

MS BAROMETER 2015

Raising the voice of people with MS

Reality check

Health inequalities

Data collection

Access to
treatment and
therapies

Advocacy

Employment



parlamentarium

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EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

About EMSP

The European Multiple Sclerosis Platform (EMSP) represents more than 700,000 people living with multiple sclerosis (MS) in Europe. Their needs are the main focus of EMSP's advocacy and awareness-raising campaigns.

EMSP aims to improve quality of life as well as access to treatment, care and employment for people with MS. En route to its ultimate vision of a world without multiple sclerosis, EMSP works to ensure that people with MS have a real voice in determining their own priorities.

EMSP was founded in 1989 and, over the years, has gained the support of 40 national MS member societies from 35 European countries.

Multiple sclerosis

Multiple sclerosis is a complex, neurological condition and no two people are affected in the same way. Symptoms range from fatigue and depression to severe mobility problems and blindness in extreme cases. Most people are diagnosed between the ages of 20 and 40, and for half of them unemployment follows, on average, three years after.

There is currently no cure for multiple sclerosis, but the condition can be managed through specialised help, starting with early diagnosis and continuing with person-centred therapies and appropriate medication. However, there is tremendous variation in access to optimal treatment and care across Europe.

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Introduction

The MS Barometer is a comparative survey based on key MS data collected by the national MS societies. First launched in 2008, the MS Barometer raises awareness on the geographical divide that underpins the difference in MS management across Europe. It also serves as a benchmarking tool outlining improvements and actions that can be adopted by national MS societies in order to influence the decision-makers. The MS Barometer targets healthcare stakeholders at all levels, including MS patients; healthcare professionals; governmental institutions; insurers and other payers; politicians and financial supporters.

As shown in previous years, disease management varies considerably from one country to another. The Barometer provides an overview of the weaknesses and challenges to be addressed in each country covered. It enables EMSP as well as individual MS societies to actively engage with the relevant stakeholders and work together to improve the quality of life of people with MS.

Now marking its fifth edition, the MS Barometer has built a strong track-record in supporting MS advocacy at both European and national level. Some of the highlight events featuring MS Barometer outputs include roundtable debates held in national Parliaments and also in the European Parliament.

How does the MS Barometer work?

The MS Barometer is a questionnaire with points scored based on the responses. The goal is for each national administration to score maximum points through the implementation of effective policies which optimise the situation for people with MS. The higher the score, the better the disease management, level of support and quality of life of people with MS.

The questionnaire is structured around the priority policy areas defined in EMSP's [Code of Good Practice](#).

1. Access to healthcare:

- 1.1 Access to treatments
- 1.2 Access to new medication accessing the market
- 1.3 Access to therapies
- 1.4 Access to health workforce (include MS carers)

2. MS Research and data collection system:

2.1 MS Research

2.2 Data collection

3. Participation in society of people with MS:

3.1 Support and education for young people

3.2 Employment

3.3 Financial independence of people with MS

4. Empowerment of people with MS:

4.1 Individual empowerment

4.2 Organisational empowerment

Key findings

The MS Barometer found both scope and potential for improvement in four key MS management areas:

1. Access to treatment and care
2. Research and data collection
3. Employment for young people
4. Patient empowerment

1) The MS Barometer reveals an urgent need to improve access to early diagnosis, personalised treatment and multidisciplinary care. These goals can be met through increasing the number of healthcare professionals (HCPs) specialised in multiple sclerosis (such as nurses and neurologists), encouraging sustained collaboration between HCPs, ensuring equity access to and systematic evaluation of innovative medical technologies (from diagnosis devices to therapies), and providing support for carers.

2) EMSP's Barometer also highlights the need for more public funding to boost MS research and data collection. As best practice from a number of European countries has shown, MS societies can play a leading role in creating and fostering multi-stakeholder partnerships that can fuel research and data collection projects. Long-term support for emerging national MS registries should be a priority, as well as finding the right treatment and care for the paediatric and progressive forms of MS.

3) The MS Barometer sheds light on the need to enable young people with multiple sclerosis to complete their studies, steer clear of social isolation and achieve good quality employment. On the road to reaching these objectives young people with MS should be supported to access the job market through traineeship schemes and helped stay in work through education programmes aimed at employers.

4) EMSP's Barometer also identifies the need for MS societies to step up engagement in local and national-decision making in order to influence policies on key topics such as reimbursement. This can be done by upholding the concept of patient-centeredness in a two-step approach: first, ensuring a permanent and significant presence of patient advocates on the boards of MS societies; and second, using the patient 'mandate' to create and maintain advisory bodies with representatives of Government and health authorities.

28 countries participated in the MS Barometer 2015, representing more than 500,000 people affected with MS.

Countries	Estimated number of people with MS
Austria	11,400
Belgium	12,000
Bosnia and Herzegovina	2,340
Bulgaria	4,250
Croatia	4,000
Denmark	12,827
Estonia	1,107
Finland	7,000
France	60,000
Germany	130,000
Greece	7,000
Hungary	20,000
Iceland	430
Ireland	7,000
Italy	68,000
Lithuania	2,621
Malta	300
Moldova	1,000
Norway	8,000
Poland	60,000
Portugal	6,500
Romania	6,000
Russia	150,000
Serbia	5,000
Spain	46,000
Sweden	17,485
Switzerland	12,500
United Kingdom	100,000

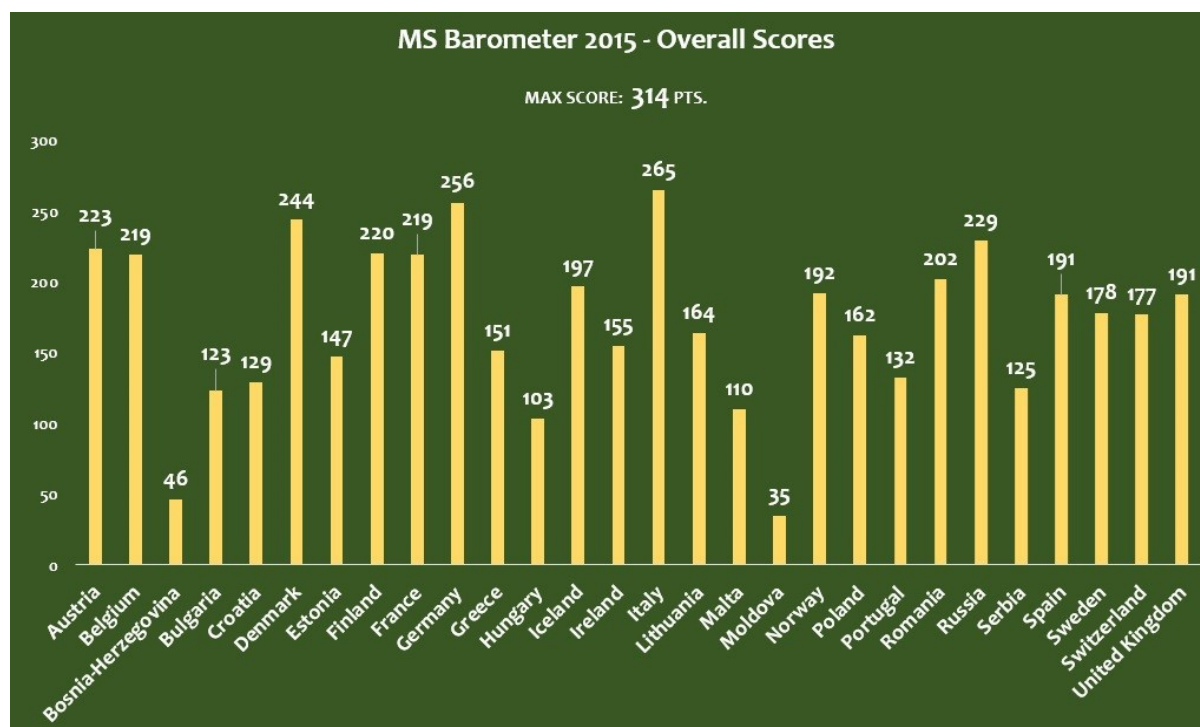
What is the estimated number of cases of paediatric MS diagnosed in your country?

“Paediatric MS” includes children and adolescents up to 18 years old.

Countries	Estimated number of cases of Paediatric MS
Austria	+15/20 per year
Belgium	240
Bosnia and Herzegovina	40
Bulgaria	<425
Croatia	-
Denmark	41
Estonia	-
Finland	150
France	700
Germany	390/1,300
Greece	700
Hungary	-
Iceland	5
Ireland	-
Italy	8,000/9,000
Lithuania	13
Malta	<10
Moldova	30/40
Norway	-
Poland	1
Portugal	500
Romania	30
Russia	4,500
Serbia	50
Spain	1,380/2,300
Sweden	35
Switzerland	-
United Kingdom	4,000

What percentage of your country's gross domestic product (GDP) was spent on healthcare in 2014?

Countries	Annual GDP % in Healthcare
Austria	11,1%
Belgium	10,2%
Bosnia and Herzegovina	-
Bulgaria	-
Croatia	7,80%
Denmark	10,4%
Estonia	5,2%
Finland	8,6%
France	12%
Germany	11,5%
Greece	<3%
Hungary	3,90%
Iceland	7,2%
Ireland	8,90%
Italy	7,2%
Lithuania	<6%
Malta	-
Moldova	3-4%
Norway	9,2%
Poland	6,7%
Portugal	9%
Romania	4%
Russia	3,6%
Serbia	3-6%
Spain	8,40%
Sweden	-
Switzerland	11%
United Kingdom	8,5%



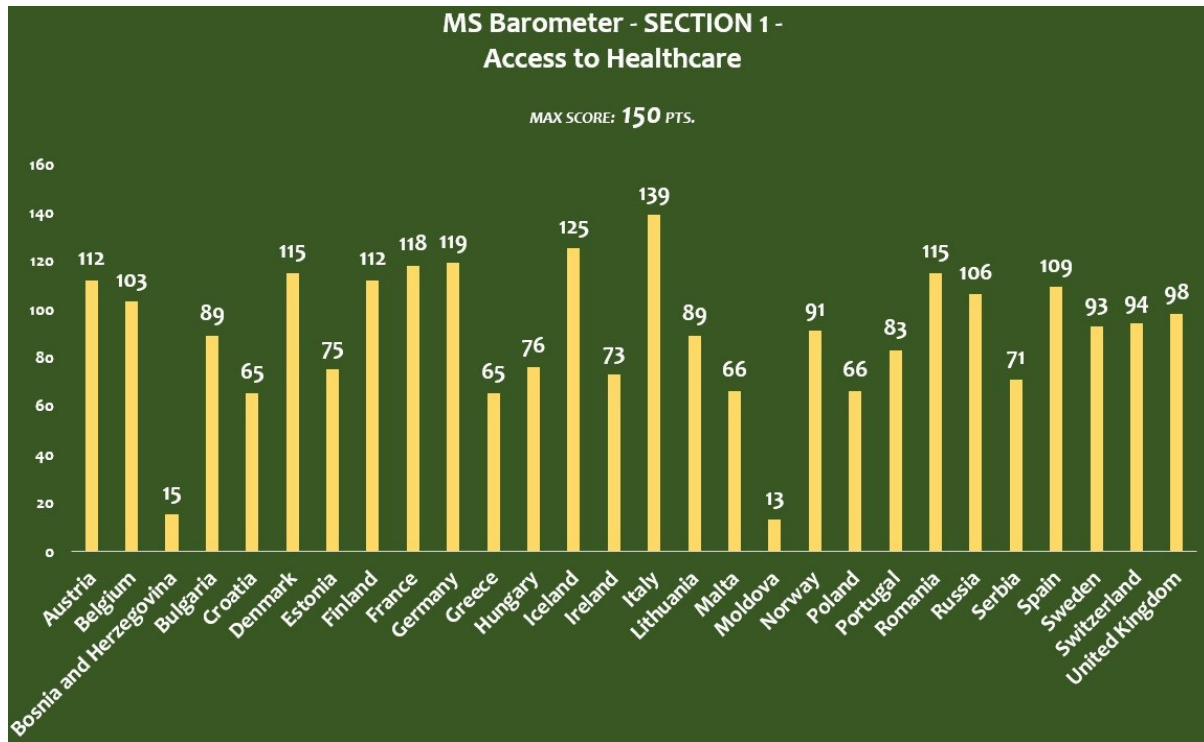
Compared to the 2013 MS Barometer findings, the huge discrepancies in MS management between Western and Eastern European countries have been found to broadly persist (see the overall scores of Moldova and Bosnia-Herzegovina against those of Italy and Germany).

These figures must be interpreted taking into consideration that not all participating countries answered all the questions in this survey due to missing data. This explains why the United Kingdom scores lower in the overall scores. The final scores were built by adding the separate scores linked to each questions.

It is also worth pointing out that the overall scores attributed to the various countries have in most cases experienced a more or less contained decrease of the number of patients with MS, except for Poland and Switzerland, which reported respectively an increase of 33% and 25% from the 2013 values.

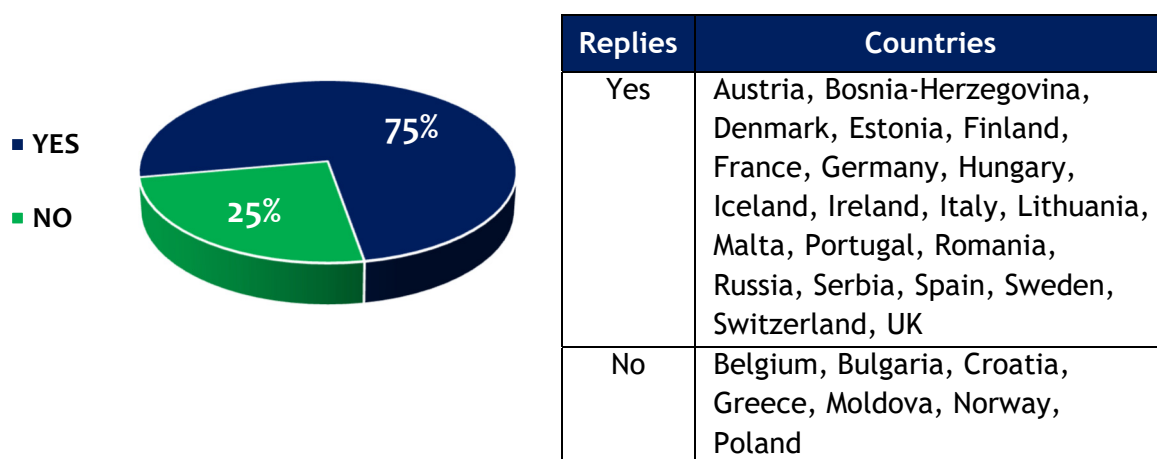
Section 1

Access to Healthcare



A) ACCESS TO TREATMENTS

- 1.1) Are there recent/updated standard guidelines used in your country to treat people diagnosed with MS (e.g. EMSP Consensus Paper “[Basic and escalating immuno-modulatory therapies in MS](#)”)?



- ❖ *The number of Western countries reporting positive results is double than the corresponding Eastern countries.*

1.2) What percentage of the total population of people with MS has received DMD treatment* in your country?

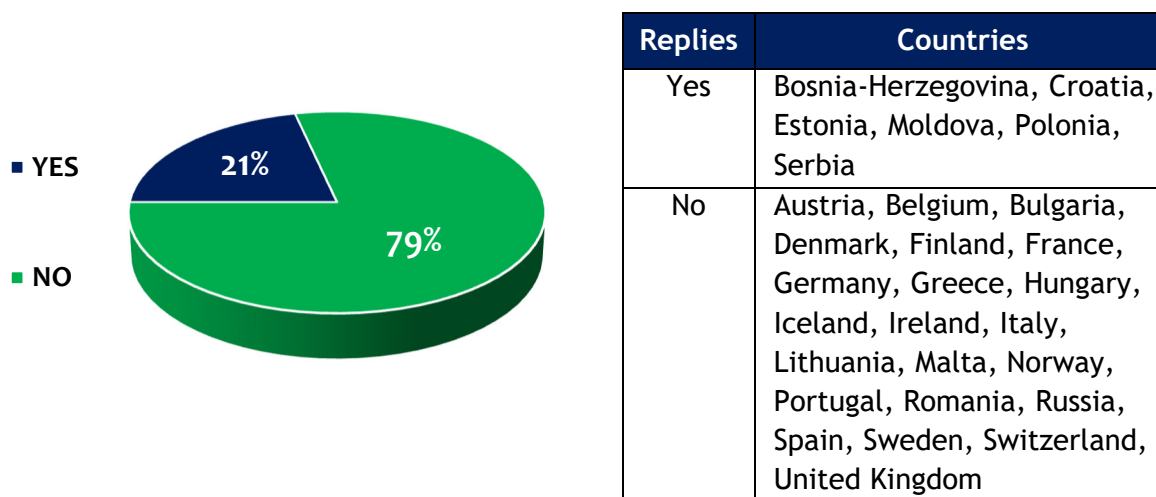
*DMD treatments include: Avonex, Aubagio, Betaferon, Copaxone, Extavia, Gyleneia, Lemtrada, Mitoxantrone (Novantrone), Rebif, Tecfidera, Tysabri.

Countries	% of population who received DMD treatment
Austria	80%
Belgium	70%
Bosnia and Herzegovina	10%
Bulgaria	30%
Croatia	35%
Denmark	44%
Estonia	50%
Finland	50%
France	70%
Germany	60%
Greece	65%
Hungary	30%
Iceland	100%
Ireland	44%
Italy	65%
Lithuania	60%
Malta	100%
Moldova	3%
Norway	45%
Poland	15%
Portugal	70%
Romania	75%
Russia	40%
Serbia	10%
Spain	65%
Sweden	80%
Switzerland	80%
United Kingdom	40%

- ❖ *Compared to 2013, Romania and Sweden have reported some very consistent improvements, while Germany and Greece have now stated some slight decreases in their percentage levels.*

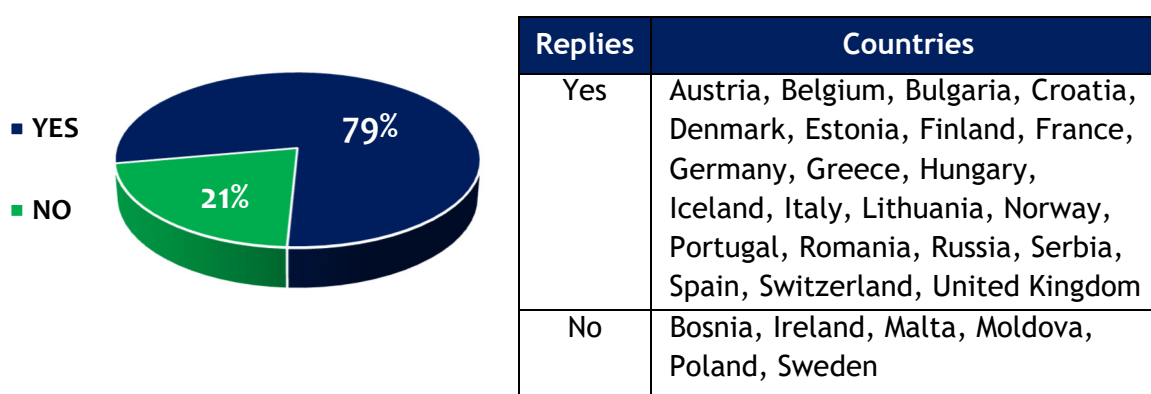
- ❖ A 30/70 ratio in favour of the Western countries is the reported outcome on this topic.

1.3) Is there a limit to the number of people with MS eligible to receive DMD treatment?



- ❖ Ireland and Romania have now joined the group of countries which are not bound by any sort of limitation in this regard.
- ❖ In Western Europe, all the surveyed countries reported positive replies, while among the Eastern European participants half experienced limitations.

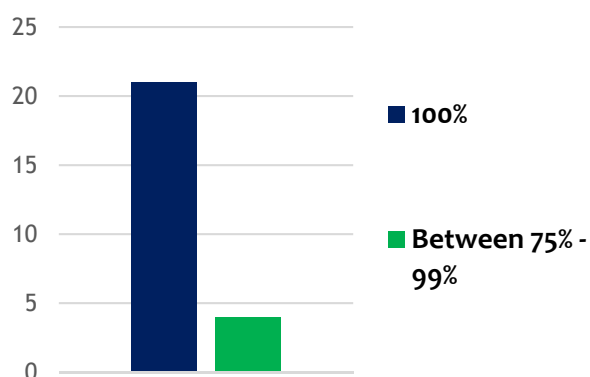
1.4) In your country, is the duration of DMD treatment restricted as a result of limited funding or reimbursement policies (i.e. for reasons other than medical factors)?



- ❖ Sweden has reported more negative outcomes than those attested in 2013.

1.5) On average, what percentage of disease-modifying drugs costs is reimbursed?

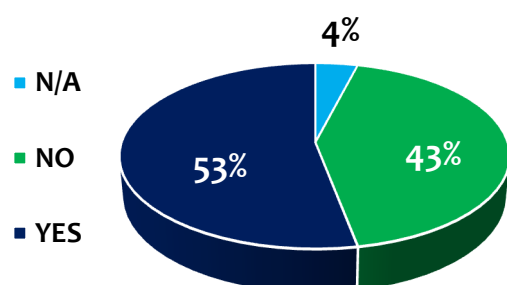
DMD treatments include: Avonex, Aubagio, Betaferon, Copaxone, Extavia, Gylenia, Lemtrada, Mitoxantrone (Novantrone), Rebif, Tecfidera, Tysabri.



Replies	Countries
100%	Austria, Bulgaria, Croatia, Denmark, Estonia, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Lithuania, Malta, Norway, Poland, Portugal, Romania, Serbia, Spain, UK
Between 75% - 99%	Belgium, Finland, Russia, Switzerland

- ❖ *Bosnia and Herzegovina, Moldova and Sweden did not provide any reply to this question.*
- ❖ *The Eastern countries perform better than the Western ones, having only one of their representatives outside of the 100% reimbursement cluster, to which it must be added almost 20% of Western countries.*

1.6) Has the country been involved in research regarding neuroprotective, and especially regenerative treatments, such as stem cells therapies?



Replies	Countries
Yes	Austria, Denmark, France, Greece, Italy, Poland, Russia, Serbia, Spain, Sweden, Switzerland, United Kingdom
No	Belgium, Bosnia-Herzegovina, Croatia, Estonia, Finland, Germany, Hungary, Iceland, Ireland, Lithuania, Malta, Moldova, Norway, Portugal, Romania

- ❖ *Bulgaria did not provide a reply to this question.*
- ❖ *The number of Western countries reporting positive results is double than the Eastern counterparts.*

1.7) If yes, what percentage of the costs are covered?

Countries	Covered Costs (%)
Denmark	100%
France	100%
Greece	40%
Italy	100%
Poland	100%
Spain	100%
Switzerland	90%
United Kingdom	100%

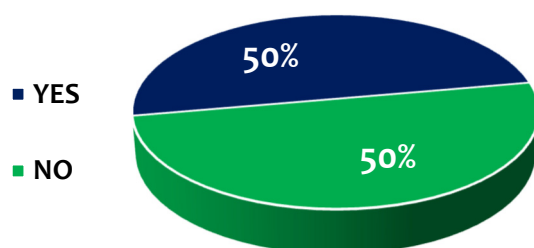
- ❖ *The percentage of coverage shows significant inequalities between Western countries (with an average value of 100% coverage) and Eastern countries (oscillating from 40% to 100% coverage levels).*

1.8) If no, are there political or medical reasons?

Countries	Political/Medical Reasons for unavailability of reimbursement
Belgium	Yes
Bosnia and Herzegovina	Yes
Bulgaria	Yes
Croatia	Yes
Germany	Yes
Hungary	Yes
Iceland	Yes
Ireland	Yes
Moldova	Yes
Norway	Yes
Romania	Yes
United Kingdom	Yes

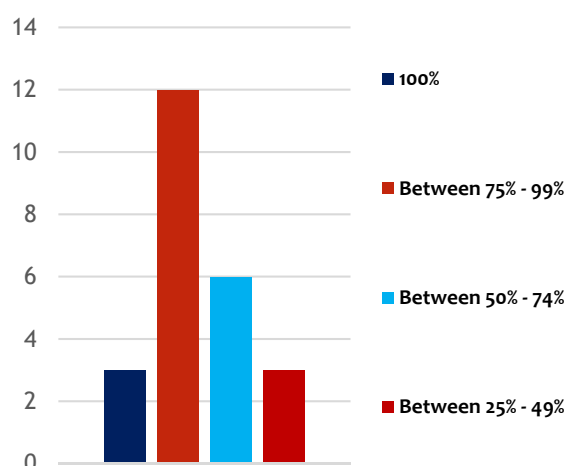
❖ *The number of Western countries reporting positive results is almost three times higher than the corresponding Eastern ones.*

1.9) Are there recent/updated standard guidelines on symptomatic treatment of MS used in your country to treat people diagnosed with MS (e.g. EMSP consensus paper III “Symptomatic Treatment of MS”)?



Replies	Countries
Yes	Austria, Denmark, Estonia, Finland, France, Germany, Hungary, Iceland, Italy, Portugal, Romania, Russia, Sweden, United Kingdom
No	Belgium, Bosnia-Herzegovina, Bulgaria, Croatia, Greece, Ireland, Lithuania, Malta, Moldova, Norway, Poland, Serbia, Spain, Switzerland

1.10) What percentage of the population of people with MS has received symptomatic treatment in your country in the past 12 months?

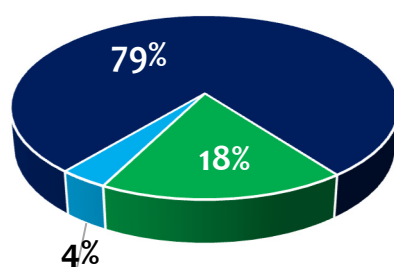


Replies	Countries
100%	Bulgaria, Finland, Iceland
Between 75% - 99%	Austria, Belgium, Denmark, Estonia, France, Ireland, Italy, Lithuania, Poland, Portugal, Russia, Switzerland
Between 50% - 74%	Germany, Greece, Hungary, Moldova, Norway, Spain
Between 25% - 49%	Croatia, Romania, Serbia

- ❖ While Serbia aligned to the Consensus Paper's guidelines, Belgium, Croatia, Greece and Norway have now reported a more negative feedback than in the past. Moreover, Bosnia and Herzegovina, Malta, Sweden and United Kingdom did not provide any reply on this matter.

1.11) Is there a limit to the duration of symptomatic treatment available other than for medical reasons?

■ NO
■ YES
■ N/A

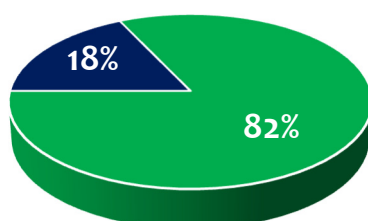


Replies	Countries
Yes	Bosnia-Herzegovina, Greece, Hungary, Lithuania, Moldova
No	Austria, Belgium, Bulgaria, Croatia, Denmark, Estonia, Finland, France, Germany, Iceland, Ireland, Italy, Malta, Norway, Poland, Portugal, Romania, Russia, Serbia, Spain, Sweden, Switzerland, United Kingdom

- ❖ *Greece reported more negative outcomes than in 2013.*
- ❖ *Bulgaria did not provide any reply on this matter.*
- ❖ *Almost half of the Eastern countries incur in limitations, while in Western Europe the surveyed countries reported an almost fully positive set of outcomes.*

1.12) Is there a limit to the number of people with MS entitled to access to any symptomatic treatment?

■ YES
■ NO

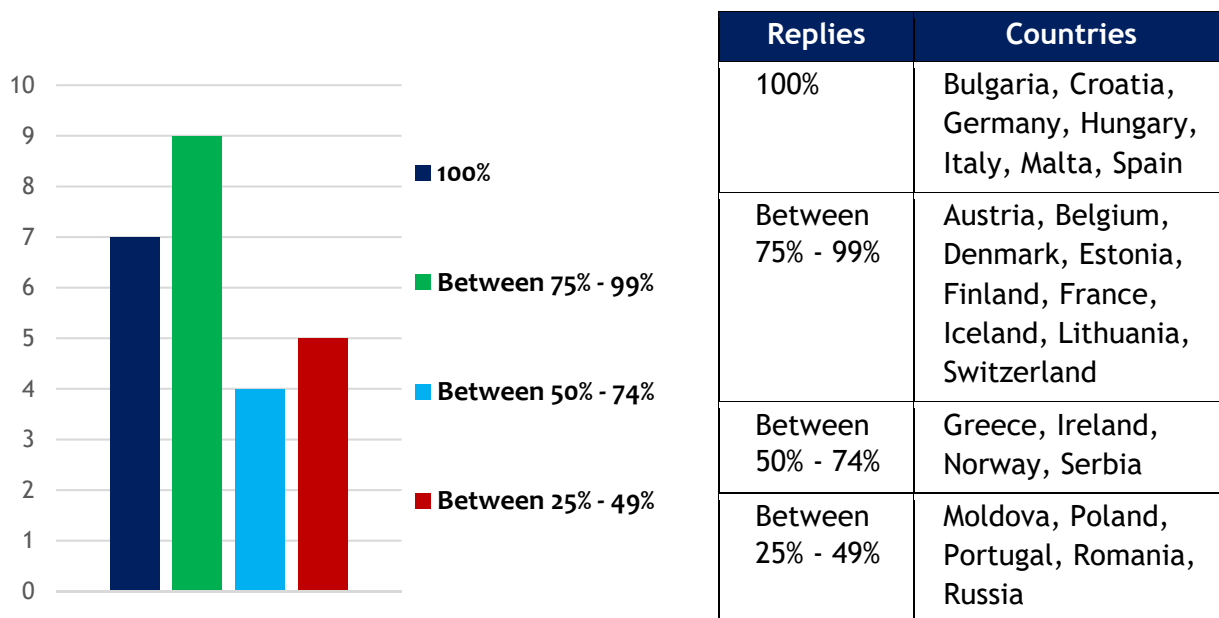


Replies	Countries
Yes	Bosnia-Herzegovina, Greece, Lithuania, Moldova, United Kingdom
No	Austria, Belgium, Croatia, Denmark, Estonia, Finland, France, Germany, Hungary, Iceland, Ireland, Italy, Malta, Norway, Poland, Portugal, Romania, Russia, Serbia, Spain, Sweden, Switzerland

- ❖ *Greece reported more negative outcomes than in 2013. At the same time, the Portuguese case experienced the exact opposite trend from 2013 to 2015.*

- ❖ While the Western countries experience no limitation at all on this topic, the Eastern ones reported an almost 50/50 ratio between positive and negative replies.

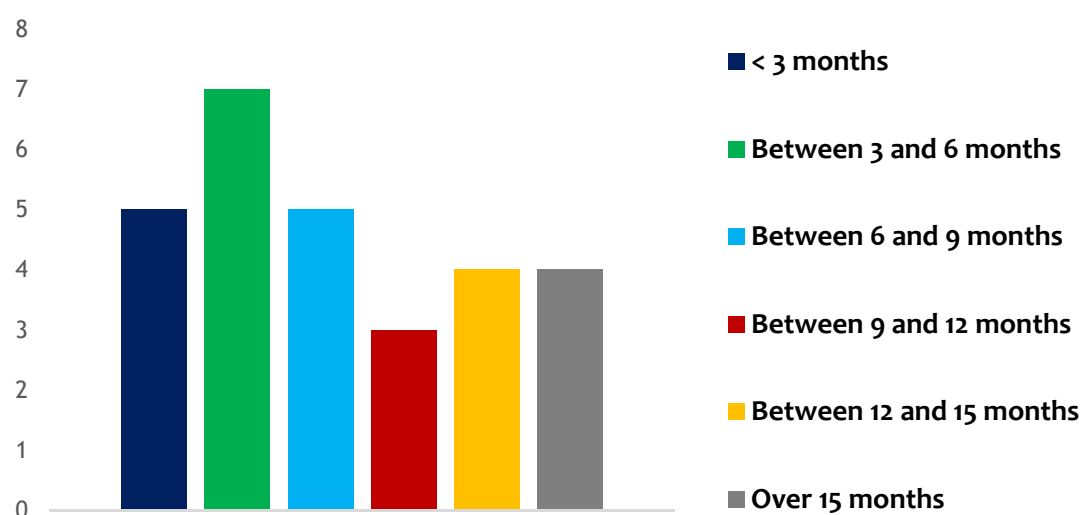
1.13) On average, what percentage of the total costs for symptomatic treatments and therapies is reimbursed on a period of 12 months?



- ❖ Improvement in 2015 of the Finnish, Italian and Spanish cases, while Ireland, Greece, Poland, Portugal and Romania have reported step backs on this matter.
- ❖ Bosnia and Herzegovina, Sweden and United Kingdom did not provide any reply on this matter.
- ❖ While the Western countries enjoy a generally high level of reimbursement, the Eastern ones reported very different national policies on this topic, varying from the highest to the lowest levels of coverage.

B) NEW MEDICATION ACCESSING THE MARKET

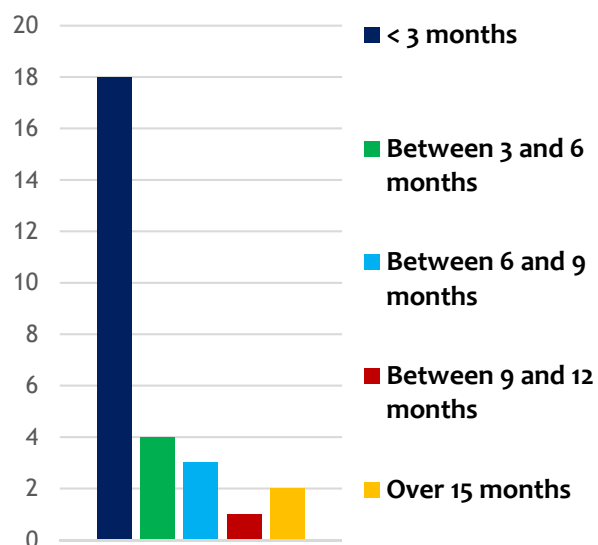
1.14) How long, on average, does it take to get a decision on drug reimbursement once it has been approved by the national drug regulatory authority or by European Medicines Agency?



Replies	Countries
< 3 months %	Bulgaria, Germany, Italy, Lithuania, Norway
Between 3 and 6 months	Croatia, Denmark, Estonia, Finland, Iceland, Sweden, Switzerland
Between 6 and 9 months	Ireland, Moldova, Russia, UK
Between 9 and 12 months	Austria, Bosnia-Herzegovina, France
Between 12 and 15 months	Belgium, Greece, Romania, Spain
Over 15 months	Hungary, Poland, Portugal, Serbia

- ❖ *Malta did not provide a reply to this question.*
- ❖ *The level of support and promptness across Europe shows a slight advantage of the Western countries over the Eastern counterparts, but the differences are not considerable.*

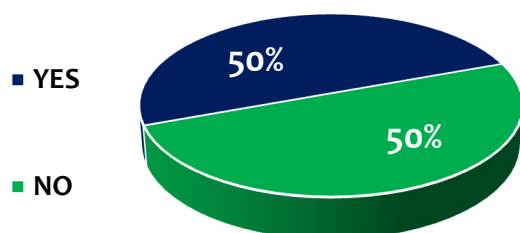
1.15) How long does it take for those people who are legally entitled to the drugs, to actually receive them?



Replies	Countries
< 3 months %	Austria, Belgium, Bulgaria, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Lithuania, Malta, Norway, Romania, Spain, Switzerland
Between 3 and 6 months	Croatia, Portugal, Russia, Sweden
Between 6 and 9 months	Denmark, Moldova, Poland
Between 9 and 12 months	United Kingdom
Over 15 months	Bosnia-Herzegovina, Serbia

- ❖ *Improvements have been reported in the Austrian, Greek, Romanian and Spanish cases, while Denmark, Portugal and Sweden have reported an increase of the time between diagnosis and treatment.*
- ❖ *The Eastern countries' performances in this area is comforting, with 50% of the countries reporting patients having access to the medicine relatively quickly.*

1.16) Is the approval of an MS drug automatically linked to its reimbursement through the Health Fund/Insurer?

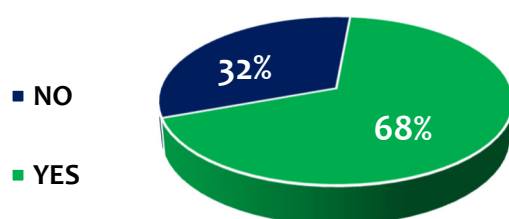


Replies	Countries
Yes	Bulgaria, Denmark, Estonia, France, Germany, Greece, Hungary, Iceland, Italy, Lithuania, Norway, Portugal, Romania, Sweden
No	Austria, Belgium, Bosnia-Herzegovina, Croatia, Finland, Ireland, Malta, Moldova, Poland, Russia, Serbia, Spain, Switzerland, United Kingdom

❖ *Improved outcomes in the Danish, Italian, Romanian and Swedish cases. Spain performs worse than in the past.*

C) ACCESS TO THERAPIES

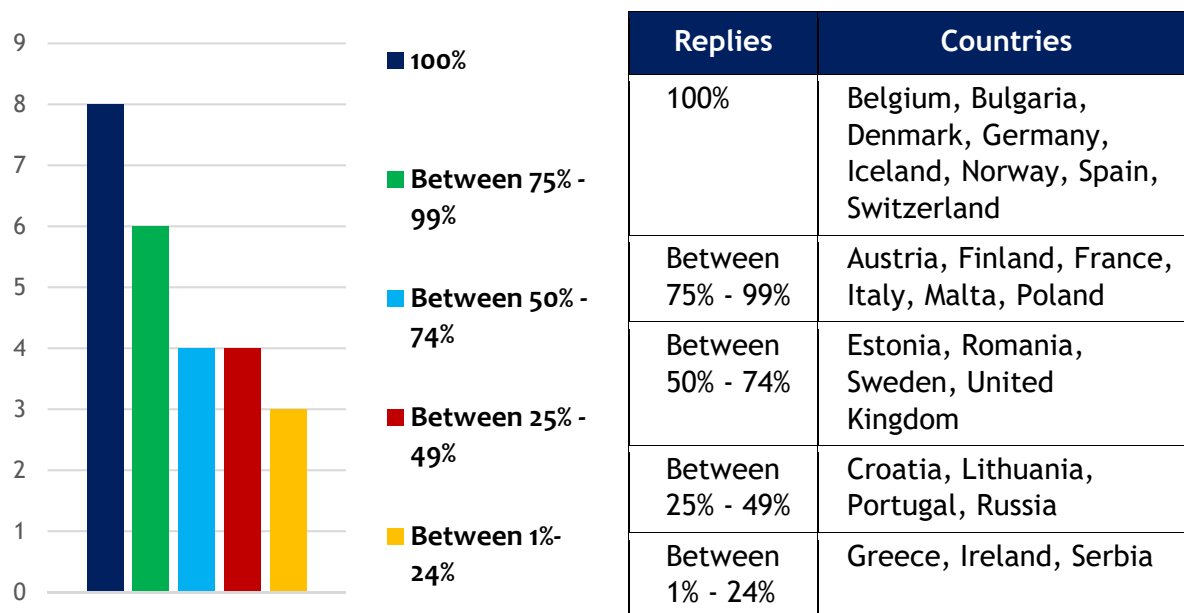
1.17) Can people diagnosed with MS in your country undergo specific rehabilitation measures for MS according to the recommendations outlined in the EMSP consensus paper “European-wide Recommendations on Rehabilitation for People affected by MS”?



Replies	Countries
Yes	Austria, Belgium, Bulgaria, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Lithuania, Norway, Romania, Russia, Serbia, Spain, Sweden, Switzerland, United Kingdom
No	Bosnia-Herzegovina, Croatia, Estonia, Greece, Hungary, Malta, Moldova, Poland, Portugal

❖ *The Eastern countries reported a nearly 50/50 ratio of replies, with a slight prevalence of negative outcomes, while the Western countries perform positively in the vast majority of cases.*

1.18) What percentage of the total population of people with MS in your country has access to a rehabilitation centres/clinics?



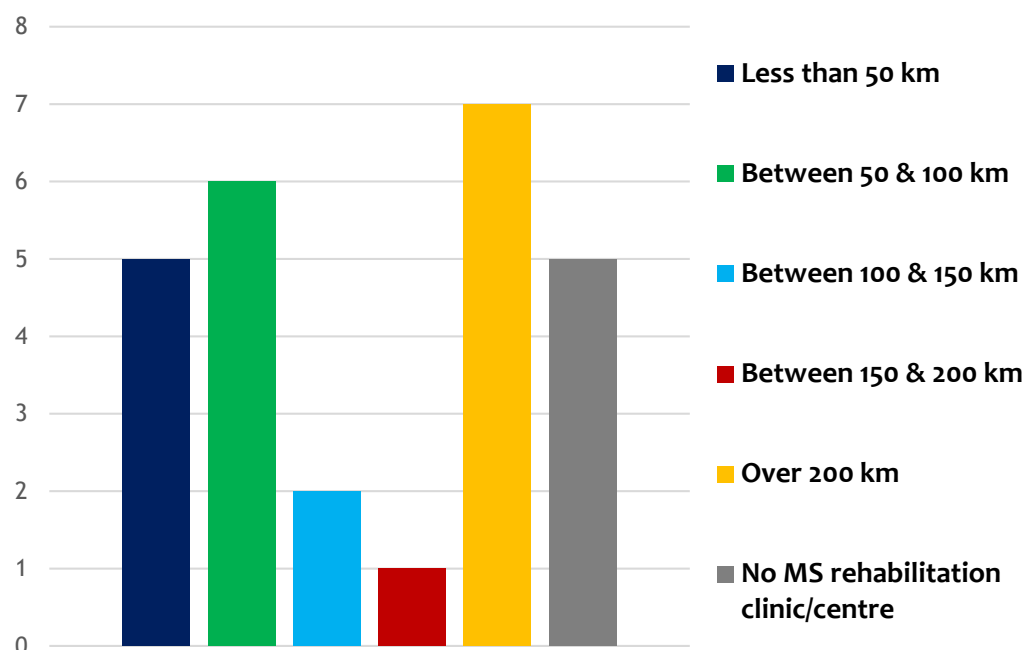
- ❖ *Enhanced outcomes were reported by Italy, Poland, Romania and Spain, while Croatia has reported a considerable reduction of its previous values.*
- ❖ *The percentage rates attested in the Western countries on this matter are sensibly higher than those reported by the Eastern ones.*

1.19) What is the estimated number of MS rehabilitation clinics/centres in your country?

Countries	Rehab Clinics/Centres
Austria	30
Belgium	12
Bosnia and Herzegovina	0
Bulgaria	0
Croatia	9
Denmark	2
Estonia	0
Finland	12
France	30
Germany	18
Greece	0
Hungary	30
Iceland	6
Ireland	0
Italy	300
Lithuania	15
Malta	0
Moldova	0
Norway	16
Poland	2
Portugal	0
Romania	8
Russia	47
Serbia	11
Spain	65
Sweden	12
Switzerland	7

- ❖ *United Kingdom did not answer this question.*
- ❖ *The Western countries indicated an amount of clinics/centres almost three times higher than that reported by the Eastern ones.*

1.20) What is the greatest geographic distance between a specialised MS rehabilitation clinic/centre and a person with MS? If no rehabilitation clinic/centre exists in your country, please make the calculation using the nearest available centre/private practices where people with MS can be treated?

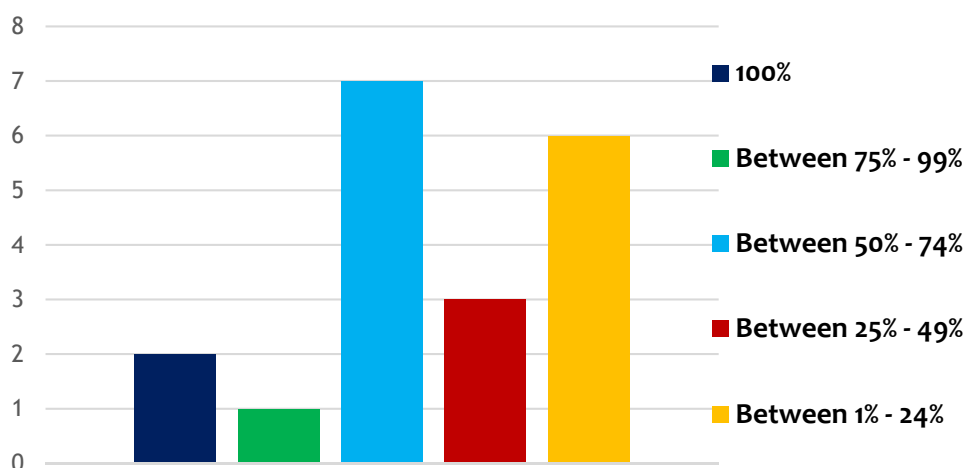


Replies	Countries
Less than 50 km	Bulgaria, Germany, Lithuania, Romania, Spain
Between 50 & 100 km	Austria, Belgium, France, Hungary, Italy, Switzerland
Between 100 & 150 km	Finland, Portugal
Between 150 & 200 km	Denmark
Over 200 km	Croatia, Estonia, Iceland, Norway, Poland, Russia, Serbia, Sweden
No MS rehabilitation clinic/centre	Bosnia-Herzegovina, Greece, Ireland, Malta, Moldova

- ❖ *Improved performances have been reported by Denmark, Italy, Portugal, Romania and Switzerland, while Croatia, Iceland, Ireland and Russia are now experiencing step backs.*
- ❖ *United Kingdom did not provide any reply.*
- ❖ *Only 25% of the Eastern countries can count on a very functional set of clinics and centres, while as many as 75% of the Western ones report very positive outcomes.*

1.21) What percentage of the total population of people with MS in your country had received rehabilitation services as out-patients within the last 12 months?

“Out-patient” refers to patient who does not reside in the hospital where he is being treated.

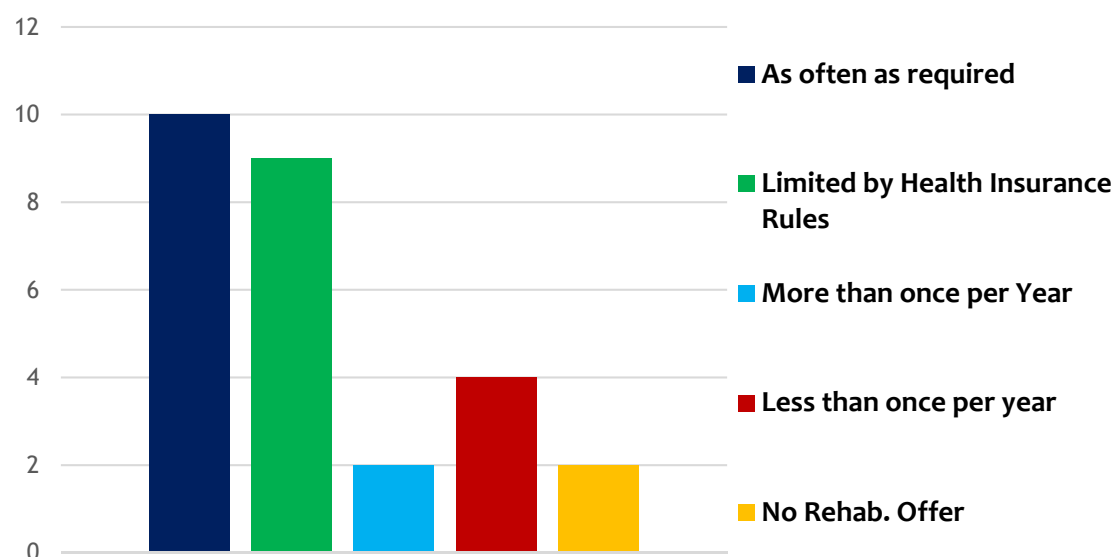


Replies	Countries
100%	Bulgaria, Iceland
Between 75% - 99%	Belgium
Between 50% - 74%	Austria, Denmark, Estonia, Finland, France, Italy, Russia
Between 25% - 49%	Lithuania, Portugal, Sweden
Between 1% - 24%	Germany, Greece, Ireland, Romania, Serbia, Spain

- ❖ *No major changes have been experienced in the last two years, except for an improvement performed by Russia.*
- ❖ *Bosnia-Herzegovina, Croatia, Hungary, Malta, Moldova, Norway, Poland, Switzerland and United Kingdom did not provide any reply to this question.*
- ❖ *The comparison between the Western and Eastern clusters of countries shows an evident disadvantage for the Eastern ones.*

1.22) If required, how often is a person with MS entitled to receive rehabilitation services as an out-patient?

“Out-patient” refers to patient who does not reside in the hospital where he is being treated.



Replies	Countries
As often as required	Denmark, Finland, France, Iceland, Italy, Malta, Norway, Romania, Spain, United Kingdom
Limited by health insurance rules	Austria, Belgium, Croatia, Estonia, Greece, Poland, Portugal, Serbia, Switzerland
More than once per year	Bulgaria, Russia
Less than once per year	Bosnia-Herzegovina, Germany, Ireland, Lithuania
No rehabilitation services as out-patients	Hungary, Moldova

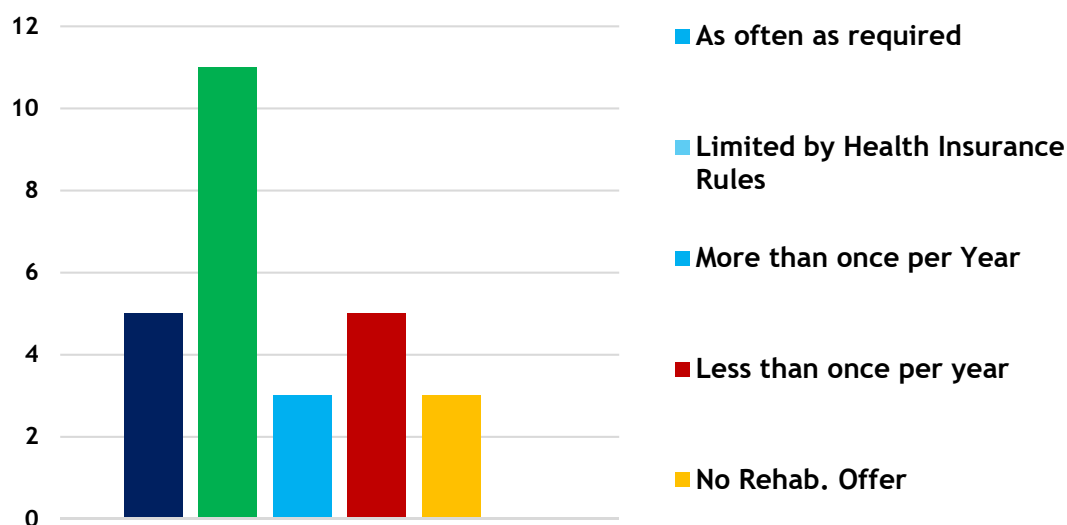
- ❖ *Improved results were reported by Croatia, Ireland, Norway, Poland, Portugal, Romania and Spain. Germany, Serbia and Switzerland have reported a considerable reduction of their previous values.*
- ❖ *Sweden did not provide any reply on this matter.*
- ❖ *The level of support on this topic is sensibly higher in the Western countries.*

1.23) What percentage of the total population of people with MS had received rehabilitation services as in-patients within the last 12 months?

Countries	% of population with MS / Rehab service as in-patient
Austria	40%
Belgium	20%
Bosnia and Herzegovina	10%
Bulgaria	100%
Croatia	45%
Denmark	7%
Estonia	30%
Finland	25%
France	30%
Germany	15%
Greece	5%
Hungary	0%
Iceland	25%
Ireland	21%
Italy	10%
Lithuania	30%
Malta	9%
Moldova	0%
Norway	0%
Poland	0%
Portugal	5%
Romania	100%
Russia	20%
Serbia	40%
Spain	5%
Sweden	0%

- ❖ *Romania and Russia reported improved outcomes, while Croatia, Denmark, Finland, Germany and Sweden experienced some step backs on this matter.*
- ❖ *Switzerland and United Kingdom did not provide an answer.*
- ❖ *The reported results from the Eastern countries display a better performing trend on this topic in comparison to the outcomes communicated by the Western countries.*

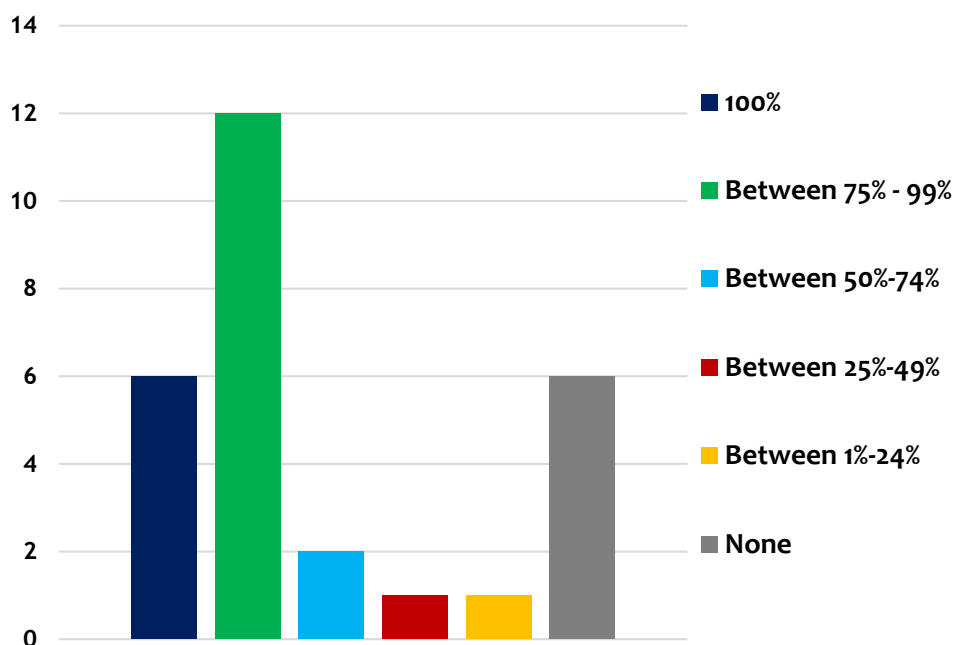
1.24) If required, how often is a person with MS entitled to receive rehabilitation services as an in-patient?



Replies	Countries
As often as required	Iceland, Italy, Malta, Romania, United Kingdom
Limited by health insurance rules	Austria, Belgium, Croatia, Estonia, Finland, Greece, Poland, Portugal, Serbia, Spain, Switzerland
More than once per year	Bulgaria, France, Russia
Less than once per year	Denmark, Germany, Ireland, Lithuania, Norway
No rehabilitation offers	Bosnia-Herzegovina, Hungary, Moldova

- ❖ Improvements have been achieved in Ireland, Poland, Portugal, Romania, Spain and UK, while Croatia, Germany, Russia and Switzerland are performing worse than in the past.
- ❖ Sweden did not provide any reply on this matter.
- ❖ The level of support on this topic is sensibly better in the Western countries.

1.25) On average, what percentage of rehabilitation costs is reimbursed?
 “Rehabilitation costs” refers to the overall expenses incurred for rehabilitation treatments and therapies for a patient (physiotherapy, occupational therapy, psychological assistance, etc.)?

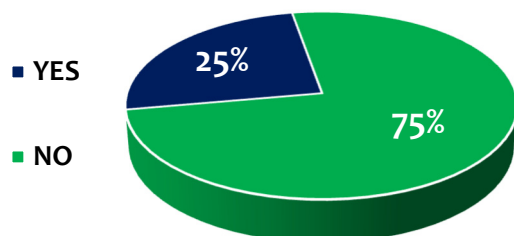


Replies	Countries
100%	Croatia, Denmark, Italy, Malta, Serbia, United Kingdom
Between 75% - 99%	Austria, Belgium, Finland, France, Germany, Iceland, Ireland, Lithuania, Norway, Romania, Russia, Switzerland
Between 50% - 74%	Poland, Spain
Between 25% - 49%	Portugal
Between 1% - 24%	Estonia
None	Bosnia-Herzegovina, Bulgaria, Greece, Hungary, Moldova, Sweden

- ❖ Considerable improvements of the Polish, Romanian, Russian, Spanish and British cases, while Germany, Ireland, Portugal, Sweden and UK have not taken any step forward.
- ❖ The records of the Eastern countries show a negative situation, with almost 50% of them not providing any kind of reimbursement, while the support given in the Western countries stands at very high level (more than 75%).

1.26) Is there a specialised palliative care programme available for people with MS in your country?

We refer to Palliative care as specialised medical care (intensive symptomatic management) for people with serious illness. It focuses on providing patients with relief from the symptoms and stress of a serious illness. The goal is to improve the quality of life of people with MS and their carers. We differentiate the specialised palliative care programme from the hospice programme care which is the “comfort care” administered when the treatment is finished and the person is considered to be terminal or to live up to 6 months.



Replies	Countries
Yes	Belgium, France, Germany, Iceland, Italy, Sweden, UK
No	Austria, Bosnia-Herzegovina, Bulgaria, Croatia, Denmark, Estonia, Finland, Greece, Hungary, Ireland, Lithuania, Malta, Moldova, Norway, Poland, Portugal, Romania, Russia, Serbia, Spain, Switzerland

- ❖ *The 2015 outcomes have highlighted the addition of France to the list of countries having specialised palliative care programmes.*
- ❖ *No Eastern countries reported positive outcomes on this. At the same time, the Western countries are in a better position, even though the lack of a specialised palliative care programme is significant.*

D) ACCESS TO HEALTH WORKFORCE (HEALTHCARE PROFESSIONALS AND CARERS)

1.27) What is the estimated number of practising neurologists in your country?

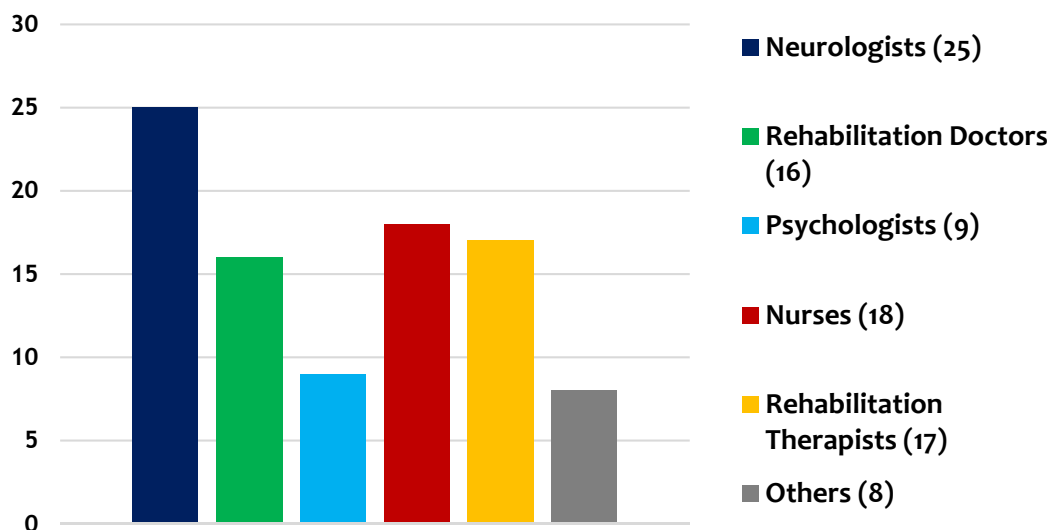
Countries	Number of practising neurologists/Country
Austria	1,000
Belgium	525
Bosnia and Herzegovina	80
Bulgaria	600
Croatia	368
Denmark	324
Estonia	100
Finland	320
France	2,300
Germany	6,095
Greece	800
Hungary	90
Iceland	17
Ireland	34
Italy	4,000
Lithuania	300
Malta	6
Moldova	0
Norway	350
Poland	5,000
Portugal	300
Romania	600
Russia	27,000
Serbia	550
Spain	1,700
Sweden	400
Switzerland	100
United Kingdom	500

❖ Overall, the Western countries reported a number of neurologists almost three times higher than that communicated by the Eastern ones.

❖ A critical situation is represented by the Moldovan case, where no neurologists seem to be actively practicing.

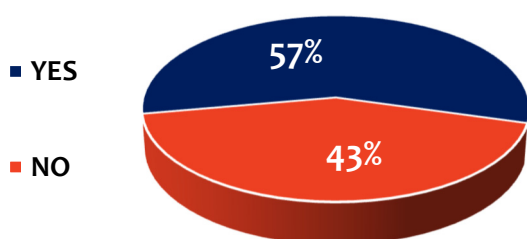
1.28) For which groups of health professionals is certified MS training available (be it within their educational/training program or after)?

Certified MS training available for:	Neurologists	Rehab. doctors	Psychologists	Nurses	Rehab. therapists	Others
Austria	X	X		X		
Belgium	X	X		X	X	X
Bosnia-Herzegovina						X
Bulgaria	X	X				
Croatia	X	X	X		X	
Denmark	X					
Estonia	X			X		
Finland				X		
France	X	X				
Germany	X	X		X	X	X
Greece	X				X	
Hungary	X	X		X	X	
Iceland	X	X	X	X	X	X
Ireland	X			X	X	X
Italy	X	X	X	X	X	
Lithuania	X			X	X	
Malta	X					
Moldova	X					
Norway	X					
Poland	X					X
Portugal	X	X		X	X	X
Romania	X	X	X	X	X	
Russia	X	X		X	X	
Serbia	X	X	X	X	X	
Spain	X	X	X	X	X	
Sweden	X	X	X	X	X	
Switzerland			X	X	X	
United Kingdom	X	X	X	X	X	X



- ❖ The 2015 outcomes have highlighted an improved service in Austria, Croatia, Germany, Ireland, Poland, Portugal, Romania, Russia, Spain and Switzerland, while some step backs were reported in Belgium and Norway.
- ❖ Overall, the Eastern countries show more negative trends than the Western ones in relation to available HCPs, though neurologists are more predominant.

1.29) Are there specialists in paediatric MS available in your country?



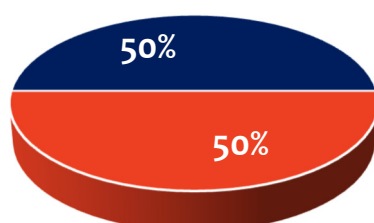
Replies	Countries
Yes	Austria, Belgium, Bulgaria, Denmark, Finland, France, Germany, Greece, Hungary, Italy, Poland, Romania, Russia, Spain, Sweden, United Kingdom
No	Bosnia-Herzegovina, Croatia, Estonia, Iceland, Ireland, Lithuania, Malta, Moldova, Norway, Portugal, Serbia, Switzerland

- ❖ While the Eastern countries showed a 50/50 ratio between positive and negative answers, the Western countries reported a more positive ratio.

1.30) Is there any initiative undertaken by healthcare professionals or the MS society to address the specific needs of people affected by paediatric MS?

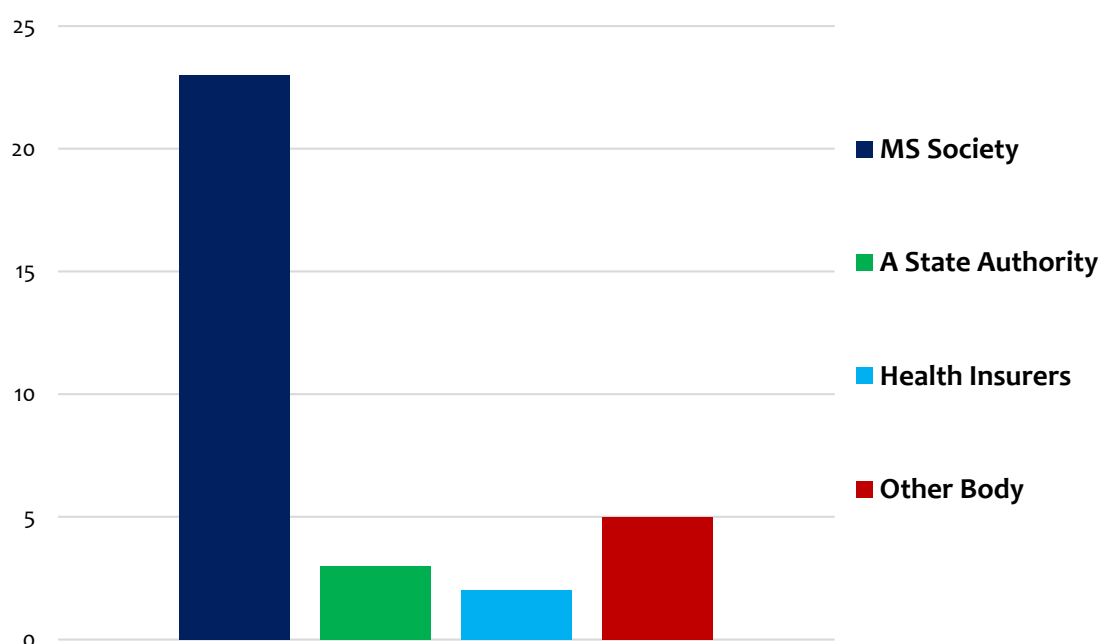
■ YES

■ NO



Replies	Countries
Yes	Bulgaria, Denmark, Finland, France, Germany, Iceland, Italy, Lithuania, Norway, Poland, Romania, Russia, Sweden, United Kingdom
No	Austria, Belgium, Bosnia-Herzegovina, Croatia, Estonia, Greece, Hungary, Ireland, Malta, Moldova, Portugal, Serbia, Spain, Switzerland

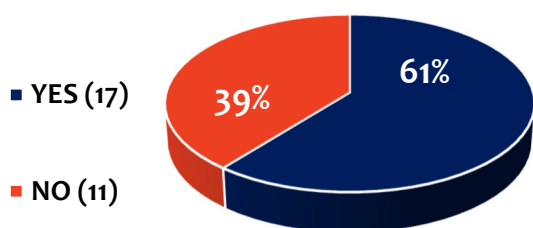
1.31) Is there an information programme for MS carers (family members, friends or professionals) in your country?



Countries	Yes, run by:				No information programme exists
	MS society (23)	A state authority (3)	Health insurers (1)	Other Body (5)	
Austria	X				
Belgium	X				
Bosnia-Herzegovina					X
Bulgaria	X				
Croatia					X
Denmark	X				
Estonia					X
Finland	X				
France	X			X	
Germany	X				
Greece	X				
Hungary					X
Iceland	X				
Ireland	X				
Italy	X	X	X	X	
Lithuania	X				
Malta	X				
Moldova	X				
Norway	X			X	
Poland	X				
Portugal	X				
Romania	X			X	
Russia	X	X		X	
Serbia					X
Spain	X	X			
Sweden	X				
Switzerland	X				
United Kingdom	X				

- ❖ *All countries gave very negative replies in almost all cases, except for the support given by the National MS Societies, which are perfectly efficient in the Western countries contrarily to the Eastern, where only the 50% of them provide such support.*

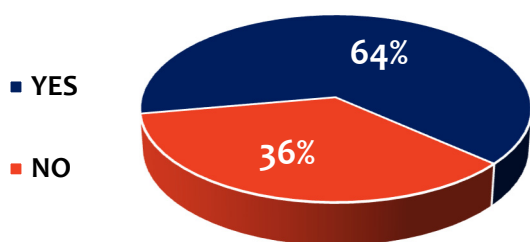
1.32) Is there a specific MS carers' network or platform available in your country?



Replies	Countries
Yes	Austria, Belgium, Denmark, Finland, Germany, Greece, Hungary, Iceland, Ireland, Italy, Lithuania, Romania, Russia, Spain, Sweden, Switzerland, United Kingdom
No	Bosnia-Herzegovina, Bulgaria, Croatia, Estonia, France, Malta, Moldova, Norway, Poland, Portugal, Serbia

- ❖ *75% of Western countries reported having such a network/ platform, while in the East more than half of the surveyed countries reported the opposite.*

1.33) Does any kind of financial support exist for carers to compensate the lack of income if they have to limit their working time due to their caring duties or drop out from the labour market?



Replies	Countries
Yes	Austria, Belgium, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Malta, Norway, Poland, Portugal, Romania, Russia, Spain, Sweden, United Kingdom
No	Bosnia-Herzegovina, Bulgaria, Croatia, Estonia, Greece, Hungary, Lithuania, Moldova, Serbia, Switzerland

- ❖ *A huge gap was displayed between Eastern countries reporting extremely negative outcomes and the Western ones displaying the exact opposite tendency.*

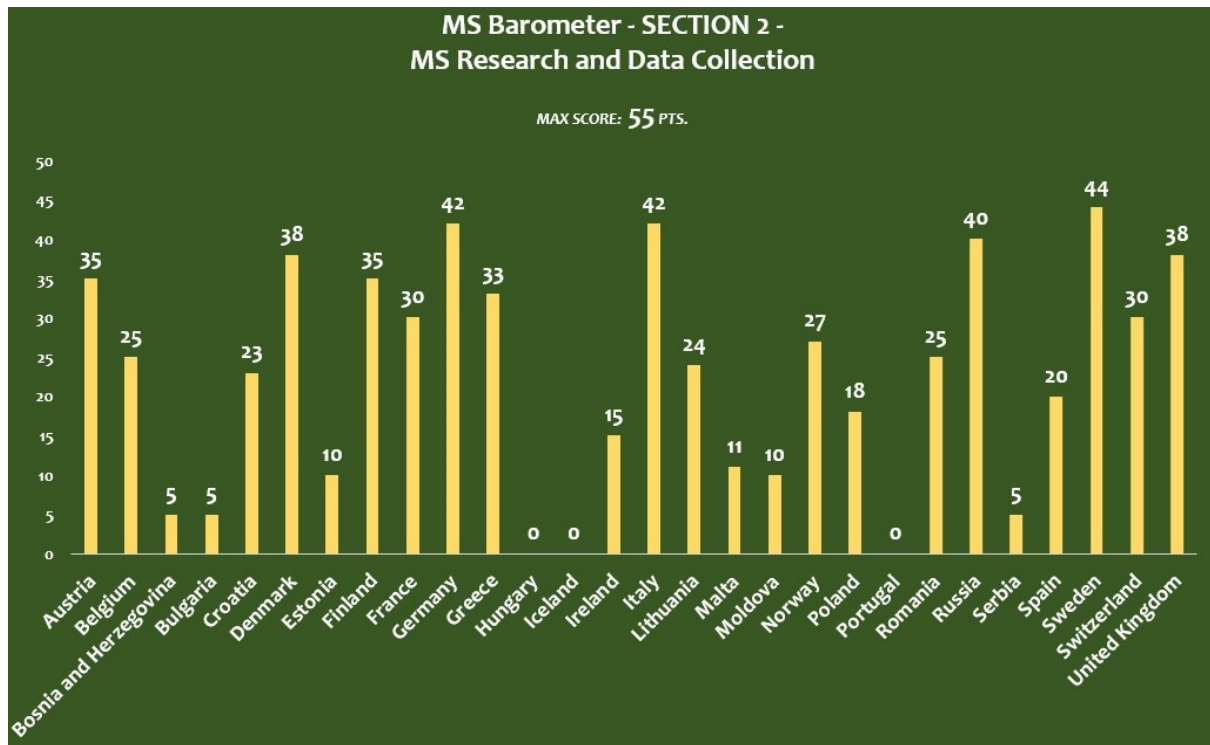
Conclusions on Section 1: access to healthcare

What can be done to improve the access to treatments and therapies for people with MS?

- ✓ Improve access to early diagnosis and access to treatment by increasing the number of available neurologists. We encourage the development of schemes to provide timely diagnostic services and improved access to treatment and therapies, according to needs.
- ✓ Further efforts are needed to make personalised treatment widely available. By increasing the numbers of healthcare professionals specialised in MS, patients will gain more time to consult with their neurologist and discuss the diagnosis, treatment and individual disease management goals.
- ✓ Health care systems across Europe need to align and use the latest agreed diagnostic criteria in order to ensure early diagnosis and disease management treatment course.
- ✓ Ensure access to the full range of disease-modifying therapies to all people affected by MS. Also ensure that MS healthcare professionals maintain treatment for as long as it proves to be efficient and monitor the disease activity progress.
- ✓ Increase efforts to ensure a coordinated multidisciplinary approach to care and continue to promote the development of specialised MS care and rehabilitation centres.
- ✓ Consolidate national tools to increase the number of specialised nurses in MS and work towards the creation of a European MS Nurse Network to improve care for all patients.
- ✓ Support the creation of information programmes and tools for MS carers (family members, friends, professionals).
- ✓ Ensure access to specialists in paediatric MS and approved treatment and therapies alongside a multidisciplinary treatment path, including care and psychological support.

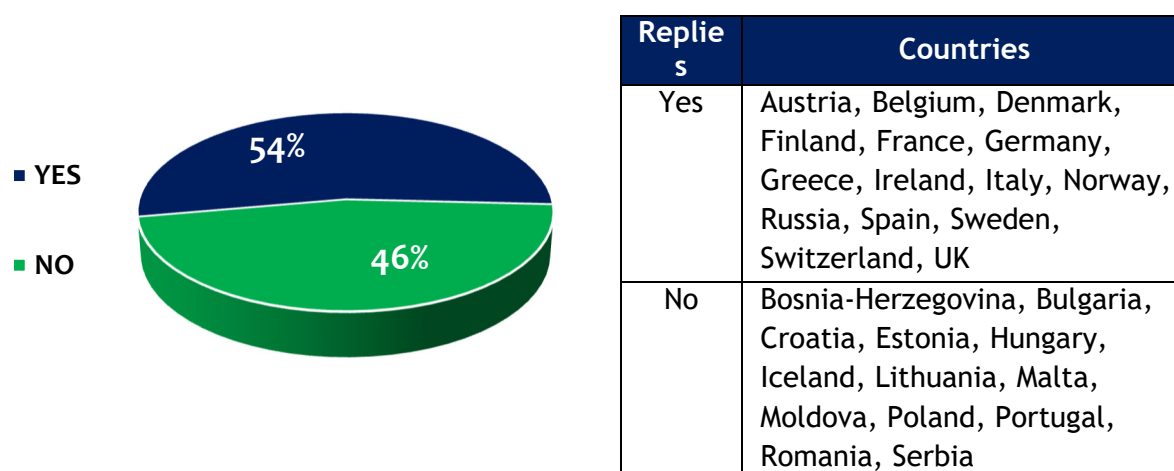
Section 2

MS Research and data collection



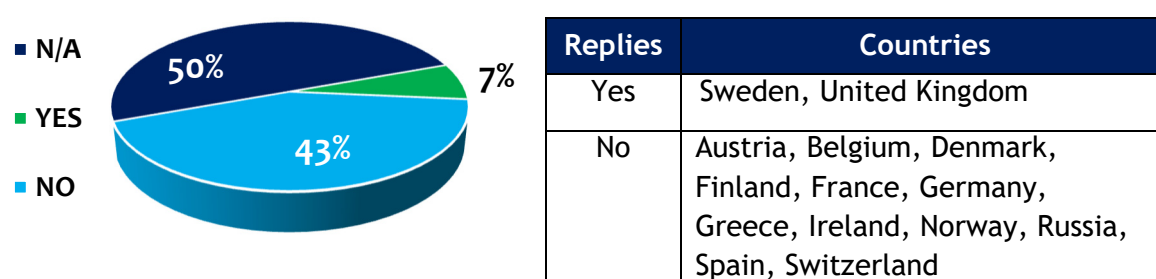
A) MS RESEARCH

2.1) Are there grants/support schemes managed financially by your MS Society which contribute to MS Research?



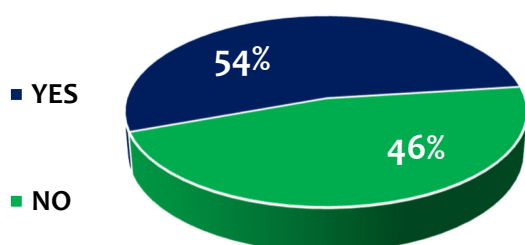
- ❖ The 2015 survey highlighted an improvement in results by both Russia and Spain.
- ❖ The Western countries have more grants and financial support available in general, while almost none of the Eastern participants do so.

2.2) Are these MS research grants/schemes supported by public funding?



- ❖ Bosnia-Herzegovina, Bulgaria, Croatia, Estonia, Hungary, Iceland, Italy, Lithuania, Malta, Moldova, Poland, Portugal, Romania and Serbia did not provide any reply on this matter.
- ❖ As a consequence of the trends reported in the previous question, only two of the Eastern countries reported the availability of limited support, while in the West the inclination in the broader majority of cases is towards some financial support.

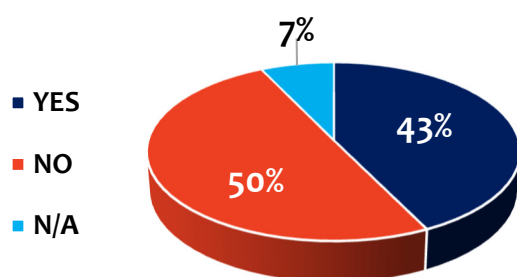
2.3) Do MS Societies have the opportunity to influence the National MS research Agenda?



Replies	Countries
Yes	Austria, Belgium, Denmark, Estonia, Finland, France, Germany, Italy, Moldova, Romania, Russia, Spain, Sweden, Switzerland, UK
No	Bosnia-Herzegovina, Bulgaria, Croatia, Greece, Hungary, Iceland, Ireland, Lithuania, Malta, Norway, Poland, Portugal, Serbia

- ❖ The 2015 survey highlighted an improvement in results by Romania, Russia, Spain and UK.
- ❖ In the East, only one third of the countries reported positively on this matter, while in the West the tendency is far more positive with two thirds of them attesting a more decisive role and power of the MS societies.

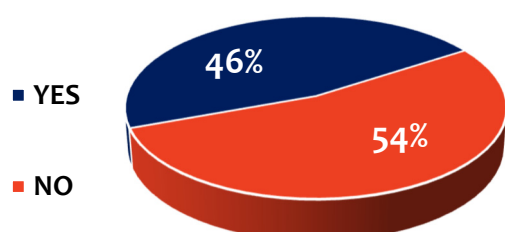
2.4) If yes, is there any initiative, research topics/projects, launched under the guidance/leadership of the MS Society?



Replies	Countries
Yes	Belgium, Denmark, Finland, Germany, Greece, Ireland, Italy, Moldova, Russia, Sweden, Switzerland, United Kingdom
No	Austria, Bosnia-Herzegovina, Croatia, Estonia, France, Hungary, Iceland, Lithuania, Malta, Norway, Poland, Portugal, Romania, Serbia,

- ❖ Bulgaria and Spain did not provide any reply on this matter.
- ❖ While the MS societies in the Western countries have a more active and decisive role, in the East of Europe the trend is not so encouraging.

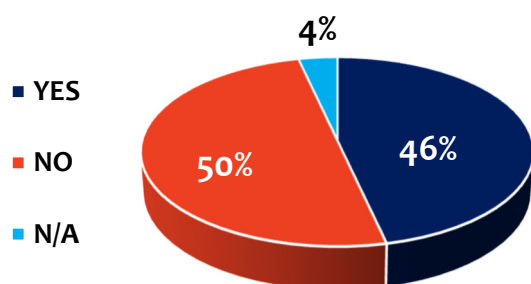
2.5) Is there any research, or ongoing or planned clinical trials for the next year addressing paediatric MS?



Replies	Countries
Yes)	Austria, Belgium, Bulgaria, Estonia, Finland, Germany, Italy, Lithuania, Poland, Romania, Russia, Serbia, Spain
No	Bosnia-Herzegovina, Croatia, Denmark, France, Greece, Hungary, Iceland, Ireland, Malta, Moldova, Norway, Portugal, Sweden, Switzerland, United Kingdom

- ❖ *Paediatric MS seems to be more central in the near future work of the Eastern countries rather than in the West. Both sides are in need for improvement and more focused work in this field.*

2.6) Is the MS Society involved in assisting the International Progressive MS Alliance?

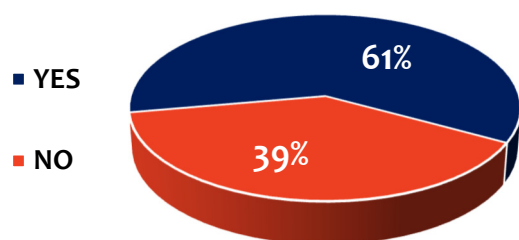


Replies	Countries
Yes	Austria, Belgium, Bosnia-Herzegovina, Denmark, France, Germany, Greece, Ireland, Italy, Lithuania, Norway, Spain, United Kingdom
No	Bulgaria, Croatia, Estonia, Finland, Hungary, Iceland, Moldova, Poland, Portugal, Romania, Russia, Serbia, Sweden, Switzerland

- ❖ *Malta did not provide any reply on this matter.*
- ❖ *Two thirds of the Eastern countries reported negative trends on this matter, while the same ratio of Western ones reported the exact opposite tendency.*

B) DATA COLLECTION ON MS AT NATIONAL LEVEL

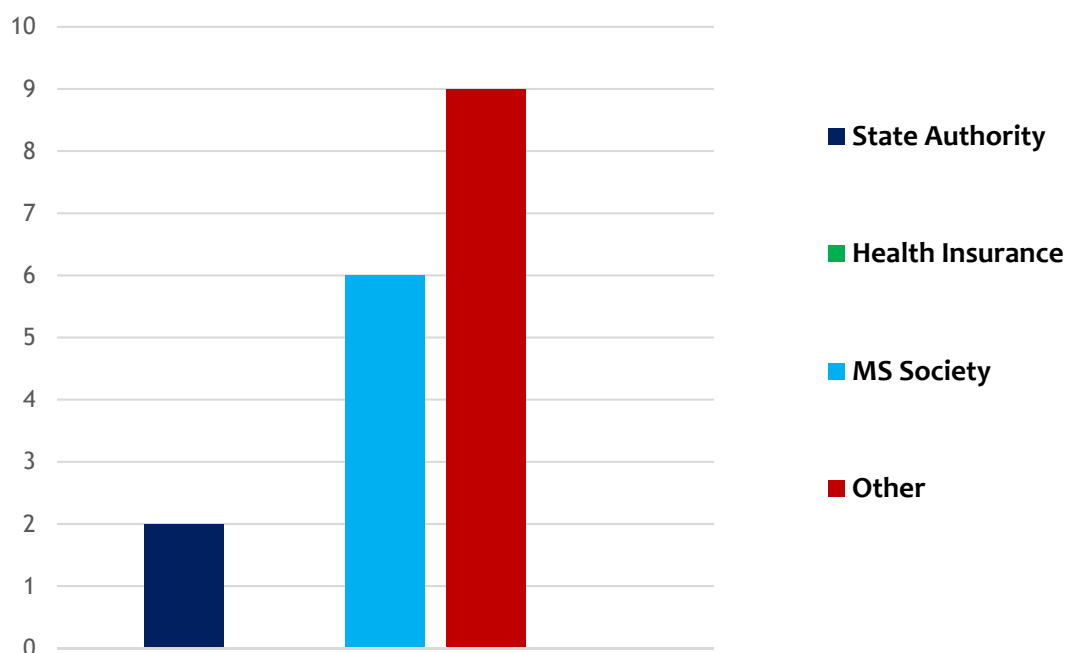
2.7) Does a National MS Register exist?



Replies	Countries
Yes	Austria, Croatia, Denmark, Finland, France, Germany, Greece, Italy, Lithuania, Malta, Norway, Poland, Romania, Russia, Sweden, Switzerland, United Kingdom
No	Belgium, Bosnia-Herzegovina, Bulgaria, Estonia, Hungary, Iceland, Ireland, Moldova, Portugal, Serbia, Spain

❖ *The number of MS registries has increased since 2013. Countries reporting new registries are: Finland, Italy, Poland, Romania and Switzerland.*

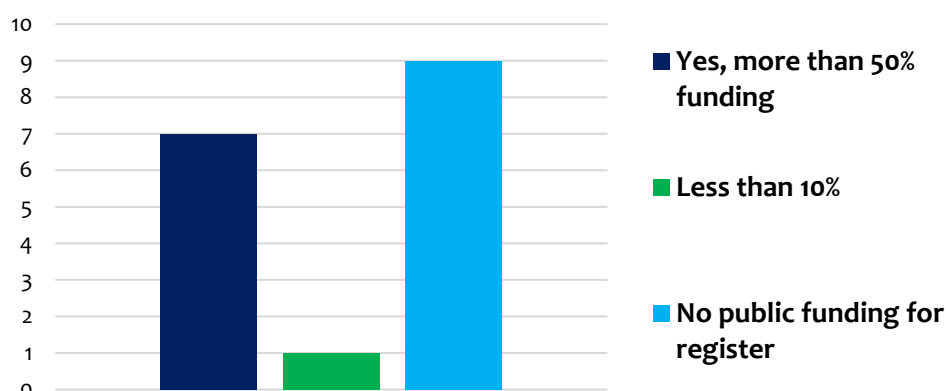
2.8) Who manages the MS register?



Replies	Countries
State Authority	Norway, Sweden
Health Insurance	-
MS Society	Croatia, Germany, Finland, Greece, Italy, Switzerland
Other	Austria, Denmark, France, Lithuania, Malta, Poland, Romania, Russia, United Kingdom

- ❖ *Belgium, Bosnia-Herzegovina, Estonia, Hungary, Iceland, Ireland, Moldova, Portugal, Serbia and Spain did not provide any reply.*
- ❖ *Of the Eastern countries benefitting from a National MS Registry, one third reported the National MS Societies as the managers of the registries. In the West the tendency is almost the same, with a slightly higher involvement from either State authorities, MS Societies or alternative bodies.*

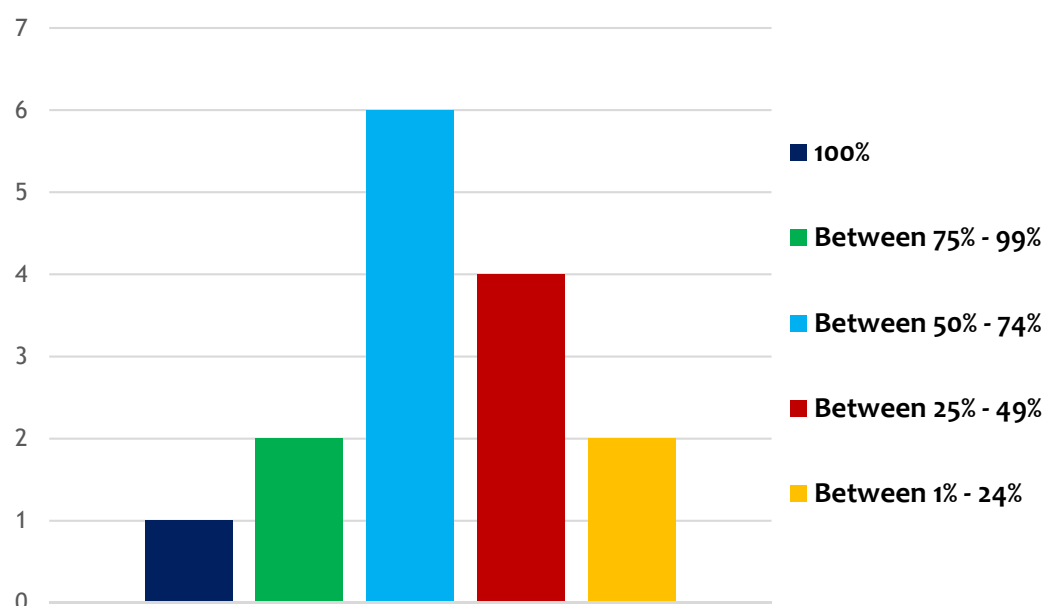
2.9) Is the register supported by public funding?



Replies	Countries
Yes, more than 50% funding	Croatia, France, Norway, Poland, Russia, Sweden, United Kingdom
Less than 10%	Denmark
No public funding for register	Austria, Finland, Germany, Greece, Italy, Lithuania, Malta, Romania, Switzerland

- ❖ *Belgium, Bosnia-Herzegovina, Estonia, Hungary, Iceland, Ireland, Moldova, Portugal, Serbia and Spain did not provide an answer.*
- ❖ *Of the Eastern countries having a National MS Registry, half reported the existence of public financial support, while in the West the ratio is slightly more negative.*

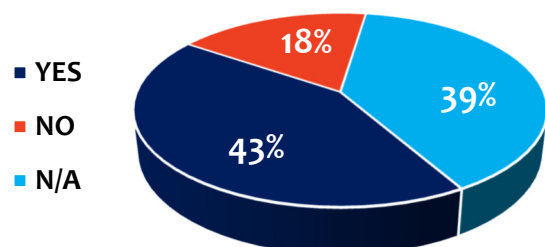
2.10) What percentage of the total population of people with MS is currently recorded in the register?



Replies	Countries
100%	Denmark
Between 75% - 99%	Malta, Sweden
Between 50% - 74%	Austria, Croatia, France, Greece, Romania, Russia
Between 25% - 49%	Germany, Italy, Lithuania, Norway,
Between 1% - 24%	Poland, United Kingdom

- ❖ *Austria, Denmark and Greece have reported an increased number of recorded patients on to the register.*
- ❖ *Of the Eastern countries benefitting from a National MS Registry, two thirds show encouraging trends, which nevertheless requires some improvements. As for the Western countries, the outcomes show a slightly less performing tendency.*

2.11) Does the information arising from the MS register have an influence on the national policy for people with MS?



Replies	Countries
Yes	Austria, Croatia, Denmark, Finland, Germany, Greece, Italy, Lithuania, Romania, Russia, Sweden, Switzerland
No	France, Malta, Norway, Poland, UK

- ❖ *The following countries did not provide an answer to the question: Belgium, Bosnia-Herzegovina, Bulgaria, Estonia, Hungary, Iceland, Ireland, Moldova, Portugal, Serbia and Spain.*
- ❖ *Croatia has reported improved incidence of the information on MS on the National policies, while Norway, Poland and UK have reported some step backs.*

Conclusions on MS research and Data collection systems

Although research in the field of MS has been active and making progress in the recent years, the Barometer shows a need for better financial support. Only 15 MS societies reported having grants contributing to MS research and among those only 2 from public funding. MS societies are playing a leading role in the initiatives for MS research in the countries where there are grants and supports.

The importance of MS societies contributing to initiate discussions and initiatives by gathering the relevant stakeholders (researchers, health policy decision makers, payers, etc.) is crucial. Good practices of MS societies being able to influence the national research agenda have been identified, with some taking the lead on new initiatives in the field of MS.

Although there is a growing interest from MS societies to be involved in the International Progressive MS Alliance, more than half are not yet involved.

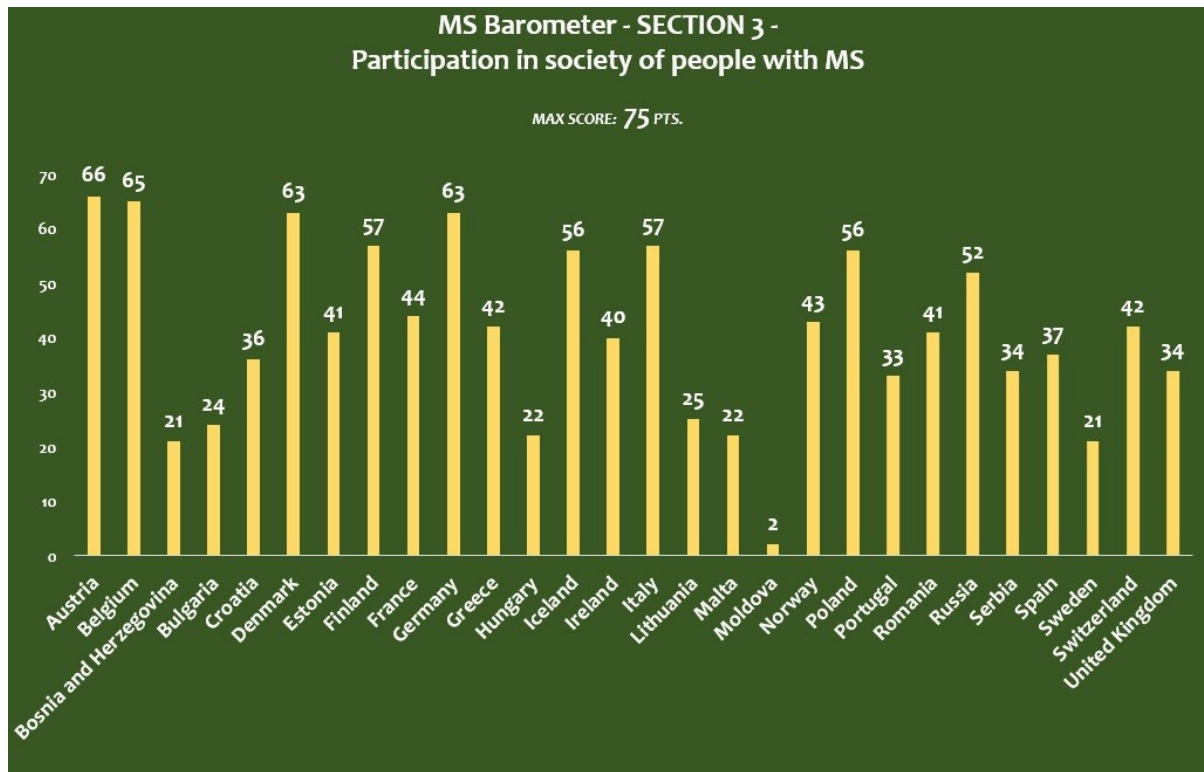
The other concern that has been identified is the lack of initiatives on Paediatric MS. This needs to be addressed both at national and European level.

MS data collection systems across Europe have been evolving over the last years and new registries were created. There are no more doubts on the potential outcomes and benefits of standardised data collection systems: they would support better MS research and patient-reported outcomes that would allow the emergence of better treatments and therapies for people with MS, and would enable improved decision-making based on real world evidence.

The lack of public funding for the existing registries threatens their long-term sustainability. Increased financial support would also allow for more patients to be registered and thus bolster data collection. MS societies should take the lead in actively approaching decision-makers to raise awareness on the benefits of the MS registries and request their support.

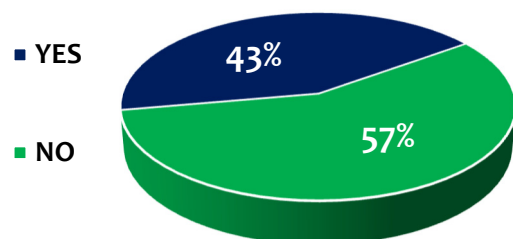
Section 3

Participation in society of people with MS



A) SUPPORT AND EDUCATION FOR YOUNG PEOPLE

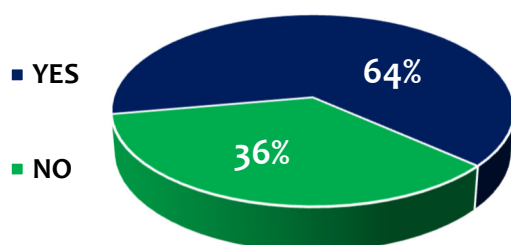
3.1) Are there any programs specifically aimed at young patients with MS (children, adolescents up to 18 years) in your country (psychological and social support)?



Replies	Countries
Yes)	Austria, Belgium, Denmark, Estonia, Germany, Greece, Iceland, Italy, Portugal, Romania, Russia, Switzerland
No	Bosnia-Herzegovina, Bulgaria, Croatia, Finland, France, Hungary, Ireland, Lithuania, Malta, Moldova, Norway, Poland, Serbia, Spain, Sweden, United Kingdom

- ❖ *Austria and Ireland have reported improved conditions compared to 2013, while Romania, Serbia and UK are now performing worse than in the past.*
- ❖ *Less than half of the countries reported running programmes for young patients.*

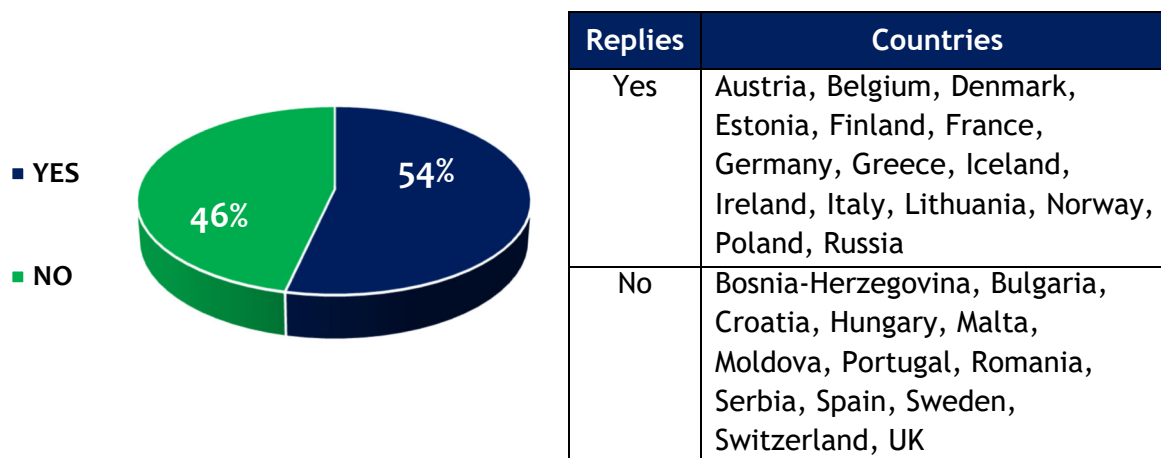
3.2) Do you have an identified network of young people with MS (young adults from 18 to 35 years old) run by the MS society?



Replies	Countries
Yes	Austria, Belgium, Denmark, Estonia, Finland, Germany, Greece, Iceland, Ireland, Italy, Lithuania, Norway, Poland, Portugal, Romania, Russia, Spain, Switzerland
No	Bosnia-Herzegovina, Bulgaria, Croatia, France, Hungary, Malta, Moldova, Serbia, Sweden, UK

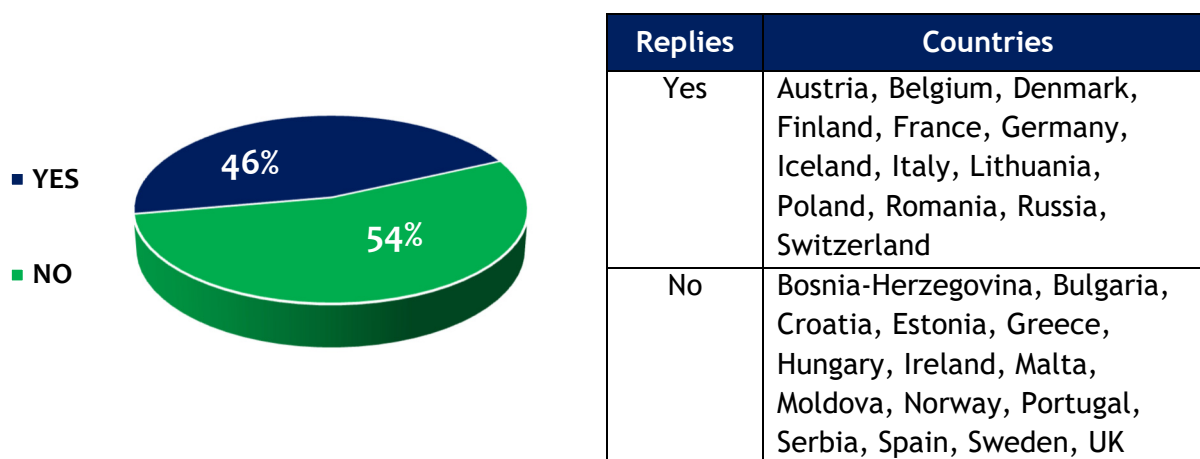
- ❖ *While Austria, Finland and Russia have improved their performances in the last two years, Sweden has encountered some steps back.*
- ❖ *Only half of the Eastern countries have a proper network of young patients, while in the Western ones the ratio increases to two thirds.*

3.3) Is there any support available to help young people with MS complete their education?



- ❖ Compared to the past, Ireland and Norway have now reached a satisfactory level of support on this matter.
- ❖ Almost half of the Eastern countries hold supporting programs for the education of young patients, while in the Western ones the ratio increases to two thirds.

3.4) Is there any support for those who have to leave the education system because of their MS?



- ❖ Poland and Romania have now reached a considerable level of support, while Croatia and UK have reported negative outcomes compared to 2013.
- ❖ Two thirds of the Eastern countries do not forecast any financial support in such cases, while in the Western ones the ratio between positive and negative feedback is almost 50/50.

B) EMPLOYMENT

3.5) What percentage of people with MS is in active work?

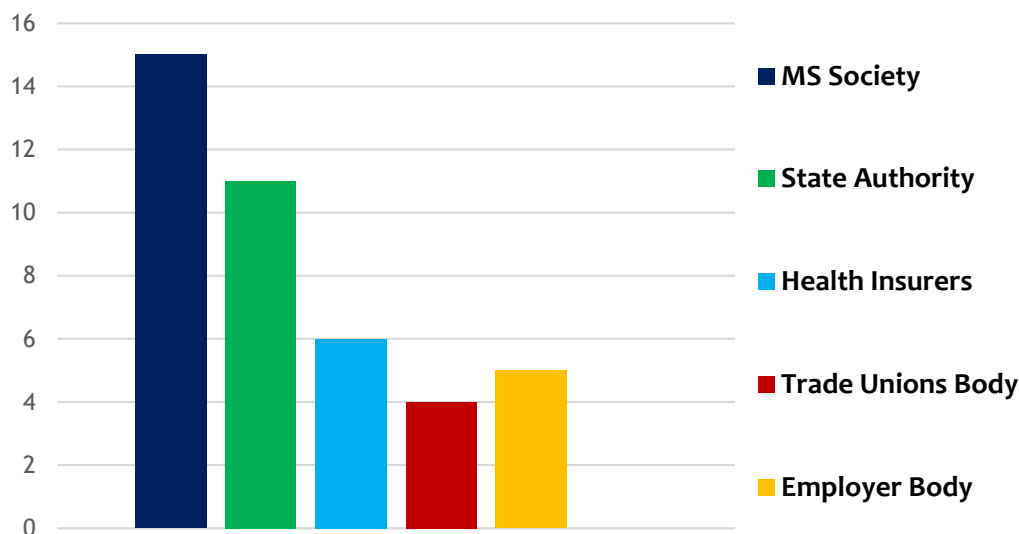
Countries	Full Time Job	Part Time Job
Austria	35%	25%
Belgium	50%	50%
Bosnia and Herzegovina	15%	20%
Croatia	15%	1%
Denmark	50%	20%
Estonia	75%	5%
Finland	35%	15%
France	35%	25%
Germany	34%	14%
Greece	30%	40%
Hungary	35%	10%
Iceland	40%	25%
Ireland	32%	11%
Italy	50%	10%
Lithuania	40%	10%
Malta	0%	0%
Moldova	20%	6%
Norway	18%	21%
Poland	0%	0%
Portugal	30%	5%
Russia	15%	5%
Serbia	15%	0%
Sweden	0%	0%
Switzerland	10%	30%

- ❖ *Bulgaria, Romania, Spain and United Kingdom did not provide any reply.*
- ❖ *Compared to 20113, Austria, Denmark, Germany and Ireland have reported higher levels of occupation of MS patients, while a decrease of the percentage levels has been experienced in Croatia, Iceland, Portugal and Russia.*
- ❖ *Although Western countries reported an average score three times higher than Eastern countries, it is clear that employment rates for people with MS are relatively low across all of Europe.*

3.6) Is there an information programme for employers and trade unions on the subject of MS or disability in general offered in your country?

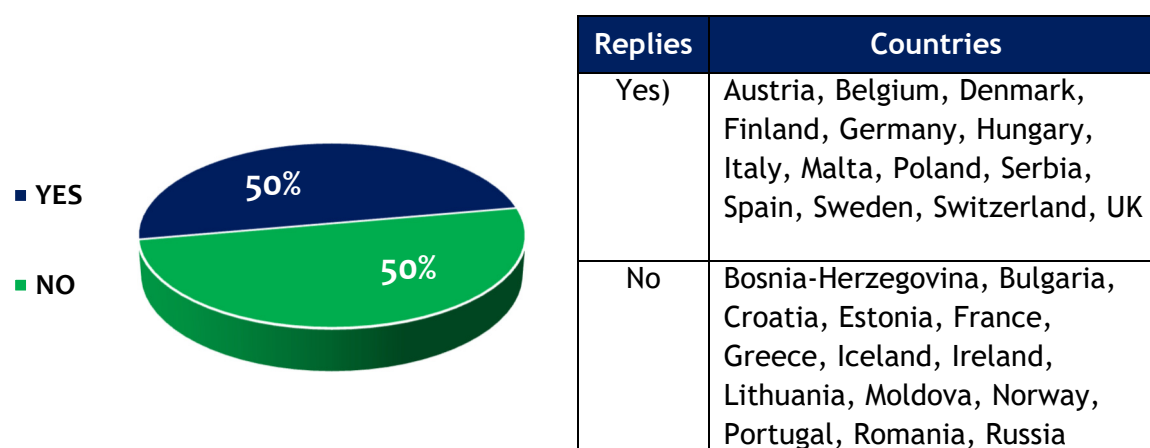
Countries	Yes, run by:				
	MS society (15)	A state authority (11)	Health insurers (6)	Employer Body (4)	Trade Union Body (5)
Austria	X		X		
Belgium	X	X	X	X	X
Bosnia- Herzegovina	X				
Bulgaria	X	X			
Croatia	X				
Denmark					
Estonia				X	
Finland	X	X	X	X	X
France		X	X		
Germany	X	X	X	X	X
Greece					
Hungary					
Iceland	X				
Ireland		X			
Italy	X				
Lithuania					
Malta					
Moldova					
Norway		X			
Poland		X			
Portugal	X				
Romania	X				
Russia	X	X			
Serbia	X	X	X	X	X
Spain	X				
Sweden		X			
Switzerland	X				
UK					

- ❖ Denmark, Greece, Hungary, Lithuania, Malta, Moldova and the United Kingdom did not answer this question.



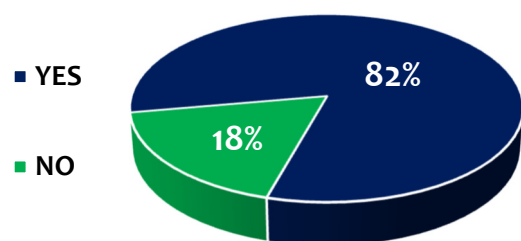
- ❖ Compared to 2013, Austria, Croatia and Serbia have reported the adoption of improved informative tools, while step backs have been recorded in Denmark, Iceland, Italy, Romania and UK.
- ❖ Reports from the Eastern countries reveal that such programmes exist mostly due to the work of national MS societies, while in the West state authorities are much more involved and supportive.

3.7) Does any kind of MS awareness-raising programme for the workplace (for employers and employees) operate in your country?



- ❖ Poland, Spain and Sweden have reported improved outcomes, while step back have been encountered in Croatia and Romania.
- ❖ Only 25% of the Eastern countries reported the existence of such a programme. Very low rate if compared with Western countries with 66%.

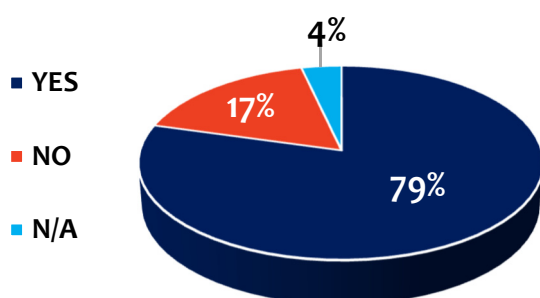
3.8) Are there incentives in place to recruit or retain people with disabilities in general or people with MS in employment?



Replies	Countries
Yes	Austria, Belgium, Bulgaria, Croatia, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Malta, Norway, Poland, Portugal, Romania, Russia, Serbia, Spain, United Kingdom
No	Bosnia-Herzegovina, Lithuania, Moldova, Sweden, Switzerland

- ❖ Compared to 2013, Portugal and UK have reached a more financially supportive system for employers.
- ❖ 75% of the Eastern countries revealed the existence of incentives within their territories, while in the West the related percentage approaches 100%.

3.9) Are people with disabilities/MS legally protected against dismissal from employment due to their condition?

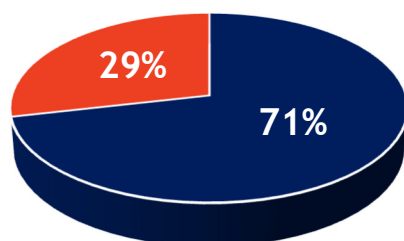


Replies	Countries
Yes	Austria, Belgium, Bosnia-Herzegovina, Croatia, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Norway, Poland, Portugal, Romania, Russia, Spain, Sweden, United Kingdom
No	Bulgaria, Lithuania, Moldova, Serbia, Switzerland

- ❖ Malta did not provide an answer to this question.
- ❖ Compared to 2013, the sole update to be reported is the step back on this matter experienced by the Serbian case.
- ❖ Two thirds of the Eastern countries reported the existence of protection programs against discrimination or unfair dismissal, while among the Western ones are protective.

3.10) Does your country have in place flexible working practice legislation for people with disabilities in general or people with MS?

■ YES
■ NO



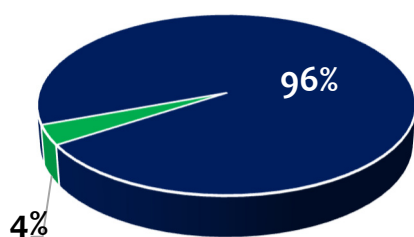
Replies	Countries
Yes	Austria, Belgium, Bosnia-Herzegovina, Bulgaria, Croatia, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Malta, Norway, Poland, Romania, Russia, Serbia, United Kingdom
No	Estonia, Hungary, Lithuania, Moldova, Portugal, Spain, Sweden, Switzerland

- ❖ *Poland has reported an improved and more inclusive legislation than that existing in 2013, while Spain and Sweden's records are now worse than in the past.*
- ❖ *Two thirds of the Eastern countries reported the existence of such legislation, while three quarters of Western countries reported the same.*

C) FINANCIAL INDEPENDENCE OF PEOPLE WITH MS

3.11) Does any kind of financial support exist for early retirement due to disability including MS? E.g.: pension fund, invalidity pension, etc.

■ YES
■ NO

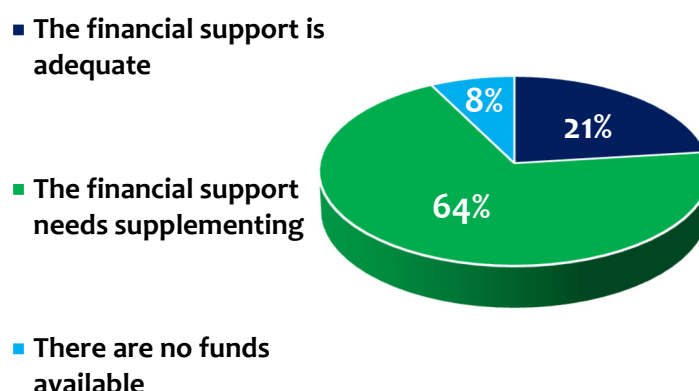


Replies	Countries
Yes	Austria, Belgium, Bosnia-Herzegovina, Bulgaria, Croatia, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Lithuania, Malta, Norway, Poland, Portugal, Romania, Russia, Serbia, Spain, Sweden, Switzerland, United Kingdom
No	Moldova

- ❖ *Positive replies were reported by all the Western and Eastern countries, except for Moldova, where the situation at national level needs to be carefully considered.*

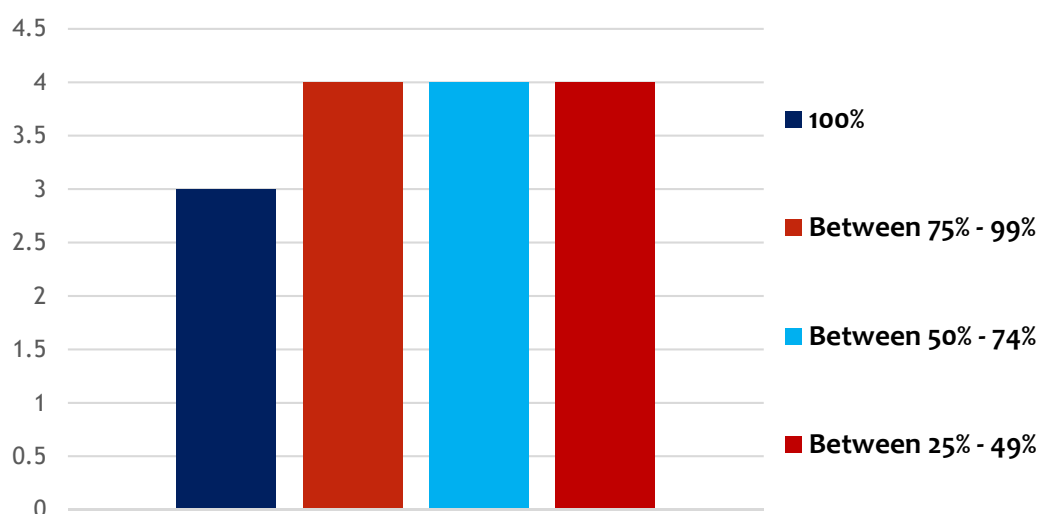
3.12) Does the financial support provide “adequate” income for people with MS according to the average income in your country?

Replies	Countries
The Financial Support is Adequate	Bulgaria, Denmark, Iceland, Italy, Norway, Spain
The Financial Support needs supplementing	Austria, Belgium, Bosnia-Herzegovina, Croatia, Estonia, Finland, France, Germany, Greece, Ireland, Poland, Portugal, Romania, Russia, Serbia, Sweden, Switzerland, United Kingdom
There are no funds available	Lithuania, Moldova



- ❖ Hungary and Malta did not provide any reply.
- ❖ *Almost all countries reported a satisfactory level of financial support, even if limited, with more positive outcome reported by the Western countries.*

3.13) What percentage of home adaptation costs is reimbursed (by any kind of sources, e.g. State Health Insurance, private insurance, MS Society, private funds, etc.)?

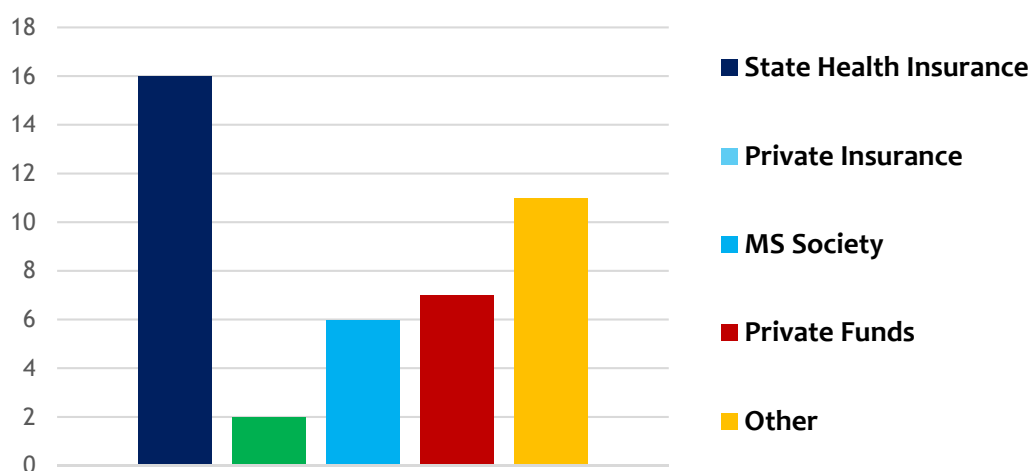


Replies	Countries
100%	Croatia, Denmark, Switzerland
Between 75% - 99%	Austria, Belgium, Iceland, Poland
Between 50% - 74%	Finland, France, Lithuania, Russia
Between 25% - 49%	Estonia, Ireland, Italy, Spain

- ❖ *The following countries did not reply: Bosnia and Herzegovina, Bulgaria, Germany, Greece, Hungary, Malta, Moldova, Norway, Portugal, Romania, Serbia, Switzerland and United Kingdom.*
- ❖ *Croatia, Ireland, Poland, Russia and Spain reported improved outcomes.*

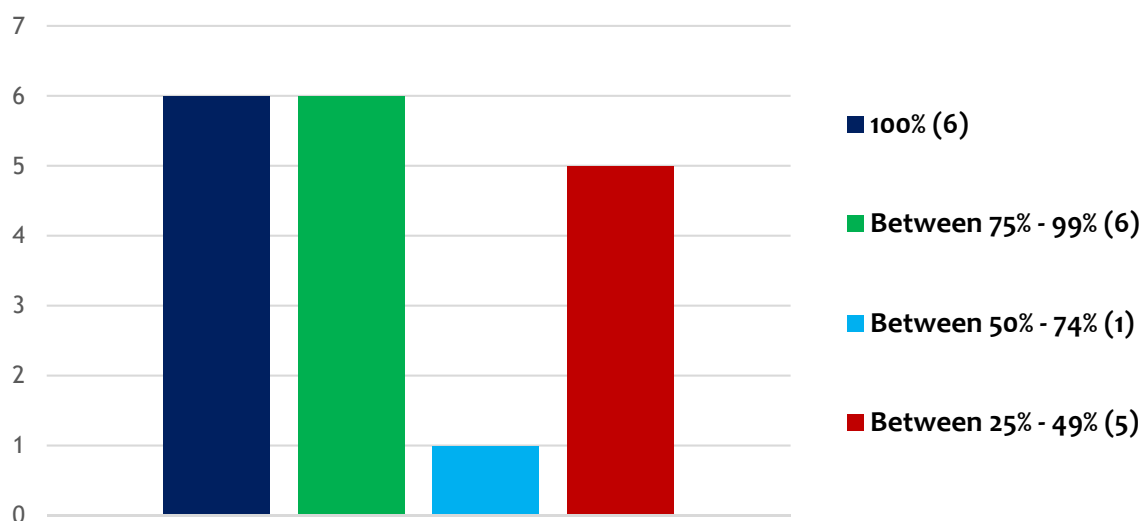
3.14) What is the source of funding for the reimbursement costs for home adaptation?

Funding Source:	State Health Insurance (16)	Private Insurance (2)	MS Society (6)	Private Funds (7)	Other (11)
Austria	X	X	X	X	
Belgium	X		X		
Bosnia-Herzegovina				X	
Bulgaria				X	
Croatia	X				
Denmark	X				X
Estonia					X
Finland					X
France	X				
Germany	X		X	X	X
Greece	X				
Hungary					X
Iceland	X				
Ireland					X
Italy	X				
Lithuania	X				
Malta	X				
Moldova					X
Norway	X				
Poland	X				X
Portugal			X	X	
Romania					X
Russia					X
Serbia				X	
Spain	X				
Sweden	X				
Switzerland	X		X		
United Kingdom		X	X	X	X



- ❖ *Improved outcomes have been reported in Croatia, Ireland, Poland, Russia and Spain.*
- ❖ *In the Eastern countries it is mostly a matter of support provided by State Health insurance or other bodies, while in the Western countries the private insurance system plays a very important role, together with the State Health insurance.*

3.15) What percentage of workplace adaptation costs is reimbursed?

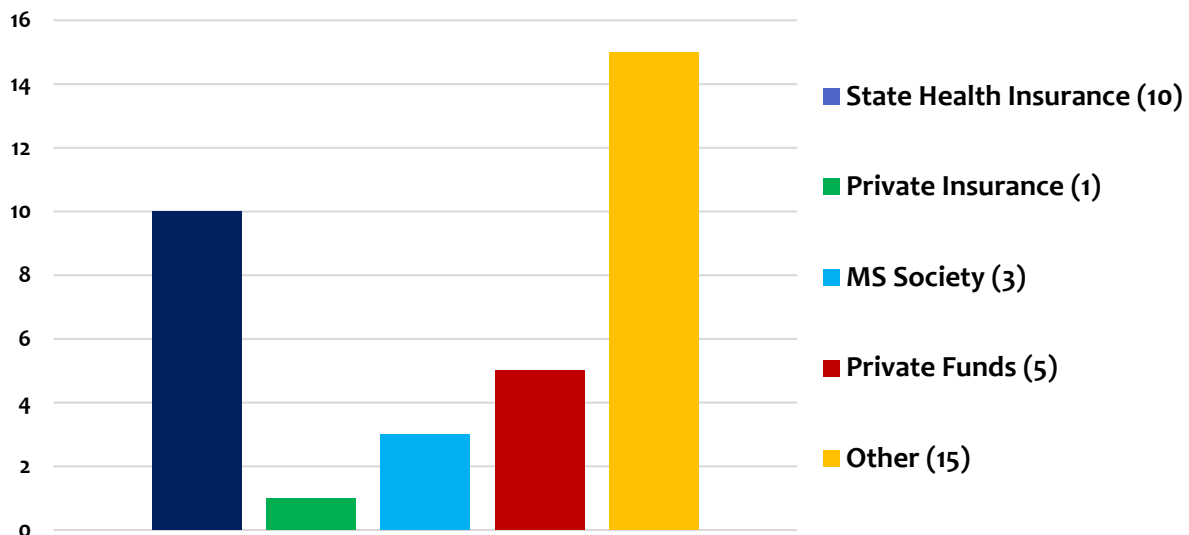


Replies	Countries
100%	Croatia, Denmark, Germany, Norway, Poland, Switzerland
Between 75% - 99%	Austria, Belgium, Finland, France, Iceland, Serbia
Between 50% - 74%	Estonia
Between 25% - 49%	Greece, Ireland, Italy, Russia, Spain

- ❖ The following countries did not reply: Bosnia and Herzegovina, Bulgaria, Hungary, Lithuania, Malta, Moldova, Portugal, Romania, Sweden and United Kingdom.
- ❖ Austria, Ireland, Russia, Serbia, Spain and Switzerland reported improved support on this matter, compared to 2013, while Greece performs now worse than in the past.
- ❖ The Western countries report a higher degree of support, with almost 100% of expenses incurred by the patient reimbursed. At the same time, only half of the Eastern countries that provided feedback reported an equal level of support. Overall, the situation related to this matter can be improved.

3.16) What is the source of funding for the reimbursement costs for workplace adaptations?

Funding Source:	State Health Insurance	Private Insurance	MS Society	Private Funds	Other
Austria	X	X	X	X	
Belgium	X			X	
Bosnia-Herzegovina	X				
Bulgaria					X
Croatia	X				
Denmark					X
Estonia					X
Finland					X
France					X
Germany					X
Greece	X				
Hungary					X
Iceland	X				
Ireland					X
Italy	X				
Lithuania				X	
Malta					X
Moldova					X
Norway	X				
Poland					X
Portugal			X	X	
Romania					X
Russia					X
Serbia					X
Spain				X	
Sweden	X				
Switzerland	X				
United Kingdom			X		X



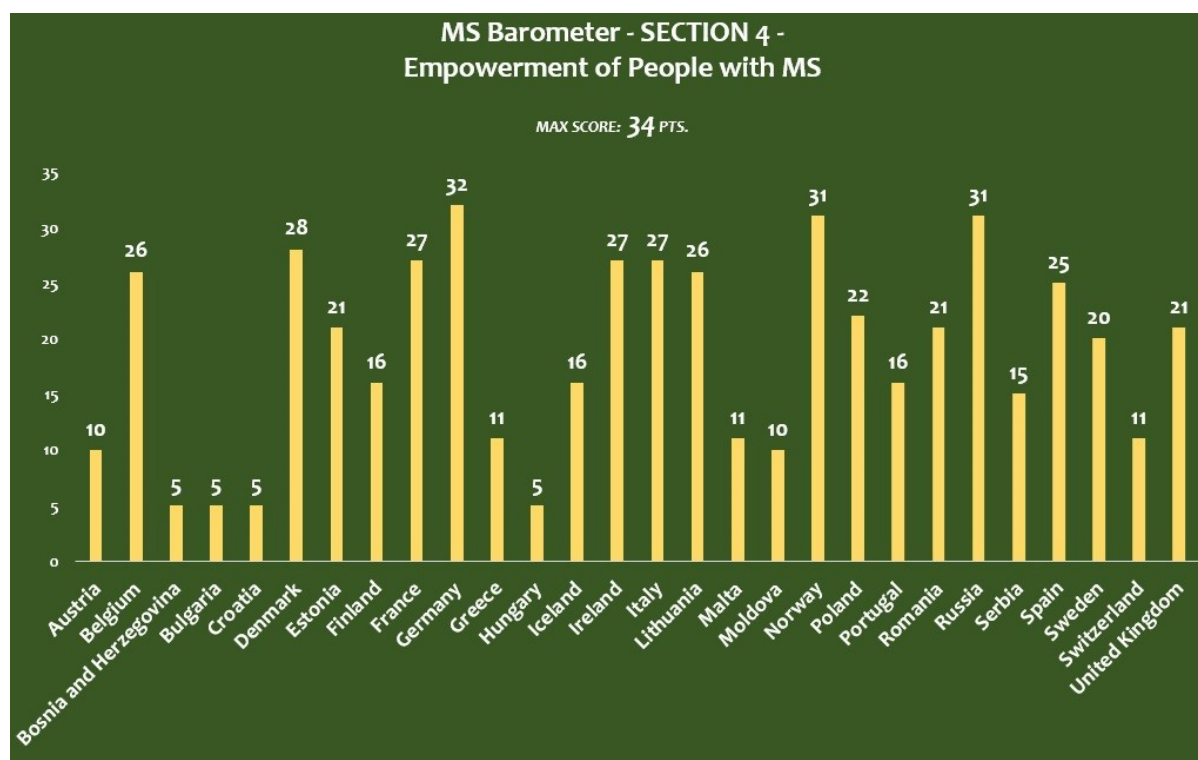
❖ *In the Eastern countries the trend is more favourable towards alternative sources, while in the Western ones the tendency is more diversified among all possible sources, except for the private insurance.*

Conclusions on Education, Employment and Financial independence of people with MS

- ✓ Young people with MS need more support from MS societies and other stakeholders in the field. With specialised support, they risk dropping out of education and becoming socially isolated.
- ✓ Develop measures to ensure that young people with MS can finish their education and have access to good quality employment opportunities such as apprenticeships or traineeships.
- ✓ Recognise the work skills and abilities of people affected by MS and provide sustainable employment for people with MS.
- ✓ Support people with MS to stay in, and return to work for their personal, psychological and financial wellbeing.
- ✓ Ensure continued support for people with MS in the workplace and educate the employers by providing them practical information and tools (such as the EMSP Toolkit for Employers) to better understand their employees with MS.
- ✓ Lobby to align health, labour and social policies and practices at national level in order to keep people with MS as healthy and productive as possible, enabling public health and economic benefits for society.

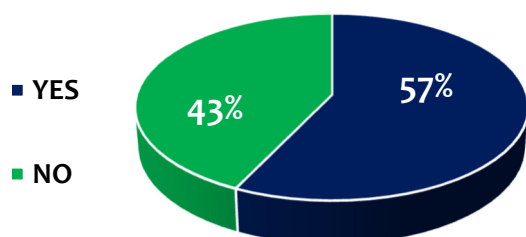
Section 4

Empowerment of people with MS



A) INDIVIDUAL EMPOWERMENT

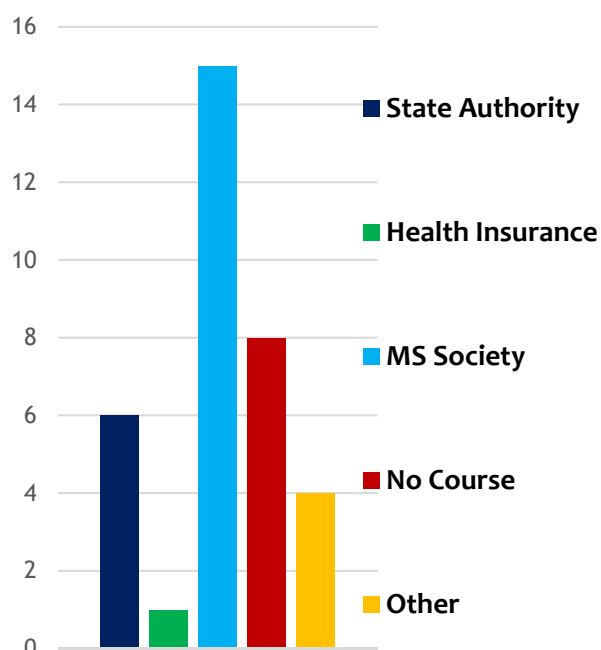
4.1) Does a self-management course exist in your country for people with MS to empower them to co-manage their own health as far as possible?



Replies	Countries
Yes	Belgium, Denmark, Estonia, Finland, France, Germany, Iceland, Ireland, Italy, Lithuania, Norway, Poland, Romania, Russia, Switzerland, United Kingdom
No	Austria, Bosnia-Herzegovina, Bulgaria, Croatia, Greece, Hungary, Malta, Moldova, Portugal, Serbia, Spain, Sweden

- ❖ *Compared to 2013, measures to improve outcomes have now been taken by Iceland, Poland and Romania.*
- ❖ *More than two thirds of the Western countries reported the existence of such a course, while in the Eastern ones the ratio is 50/50 between those following self-management courses and those not.*

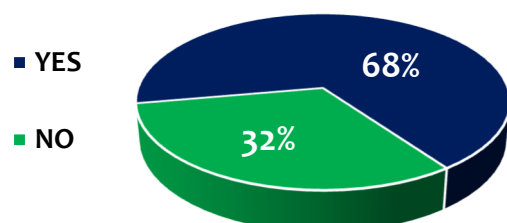
4.2) Who runs the self-management course for people with MS?



Replies	Countries
State authority	Denmark, France, Greece, Ireland, Italy, Norway
Health insurance	Germany
MS Society	Belgium, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Lithuania, Poland, Portugal, Romania, Russia, Switzerland, United Kingdom
No course	Austria, Bosnia-Herzegovina, Bulgaria, Croatia, Hungary, Moldova, Serbia, Sweden
Other	Denmark, Estonia, Malta, Poland

- ❖ Among the Western countries, Austria and Sweden reported not having such training at all, while the tendency for the remaining countries is different, with more support provided by the national MS societies and, limited, by State authorities, health insurers and other stakeholders. As for the Eastern countries, only half of them reported having such training, in the majority of cases managed by the MS societies and very rarely cases by State authorities and other bodies.

4.3) Can a person with MS liaise with a multi-disciplinary team in the management of their condition?

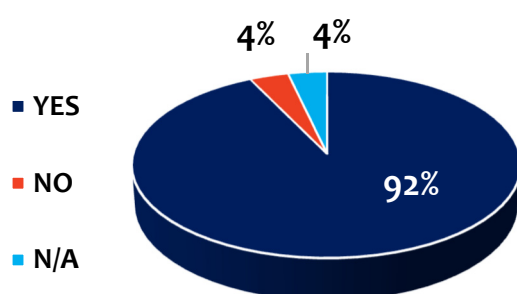


Replies	Countries
Yes	Austria, Belgium, Denmark, Estonia, Finland, France, Germany, Iceland, Ireland, Italy, Lithuania, Malta, Norway, Portugal, Romania, Russia, Spain, Sweden, UK
No	Bosnia-Herzegovina, Bulgaria, Croatia, Greece, Hungary, Moldova, Poland, Serbia, Switzerland

- ❖ Compared to the data collected in 2013, the only considerable change occurred in Austria, where improvements on this issue have been attested.

B) ORGANISATIONAL EMPOWERMENT

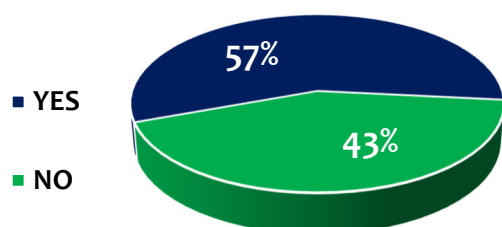
4.4) Are people with MS members of the Governance body (Board or Committees) of the national MS society?



Replies	Countries
Yes	Austria, Belgium, Bosnia-Herzegovina, Bulgaria, Croatia, Denmark, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Lithuania, Moldova, Norway, Poland, Portugal, Romania, Russia, Serbia, Spain, Sweden, Switzerland, UK
No	Estonia

- ❖ Malta did not provide a reply.
- ❖ The reported outcomes display two opposite tendencies between East and West: only one third of Eastern countries provided positive feedback on this matter, while, among the Western ones, only Switzerland replied negatively.

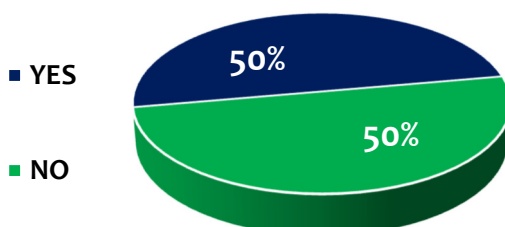
4.5) Is there a consultation group/body on MS that advises the Government on neurological diseases or specifically on MS policies?



Replies	Countries
Yes	Belgium, Denmark, France, Germany, Ireland, Italy, Lithuania, Malta, Norway, Poland, Portugal, Romania, Russia, Serbia, Spain, Sweden
No	Austria, Bosnia-Herzegovina, Bulgaria, Croatia, Estonia, Finland, Greece, Hungary, Iceland, Moldova, Switzerland, UK

- ❖ *Ireland reported updates in positive direction while Austria, Greece and UK records appear more negative than in the past.*
- ❖ *More than two thirds of Western countries reported such groups/bodies, while in the East the ratio is 50/50 with a slight prevalence of negative feedback.*

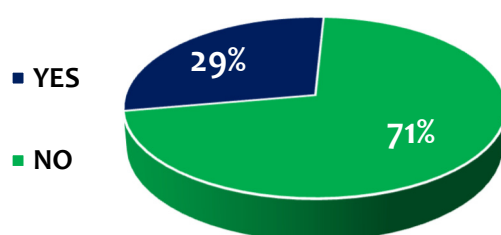
4.6) Are people with MS or the MS society represented in the consultation group/body?



Replies	Countries
Yes	Belgium, Denmark, Estonia, France, Germany, Ireland, Italy, Lithuania, Moldova, Norway, Poland, Russia, Spain, Sweden
No	Austria, Bosnia-Herzegovina, Bulgaria, Croatia, Finland, Greece, Hungary, Iceland, Malta, Portugal, Romania, Serbia, Switzerland, UK

- ❖ *Compared to 2013, improved results are now being recorded, with Denmark, Ireland, Norway, Poland, Spain and Sweden having reported now the existence of a consultation group/body being represented also by people with MS.*

4.7) Is the MS society a member of the body that decides on the reimbursement of new MS therapies/treatments?



Replies	Countries
Yes	Estonia, Germany, Greece, Norway, Russia, Serbia, Spain, UK.
No	Austria, Belgium, Bosnia-Herzegovina, Bulgaria, Croatia, Denmark, Finland, France, Hungary, Iceland, Ireland, Italy, Lithuania, Malta, Moldova, Poland, Portugal, Romania, Sweden, Switzerland

- ❖ *Reports of enhanced participation of the MS Society in this field were communicated by Greece, Norway, Russia, Serbia, Spain and the UK.*
- ❖ *Two thirds of the Eastern countries and third quarters of Western countries reported not having their reference MS societies among the members of the National decisional bodies.*

Conclusions on Empowerment of people with MS

Taking into account the results of our MS Barometer study, EMSP encourages member societies to step up engagement in local and national decision-making regarding MS policies such as reimbursement of existent and upcoming treatment and therapies. As the Barometer indicates, a good solution would be to create and maintain consultation or advisory bodies with representatives of Government and relevant health authorities.

EMSP also strongly advises member societies to place the priorities of people living with MS at national level high on the agenda of their policy outreach process.

One important recommendation derived from the MS Barometer is to ensure a permanent and significant representation of patient advocates on the boards of local and national MS associations.

Sources of information

All data collected in the MS Barometer has been provided by the national MS societies supported by their Medical Advisory Boards. The sources of information vary from members' databases to studies, or national, or regional public sources (such as National Health Ministries or Health insurances), or health professionals (e.g. Medical Advisory Boards of the MS society). Where possible, the sources have been recorded.

Acknowledgement

We would like to thank all EMSP member organisations who have been continuously supporting the MS Barometer over the years by completing the questionnaire, and especially for those who participated in the 2015 MS Barometer: Austria (Dr. Jörg Kraus), Belgium (Christiane Tihon), Bosnia and Herzegovina (Sanela Jažić), Bulgaria (Daniela Shikova), Croatia (Tanja Malbasa, Tamara Mikolčić), Denmark (Niels Steenstrup Zeeberg), Estonia (Katrin Rüütel), Finland (Helena Ylikylä-Leiva), France (Bastien Roux), Germany (Michaela Mai, Susanne Schoenemeier), Greece (Dimitra Kalogianni), Hungary (Éva Bocskay), Iceland (Berglind Gudmundsdottir), Ireland (Ava Battles, Harriet Doig), Italy (Mario Alberto Battaglia), Lithuania (Aldona Droseikiene), Malta (Dr. Josanne Aquilina, Carmen Muscat), Moldova (Alina Verbnîi), Norway (Gurli Vagner), Poland (Magdalena Fac-Skhirtladze, Marta Szantroch), Portugal (Susana Protásio, Luísa Sacchetti Matias, Prof Joao Correia de Sá), Romania (Bungărdean Cristina), Russia (Pavel Zlobin, Yan Vlasov), Serbia (Dragana Sutovic-Ilic), Spain (Pedro Carrascal), Sweden (Annica Bernehjält), Switzerland (Christoph Knüsli) and the United Kingdom (Sarah Nicholson, Dan Rattigan, Diane Redfern-Tofts).

The analysis of the results was undertaken by Xenia Schulz from the University Medical Center Göttingen (Germany) and the report prepared by EMSP team members.

We would like to thank also our sponsors for the continuous support allowing EMSP and its members to raise the voice of people with MS across Europe.