

MS Barometer 2011

A means of measuring MS management and quality of life of Persons with Multiple Sclerosis

In 2008, the European Multiple Sclerosis Platform launched the MS Barometer as a new means to provide for the first time data to verify general knowledge on the quality of life of persons affected by Multiple Sclerosis and data underpinning the lobby effort of the European Multiple Sclerosis Platform and its members for so many years.

Multiple Sclerosis

Multiple Sclerosis (MS) knows no geographic boundaries. MS is an inflammatory disease of the central nervous system that is often progressively disabling.

MS affects more than 600,000 persons in Europe, affecting twice as many women as men. Most patients are diagnosed between the ages of 20 and 40.

To date, there is no cure and no preventive measures.

MS Barometer 2011

A means of measuring MS
management and quality of life of
Persons with Multiple Sclerosis

In 2008, the European Multiple Sclerosis platform (EMSP) launched the MS Barometer as a new means able to provide - for the first time - data to verify general knowledge on the management of MS and the Quality of life of Persons with Multiple Sclerosis (PwMS). The collected data underpin the lobby effort of EMSP and its members towards the European institutions and the national authorities

The MS Barometer is a bench-marking tool which covers seven areas pertaining to the MS environment at the national level: 1. Access to treatment and therapies; 2. Research agenda on MS; 3. Employment and job retention; Empowerment of PwMS; 4. Reimbursement of costs related to MS; 5. Accurate data collection on MS at national level; 6. Medication coming on the market.

A high score in each category indicates that the atmosphere for PwMS is fair – the quality of policies and programmes effectively reduces the pressure in their daily lives. The scoring system highlights the strong points of national policy, while also identifying gaps in service provision that place undue pressure on PwMS (whether it be related to medical, socio-economic or quality of life issues).

The results of the MS Barometer 2008 and 2009 confirmed the tremendous gaps between EU countries in terms of access to care and treatment, as well as in the quality of life of PwMS. Eliminating such disparities is a key aim of the MS Code of Good Practice. The MS Barometer allows

identifying the contributing factors and addresses the challenge by measuring specific aspects of how individual countries manage MS and how policy decisions affect the pressure experienced by individual PwMS. The MS Barometer also functions as a bench-marking tool that facilitates comparison across all participating countries. As such, it helped national administrations to identify areas in which they excel on a pan-European scale, as well as those in which they are weak.

The results of the MS Barometer were widely disseminated both at European and national level providing evidence for lobbying among policy decision-makers, during European conferences as well as National High level roundtables.

The second round of the MS Barometer was launched 2009. For that purpose, the MS Barometer was revised improved on the basis of results and feedback from the MS Community received after the publication of the first results. The survey itself has been re-written to provide more accurate and reliable data and anew submitted to national MS Societies for completion. Twenty-nine MS Societies participated in 2009.

The participating countries in 2011 are: Austria, Belarus, Belgium, Bosnia-Herzegovina, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Lithuania, Luxembourg, Malta, Netherlands, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland and United Kingdom.

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MS BAROMETER 2011

Questionnaire

Section 1: Access to treatment and therapies

Neurologist PwMS ratio

- 1.1 If you divide the estimated number of PwMS in your country by the number of practicing neurologists in your country, what is the relation figure?

MS Training for health professionals

- 1.2 For which health professionals is certified MS training available?

Immuno-modulating therapy

- 1.3 Can PwMS in your country be treated according to the recommendations outlined in the EMSP Consensus Paper "Basic and escalating immunomodulatory therapies in MS"?
- 1.4 What % of the total population of PwMS does actually receive DMD treatment in your country? DMD treatments include: Avonex, Betaseron, Copaxone, Novantrone, Rebif and Tysabri.
- 1.5 Is there a limit to the numbers of people eligible to receive DMD treatment?
- 1.6 Is there a limit to the duration of treatment with DMDs determined by anything other than medical reasons - decided by the relevant health professional and PwMS together?

Symptomatic treatment

- 1.7 Can PwMS be treated in accordance with the recommendations outlined in the EMSP Consensus Paper III "Symptomatic treatment of MS" in your country?
- 1.8 What % of the population of PwMS currently receives symptomatic treatment in your country?
- 1.9 Is there a limit to the duration of symptomatic treatment available other than for medical reasons?
- 1.10 Is there a limit to the number of PwMS entitled to access any symptomatic treatment?

Rehabilitation

- 1.11 Can PwMS 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"?
- 1.12 What is the estimated population of PwMS in your country which access to the rehabilitation centers?
- 1.13 If you divide the number of PwMS by the number of specialists rehabilitation clinics, what figure do you come to?
- 1.14 What is the greatest distance between a specialist rehabilitation center and a PwMS? If no specialist rehabilitation center exists in your country, please make the calculation using the center where PwMS can be treated?

PwMS on an out-patient basis

- 1.15 What % of the total population of PwMS in your country currently receives rehabilitation services as out-patients?
- 1.16 If required, how often a PwMS is entitled to receive rehabilitation services as out-patient?

PwMS on an in-patient basis

- 1.17 What % of the total population of PwMS currently receives rehabilitation services as in-patients?
- 1.18 If required, how often a PwMS can receive rehabilitation services as an in-patient?

Palliative care

- 1.19 Is there a Palliative Care programme specialised for PwMS in your country?

Section 2: Research agenda on MS

- 2.1 Are there grants/support schemes managed by your MS Society which contribute financially to MS research?
- 2.2 Are these MS research grants/schemes supported by public funding?
- 2.3 Are MS societies consulted in influencing the national research agendas on MS?

Section 3: Employment and Job retention

- 3.1 Is there information programme for employers and trade unions on the subject of MS or disability in general offered in your country?
- 3.2 Does any kind of MS awareness raising programme for the workplace (for employers and employees) exist?
- 3.3 Are there incentives in place to hire or retain people with disabilities in general or PwMS in employment?
- 3.4 Is it legally possible for people with disabilities in general or PwMS to remain at work if he/she has MS?
- 3.5 Is there flexible working practice legislation in place for people with disabilities in general or PwMS to avail of?
- 3.6 What % of PwMS is in active work?
 - a. Full time job
 - b. Part-time job
- 3.7 Does a pension fund exist for early retirement due to disability including MS?
- 3.8 Does the pension fund provide "adequate" income for PwMS according to the average income in your country?

Section 4: Empowerment of PwMS

- 4.1 Is there a consultation group/body on MS that advises Government on neurological diseases or specifically on MS policies?
- 4.2 Are PwMS represented in the consultation group/body?
- 4.3 Is the MS Society a member of the body that decides on the reimbursement of a new MS therapy?
- 4.4 Does the national MS Society have formal consultative status with your national administration?
- 4.5 Does a self-management course exist in your country for PwMS to empower them to co-manage their own health as far as possible?

- 4.6 Who runs the self-management course for PwMS?
- 4.7 Can a PwMS interface with a multi-disciplinary team in the management of their condition?

Section 5: Reimbursement of costs related to MS

- 5.1 What % of DMD costs is reimbursed?
- 5.2 What % of the costs for symptomatic therapy is reimbursed?
- 5.3 What % of rehabilitation costs is reimbursed?
- 5.4 What % of home adaptation costs is reimbursed?
- 5.5 What % of workplace adaptation costs is reimbursed?
- 5.6 What % of your country's GDP is spent on healthcare?

Section 6: Accurate data collection on MS at national level

- 6.1 Does a national MS register exist?
- 6.2 Who manages the MS register?
- 6.3 Is the register supported by public funding?
- 6.4 If a register exists, what % of PwMS is currently recorded on the register?
- 6.5 Does the information coming from the MS register have an influence on the national policy for PwMS?

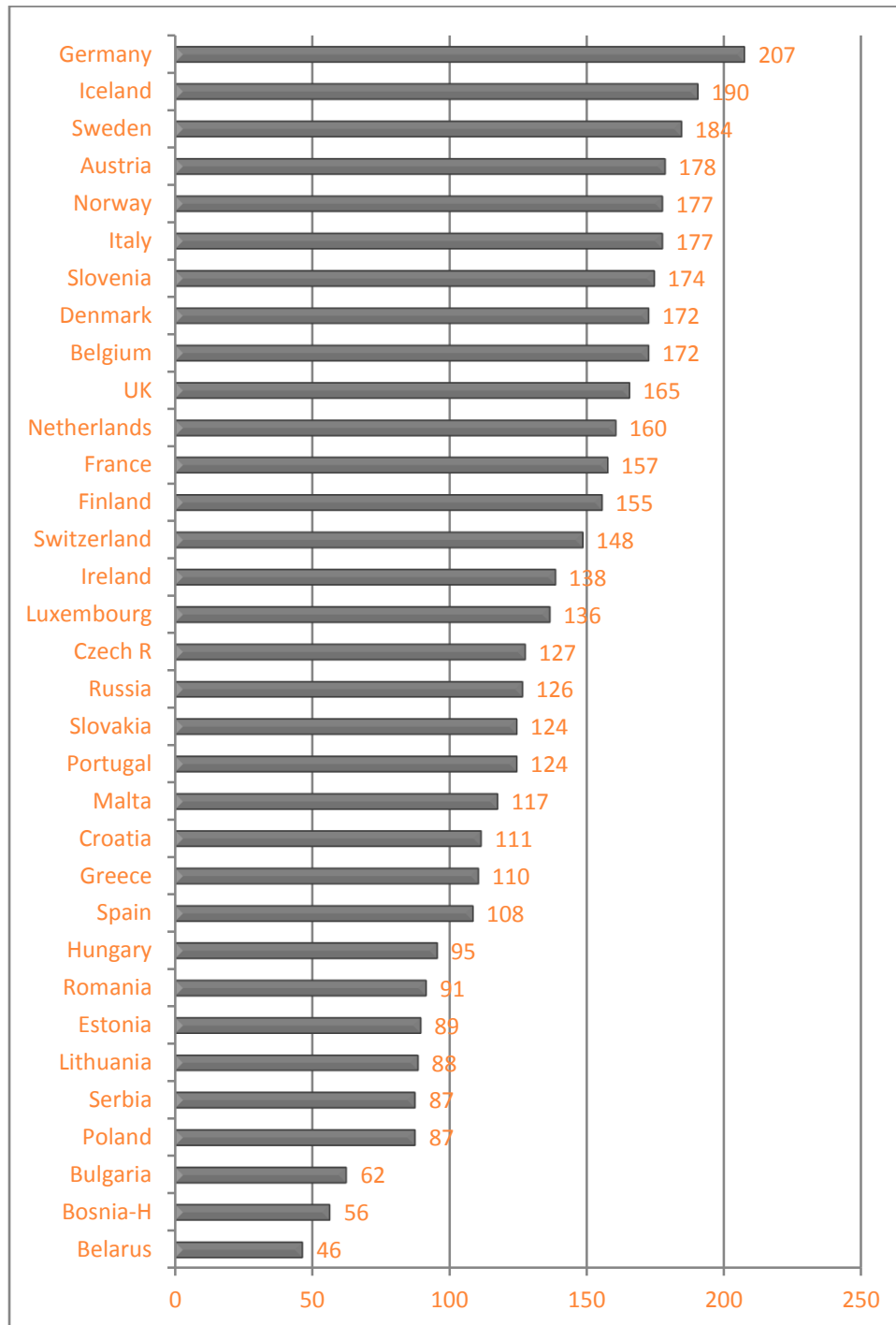
Section 7: Medication coming to the market

- 7.1 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 EMA?
- 7.2 How long does it take for PwMS, legally entitled to receive the drug, to get it?
- 7.3 Is the approval of an MS drug automatically linked to its reimbursement through the Health Fund/Insurer?

Scoring:

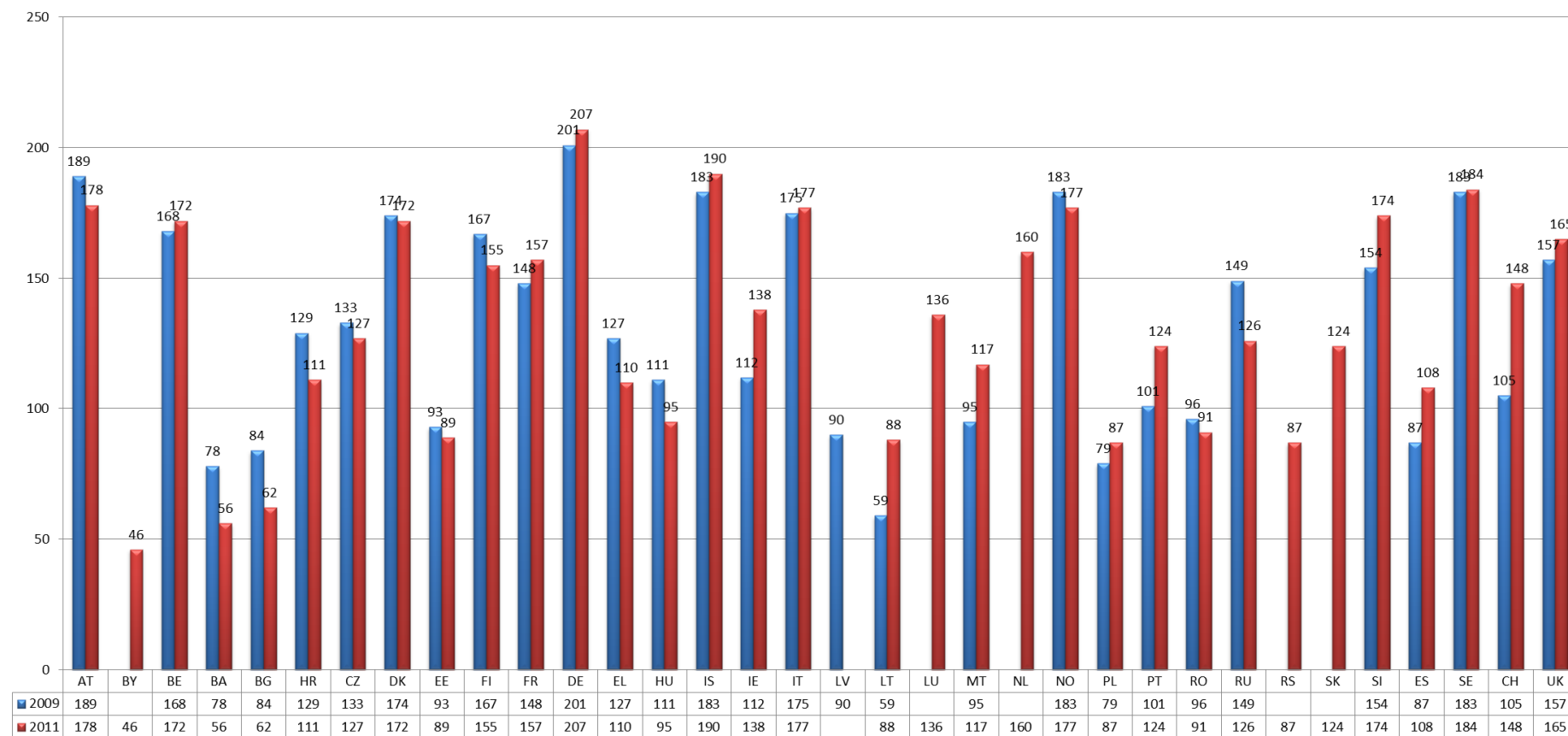
<u>Category</u>	<u>Scoring on</u>	<u>Max Score (per section)</u>
Access to treatment	19 questions	70
Research agenda on MS	3 questions	15
Employment	8 questions	35
Empowerment of PwMS	7 questions	35
Reimbursement of costs	6 questions	30
Data collection	5 questions	25
Medication on the market	3 questions	15
TOTAL BAROMETER SCORE 225		

Overall MS Barometer 2011 results

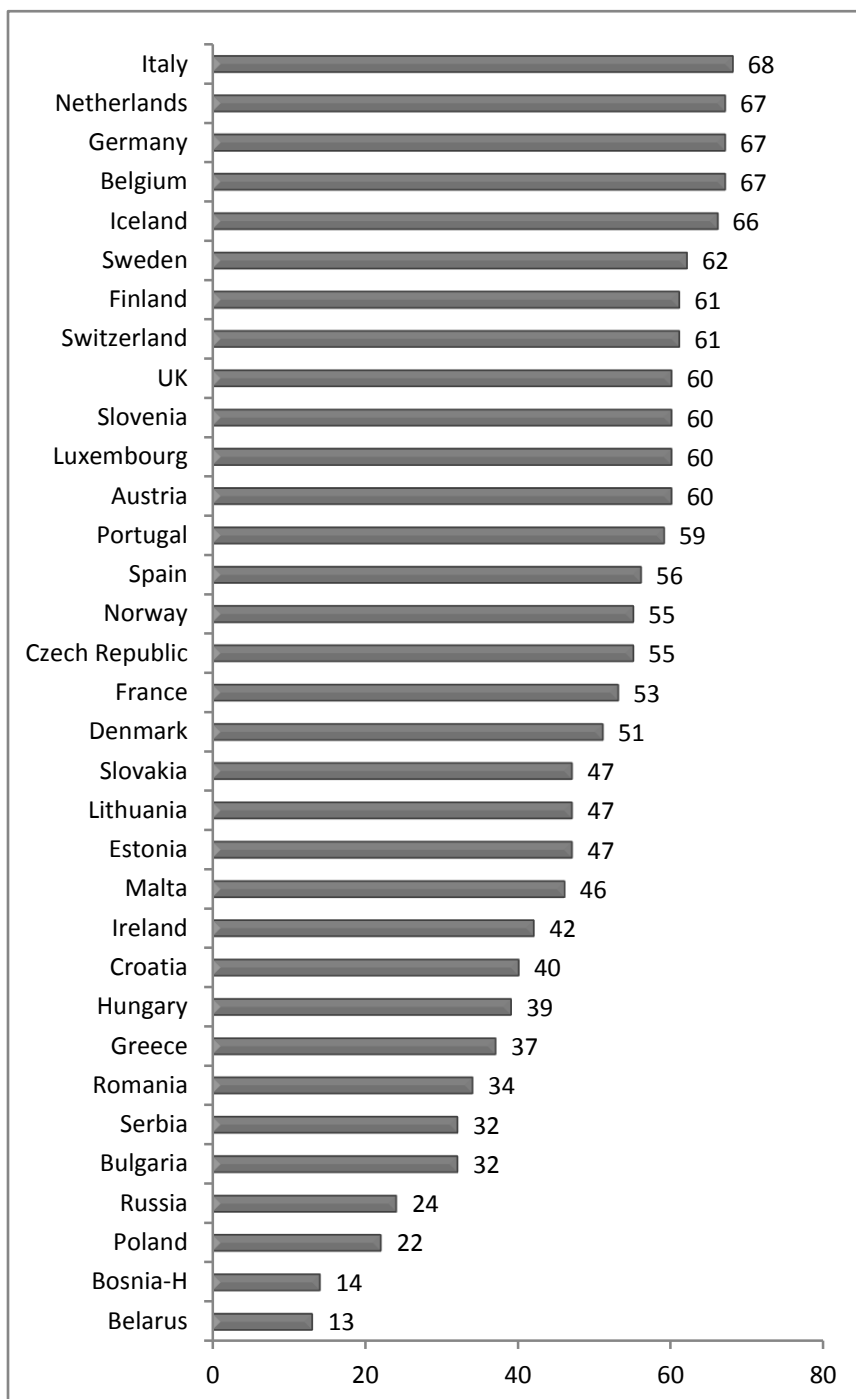


Comparison overall results 2009/2011

■ 2009 ■ 2011



Section 1: Access to treatments and therapies



Neurologist PwMS ratio

1.1 If you divide the estimated number of PwMS in your country by the number of practicing neurologists in your country, what is the relation figure?

One neurologist for:

<100 PwMS (5 pts)	<200 PwMS (4 pts)	<300 PwMS (3 pts)	<400 PwMS (2 pts)	<500 PwMS (1 pt)	>500 PwMS (0 pt)
Austria Belgium Bulgaria Czech Republic Denmark Estonia Finland France Germany Hungary Iceland Italy Lithuania Luxembourg Malta Norway Portugal Romania Slovenia Spain Sweden Switzerland	Bosnia- Herzegovina Croatia Netherlands	Greece Slovakia UK	Russia	Serbia	Belarus Ireland Poland

MS Training for health professionals

1.2 For which health professionals is certified MS training available?

Y= Training are available

<i>Countries</i>	<i>Neurologist</i>	<i>Rehab. Dr.</i>	<i>Psychologists</i>	<i>Nurses</i>	<i>Rehab. Therapists</i>	<i>Others</i>	<i>Total points</i>
Belgium	Y	Y	Y	Y	Y		5
Czech Republic	Y	Y	Y	Y	Y		5
Germany	Y	Y	Y	Y	Y		5
Iceland	Y	Y	Y	Y	Y		5
Italy	Y	Y	Y	Y	Y		5
Lithuania	Y	Y	Y	Y	Y		5
Slovenia	Y	Y	Y	Y	Y		5
Sweden	Y	Y	Y	Y	Y		5
Netherlands	Y	Y	Y	Y	Y		5
UK	Y	Y	Y	Y	Y		5
Austria	Y	Y					4
Finland	Y	Y		Y	Y		4
Norway	Y	Y					4
Ireland	Y	Y		Y			4
Switzerland	Y		Y	Y		Physiotherapists	3
Hungary	Y			Y			2
Slovakia				Y			2
Russia	Y			Y			2
Belarus	Y			Y		General practitioners	2
Poland	Y				Y		2
Denmark	Y						1
Luxembourg	Y						1
Malta	Y						1
Portugal	Y						1
Romania	Y						1
Spain	Y						1
Croatia	Y						1
Greece			Y				1

No training available in: Bulgaria, Estonia, France, Bosnia-Herzegovina and Serbia.

Immuno-modulating therapy

1.3 Can PwMS in your country be treated according to the recommendations outlined in the EMSP Consensus Paper "Basic and escalating immunomodulatory therapies in MS"¹?

Yes (5 pts)	No (0 pt)
Belgium	Lithuania
Czech Republic	Belarus
Germany	Poland
Iceland	Croatia
Italy	Bosnia-Herzegovina
Slovenia	Serbia
Sweden	
Netherlands	
UK	
Austria	
Finland	
Norway	
Ireland	
Switzerland	
Hungary	
Slovakia	
Russia	
Denmark	
Luxembourg	
Malta	
Portugal	
Romania	
Spain	
Greece	
Bulgaria	
Estonia	
France	

¹ Basic and escalating immunomodulatory treatments in Multiple Sclerosis, Current therapeutic recommendations, EMSP, Dec. 2003, updated in 2008:
<http://emsp.org/attachments/article/134/2therapy08.pdf>

1.4 What percentage of the total population of PwMS does actually receive DMD* treatment in your country? *DMD treatments include: Avonex, Betaseron, Copaxone, Novantrone, Rebif and Tysabri.

Countries	%
Austria	70
Belarus	0
Belgium	63
Bosnia-Herzegovina	5
Bulgaria	12
Croatia	22
Czech Republic	25
Denmark	35
Estonia	27,4
Finland	50
France	40
Germany	70
Greece	65
Hungaria	16
Iceland	60
Ireland	32
Italy	65
Lithuania	70
Luxembourg	80
Malta	50
Netherlands	50
Norway	43
Poland	7
Portugal	70
Romania	20
Russia	40
Serbia	10
Slovakia	50
Slovenia	40
Spain	50
Sweden	45
Switzerland	70
UK	12

1.5 Is there a limit to the numbers of people eligible to receive DMD treatment?

No (5pts)	Yes (0 pt)
Belgium	Czech Republic
Germany	Hungary
Iceland	Russia
Italy	Romania
Slovenia	Greece
Sweden	Bulgaria
Netherlands	Lithuania
UK	Belarus
Austria	Poland
Finland	Croatia
Norway	Bosnia-Herzegovina
Ireland	Serbia
Switzerland	
Slovakia	
Denmark	
Luxembourg	
Malta	
Portugal	
Spain	
Estonia	
France	

1.6 Is there a limit to the duration of treatment with DMDs determined by anything other than medical reasons - decided by the relevant health professional and PwMS together?

No (5 pts)	Yes (0 pt)
Belgium	Slovakia
Germany	Russia
Iceland	Bulgaria
Italy	Belarus
Slovenia	Poland
Sweden	Bosnia-Herzegovina
Netherlands	
UK	
Austria	
Finland	
Norway	
Ireland	
Switzerland	
Denmark	
Luxembourg	
Malta	
Portugal	
Spain	
Estonia	
France	
Czech Republic	
Hungary	
Romania	
Greece	
Lithuania	
Croatia	
Serbia	

Symptomatic treatment

1.7 Can PwMS be treated in accordance with the recommendations outlined in the EMSP Consensus Paper III "Symptomatic treatment of MS²" in your country?

Yes (5pts)	No (0pt)
Belgium	Ireland
Germany	Serbia
Iceland	Bulgaria
Italy	Belarus
Slovenia	Poland
Sweden	Bosnia-Herzegovina
Netherlands	
UK	
Austria	
Finland	
Norway	
Switzerland	
Denmark	
Luxembourg	
Malta	
Portugal	
Spain	
Estonia	
France	
Czech Republic	
Hungary	
Romania	
Greece	
Lithuania	
Croatia	
Slovakia	
Russia	

² Symptomatic treatment of Multiple Sclerosis, EMSP, Dec.2006, revised in April 2008:
<http://emsp.org/attachments/article/134/3treatment08.pdf>

1.8 What percentage of the population of PwMS currently receives symptomatic treatment in your country?

Countries	%
Austria	85
Belarus	unknown
Belgium	70
Bosnia-Herzegovina	10
Bulgaria	35
Croatia	75
Czech Republic	100
Denmark	70
Estonia	unknown
Finland	100
France	80
Germany	80
Greece	68
Hungaria	30
Iceland	100
Ireland	85
Italy	80
Lithuania	100
Luxembourg	50
Malta	100
Netherlands	70
Norway	70
Poland	unknown
Portugal	100
Romania	50
Russia	20
Serbia	40
Slovakia	100
Slovenia	80
Spain	80
Sweden	0
Switzerland	90
UK	unknown

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

No (5 pts)	Yes (0 pt)
Belgium	Hungary
Germany	Russia
Iceland	Belarus
Italy	Poland
Slovenia	
Sweden	
Netherlands	
UK	
Austria	
Finland	
Norway	
Switzerland	
Denmark	
Luxembourg	
Malta	
Portugal	
Spain	
Estonia	
France	
Czech Republic	
Romania	
Greece	
Lithuania	
Croatia	
Slovakia	
Ireland	
Serbia	
Bulgaria	
Bosnia-Herzegovina	

1.10 Is there a limit to the number of PwMS entitled to access any symptomatic treatment?

No (5pts)	Yes (0 pt)
Belgium	Croatia
Germany	Russia
Iceland	Belarus
Italy	
Slovenia	
Sweden	
Netherlands	
UK	
Austria	
Finland	
Norway	
Switzerland	
Denmark	
Luxembourg	
Malta	
Portugal	
Spain	
Estonia	
France	
Czech Republic	
Romania	
Greece	
Lithuania	
Slovakia	
Ireland	
Serbia	
Bulgaria	
Bosnia-Herzegovina	
Hungary	
Poland	

Rehabilitation

1.11 Can PwMS 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 MS³"?

Yes (5 pts)	No (0 pt)
Belgium	Malta
Germany	Estonia
Iceland	Romania
Italy	Greece
Slovenia	Bosnia-Herzegovina
Sweden	Hungary
Netherlands	
UK	
Austria	
Finland	
Norway	
Switzerland	
Denmark	
Luxembourg	
Portugal	
Spain	
France	
Czech Republic	
Lithuania	
Slovakia	
Ireland	
Serbia	
Bulgaria	
Polish	
Croatia	
Russia	
Belarus	

³ European-wide Recommendations on Rehabilitation for People affected by Multiple Sclerosis, EMSP, RIMS, Oct. 2004: <http://emsp.org/attachments/article/134/4rehabilitation08.pdf>

1.12 What is the estimated population of PwMS in your country which access to the rehabilitation centers?

Countries	%
Austria	100
Belarus	5
Belgium	15
Bosnia-Herzegovina	0
Bulgaria	5500
Croatia	100
Czech Republic	100
Denmark	100
Estonia	75
Finland	35
France	45
Germany	100
Greece	27
Hungaria	15
Iceland	100
Ireland	10
Italy	60
Lithuania	50
Luxembourg	30
Malta	5
Netherlands	100
Norway	100
Poland	1
Portugal	40
Romania	5
Russia	25
Serbia	100
Slovakia	30
Slovenia	90
Spain	45
Sweden	60
Switzerland	20
UK	70

1.13 If you divide the number of PwMS by the number of specialists rehabilitation clinics, what figure do you come to?

<1000 PwMS	<1500 PwMS	<2000 PwMS	< 2500 PwMS	>2500 PwMS	No MS rehabilitation clinic exists
Belgium	Germany		Denmark	UK	Slovakia
Iceland	Slovenia			France	Bulgaria
Italy	Austria			Czech Republic	Malta
Sweden	Switzerland			Ireland	Romania
Netherlands	Spain			Serbia	Greece
Finland	Estonia			Poland	Bosnia-Herzegovina
Norway				Russia	Hungary
Luxembourg				Belarus	
Portugal					
Lithuania					
Croatia					

1.14 What is the greatest distance between a specialist rehabilitation center and a PwMS? If no specialist rehabilitation center exists in your country, please make the calculation using the center where PwMS can be treated?

Less than 50 km	Between 50 & 100 km	Between 100 & 150 km	Between 150 and 200 km	Over 200km	No rehab centre
Luxembourg	Belgium	Italy	Croatia	Iceland	Bulgaria
Germany	Netherlands	Finland	Greece	Sweden	Malta
	Lithuania	Portugal		Norway	Bosnia-Herzegovina
	Austria	Slovenia		Estonia	
	Switzerland			Denmark	
	Spain			UK	
	France			Czech Republic	
	Slovakia			Ireland	
	Hungary			Serbia	
				Poland	
				Russia	
				Belarus	
				Romania	

PwMS on an out-patient basis

1.15 What percentage of the total population of PwMS in your country currently receives rehabilitation services as out-patients?

Countries	%
Austria	70
Belarus	unknown
Belgium	80
Bosnia-Herzegovina	80
Bulgaria	0
Croatia	30
Czech Republic	30
Denmark	70
Estonia	unknown
Finland	50
France	60
Germany	80
Greece	25
Hungaria	1
Iceland	65
Ireland	20
Italy	50
Lithuania	20
Luxembourg	30
Malta	10
Netherlands	90
Norway	unknown
Poland	unknown
Portugal	unknown
Romania	10
Russia	2
Serbia	10
Slovakia	60
Slovenia	50
Spain	40
Sweden	48
Switzerland	40
UK	unknown

1.16 If required, how often a PwMS is entitled to receive rehabilitation services as out-patient?

As often as required	Limited by health insurance rules	More than once per year	Less than once per year	No rehabilitation offered
Luxembourg	Germany	Spain	Lithuania	Romania
Switzerland	Belgium	Norway	Russia	Bosnia-Herzegovina
France	Netherlands	Ireland	Belarus	
Italy	Austria	Bulgaria		
Finland	Slovakia			
Portugal	Hungary			
Iceland	Slovenia			
Estonia	Croatia			
Denmark	Greece			
UK	Sweden			
Serbia	Czech Republic			
Malta				

PwMS on an in-patient basis

1.17 What percentage of the total population of PwMS currently receives rehabilitation services as in-patients?

Countries	%
Austria	Unknown
Belarus	unknown
Belgium	20
Bosnia-Herzegovina	0
Bulgaria	15
Croatia	62
Czech Republic	100
Denmark	10
Estonia	unknown
Finland	30
France	30
Germany	40
Greece	12
Hungaria	1
Iceland	20
Ireland	10
Italy	10
Lithuania	80
Luxembourg	10
Malta	unknown
Netherlands	10
Norway	10
Poland	unknown
Portugal	unknown
Romania	5
Russia	1
Serbia	40
Slovakia	30
Slovenia	50
Spain	10
Sweden	20
Switzerland	20
UK	unknown

1.18 If required, how often a PwMS can receive rehabilitation services as an in-patient?

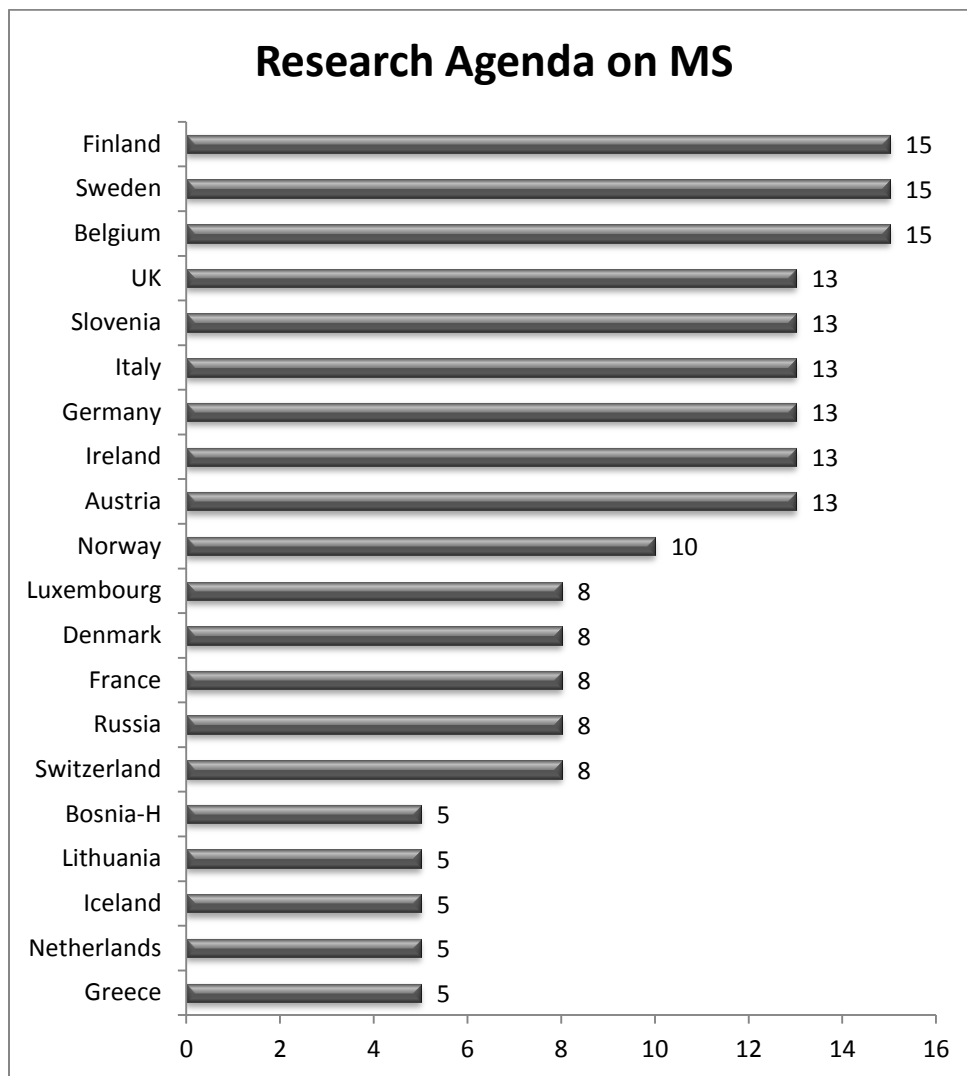
As often as required	Limited by health insurance rules	More than once per year	Less than once per year	No rehabilitation offered
Switzerland	Luxembourg	France	Estonia	Bosnia-Herzegovina
Italy	Finland	Ireland	Denmark	
Portugal	Serbia	Belarus	Greece	
Iceland	Germany		Sweden	
UK	Belgium		Norway	
Malta	Austria		Lithuania	
Netherlands	Slovakia		Russia	
	Hungary		Romania	
	Slovenia			
	Croatia			
	Czech Republic			
	Poland			
	Spain			
	Bulgaria			

Palliative care

1.19 Is there a Palliative Care programme specialised for PwMS in your country?

Yes (5 pts)	No (0 pt)
Italy	Switzerland
Iceland	Portugal
UK	Malta
Netherlands	Luxembourg
Germany	Finland
Belgium	Serbia
Czech Republic	Austria
Sweden	Slovakia
	Hungary
	Slovenia
	Croatia
	Poland
	Spain
	Bulgaria
	France
	Ireland
	Belarus
	Estonia
	Denmark
	Greece
	Norway
	Lithuania
	Russia
	Romania
	Bosnia-Herzegovina

Section 2: Research Agenda on MS



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

Yes (5 pts)	No (0 pt)
Switzerland	Czech Republic
Austria	Bulgaria
Ireland	Poland
Belgium	Belarus
Sweden	Greece
Germany	Serbia
Russia	Croatia
France	Netherlands
Italy	Iceland
Norway	Estonia
Denmark	Lithuania
Luxembourg	Portugal
Finland	Romania
Slovenia	Slovalia
UK	Bosnia-Herzegovina
	Malta
	Hungary
	Spain

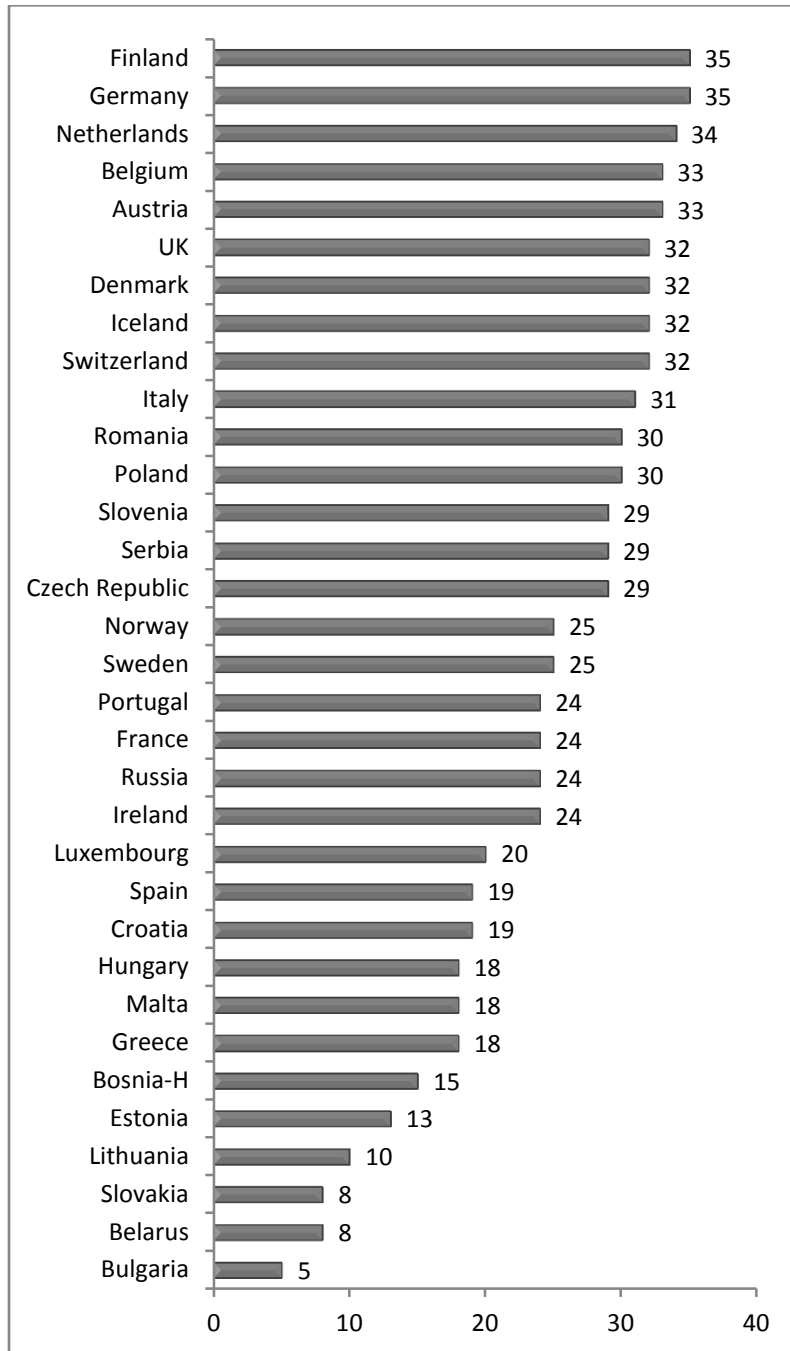
2.2 Are these MS research grants/schemes supported by public funding?

Over 50%	Under 50%	0%
Belgium	Switzerland	
Sweden	Austria	
Norway	Ireland	
Finland	Germany	
	Russia	
	France	
	Italy	
	Denmark	
	Luxembourg	
	Slovenia	
	UK	

2.3 Are MS societies consulted in influencing the national research agendas on MS?

Yes (5 pts)	No (0 pt)
Belgium	Norway
Sweden	Switzerland
Finland	Russia
Austria	France
Ireland	Denmark
Germany	Luxembourg
Italy	Czech Republic
Slovenia	Bulgaria
UK	Poland
Greece	Belarus
Netherlands	Serbia
Iceland	Croatia
Lithuania	Estonia
Bosnia-Herzegovina	Portugal
	Romania
	Slovalia
	Malta
	Hungary
	Spain

Section 3: Employment and Job retention



3.1 Is there information programme for employers and trade unions on the subject of MS or disability in general offered in your country? Y = Yes

	Yes, run by:					No	Total
	MS Society	State Authority	Health Insurers	Employer Body	Trade Union body	No programme exists	
Belgium	Y	Y	Y	Y	Y		5
Germany	Y	Y	Y	Y	Y		5
Finland	Y	Y	Y	Y	Y		5
Netherlands		Y		Y	Y		4
Austria	Y	Y	Y				3
Switzerland	Y	Y					2
Poland	Y	Y					2
Iceland	Y	Y					2
Denmark	Y	Y					2
Romania	Y			Y			2
UK	Y	Y					2
Ireland		Y					1
Czech Republic				Y			1
Serbia	Y						1
Russia	Y						1
Croatia	Y						1
France	Y						1
Italy	Y						1
Portugal	Y						1
Slovenia	Y						1

Spain	Y						1
Bulgaria						Y	0
Sweden						Y	0
Belarus						Y	0
Greece						Y	0
Estonia						Y	0
Norway						Y	0
Lithuania						Y	0
Luxembourg						Y	0
Slovakia						Y	0
Bosnia- Herzegovina						Y	0
Malta						Y	0
Hungary						Y	0

3.2 Does any kind of MS awareness raising programme for the workplace (for employers and employees) exist?

Yes (5 pts)	No (0 pt)
Belgium	Ireland
Germany	Russia
Finland	Croatia
Netherlands	France
Austria	Bulgaria
Switzerland	Sweden
Poland	Belarus
Iceland	Greece
Denmark	Estonia
Romania	Norway
UK	Lithuania
Czech Republic	Luxembourg
Serbia	Slovakia
Italy	Bosnia-Herzegovina
Portugal	Malta
Slovenia	Hungary
Spain	

3.3 Are there incentives in place to hire or retain persons with disabilities in general or PwMS in employment?

Yes (5 pts)	No (0 pt)
Belgium	Bulgaria
Germany	Belarus
Finland	Greece
Netherlands	Estonia
Austria	Lithuania
Switzerland	Slovakia
Poland	Bosnia-Herzegovina
Iceland	Malta
Denmark	
Romania	
UK	
Czech Republic	
Serbia	
Italy	
Portugal	
Slovenia	
Spain	
Ireland	
Russia	
Croatia	
France	
Sweden	
Norway	
Luxembourg	
Hungary	

3.4 Is it legally possible for persons with disabilities in general or PwMS to remain at work if he/she has MS?

Yes (5 pts)	No (0 pt)
Belgium	Spain
Germany	Belarus
Finland	
Netherlands	
Austria	
Switzerland	
Poland	
Iceland	
Denmark	
Romania	
UK	
Czech Republic	
Serbia	
Italy	
Portugal	
Slovenia	
Ireland	
Russia	
Croatia	
France	
Sweden	
Norway	
Luxembourg	
Hungary	
Bulgaria	
Greece	
Estonia	
Lithuania	
Slovakia	
Bosnia-Herzegovina	
Malta	

3.5 Is there flexible working practice legislation in place for people with disabilities in general or PwMS to avail of?

Yes (5 pts)	No (0 pt)
Belgium	Portugal
Germany	Croatia
Finland	Luxembourg
Netherlands	Hungary
Austria	Bulgaria
Switzerland	Estonia
Poland	Lithuania
Iceland	Slovakia
Denmark	Bosnia-Herzegovina
Romania	Spain
UK	Belarus
Czech Republic	
Serbia	
Italy	
Slovenia	
Ireland	
Russia	
France	
Sweden	
Norway	
Greece	
Malta	

3.6 What percentage of PwMS is in active work?

a. Full time job

Countries	%
Austria	45
Belarus	5
Belgium	40
Bosnia-Herzegovina	30
Bulgaria	30
Croatia	20
Czech Republic	30
Denmark	11
Estonia	unknown
Finland	35
France	25
Germany	32
Greece	35
Hungaria	5
Iceland	40
Ireland	22
Italy	50
Lithuania	10
Luxembourg	50
Malta	10
Netherlands	25
Norway	unknown
Poland	unknown
Portugal	44
Romania	unknown
Russia	50
Serbia	10
Slovakia	15
Slovenia	30
Spain	50
Sweden	unknown
Switzerland	40
UK	unknown

b. Part-time job

Countries	%
Austria	15
Belarus	25
Belgium	34
Bosnia-Herzegovina	0
Bulgaria	1
Croatia	0,59
Czech Republic	50
Denmark	24
Estonia	unknown
Finland	15
France	35
Germany	13
Greece	20
Hungaria	2
Iceland	25
Ireland	24
Italy	10
Lithuania	40
Luxembourg	10
Malta	5
Netherlands	30
Norway	unknown
Poland	unknown
Portugal	unknown
Romania	unknown
Russia	10
Serbia	1
Slovakia	10
Slovenia	60
Spain	10
Sweden	unknown
Switzerland	30
UK	unknown

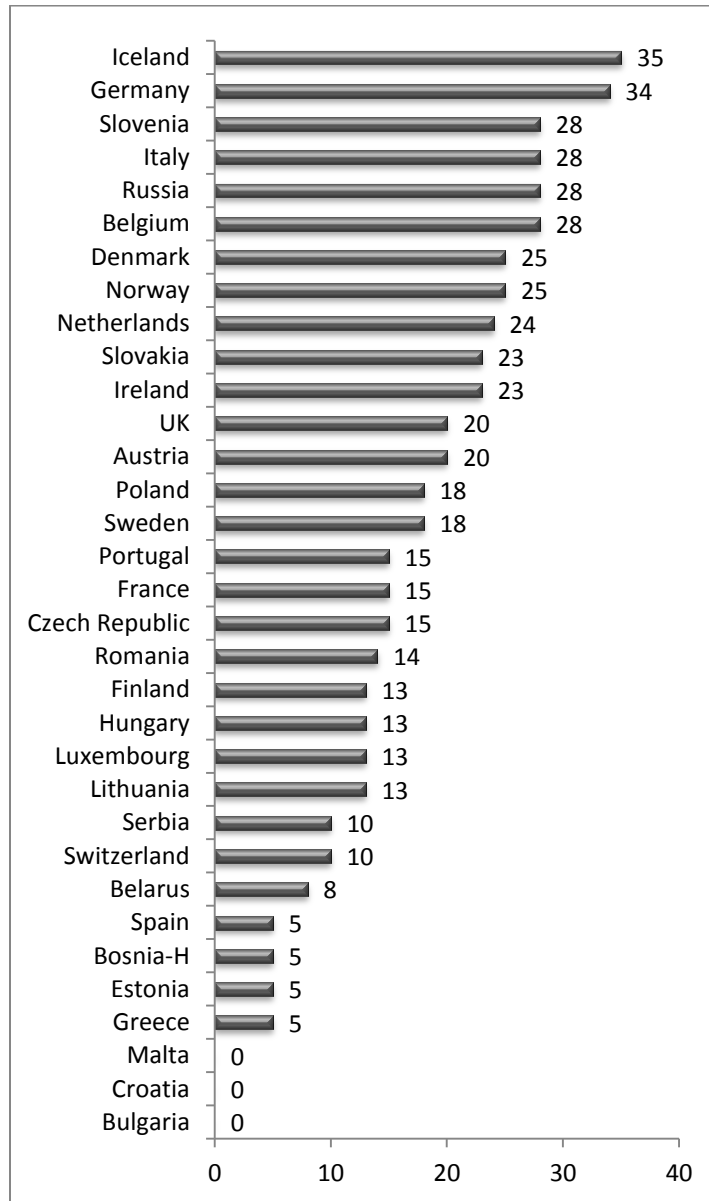
3.7 Does a pension fund exist for early retirement due to disability including MS?

Yes (5 pts)	No (0 pt)
Belgium	Bulgaria
Germany	Slovakia
Finland	
Netherlands	
Austria	
Switzerland	
Poland	
Iceland	
Denmark	
Romania	
UK	
Czech Republic	
Serbia	
Italy	
Slovenia	
Ireland	
Russia	
France	
Sweden	
Norway	
Greece	
Malta	
Portugal	
Croatia	
Luxembourg	
Hungary	
Estonia	
Lithuania	
Bosnia-Herzegovina	
Spain	
Belarus	

3.8 Does the pension fund provide "adequate" income for PWMS according to the average income in your country?

Pension inadequate	Pension needs supplementing	No pension funds exists
Germany	Belgium	Lithuania
Finland	Poland	Bulgaria
Netherlands	Romania	
Austria	Czech Republic	
Switzerland	Serbia	
Iceland	Slovenia	
Denmark	Ireland	
UK	Russia	
Italy	France	
Sweden	Greece	
Norway	Malta	
Luxembourg	Portugal	
Bosnia-Herzegovina	Croatia	
	Hungary	
	Estonia	
	Spain	
	Belarus	
	Slovakia	

Section 4: Empowerment of PwMS



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

Yes (5 pts)	No (0 pt)
Austria	Switzerland
Ireland	Bulgaria
Czech Republic	Sweden
Belgium	Belarus
Germany	Greece
Poland	Croatia
Serbia	Estonia
Russia	Lithuania
France	Luxembourg
Netherlands	Bosnia-Herzegovina
Italy	Malta
Iceland	Finland
Norway	Spain
Denmark	
Portugal	
Romania	
Slovakia	
Hungary	
Slovenia	
UK	

4.2 Are PwMS represented in the consultation group/body?

Yes (5 pts)	No (0 pt)
Austria	Czech Republic
Ireland	Serbia
Belgium	France
Germany	Norway
Poland	Denmark
Russia	Romania
Netherlands	Hungary
Italy	UK
Iceland	Switzerland
Portugal	Bulgaria
Slovakia	Sweden
Slovenia	Greece
Belarus	Croatia
	Estonia
	Lithuania
	Luxembourg
	Bosnia-Herzegovina
	Malta
	Finland
	Spain

4.3 Is the MS Society a member of the body that decides on the reimbursement of a new MS therapy?

Yes (5 pts)	No (0 pt)
Germany	Austria
Poland	Ireland
Iceland	Belgium
	Russia
	Netherlands
	Italy
	Portugal
	Slovakia
	Slovenia
	Belarus
	Czech Republic
	Serbia
	France
	Norway
	Denmark
	Romania
	Hungary
	UK
	Switzerland
	Bulgaria
	Sweden
	Greece
	Croatia
	Estonia
	Lithuania
	Luxembourg
	Bosnia-Herzegovina
	Malta
	Finland
	Spain

4.4 Does the national MS Society have formal consultative status with your national administration?

Yes (5 pts)	No (0 pt)
Germany	Poland
Iceland	Ireland
Austria	Netherlands
Belgium	Portugal
Russia	Slovakia
Italy	Belarus
Slovenia	Serbia
Czech Republic	Romania
France	Hungary
Norway	UK
Denmark	Bulgaria
Switzerland	Croatia
Sweden	Estonia
Greece	Lithuania
Bosnia-Herzegovina	Luxembourg
	Malta
	Finland
	Spain

4.5 Does a self-management course exist in your country for PwMS to empower them to co-manage their own health as far as possible?

Yes (5 pts)	No (0 pt)
Germany	Austria
Iceland	Czech Republic
Belgium	France
Russia	Switzerland
Italy	Greece
Slovenia	Bosnia-Herzegovina
Norway	Poland
Denmark	Portugal
Sweden	Belarus
Ireland	Serbia
Netherlands	Romania
Slovakia	Bulgaria
Hungary	Croatia
UK	Estonia
Lithuania	Malta
Luxembourg	Spain
Finland	

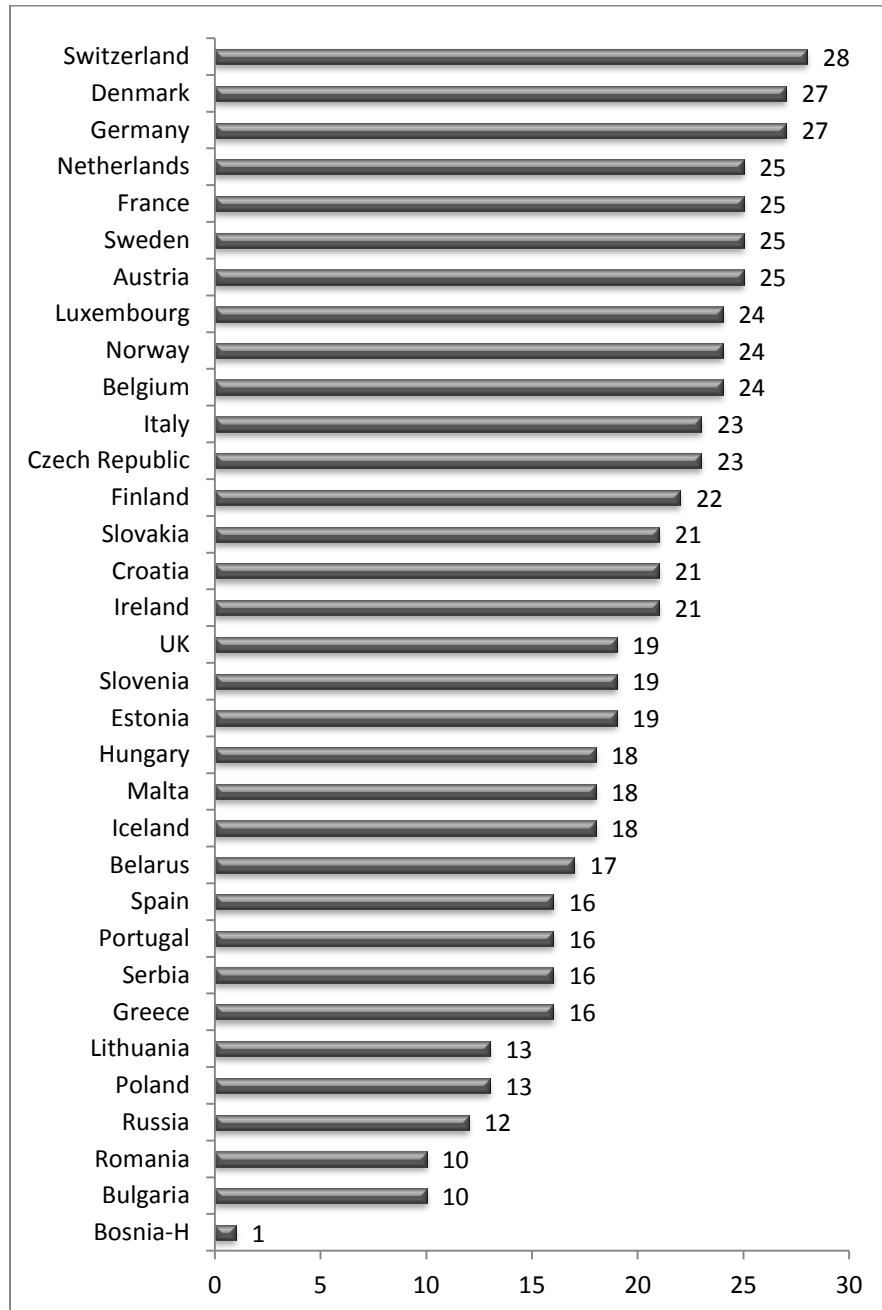
4.6 Who runs the self-management course for PwMS?

The self-management course for PwMS is run by :			
State Authority	Health Insurance	MS Society	Other
Iceland	Germany	Belgium	Austria
Norway	Netherlands	Russia	Czech Republic
Denmark	Romania	Italy	France
UK		Slovenia	Switzerland
		Sweden	Greece
		Ireland	Bosnia-Herzegovina
		Slovakia	Portugal
		Hungary	Serbia
		Lithuania	Bulgaria
		Luxembourg	Croatia
		Finland	Estonia
		Poland	Malta
		Belarus	Spain

4.7 Can a PwMS interface with a multi-disciplinary team in the management of their condition?

Yes (5 pts)	No (0 pt)
Iceland	Hungary
Norway	Poland
Denmark	Belarus
UK	Greece
Germany	Bosnia-Herzegovina
Netherlands	Bulgaria
Romania	Croatia
Belgium	Malta
Russia	
Italy	
Slovenia	
Sweden	
Ireland	
Slovakia	
Lithuania	
Luxembourg	
Finland	
Austria	
Czech Republic	
France	
Switzerland	
Portugal	
Serbia	
Estonia	
Spain	

Section 5: Reimbursement of costs related to MS



5.1 What percentage of DMD costs is reimbursed?

100%	Between 75% – 99%	Between 50% - 74%	Between 25% - 49%	Less than 25%	None
Switzerland	Belgium				Belarus
Austria	Sweden				Bosnia- Herzegovina
Ireland	Russia				
Czech Republic	Netherlands				
Bulgaria	Lithuania				
Germany	Finland				
Poland	UK				
Greece					
Serbia					
Croatia					
France					
Italy					
Iceland					
Estonia					
Norway					
Denmark					
Portugal					
Romania					
Luxembourg					
Slovakia					
Malta					
Hungary					
Slovenia					
Spain					

5.2 What percentage of the costs for symptomatic therapy is reimbursed?

100%	Between 75% – 99%	Between 50% - 74%	Between 25% - 49%	Less than 25%	None
Switzerland	Austria	Serbia	Portugal	Bulgaria	Bosnia- Herzegovina
Ireland	Italy	Norway	Russia	Poland	
Czech Republic	Estonia	Romania			
Germany	Denmark	Slovakia			
Greece	Luxembourg	Hungary			
Croatia	Belgium	Spain			
France	Sweden	Finland			
MS Society of Iceland	Netherlands	UK			
Malta	Lithuania				
Slovenia	Belarus				

5.3 What percentage of rehabilitation costs is reimbursed?

100%	Between 75% – 99%	Between 50% - 74%	Between 25% - 49%	Less than 25%	None
Switzerland	Slovenia	Malta	Greece	Bulgaria	Romania
Ireland	Austria	Estonia	Russia	Poland	Bosnia- Herzegovina
Czech Republic	Luxembourg	Spain			
Germany	Belgium	UK			
Croatia	Sweden	Portugal			
France	Netherlands				
Iceland	Lithuania				
Italy	Belarus				
Denmark	Norway				
Serbia	Finland				
Slovakia					
Hungary					

5.4 What percentage of home adaptation costs is reimbursed?

100%	Between 75% – 99%	Between 50% - 74%	Between 25% - 49%	Less than 25%	None
Denmark	Switzerland	Czech Republic	Malta	Ireland	Croatia
Slovakia	Austria	Germany	Estonia	Slovenia	Iceland
Sweden	Luxembourg	France	Poland	Spain	Serbia
Netherlands	Belgium	Italy		Portugal	Lithuania
	Norway	Hungary		Greece	Bulgaria
		Belarus		Russia	Romania
		Finland			Bosnia-Herzegovina
		UK			

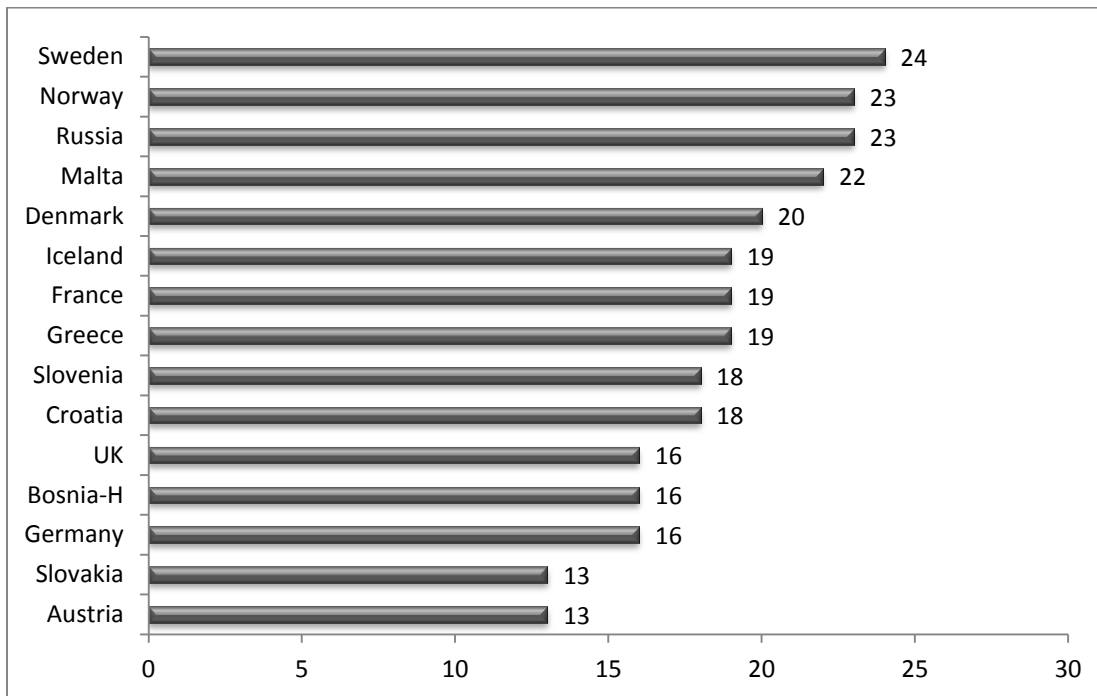
5.5 What percentage of workplace adaptation costs is reimbursed?

100%	Between 75% – 99%	Between 50% - 74%	Between 25% - 49%	Less than 25%	None
Denmark	Sweden	Czech Republic	Estonia	Slovenia	Slovakia
Norway	Netherlands	France	Poland	Spain	Hungary
Germany	Switzerland	Italy	Ireland	Greece	Malta
	Austria	UK	Portugal	Russia	Iceland
	Luxembourg		Croatia	Serbia	Lithuania
	Belgium			Bulgaria	Romania
	Belarus				Bosnia-Herzegovina
	Finland				

5.6 What percentage of your country's GDP is spent on healthcare?

Greater than 15%	Between 11% - 14%	Between 7% - 10%	Between 3% - 6%	Less than 3%
Switzerland	Germany	Denmark	Belarus	Lithuania
	Sweden	Norway	Czech Republic	Bosnia- Herzegovina
	Netherlands	Luxembourg	Poland	
	Austria	Italy	Greece	
	Belgium	UK	Russia	
	Finland	Estonia	Serbia	
	France	Ireland	Bulgaria	
	Croatia	Portugal	Hungary	
		Slovenia	Romania	
		Spain		
		Slovakia		
		Malta		
		Iceland		

Section 6: Accurate data collection on MS at national level



6.1 Does a national MS register exist?

Yes (5 pts)	No (0 pt)
Austria	Switzerland
Sweden	Ireland
Germany	Czech Republic
Greece	Bulgaria
Russia	Belgium
Croatia	Poland
France	Belarus
Iceland	Serbia
Norway	Netherlands
Denmark	Italy
Slovakia	Estonia
Bosnia-Herzegovina	Lithuania
Malta	Portugal
Slovenia	Romania
UK	Luxembourg
	Hungary
	Finland
	Spain

6.2 Who manages the MS register?

France	EDMUS Foundation
Sweden	Karin Lycke Forskningssjuksköterska, MPH Institutionen för klinisk neurovetenskap (CNS) Besöks- och postadress: Karolinska Institutet, Institutet för miljömedicin (IMM) Enheten för kardiovaskulär epidemiologi
Germany	DMSG
Greece	
Russia	
Croatia	Croatian MS Society
Iceland	Sverrir Bergmann till 2011
Norway	Norsk MS-register og Biobank
Denmark	1. The Danish Multiple Sclerosis Treatment Registry funded and managed by the State authority (Day to day manager: Nils Koch-Henriksen) 2. The Danish Multiple Sclerosis Registry is funded by the Danish MS Society and a neurologist, Nils Koch- Henriksen.
Slovakia	
Bosnia Herzegovina	
Slovenia	
UK	
Austria	Managed by the Austrian Neurological Society National MS Register for Tysabri and Gilenya
Malta	Dr Malcolm Vella, a doctor working at Mater Dei Hospital in Malta

6.3 Is the register supported by public funding?

Yes			No
More than 50%	Between 10% - 49%	Less than 10%	
France Sweden Russia Croatia Norway Malta		Greece	Germany Iceland Denmark Slovakia Bosnia-Herzegovina Slovenia UK Austria

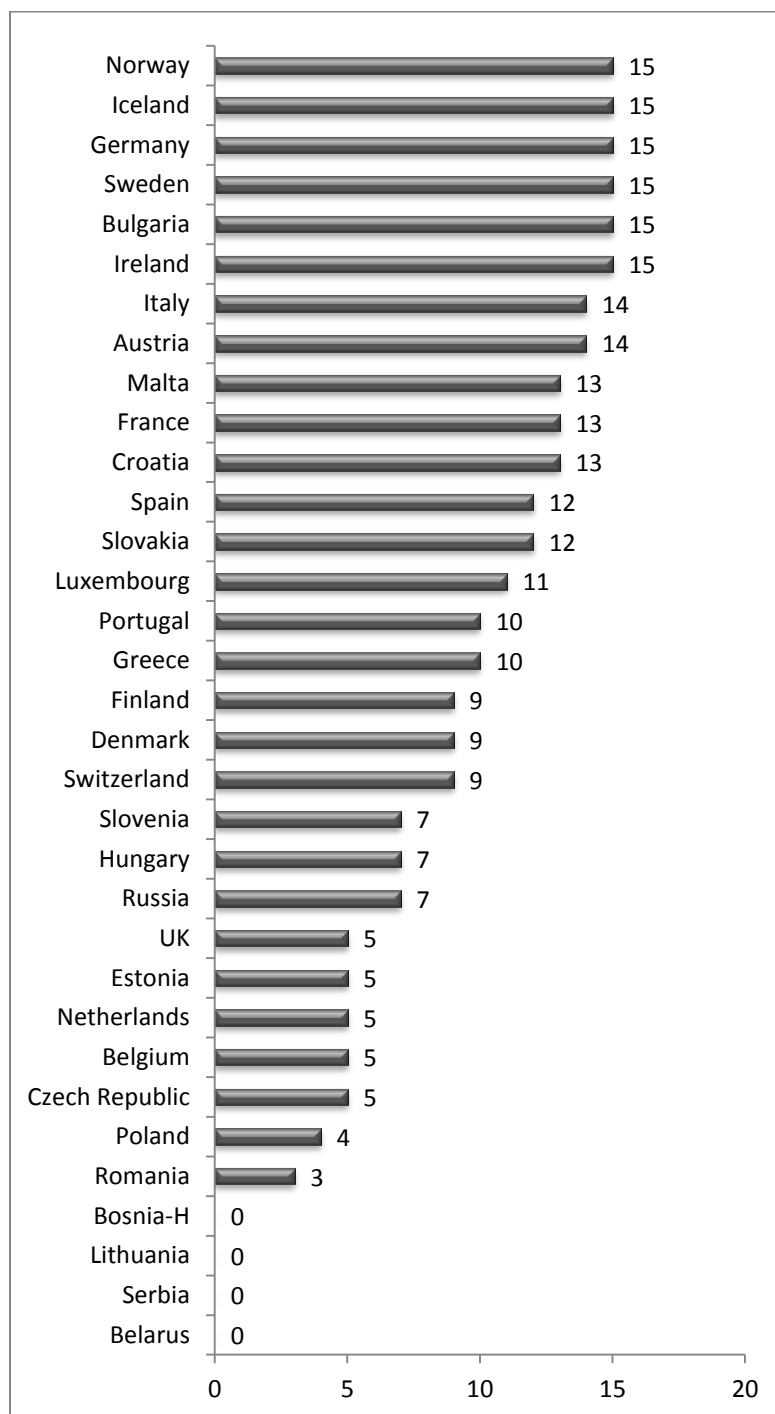
6.4 If a register exists, what % of PwMS is currently recorded on the register?

Between 95% - 100%	Between 75% - 94%	Between 50% - 74%	Between 25% - 49%	Between 1% - 24%
Malta Denmark	Sweden Iceland	France Russia Croatia Norway Greece Slovakia Slovenia		Germany Bosnia-Herzegovina UK Austria

6.5 Does the information coming from the MS register have an influence on the national policy for PwMS?

Yes (5 pts)	No (0 pt)
Malta	France
Denmark	Croatia
Sweden	Slovakia
Iceland	
Russia	
Norway	
Greece	
Slovenia	
Germany	
Bosnia-Herzegovina	
UK	
Austria	

Section 7: Medication coming to the market



7.1 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 EMA⁴?

< 3 months	3-6 months	6-9 months	9-12 months	12-15 months	> 15 months
Ireland	Switzerland	Greece	Hungary	Netherlands	Czech Republic
Bulgaria	Austria	Russia		Romania	Belgium
Sweden	Croatia	France			Poland
Germany	Italy	Luxembourg			Belarus
Iceland	Finland	Slovakia			Serbia
Norway	Slovenia	Malta			Estonia
Denmark		Spain			Lithuania
Portugal		UK			Bosnia-Herzegovina

⁴ **European Medicine Agency (EMA)**: is a decentralised agency of the European Union, located in London, responsible for the scientific evaluation of medicines developed by pharmaceutical companies for use in the European Union. www.ema.europa.eu

7.2 How long does it take for PwMS, legally entitled to receive the drug, to get it?

< 3 months	3-6 months	6-9 months	9-12 months	12-15 months	> 15 months
Ireland	Denmark	Slovenia	Greece		Czech Republic
Bulgaria	Croatia	Luxembourg	UK		Belarus
Sweden	Russia		Romania		Serbia
Germany	Slovakia				Lithuania
Iceland	Spain				Bosnia-Herzegovina
Norway	Netherlands				
Portugal	Poland				
Switzerland					
Austria					
Italy					
Finland					
France					
Malta					
Hungary					
Belgium					
Estonia					

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

Yes (5 pts)	No (0 pt)
Ireland	Portugal
Bulgaria	Switzerland
Sweden	Finland
Germany	Hungary
Iceland	Belgium
Norway	Estonia
Austria	Denmark
Italy	Russia
France	Netherlands
Malta	Poland
Croatia	Slovenia
Slovakia	UK
Spain	Romania
Luxembourg	Belarus
Greece	Serbia
Czech Republic	Lithuania
	Bosnia-Herzegovina

About EMSP

Founded in 1989, the European Multiple Sclerosis Platform (EMSP) is the umbrella organization for 38 MS Societies operating in 34 European countries.

Full members: Austria, Belarus, Belgium, Bosnia-Herzegovina, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France (LFSEP), Germany, Greece (GMSS), Hungary (MSMT), Iceland, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, The Netherlands, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Slovenia, Spain (AEDEM-COCEMFE), Sweden, Switzerland, United Kingdom

Associate members: France (UNISEP), Greece (Hellenic Federation of Persons with MS), Hungary (SMBOE), Spain (FELEM)

The EMSP lobbies at the European level to uphold the rights of persons with MS. Its activities derive from a mission comprising five main objectives:

- To encourage MS Research through recognized organisations;
- To exchange and disseminate information related to MS;
- To promote collaborative programmes among national MS Societies in Europe;
- To Facilitate interaction between institutions of the European Union, the Council of Europe and other organisations;
- To propose new measures to advance the rights of Persons with MS and ensure their participation in society.

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