ATLAS OF **MS** 2013

MAPPING MULTIPLE SCLEROSIS
AROUND THE WORLD

Multiple Sclerosis International Federation (MSIF)

MSIF is the world's only global network of MS organisations. We have 44 member organisations from around the globe, as well links to many other smaller organisations. Together we lead the fight against MS and work to improve the quality of life of people affected by MS wherever they live.

We bring together the work of MS organisations to help people affected by MS around the world. Along with our members, we campaign for increased international awareness of MS, provide information and support to people affected by MS, and support international research to discover better treatments and ways to manage the disease.

Our vision is a world without MS.

Our mission is to lead the global MS movement to improve the quality of life of people affected by MS and to support better understanding of the treatment of MS by facilitating international cooperation between MS societies, the international research community and other stakeholders.

Find out more at www.msif.org

Members of MSIF
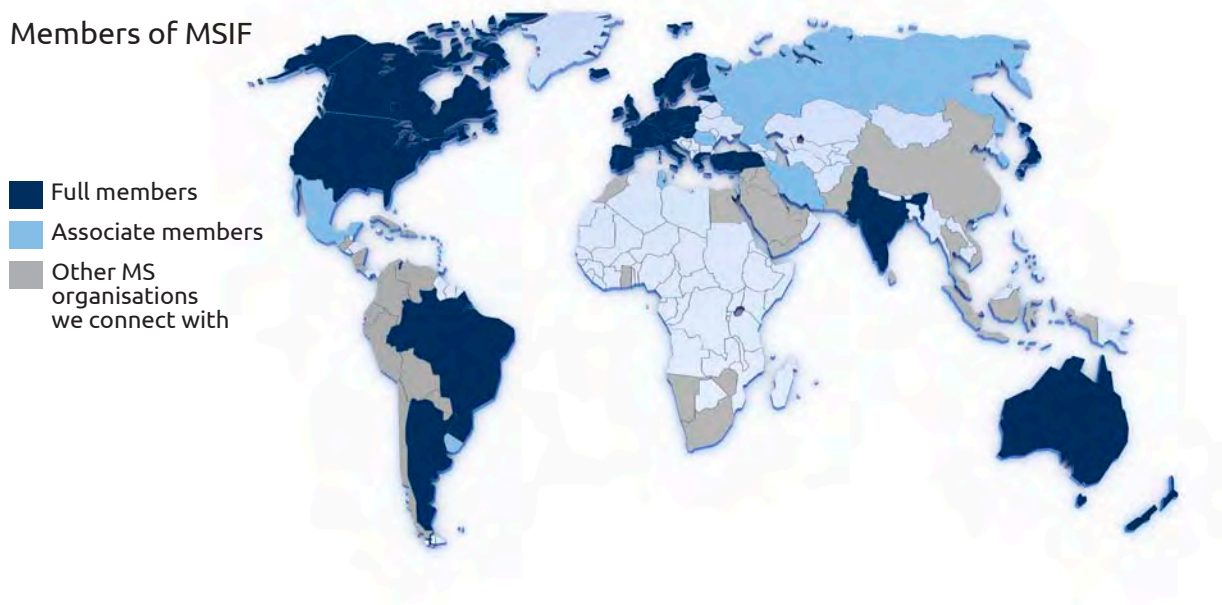
- Full members
- Associate members
- Other MS organisations we connect with

WELCOME

Multiple sclerosis (MS) is one of the world's most common neurological disorders. In many countries, it is the leading cause of non-traumatic disability in young adults. While some people with MS experience little disability during their lifetime, as many as 60% may be unable to walk without assistance 20 years after onset. This has major implications for the quality of life of people with MS and their families and friends, and for the cost to society if their condition is not managed adequately.

Despite our awareness of the considerable impact of MS, information about the resources available to support people with MS is often lacking. The *Atlas of MS* 2013 updates the information we collected in 2008 on the global epidemiology of MS and the resources to diagnose, inform, treat, rehabilitate, support and provide services to people with MS around the world. It includes information from countries that were unable to provide data in 2008, and on paediatric MS and neuromyelitis optica (NMO). It also has new sections on treatments for MS, reflecting the advances in this area over the last five years.

Reliable data concerning the worldwide distribution of MS provides useful insights about the disease, and helps to identify where there are unmet needs. Knowledge of the resources available to address MS in different countries highlights the striking differences, gaps and inadequacies in clinical management, access to services and assistance schemes that help people with MS improve their quality of life.

This report is a snapshot of MS around the world today. We know data on MS is constantly evolving as results from new studies are reported. We hope that, over time, data will be provided through the website **www.atlasofms.org** for countries where information is scarce.

We have strived to improve the robustness of the *Atlas of MS* 2013 by strengthening the sourcing and referencing of information provided, though in some instances the data are still the best available estimates. In spite of this, the *Atlas* remains the most comprehensive compilation of MS resources in the world. Its data should be used by health policy makers, medical charities and the private sector to help identify and address priorities for improvements to MS resource provision. For researchers in MS, it should help guide the direction of future studies and support international collaborations such as the Progressive MS Alliance.

Most importantly, we hope the information in the *Atlas* will be used by people with MS around the world – and the organisations that represent them – to communicate with and influence the private sector, policy makers and governments in their campaigns for better support and quality of life for people with MS.

Professor Alan J Thompson
Chairman of the MSIF International
Medical and Scientific Board

Peer Baneke
MSIF Chief Executive

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INTRODUCTION

Global information on epidemiology and the availability of resources and services for people with MS is scarce, fragmented, and relates mainly to high-income countries. The first *Atlas of MS*, published in 2008 as a joint project by MSIF and the World Health Organization, started to fill this information gap with the help of key informants from different fields working to improve the quality of life of people with MS around the world.

The MSIF *Atlas of MS* 2013 project aims to update this information and map data, resources and services by compiling and calculating their distribution by country, region and income levels. The key differences in the 2013 survey were the use of an online questionnaire and the addition of new questions that cover a range of topics, including newly licensed therapies, neuromyelitis optica (NMO) and paediatric MS.

The *Atlas of MS* 2013 update brings increased rigour to estimates of epidemiology of MS around the world, by stipulating that those completing the survey should include a list of the sources of data they provide.

The primary purposes of this report are:

- to stimulate additional systematic data gathering, particularly data on the epidemiology of MS
- to highlight gaps in resources and services, and
- to encourage the development of much needed policy, services and training.

We very much hope that this *Atlas of MS* publication and the related database (www.atlasofms.org) will serve these purposes.

KEY FINDINGS

The estimated number of people with MS has increased from 2.1 million in 2008 to 2.3 million in 2013.

- This finding reinforces the conclusions of the published epidemiological literature.

- MS is found in every region of the world.

- The 2:1 ratio of women to men with MS has not changed significantly since 2008.

Support and health care services have improved but substantial global inequalities remain:

- The number of neurologists has increased by 30% since 2008.

- The number of MRI machines in emerging countries has doubled in five years.

- High income countries have 100 times more neurologists per head than low income ones.

- One in five countries has no organisation providing support to people with MS.

- There are substantial inequalities in the availability of and access to disease-modifying therapies.

- Many countries do not have robust systems to monitor MS, such as registries.

More research is needed:

- In relation to quality of life and experiences of people with MS.

- To measure the indirect costs of MS.

- To understand sources and causes of inequalities in access to support, health care services and therapies.

- To monitor MS and related disorders through epidemiological studies and the establishment of registries.

RECOMMENDED ACTIONS

We call on policy makers, health professionals and MS organisations to make use of the data in the *Atlas of MS* 2013 to:

- Ensure improved diagnosis, treatment, information and resources are accessible to all that need them, regardless of where they live.

- Call for more research into effective treatments and practical ways to improve quality of life for people with MS, especially for people with progressive MS, for whom there are currently no disease-modifying therapies available.

- Raise awareness and understanding of MS among the general public, employers and health care professionals.

- Support MS organisations and patient groups, by investing in them and developing their capacity.

- Work together to make treatments more affordable, either directly or through wider reimbursement by insurance or government.

MAKE THE *ATLAS OF MS* WORK FOR YOU

You can analyse the full results, maps and database at **www.atlasofms.org** This is the only up-to-date online source of information on the world-wide epidemiology of MS, and the global availability and accessibility of resources for people with MS.

On it you can query the data, look at maps, compare results between 2008 and 2013 and download data in Excel, enabling you to further analyse the results. Ideas for using the *Atlas of MS* could include:

Regional comparisons
How does your country or region compare to others? Has it changed since 2008?

Epidemiology
How many people have MS or NMO?

Diagnosis and clinical management
Which diagnosis criteria are most commonly used? How many neurologists or MRI machines are available?

Treatment of MS
Which types of treatment are available?

Support for people with MS
Which types of information are available? Is there an MS organisation or support group in your country?

Quality of life
What anti-discrimination laws are there to protect people with MS? Are benefits available?

EPIDEMIOLOGY OF MS

Epidemiology is the study of the causes, patterns and effects of health and disease conditions in defined populations.

The number of people with MS has increased

The estimated number of people with MS has increased from 2.1 million in 2008 to 2.3 million in 2013.

The global median prevalence used to calculate this figure has increased from 30 (in 2008) to 33 per 100,000 (in 2013). It is not clear if this increase is due to better diagnosis and reporting, or to other causes.

Data sources for the 2013 figure are more robust than in 2008. Ninety two countries (accounting for 79% of the world population) provided prevalence data in 2013. Forty seven of these countries (51%) provided a reference to at least one published peer-reviewed paper reporting the results of a local or national epidemiological study, while another 18 (20%) referred to a register (local or national) or study that was not published in a peer-reviewed journal.

PREVALENCE BY COUNTRY (2013)

People per 100,000 with MS

- >100
- 60.01-100
- 20.01-60
- 5.01-20
- 0-5
- Data not provided
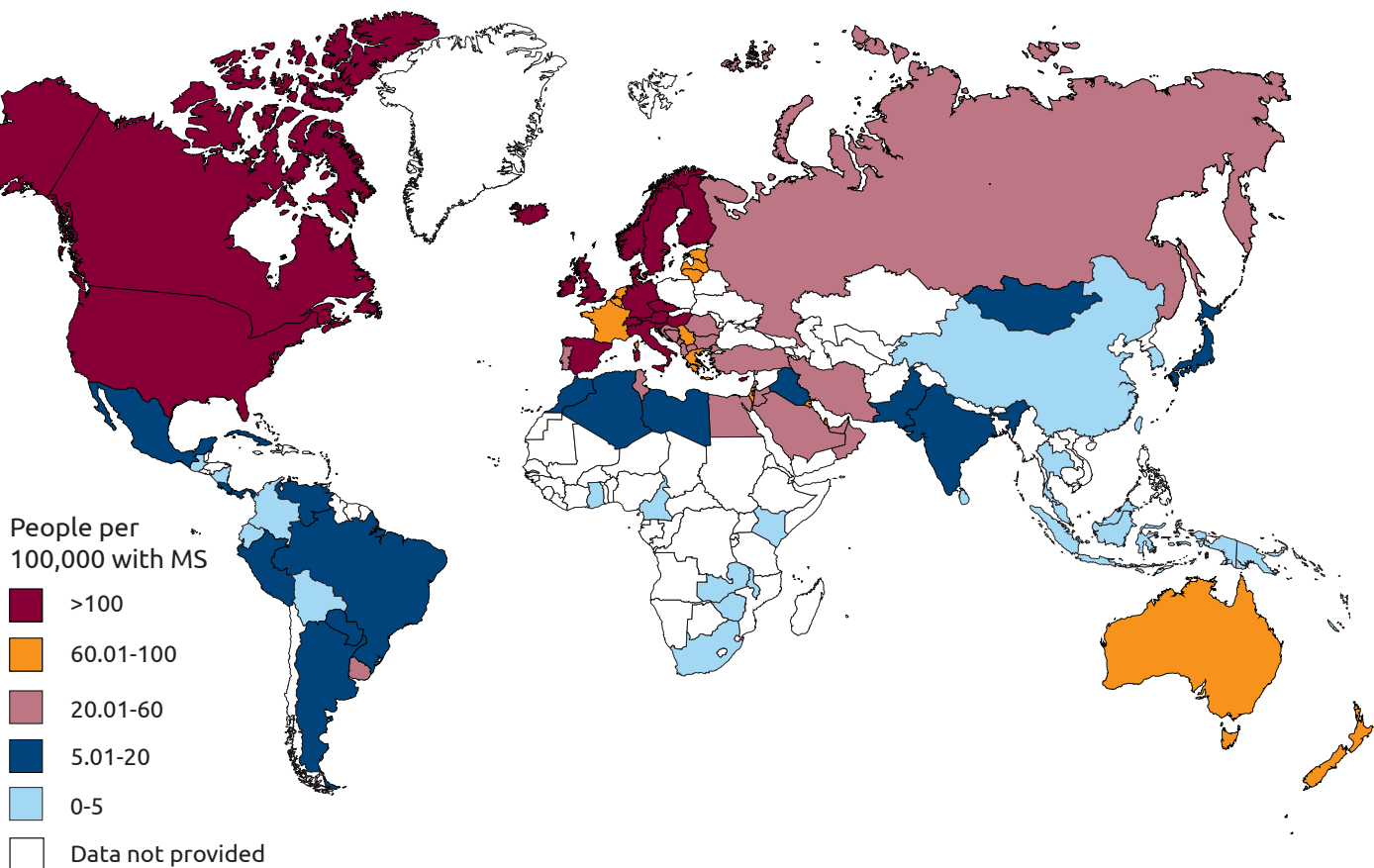
CALCULATING POOLED PREVALENCE

We have used global median prevalence in this report so that direct comparisons can be made with the 2008 report, which also used median prevalence.

An alternative way of calculating the number of people with MS is to use pooled prevalence, a potentially more robust method. Pooled prevalence is a measure that allows the relative size of a country's population to be taken into account.

Pooled prevalence is the total number of people with MS divided by the total world population, and then multiplied by 100,000.

The *Atlas of MS* 2013 survey revealed that there were about 1.6 million people with MS in the 92 countries that provided data. Using this figure and the United Nations medium growth population projection for 2013, pooled prevalence was calculated at 29/100,000. Based on pooled prevalence analysis, the number of people with MS in the world in 2013 was 2.0 million, compared to 1.8 million in 2008.

It is likely that both pooled and median prevalence underestimate the true global burden of MS.

Variations in prevalence

While MS is present in all regions of the world, its prevalence varies greatly, being highest in North America and Europe (140 and 108 per 100,000 respectively) and lowest in Sub-Saharan Africa and East Asia, at 2.1 and 2.2 per 100,000 respectively.

Prevalence also varies considerably within regions. For example the highest prevalence in Europe is 189 per 100,000 in Sweden, and the lowest is 22 per 100,000 in Albania.

Previously, it has been reported that the prevalence of MS varies according to latitude. The *Atlas of MS* 2013 also found this. For example, in South America, the prevalence for MS in Argentina – considered a medium risk country for MS – is estimated to be 18 per 100,000, which is six times higher than the prevalence of 3.2 per 100,000 recorded for Ecuador, a low risk country for MS[1].

1. Evans C. et al. "Incidence and prevalence of multiple sclerosis in the Americas: a systematic review." Neuroepidemiology. 2013;40(3):195-210. doi: 10.1159/000342779.

There are twice as many women as men with MS overall

The survey findings reinforce the fact that MS is twice as common among women than men. This ratio has not changed significantly since 2008.

The ratio of women to men with MS varies, and is considerably higher in some regions, such as East Asia where the female-to-male ratio is 3.0, and the Americas where it is 2.6.

Within regions there are countries where the ratio is considerably higher than average. For example in Iran the ratio is 2.8 women to each man with MS, well above that for the Eastern Mediterranean region as a whole, and studies indicate that the ratio of women to men with MS has increased significantly over recent decades[2].

The reason for this difference in MS risk between men and women is not fully understood, and neither is the cause of the apparent increase in the ratio in many countries over recent decades, though it is likely to be caused by the interaction of changes in a range of social and environmental factors with underlying genetic differences.

2. Elhami S.R. et al. "A 20-year incidence trend (1989-2008) and point prevalence (March 20, 2009) of multiple sclerosis in Tehran, Iran: a population-based study." Neuroepidemiology. 2011;36(3):141-7. doi: 10.1159/000324708.
3. Chitnis T, Glanz B, Jaffin S, Healy B. "Demographics of pediatric-onset multiple sclerosis in an MS center population from the Northeastern United States." Mult Scler. 2009 May;15(5):627-31. doi: 10.1177/1352458508101933".

The average age of MS onset is 30 years

This survey confirms earlier findings that MS is usually diagnosed during early adulthood (although people can be diagnosed at any age) and that people are living with this progressive neurological disease for many decades.

It most often hits people at a time when they are forging their career, finding a long-term partner or having children. MS can therefore impact on the social and economic wellbeing of the individual, as well as on their families and partners.

PAEDIATRIC MS

Published epidemiological research indicates that 2-5% of people with MS are diagnosed under the age of eighteen[3]. In our survey, we found that there were an estimated 7,000 people under 18 with MS in the 34 countries that provided data, mainly in Europe, Eastern Mediterranean and North America. The pooled prevalence of paediatric MS in these 34 countries is 0.63 per 100,000. However, this is likely to be an underestimate as in almost all countries providing data, the estimate was based on the numbers attending a few specialist treatment centres.

Under 18s with MS have different treatment and support needs to adults. However, there are only a small number of cases of paediatric MS and a limited number of specialists, and therefore international collaboration is vital. We are proud to support and coordinate the groundbreaking work of the International Paediatric MS Study Group (www.ipmssg.org).

NEUROMYELITIS OPTICA (NMO)

Neuromyelitis optica (NMO), also known as Devic's disease, is an autoimmune condition that shares many of the clinical features of MS. It is characterised by relapses (or attacks) of the optic nerves (optic neuritis) and spinal cord (transverse myelitis). NMO was only confirmed as a distinct disease 10 years ago, with the identification of the anti-Aquaporin 4 antibody.

Our survey found that there is very limited data on NMO. Only 39 countries provided data, which gave a pooled prevalence of 1 per 100,000 people. NMO appears to be less frequent than MS, but in some regions it is more common. For example the pooled prevalence for Japan, Singapore and Taiwan is 2.6 per 100,000.

There appears to be very limited specific information for people diagnosed with NMO around the world, although some MS organisations offer services and information for people with NMO, and others are developing these resources.

Types of MS at diagnosis

At the time of diagnosis, 85% of people had relapsing-remitting MS. It has been estimated that up to 80% of these people will go on to develop secondary progressive MS[4]. 10% of people were diagnosed with primary progressive MS and 5% with progressive relapsing MS. There was no significant variation between regions or income groups in the prevalence of the different types of MS at diagnosis.

Relapsing-remitting	85%
Primary progressive	10%
Progressive relapsing	5%

8 OUT OF 10 PEOPLE WHO ARE DIAGNOSED WITH RELAPSING-REMITTING MS DEVELOP SECONDARY PROGRESSIVE MS

| Secondary progressive | |

4. "Setting new standards in multiple sclerosis care and research." Editorial in Lancet Neurol. 2012 Oct;11(10):835. doi: 10.1016/S1474-4422(12)70214-4.

DIAGNOSIS AND CLINICAL MANAGEMENT OF MS

The survey found a rise in the global number of neurologists

In the 97 countries providing data, our study found that there was an overall increase of about 30% in the number of neurologists around the world. The majority of this was due to increases in the reported number of neurologists in the Americas and Western Pacific, and the increase was proportionally higher in the low income group countries than in the middle and high income group countries. The estimated global number of neurologists per 100,000 has risen from 1.01 to 1.32.

This now means that on average, there are about 22 people with MS per neurologist across the globe although this number will vary significantly between regions and income groups. For example, the median number of neurologists per 100,000 people is 3.6 for high income group countries, but only 0.03 for low income group countries.

MS IRELAND'S CAMPAIGN

The information in the *Atlas of MS* can be a powerful advocacy tool, raising awareness of MS as a global disease, and of the lack of sufficient resources available to diagnose, inform, treat, rehabilitate and support people with MS worldwide.

The 2008 *Atlas* found that Ireland had the lowest number of neurologists per capita in the European Union. It was one of the tools MS Ireland and the Neurological Alliance of Ireland used to persuade the Irish government to make a commitment to ensuring that there is one neurologist per 100,000 people, which represents a total of 42. In 2003 there were 14 neurologists in Ireland, and by 2013 that had increased to 34 approved neurology posts.
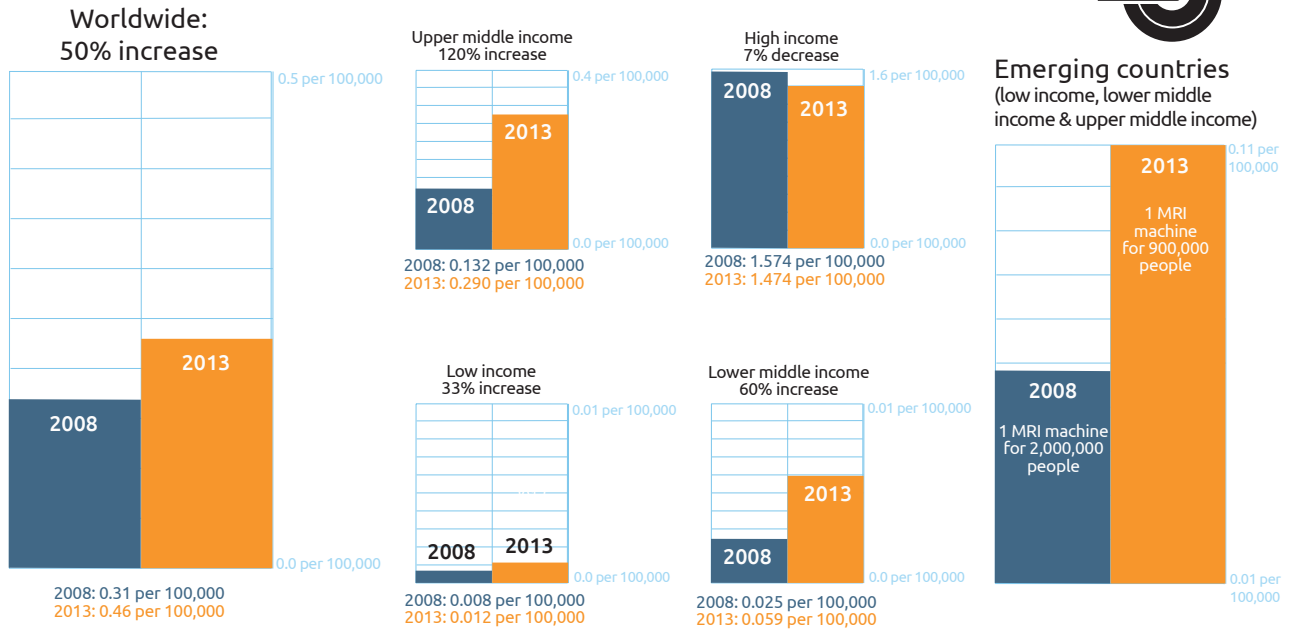
NEUROLOGISTS PER 100,000 POPULATION

2008 1.01 per 100,000

2013 1.32 per 100,000
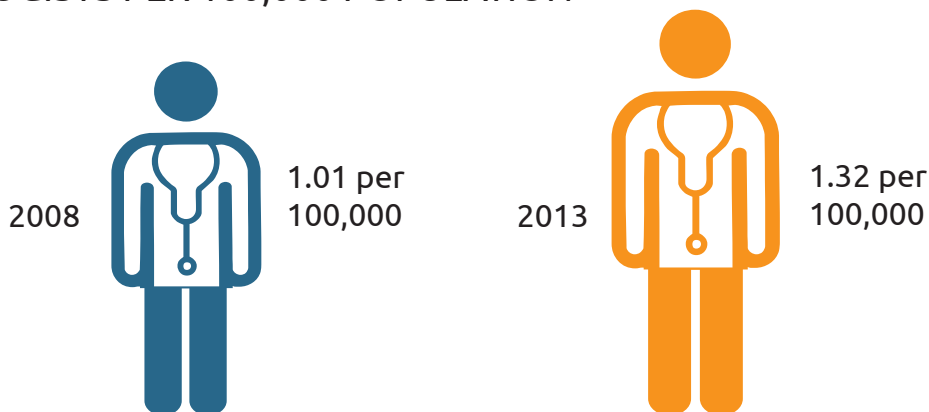
The number of neurologists worldwide has increased by 30% since 2008

MRI MACHINES PER 100,000 POPULATION

Increase from 2008 to 2013

Worldwide:
50% increase

0.5 per 100,000

2013

2008

0.0 per 100,000

2008: 0.31 per 100,000
2013: 0.46 per 100,000

Upper middle income
120% increase

0.4 per 100,000

2013

2008

0.0 per 100,000

2008: 0.132 per 100,000
2013: 0.290 per 100,000

Low income
33% increase

0.01 per 100,000

2008 2013

0.0 per 100,000

2008: 0.008 per 100,000
2013: 0.012 per 100,000

High income
7% decrease

1.6 per 100,000

2008 2013

0.0 per 100,000

2008: 1.574 per 100,000
2013: 1.474 per 100,000

Lower middle income
60% increase

0.01 per 100,000

2013

2008

0.0 per 100,000

2008: 0.025 per 100,000
2013: 0.059 per 100,000

Emerging countries
(low income, lower middle
income & upper middle income)

2013

1 MRI
machine
for 900,000
people

0.11 per
100,000

2008

1 MRI machine
for 2,000,000
people

0.01 per
100,000

The number of MRI machines in emerging countries has doubled in five years

Since 2008, there has been a large increase in the number of MRI machines available (an increase from 0.31 to 0.46 per 100,000 people). This increase was found in all regions of the world and World Bank income groups for the 91 countries for which data was provided, and brought the total number of reported MRI machines in these countries to just under 19,000.

The increase was most striking in emerging countries – countries with a low, lower middle or upper middle income as defined by the World Bank – many of which saw the numbers of MRI machines per 100,000 people more than double.

The most common diagnostic criteria for MS are the McDonald Criteria

The McDonald Criteria make use of advances in MRI techniques to allow diagnosis to be made at an earlier stage, and therefore offer the potential for earlier treatment and support. 96% of the 98 countries that provided data in our study reported using the McDonald Criteria, including 100% of high and upper middle income countries, 89% of lower middle income, and 87% of low income countries.

While the availability of MRI machines has improved since 2008 in almost all countries, they are not yet accessible to all people, and our survey noted that the reported use of older diagnostic criteria that are not so reliant on the availability of MRI was higher in low and middle income countries.

96%
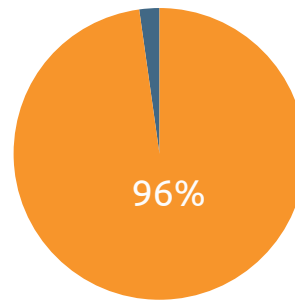
■ Countries using McDonald Criteria
■ Countries not using McDonald Criteria

These were distributed across the income groups as follows:

Low income	87%
Lower middle income	89%
High and upper middle income	100%

0%   50%   100%

Sensory		40%
Visual		30%
Balance		24%
Motor		39%
Cognitive		10%
Pain		15%
Urinary	W.C.	17%
Sexual		20%
Fatigue		30%

0%   50%
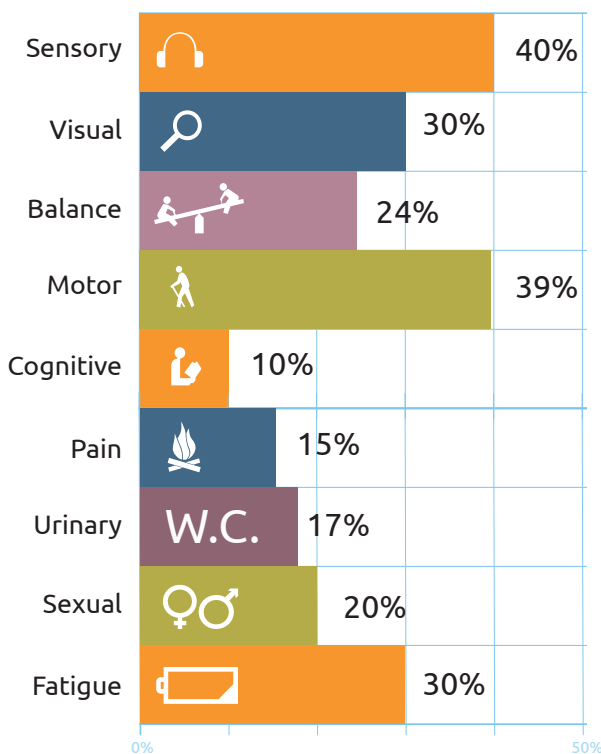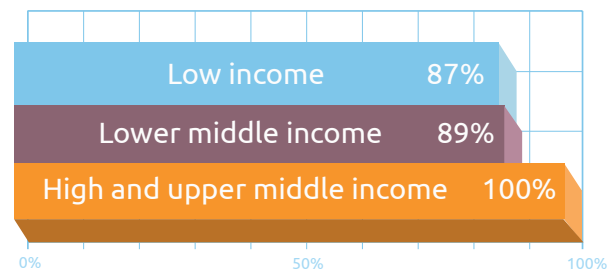
Most common presenting symptoms

In our global survey, the most common presenting symptoms were found to be sensory (40%) and motor (39%), and the least common were pain (15%) and cognitive issues (10%).

Everyone's experience of MS is different, and this survey highlights the variety of symptoms that may be present at disease onset. Some symptoms such as visual and motor defects may be more likely to prompt a consultation with a neurologist while others such as fatigue are more difficult to measure and therefore may go unrecorded. Similarly, symptoms related to urinary and sexual issues may be less likely to be discussed by people with MS in some cultures.

Availability of health care professionals

Multiple sclerosis is a very variable disorder, associated with a wide range of symptoms, which means that people with MS often have complex clinical needs. Access to a wide range of clinical specialists is important to ensure the health and quality of life of people with MS.

In the 52 countries that provided data, a neurologist, MS nurse, physiotherapist, urologist, gynaecologist, ophthalmologist, pharmacist, clinical psychologist, psychiatrist, occupational therapist, speech therapist, social worker, pain management specialist, chiropodist/podiatrist, continence advisor and dietician were available in most countries.

Multidisciplinary teams offer a wide range of specialist MS health care services in one location, providing greater breadth and depth of comprehensive, continuous care for people with MS in a coordinated, interdisciplinary fashion, and facilitate timely access to assessment, expertise and advice for people with MS whose needs may vary according to the stage of their condition.

36 countries reported the presence of hospital-based multidisciplinary teams. Neurologists (100%), physiotherapists (94%) and MS nurses (80%) were the most frequent members of these teams, whereas pain management specialists (25%), continence advisors (17%) and chiropodists or podiatrists (8%) appeared far less frequently in hospital-based multidisciplinary teams.

It should be noted that availability of specialists does not mean the service can be accessed by a person with MS requiring it. In several countries, our contacts informed us that particular services, while available, were only accessible by a limited number of people due to low numbers of specialists available, cost to the person with MS and/or transport difficulties.

On a global level, it is challenging to separate availability from access due to a lack of health data.

> **In 2013, the UK MS Society conducted a study that found people with MS face a lottery when accessing treatments and care. For example, 71% of people with MS received unpaid care from a friend or family member.**
>
> **Read more: mslottery.mssociety.org.uk.**

Paul Burstow MP, Chair of the UK All-Party Parliamentary Group on MS, with Hilary Sears, Chairman of the UK MS Society, at the launch of the UK MS Lottery campaign in 2013.
Photo credit: UK MS Society. Photographer: Theo Wood.

TREATMENT OF MS

Availability of drugs to treat MS

Disease-modifying therapies (DMTs) were part or fully funded by government in most countries (101 countries provided data). This refers to money for health services raised by taxation through social insurance or through compulsory or mandated health insurance.

For 76% of countries, the cost of DMTs was subsidised or fully funded by government. In all of these countries at least one platform therapy was available. Platform therapies for MS are interferon β1a (IM), interferon β1a (SC), interferon β1b and glatiramer acetate. 50% also had access to the more powerful therapy natalizumab, and 45% to fingolimod, the first oral DMT for MS[5].

There was considerable variability between income groups in access to government funded therapies. Government funded DMTs were available in 96% of high income group countries, but in only 45% of lower middle income group countries and in none of the low income group countries. Access to the newer therapies natalizumab and fingolimod was widespread only in the high income group countries and limited in middle income group countries.

Of the 90 countries that provided a reason why not all people with MS are receiving DMTs, affordability was ranked as the most common by 46%, which rose to 86% in the 21 low and lower middle income countries that answered this question.

AVAILABILITY OF DISEASE-MODIFYING THERAPIES FOR MS THAT ARE FUNDED FULLY OR PARTLY BY THE GOVERNMENT

HIGH INCOME COUNTRIES

Fingolimod	76%
Natalizumab	82%
Platform therapies	96%

0%　　50%　　100%

UPPER MIDDLE INCOME COUNTRIES

Fingolimod	32%
Natalizumab	43%
Platform therapies	89%

0%　　50%　　100%

LOWER MIDDLE INCOME COUNTRIES

Fingolimod	10%
Natalizumab	10%
Platform therapies	45%

0%　　50%　　100%

LOW INCOME COUNTRIES

Fingolimod	0%
Natalizumab	0%
Platform therapies	0%

0%　　50%　　100%
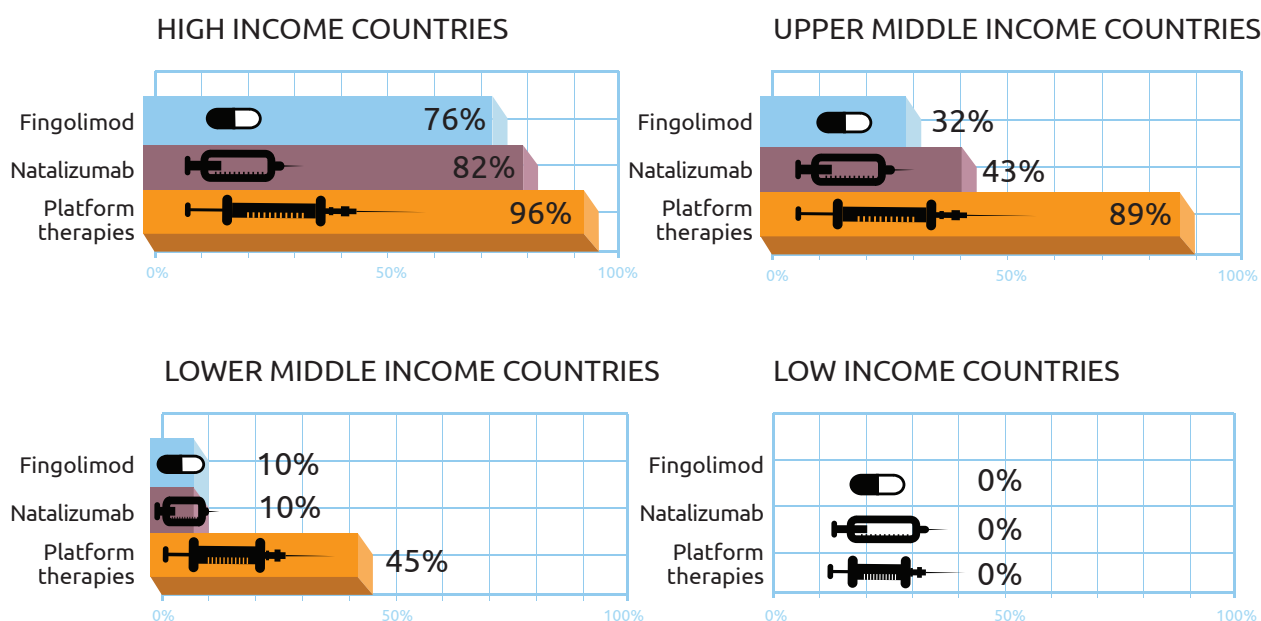
In countries where DMTs are available through government funded schemes, they may not be accessible to all people who need them, as in some cases the government may not fund the full cost of treatment, or may provide treatment to a limited number of people with MS in each year.

Corticosteroid drugs to treat MS relapses were available in all countries that provided data (100 countries). However availability of plasmapheresis as a second line therapy was more limited, being available in only 53% of countries, almost all of which are in the higher income groups.

Treatments for MS symptoms were widely available.

Availability of rehabilitation depended on type of therapy

Physiotherapy was available in almost all (99%) of the 100 countries that provided data on rehabilitation services.

Cognitive rehabilitation was the least available of the rehabilitation services worldwide, being available in only 48% of countries, even though cognitive problems can affect 40-70% of people with MS. This lack of availability may relate in part to the challenge in proving the efficacy of cognitive rehabilitation, highlighting the need for rigorous research on this important aspect of the management of MS.

There was significant variation in the availability of cognitive rehabilitation, occupational therapy and occupational rehabilitation across income groups and regions.

Dr Darshpreet Kaur, a physiotherapist and former MSIF Du Pré research award recipient, works with people with MS in India.

5. The *Atlas of MS* 2013 survey was drafted and circulated to country coordinators prior to the granting of regulatory approval in most countries to the oral disease modifying therapies Teriflunomide (Aubagio) and Dimethyl fumarate (Tecfidera).

SUPPORT FOR PEOPLE WITH MS

One in five countries has no organisations supporting people with MS

Twenty per cent of the 103 countries that provided information do not have a national or local group supporting people with MS. However, the number of countries with such organisations has increased since 2008, from 73% to 80%, and new groups are being established.

For example MSIF is currently working with local volunteers to establish a support organisation for people with MS in China (go to www.msnmo.org to find out more). However, only 14% of low-income countries and 55% of lower-middle countries have an MS support group.

CAPACITY-BUILDING IN THE ARABIC-SPEAKING REGION

MSIF's capacity-building programme in the Eastern Mediterranean region has helped increase the number of countries with MS support groups from 8 to 13 since 2008. This is reflected in the increase in information resources provided in the region, although this could also relate to increased access to the internet (see opposite).

Participants from MS societies in Jordan, Yemen and Lebanon doing a group exercise during MSIF's regional training event in Dubai in March 2013

More information is available to people with MS

There was a general increase in the information support available globally compared to 2008, with 78% having at least two of the three following resources: a telephone helpline, printed material and/or a website.

Only 14% of countries had a full range of information resources (telephone helpline, printed material, website,

newsletter and audio-visual materials) from at least two sources of information (i.e. health professionals, a MS support group or organisation or pharmaceutical companies). People in these countries had a choice of information and channels to meet their needs to enable them to make an informed choice.

SUPPORT SERVICES FOR PEOPLE WITH MS

GLOBALLY

Service	2008	2013
Telephone helplines	53.7%	68.6%
Printed material	70%	80.4%
Audio visual material	58.8%	70%
Newsletters	49.1%	59.8%
Websites	53.6%	68.6%

0%   50%   100%

COUNTRIES IN THE EASTERN MEDITERRANEAN

Service	2008	2013
Telephone helplines	26.7%	71.6%
Printed material	40%	76%
Audio visual material	50%	59%
Newsletters	20%	47%
Websites	33.3%	65%

0%   50%   100%
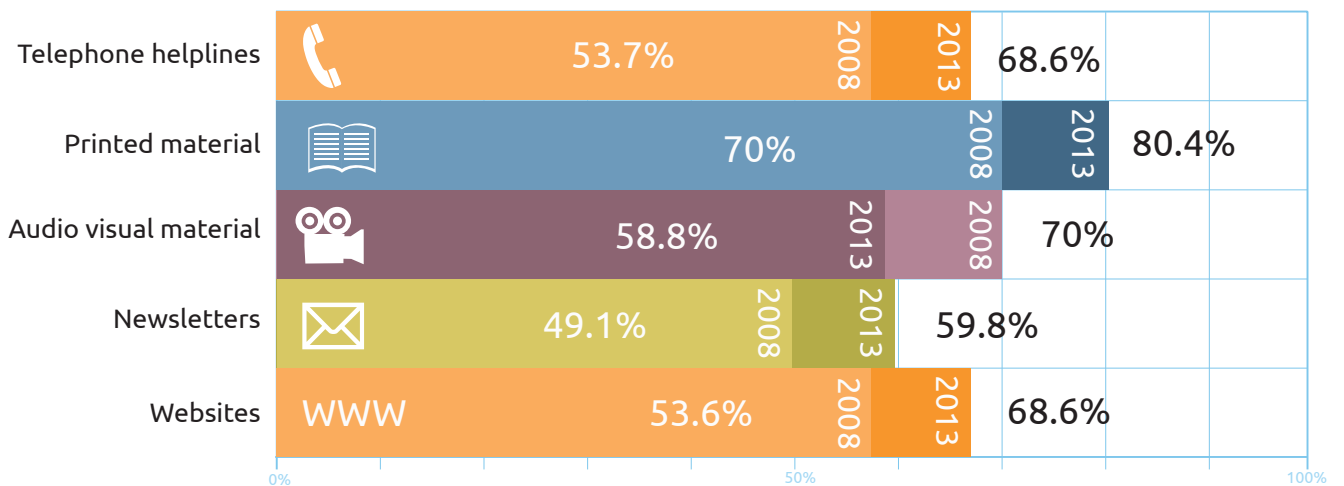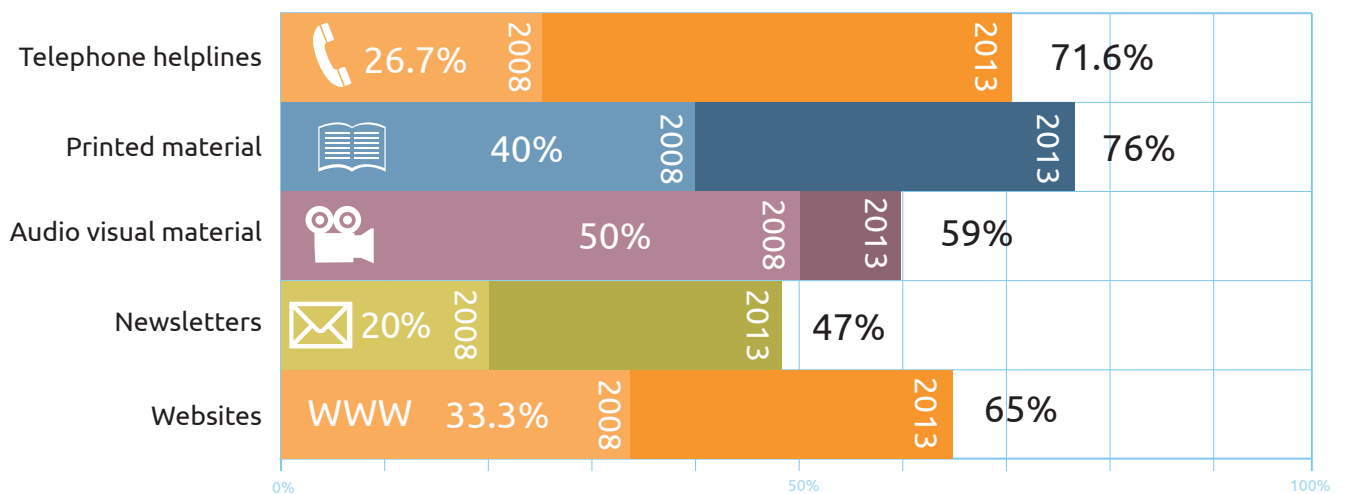
QUALITY OF LIFE

Anti-discrimination laws

Of the 100 countries providing data, 71% said that anti-discrimination laws covered people with MS and other disabilities in their country. A lower percentage of countries in the Eastern Mediterranean region and South East Asia had these laws to protect people with disabilities.

Financial support from government

78% of countries stated that disability entitlements were available to people with MS. These entitlements included monetary compensation (65%), tax benefits (41%), rehabilitation and health benefits (64%), benefits in the home (50%) and workplace (58%), and other benefits such as housing or transport (29%).

There were clear inequalities between income groups in the provision of disability entitlements, for example financial entitlements in the form of money compensation and/or tax benefits were provided by 95% of higher income countries, but this fell to 64% for upper middle income countries and to just 35% for lower middle and low income countries.

The *Principles to Promote the Quality of Life of People with Multiple Sclerosis*[6] published by MSIF in 2005 includes the principle that:

"Disability entitlements and services are available to those in need, provide an adequate standard of living, and have flexibility to allow for the disease variability that is characteristic of multiple sclerosis."

The MSIF *Atlas of MS* 2013 survey highlights the progress that is still to be made in ensuring that every country has adequate systems in place to promote the quality of life of people with MS.

> In Australia in 2010, annual costs per person with MS averaged nearly AU$50,000, with the largest cost component being lost productivity. It is surely cost-effective for governments to prioritise workplace assistance schemes for people with MS to maintain their employment as long as possible.

Rex Simmons, MS Australia

6. "Principles to Promote the Quality of Life of People with Multiple Sclerosis" Published by Multiple Sclerosis International Federation ISBN 0-9550139-0-9. Available to download from www.msif.org/about-ms/publications-and-resources.aspx

THE PRINCIPLES TO PROMOTE THE QUALITY OF LIFE OF PEOPLE WITH MS

The ten principles are:

• People with MS are empowered as full participants in their communities and in decision-making about the management and treatment of the disease.

• People with MS have access to medical care, treatments and therapies appropriate to their needs.

• People with MS have access to a wide range of age-appropriate care services that enable them to function as independently as possible.

• People with MS have the information and services they need to maintain positive health practices and a healthy lifestyle.

• People with MS have access to their communities through accessible public transportation and assistive technology for personal automobiles.

• Family members and caregivers receive information and support to mitigate the effects of MS.

• Support systems and services are available to enable people with MS to continue employment as long as they are productive and desire to work.

• Disability entitlements and services are available to those in need, provide an adequate standard of living, and have flexibility to allow for the disease variability that is characteristic of multiple sclerosis.

• MS does not inhibit the education of people with MS, their families or careers.

• Accessibility, both of public buildings and in the availability of accessible homes and apartments, is essential to independence for people with MS.
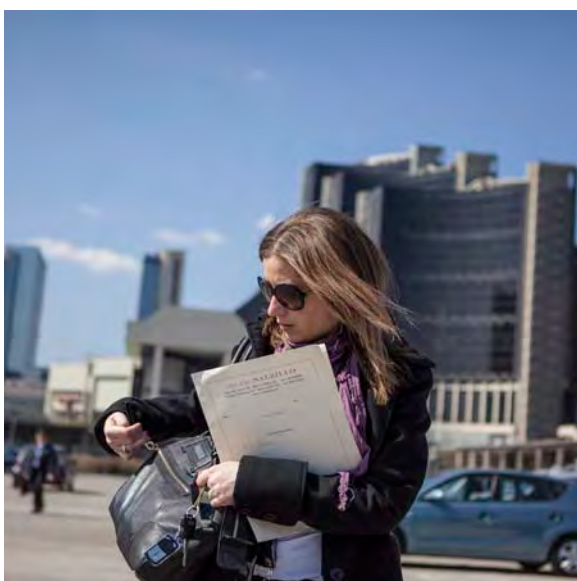
Napoli , Italy 03/2012.
Stefania Salzillo, who has MS, is pictured here, leaving the Court of Justice in Napoli, Italy as part of the European MS Platform's www.underpressureproject.eu. She says: "There are very few parking lots for disabled, and most public and private buildings do not have the appropriate access facilities, this forces disabled people to isolate themselves: they stop working, they give up their social life and even sports."
Photo credit: EMSP. Photographer: Walter Astrada.

CONCLUDING REMARKS

The *Atlas of MS* 2013 brings increased rigour to estimates of epidemiology of MS around the world and we hope that it will encourage further international epidemiological and socio-economic comparative research by highlighting the similarities and differences between countries and regions. It will also help the global MS community to increase policy impact, and facilitate international advocacy for the interests of people affected by MS.

The *Atlas of MS* 2013 provides new data on paediatric MS and neuromyelitis optica (NMO) and highlights the need for further research to determine the number of people affected by these conditions, who have specific support and therapy requirements that differ from those of other people with MS.

The *Atlas of MS* 2013 highlights that, although there have been improvements in the availability of care, treatment, support and services, these are not evenly distributed across the world and can vary between regions and even within countries.

The findings in the *Atlas of MS* 2013 about the availability of treatments and how accessible they are to people with MS highlight the important issue of affordability. There is a need to maintain oversight of treatment costs and, where appropriate, advocate to make treatments more affordable, directly and/or through increasing the reimbursement of treatment costs through insurance or government.

The 2008 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) reaffirms that people with disabilities have human rights and that they should be able to enjoy them on an equal basis with other people. The Convention sets out the measures governments are expected to take to remove them and to ensure the rights of disabled people are protected. In particular, the *Atlas of MS* 2013 suggests that there are gaps between the articles in the Convention and the reality for people with MS.

Consequently, the Convention, together with the *Atlas of MS,* can be a useful tool to use to advocate for change in your country.

Esclerosis Multiple Uruguay advocating for the rights of people with MS in Uruguay on World MS Day 2012.

METHODOLOGY

All data contained in the *Atlas of MS* 2013 has been collected in a large international study from October 2012 to June 2013. An online questionnaire was drafted in English based on the original questionnaire used in 2008. A long version was circulated to countries that were better placed to provide more detailed data and a shorter version capturing the key information was developed for the remaining countries.

A glossary of terms used in the questionnaire was also prepared to ensure that the questions were understood in the same way by different respondents.

The final version of the questionnaire covered a wide range of issues broken down into the following sections: epidemiology, clinical management, diagnosis, treatment, support available, quality of life, NMO and paediatric MS.

The next step of the process was to identify the most relevant and appropriate person in each country to be invited to act as "country coordinator", who would be the focal point for gathering information and data within that country and organising the completion of the eight sections of the questionnaire.

For those countries with MSIF member societies or corresponding organisations, the country coordinator was either the senior staff member or senior volunteer of the society or the country representative on the MSIF International Medical & Scientific Board. For countries with no MSIF connection, the country coordinators who provided data for the 2008 *Atlas of MS* were contacted in the first instance. In situations where this approach was not successful, contacts were sought through various sources such as the World Federation of Neurology, the scientific literature and recommendations by colleagues.

The country coordinators were requested to oversee the completion of the questionnaire, making use of all possible sources of information available to them. All respondents were asked to follow the glossary definitions closely, to maintain uniformity and comparability of the information received. Several repeat requests for completion of the questionnaire were sent to the country coordinator in cases where there was a delay in returning the completed questionnaire. In the case of incomplete or internally inconsistent information, the respondents were contacted to provide further information or clarification. Contacts were requested to provide source information for epidemiological data, and where possible these sources were used to verify the data provided.

Eventually, data was gathered from 104 countries and entered in an electronic database. This includes 12 new countries since 2008. In addition, 20 countries that participated in 2008 but did not provide an update in 2013 are included in the database bringing the total to 124 countries. Population figures were taken from the UN population prospects 2013 (medium growth).

THE WORLD HEALTH ORGANIZATION REGIONS

Countries were grouped into the six WHO regions (Africa, the Americas, Eastern Mediterranean, Europe, South-East Asia and Western Pacific) and also into other relevant groupings as seen on the website.

For epidemiological analysis, the WHO regions of Africa, the Americas and Western Pacific were further subdivided into the following categories:

WHO African Region
North Africa: Algeria
Sub-Saharan Africa: Cameroon, Côte d'Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana, Guinea, Kenya, Malawi, Nigeria, South Africa, Zambia, Zimbabwe

WHO Region of the Americas
North America: United States of America, Canada
Latin American and the Caribbean: Argentina, Bolivia, Brazil, Colombia, Costa Rica, Cuba, Ecuador, Guatemala, Mexico, Nicaragua, Panama, Paraguay, Peru, Uruguay, Venezuela

WHO Western Pacific Region
Australasia: Australia, New Zealand
East Asia: China, Japan, Malaysia, Mongolia, Republic of Korea, Singapore, Taiwan

Countries were also grouped by income levels, based on the World Bank income categories as follows: low income (<US$1,035), lower middle income (US$1,036-4,085), upper middle income (US$4,086-12,615) and high income (>US$ 12,616).

The data was analysed using MS Excel.

Representativeness of data collected
Completed questionnaires were received from 104 of 193 countries. Data was collected from 41 countries in the European Region (77%), 18 countries in the Region of the Americas (51%), 13 countries in the African Region (26.1%), 17 countries in the Eastern Mediterranean Region (77%), 9 countries in the Western Pacific Region (33%), and 6 countries in the South-East Asia Region (54%). In terms of population covered, the data pertain to 79% of the world population.

LIMITATIONS

The most important limitation of the dataset is that in the majority of countries a single key person was the source of most or all information. Although most respondents had access to numerous official and unofficial sources of information and were able to consult neurologists within the country, the data received should still be considered as reasonably, but not completely, reliable and accurate. In some instances the data are the best estimates by the respondents. In spite of this limitation, the *Atlas of MS* remains the most comprehensive compilation of MS resources in the world.

Because the sources of information in most countries were the key people working in the field of MS, the dataset mainly covers countries where there are MS societies, neurologists or other specialists with an interest in MS or neurology. It is therefore likely that the *Atlas of MS* gives an over positive view of neurological resources in the world, and there are likely to be very limited or no resources in many of the remaining 89 of the countries that did not provide data.

Data from newer topics such as NMO were not available in many countries including USA and Canada. Data on paediatric MS was only available in a minority of countries and when available, data was often incomplete. We hope the *Atlas of MS* will stimulate new and rigorous data collection in these areas.

The availability of data on incidence was more limited than that on prevalence, and was provided by only 52 of the 104 countries that participated in the survey. Incidence data is important for monitoring changes in rates of MS over time and in specific populations, where it can provide more accurate measures than prevalence as it is not affected by changes in survival due to improved therapy and clinical management.

ACKNOWLEDGEMENTS

Global information on epidemiology and the
availability of resources and services for people with
MS is scarce, fragmented, and relates mainly
to high-income countries.

The first *Atlas of MS*, published in 2008 as a joint project
by MSIF and the World Health Organization, started to fill
this information gap with the help of key informants from
different fields working to improve the quality of life of
people with MS around the world.

The *Atlas of MS* 2013 updates this information and maps
data, resources and services by compiling and calculating
their distribution by country,
region and income levels.

The *Atlas of MS* 2013 includes new topics: newly licensed
therapies, neuromyelitis optica, and paediatric MS.

For more information or to find data for your
country, region or the world go to www.atlasofms.org