

Atlas

MULTIPLE SCLEROSIS
RESOURCES
IN THE WORLD
2008



World Health
Organization



multiple sclerosis
international federation

Atlas

**M U L T I P L E S C L E R O S I S
R E S O U R C E S
I N T H E W O R L D
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**World Health
Organization**



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◆ Multiple sclerosis (MS) is one of the most common neurological disorders and causes of disability in young adults. Although some people with MS experience little disability during their lifetime, up to 60% are no longer fully ambulatory 20 years after onset, with major implications for their quality of life and the financial cost to society. Most people with MS have a normal or near-normal life expectancy. In rare cases, MS is so malignantly progressive it is terminal. Despite our awareness of the considerable impact of MS, there is a serious lack of information about the resources available to address it.

To meet this need, the World Health Organization (WHO) and the Multiple Sclerosis International Federation (MSIF) undertook a major collaborative effort to determine the global epidemiology of MS and the resources to diagnose, inform, treat, rehabilitate, support and provide services to people with MS. As a part of this effort, between 2005 and 2007, 112 countries, representing 87.8% of the world population, were surveyed.


Benedetto Saraceno
Director
Department of Mental Health and Substance Abuse
World Health Organization

The data and information gathered clearly indicate that no one country provides adequate resources and that the availability of resources varies widely between countries both within regions and throughout the world. In many low and middle income countries where resources are available, they are grossly inadequate. There continue to be major problems worldwide in delivering a model of care that provides truly coordinated services. There is serious inequity of service provision both within and between countries, and an inordinate reliance on family and friends to provide essential care.

The value of the Atlas of Multiple Sclerosis (Atlas of MS) is in replacing impressions and opinions with facts and figures. The findings have specific implications for the work of health professionals, patient groups, the health industry and governments and will inform national and regional advocacy and development policies.

We hope that the Atlas of MS will be used by people with MS, health professionals and MS groups and organizations to stimulate and inform campaigns for improvements in the services and support provided to people with MS and those with an interest in their well-being and quality of life.

Alan Thompson
Chairman
International Medical and Scientific Board
Multiple Sclerosis International Federation

 The Atlas of MS provides, for the first time, information and data on the global epidemiology of MS and the availability and accessibility of resources for people with MS at the country, regional, and global levels.

Knowing what resources are available in different countries helps to provide useful insights and highlight differences, gaps and inadequacies. Such internationally comparable statistics on resources enable assessment and comparison of the performance of national health systems and the health of the particular populations they serve.

The Atlas of MS provides this information, considers the resulting implications and suggests ways forward in the global effort to improve the planning and delivery of health care services. It is not only a reference, which relevant individuals, groups and organizations can consult, but it is also an overview of the current issues facing people with and affected by MS and those who work tirelessly to provide support and services for them.


Tarun Dua and Shekhar Saxena
Department of Mental Health and Substance Abuse
World Health Organization

The delivery of patient or person centred care, for people with long-term conditions, is becoming increasingly popular. The success of the implementation of this approach in the support of people with MS varies significantly around the world. In part, this reflects the differences in prevalence and therefore the relative importance afforded to the disease within a country's health system. In addition, diagnostic equipment and treatment are expensive. The need to invest in initiatives to help people with MS remain employed also varies. For example, in the majority of high income countries the costs of treatment are often borne by the government or insurance companies whereas in other regions the costs are borne by people with MS and their families.

We are aware of several limitations of the data presented in the Atlas of MS and welcome all suggestions that would help to improve the quantity and quality of data, especially from countries where information on MS is scarce.

The Atlas of MS is a unique information and advocacy tool to support initiatives to develop public policy, service provision and support and ultimately to improve the quality of life of people with MS. We hope the Atlas of MS will stimulate further discussion, debate, research and data collection on the epidemiology of MS and the resources available to manage it.

Paul Rompani
Deputy Chief Executive
Multiple Sclerosis International Federation

 The Atlas of MS is a project of WHO and MSIF supervised and coordinated by Dr Tarun Dua (WHO) and Dr Shekhar Saxena (WHO). Dr Benedetto Saraceno provided vision and guidance to the project.

The project was carried out in close collaboration with an MSIF Work Group coordinated by its Deputy Chief Executive Paul Rompani. Work Group members include Alan Thompson (Institute of Neurology, University College London), Mario Battaglia (University of Siena), Ian Douglas (MSIF), Bernadette Porter (National Hospital for Neurology and Neurosurgery, University College London) and Paul Rompani (MSIF)

The development of the questionnaire and glossary and the final report was informed by an MSIF Oversight Group with the following members: Professor Alan J Thompson (the United Kingdom); Professor Alexei N Boiko (Russian Federation); Dr Fernando J. Cáceres (Argentina); Professor Hans-Peter Hartung (Germany); Professor Jürg Kesselring (Switzerland); Dr Bhim S Singhal (India); Professor Aksel Siva (Turkey); and Dr Ernest Willoughby (New Zealand).

Dr Marco Garrido-Cumbrera (WHO) assisted in the development of the survey design and questionnaire, data collection and project management.

Dr Tarun Dua and Paul Rompani were responsible for completion of the data collection, data analyses, overall project management and the writing of this report. Ms Rosa Seminario and Ms Rosemary Westermeyer helped with the data management and provided administrative support.

The information from various countries, areas and territories was provided by key persons working in the field of MS and/or neurology identified by MSIF, WHO regional offices, the offices of WHO Representatives and the World Federation of Neurology. The respondents also handled the many requests for clarification arising from the data. Contributions of all these individuals has been valuable in the production of this report. The list of respondents is included at the end of the Atlas of MS.

Assistance in preparing the Atlas of MS for publication was received from Tushita Bosonet and Chris Burgisser (graphic design), Steve Ewart (maps) and Susan Kaplan (editing).

The contribution of each of the team members and partners, together with input from many other unnamed people, has been vital to the success of this project.

◆ At present, information on the availability of resources and services for people with MS is scarce, fragmented, and relates mainly to high income countries.

One of the objectives of the Atlas of MS is to start filling this information gap with the help of key informants from different fields who are working to improve the quality of life of people with MS in all Member States of WHO, Associate Members of WHO, and areas and territories. This project aimed to map resources and services by compiling and calculating their distribution by regions and income levels.

Developing the Atlas of MS presented some unique challenges that reflect the current status of MS services in countries with low or middle incomes. Large differences

are seen between high income countries and countries with low or middle incomes with regard to the availability and the type of services and resources.

The Atlas of MS does not rely solely on data gathered through the Atlas of MS questionnaire. References from the MSIF's *Principles to Promote the Quality of Life of People with Multiple Sclerosis* (available at www.msif.org) are included to inform and supplement the data collected.

The primary purposes of this report are to stimulate additional systematic data gathering and to encourage the development of much needed policy, services and training. We very much hope that this initial publication will serve these purposes.

◆ All the information and data contained in the Atlas of MS have been collected in a large international study made in the two-year period from 2005 to 2007, which included more than 100 countries spanning all WHO regions and continents.

Data collection

The Atlas of MS is based on the information and data collected by WHO and MSIF. At WHO, the work was led by headquarters in close collaboration with the regional offices.

The first step in the development of the Atlas of MS was to identify specific areas where information related to MS resources and services was lacking. To obtain this information, a questionnaire was drafted in English in consultation with a group of people from WHO and MSIF. 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. Subsequently, the draft questionnaire and glossary were reviewed by selected experts. The resulting questionnaire was developed further, in consultation with the Atlas of MS Oversight Group, and pilot tested and necessary changes were made. The definitions used in the glossary are working definitions for the purpose of the Atlas of MS project, and do not constitute official WHO definitions.

The final version of the questionnaire covered a wide range of issues broken down into the following eight separate sections:

- ◆ epidemiology of MS
- ◆ MS groups and organizations
- ◆ support available to people affected by MS
- ◆ diagnosis of MS
- ◆ management of MS
- ◆ treatment of MS
- ◆ quality of life of people with MS
- ◆ issues in MS care.

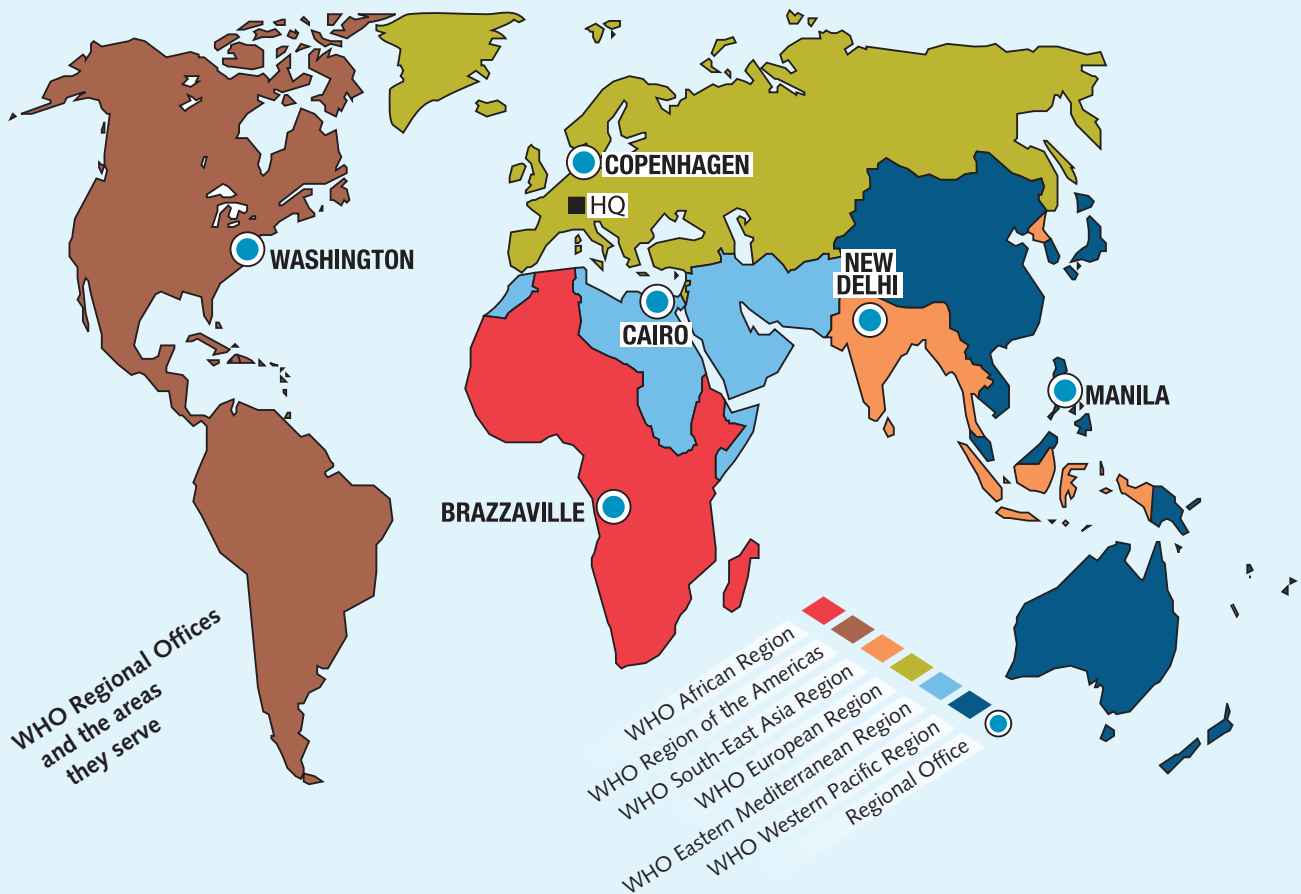
The next step of the process was to identify the most relevant and appropriate person in each country to be invited to act as "country coordinator" to be the focal point for gathering information and data within that country and organizing the completion of the eight sections of the questionnaire.

For those countries with MSIF member societies or corresponding organizations, 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. In addition, WHO regional offices were asked to identify a key person working in the field of MS or neurology in those countries where the MSIF has no liaison person or this person was not available or not responsive. For countries with no MSIF connection, the country coordinators were either WHO contacts developed through the production of the *WHO Atlas: Country Resources for Neurological Disorders, 2004*, individuals identified by MSIF staff or members of the World Federation of Neurology.

The country coordinators were asked to consider which individuals, groups and organizations in their country would be best placed to complete the eight sections of the questionnaire. The country coordinators were requested to coordinate 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. Throughout this process, the Atlas of MS Project Work Group responded to questions and requests for clarification. 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. Where appropriate, documents were requested to support completed questionnaires.

Eventually completed questionnaires were received from 64 countries. Another attempt was made to contact countries that had not responded through MSIF member societies and corresponding organizations, and contacts identified through WHO Regional Offices and World Federation of Neurology. In order to improve representation across all WHO regions, a shorter questionnaire was developed for completion by contacts in those countries where little is known about MS and/or there is low prevalence of MS. As a result of the extra effort, data was gathered from 112 countries.

An electronic database was generated and received data was entered. Both quantitative and qualitative data was entered using suitable codes. Population figures were taken from the World Health Report 2006 (WHO, 2006). Countries were grouped into the six WHO regions (Africa, the Americas, Eastern Mediterranean, Europe, South-East Asia and Western Pacific).



The income group of the countries was based on the 2002 gross national income (GNI) per capita according to the World Bank list of economies, July 2003. The GNI groups were as follows: low income (US\$ 905 or less), lower middle income (US\$ 906–3595), upper middle income (US\$ 3596–11 115) and high income (US\$ 11 116 or more).

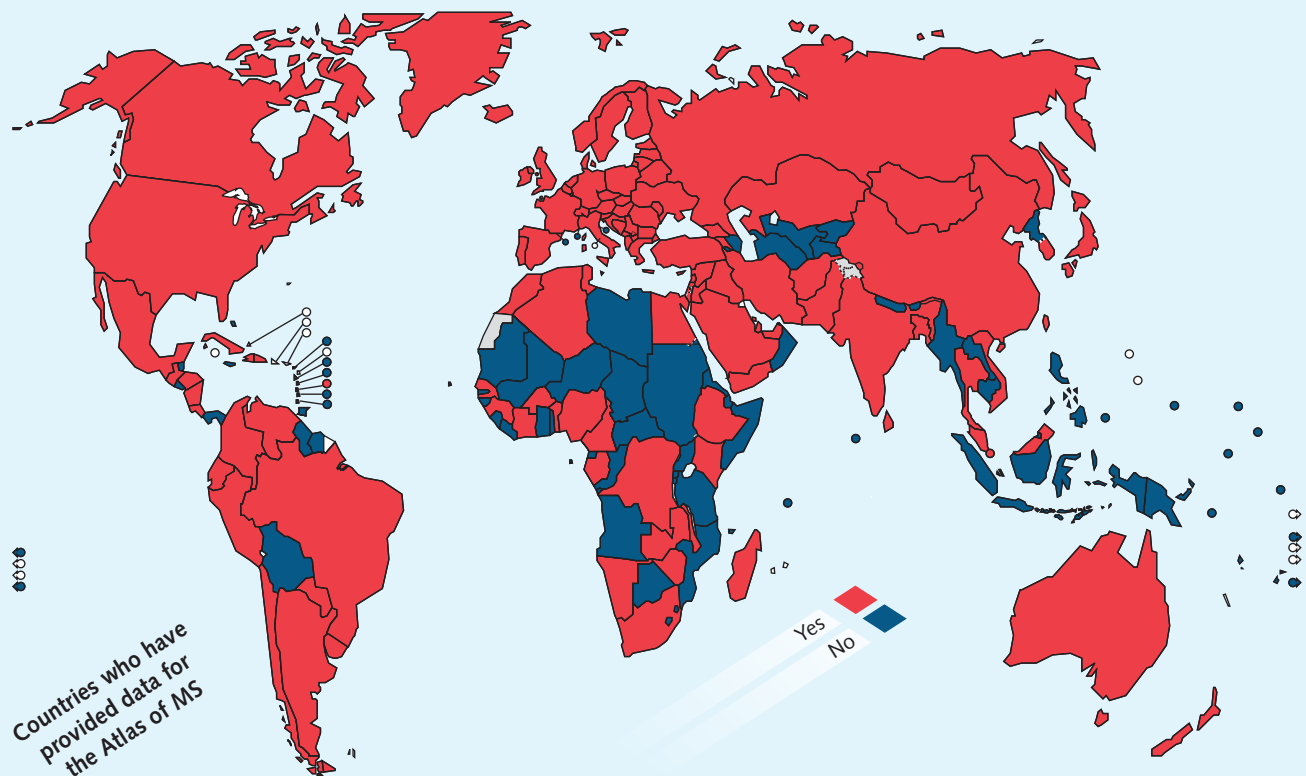
The data was analysed using Stata (special edition) version 9 software. Values for continuous variables were grouped into categories based on distribution. Frequency distributions and measures of central tendency (mean, medians and standard deviations) were calculated as appropriate.

The published literature regarding some of the themes was also reviewed and the evidence summarized. The results of the analysis were presented in a draft report which was reviewed by leading experts in the field of MS and regional advisers of the six WHO regions, and their comments were incorporated.

Representativeness of data collected

Completed questionnaires were received from 111 of the 193 WHO Member States and one Special Administrative Region (Hong Kong), all of which are henceforth referred to as countries for the sake of convenience. Of these 112 countries, 66 (59%) completed the original long version of the questionnaire whereas 46 (41%) completed the shorter version.

The data were collected from 44 countries in the European Region (84.6%), 20 countries in the Region of the Americas (57.1%), 18 countries in the African Region (39.1%), 16 countries in the Eastern Mediterranean Region (76.2%), 9 countries in the Western Pacific Region (33.3%), and 4 countries in the South-East Asia Region (36.4%).



In terms of population covered, the data pertain to 87.8% of the world population; 97.1% of the population in the Americas, 94.2% in Europe, 93.7% in the Western Pacific, 89.8% in the Eastern Mediterranean, 80.2% in South-East Asia and 70.3% in Africa.

Limitations

The most important limitation of the dataset is that in 67 of the 112 countries a single key person was the source of 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, and 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 is the most comprehensive compilation of MS resources in the world ever attempted.

Because the sources of information in most countries were the key persons working in the field of MS, the dataset mainly covers countries where there are MS societies, neurologists or other experts 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, if we consider the lack of experts or health professionals with an interest in MS or neurology, which suggests that there are likely to be very few or no resources in the remaining 82 (42%) of the WHO Member States.

While attempts have been made to obtain all the required information from all countries, in some countries this was not possible. Hence, the denominator for the various themes is different and this has been indicated in each theme. The most common reason for missing data was either the non-availability of the information in the country or the lack of a relevant or appropriate informant willing or able to provide a professional opinion.

The data regarding the epidemiology of MS represent an estimate and were not collected and calculated using stringent epidemiological research methods. The data were compared with the published evidence available from various countries.

Certain questions were framed in such a way that the response could be either "yes" or "no". Although this facilitated a rapid gathering of information, it failed to reflect differences in coverage and quality. Respondents may have replied positively to the question of availability of services in the country even if only a very limited number of such facilities were available in a few large cities. Furthermore, the response does not provide information about distribution across rural or urban settings or across different regions within the country.

It is possible that definitions for various terms vary from country to country. As a result, countries may have had difficulties in interpreting the definitions provided in the glossary. While all possible measures have been taken to compile code and interpret the information given by countries using uniform definitions and criteria, it is possible that some errors may have occurred during data handling.

Data organization and presentation


The data included in the Atlas of MS are organized in 10 broad themes. The graphic displays include maps of the world with colour-coded country data. Regional maps show aggregate figures by WHO regions. Bar and pie charts are provided to illustrate frequencies, medians and means as appropriate.

Since the distribution of most of the data is skewed, the median has been used to depict the central tendency of the various variables. Where the range of data is presented it is always the interquartile range.

Selected salient findings from analysis of the data are described for each of the specific themes. No attempt has been made to provide a description of all the possible findings arising out of the data analyses presented.

Limitations specific to each theme should be kept in mind when interpreting the data and their analyses. Some implications of the findings and/or recommendations for further development of resources for MS are highlighted.

In addition to the information collected as a part of the Atlas project, the Atlas of MS also makes reference to the MSIF publication *Principles to Promote the Quality of Life of People with Multiple Sclerosis*, which can be accessed at www.msif.org.



The following pages present
the results of the Atlas of MS
by themes

◆ Limitations

- ◆ Comparability of different prevalence and incidence rates across diverse populations can be difficult to achieve because of various factors that may interfere: the choice of diagnostic criteria; the different study methodologies; and the studies being done at different times, in different geographical areas, with variability in population sizes, age structures, ethnic origins and composition of the groups studied.
- ◆ Complete case ascertainment depends on access to medical care, local medical expertise, the number of neurologists, accessibility to and availability of new diagnostic

procedures, the degree of public awareness about MS and the investigators' zeal and resources.

- ◆ In the Atlas of MS, figures from most of the countries refer to local epidemiological studies, reported in the scientific literature. National or regional registers are only available in a few countries.
- ◆ In some cases the figures provided are up to date while others may be underestimated, being based on the last available epidemiological studies, which may be some time ago.

◆ Salient findings

- ◆ Globally, the median estimated **prevalence** of MS is 30 per 100 000 (with a range of 5–80) (Figure 1.1).
- ◆ Regionally, the median estimated prevalence of MS is greatest in Europe (80 per 100 000), followed by the Eastern Mediterranean (14.9), the Americas (8.3), the Western Pacific (5), South-East Asia (2.8) and Africa (0.3) (Figure 1.2).
- ◆ By income category, the median estimated prevalence of MS is greatest in high income countries (89 per 100 000), followed by upper middle (32), lower middle (10) and low income countries (0.5) (Figure 1.3).
- ◆ The countries reporting the highest estimated prevalence of MS include Hungary (176 per 100 000), Slovenia (150), Germany (149), United States of America (135), Canada (132.5), Czech Republic (130), Norway (125), Denmark (122), Poland (120) and Cyprus (110).
- ◆ Globally, the median estimated **incidence** of MS is 2.5 per 100 000 (with a range of 1.1–4).
- ◆ Regionally, the median estimated incidence of MS is greatest in Europe (3.8 per 100 000), followed by the Eastern Mediterranean (2), the Americas (1.5), the Western Pacific

(0.9) and Africa (0.1). No countries in South-East Asia provided data.

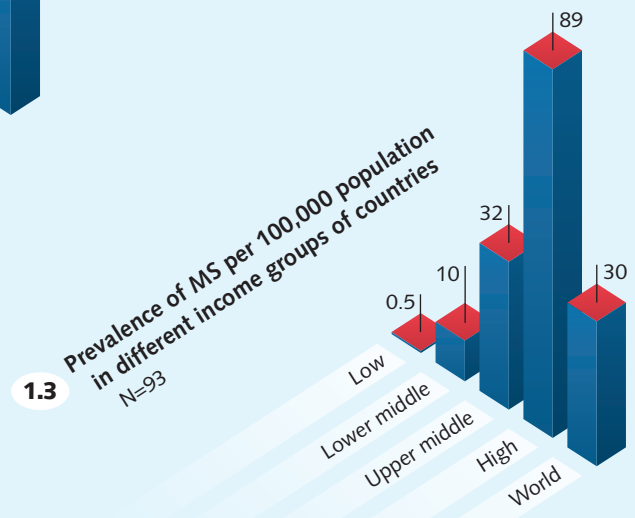
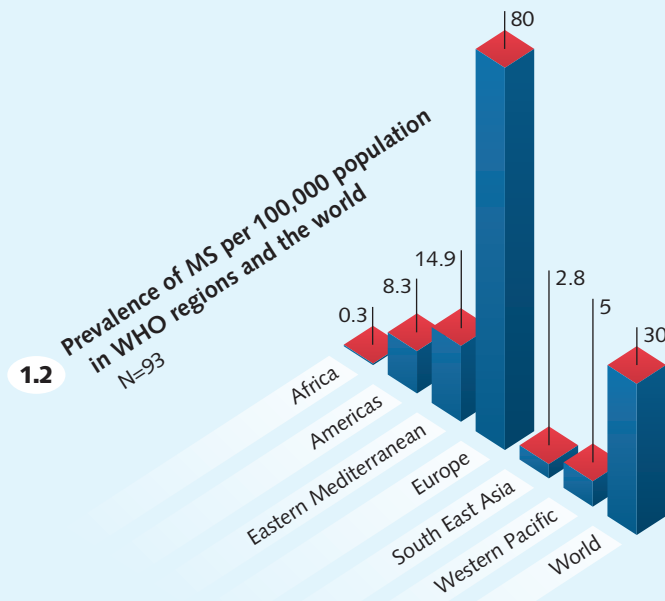
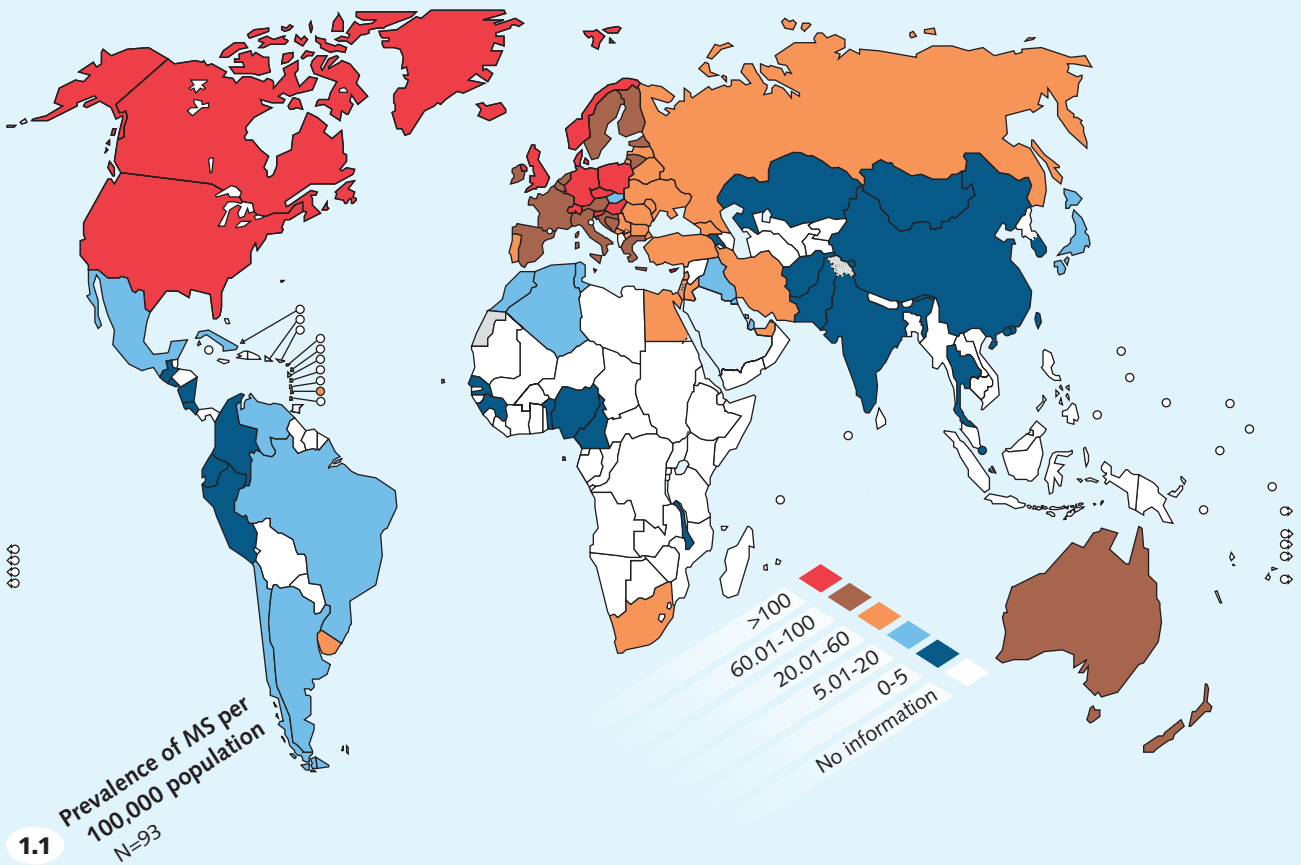
- ◆ By income category, the median estimated incidence of MS is greatest in high income countries (3.6 per 100 000), followed by upper middle (2.2), lower middle (1.1) and low income countries (0.1).
- ◆ The countries reporting the highest estimated incidence of MS include Croatia (29 per 100 000), Iceland (10), Hungary (9.8), Slovakia (7.5), Costa Rica (7.5), United Kingdom (6), Lithuania (6), Denmark (5.9), Norway (5.5) and Switzerland (5).
- ◆ The **total** estimated number of people diagnosed with MS, reported by the countries that responded, is 1 315 579 (approximately 1.3 million) of whom approximately 630 000 are in Europe, 520 000 in the Americas, 66 000 in the Eastern Mediterranean, 56 000 in the Western Pacific, 31 500 in South-East Asia and 11 000 in Africa. The reader should keep in mind that there are no data for some of the mega countries such as Russian Federation, where the total number of people has been suggested to be quite high in anecdotal reports.

◆ Implications

- ◆ This study definitively confirms that MS is a global disease and not a disease solely of the more developed “northern” and “western” countries.
- ◆ No country that responded to the survey was free of MS although the survey did show relatively wide variations in both incidence and prevalence. An improved understanding of both the genetic and environmental factors influencing the disease is likely to lead to an understanding of why this is the case.
- ◆ The disease is less common among non-white individuals than whites but MS was detected in all the countries surveyed, and comments from the respondents in a number of countries in Africa suggested that they were finding more MS as the availability and accessibility of diagnostic facilities, particularly MRI, improved.

- ◆ Typically, our results confirmed the well established suggestion that there are strong geographical patterns to the disease and that the frequency of MS varies by geographical region throughout the world, increasing with distance from the equator in both hemispheres.
- ◆ The unequal distribution of important diagnostic tools (e.g. MRI scanners) is likely to result in under-recording of MS in many low-income countries. This effect is also likely to be reinforced by either ignorance among professionals or the belief, in some of those countries that MS does not occur in these countries.
- ◆ The lack of data in approximately two thirds of the countries that responded reflects the lack of published reports in medical literature regarding the epidemiology of MS.

TOTAL NUMBERS, PREVALENCE AND INCIDENCE

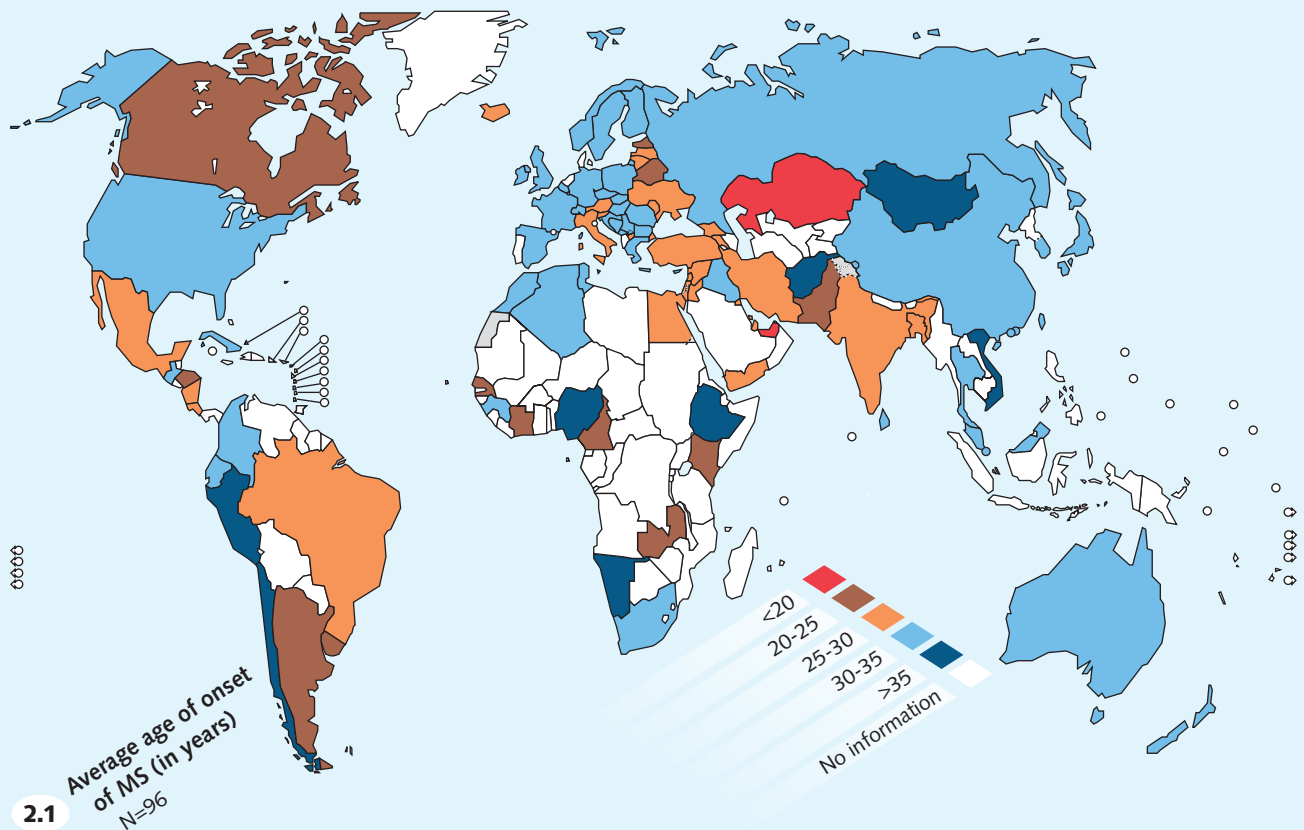


Salient Findings

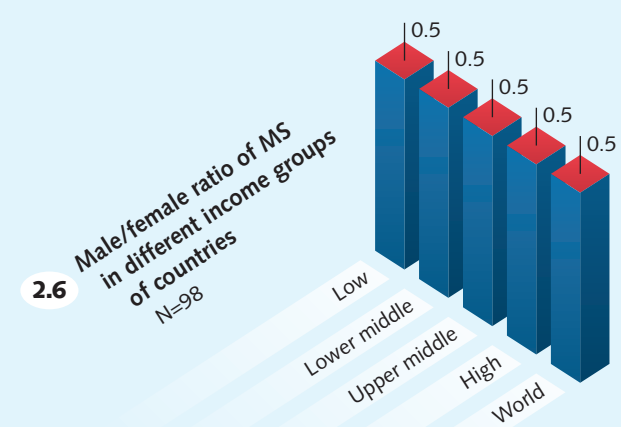
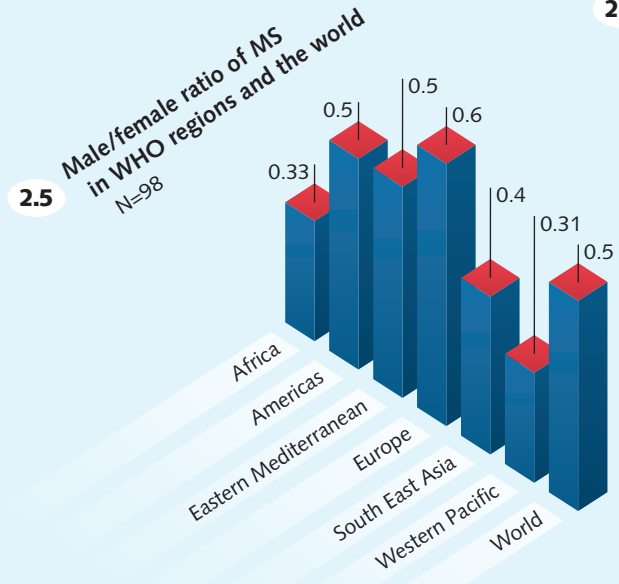
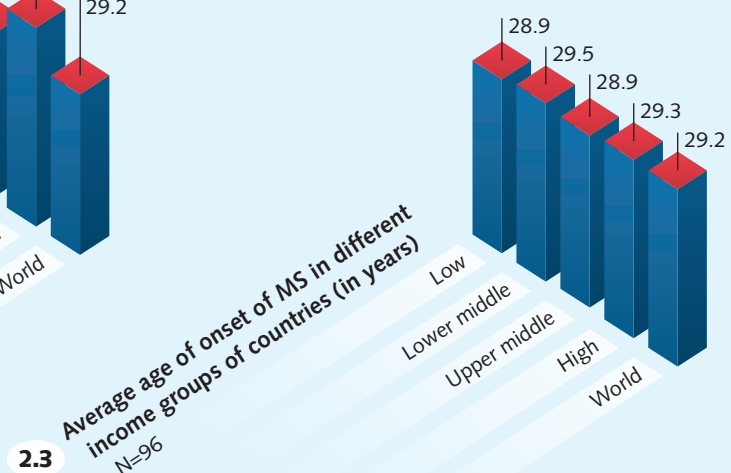
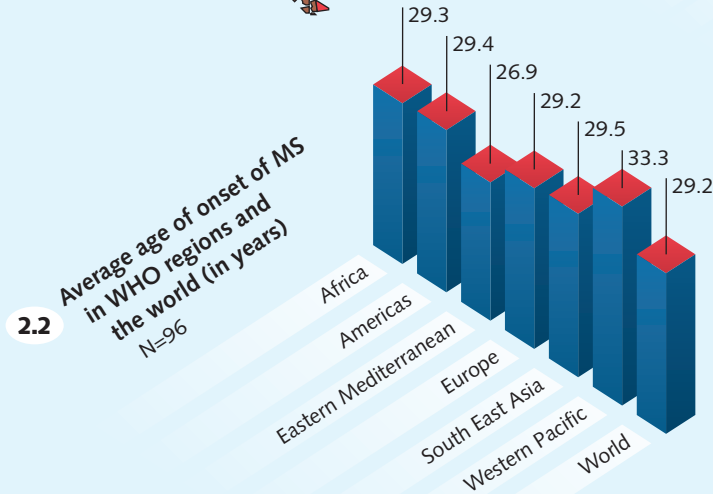
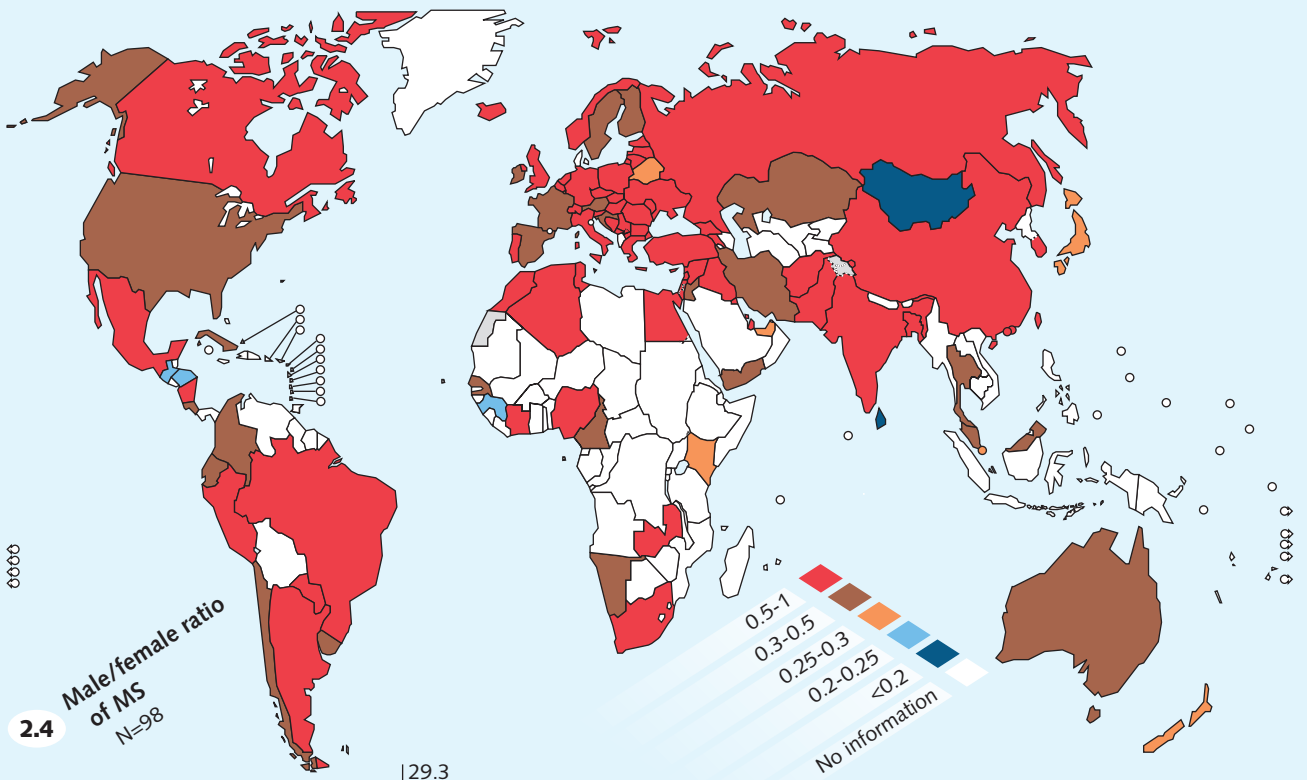
- ◆ Globally, the interquartile range for age of onset of MS symptoms is between 25.3 and 31.8 years with an **average age of onset** of 29.2 years (Figure 2.1).
- ◆ Regionally, the average age of onset is lowest in the Eastern Mediterranean (26.9) followed by similar average age of onset in Europe (29.2), Africa (29.3), the Americas (29.4), and South-East Asia (29.5) and highest in Western Pacific (33.3) (Figure 2.2).
- ◆ By income category, the estimated average age of onset is 28.9 years for the low and upper middle income countries and 29.5 and 29.3 years for high and lower middle income countries (Figure 2.3).
- ◆ Globally, the median estimated **male/female ratio** is 0.5, or 2 women for every 1 man (with a range of 0.40 to 0.67) (Figure 2.4).
- ◆ Regionally, the median estimated male/female ratio is lowest in Europe (0.6), the Eastern Mediterranean (0.55) and the Americas (0.5) and highest in South-East Asia (0.4), Africa (0.33) and the Western Pacific (0.31) (Figure 2.5).
- ◆ By income category, the median estimated male/female ratio is same in all income group of countries (0.50) (Figure 2.6).

Implications

- ◆ The data support the findings that MS is more common among women than men and that symptoms appear at around 30 years of age, when people are most economically active and when they would be most likely to be starting or supporting a family.
- ◆ It is thus important that policy-makers fully understand the implications of lost production, as well as of the treatment regimes, on the full costs of MS, so that the value of policies targeting MS can be properly and fully accounted for.
- ◆ Although the sample size is relatively small, the findings also suggest that the age of onset is lower in many developing countries and this might be suggestive of an avenue for future research.

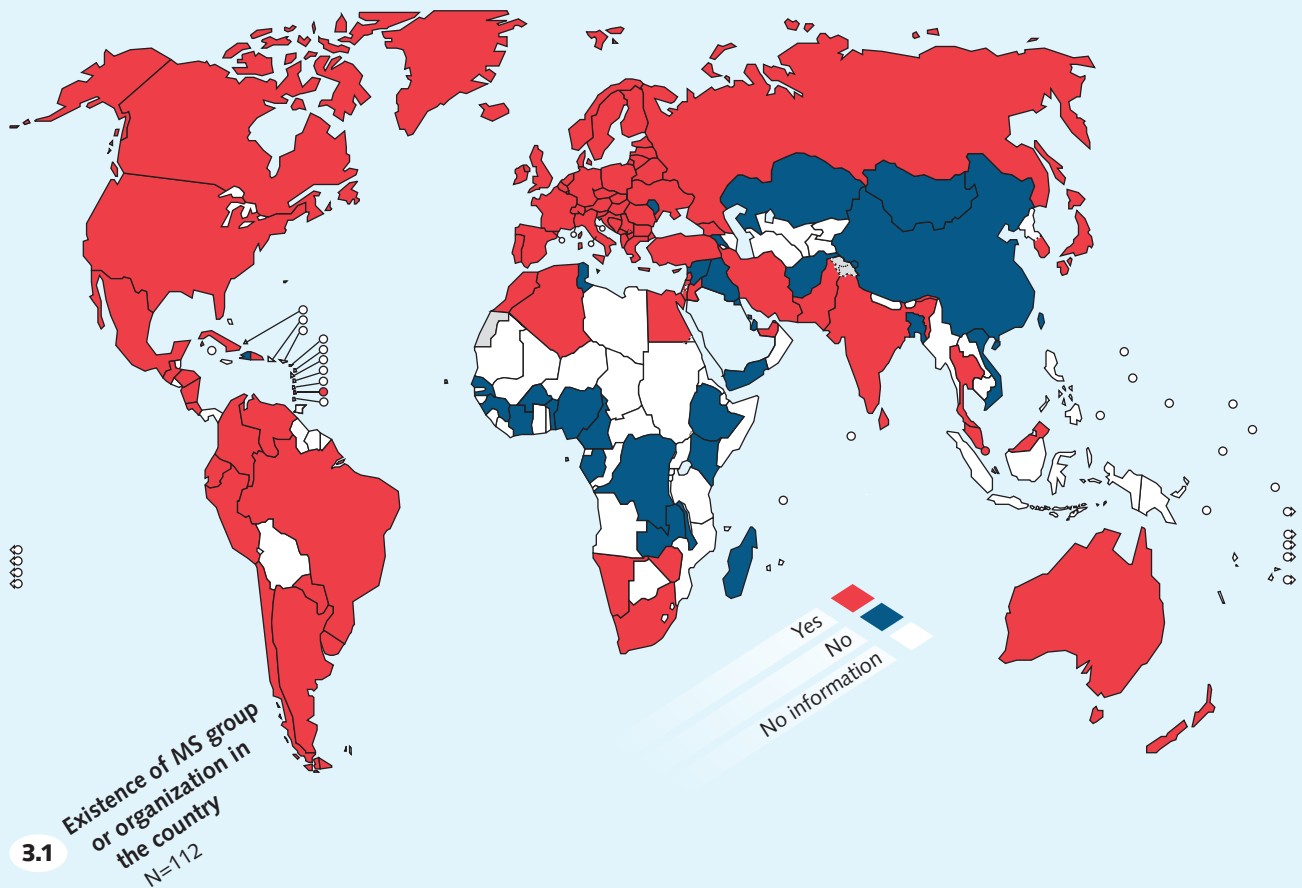


AVERAGE AGE OF ONSET AND MALE/FEMALE RATIO



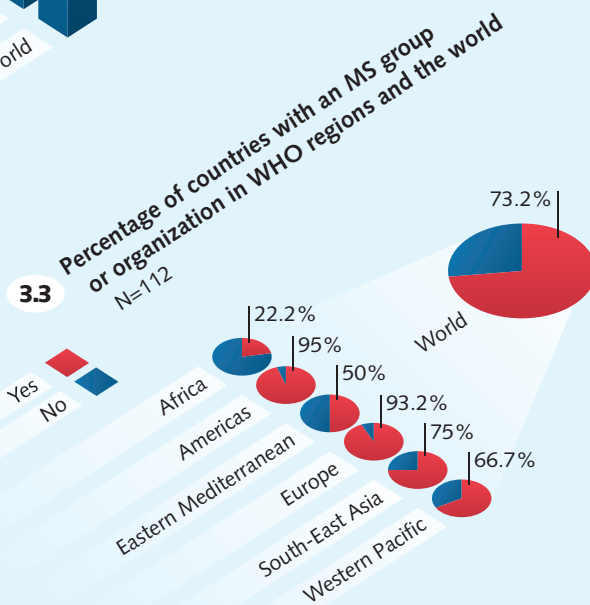
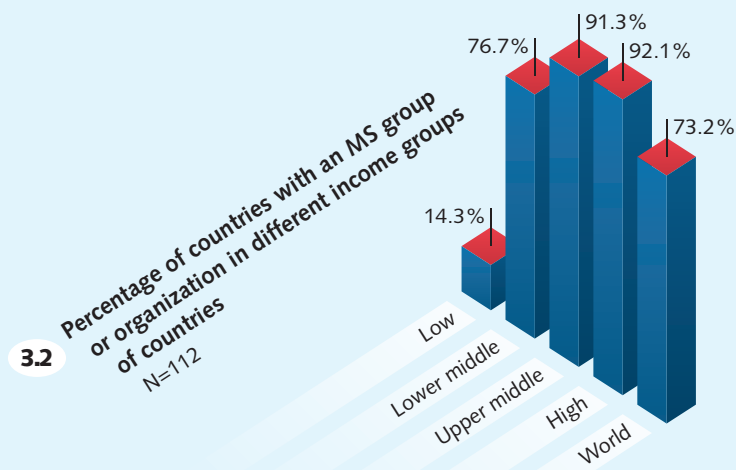
◆ Salient Findings

- ◆ Globally, an MS group or organization exists in 73.2% of the countries that responded (Figure 3.1).
- ◆ By income category, an MS group or organization exists in 92.1% of all high income countries followed closely by upper middle income countries (91.3%), and then by lower middle (76.7%) and least in low income countries (14.3%) (Figure 3.2).
- ◆ Regionally, an MS group or organization exists in 95% of the countries that responded in the Americas, followed by Europe (93.2%), South-East Asia (75%), the Western Pacific (66.7%), the Eastern Mediterranean (50%) and Africa (22.2%) (Figure 3.3).



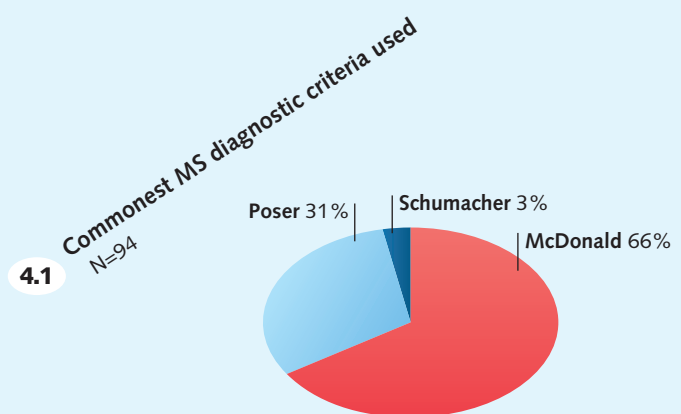
◆ Implications

- ◆ Many countries in the world have no patient-driven support for people with MS, with low income countries being significantly less likely than high income countries to have such groups. Inevitably this will have an impact on people with MS in those countries, as MS groups or organizations usually play an important role in distributing information and providing support and services.
- ◆ There is no firm relationship between support and incidence, with, for example, the Eastern Mediterranean having the second-highest incidence but lying fifth in provision of patient-driven MS support.
- ◆ The lack of an MS group or organization in a country will affect its reporting on cases of MS, as such groups are well placed to provide qualitative as well as quantitative data.



◆ Salient Findings

- ◆ The McDonald Criteria are the **diagnostic criteria**, most commonly used in 66% of the countries that responded, followed by the Poser Criteria used in 31% and the Schumacher Criteria used in 3% of countries (Figure 4.1).
- ◆ Regionally, the McDonald criteria are the criteria most commonly used in the Eastern Mediterranean (83.3%) followed by the Americas (70.6%), Europe (70%), South-East Asia (66.7%), Africa (50%) and the Western Pacific (42.9%) (Figure 4.2).
- ◆ Regionally, the Poser criteria are the criteria most commonly used in the Western Pacific (57.1%) followed by Africa (35.7%), South-East Asia (33.3%), Europe (30%), the Americas (29.4%) and the Eastern Mediterranean (8.3%).
- ◆ The McDonald criteria are the criteria most commonly used in 79.4% of high income countries, 65% of upper middle income countries, 56.5% of lower middle income countries and 52.9% of low income countries (Figure 4.3).
- ◆ The Poser criteria are the criteria most commonly used in 43.5% of lower middle income countries, 35% of upper middle income countries, 29.4% of lower income countries and 20.6% of high income countries.
- ◆ MRI is available in all (100%) of the countries that responded; spinal tap (lumbar puncture) is available in 96.9% of countries and evoked potentials in 95.3%.
- ◆ Globally, the median estimated **number of MRI machines** is 0.12 per 100 000 (with an interquartile range of 0.04–0.43) (Figure 4.4).
- ◆ Regionally, the median estimated number of MRI machines per 100 000 is greatest in the Western Pacific (0.35), followed by Europe (0.31), the Eastern Mediterranean (0.17), the Americas (0.08), South-East Asia (0.03) and Africa (0.004) (Figure 4.5).
- ◆ By income category, the median estimated number of MRI machines per 100 000 is greatest in high income countries (0.76 per 100 000), followed by upper middle (0.15), lower middle (0.07) and low income countries (0.01) (Figure 4.6).
- ◆ Globally, the median **time from initial presentation to MRI** is between 1 week and 6 weeks with a range of 0 to 144 weeks (12 years).
- ◆ The median **time from initial presentation to diagnosis** is between 4 weeks and 48 weeks with a range of 1 week to 480 weeks (40 years).
- ◆ 31% of the countries that responded noted that MS is diagnosed in their country without MRI.

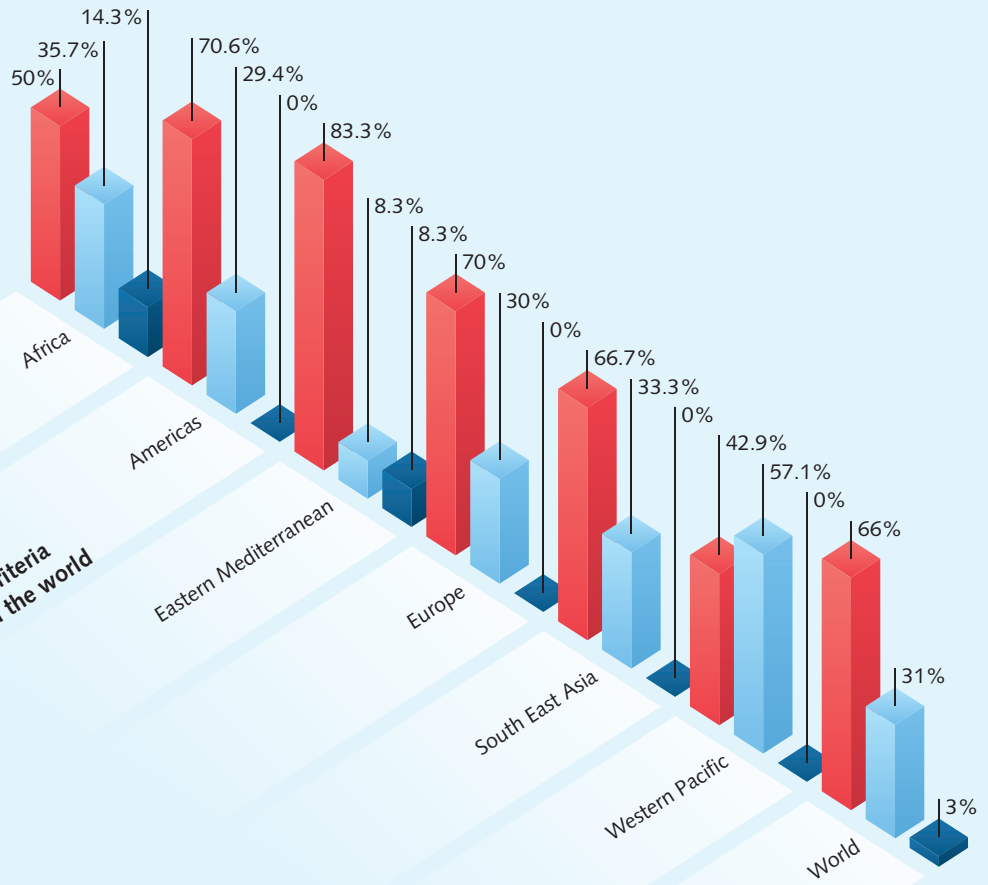


4.2

Commonest MS diagnostic criteria used in WHO regions and the world

N=94

Mc Donald
Poser
Schumacher

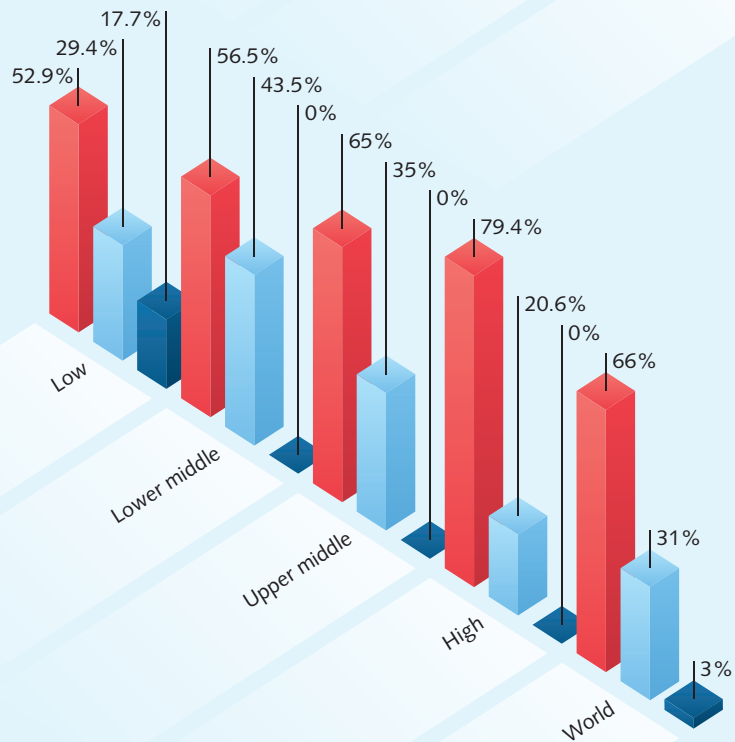


4.3

Commonest MS diagnostic criteria used in different income groups of countries

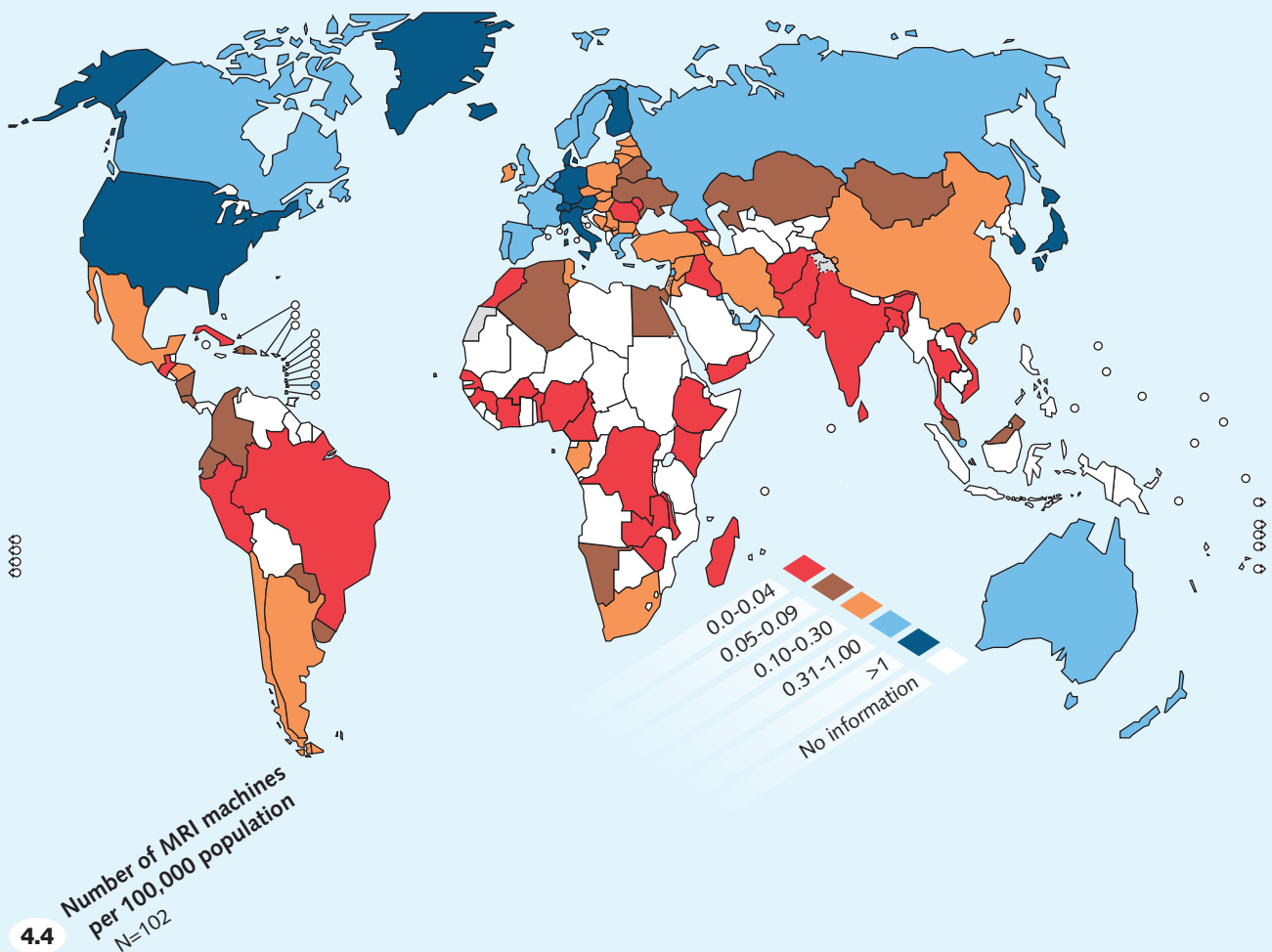
N=94

Mc Donald
Poser
Schumacher



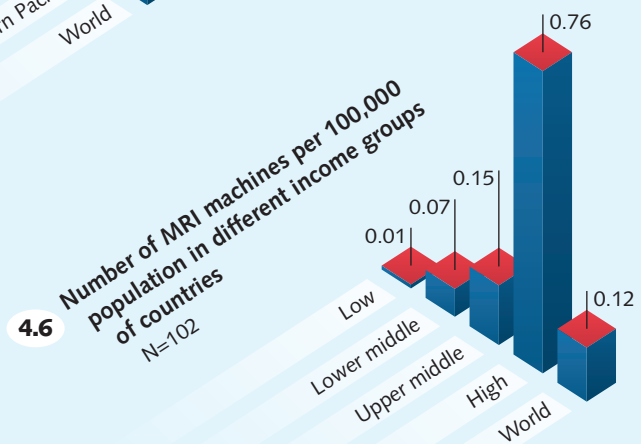
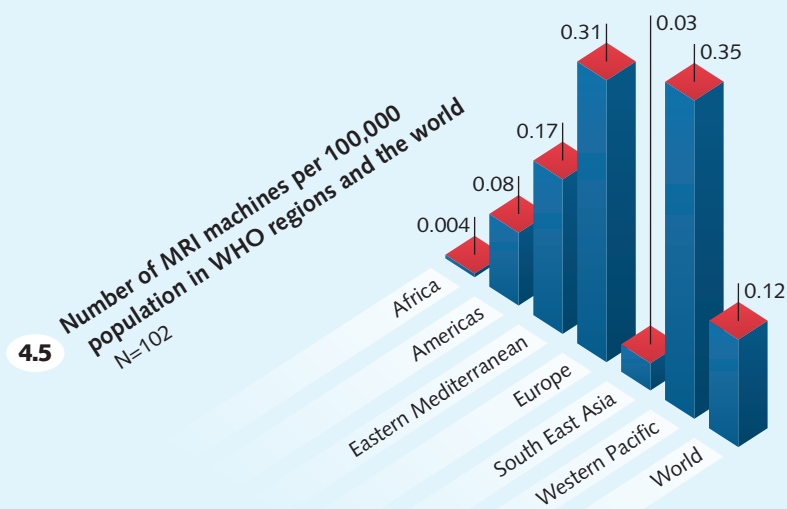
◆ Implications

- ◆ Although there are diagnostic criteria available to support the neurologist, unlike for many other diseases, there is still no single straightforward specific “positive or negative” diagnostic test for MS and none of the tests available are 100% conclusive. The clinical diagnosis of MS is heavily reliant on the skill of the neurologist in taking and interpreting the patient’s medical history, conducting a neurological examination and performing and interpreting MRI. Typically, a neurologist will diagnose MS by a combination of observing a person’s symptoms, and ruling out other possibilities.
- ◆ Because the time of initial diagnosis is particularly stressful, it deserves special attention from health care and other providers.
- ◆ Clinical data alone may be sufficient for a diagnosis of MS. If an individual has experienced two temporally distinct neurological episodes characteristic of MS, and also has consistent abnormalities on physical examination, a diagnosis of MS can be made with no further testing, once other diseases have been excluded.
- ◆ The availability of MRI technology and broad adoption of common diagnostic criteria, predominantly the McDonald Criteria, has made it easier for neurologists to give a diagnosis of clinically definite MS. However, the wide variance in the availability and accessibility of MRI technology means that the time between the initial presentation and the point at which the person gets scanned (which usually means a definite diagnosis can be made) varies widely.
- ◆ MS is not always easy to diagnose in its early stages. Typically, people who have been diagnosed with clinically definite MS will have been through several diagnostic stages which can be an unsettling, frightening and psychologically traumatic experience for the individual and his or her family. As the data suggest, this process is often drawn out over months or years.
- ◆ The results presented highlight how inequalities in global wealth impact on the provision of diagnostic services for people with MS, and how difficult and long the path to diagnosis is for many of them.



◆ Relevant quality of life principles

- ◆ 2.2.1. Physicians must be sensitive to the major psychological, social, financial, vocational and medical impact of telling a person that she or he has MS. Patients must have adequate time to ask questions of the physician. Newly diagnosed patients should be referred to the national MS society and to an MS nurse specialist or other health professional with MS treatment and counselling experience.
- ◆ 2.2.2. At the time of the initial diagnosis, people with MS must have access to information about MS that is specific to newly diagnosed individuals, together with information on local and national medical, support, rehabilitation, and life-planning services.



◆ Limitations

- ◆ The question on the most common topic of printed information was answered by only 61 countries – the actual figures are likely to be lower.
- ◆ A limitation of all data relating to “availability” of a resource is that whether or not a resource is available in a country has no bearing on the access to that resource.

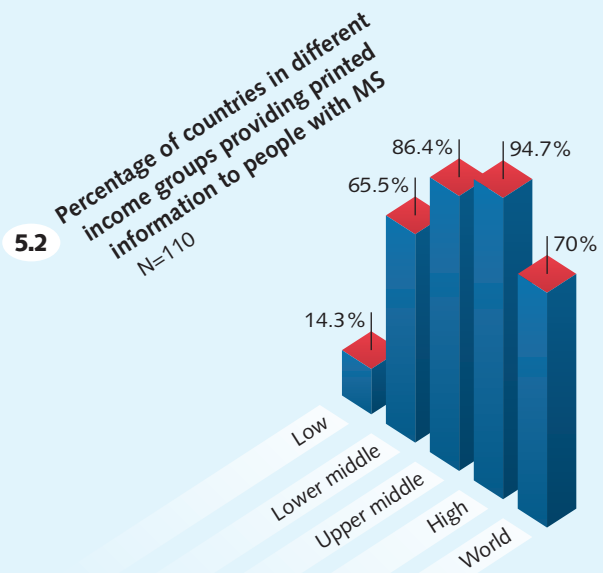
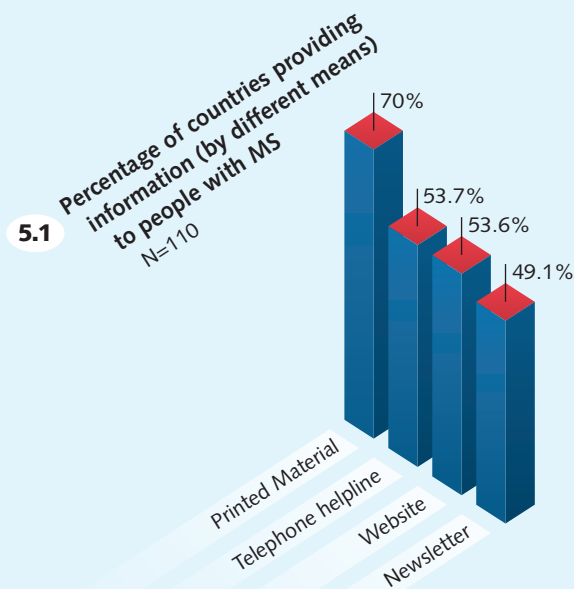
◆ Salient Findings

- ◆ The most common **means of providing information** to people with MS (by MS organizations, health professionals and pharmaceutical companies) in those countries that responded is through the distribution of printed material (70%) (Figure 5.3), followed by a telephone helpline (53.7%), a website (53.6%) and a newsletter (49.1%) (Figure 5.1).
- ◆ **Printed material** is available in 97.7% of the European countries that responded followed by 89.5% of those in the Americas, 55.6% in the Western Pacific, 50% South-East Asia, 40% in the Eastern Mediterranean and 16.7% of African countries.
- ◆ Printed material is available in 94.7% of high income countries, 86.4% of upper middle income countries, 65.5% of lower income countries and 14.3% of low income countries (Figure 5.2).
- ◆ The **most common topic of printed information** is general information, provided in 91.8% of the countries that responded, followed by symptoms (83.6%), treatment (78.7%), lifestyle (diet, exercise, daily living) (55.7%), rehabilitation (45.9%), family issues (children and pregnancy) (42.6%), alternative or complementary therapy (29.5%), research (29.5%), employment (24.6%) and communication (hearing and speech) (16.4%).
- ◆ A **website** is available in 84.1% of the European countries that responded, followed by 47.4% of those in the Americas, 44.4% in the Western Pacific, 33.3% in the Eastern Mediterranean, 25% in South-East Asia and 11.1% of African countries.
- ◆ A website is available in 81.6% of high income countries, 77.3% of upper middle income countries, 31% of lower income countries and 9.5% of low income countries.
- ◆ A **telephone helpline** is available in 79.1% of the European countries that responded, followed by 68.4% in the Americas, 44.4% in the Western Pacific, 26.7% in the Eastern Mediterranean, 25% in South-East Asia and 5.9% of the African countries that responded (1 out of 17).
- ◆ A telephone helpline is available in 84.2% of high income countries, 68.2% of upper middle income countries, 37% of lower income countries and 4.8% of low income countries
- ◆ A **newsletter** is available in 77.3% of the European countries that responded, followed by 55.6% in the Western Pacific, 47.4% in the Americas, 25% in South-East Asia, 20% in the Eastern Mediterranean and 5.6% of Africa countries that responded.
- ◆ A newsletter is available in 81.6% of high income countries, 68.2% of upper middle income countries, 24.1% of lower income countries and 4.8% of low income countries.

◆ Implications

- ◆ Our survey again highlights the significant inequalities in the provision of basic and more specific forms of information. For example, printed material is available in nearly 95% of high income countries, but in less than 15% of low income countries. It is interesting to note the relatively high provision of information via the Internet, which may be a reflection of the flexibility of the medium, the age group concerned and their embrace of technology. It is also probable that in countries where MS is less commonly diagnosed, the absence of readily available information is likely to further depress incidence figures.
- ◆ People with MS seek and use relevant, current, and specific information to help them cope with their disease, retain their independence and empower them to make informed decisions. For people with any chronic disease, accurate and readily understandable information helps support their independence and gives them some control over their own health pathway. Access to relevant information, both at the time of diagnosis and throughout the course of the disease, provided in an appropriate way, could significantly improve the quality of life of people with MS.

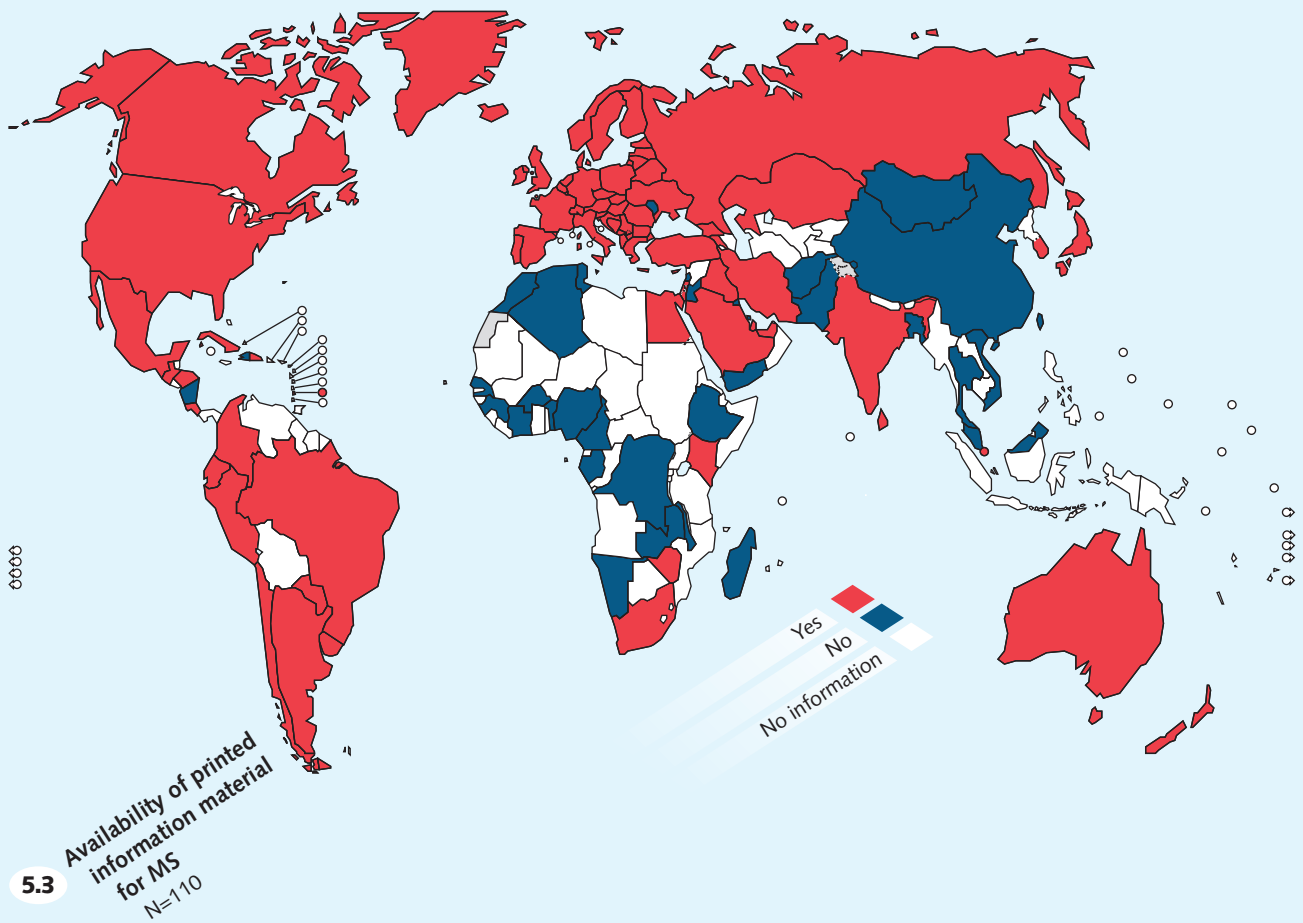
- ◆ The quality of communication at the time of diagnosing a chronic disease influences patient health outcomes. This is particularly the case for MS, which is not only unpredictable but also plays out over a long period, often many years. Uncertainty over the cause, course and control of MS means there is a constant high level of demand for information relating to the disease.
- ◆ This demand has been responded to by specific MS groups or organizations, and, to a lesser extent, by public health authorities and pharmaceutical companies. Information is still predominantly provided in printed publications, but the growth of the Internet is providing a powerful means of providing and sharing information. Although it has improved greatly, there is considerable scope for further improving provision of information to people with MS and there is still a long way to go before all needs are satisfied. There are a variety of barriers to obtaining information and, in many cases, the gap between the information required and that received is vast.



◆ Relevant quality of life principles

◆ 1.5. People with MS must be empowered to take control of the decisions affecting their lives and to self-manage the disease as much as possible. To encourage the highest possible degree of self-management, they should be able to gain access to a broad range of information, advice and education regarding the nature of MS, its treatment, and methods for improving quality of life. Access to this information is to be provided through multiple sources, including books, pamphlets, websites, and health and social service professionals. Mutual or peer support opportunities should also be available to people with MS.

◆ 4.1. People with MS must be offered good quality information as well as training for a wide range of health promotion practices, depending on patient preferences and their effectiveness in enhancing quality of life for the individual.



◆ Limitations

- ◆ Questions on the services provided to people with MS were only answered by between 50 and 62 countries, the majority of which are economically advanced. Consequently the findings are less global than those reported elsewhere in the Atlas of MS and probably paint an over positive picture.
- ◆ Support and services on various issues could be provided by more than one group such as MS organizations, health professionals or pharmaceutical industry.

◆ Salient Findings

Advocacy and campaigning

- ◆ In 32% of the countries that responded, **advice to governments** about MS matters is not provided whereas in 55% of countries the government is advised by the MS organization, in 34% by health professionals in the public sector and in 3% by the pharmaceutical/biotech industry.
- ◆ In 32% of the countries that responded, there is no **lobbying or campaigning** to improve the rights, entitlements and quality of life of people with MS whereas in 65% of countries that responded, the MS organization lobbies and campaigns on these issues; in 23% of countries, these activities are also undertaken by health professionals in the public sector and in 16% also by industry.

Personal support

- ◆ In 37% of countries that responded, **employment advice** for people with MS is not provided, whereas it is provided by the MS organization in 57%, by health professionals in the public sector in 24% and by industry in 3% of countries.
- ◆ In 29% of the countries that responded, general **legal advice** for people with MS is not provided, whereas in 67% of countries that responded it is provided by the MS organization, in 21% by health professionals in the public sector and in 8% by industry.
- ◆ In 24% of the countries that responded, **education advice** for people with MS is not provided, whereas in 67% of countries that responded it is provided by the MS organization, in 32% by health professionals in the public sector and in 11% by industry.
- ◆ In 24% of countries that responded, **courses for people with MS** are not provided, whereas they are provided by the MS organization in 71% of countries, by health professionals in the public sector in 30% and by industry in 21%.
- ◆ In 21% of the countries that responded, there are no **home visits to people with MS**, whereas in 68% of countries that responded training is provided by the MS organization, in 30% by health professionals in the public sector and in 13% by industry.
- ◆ In 22% of the countries that responded, **self help and mutual support groups** are not organized for people with MS, whereas in 76% of countries that responded training is provided by the MS organization, in 8% by health professionals in the public sector and in 3% by industry.
- ◆ In 30% of the countries that responded, **adaptations, living aids or technical support** are not provided for people with MS, whereas in 51% of countries that responded they are provided by the MS organization, in 33% by health professionals in the public sector and in 2% by industry.
- ◆ In 45% of the countries that responded, **transport** is not provided for people with MS, whereas in 48% of countries that responded transport is provided by the MS organization, in 7% by health professionals in the public sector and in 2% by industry.

Education and training

- ◆ In 8% of the countries that responded, educational **meetings, seminars and conferences** are not organized whereas in 83% of countries that responded they are provided by the MS organization, in 54% by health professionals in the public sector and in 46% by industry.
- ◆ In 17% of the countries that responded, **specific training for health professionals in MS** is not available, whereas in 41% of countries that responded training is provided by the MS organization, in 70% by health professionals in the public sector and in 40% by industry.

Family and carers

- ◆ In 11% of the countries that responded, **information for family and carers** is not provided, whereas in 79% of countries that responded it is provided by the MS organization, in 33% by health professionals in the public sector and in 21% by industry.
- ◆ In 61% of the countries that responded, **respite care for family and carers** is not provided, whereas in 24% of countries that responded it is provided by the MS organization

and in 19% by health professionals in the public sector. No respite care is provided by industry.

- ◆ In 65% of the countries that responded, **financial or work benefits for family and carers** are not provided, whereas in 21% of countries that responded they are provided by the MS organization, in 14% by health professionals in the public sector and in 2% by industry.

◆ Implications

Advocacy and campaigning

- ◆ In those countries where no patient group or organization is advising, lobbying and campaigning government, the needs of people with MS will not inform decisions.

Education and training

- ◆ The early-stage symptoms are easily confused with those of other diseases. It is a matter of concern therefore that in about one in six countries, health care professionals are not receiving any training to help them identify and treat people with MS.
- ◆ Health and social care professionals should provide people with MS with the knowledge, skills and confidence to participate actively in all aspects of their own care and encourage and support them to become expert patients.
- ◆ There is a specific lack of public and professional awareness of the dimension of MS in the domains of epidemiology and impact of disease on individuals, carers and society, including impact on individual loss of independence, and cost of long-term care. In particular, the chronic progressive nature of MS must be better conveyed to all.

Personal support

- ◆ MS is a disease that can easily lead to feelings of isolation. Typically at some point it leads to significant physical disability and also often forces people to leave paid employment. In this context aids and adaptations can transform the lives of people with MS and extend their period of independence. Our survey found that in three out of every ten countries no aids or adaptations are available from any source.
- ◆ Without adequate education, advice and support people with MS are unaware of how best to cope with their MS and remain in education or employment. The greatest economic impact of MS is the loss of income resulting from the person with MS (and their carer) leaving employment.
- ◆ There is evidence that people with long-term conditions such as MS value participation in mutual support groups, which despite being cheap and easy to organize are not available in 22% of the countries that responded.
- ◆ Mobility for people with MS can be greatly enhanced when they continue to drive or when alternative transport is available. People with MS may have difficulty with using transport because of their functional disabilities, cognitive impairment and use of mobility aids, yet public transport, often their only possible option, is sometimes not available or is difficult to use. In the 45% of countries we surveyed where no transport support is available, people with MS remain isolated inside their homes, with inhibited ability to participate in life in the community and limited access to the best services and support.

Family and carers

- ◆ MS is a disease that impacts on the whole family. The well-documented high emotional and physical burden of MS, which rises as the disease progresses, is borne by the family who provide emotional support, help with daily tasks, chores and intimate help. Many family members adjust very well to the caring role; however there is evidence that caring can have a detrimental impact on a carer's psychological well-being. One of the biggest conflicts that carers face is the need to work in order to meet essential family needs. Studies have shown that caregivers perceive levels of social support to be low and value respite facilities. It is important that there is support for family members, of which respite care is the most important type. Our finding that no such provision exists in six out of ten countries surveyed is of grave concern and should lead to a review of this situation. The poor provision of respite could contribute to a high societal cost of MS, as family members and carers experience frustration, exhaustion and burn out. (See MSIF, *Caregiving in MS, MS in focus*, issue 9, January 2007.)
- ◆ A better understanding of the socioeconomic costs of MS to individuals, families, carers and the community is needed to continue to challenge health, welfare and employment policies and to break the link between the onset of MS and the subsequent social and economic disadvantage that so often occurs. The unpaid care provided by family and friends must be officially recognized and carers need to be valued and supported in the enormous role they play in the care of people with MS.
- ◆ These findings highlight the key role played by MS organizations in supporting, representing, advising and supporting people with MS and acknowledging and addressing the special needs of caregivers. Most MS-related services are provided to the person with MS by family members and other informal carers, who are themselves profoundly affected by having a relative or friend with MS. These family members and friends benefit from services designed to help them cope with the stress and other impacts of the disease. Children can be affected by having a parent with MS and may not fully understand the reasons for a parent's health problems, and think they have somehow caused them or feel neglected as a member of the family.

◆ Relevant quality of life principles

- ◆ 1.1. People with MS must be able to realize their full potential. They should have the opportunity to travel to places outside the home, work at jobs, acquire an education, and do the other things that people without disabilities do. They should have the opportunity to participate in community life as much as is possible and desired.
- ◆ 3.1. People with MS must have access to a wide range of home, community-based and respite care services that help individuals to remain in their own homes for as long as possible.
- ◆ 3.2. Institutional or residential services, such as nursing homes, should be used only if home and community-based care is no longer appropriate. Services in these institutional facilities must be designed to take account of the interests and needs of people with MS, who are typically younger than other residents.
- ◆ 3.3. Paid professional continuing care providers must receive adequate training in the specific features of MS, and adequate pay, fringe benefits, and supervision.
- ◆ 5.1. Services and training must be available to family members and other informal carers affected by MS as well as to the person with MS. They must also be provided with information about available community services that may provide support.
- ◆ 5.2. Respite care must be available to relieve the burden on family members and other informal carers. It should be available either in the home or in institutions providing continuing care.
- ◆ 5.3. Family members and other informal caregivers must be routinely evaluated to assess their physical and emotional stress and other personal needs related to caregiving.
- ◆ 5.4. People with MS and their families must have access to family and relationship counselling.
- ◆ 5.5. Services must be available to people with MS to aid them in fulfilling their parenting responsibilities. Children are to be protected from having to take on inappropriate roles as caregivers for parents with MS.
- ◆ 5.6. Services must be available to prevent physical, financial and psychological abuse of people with MS by family members and other informal caregivers.
- ◆ 6.1. Services should be available to enable people with MS to continue to drive their own cars for as long as possible, if desired.
- ◆ 6.2. For people with MS who cannot or do not drive, accessible transport services must be available and affordable.

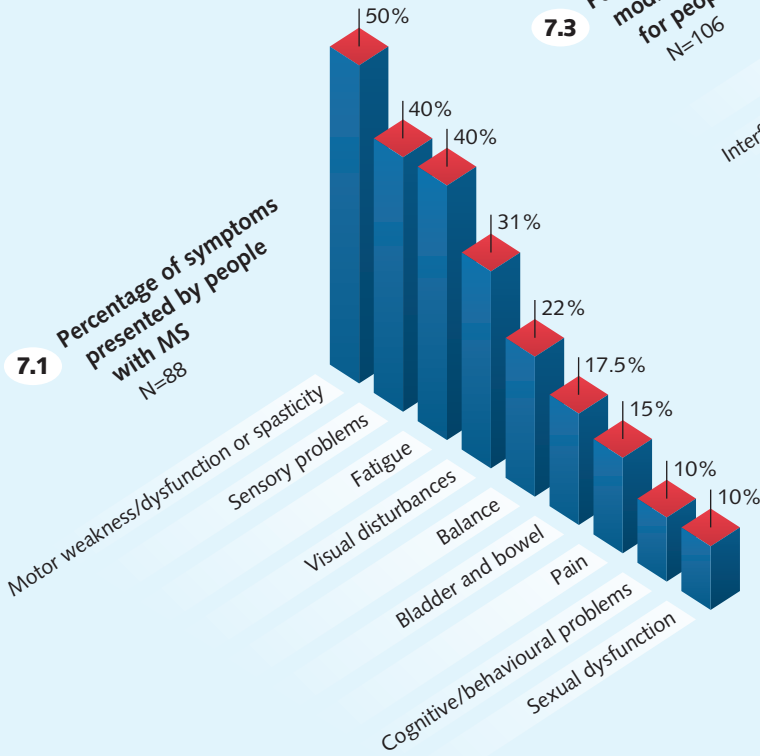
◆ Limitations

- ◆ Questions on the symptoms and recently licensed treatments of MS were only answered, in most cases, by approximately 78 countries, the majority of which are high income countries. Consequently the findings are less global than they are elsewhere in this Atlas of MS and probably paint an overly positive picture.

◆ Salient Findings

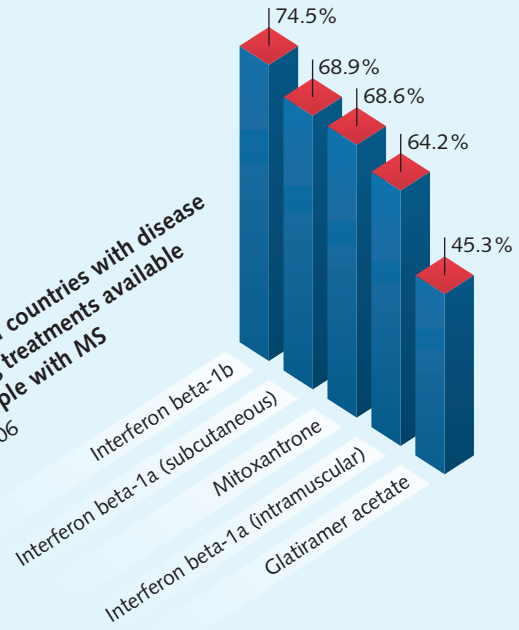
- ◆ The most **common presenting symptom** of MS is motor weakness, dysfunction or spasticity, seen in 50% of patients in the countries that responded, followed by sensory problems and fatigue (40%), visual disturbances (31%), disturbed balance (22%), bladder and bowel problems (17.5%), pain (15%), cognitive or behavioural problems and sexual dysfunction (10%) (Figure 7.1).
- ◆ **Drugs to treat the MS symptom** of pain are available in 96% of the countries that responded, whereas drugs are available to treat urinary, bladder and bowel problems in 89.9% of countries, sensory disturbances in 85%, fatigue in 82.7%, sexual dysfunction in 81.8%, motor weakness, dysfunction or spasticity in 77%, cognitive or behavioural symptoms in 72.9%, visual weakness in 56.6% and balance in 52.5% of countries (Figure 7.2).
- ◆ The **disease-modifying treatment**, interferon beta-1b, is available in 74.5% of countries that responded, whereas interferon beta-1a (subcutaneous) is available in 68.9% of countries, mitoxantrone in 68.6%, interferon beta-1a (intramuscular) in 64.2% and glatiramer acetate in 45.3% (Figure 7.3).
- ◆ The median **percentage of people with MS eligible to receive disease-modifying treatment** that do receive it in all countries that responded is 50%. The median percentage of people receiving disease-modifying treatment in high income countries is 75%, in upper middle income countries 40%, in lower middle income countries 34% and in low income countries 10% (Figure 7.4).
- ◆ Patient choice and funding policy (61.1% and 57.7%, respectively) were given by countries that responded as the main **reasons why less than 100% of eligible people with MS do not receive disease-modifying treatment**, whereas general clinical practice and access to a neurologist were less likely reasons why people with MS do not receive disease-modifying treatment (29.6% and 27.8%, respectively) (Figure 7.5).
- ◆ A limitation of all data relating to “availability” of a resource is that whether or not a resource is available in a country has no bearing on access to that resource.
- ◆ The median percentage of the **cost of disease-modifying treatments paid by government** is 80%, by insurance 31.6% and by the individual 0%. However, the range for all three sources of financing is 0–100%. In some countries the individual is expected to pay the total cost of disease-modifying treatments, whereas in others the total cost is covered by the government.
- ◆ The most **common steroid used for treating exacerbations and relapses** in 94.1% of countries that responded is methylprednisolone, whereas prednisolone is available in 73% of countries and dexamethasone in 44.6%.
- ◆ The five most prevalent **alternative or complementary approaches** used in more than 50% of the countries that responded are diet and nutrition (88.3%), acupuncture (86.7%), herbal medicine (81.7%), massage (78.3%) and homeopathy (73.3%).
- ◆ Other alternative or complementary approaches used in some of the countries that responded include chiropractics and osteopathy (41.7%), aromatherapy (40%), hyperbaric oxygen (40%), cannabis (38.3%), Ayurvedic medicine (36.7%), Pilates (36.7%), dentistry (replacement of fillings)(36.7%), biofeedback (35%), macrobiotics (31.7%), naturopathy (28.3%), hypnotherapy (21.7%), hypnosis (18.3%) and iridology (18.3%).

7.1 Percentage of symptoms presented by people with MS
N=88



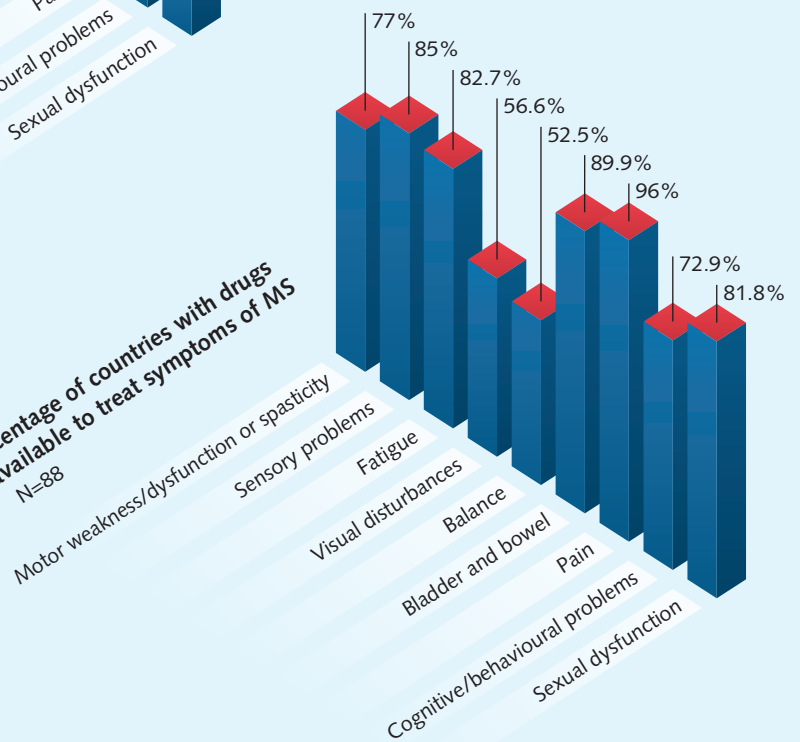
7.3

Percentage of countries with disease modifying treatments available for people with MS
N=106



7.2

Percentage of countries with drugs available to treat symptoms of MS
N=88



◆ Implications

Presenting symptoms – symptomatic treatments

- ◆ Our understanding of symptomatic pain has been improving. Until the mid-1980s MS was widely considered to be a painless condition. It is now widely recognized that MS can cause pain and that at least one third of all people with MS will feel some level of pain at some time. (See MSIF, Pain and MS, MS in focus, issue 10, July 2007)
- ◆ MS can affect a person's emotions as well as his or her body. Although this has been recognized since MS was first described in the 19th century, it is only more recently that we have begun to understand more about the emotional and behavioural symptoms of MS, which can include depression. These symptoms are sometimes overlooked, not fully acknowledged, or even dismissed as an understandable emotional reaction to the condition.
- ◆ Less well understood by both neurologists and the public at large, is fatigue associated with MS. In general, researchers are increasing their efforts to understand fatigue, as the majority of people with MS will experience this invisible but severe and disabling symptom at some point during the course of their disease. Fatigue impacts on a person's health-related quality of life and ability to work. Health care professionals need to include assessments of fatigue in their routine care of patients with MS and should be able to offer strategies to help them deal with any fatigue they might experience. (See MSIF, Fatigue, MS in focus, issue 1, February 2003)
- ◆ The use of symptomatic treatments is widespread, but the fact that the most common presenting systems are motor weaknesses underlines the need for better understanding of how transport and drug delivery options will overlap with care and treatment possibilities.

Availability, cost, reimbursement for disease-modifying treatment

- ◆ The data highlight the significant income inequalities that exist around provision of, and those who are likely to benefit from disease-modifying treatments.

Relapse treatments

- ◆ The most common treatments are based on steroids with powerful anti-inflammatory properties. Steroids are relatively inexpensive (particularly compared to most disease-modifying treatment) and the country-by-country income gradient associated with their use is relatively shallow.

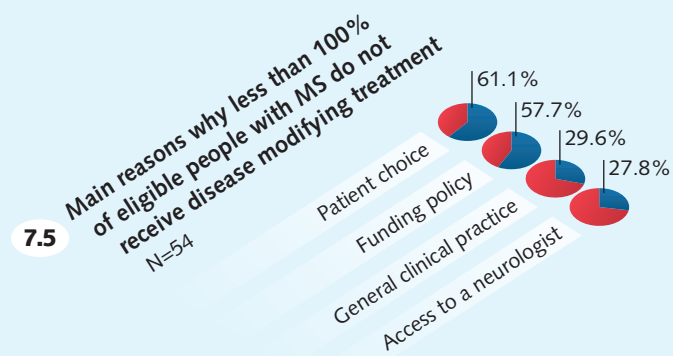
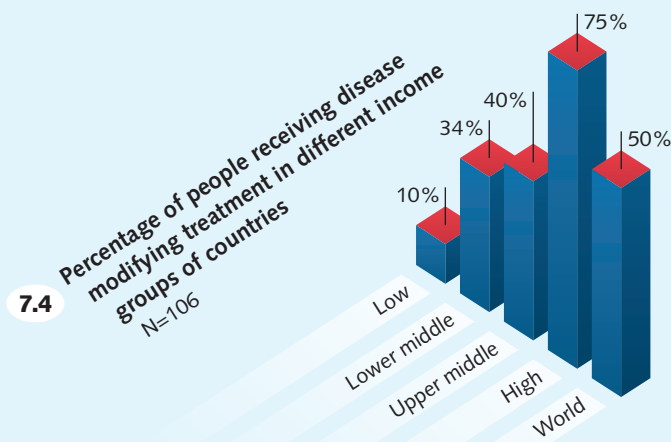
Complementary treatments

- ◆ MS is a chronic condition for which there is no cure and only limited symptomatic treatments. Furthermore, the costs of treatments that have been associated with some reduction in relapse rates (typically the interferons) tend to be high irrespective of who is funding the drugs. In this environment, people with MS tend to actively seek remedies or treatments that will ameliorate the impact of their symptoms and often these are approaches that would be classed as "complementary" or "alternative".
- ◆ There is a wide range of complementary (and alternative) therapies being used by people with MS. Typically, there is little if any evidence to support their use (few if any have been properly scientifically tested).
- ◆ Finding some way to do rigorous blinded testing of such treatments would be of considerable benefit to people affected by MS.

See MSIF, MS: The guide to treatment and management, 2006, Demos

◆ Relevant quality of life principles

- ◆ 2.1.1. All people with MS must have access to evidence-based, quality health care.
- ◆ 2.1.2. Health care for people with MS includes medically-effective treatments, including symptom and disease modifying drugs, rehabilitation services, appropriate and affordable enabling technology that is tailored to the needs of people with MS, and continuing care services. People with MS have access to medical care, treatments and therapies appropriate to their needs.
- ◆ 2.4.1. Medically-effective and culturally-appropriate treatments must be available to address the symptoms of MS, including (but not limited to) fatigue, depression, cognitive impairment, impaired sexual function, pain, bladder and bowel dysfunction, limited mobility, vision problems, and others. Health professionals must consider in a systematic way whether a person with MS has additional, sometimes "hidden" symptoms or problems that can affect QOL.



◆ Limitations

- ◆ A limitation of all data relating to the “availability” of a resource is that whether or not a resource is available in a country has no bearing on access to that resource.

◆ Salient Findings

- ◆ Globally, the median estimated number of neurologists is 1.01 per 100 000 of the population (with an interquartile range of 0.25–3.95).
- ◆ Globally, the median estimated number of MS neurologists is 0.04 per 100 000 (with an interquartile range of 0–0.19) (Figure 8.1).
- ◆ Regionally, the median estimated number of **MS neurologists** per 100 000 is greatest in Europe (0.19) followed by the Americas (0.03) the Western Pacific (0.01) and the Eastern Mediterranean (0.004). The median estimated number of MS neurologists per 100 000 in South-East Asia and Africa is zero.
- ◆ By income category, the median estimated number of MS neurologists per 100 000 is greatest in high income countries (0.21 per 100 000), followed by upper middle (0.07) and lower middle income countries (0.02). The median estimated number of MS neurologists per 100 000 in low income countries is zero.
- ◆ Globally, the median estimated number of **MS nurses** per 100 000 is 0 (with an interquartile range of 0–0.07), although 44.2% of the countries that responded suggested that MS nurses exist in their country (Figure 8.2).
- ◆ Regionally, there are MS nurses in 75% of the countries that responded in Europe, followed by South-East Asia (50%), the Americas (44.4%), the Western Pacific (44.4%) and the Eastern Mediterranean (14.3%). None of the 18 countries that responded in Africa has MS nurses.
- ◆ Regionally, the median estimated number of MS nurses per 100 000 is greatest in Europe (0.07) followed by South-East Asia (0.0004). The median estimated number of MS nurses per 100 000 in the Americas, the Western Pacific, the Eastern Mediterranean and Africa is zero.
- ◆ Regionally, patients with MS are seen by an MS nurse in 79.4% of the countries that responded in Europe followed by the Americas (72.7%), the Western Pacific (33.3%), the Eastern Mediterranean (14.3%) and Africa (5.9%). No people with MS (0%) in any of the countries in South-East Asia that responded are seen by an MS nurse.
- ◆ MS nurses exist in 80.1% of the high income countries that responded, 55% of the upper middle income countries, 18.5% of the lower middle income countries and 4.8% low income countries.
- ◆ By income category, the median estimated number of MS nurses per 100 000 in high income countries is 0.12 per 100 000. The median estimated number of MS nurses per 100 000 in upper middle, lower middle and low income countries is zero.
- ◆ By income category people with MS are seen by an MS nurse in 87.5% of high income countries followed by upper middle (62.5%) and lower middle (15%). No people with MS (0%) are seen by an MS nurse in any of the low income countries that responded.
- ◆ In 82.4% of the countries that have MS nurses there is MS-specific education or training, whereas MS nurses can undertake the international accredited MS nursing exam in only 20.6% of countries.
- ◆ Globally, patients with MS are seen by a physiotherapist in 92.1% of the countries that responded, followed by a psychologist or psychiatrist (78.4%), urologist (76.1%), occupational therapist (61.4%), social worker (56.8%), gynaecologist (56.8%), speech therapist (53.4%) and MS nurse (46.6%).
- ◆ Globally, hospital-based interdisciplinary teams are available in 73.3% of the countries that responded whereas community based interdisciplinary teams are available in 32.8% of the countries that responded.

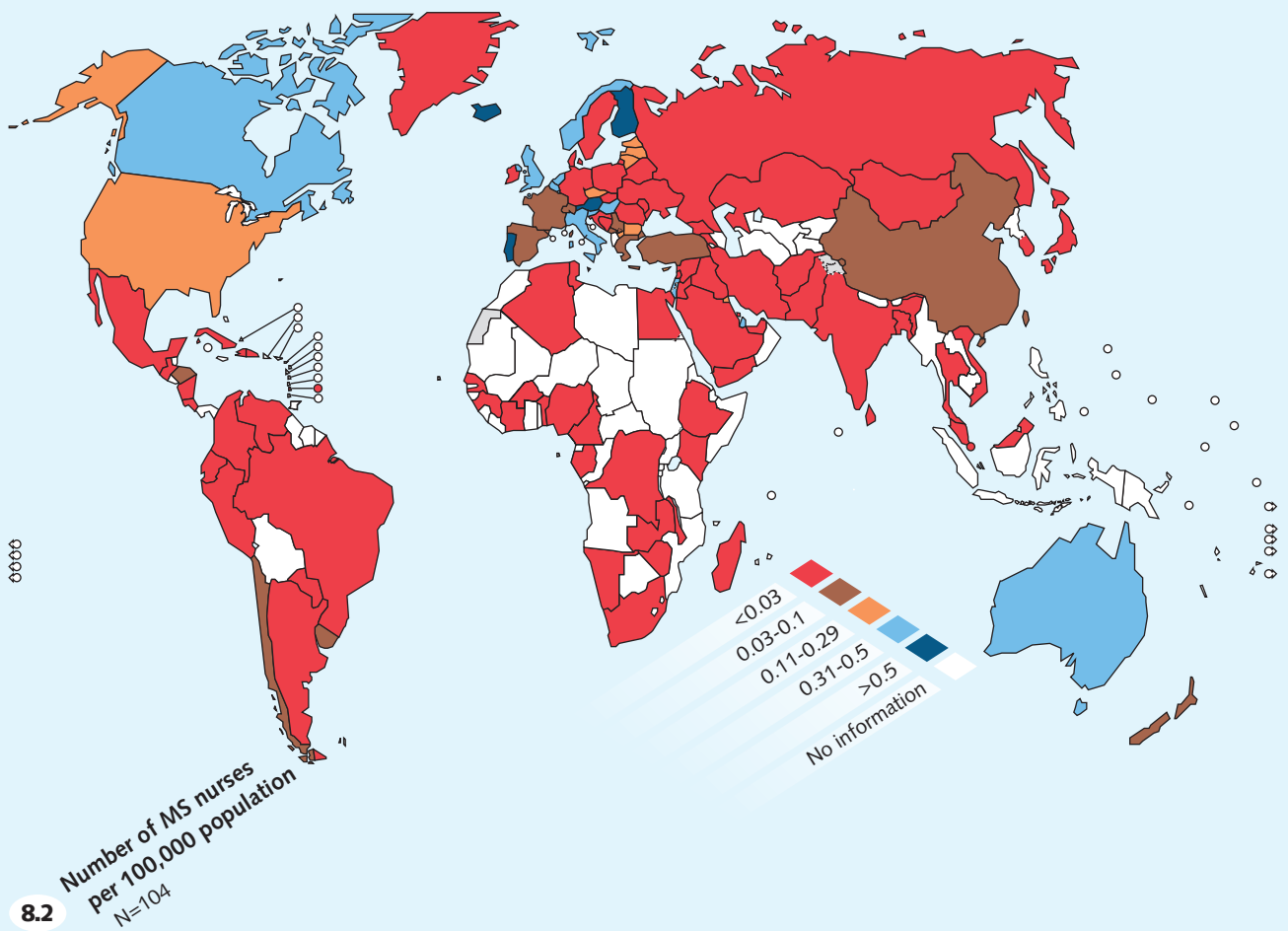
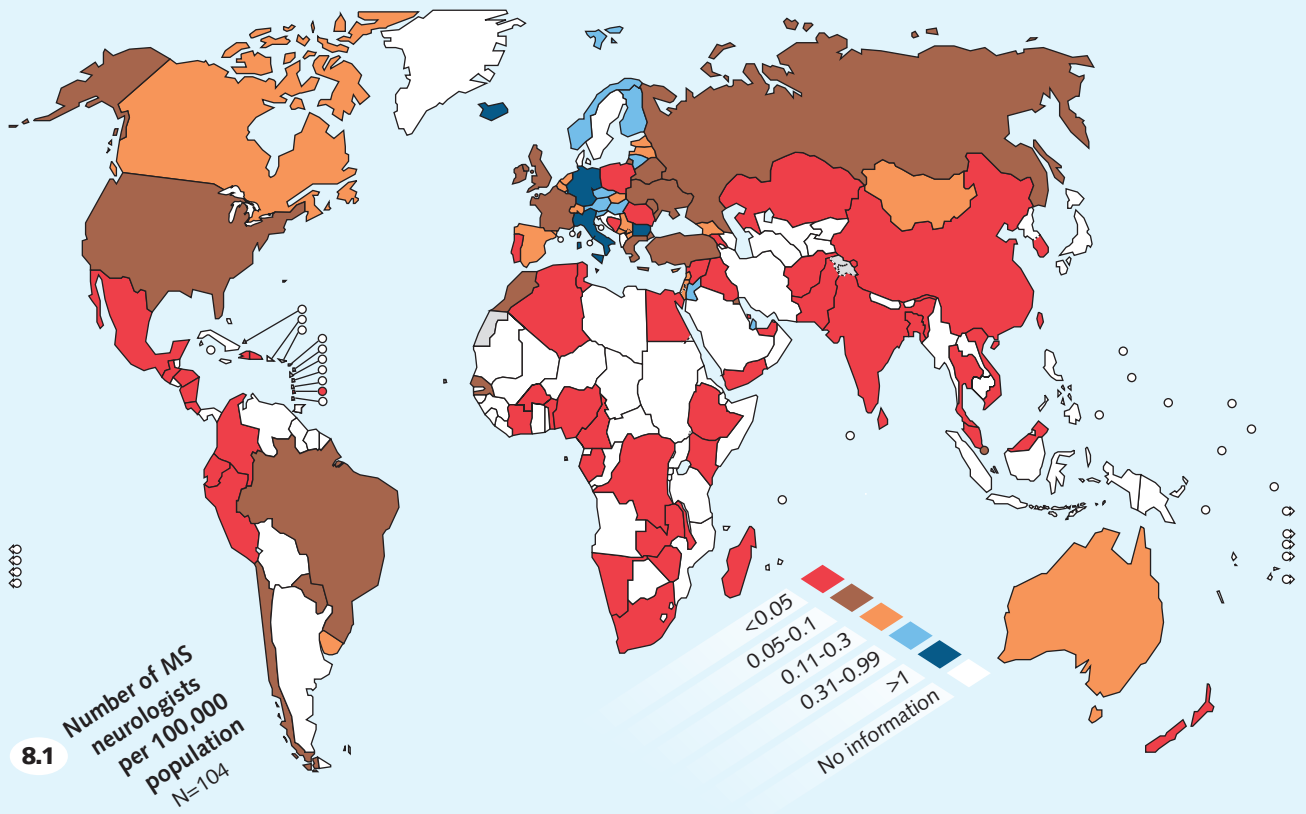
◆ Implications

MS neurologists

- ◆ Without neurologists MS cannot be diagnosed or treatments implemented. The Atlas of MS highlights where resources are currently lacking

MS nurses

- ◆ An MS nurse plays a vital role as an educator, care provider, and advocate for patients and families affected by MS and MS nurses are emerging as a leading force in providing care to people with MS. While there is currently little evidence of effectiveness for the MS nurse specialist role, there is evidence for its appropriateness, although more rigorous primary research is required to test this.



◆ Implications

Other health professionals

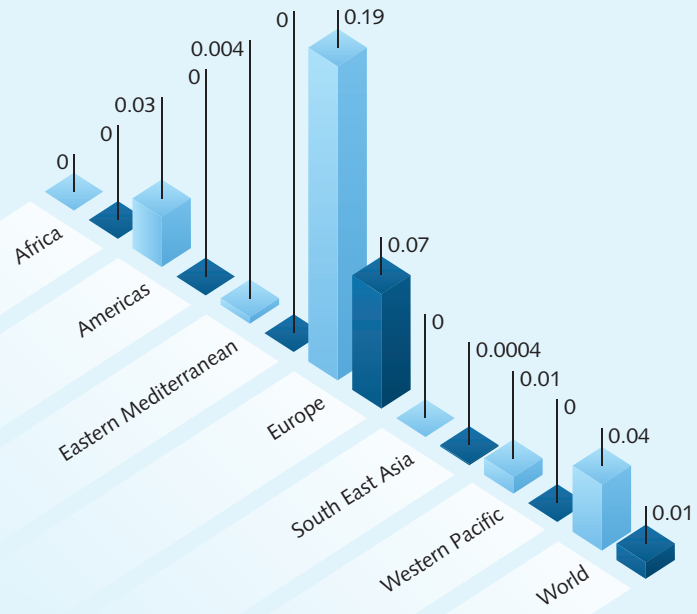
- ◆ The delivery of care for people with long-term diseases is becoming increasingly “patient centred”, and a culture of treatment by interdisciplinary teams is emerging. There is relatively widespread evidence (see references from the MSIF’s Principles to Promote the Quality of Life of People with Multiple Sclerosis (available at www.msif.org)) that the best approach to treating people with MS is through interdisciplinary teams. Within this model, the aim is to offer patients a seamless service, which typically involves bringing together various health professionals including doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists and social workers. Other professionals with expertise in treating neurologically disabled people cover dietetics, continence advisory and management services, pain management, chiropody, podiatry and ophthalmology services.
- ◆ Hospital-based interdisciplinary teams were reported to exist in nearly three quarters of the countries that responded, whereas community-based teams were reported in just under one third of countries. The interdisciplinary approach brings together professionals with a range of relevant skills who have the ability to contribute to a group effort on behalf of the patient, resulting in a synergistic treatment programme producing more effective care than each discipline could achieve individually.
- ◆ The interdisciplinary approach typically makes it easier for people with MS to gain access to disease-modifying treatments and therapies, and is to be encouraged. Our survey has found a wide range of waiting times before people with MS can see an interdisciplinary team, and it should be a priority to reduce this wait where possible.
- ◆ The findings suggest that globally MS is being managed in a medical model of care that relies on hospital infrastructures to deliver hence delays at diagnosis and a lack of support in community care, transport and respite care.

◆ Relevant quality of life principles

- ◆ 2.3.1. Medical care is to be provided by clinicians who have expertise in MS, including neurologists. In order to ensure prompt and expert treatment of the wide range of symptoms and disabilities that people with MS may experience, both care and case management must be provided by multidisciplinary teams that specialize in MS.
- ◆ 2.3.2. As appropriate, people with MS must be offered a broad range of services beyond those provided by physicians and nurses, including physical, occupational, and and speech therapy, counselling, and other services. The purpose and potential benefits of those services are to be clearly explained to them.
- ◆ 2.3.6. All neurologists, primary care physicians, nurses, and other health professionals who work with people with MS must have the goal of promoting QOL, and not just clinical management of the disease.

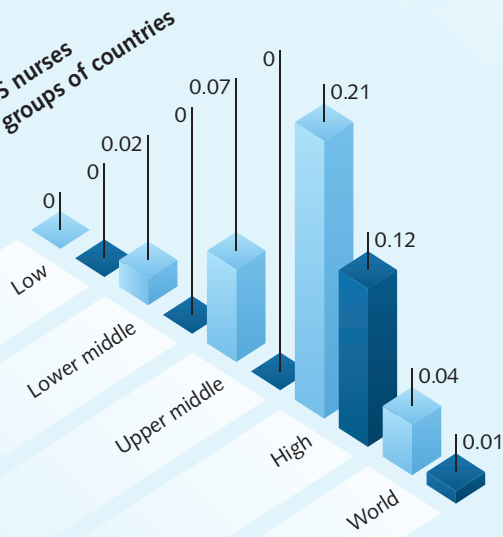
8.3 Number of MS neurologists and MS nurses per 100,000 in WHO regions and the world
N=104

MS neurologists
MS nurses



8.4 Number of MS neurologists and MS nurses per 100,000 in different income groups of countries
N=104

MS neurologists
MS nurses



◆ Limitations

- ◆ Questions on the availability of disability entitlements were only answered by between 50 and 70 countries, the majority of which are economically advanced econo-

mies. Consequently the findings are less global than they are elsewhere in this Atlas of MS and probably paint an over positive picture.

◆ Salient Findings

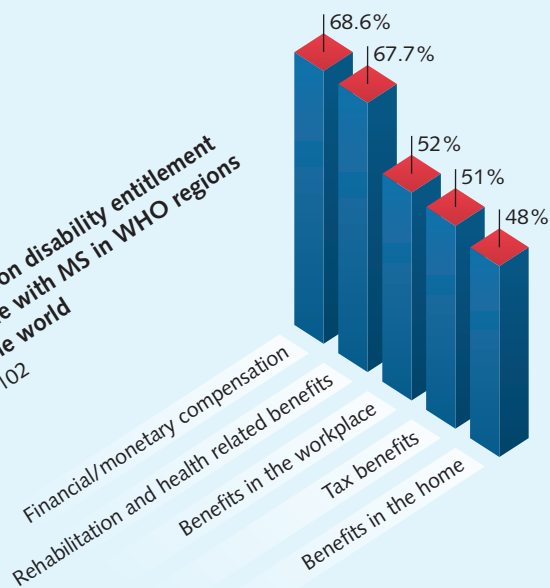
- ◆ The most **common disability entitlement** for people with MS is financial or monetary compensation (including pension and allowances) available in 68.6% of countries that responded, followed by rehabilitation and health-related benefits (67.7%), benefits in the workplace (52%), tax benefits (51%) and benefits in the home (48%) (Figure 9.2).
- ◆ Regionally, **financial or monetary compensation** (including pension and allowances) is available to people with MS in 90% of countries in Europe that responded, followed by 77.8% of those in the Western Pacific, 72.2% of those in the Americas, 64.3% of those in the Eastern Mediterranean, 25% of those in South East Asia and 18.8% of the African countries that responded (Figure 9.1).
- ◆ Financial or monetary compensation (including pension and allowances) is available to people with MS in 90% of the upper middle income countries that responded, 88.9% of high income countries, 55.6% of lower middle income countries and 26.3% of the low income countries.
- ◆ Regionally, **rehabilitation and health benefits** are available to people with MS in 85% of the countries in Europe that responded, followed by 78.6% of those in the Eastern Mediterranean, 77.8% of those in the Western Pacific, 66.7% of those in the Americas, 50% of those in South East Asia and 12.5% of the African countries that responded.
- ◆ Rehabilitation and health benefits are available to people with MS in 94.4% of high income countries, 85% of upper middle income countries, 59.3% of lower middle income countries and 10.5% of the low income countries.
- ◆ Regionally, **benefits in the home** (e.g. for adaptations) for people with MS were reported to be available in 75% of European countries followed by 44.4% of countries in the Americas and the Western Pacific, 35.7% of those in the Eastern Mediterranean, 25% of those in South East Asian and 6.3% of African countries.
- ◆ By income band, financial support in the form of tax benefits was reported to be available in 75% of high income countries, 70% of upper middle income countries, 29.6% of lower middle income countries and none (0%) of the low income countries.
- ◆ Regionally, **tax benefits** or relief were reported to be available in 72.5% of the European countries that responded, followed by 50% of those in the Eastern Mediterranean and South East Asia, 44.4% of those in the Americas, 33.3% of those in the Western Pacific and 12.5% of the African countries that responded.
- ◆ Tax benefits or relief are available in 75% of the upper middle income countries that responded, 69.4% of the high income countries, 37% of the lower middle income countries and 10.5% of the low income countries.
- ◆ Regionally, **workplace benefits** for people with MS are available in 67.5% of European countries that responded, followed by 57.1% of those in the Eastern Mediterranean, 50% of those in the Americas, 33.3% of those in the Western Pacific, 31.3% of African countries and 25% of South East Asian countries (Figure 9.3).
- ◆ Workplace benefits for people with MS are available in 69.4% of the high income countries, 60% of the upper middle income countries, 44.4% of the lower middle income countries and 21.1% of the low income countries (Figure 9.4).

◆ Implications

- ◆ Recent research in the UK has shown that most people with MS are in employment at the time of diagnosis, but that employment loss starts shortly after diagnosis and 80% of people with MS are unemployed within ten years of diagnosis. Although they focus on one country, these findings illustrate the need to develop vocational rehabilitation programmes that enable people with MS to gain access to, maintain or return to employment, or other useful occupation
- ◆ Many people with MS leave the labour force because of the symptoms of the disease, such as fatigue, functional disability and cognitive impairment. Leaving the workforce can have a major effect on family income as well as on an individual's self esteem. Some people with MS could continue to work if employers were to provide assistance and restructure their work. A wide range of accommodations or adaptations are possible, including part-time work, additional breaks in the work day, working only in the mornings, reducing the room temperature, changing work tasks, telecommuting, reducing travel, providing ramps and providing offices near restrooms, among others. Governments and social service providers can contribute by providing vocational rehabilitation and training programmes.
- ◆ The need to integrate health and employment teams to improve vocational rehabilitation is now well recognized. Services offered should include provision of mechanisms for people with MS to make adjustments in their careers and to continue working for as long as they wish to. Early intervention is vital to support and train people to enable them to obtain, maintain, and advance in jobs that are compatible with their interests, abilities and experience. Poor support for employment and inadequate financial advice has the potential to add to the global economic cost of MS.
- ◆ Many people with MS who leave the labour force are dependent on disability entitlements and means-tested cash assistance for their income. Thus, the eligibility criteria, payment levels and administration of these entitlements have a direct impact on the quality of life of people with MS. Eligibility criteria and application procedures for public and private disability entitlements and means-tested cash assistance must be fair and not unduly burdensome nor restrictive. Cash payments for public and private disability benefits and means-tested cash assistance must be high enough to allow people with MS to have an adequate standard of living.
- ◆ Disability entitlements and services must be flexible, allowing for partial disability, to enable people with MS to take time off when needed or to continue working part-time, if desired. They must provide an adequate standard of living, and have the flexibility to allow for the disease variability that is characteristic of MS.

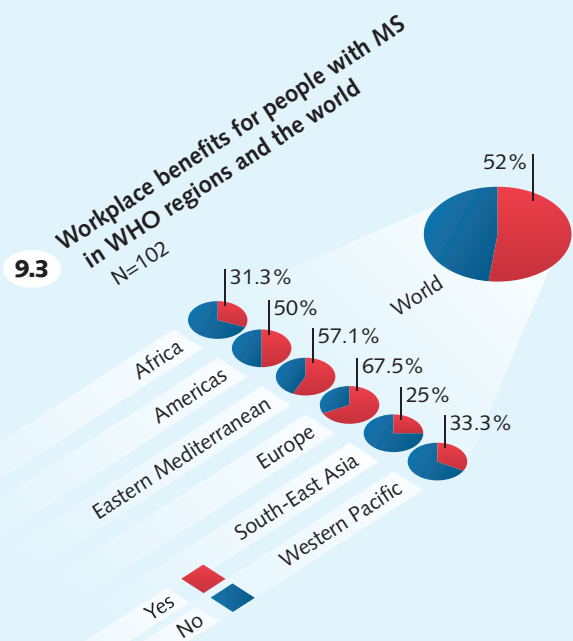
9.2

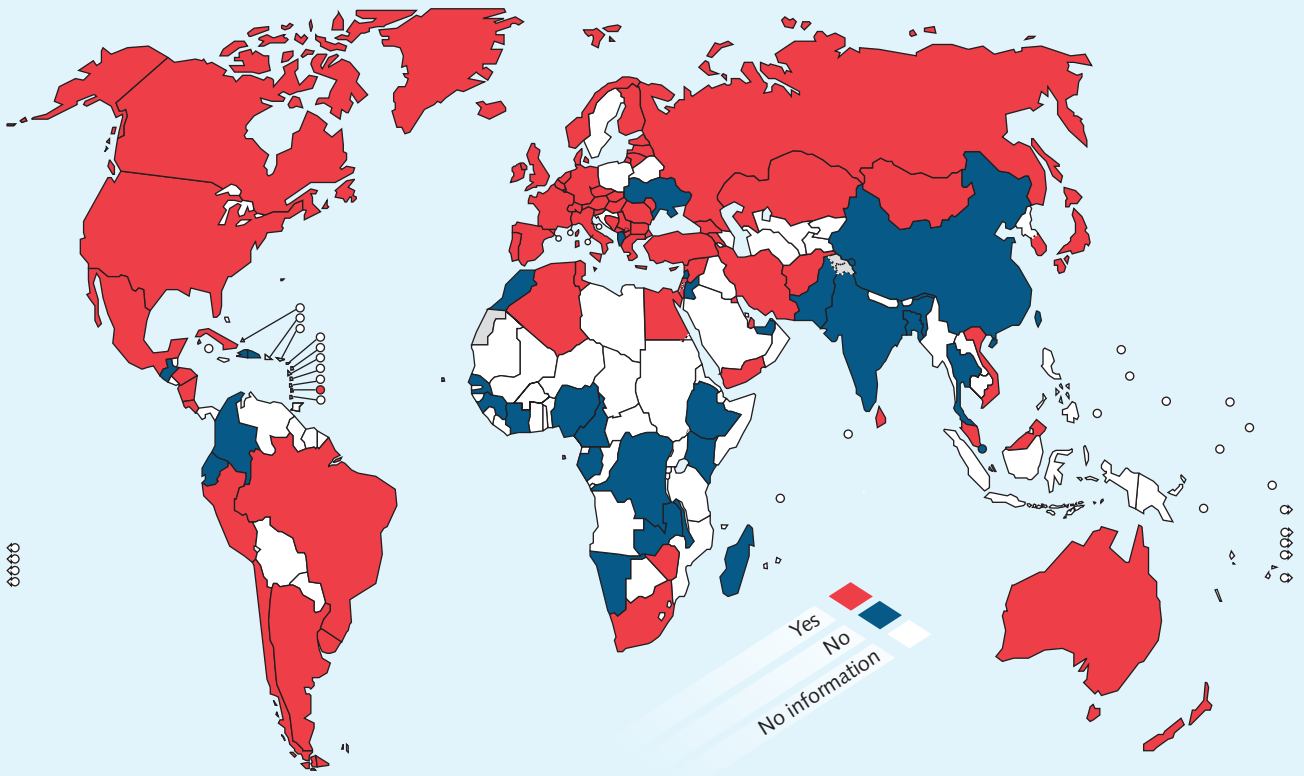
Most common disability entitlement for people with MS in WHO regions and the world
N=102



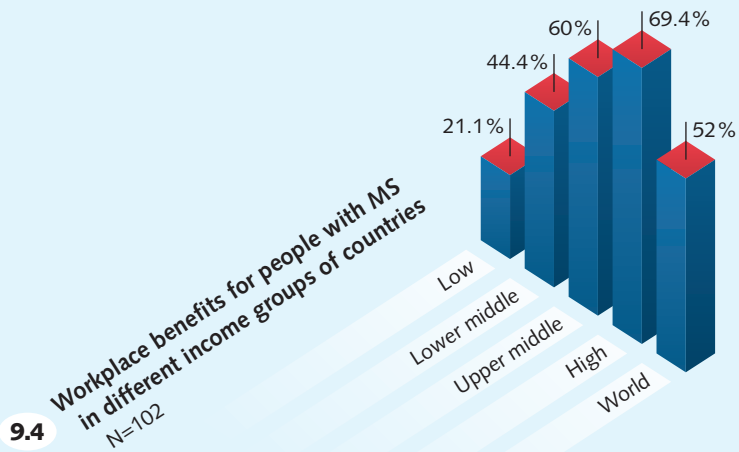
◆ Relevant quality of life principles

- ◆ 1.4. People with MS should have access to treatments, programmes, and services without regard to their ability to pay.
- ◆ 1.6. Legislation must be enacted that protects the rights of people with MS and other people with disabilities against discrimination in all aspects of social and community life. Enforcement of these laws is to be consistent and effective. Among other things, these laws require governments, employers, building owners, transportation organizations, and others to make reasonable adjustments to improve accessibility for people with disabilities. These laws are to ensure that people with MS have access to all types of financial instruments, including current accounts and savings accounts, credit cards, insurance, loans, and all forms of financial assistance.
- ◆ 7.1. Services must be available to allow people with MS to continue employment as long as they are productive and desire to work.
- ◆ 7.2. Employers must provide job modifications and other adaptations or accommodations to enable people with MS to continue working. Employers must be educated about the nature and symptoms of MS, and how job modifications can often enable people with MS to remain productive employees for many years.
- ◆ 7.3. Employers should provide time off for family members and other informal care-givers to accommodate the unexpected needs of people with MS. Employers should be educated about the roles of family members in treating and managing acute exacerbations and symptoms of MS.
- ◆ 7.4. Vocational rehabilitation and training services must be available to help people with MS return or stay in the labour force, if desired.
- ◆ 7.5. When people with MS do retire from paid employment, they must be provided counselling and encouragement to develop alternative, voluntary activities that can fill the void often left by the loss of work. The transition out of paid employment is to be planned well in advance to ensure people with MS receive all of the services to which they are entitled, to prepare for alternate occupations or activities, and to avoid the stress that may accompany abrupt, unplanned transitions from work to retirement.
- ◆ 8.1. Eligibility criteria and application procedures for public and private disability entitlements and means-tested cash assistance must be fair and not unduly burdensome nor restrictive.
- ◆ 8.2. Cash payment levels for public and private disability benefits and means-tested cash assistance must be high enough for people with MS to have an adequate standard of living.
- ◆ 8.3. Disability entitlements must be flexible, allowing for partial disability, to enable people with MS to take time off when needed or to continue working part-time, if desired.





9.1 Availability of financial/monetary compensation for people with MS
N=102

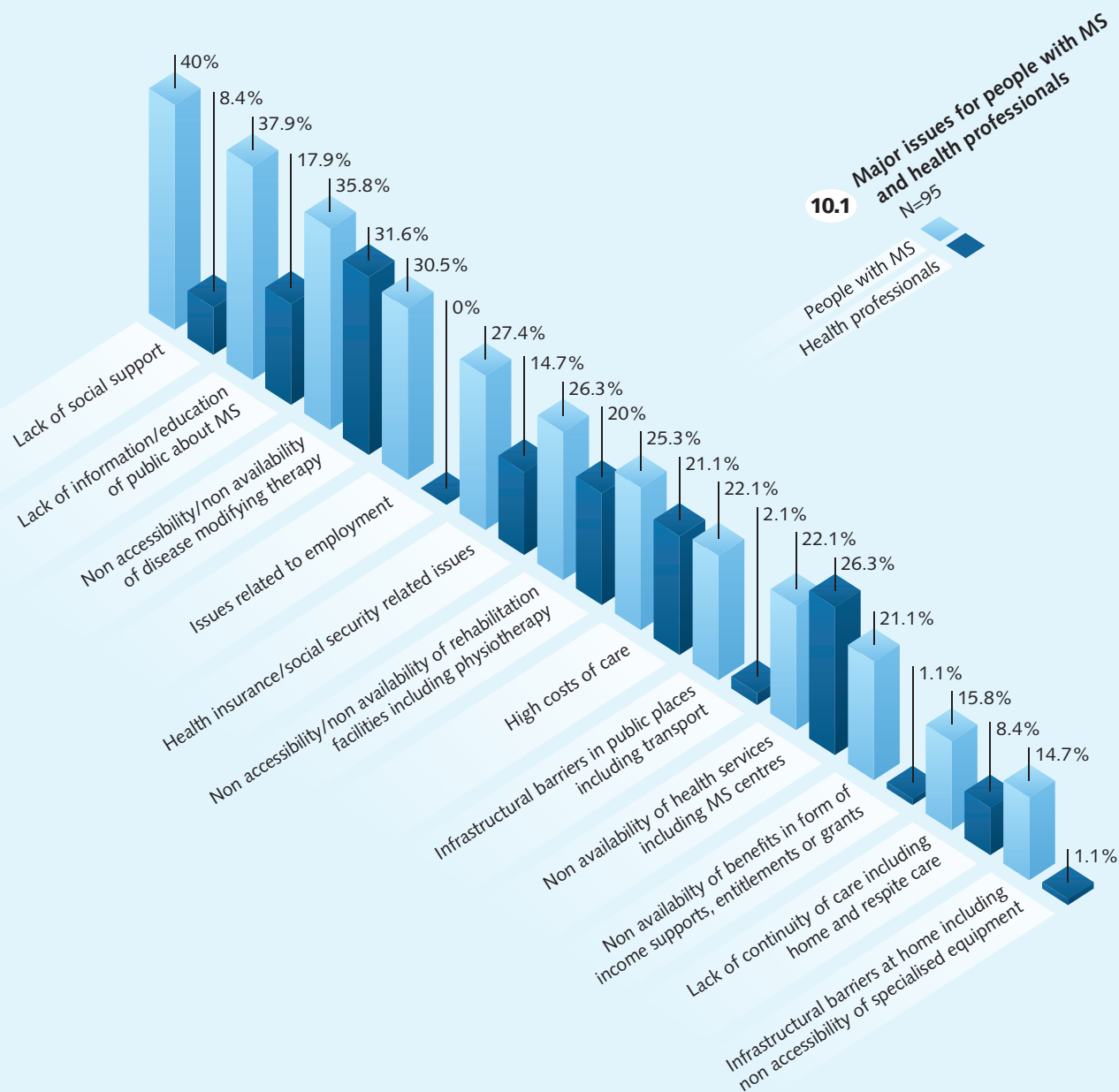


9.4 Workplace benefits for people with MS in different income groups of countries
N=102

Salient Findings

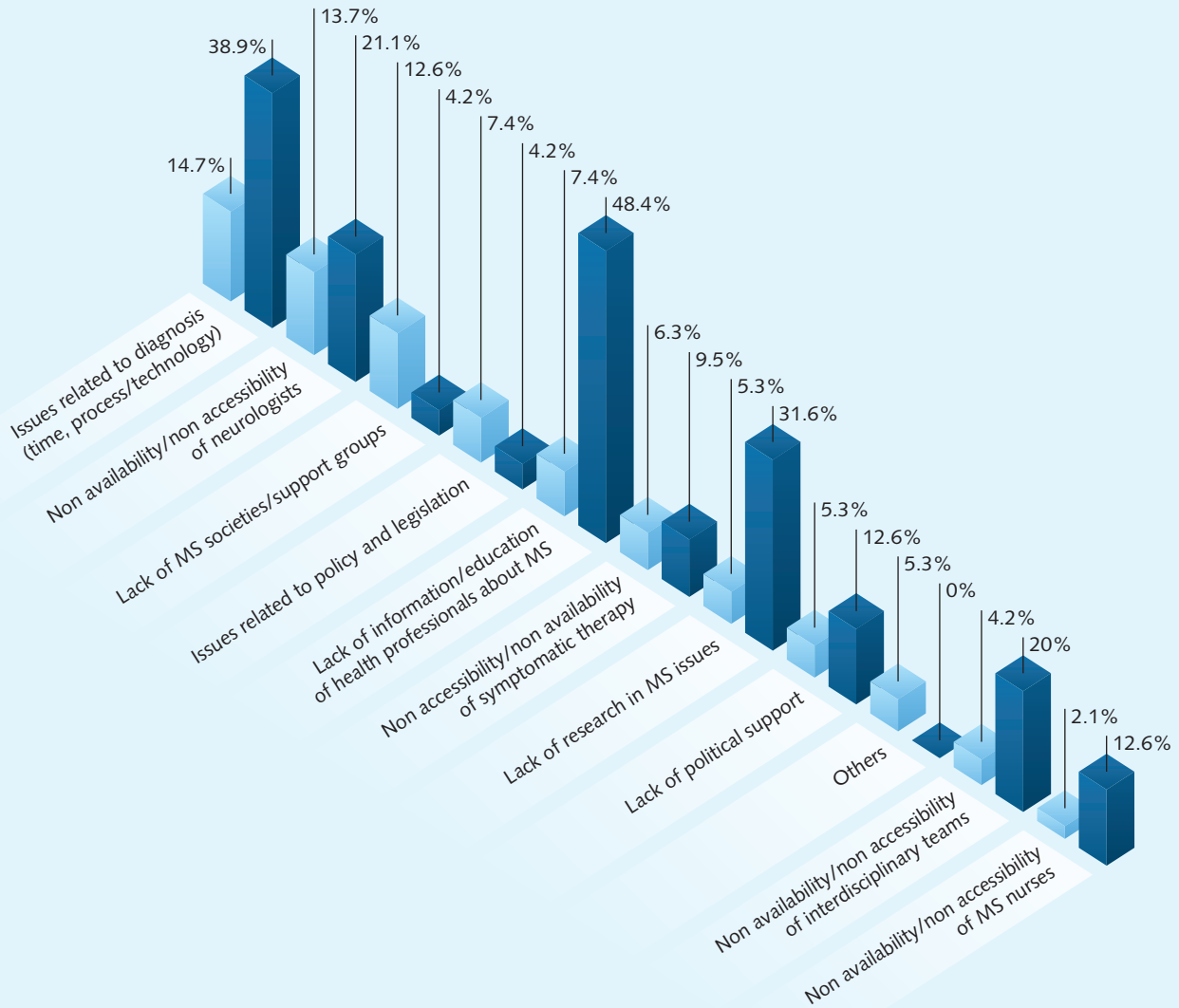
- ◆ The major issue for people living with MS, experienced in 40% of the countries that responded, was the lack of social support followed by the lack of information for and education of the public about MS (37.9%), the lack of accessibility to and availability of disease-modifying treatments (35.8%), issues related to employment (30.5%) and health insurance and social security related issues (27.4%) (Figure 10.1).
- ◆ The major issues for health professionals involved in MS care include the lack of information for and education of health professionals about MS, experienced in 48.4% of the countries that responded, issues related to the time it takes to diagnose MS (i.e. the process/technology required) (38.9%), the lack of accessibility to and availability of disease-modifying treatments (31.6%), lack of research in MS issues (31.6%) and the non-availability of health services, including MS centres (26.3%) (Figure 10.1).

- ◆ The major changes to improve MS care desired by the country contributors include informing and educating health professionals about MS, suggested by 43.2% of the countries that responded, informing and educating the public about MS (38.9%), making health services, including MS centres, available (35.8%), making rehabilitation facilities, including physiotherapy, accessible and available (33.7%), developing MS societies and support groups (27.4%) and improving and expanding research into MS issues (26.3%).



◆ Implications

- ◆ Globally MS is being managed in a medical model rather than a model that combines medical and social needs.



Epidemiology

- ◆ MS is a global disease – no country that responded to the Atlas of MS survey was free of MS.
- ◆ MS is more common among women than men.
- ◆ Symptoms appear at around 30 years of age.
- ◆ The survey revealed the geographical patterns associated with the disease.
- ◆ There is a lack of reliable, valid and robust data from epidemiological or economic impact studies and reports published in medical literature (especially in Africa and parts of Asia where the prevalence is reported to be low).

MS Organizations

- ◆ Many countries in the world have no patient-driven support for people with MS.

Diagnosis

- ◆ The availability and accessibility of magnetic resonance imaging (MRI) technology varies widely.
- ◆ Time from onset of symptoms to diagnosis varies widely – often being drawn out over many months or years.
- ◆ Inequalities in global wealth impact on the provision of diagnostic services.

Information

- ◆ There are inequalities in the provision of basic and more specific forms of information – in many cases the gap between information required and received is vast.

Support and services

- ◆ The needs of people with MS do not inform decision-making
- ◆ Health care professionals are not receiving any (or enough) training to help them to identify and treat people with MS.
- ◆ There is a lack of public and professional awareness of MS and its impact.
- ◆ There is little understanding of the socioeconomic costs of MS to individuals, families, carers and the community.
- ◆ Owing to inadequate education, advice and support, people with MS are unaware of how best to cope with their MS and remain in education or employment.
- ◆ In many countries mutual support groups do not exist.
- ◆ In many countries no aids or adaptations are available from any source.
- ◆ Accessible public transport is often unavailable or difficult to use and there is little alternative transport support.
- ◆ Poor provision of respite is widespread.
- ◆ There is a need for better understanding of how transport and drug delivery options will overlap with care and treatment possibilities.
- ◆ Income inequalities have significant effects on the provision of treatment and services
- ◆ People with MS actively seek and use a wide range of “complementary” or “alternative” remedies or treatments which have not been tested in clinical trials.
- ◆ The findings confirm the key role played by MS organizations.

Human resources

- ◆ In some countries the lack of neurologists knowledgeable about MS hampers diagnosis and the provision of treatments and therapy.
- ◆ There is a general lack of MS nurses.
- ◆ Inadequate use is made of interdisciplinary teams in community settings.
- ◆ MS is being managed in a medical, not a social, model of care.

Disability entitlements, legislation and insurance

There is a need to integrate health and employment teams to improve vocational rehabilitation (a process whereby people with MS can be enabled to access, maintain or return to employment or other useful occupation).

- ◆ People with MS are often dependent on disability entitlements and cash assistance for their income.
- ◆ The eligibility criteria, payment levels and administration of disability entitlements and cash assistance have a direct impact on the quality of life of people with MS.

Major issues

The major issues for people living with MS are:

- ◆ lack of social support
- ◆ lack of information and education of the public about MS
- ◆ lack of access to and availability of disease-modifying treatments
- ◆ issues related to employment
- ◆ health insurance and social security-related issues.

The major issues for health professionals involved in MS care are:

- ◆ lack of information for and education of health professionals about MS
- ◆ issues related to the time it takes to diagnose and the process and technology required
- ◆ lack of access to and availability of disease-modifying treatments
- ◆ lack of research in MS issues
- ◆ lack of health services, including MS centres.

The major changes needed to improve MS care are:

- ◆ to inform and educate the public and health professionals about MS
- ◆ to make health services, including MS centres and rehabilitation facilities, accessible and available
- ◆ develop MS societies and support groups
- ◆ improve and expand research into MS issues.


◆ The value of the Atlas of MS is in replacing impressions and opinions with facts and figures. The findings have specific implications for the work of health professionals, patient groups, the health industry and governments – and will inform national and regional advocacy and development policies.

MS usually affects people when they are young, starting a family and developing their career. The impact on the quality of life of people with MS and the financial implications for society are therefore long lasting and profound. The study highlights worrying discrepancies between countries in their support to people affected by MS and these discrepancies are evident even within country groupings of comparable economic development, such as the European Union. We call on policy makers, health professionals and patient groups to make use of the data in the Atlas of MS to act to close those gaps.

The Atlas of MS can be used as a tool to raise awareness of the global MS situation and encourage decision-makers, public bodies and governments to:

- ◆ Raise greater awareness and understanding of MS in their countries among the general public, employers and health care professionals.
- ◆ Invest more in diagnostic tools and techniques.
- ◆ Invest in the education and training of health professionals.
- ◆ Stimulate and support the expansion of better research into MS and MS issues.
- ◆ Develop and strengthen initiatives and structures to make health services offering treatment and rehabilitation equally available and accessible to all people with MS with a view to keeping them in employment.
- ◆ Invest in and support the development of the capacity of MS societies and patient groups to support public, private and non-profit initiatives to develop public policy, service provision and support.

All stakeholders need to invest in the way forward, to improve the quality of life of people with MS, and to reduce the long term financial impact on them and on society as whole.

 We are most grateful to the following country coordinators and their colleagues for taking the time and effort to gather the information and data required to complete the MS Atlas questionnaire:

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Australia	<i>Trevor Farrell Rex Simmons Elizabeth McDonald W.M. Carroll</i>
Austria	<i>Lüder Deecke Fritz Leutmezer Helene Kallina</i>
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Country, territory or area	Name	Country, territory or area	Name
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Country, territory or area	Name	Country, territory or area	Name
Portugal	<i>Jorge Da Silva Rui Pedrosa</i>	United Arab Emirates	<i>Jihad Said Inshasi</i>
Qatar	<i>Hassan Al Hail</i>	United Kingdom of Great Britain and Northern Ireland	<i>Sharon Haffenden Alasdair Coles Lynda Finn Kathryn White Jane Petty</i>
Republic of Korea	<i>Kwang Ho Lee</i>	United States of America	<i>Nicholas G. LaRocca Beverly Noyes John Richert Nancy Holland Susan Sanabria</i>
Romania	<i>Berha Mihaela Vasile Titus Mihai</i>	Uruguay	<i>Carlos Oehninger Gatti</i>
Russian Federation	<i>Alexey Boiko</i>	Venezuela (Bolivarian Republic of)	<i>Arnoldo Soto</i>
Saudi Arabia	<i>Amal Abdulrahman</i>	Viet Nam	<i>Le Duc Hinh</i>
Senegal	<i>Fatou Sene Diouf</i>	Yemen	<i>Hesham Awn</i>
Serbia	<i>Tatjana Dakic Tatjana Pekmezovic Nevenka Rasic Jelena Drulovic Vanja Taleski Lenka Babic</i>	Zambia	<i>Masharip Atadzhanov</i>
Singapore	<i>Benjamin Ong</i>	Zimbabwe	<i>Jens Mielke</i>
Slovakia	<i>Lubica Prochazkova</i>		
Slovenia	<i>Beatrika Koncan-Vracko</i>		
South Africa	<i>Jan Jakob Stephanus (Fanie) Du Toit Girish Modi</i>		
Spain	<i>Águeda Alonso Sánchez</i>		
Sri Lanka	<i>Udaya Kumara Ranawaka</i>		
Sweden	<i>Arja Hill</i>		
Switzerland	<i>Vera Rentsch Andrea Gerfin Jürg Kesselring Herbert Keller</i>		
Syrian Arab Republic	<i>Ahmad Khalifa</i>		
Thailand	<i>Naraporn Prayoonwiwat</i>		
The former Yugoslav Republic of Macedonia	<i>Lodi Gogovska</i>		
Tunisia	<i>Chokri Mhiri</i>		
Turkey	<i>Aysegül Ünlüsoy Aksel Siva Nevin Sutlas</i>		
Ukraine	<i>Nehrych Tetiana</i>		

- ◆ **Advice and advocacy:** a combination of individual and social actions and activities designed to provide advice and gain political commitment, policy support, social acceptance and health systems support for people with MS.
- ◆ **Age of onset:** the age of the person when the MS symptoms first appeared.
- ◆ **Audio-visual material:** materials other than books that present information in audible and pictorial form such as audio cassettes, video tapes, CDs, DVDs, slides, mp3s and mp4s.
- ◆ **Complementary and alternative therapies:** a broad set of health care practices that are not integrated into the dominant health care system. It could be a different approach from conventional medicine (alternative) or used together with conventional medicine (complementary). These could be medication or non-medication therapies. Traditional medicine is also in some countries used as a term for these therapies.
- ◆ **Diagnostic criteria:** as the symptoms, signs and course of MS are diverse, diagnosis of MS is based on the identification of a clinical syndrome and its progression over time. Various diagnostic criteria have been proposed that group patients into subcategories based on the “certainty” of diagnosis.
- ◆ **Disability entitlements:** can come from either the public (state) or private (employer) sector. Disability entitlements are benefits payable as a legal right in cases of MS that cause physical, mental or intellectual impairment leading to functional limitations.
- ◆ **Disease-modifying drugs:** a group of drugs that impact the course of MS by slowing the progression of the disease and decreasing or reducing the number, frequency and severity of clinical attacks (also called relapses or exacerbations), reducing the accumulation of lesions within the brain and spinal cord (damaged or active disease areas) as seen on MRI and which appear to slow down the accumulation of disabilities.
- ◆ **Education and training:** to improve the knowledge of people with MS and their carers, and that of health professionals and society about MS, its consequences, and understanding of psychosocial and occupational problems to encourage them to cope actively with the disorder and live with as few limitations as possible.
- ◆ **Fatigue:** the awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization, and/or restoration of resources needed to perform activity. Mental fatigue can vary between mild and severely disabling and is usually exacerbated by exercise, and by increased bodily or ambient temperature. Mental fatigue usually follows a daily pattern and many people with MS report that they feel fine during the first few hours of the day but, by afternoon or early evening, feel completely exhausted. Fatigue in people with MS appears to be unrelated to physical disability status and many people with MS complain of fatigue even when all their other symptoms are mild or in complete remission.
- ◆ **Health professionals:** personnel involved in providing care to people with MS such as doctors, neurologists, nurses, social workers, physiotherapists and occupational therapists.
- ◆ **Incidence:** estimated number of new cases of MS diagnosed over a defined period of time in a specified population usually given as number per 100 000 population.
- ◆ **Information:** communication of knowledge by various channels regarding, for example, symptoms, prognosis, treatment, support services, lifestyle, family issues, legislation and research.
- ◆ **Interdisciplinary teams:** people with MS have complex needs that require inputs from a variety of specialties and services. These interdisciplinary teams could be hospital or community based.
- ◆ **Male/female ratio:** the numbers of females with MS for every male with MS.
- ◆ **McDonald criteria:** a set of clinical parameters utilizing advances in MRI imaging techniques developed in 2001 (updated in 2005) by an international panel in association with the NMSS and the MSIF. They make the diagnostic process faster and more precise and are intended to replace the Poser Criteria (1983) and the Schumacher Criteria (1965).

- ◆ **Motor weakness/dysfunction or spasticity:** include involuntary contractions, jerking and twitching of muscles, muscle weakness, partial or mild paralysis, stiffness, restricted free movement of affected limbs, involuntary leg movements, foot drag, slurred speech and related speech problems.
- ◆ **MS groups and organizations:** a non-profit patient-driven organization that works on issues related to MS in the country. It may also be called an association, society, league, federation, foundation, union or other appropriate title, depending upon the regulations and/or practice of the country.
- ◆ **MS neurologist:** a neurologist whose professional interests and activities are related exclusively or specifically to the care of people with MS. He or she runs a clinic or service for MS patients separate from other neurological practice, provides overall management of care, neurological testing and evaluation, and prescribes medications and monitors their effectiveness.
- ◆ **MS nurse:** a licensed or registered nurse whose professional interests and activities are related exclusively or specifically to the care of people with MS either through direct practice, research, education or administration.
- ◆ **Prevalence:** estimated total number of cases of MS at a particular point in time in a specified population usually given as number per 100 000 population.
- ◆ **Relapse:** (also called a clinical/neurological attack, exacerbation or flare-up) is the subacute appearance of a neurological abnormality that must be present for at least 24 hours in the absence of fever or infection and characterized by the sudden worsening of an MS symptom or symptoms or the appearance of new symptoms. ◆ **Respite care:** refers to services that provide people with temporary relief from tasks associated with caregiving (e.g. in-home assistance, short nursing home stays and adult day care).
- ◆ **Self help and mutual support groups:** mutual support is based on the concept that people who share common experiences can provide one another with emotional support, fellowship and information. For people with MS and their families, mutual support groups offer the opportunity to exchange experiences and to give and receive support, information and encouragement.
- ◆ **Sensory symptoms:** include burning, itching and electrical shock sensations, numbness/loss of sensation, tingling, buzzing, vibration sensations and loss of awareness of location of body parts.
- ◆ **Source of financing:** in this context, out-of-pocket payments refer to payments made for MS care by the consumer or his family; insurance refers to a premium that the health care consumer voluntarily pays to a private insurance company which, in return, pays for part or all of a consumer's MS care services; government refers to money for health services raised by taxation or through social insurance.

The results of the survey made for the ATLAS OF MS reveal a lack of services and resources allocated to the care of people with MS. The situation is of particular concern in most low and middle income countries. The data clearly indicate that:

- ◆ no one country provides adequate resources;
- ◆ in many countries the resources that are available are grossly inadequate;
- ◆ the availability of resources varies widely between countries both within all regions and worldwide

The value of the Atlas of MS is in replacing impressions and opinions with facts and figures.

This joint report by the World Health Organization and the Multiple Sclerosis International Federation includes information from 112 countries, representing almost 88% of the world population.

It is hoped that this Atlas of MS will enhance knowledge and awareness of the global and regional disparities in resources and services for people with MS at country level and will help in the development of policies and programmes for this group of people.



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