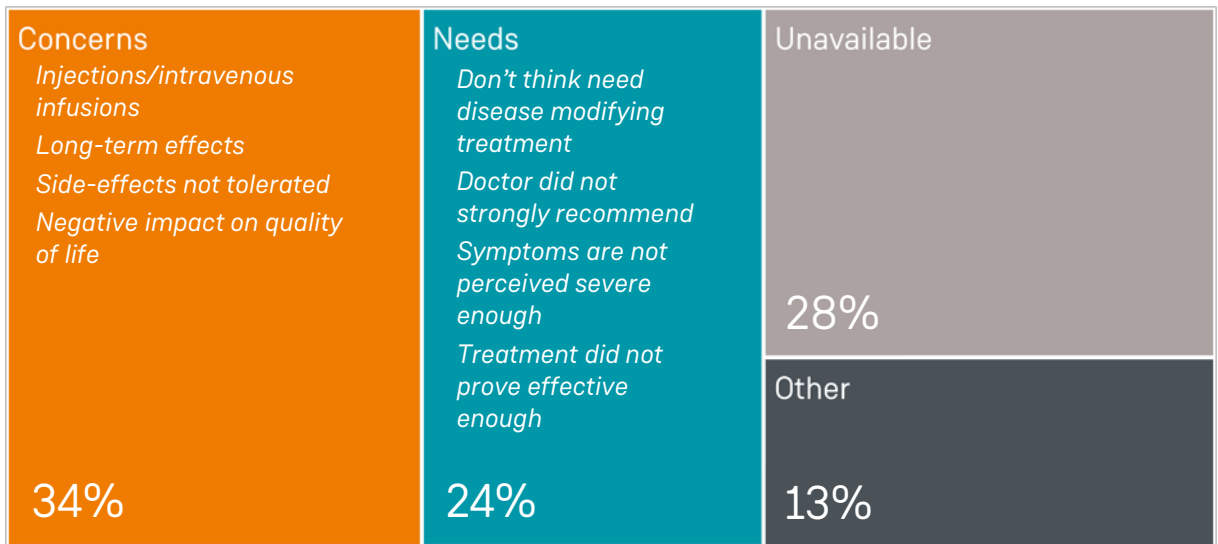


Figure 2: Patients' self reported most important reasons for not taking a DMT

## DMT availability

- In PPMS and PRMS unavailability is high, but if made available there is still further work to do on uptake because concerns are still high.
- Different MS types have different reasons and priorities, however availability is most important for people with PPMS.
- 56% of Swedish respondents with self-identified SPMS who were not taking a DMT said that they believed no suitable medicine is available.

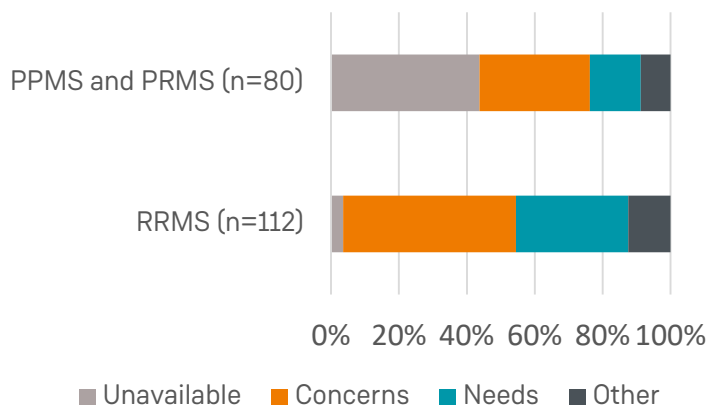


Figure 3: The most important reason for not taking DMT varies according to type of disease

# Treatment Priorities

## New treatment priorities

- Patients prioritise reduced symptoms and disease progression over side effects and give little weight to practical considerations.
- Patient do not prioritise clinician’s reassurance and may welcome other forms of support, these need to be explored further to ensure further support is impactful.
- English speaking country respondents are, when compared to their mainland European peers, more likely to say they value symptom reduction as opposed to progression slowing. There is scope here to tailor messages so that they are country specific.

<b>Most important</b>  <b>Least important</b>	Disease and symptom improvement	The possible reduction of symptoms The possible reduction in the relapses experienced A slowing down of my disease progression
	Treatment harm reduction	The possible side effects from the treatment The possible long-term harms from medication
	Practicalities	The way in which the medication would be taken (e.g. oral, injection, intravenous) How often the medication would have to be taken
	Opinions	The doctor's opinion about the treatment

Figure 4: Factors that influence starting a new disease modifying treatment for MS

### Disease and symptom reductions

- Symptom priorities highlight importance of increasing independence.
- Combatting fatigue, maintaining walking/mobility capabilities and alleviating problems like bladder and bowel control difficulties and sight impairments.

<b>Most important</b>  <b>Least important</b>	Feeling less tired and fatigued
	Reduction in spasms and stiffness
	Reduction in pain Reduction in tremors or shaking
	Fewer sexual problems

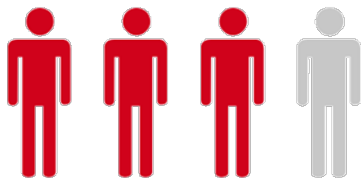
Figure 5: Factors that people with MS hope to see in terms of reductions in their symptoms from MS treatment

For new treatment indications the focus is about the benefits DMTs would bring for people with MS, the communications of these benefits need to be tailored so that they align to treatment priorities.

# Treatment Expectations

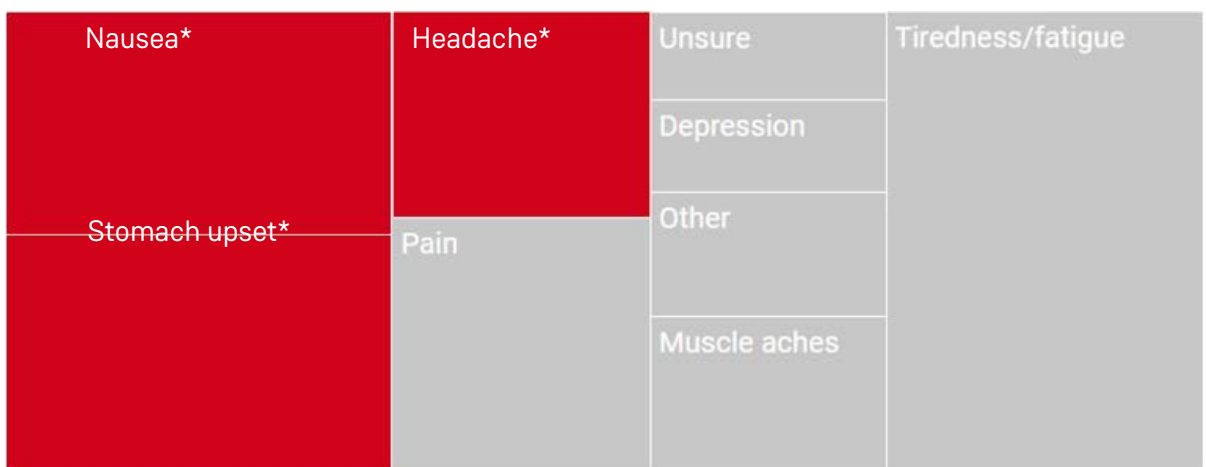
## Treatment initiation expectations

- Almost three quarters of the respondents expect side effects from any new medication, this ranged from more than 90% in Germany to near 50% in Spain.
- People expect general medicinal side effects such as stomach aches, nausea, headaches and muscle aches, similar to 'flu-like' symptoms expected with longstanding treatments such as interferons.



- Nearly 3 in 4 MS patients expect side-effects from a new treatment
- Around 1/3 of these expected side effects are not treatment specific

- Most commonly identified side effect expectation was fatigue
- Fatigue and depression indicate ambiguity between disease symptoms and side effects
- General side effects make up around 1/3 of expected side effects which are not treatment specific, managing these general side effects can help increase adherence to DMTs



\*Stomach upset, headache and nausea are all general and not treatment specific side effects

Figure 6: Side effect expectations of DMTs



# Quality of life

## Improvement in quality of life

### Key priorities

- People with MS want to be more active and energetic.
- People with MS want to enjoy improved sense of wellbeing.
- People with MS want to live without disease symptoms.
- Managing concerns around side effects is important to improve adherence to DMTs.

### Key expectations

- People with MS expect improvements that lead to greater independence.
- People with MS expect that the improvement from their treatment will be clearly separated from the symptoms of the disease.



Figure 7: Factors that are important from a new treatment for MS to improve quality of life

# MS and the Future

The highest priority globally was a treatment that assured people with MS that their MS will not progress any further over a medicine for symptom relief

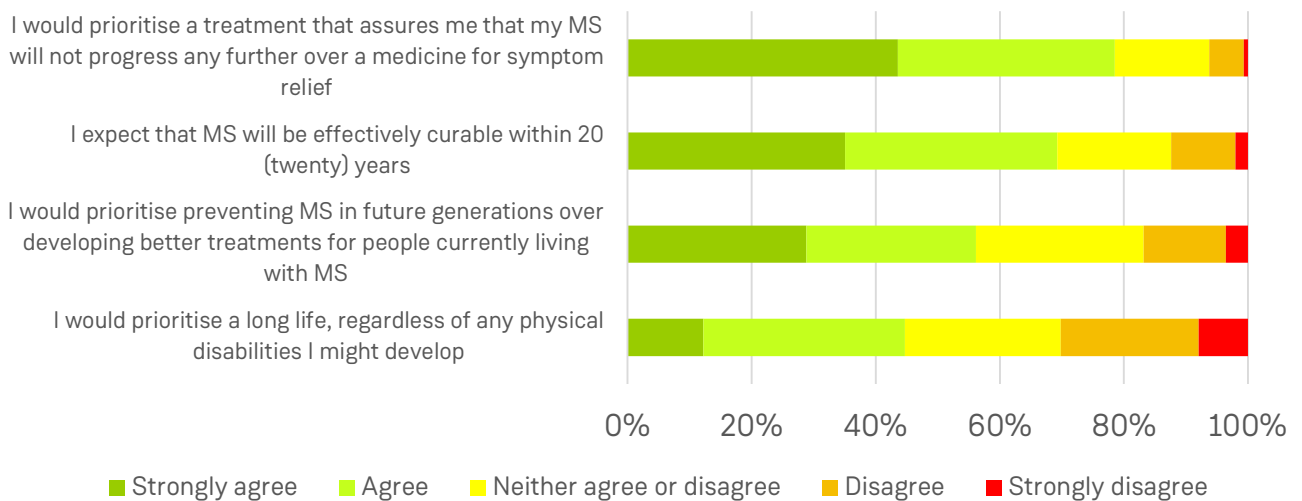


Figure 8: Factors that people with MS hope to see in terms of reductions in their symptoms from MS treatment

## Variations across nationalities

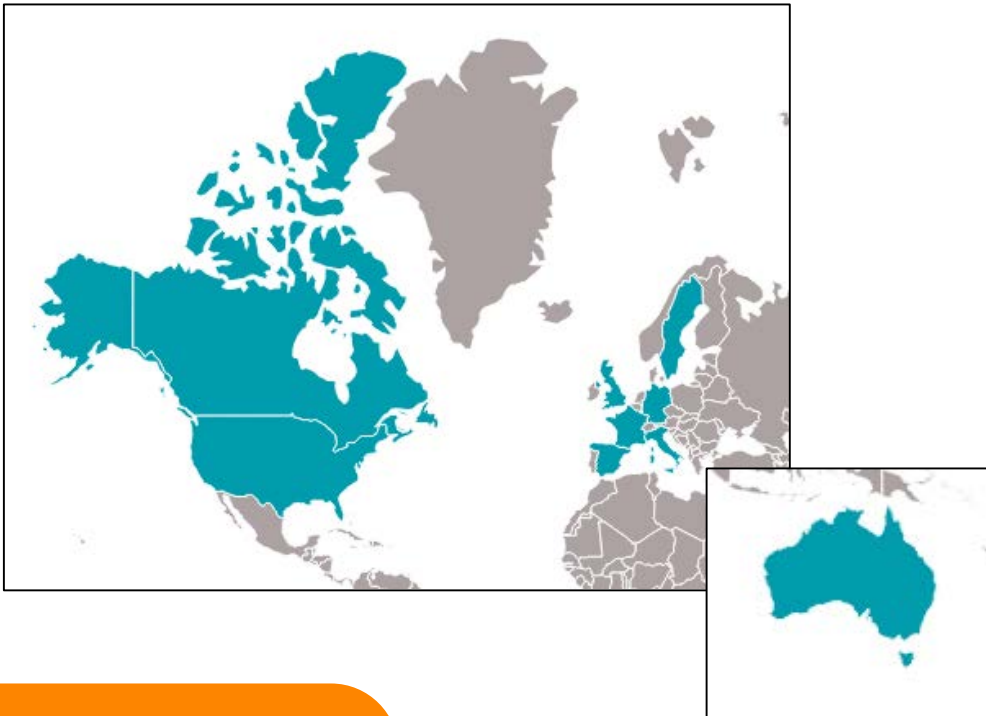
- Preventing MS in future generations was agreed overall and averaged at 56%, but in France and USA the agreement was above the average at 82% and 76% respectively.
- On average 44% agreed or strongly agreed with the statement to prioritise a long life, regardless of any physical disabilities. There was a split between mainland Europe and other countries. American (71%), Canadian (64%), British (61%) and Australian (57%) respondents were most likely to say that they agreed, but less than 30% living in France, Germany, Italy, Spain and Sweden expressed any degree of agreement. Mainland Europeans were about twice as likely to disagree.

Expecting MS to be effectively curable in 20 years was agreed by 69% overall, but this was higher with Americans on a DMT with PPMS/PRMS with 95% agreeing.

# MS and the Future

Expectations for effectively curing MS were the lowest in the UK

Proportionally side effects expected from DMT were the highest in Germany and Italy



56% Swedish respondents with self-identified Secondary Progressive MS who were not taking a DMT said that they believed no suitable medicine is available. Further work in the clinician approach in Sweden and cultural beliefs need to be explored.

Spanish MS patients remained the most optimistic with the greatest expectation that MS will effectively be curable within 20 years

Globally cultural differences, different healthcare services, and access to DMTs have highlighted the different expectations people with MS have for their future

# Recommendations

## **Understanding treatment trade-offs**

- Although patients prioritise and expect efficacy in future treatments the greatest treatment barriers are currently concerns about the treatments; further research is needed to understand the specific trade-offs patients may have and how these interplay with individual disease-specific, as well as contextual factors.

## **Removing barriers to disease comprehension**

- Patient perceptions and priorities around the disease and treatment may not accurately be reflected in communications using concepts such as brain health and further support for patients in understanding the implications of their condition is required internationally.

## **Holistic approach supporting people with MS**

- Providing psychological support for people with MS, combining medical, nursing, pharmaceutical, psychological and social care in a holistic approach that maximise their synergistic value is needed to overcome gaps in understanding on disease and treatment trajectory and can help improve patient outcomes.

# Appendix

Table 1: Demographics results table

Country	Total no. of respondents M&F combined	% F	Average age at time of response (M&F)	Average time since diagnosis (years)	% of T (including DKs) with RRMS	% with SPMS	PPMS incl. PRMS	% with PPMS, including PRMS	% of DK
Australia	28	93%	47.0	7.1	71.4%	10.7%	4	14.3%	3.6%
Canada	28	50%	42.0	9.6	50.0%	25.0%	7	25.0%	0.0%
France	102	58%	37.8	7.5	65.7%	7.8%	12	11.8%	14.7%
Germany	85	86%	36.2	7.7	68.2%	5.9%	12	14.1%	11.8%
Italy	18	72%	46.1	12.3	50.0%	11.1%	3	16.7%	22.2%
Spain	61	52%	47.7	15.1	60.7%	21.3%	9	14.8%	3.3%
Sweden	337	79%	50.9	11.8	43.9%	26.1%	46	13.6%	16.3%
United Kingdom	139	59%	42.0	9.3	76.3%	8.6%	21	15.1%	0.0%
United States of America	242	56%	39.2	7.6	49.6%	19.4%	74	30.6%	0.4%
	1040						188		

**Total split by gender**

Male (all countries)	308	43.4	8.9	48.7%	18.2%	84	27.3%	5.8%
Female (all countries)	727	44.1	10.1	58.6%	17.7%	104	14.3%	9.4%
Prefer not to say (FR 3, SE 1, USA 1)	5	42.5	6.5	60.0%	0.0%	0	0.0%	40.0%
	1040					188		