

MS Barometer 2013

Widespread health inequalities revealed

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's flagship projects aim to improve quality of life as well as access to treatment, care and employment. 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 39 national MS member societies from 34 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-centered therapies and appropriate medication. However, there is tremendous variation in access to optimal treatment and care across Europe.

Contents

Introduction

Methodology

Main areas of interest for the people with MS

General observations

- Huge disparities across Europe

- Key findings

Detailed scores

Overall results

- Section 1: Access to treatments and therapies

- Section 2: MS research

- Section 3: Education, employment and job retention

 - Young people with MS and education

 - MS and employment

- Section 4: Involvement and empowerment of people with MS

- Section 5: Reimbursement of costs related to MS

- Section 6: Accurate national data collection on MS

- Section 7: Medication coming to the market

Call for action

Sources of information

Acknowledgement

Introduction

Since its foundations in 1989, the European Multiple Sclerosis Platform (EMSP) has been representing the voice of people with multiple sclerosis (MS) with the goal of improving management of the condition and quality of life.

During the course of developing a wide range of EMSP projects and advocacy activities, consultation with stakeholders it became clear that there was a lack of information on management of MS across Europe. To address that and be able to provide meaningful figures, in 2008, EMSP developed a unique benchmarking tool called the MS Barometer.

The MS Barometer 2013 aims to provide regular update of the information gathered in previous years and compare the evolution of disease management and the situation of people with MS across Europe. The MS Barometer is used as a lobbying tool in approaching national administrations to advocate for changes in policies that at present impact negatively on the lives of people with MS.

The results from this benchmarking tool have proven to be most valuable. The information has been used in advocacy activities, both at European and national level among the political decision-makers. Furthermore it highlights the huge disparities in access to appropriate healthcare and health professionals for people with MS and the unacceptable variations in their quality of life from one country to another.

Methodology

The MS Barometer consists of a series of questions, with scores allocated according to the responses provided in. The aim is to have points awarded recognition of the effectiveness of policies that optimise the situation of people with MS in each country. The higher the score, the better the disease management, level of support and therefore the quality of life of people with MS.

The data contained in the 2013 MS Barometer was collected through an online questionnaire completed by EMSP member organisations, from July to October 2013. This was an improved version of the initial questionnaire from 2008, reviewed for subsequent editions of the MS Barometer in 2009, 2011 and 2013 to enhance accuracy and reliability. For this purpose, consultation with EMSP member organisations was launched in May 2013. A glossary was developed to improve the understanding of the questions by the respondents despite potential language barriers.

Although the original, core structure of the MS Barometer was retained in 2013, it was decided to extend the questionnaire further in the field of education and employment to collect more information on barriers faced by young people with MS, especially at a time of economic crisis affecting society at large.

The comparability of data from the 2013 Barometer with the results from 2011 is limited only to those questions which were not affected by the review in 2013.

The questionnaire was sent to all EMSP member organisations as they are the main contact points in EU countries which can provide the information. Members were asked to add the data sources and references to ensure reliable information was submitted.

The data was gathered from 25 countries, compared to 33 in 2011. The reason for the reduction in the number of responding countries was identified as the lack of time to collect, process and convey 'on-the-ground' information, but the 2013 edition of the MS Barometer keeps the questionnaire open for other member societies to join in once they have their data.

Main areas of interest for the people with MS

Seven priority thematic areas have been identified:

1. Access to treatments and therapies
2. Research agenda in MS
3. Education, employment & job retention
4. Empowerment of people with MS
5. Reimbursement of costs
6. Accurate data collection
7. Medication coming to the market

General observations

Huge disparities across Europe

Once more, the MS Barometer has revealed striking disparities between European countries in terms of management of multiple sclerosis. The results show the challenges faced by people with multiple sclerosis who strive for a fully empowered and participative life in society despite the disease. Although no one institution can be held accountable for this alarming situation, responsibilities have to be defined in order to undertake the appropriate steps and tackle the barriers which stand in the way of people with multiple sclerosis improving their quality of life and contributing in all aspects to society.

Despite recognised fundamental rights¹ - such as equality (non-discrimination, integration of people with disabilities), freedom (in terms of education, employment), solidarity (social security and assistance, health care) – and despite the Member States' efforts to ensure that appropriate legislation is adopted to respect those rights, the reality shown by the MS Barometer figures are disturbing because they reveal a “two-speed Europe”. Indeed, depending on which country you live in, the quality of life can be radically different.

Key findings

Access to treatments and therapies is not available in all countries in the most efficient way for people affected by MS. To remedy to this situation: the endorsement of the European guidelines for standard treatments and therapies - such as the European Code of Good Practice - by health professionals and national authorities, together with a specialised training for MS, is recommended.

It is also important to reduce administrative barriers in order to access available treatments on the market within Europe. Once the drugs are approved, national administrative procedures should not prevent patients from accessing them. Everyone has a right to benefit from effective medical treatment.

Active participation of people with MS in society **requires proper access to education and employment**. Thus, it is important to ensure that young people diagnosed with MS during the course of their education receive the appropriate support to help them complete their studies.

The results reveal that although **legal protection of workers** exists in Social and Labour legislation of most of the European countries, the number of people with MS at work remains low. There is a huge gap between the letter of the law and the reality for people with MS.

Empowerment and involvement of people with MS in the decision-making process also needs attention - people affected by MS are best placed to represent themselves and their needs. The

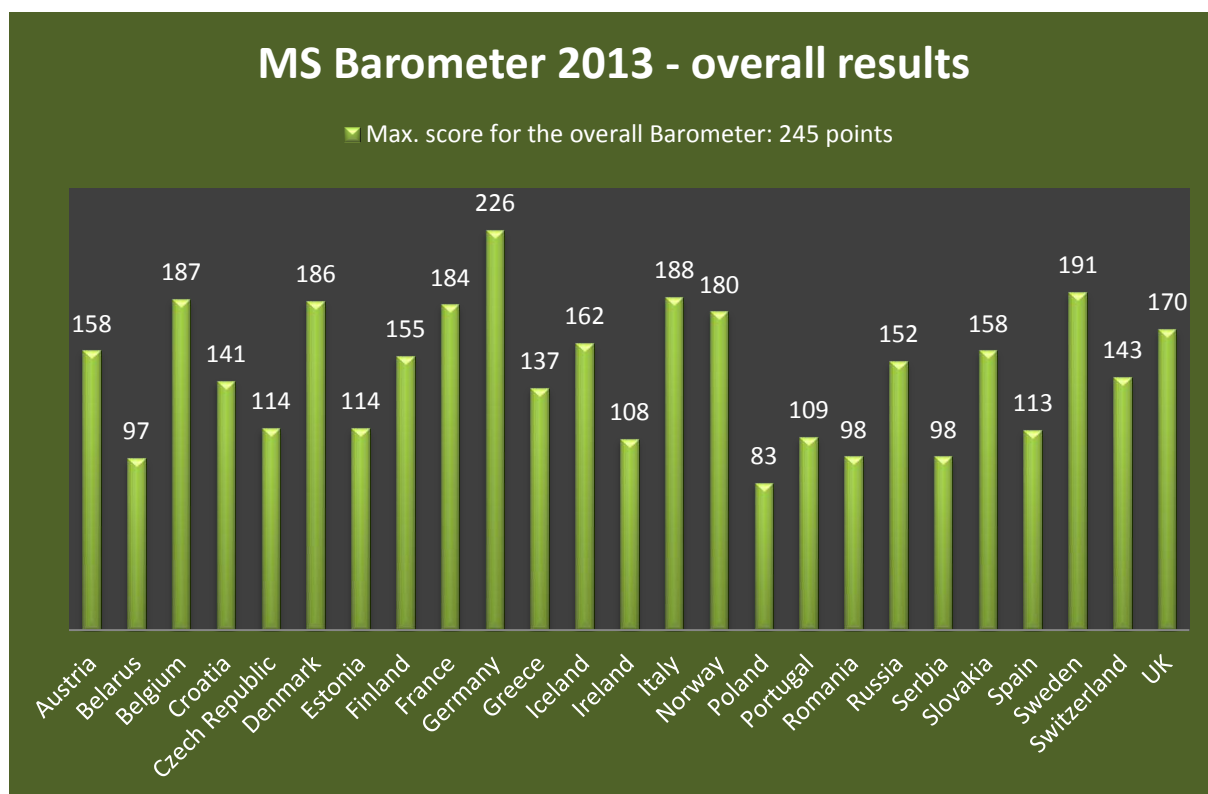
¹ Charter of fundamental rights of the European Union (2010/C 83/02)

decision-making process should provide for more room for those directly affected to be heard and consulted.

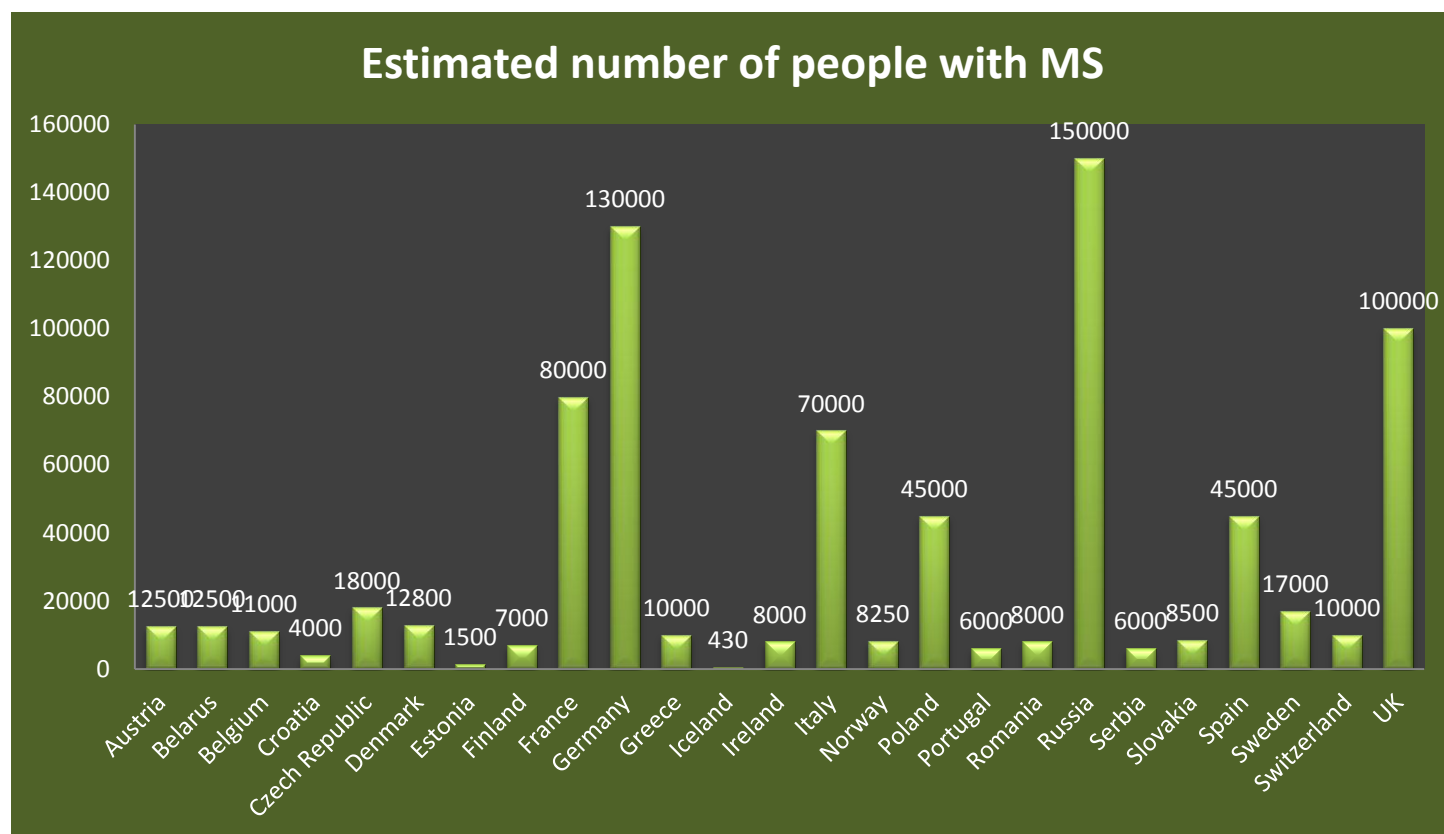
Multiple sclerosis is a disease for which there is currently no cure. Therefore, in order to support research **data collection is vital**. Very few MS national registers exist to date. Public authorities should be aware of the necessity to develop such registers, not only for research but also as potential data provider for shaping and adopting the most effective policies to improve the situation of people with MS in each country.

Detailed scores

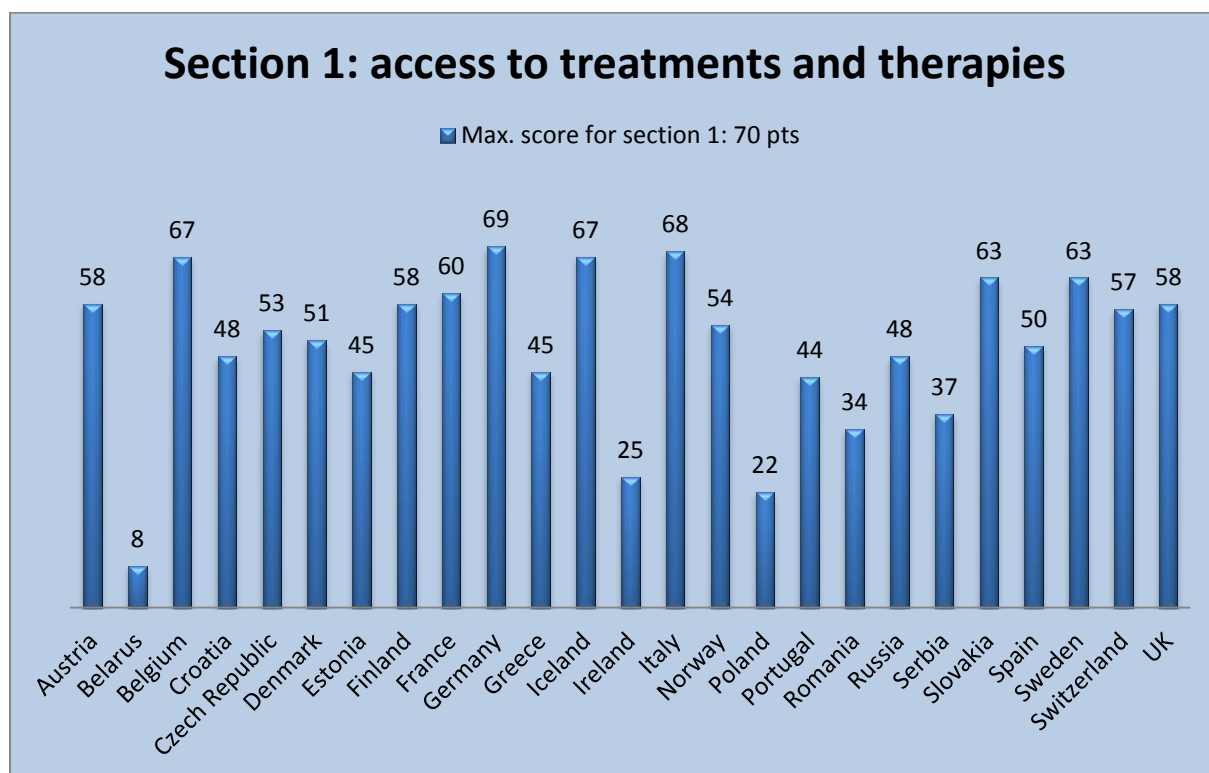
Overall results



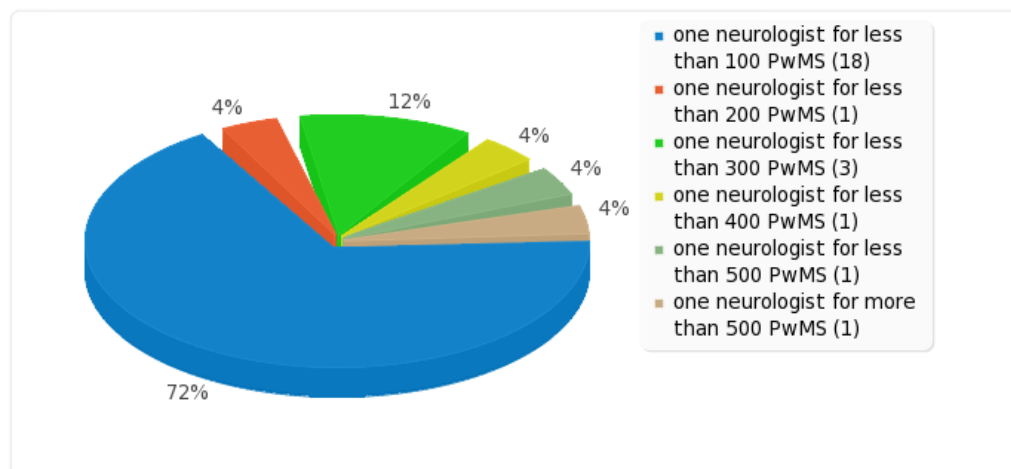
25 countries participated in the MS Barometer 2013 representing an estimated 505,175 people affected with MS in those countries: Austria, Belarus, Belgium, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Spain, Sweden, Switzerland and the United Kingdom.



Section 1: Access to treatments and therapies



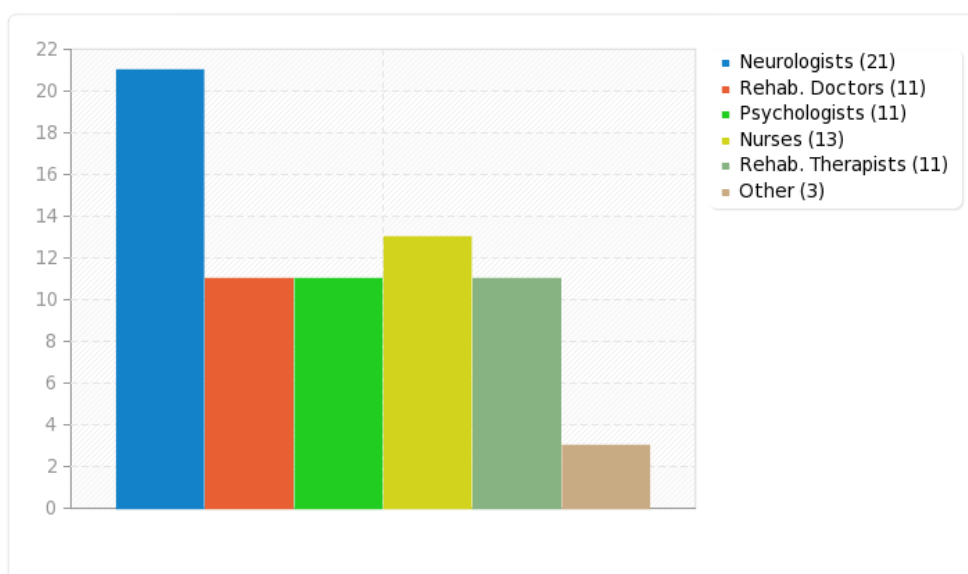
1.1 If you divide the estimated number of people with MS in your country by the number of practicing neurologists in your country, what is the relative figure?



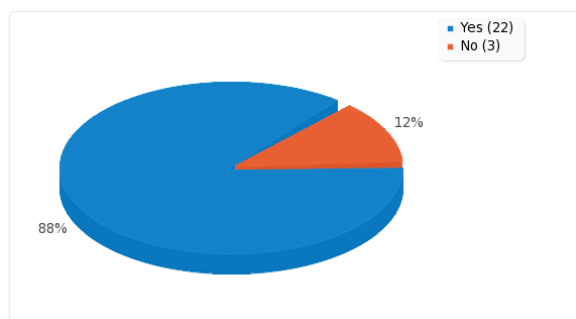
Answers	Countries
One neurologist for less than 100 people with MS	Austria, Belgium, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Iceland, Italy, Norway, Poland, Portugal, Romania, Slovakia, Sweden, Switzerland
One neurologist for less than 200 people with MS	Spain
One neurologist for less than 300 people with MS	Croatia, Ireland, United Kingdom
One neurologist for less than 400 people with MS	Russia
One neurologist for less than 500 people with MS	Serbia
one neurologist for more than 500 people with MS	Belarus

1.2 For which groups of health professionals is certified MS training available?

Certified MS training available for:	Neurologists	Rehab. Doctors	Psychologist	Nurses	Rehab. Therapists	Others
Austria	Yes	No	No	No	No	Neuro-rehab. specialist
Belarus	Yes	No	Yes	Yes	No	
Belgium	Yes	Yes	Yes	Yes	Yes	
Croatia	Yes	No	No	No	No	
Czech Republic	Yes	Yes	Yes	Yes	Yes	
Denmark	Yes	No	No	No	No	
Estonia	Yes	No	No	No	No	
Finland	No	No	No	Yes	No	
France	Yes	Yes	No	No	No	
Germany	Yes	Yes	Yes	Yes	Yes	
Greece	Yes	No	No	No	Yes	
Iceland	Yes	Yes	Yes	Yes	Yes	Social worker
Ireland	No	No	No	Yes	No	
Italy	Yes	Yes	Yes	Yes	Yes	
Norway	Yes	Yes	No	No	No	
Poland	No	No	No	No	No	
Portugal	Yes	No	No	No	No	
Romania	Yes	No	No	No	No	
Russia	Yes	No	No	Yes	No	
Serbia	Yes	Yes	Yes	Yes	Yes	
Slovakia	Yes	Yes	Yes	Yes	Yes	
Spain	Yes	No	No	No	No	
Sweden	Yes	Yes	Yes	Yes	Yes	
Switzerland	No	No	Yes	No	Yes	
UK	Yes	Yes	Yes	Yes	Yes	



1.3 Can people diagnosed with MS in your country be treated according to the recommendations outlined in the EMSP Consensus Paper “[Basic and escalating immuno-modulatory therapies in MS](#)”?



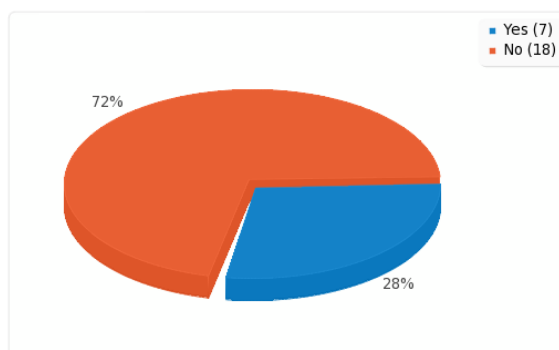
Replies	Countries
Yes	Austria, Belgium, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Norway, Portugal, Romania, Russia, Slovakia, Spain, Sweden, Switzerland, UK
No	Belarus, Poland, Serbia

1.4 What % of the total population of people with MS does actually receive DMD treatment* in your country?

***DMD treatments include: Avonex, Betaseron, Copaxone, Novantrone, Rebif, Tysabri, Extavia and Gilenya.**

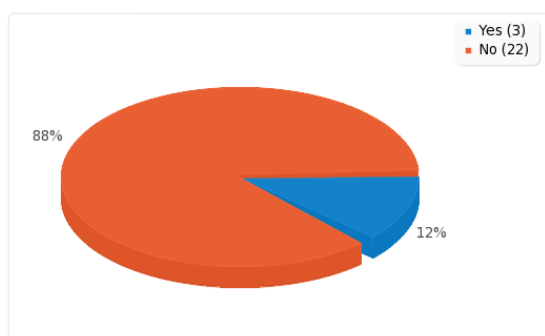
Country	% of the total population of people with MS does actually receive DMD treatment
Austria	65
Belarus	0
Belgium	70
Croatia	20
Czech Republic	25
Denmark	40
Estonia	33
Finland	50
France	70
Germany	70
Greece	70
Iceland	70
Ireland	unknown
Italy	65
Norway	45
Poland	11
Portugal	70
Romania	25
Russia	40
Serbia	10
Slovakia	unknown
Spain	55
Sweden	45
Switzerland	unknown

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



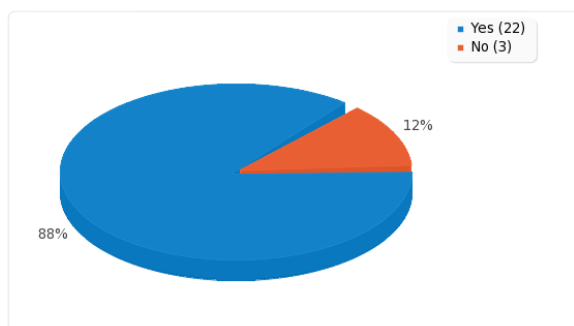
Replies	Countries
Yes	Belarus, Croatia, Czech Republic, Ireland, Poland, Romania, Serbia
No	Austria, Belgium, Denmark, Estonia, Finland, France, Germany, Greece, Iceland, Italy, Norway, Portugal, Russia, Slovakia, Spain, Sweden, Switzerland, UK

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



Replies	Countries
Yes	Belarus, Ireland, Poland
No	Austria, Belgium, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Iceland, Italy, Norway, Portugal, Romania, Russia, Serbia, Slovakia, Spain, Sweden, Switzerland, UK

1.7 Can people with MS be treated in accordance with the recommendations outlined in the EMSP consensus paper III "Symptomatic Treatment of MS" in your country?

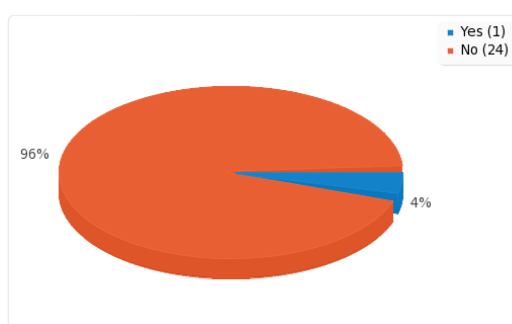


Replies	Countries
No	Belarus, Poland, Serbia
Yes	Austria, Belgium, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Norway, Portugal, Romania, Russia, Slovakia, Spain, Sweden, Switzerland, UK

1.8 What % of the population of people with MS currently receives symptomatic treatment in your country?

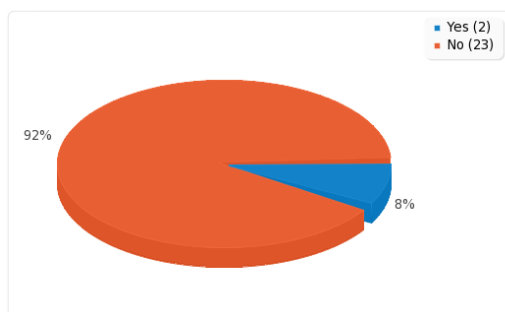
Country	% of the total population of people with MS currently receiving symptomatic treatment
Austria	85
Belarus	25
Belgium	70
Croatia	60
Czech Republic	100
Denmark	80
Estonia	Unknown
Finland	100
France	90
Germany	80
Greece	unknown
Iceland	100
Ireland	70
Italy	80
Norway	70
Poland	90
Portugal	85
Romania	60
Russia	50
Serbia	45
Slovakia	unknown
Spain	75
Sweden	unknown
Switzerland	unknown

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



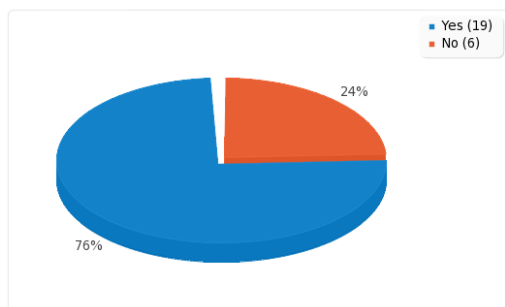
Only Belarus reported a limit to the duration of symptomatic treatment available other than medical reason.

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



In Belarus and Portugal the number of people with MS entitled to access to symptomatic treatment is limited.

1.11 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](#)”?

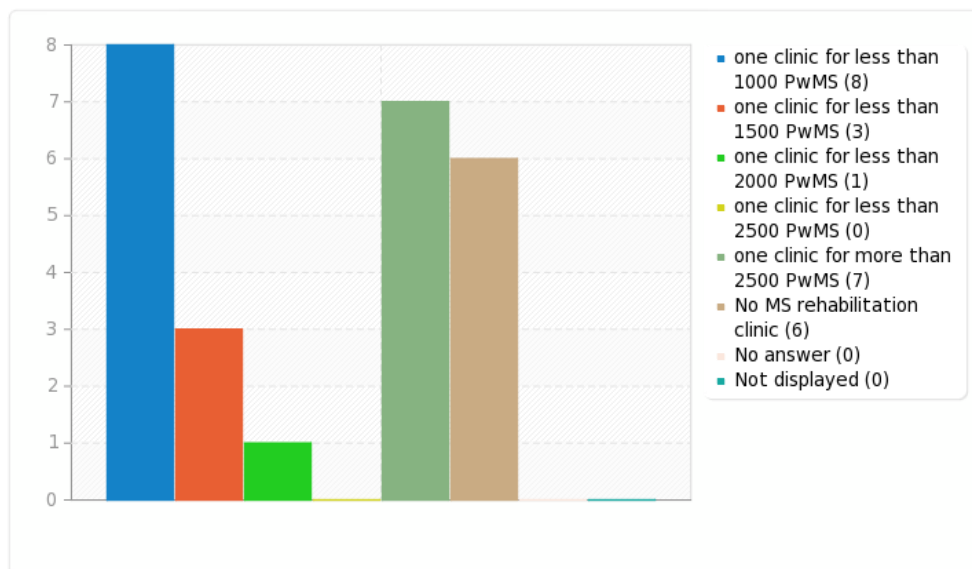


In Belarus, Estonia, Greece, Ireland, Poland and Romania the recommendations outlined in the European Consensus Paper on Rehabilitation for people with MS are not yet applied.

1.12 What % of the total population of people with MS in your country currently has access to rehabilitation centres?

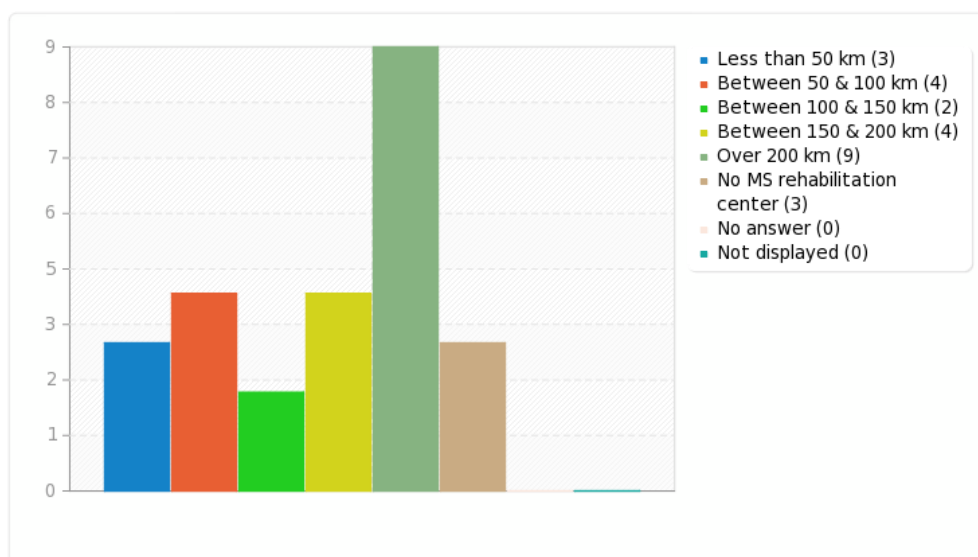
Country	% of the total population of people with MS
Austria	75
Belarus	25
Belgium	100
Croatia	100
Czech Republic	100
Denmark	100
Estonia	75
Finland	85
France	80
Germany	100
Greece	12
Iceland	100
Ireland	0
Italy	70
Norway	100
Poland	5
Portugal	30
Romania	10
Russia	30
Serbia	15
Slovakia	100
Spain	15
Sweden	60
Switzerland	100
UK	70

1.13 If you divide the number of people with MS by the number of specialised rehabilitation clinics, what figure do you come to?



Answers	Countries
One clinic for less than 1000 people with MS	Austria, Belgium, Finland, Iceland, Italy, Norway, Slovakia, Sweden
One clinic for less than 1500 people with MS	Croatia, Germany
One clinic for less than 2000 people with MS	Switzerland
One clinic for more than 2500 people with MS	Denmark, France, Poland, Portugal, Russia, Serbia, UK
No MS rehabilitation clinic	Belarus, Czech Republic, Estonia, Greece, Ireland, Romania, Spain

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



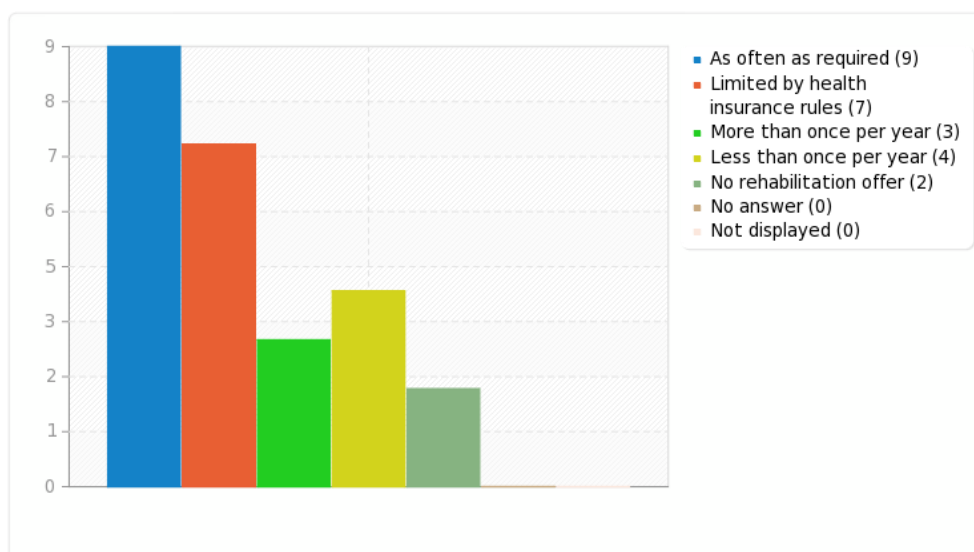
Answers	Countries
Less than 50 km	Germany, Slovakia, Spain
Between 50 & 100 km	Austria, Belgium, Czech Republic, France
Between 100 & 150 km	Finland, Italy
Between 150 & 200 km	Croatia, Iceland, Russia, Switzerland
Over 200 km	Denmark, Estonia, Ireland, Norway, Poland, Portugal, Serbia, Sweden, UK
No MS rehabilitation centre	Belarus, Greece, Romania

1.15 What % of the total population of people with MS in your country currently receives rehabilitation services as out-patients?

Country	% of the total population of people with MS receiving rehabilitation services as out-patients
Austria	60
Belarus	75
Belgium	80
Croatia	26
Czech Republic	10
Denmark	70
Estonia	unknown
Finland	60
France	60
Germany	80
Greece	15
Iceland	100
Ireland	unknown
Italy	50
Norway	unknown
Poland	unknown
Portugal	30
Romania	10
Russia	10
Serbia	10
Slovakia	unknown
Spain	20
Sweden	48
Switzerland	unknown
UK	unknown

1.16 If required, how often is a person with MS is 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.



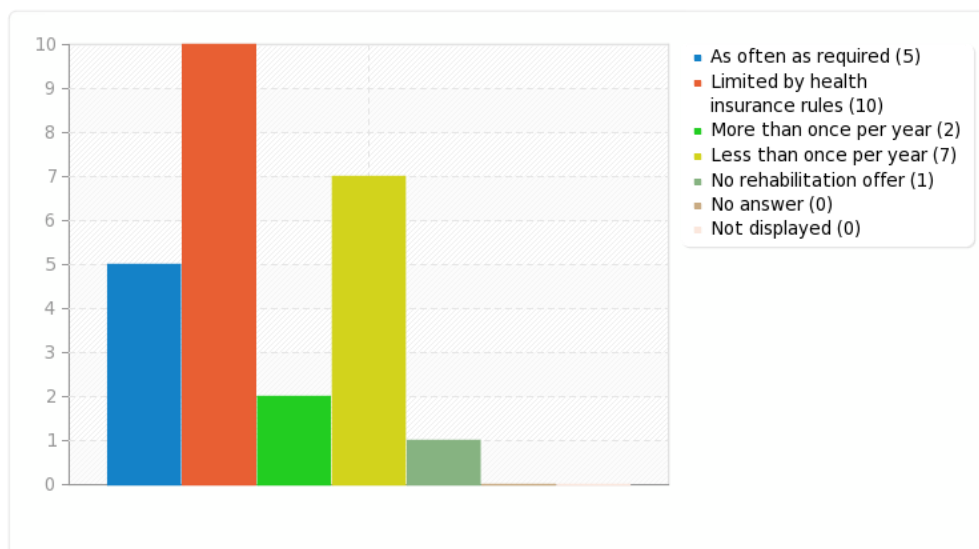
Answers	Countries
As often as required	Czech Republic, Denmark, Finland, France, Germany, Iceland, Italy, Serbia, Switzerland
Limited by health insurance rules	Austria, Belgium, Estonia, Greece, Slovakia, Sweden, UK
More than once per year	Croatia, Norway, Portugal
Less than once per year	Belarus, Poland, Russia, Spain
No rehabilitation offer	Ireland, Romania

1.17 What % of the total population of people with MS currently receives rehabilitation services as in-patients?

Country	% of the total population of people with MS receiving rehabilitation services as in-patients
Austria	40
Belarus	50
Belgium	20
Croatia	60
Czech Republic	100
Denmark	10
Estonia	
Finland	30
France	30
Germany	40
Greece	5
Iceland	25
Ireland	unknown
Italy	10
Norway	unknown
Poland	unknown
Portugal	5
Romania	5
Russia	10
Serbia	40
Slovakia	unknown
Spain	5
Sweden	20
Switzerland	unknown
UK	unknown

1.18 If required, how often is it that a person with MS can receive rehabilitation services as an in-patient?

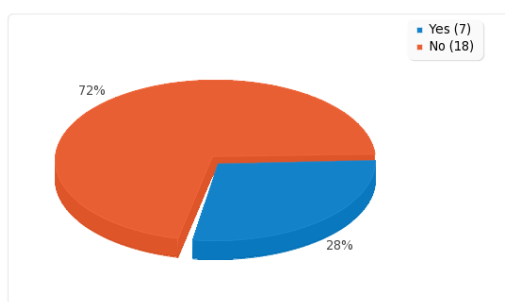
“In-patient” refers to patient who stays in a hospital or rehabilitation facilities while receiving medical care or treatment (for at least one night)



Answers	Countries
As often as required	Croatia, Germany, Iceland, Italy, Switzerland
Limited by health insurance rules	Austria, Belgium, Czech Republic, Estonia, Finland, Greece, Russia, Serbia, Slovakia, UK
More than once per year	France, Portugal
Less than once per year	Belarus, Denmark, Norway, Poland, Romania, Spain, Sweden
No rehabilitation offer	Ireland

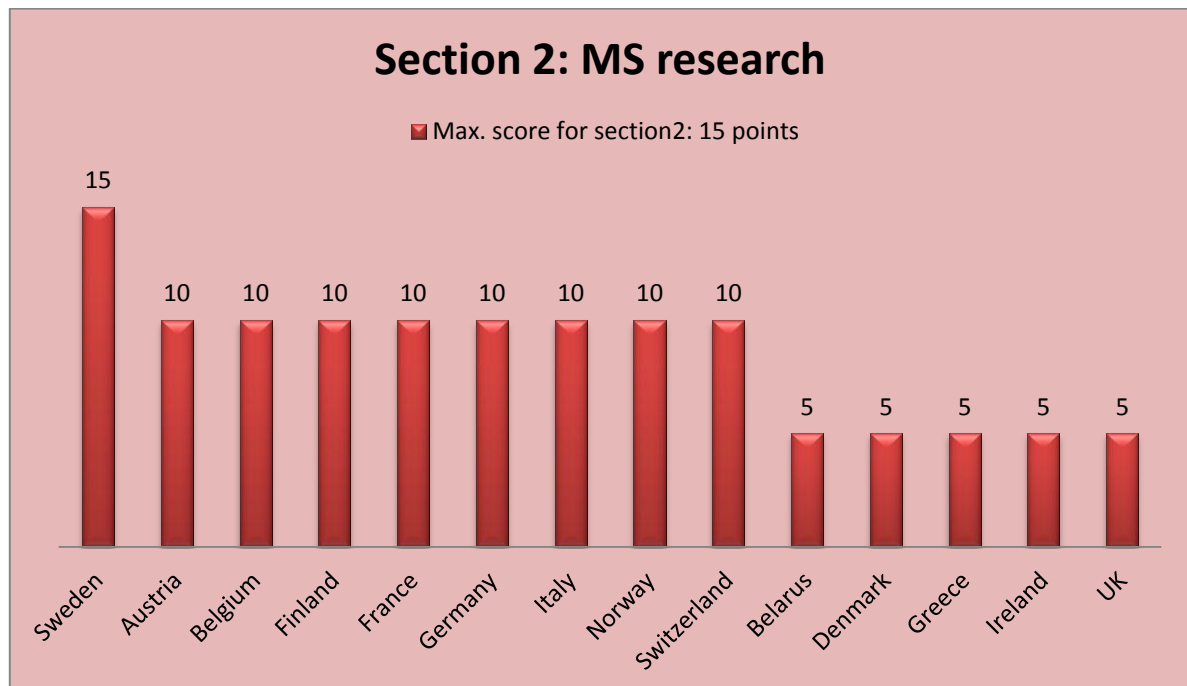
1.19 Is there a specialised palliative care programme available for people with MS in your country?

“Palliative care” is an area of healthcare that focuses on relieving and preventing the suffering of the patients from their symptoms. The goal being to improve the quality of life for both the patients and their families.

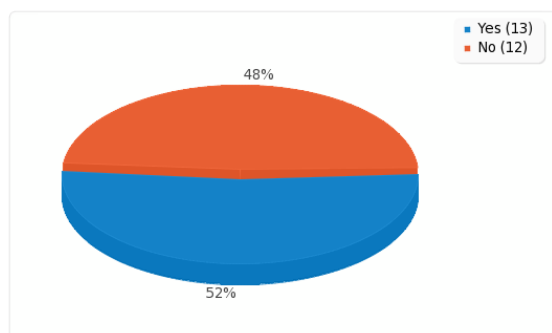


Only 7 countries have reported having specialised palliative care programme available for people with MS: Belgium, France, Germany, Iceland, Italy, Sweden and the UK.

Section 2 : MS research

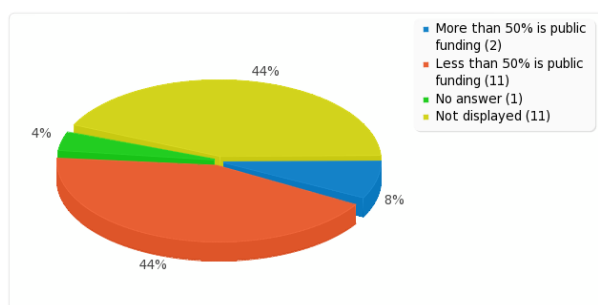


2.1 Are there grants/support schemes managed by your MS Society which contribute financially to MS Research?



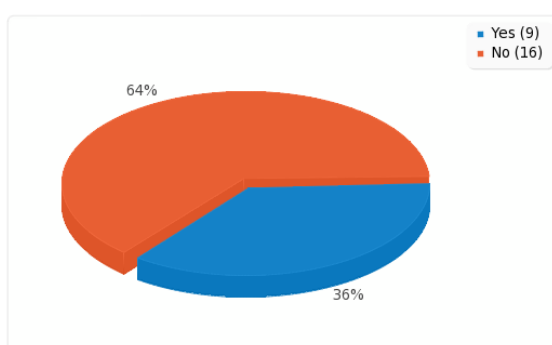
Replies	Countries
Yes	Austria, Belgium, Denmark, France, Finland, Germany, Greece, Ireland, Italy, Norway, Sweden, Switzerland, UK
No	Belarus, Croatia, Czech Republic, Estonia, Iceland, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Spain

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



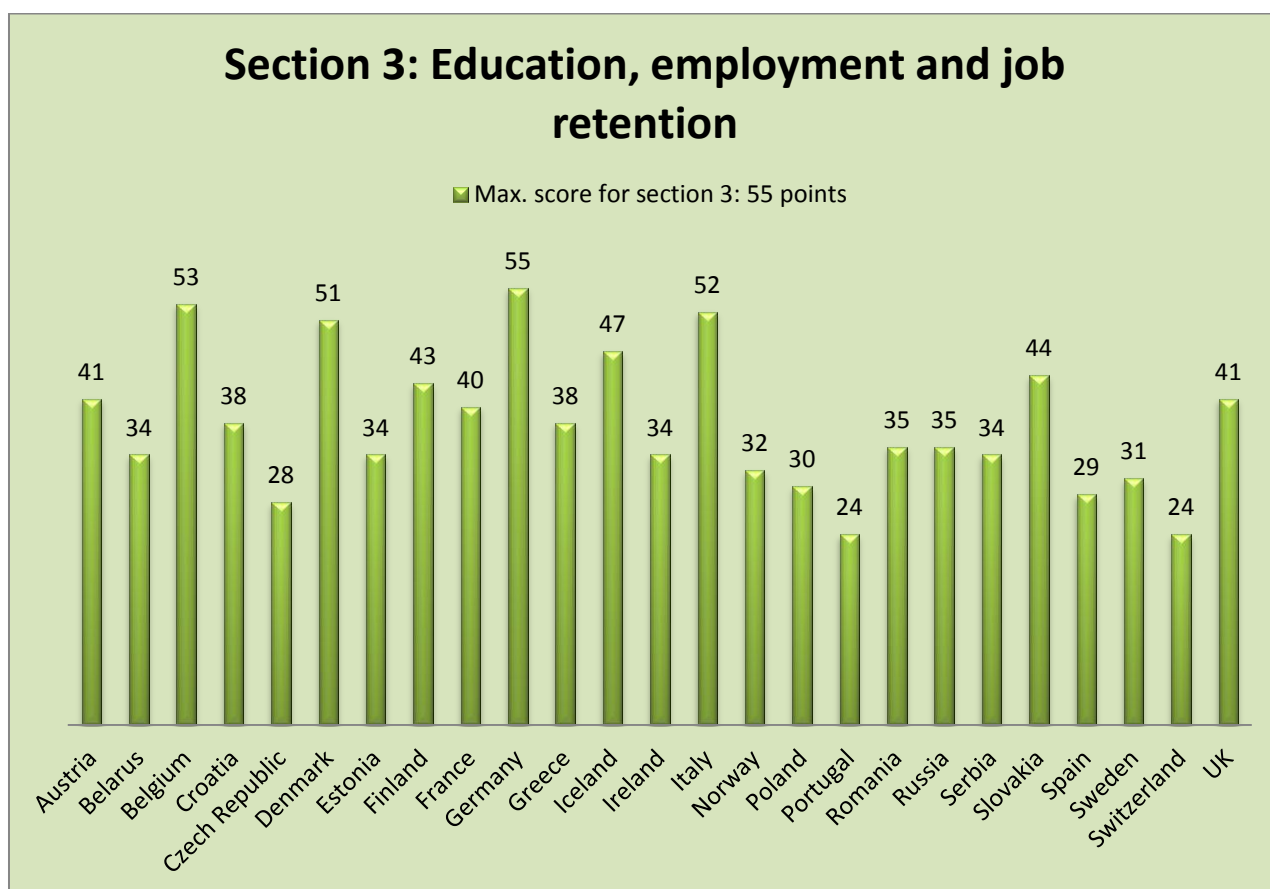
Only 13 countries have reported MS research grants/schemes support by public funding and among them only 2 receive more than 50% of public funding.

2.3 Do MS societies have an opportunity to influence the national MS research agenda?



Replies	Countries
Yes	Austria, Belarus, Belgium, Finland, France, Germany, Italy, Sweden, Switzerland
No	Croatia, Czech Republic, Denmark, Estonia, Greece, Iceland, Ireland, Norway, Poland, Portugal, Romania, Russia, Serbia, Slovakia, Spain, UK

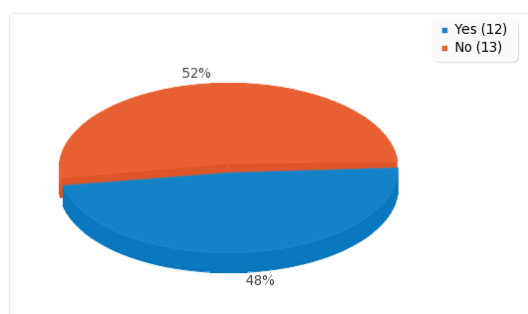
Section 3: Education, employment and job retention



Young people with MS and Education

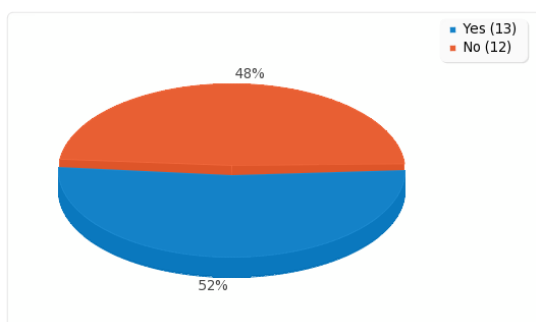
Young people with multiple sclerosis: people diagnosed with multiple sclerosis aged 35 and under.

3.1 Are there any particular programs specifically aimed at young people with MS in your country?



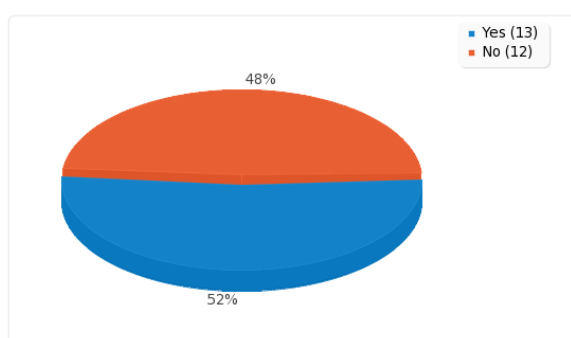
The countries which have reported having specific programs targeting young people with MS are the following: Belgium, Denmark, Germany, Greece, Iceland, Ireland, Italy, Portugal, Serbia, Slovakia, Switzerland and UK.

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



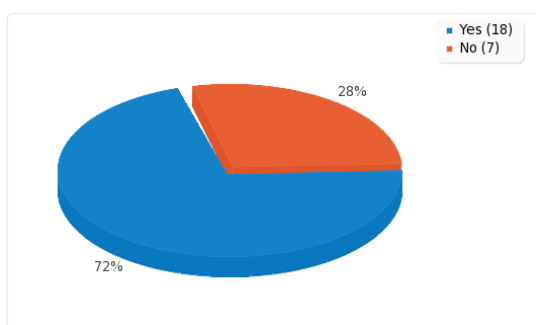
The countries that provide support to help young people with MS complete their education are the following: Austria, Belgium, Denmark, Finland, France, Germany, Greece, Iceland, Italy, Poland, Russia, Slovakia and UK.

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



The countries that provide support to those who have left the education system because of MS are the following: Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Germany, Iceland, Italy, Russia, Slovakia and UK.

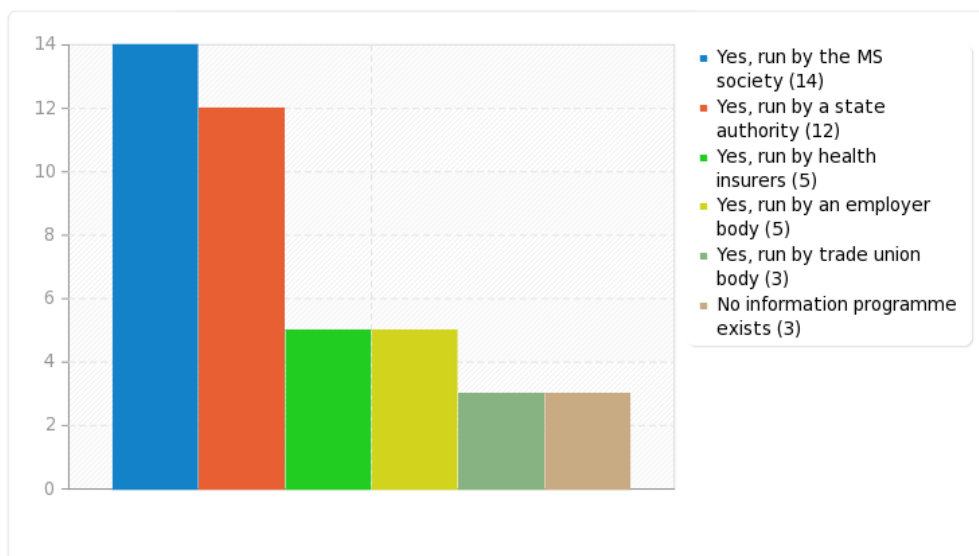
3.4 Do you have an identified network of young people with MS run by the MS society?



The MS Societies in the following countries have an identified network of young people with MS: Belarus, Belgium, Croatia, Denmark, Estonia, Germany, Greece, Iceland, Ireland, Italy, Norway, Poland, Portugal, Romania, Slovakia, Spain, Sweden and Switzerland.

MS and Employment

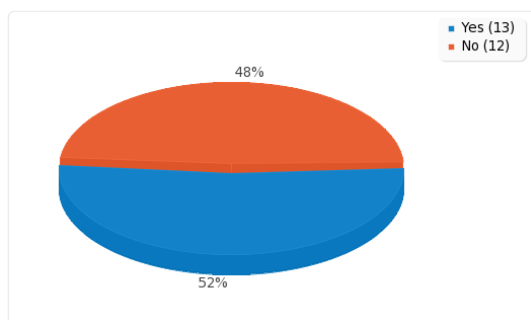
3.5 Is there an information programme for employers and trade unions on the subject of MS or disability in general offered in your country?



Countries	Yes, run by:					No information programme exists
	MS society	A state authority	Health insurers	Employer body	Trade union body	
Austria	Yes	No	No	No	No	No
Belarus	Yes	No	No	No	No	No
Belgium	Yes	Yes	Yes	Yes	Yes	No
Croatia	No	No	No	No	No	Yes
Czech Republic	No	No	No	No	No	Yes
Denmark	Yes	No	No	No	No	No
Estonia	Yes	No	No	No	No	No
Finland	Yes	Yes	Yes	Yes	Yes	No
France	No	Yes	Yes	No	No	No
Germany	Yes	Yes	Yes	Yes	Yes	No
Greece	No	No	No	No	No	Yes
Iceland	No	Yes	No	Yes	No	No
Ireland	No	Yes	No	No	No	No
Italy	Yes	Yes	No	No	No	No
Norway	No	Yes	No	No	No	No
Poland	No	Yes	No	No	No	No
Portugal	No	Yes	No	No	No	No
Romania	Yes	No	No	Yes	No	No
Russia	Yes	No	Yes	No	No	No
Serbia	Yes	No	No	No	No	No
Slovakia	No	Yes	No	No	No	No
Spain	Yes	No	No	No	No	No
Sweden	No	Yes	No	No	No	No

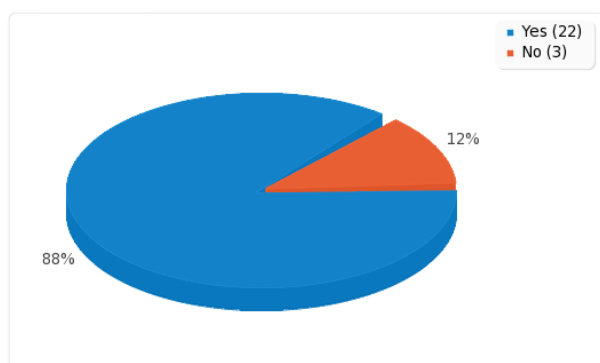
Switzerland	Yes	No	No	No	No	No
UK	Yes	No	No	No	No	No

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



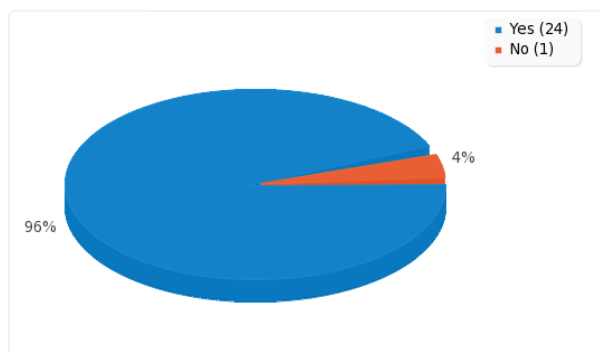
MS awareness raising programmes for the workplace (for employers and employees) operate in the following countries: Austria, Belarus, Belgium, Croatia, Denmark, Estonia, Finland, Germany, Italy, Romania, Serbia, Switzerland and UK.

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



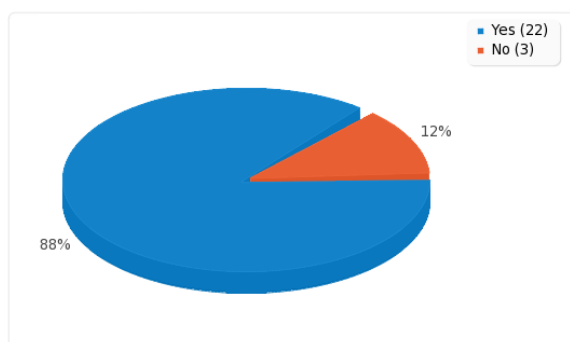
Although, most of the countries do have incentives in place to recruit or retain people with disabilities in general in employment; this is not the case for Portugal, Switzerland and UK.

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



The only country which reported that it is not legally possible for a person with disability to remain at work is Switzerland.

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



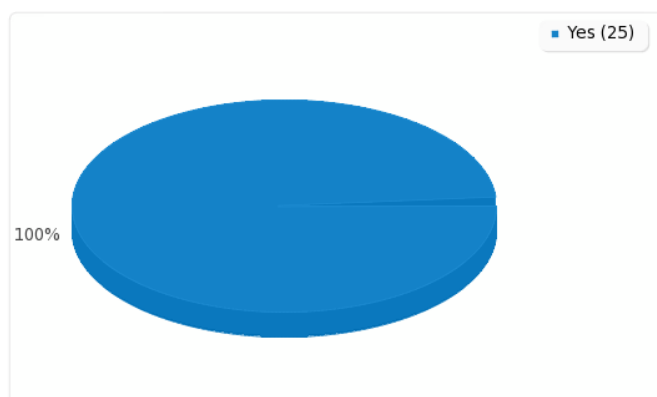
Flexible working practice legislation does not exist in countries such as Poland, Portugal and Switzerland.

3.10 What % of people with MS is in active work?

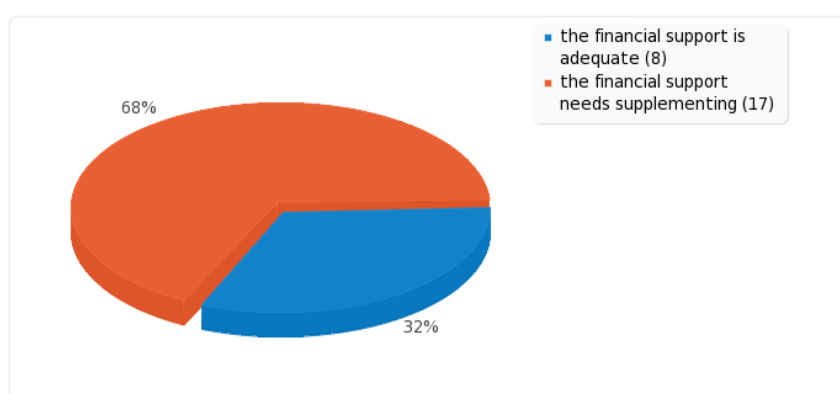
Country	% of people with MS in active work- full time job	% of people with MS are in active work- part time job
Austria	35	15
Belarus	0	23
Belgium	50	50
Croatia	21	1
Czech Republic	10	20
Denmark	8	25
Estonia	unknown	unknown
Finland	35	15
France	35	25
Germany	33,4	13,4
Greece	unknown	unknown
Iceland	50	unknown
Ireland	11,86	11,86
Italy	50	10
Norway	18	21
Poland	unknown	unknown
Portugal	45	unknown
Romania	unknown	unknown
Russia	20	10
Serbia	15	1
Slovakia	unknown	unknown
Spain	unknown	unknown
Sweden	unknown	unknown
Switzerland	unknown	unknown
UK	8	11

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

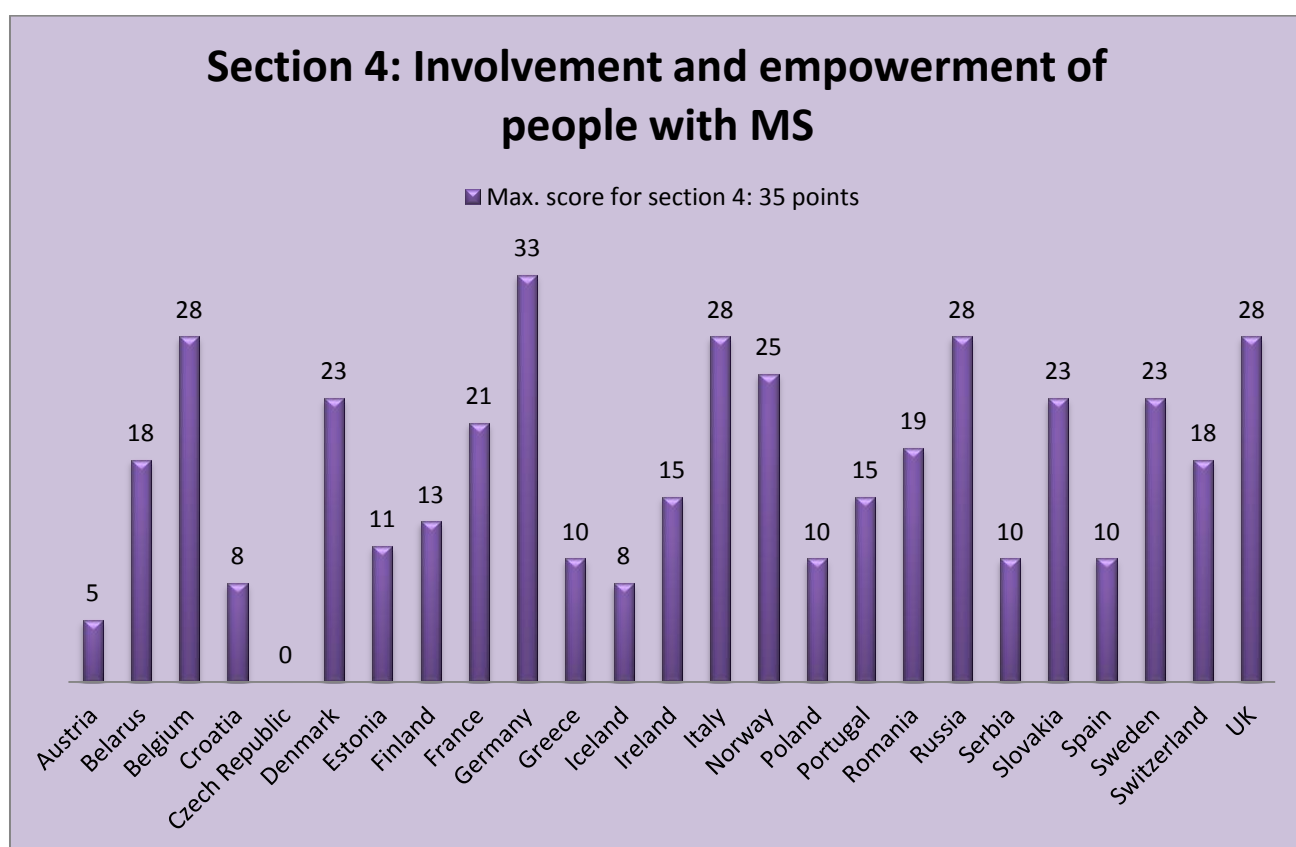
Pension fund: is a fund reserved to pay workers' pensions when they retire from service due to their age or disability.



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

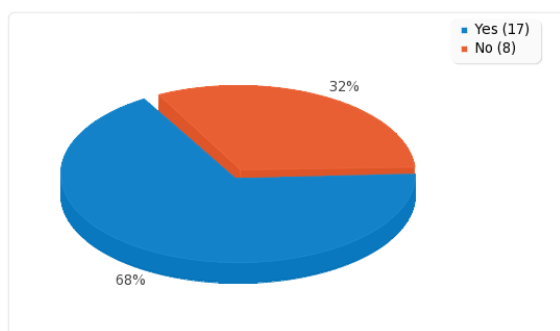


Section 4: Involvement and empowerment of people with MS



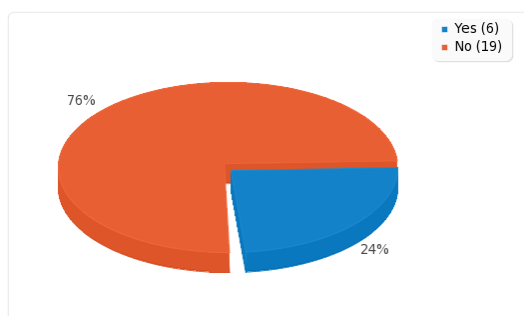
Empowerment of people with MS: is defined here as to give the opportunity for people with MS to be independent and to influence their care and treatment.

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



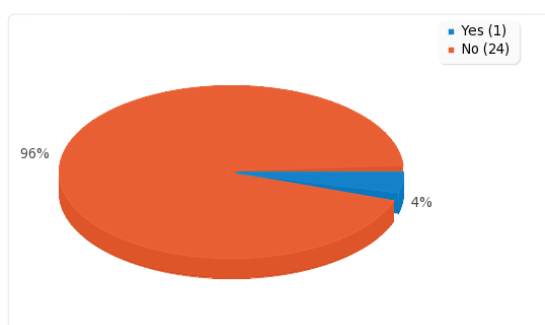
The following countries do not have consultation group/body that advises Government on neurological disease or MS policies: Belarus, Croatia, Czech Republic, Estonia, Finland, Iceland, Ireland and Switzerland.

4.2 Are people with MS represented in the consultation group/body?



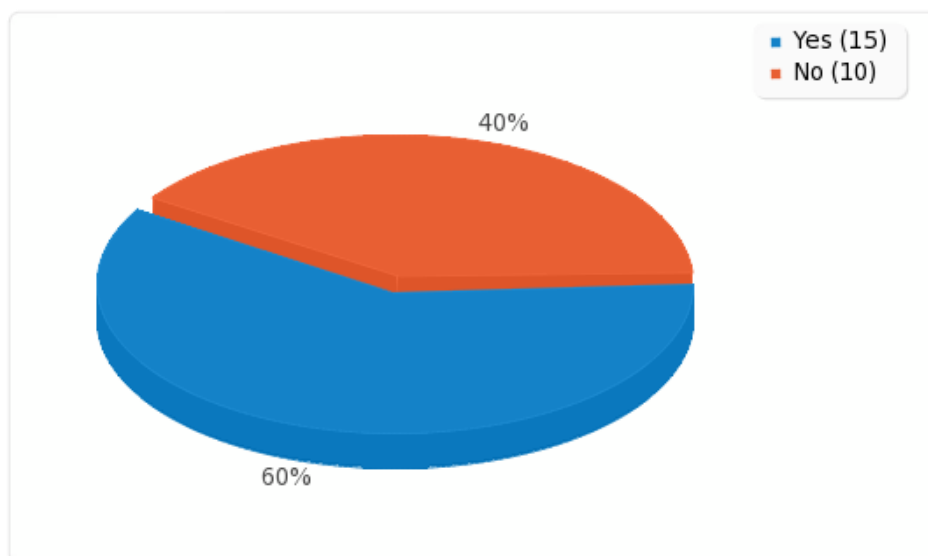
Among the countries who have reported having a consultation group/body advising national authorities and policy decision makers, only 6 have people with MS represented on those bodies: Belgium, Germany, Italy, Russia, Slovakia and UK.

4.3 Is the MS society a member of the body that decides on the reimbursement of new MS therapies?



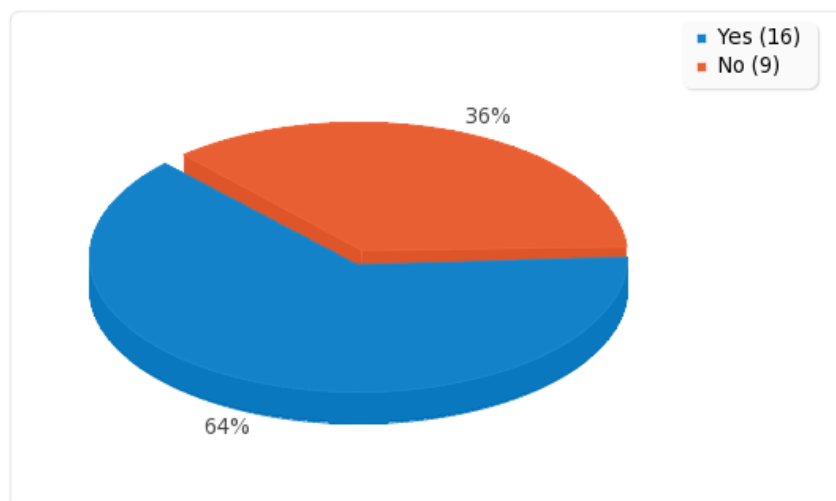
The German MS Society is the only respondent to have an influence on decisions on the reimbursement of new MS therapies at national level.

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



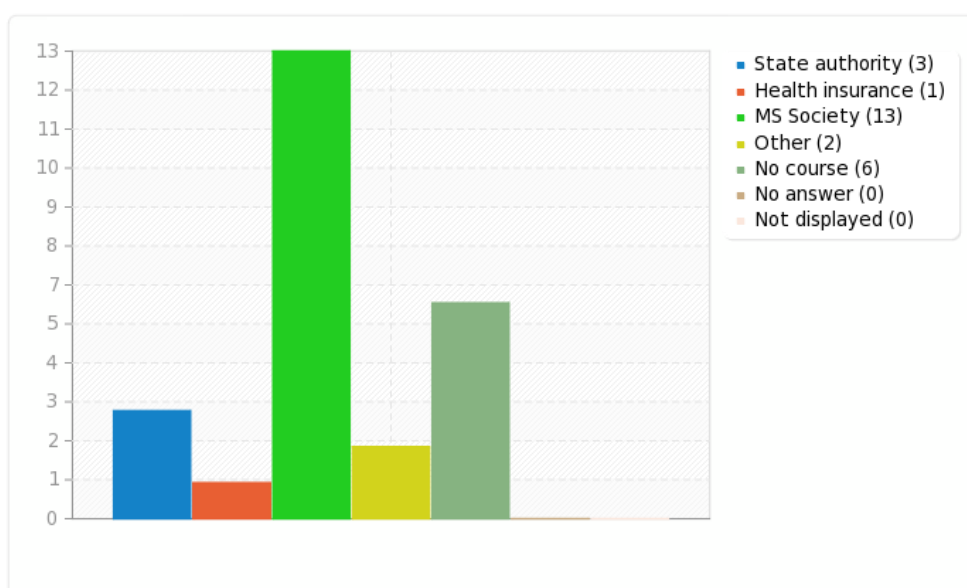
Replies	Countries
Yes	Belarus, Belgium, Denmark, France, Germany, Italy, Norway, Poland, Portugal, Romania, Russia, Slovakia, Sweden, Switzerland and UK
No	Austria, Croatia, Czech Republic, Estonia, Finland, Greece, Iceland, Ireland, Serbia and Spain

4.5 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?



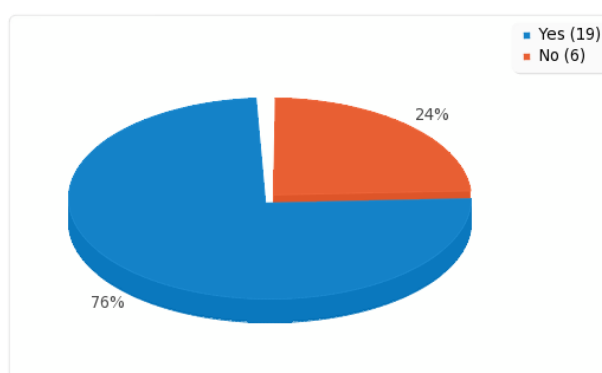
Replies	Countries
Yes	Belarus, Belgium, Croatia, Denmark, Estonia, Finland, France, Germany, Ireland, Italy, Norway, Russia, Slovakia, Sweden, Switzerland and UK
No	Austria, Czech Republic, Greece, Iceland, , Poland, Portugal, Romania, Serbia and Spain

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



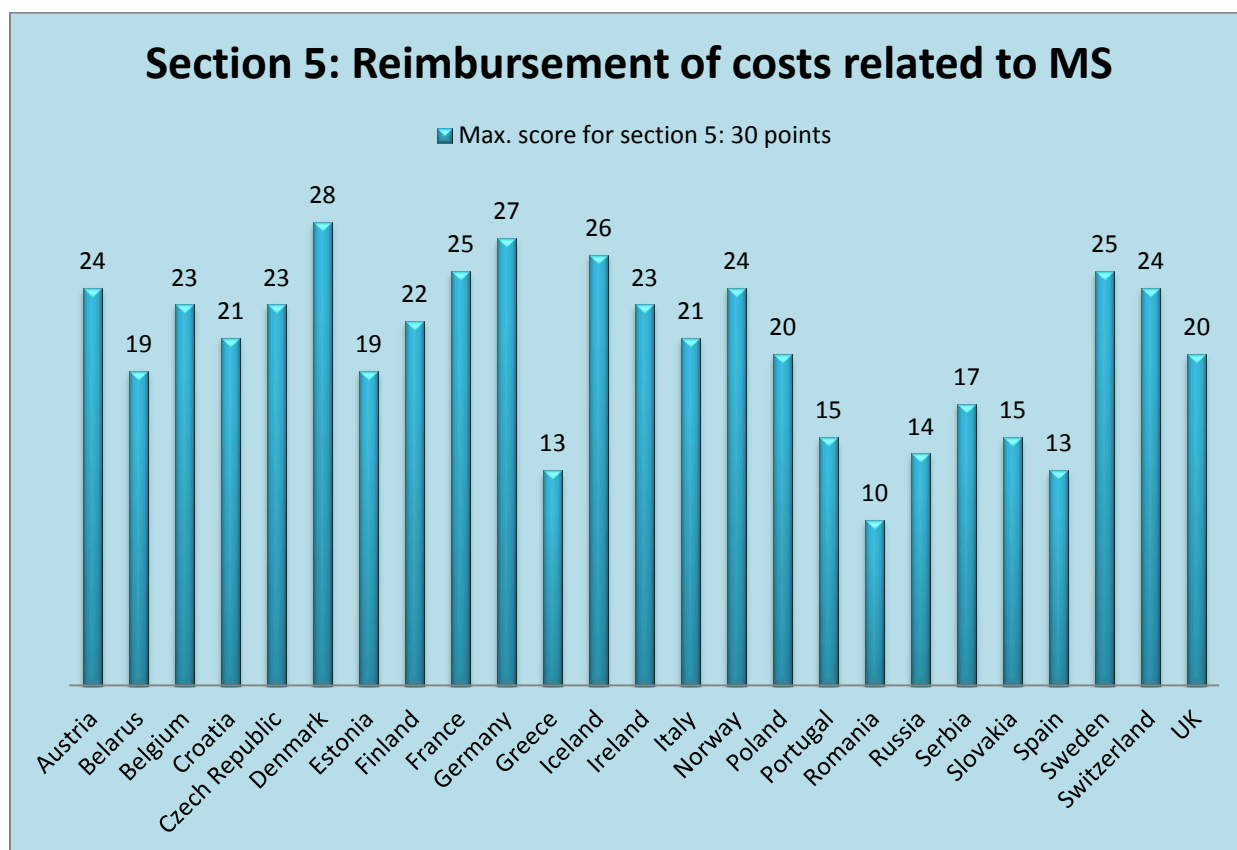
Answers	Countries
State authority	Greece, Ireland, Norway
Health insurance	Romania
MS Society	Belarus, Belgium, Croatia, Denmark, Finland, Germany, Iceland, Italy, Italy, Russia, Slovakia, Sweden, Switzerland and UK
Other	Estonia, France
No course	Austria, Czech Republic, Poland, Portugal, Serbia, Spain

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



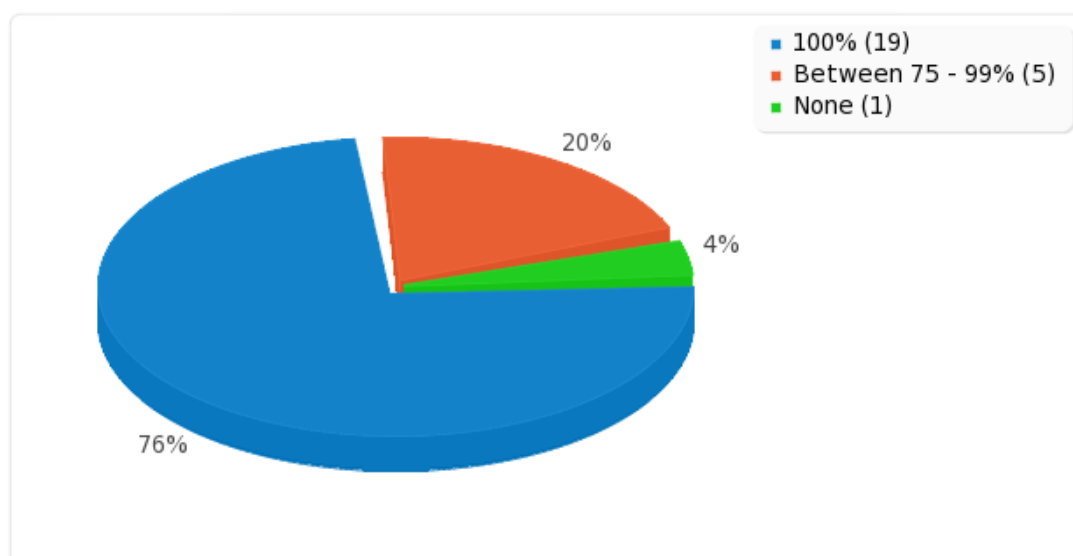
6 countries among the respondents reported not having multi-disciplinary teams for the management of the condition of people with MS: Austria, Croatia, Czech Republic, Greece, Poland and Slovakia.

Section 5: Reimbursement of costs related to MS



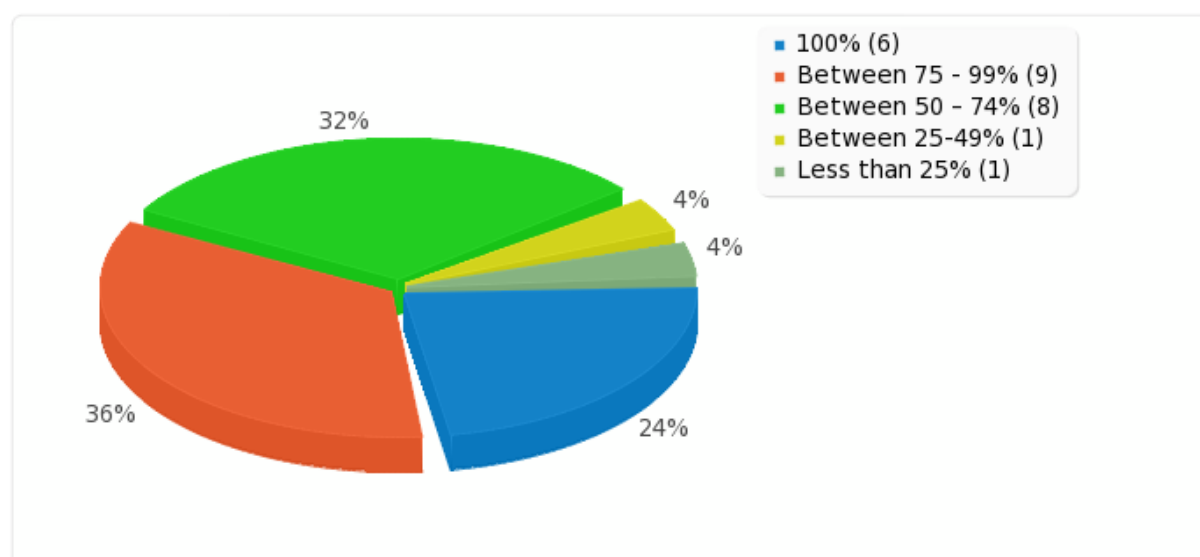
5.1 What percentage of disease-modifying drugs costs is reimbursed?

DMD treatments include: Avonex, Betaseron, Copaxone, Novantrone, Rebif, Tysabri, Extavia and Gilenya.



Answers	Countries
100%	Austria, Croatia, Czech Republic, Denmark, Estonia, France, Germany, Greece, Iceland, Ireland, Italy, Norway, Poland, Portugal, Romania, Serbia, Slovakia, Spain and UK
Between 75 - 99%	Belgium, Finland, Russia, Sweden, Switzerland
None	Belarus

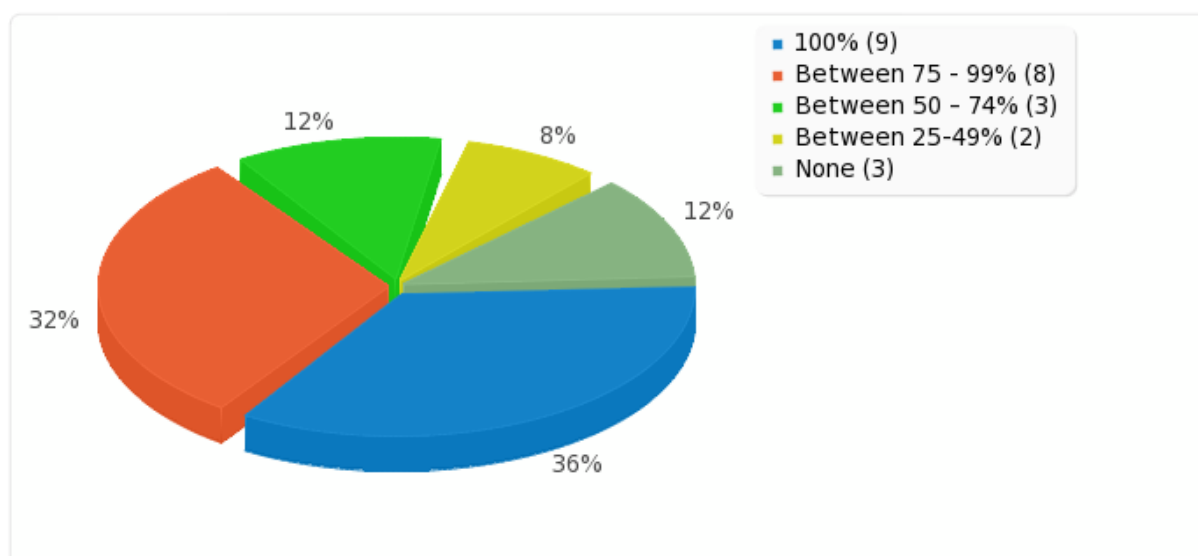
5.2 What percentage of the costs for symptomatic therapy is reimbursed?



Answers	Countries
100%	Belarus, Croatia, Czech Republic, France, Germany, Ireland
Between 75 - 99%	Austria, Belgium, Denmark, Estonia, Greece, Iceland, Italy, Sweden, Switzerland
Between 50 – 74%	Finland, Norway, Poland, Portugal, Romania, Serbia, Spain, UK
Between 25-49%	Russia
Less than 25%	Slovakia

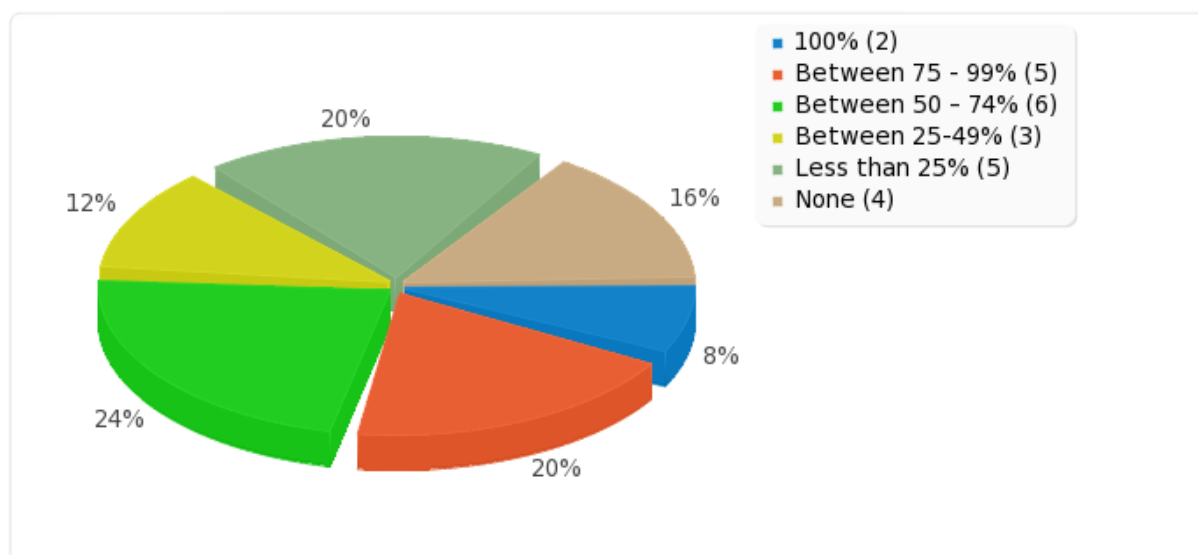
5.3 What percentage of rehabilitation costs is reimbursed?

“Rehabilitation costs” refers to the overall expenses occurring for rehabilitation treatments and therapies for a patient (physiotherapy, occupational therapy, psychological assistance, etc.)



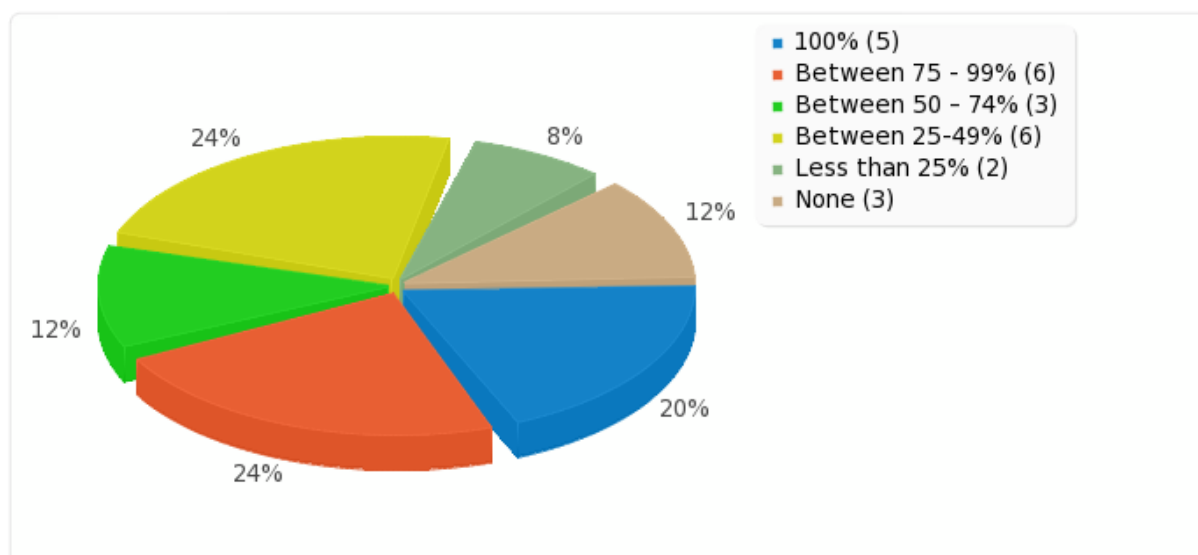
Answers	Countries
100%	Belarus, Croatia, Czech Republic, Denmark, Germany, Ireland, Italy, Portugal, Serbia
Between 75 - 99%	Austria, Belgium, Finland, France, Iceland, Norway, Sweden, Switzerland
Between 50 – 74%	Estonia, Slovakia, UK
Between 25-49%	Poland, Russia
None	Greece, Romania, Spain

5.4 What percentage of home adaptation costs is reimbursed?



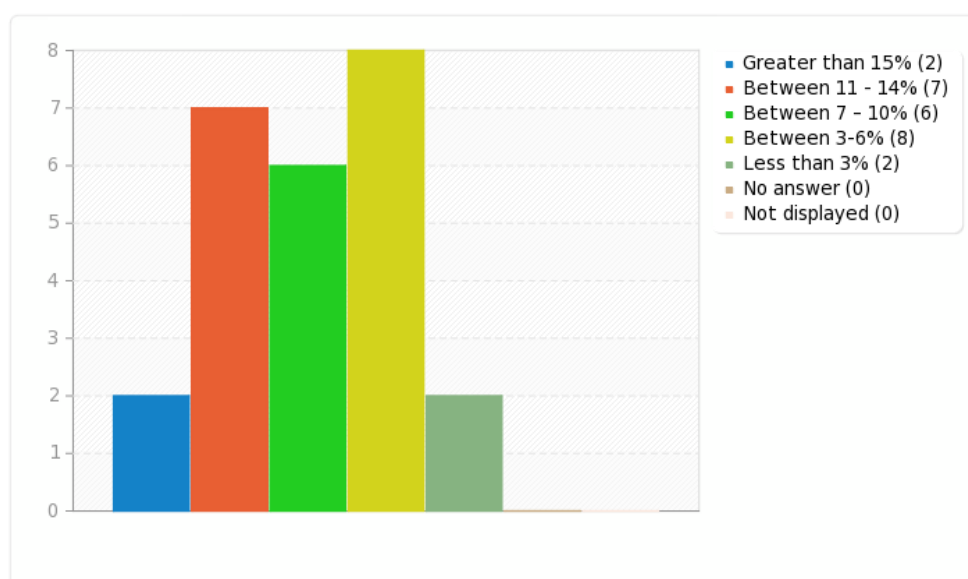
Answers	Countries
100%	Denmark, Sweden
Between 75 - 99%	Austria, Belgium, Czech Republic, Iceland, Norway
Between 50 – 74%	Finland, France, Germany, Poland, Switzerland, UK
Between 25-49%	Estonia, Italy, Slovakia
Less than 25%	Belarus, Croatia, Ireland, Russia, Spain
None	Greece, Portugal, Romania, Serbia

5.5 What percentage of workplace adaptation costs is reimbursed?



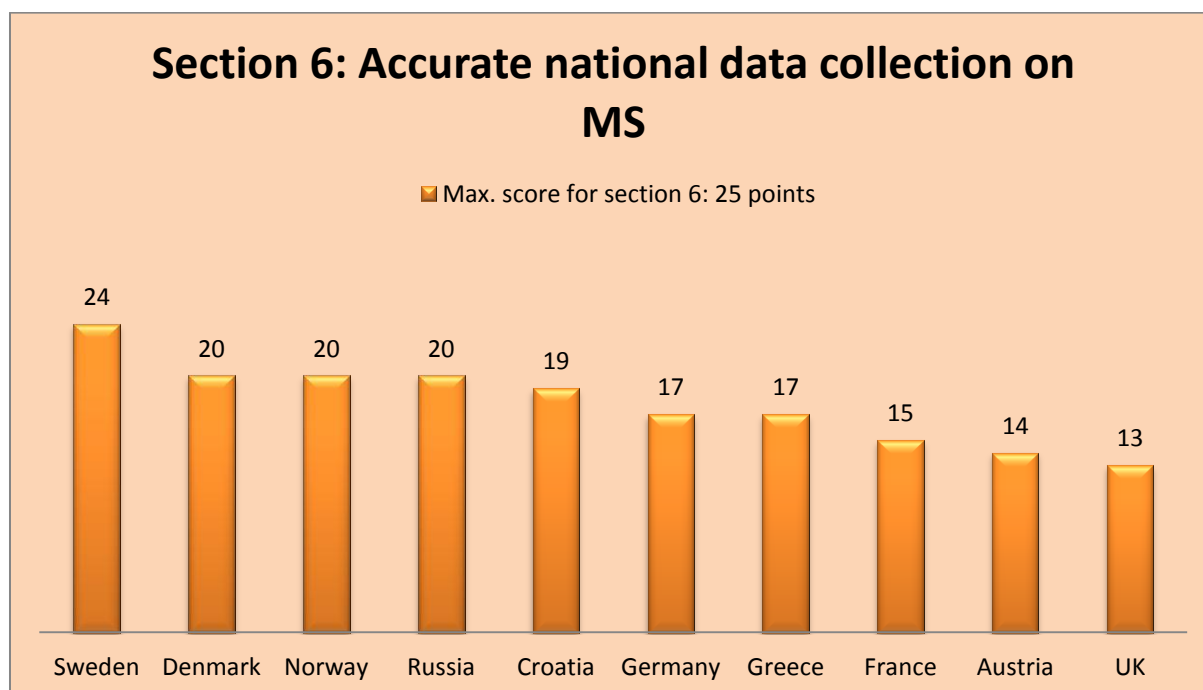
Answers	Countries
100%	Belarus, Denmark, Germany, Norway, Poland
Between 75 - 99%	Belgium, Finland, France, Iceland, Sweden, Switzerland
Between 50 – 74%	Austria, Greece, UK
Between 25-49%	Croatia, Czech Republic, Estonia, Italy, Serbia, Slovakia
Less than 25%	Ireland, Russia
None	Portugal, Romania, Spain

5.6 What percentage of your country's GDP has been spent on healthcare in 2012?

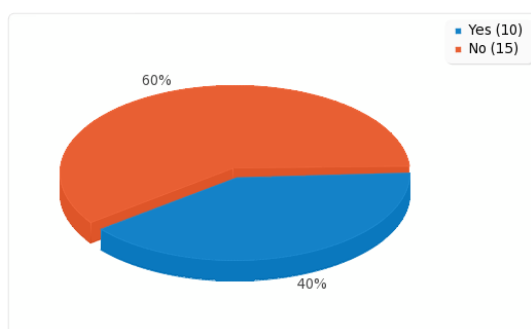


Answers	Countries
Greater than 15%	Iceland, Switzerland
Between 11 - 14%	Austria, Denmark, Finland, France, Germany, Ireland, Sweden
Between 7 – 10%	Belgium, Estonia, Italy, Norway, Spain, UK
Between 3-6%	Belarus, Croatia, Czech Republic, Poland, Portugal, Romania, Russia, Serbia
Less than 3%	Greece, Slovakia

Section 6 : Accurate national data collection on MS



6.1 Does a national MS register exist?



Countries which have a national MS register:
Austria, Croatia, Denmark, France, Germany,
Greece, Norway, Russia, Sweden and UK.

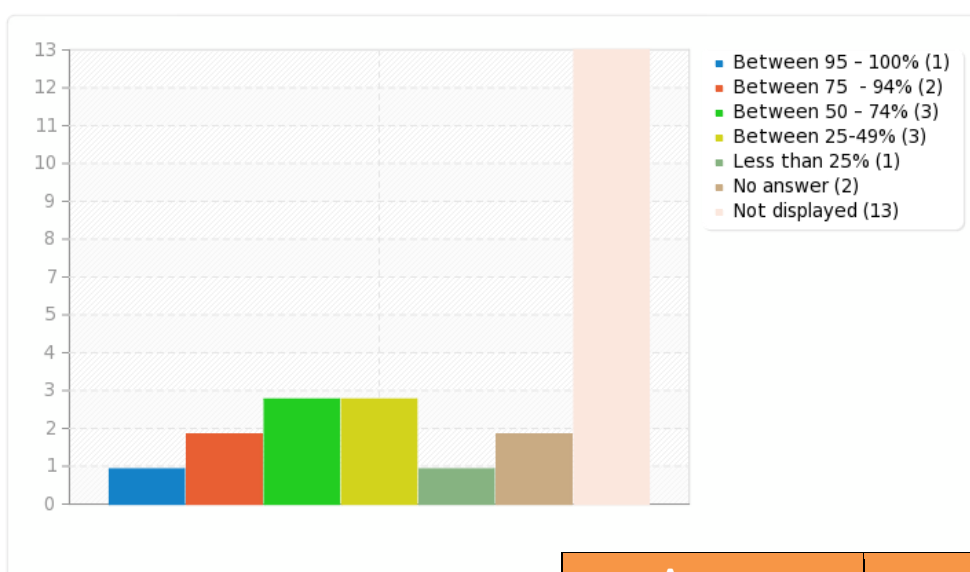
6.2 Who manages the MS register?

Answers	Countries
State authority	Sweden
MS Society	Croatia, Denmark, Germany, Greece
Other	Austria, France, Norway, Russia, UK

6.3 Is the register supported by public funding?

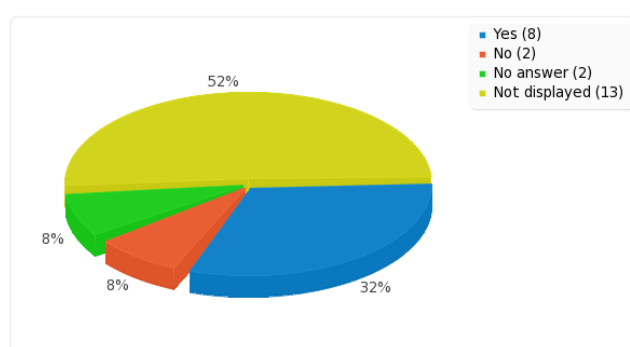
Answers	Countries
More than 50% funding	Croatia, France, Norway, Russia, Sweden
No public funding for register	Austria, Denmark, Germany, Greece, UK

6.4 If a register exists, what % of people with MS is currently recorded on the register?



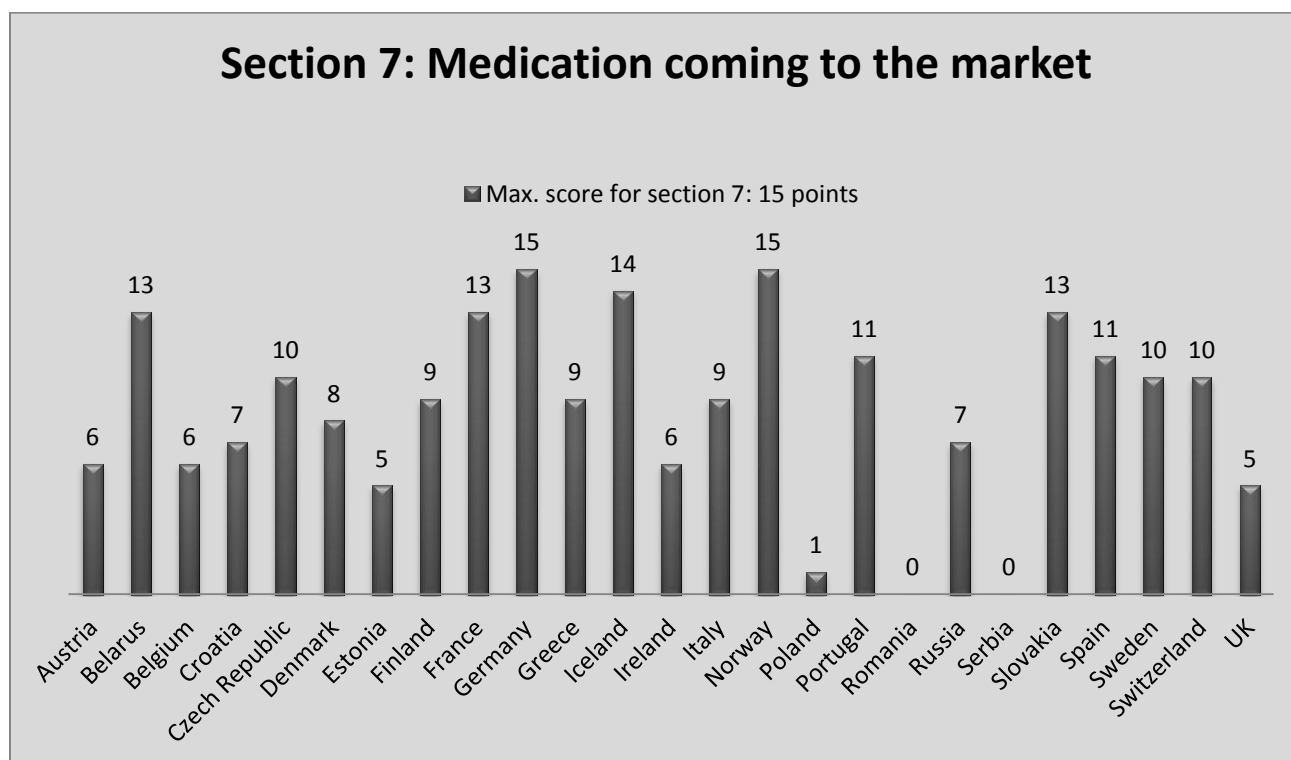
Answers	Countries
Between 95 – 100%	Denmark
Between 75 - 94%	Croatia, Sweden
Between 50 – 74%	France, Norway, Russia
Between 25-49%	Austria, Germany, Greece
Less than 25%	UK

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

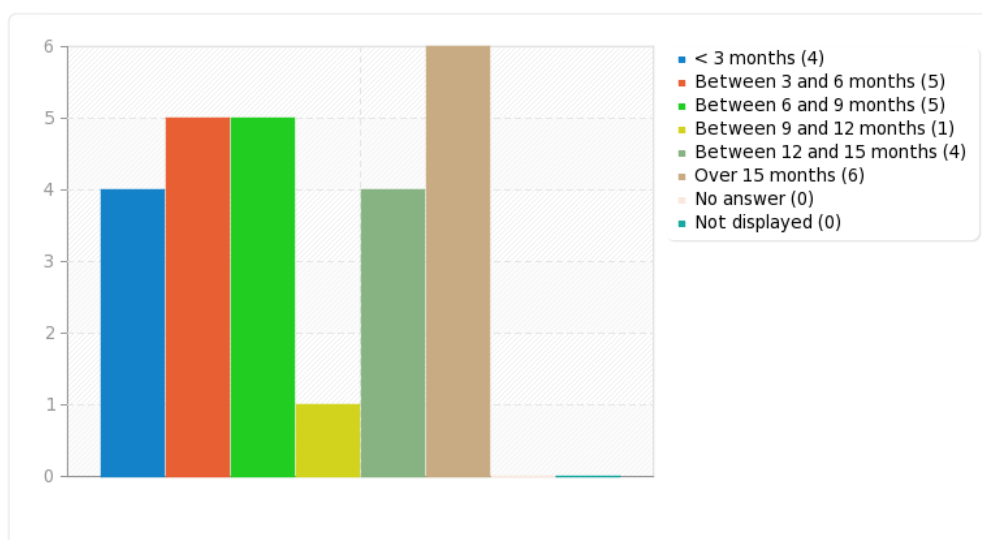


Only Croatia and France have reported that the information coming from the MS Register has no influence on the national policy with MS.

Section 7: Medication coming to the market

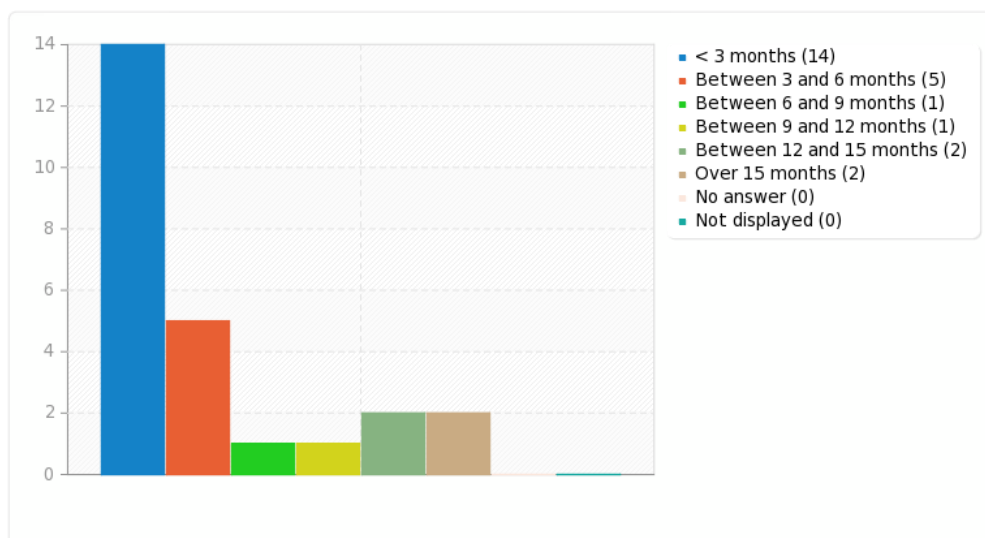


7.1 How long, on average, does it take to get a decision on drug reimbursement once it has been approved by the national drug regulatory authority or by European Medicines Agency?



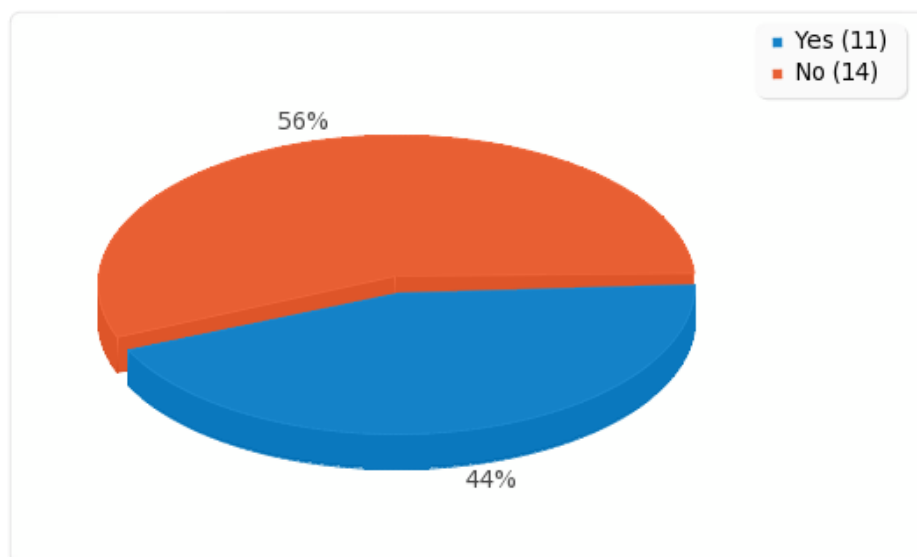
Answers	Countries
< 3 months	Germany, Norway, Sweden, Switzerland
Between 3 and 6 months	Belarus, Finland, Iceland, Italy, Slovakia
Between 6 and 9 months	Austria, Denmark, France, Russia, UK
Between 9 and 12 months	Spain
Between 12 and 15 months	Belgium, Croatia, Ireland, Portugal
Over 15 months	Czech Republic, Estonia, Greece, Poland, Romania, Serbia

7.2 How long does it take for those people who are legally entitled to specific drugs, to actually receive them?



Answers	Countries
< 3 months	Belgium, Czech Republic, Denmark, Estonia, Finland, France, Germany, Iceland, Ireland, Italy, Norway, Portugal, Sweden, Switzerland
Between 3 and 6 months	Belarus, Greece, Russia, Slovakia, Spain
Between 6 and 9 months	Austria
Between 9 and 12 months	UK
Between 12 and 15 months	Croatia, Poland
Over 15 months	Romania, Serbia

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



Replies	Countries
Yes	Belarus, Croatia, Czech Republic, France, Germany, Greece, Iceland, Norway, Portugal, Slovakia, Spain
No	Austria, Belgium, Denmark, Estonia, Finland, Ireland, Italy, Poland, Romania, Russia, Serbia, Sweden, Switzerland, UK

Call for action

EMSP has been active in each of the areas of importance for people with MS since its foundation through different projects. EMSP continues to partner with experts and patients from all over Europe to conduct its flagships projects:

The European MS Barometer – which supports EMSP's and member organisations' advocacy activities of EMSP and its members and which supports key actions to improve the quality of life of people with MS.

Under Pressure – a multimedia project involving renowned photographers, illustrating the healthcare inequalities captured in the MS Barometer through powerful photos and videos.

EUREMS – a European data register initiative aiming at developing a cross-border MS information infrastructure which combines medical data with socio-economic information.

MS Nurse Pro – an accredited online education programme promoting the role of MS nurses and the provision of care across Europe.

Believe and Achieve – an awareness-raising campaign to improve access to employment and training for young people with MS in Europe.

MS continues to pose important challenges for individuals and society. The current total cost of dealing with multiple sclerosis in Europe has been estimated at 15 billion euros per year.

This problem will not simply go away with time. It is up to organisations such as EMSP, together with people affected by MS, policy-makers, specialists and researchers, to work with urgency towards a world without MS.

Sources of information

All data collected in the MS Barometer has been provided by the national MS societies. 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 2013 MS Barometer:

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For further information on the MS Barometer 2013,

please visit EMSP website: www.emsp.org.

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