Atlas of MS
3rd edition

Mapping multiple sclerosis around the world
key epidemiology findings

Foreword

We established the Atlas of MS in 2008 with the World Health Organization to address the huge lack of data on MS around the globe. We continued to refine and improve the methodology with our second edition in 2013 and this newest edition is no exception. We've been able to collect data from 115 countries covering 87% of the world's population. We have also improved the way we fill in the gaps, making our estimate of 2.8 million people living with MS worldwide our most accurate yet. The Atlas shows a much larger number of children and young people under 18 living with MS than was known before. It confirms the high proportion of females living with MS and shows a variation in this proportion between different regions. These and other findings need attention in medical research and in the shaping of healthcare and policies to improve the quality of life of people living with MS.

Since the last edition of the Atlas of MS in 2013, we have seen continued improvement in diagnostic guidelines and their global adoption is enabling many people with MS to be diagnosed earlier in the disease course. This is one of the factors contributing to our higher estimate of the total number of people living with MS. Of course, importantly, an earlier diagnosis opens up the window for earlier effective intervention with disease modifying therapies and offers the possibility to postpone the accumulation of disability.

Globally there have been improvements in data quality, with 14 new countries being able to report data for the first time and 84% citing peer-reviewed or MS registry data for their prevalence figures, an increase of 13% since 2013. But there are still big gaps in our understanding, particularly around incidence, pediatric MS and MS in low income countries and Africa.

We hope that the MS community will help us fill these gaps and help keep the Atlas up to date, by reporting new epidemiology data through the website www.atlasofms.org and that people affected by MS, healthcare professionals, researchers and MS patient groups and organisations will make the most of this vital open-source resource.

Peer Baneke
CEO of the MS International Federation

This 3rd edition of the Atlas of MS provides updated data on the prevalence and incidence of multiple sclerosis around the world. The information presented in this 3rd edition will guide policy-makers, health planners and specialists, in order to decrease inequities and improve care to MS patients globally. It provides a valuable tool for decision making and the planning of services to diagnose, treat and support people with MS.

Tarun Dua
Unit Head, Brain Health Unit, Department of Mental health and substance use, World Health Organization

What is MS?

- **Multiple sclerosis (MS) is a neurological condition that affects the brain and spinal cord (the central nervous system), which control all bodily functions.**

- **MS causes damage to the coating that protects the nerves (myelin). Myelin insulates nerves, acting like the covering of an electric wire. The loss of myelin (demyelination) is accompanied by a disruption in the ability of the nerves to conduct electrical impulses to and from the brain. This causes a range of MS symptoms, such as blurred vision, weak limbs, tingling sensations, dizziness and fatigue.**

- **MS symptoms vary widely between people. For some people, MS is characterised by periods of relapse and remission while for others it has a progressive pattern. For everyone with MS, it makes life unpredictable. It is a common life-long condition and in many countries, it is the leading cause of non-traumatic neurological disability in young adults. This has major implications for the quality of life of people with MS and their families and friends, and for the cost to society if their condition is not adequately managed.**

Introduction

Global information on MS epidemiology and healthcare accessibility for people affected by MS is fragmented. The Atlas of MS aims to bring together all available information in an open-source data set to allow a more complete understanding of the burden of the disease and provide useful insights on how it varies across the world.

> **The Atlas of MS is unique in that it is not a standard review of the published literature, but instead seeks to reach out to organisations and experts in every country in the world asking them to provide the most up-to-date information on MS.**

The first Atlas of MS - published in 2008 as a joint project by the MS International Federation (MSIF) and the World Health Organization - was one of the most cited global resources on MS. The 2013 edition has been used to inform research initiatives as well as for campaigning and advocacy.

Together with our international working group, panel of expert advisors and our epidemiology partner McKing Consulting Corporation, we have strived to improve the volume, reach and accuracy of the data in this 3rd edition. Additionally, we have focused on making the data more accessible by improving the website as well as providing extra materials such as country factsheets. This edition of the Atlas collected data around the following themes:

- **Epidemiology of MS:** focuses on the number of people with MS, how this varies across the globe, as well as demographic data such as age and gender.

- **Clinical management of MS:** looks at the clinical management of MS and places particular emphasis on the barriers to accessing healthcare and disease modifying treatments.

This report presents the key epidemiological findings. The clinical management data will be available in early 2021 – sign up on the website to be notified of its release (www.atlasofms.org).

What is epidemiology?

Epidemiology is the study of the number of people affected by a condition and how it varies across different groups of people (demographics, regions, nations). It is also used to illuminate risk factors and changes over time.

Two common epidemiological terms are prevalence and incidence:

- **Prevalence** is the number of people who are living with a condition. This can be shown as the estimated number of people or as the number per 100,000 people.

- **Incidence** refers to the number of new cases of a condition diagnosed within a set period of time, normally the number of people diagnosed in a year.

Summary of key findings

There are **2.8 million people** living with MS around the globe. This is our most accurate and up-to-date estimate of the number of people living with MS worldwide.

This equates to **1 in 3,000 people** in the world living with MS. In countries with the highest prevalence, as many as **1 in every 300** people have MS.

The estimated number of people with MS globally has **increased from 2.3 million** people in 2013.

Several factors are likely to be contributing to the increase, including: better counting methods nationally and globally as well as improved diagnosis, people with MS living longer and global population growth. However, from the data available we cannot rule out that there may also be some increase in the risk of developing MS.

Every 5 minutes, someone, somewhere in the world is diagnosed with MS[1].

Although the number of people with MS has increased, gender and age at diagnosis remain similar to those seen in the 2013 Atlas of MS, as does the regional distribution around the globe.

MS not only affects adults - there are at least **30,000 people** living with MS who are **under 18**[2]. This number is considerably higher than reported in 2013. It likely reflects a number of childhood MS prevalence studies that have been completed since then and more countries reporting data rather than an increased incidence of MS amongst children.

Data quality has improved. Experts from **84% of countries** were able to cite peer-reviewed publications, MS registries or electronic health records as their source of prevalence data, compared to 71% in 2013.

Availability of high quality epidemiological data varies considerably across the world and despite improvements in the number of countries reporting data to the Atlas, there are still big gaps in our evidence on MS globally.

[2] Pediatric data is limited worldwide – only 47 countries provided this data

Recommendations

The Atlas of MS is a powerful tool to raise awareness and drive change that improves the quality of life for people affected by MS across the globe. We call on governments, policy makers, healthcare professionals and the MS movement to make the most of this open-data resource by:

1 Using and updating the statistics in the Atlas, to discover new insight, stimulate additional research, raise awareness of MS and support evidence-based advocacy efforts.

2 Implementing systematic evidence collection in countries where there are gaps, particularly in low and lower middle income countries, to enable a more comprehensive understanding of the epidemiology of MS at the country, regional and global level.

3 Prioritising the collection of incidence data to better understand the future trajectory of MS cases and plan healthcare resources for diagnosis and treatment accordingly.

4 Recognising that some groups of the population are disproportionally affected by MS (females and young adults) and ensuring that this is accounted for as part of healthcare and support systems.

5 Improving awareness that children and young people can develop MS. Enhance steps to collect data on pediatric cases as well as ensuring they have access to prompt diagnosis, the relevant treatments, specialist healthcare professionals as well as sufficient support for those affected and their families.

6 Funding and implementing research projects to investigate how genetics, environments and other factors increase people's chances of developing MS and identifying interventions that could prevent or delay onset.

Using epidemiology data as an advocacy tool

A recent epidemiological study led by the National MS Society (NMSS) showed the number of people with MS in the United States was nearly **1 million people (913,925)**. This was **more than twice** the previously reported number from a national study in 1975 and subsequent updates.

NMSS has successfully leveraged this revised prevalence estimate to increase investment in MS research and improve MS data collection at a national level. Here are two of the successes this data-driven advocacy has had so far:

- The U.S. Congress increased investment in MS research at the Department of Defense by **$10 million USD** and the House of Representatives has earmarked a possible further increase to **$20 million USD** for the programme in 2021.

- The U.S. Centers for Disease Control and Prevention (CDC) established and funded the National Neurological Conditions Surveillance System. The CDC launched 2 pilot programmes, one in MS and one in Parkinson's Disease, to identify U.S. incidence and prevalence for those diseases.

Methodology

The 3rd edition of the Atlas of MS is an ambitious project. We sought to make several improvements on the 2013 publication: broadening the reach by including new countries, achieving greater population coverage, and increasing confidence in the data and accuracy of the global prevalence estimate. As well as improving the accessibility and usability of the statistics.

To help with this ambition, we recruited a working group and panel of expert advisors to help guide the project, the questionnaire design and analysis, ensuring our advice was wide reaching across different parts of the globe. Furthermore, we partnered with epidemiology experts McKing Consulting Corporation in the US, to ensure the highest quality data collection and analysis approaches underpinned the project.

The Atlas working group

The working group consisted of representatives from 13 MSIF members across 12 countries, covering 5 of the 6 WHO regions.

The Atlas expert advisors

A panel of 10 expert advisors who brought epidemiological, clinical and access expertise from 9 countries in the European, Americas and Western Pacific WHO regions.

Data collection and response rates

Data was collected via an international online survey completed by experts in participating countries between September 2019 and March 2020. English, Spanish, French and PDF versions of the survey were available to encourage greater response rates and to encourage collaboration with other national experts.

The epidemiology questionnaire covered a wide range of data points: prevalence, incidence, mean age of diagnosis, type of MS and patient registries. It was piloted prior to launch to test clarity, understanding and ease of completion.

138 countries[3] enrolled to take part in the Atlas of MS 3rd edition. Country coordinators were identified in each of these countries to be the focal point for gathering the relevant information; typically, they were representatives from MS organisations, neurologists, epidemiologists or researchers. Contacts were identified through MSIF's network of MS organisations (members and non-members), our International Medical and Scientific Board, International Working Group on Access, previous Atlas contacts, the World Federation of Neurology, the Atlas working group and expert advisors, the various regional International Committees for the Treatment and Research in Multiple Sclerosis (TRIMS) as well as from scientific literature. We thank everyone who was involved and helped us achieve a wider reach in this edition.

80 countries did not have an identified coordinator or did not agree to participate – these tended to be countries with small populations, without MS organisations or where neurologists could not be identified.

Country coordinators were asked to complete the questionnaire, making use of all possible sources of information available to them and collaborating with other experts in the country where possible/necessary. A glossary of terms was provided to improve the uniformity and comparability of the information received.

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[3] The word 'countries' is used throughout to reference the 218 countries/territories that were recognised by this project (combining members of the United Nations (UN), the World Health Organization (WHO) and the World Bank).

Experts in 115 countries responded (a response rate of 83%) including 9 countries[4] that reported in 2008 but not 2013 and 14 countries from which data was reported to the Atlas of MS for the first time (Bhutan, Burundi, Cape Verdi, Central Africa Republic, Djibouti, Kosovo, Kyrgyzstan, Lao, Nepal, Niger, Puerto Rico, Sudan, Timor-Leste, Togo). Additionally there were 14[5] countries that provided data in 2013 but not for this latest edition.

The map below shows the countries from which data was reported (in orange).

● Countries that provided epidemoilogy data for the Atlas of MS 3rd Edition

Created with mapchart.net ©

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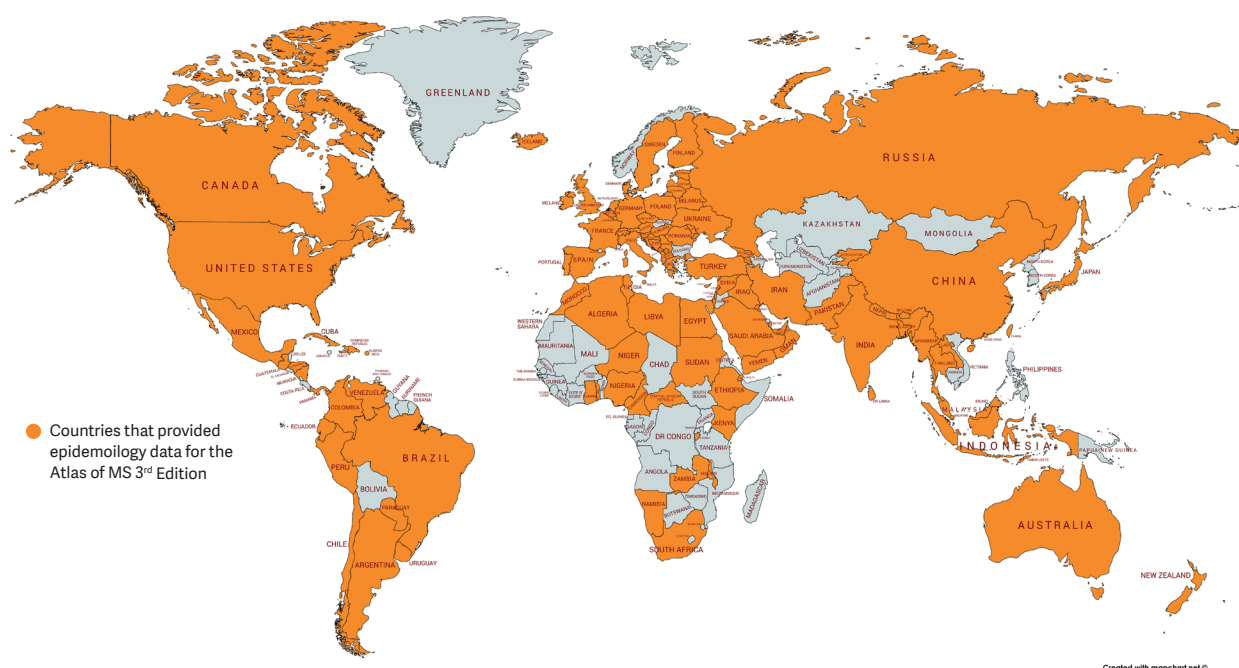
4 9 countries took part in 2008 but not 2013 (Belarus, Chile, Georgia, Haiti, Honduras, Hong Kong, Namibia, Syrian Arab Republic and Ukraine)

5 14 countries reported in 2013 but not in 2020 (Bahrain, Bolivia, Bulgaria, Costa Rica, Core d'Ivoire, Democratic Republic of the Congo, Guinea, Jordan, Liechtenstein, Mongolia, Norway, the Republic of Korea, Slovakia and Zimbabwe)

Regional analysis

Countries were grouped into the six World Health Organization (WHO) regions (Africa, the Americas, Eastern Mediterranean, Europe, South-East Asia and Western Pacific) and four World Bank income levels (High, Upper Middle, Lower Middle and Low).

Population data from the 2019 UN population prospects was used for the analyses. The data was analysed using MS Excel.

The World Health Organization (WHO) regions

WHO regions
- Africa
- Americas
- Eastern Mediterranean
- Europe
- South-East Asia
- Western Pacific
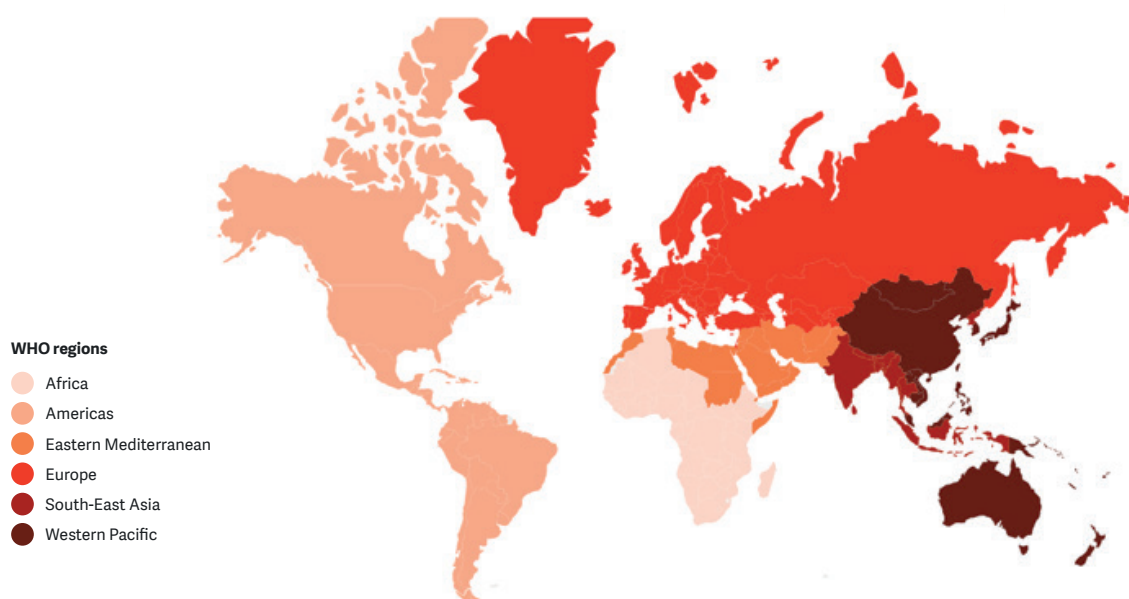
World Bank Income (June 2019)

World Bank Income
- Low income
- Lower middle income
- Upper middle income
- High income
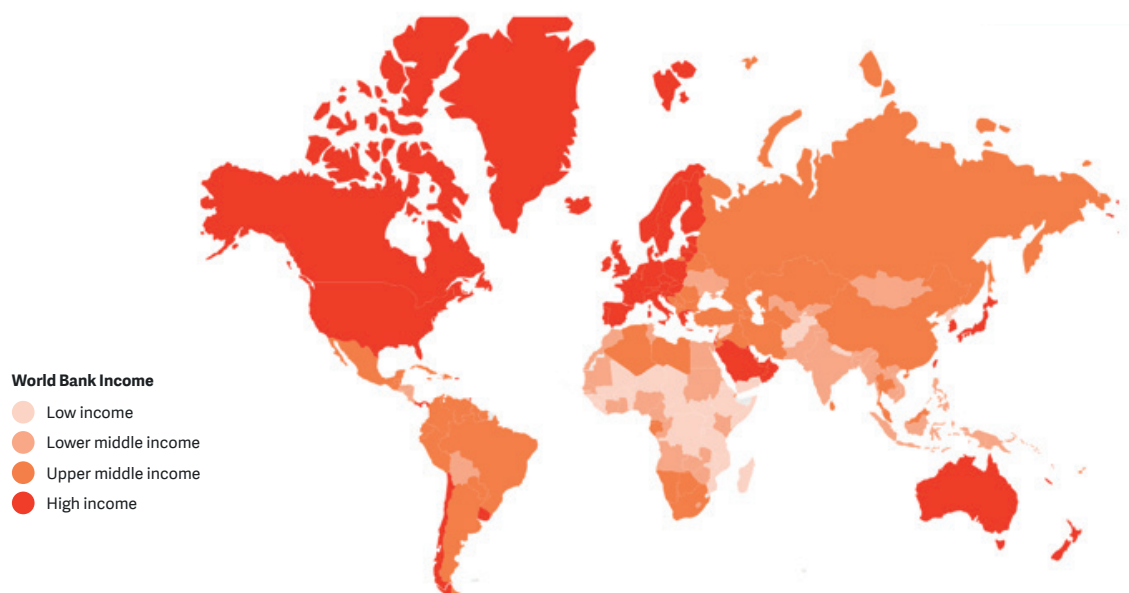
Representativeness and data quality

115 countries took part in the Atlas epidemiology survey. These countries represented 87% of the world population.
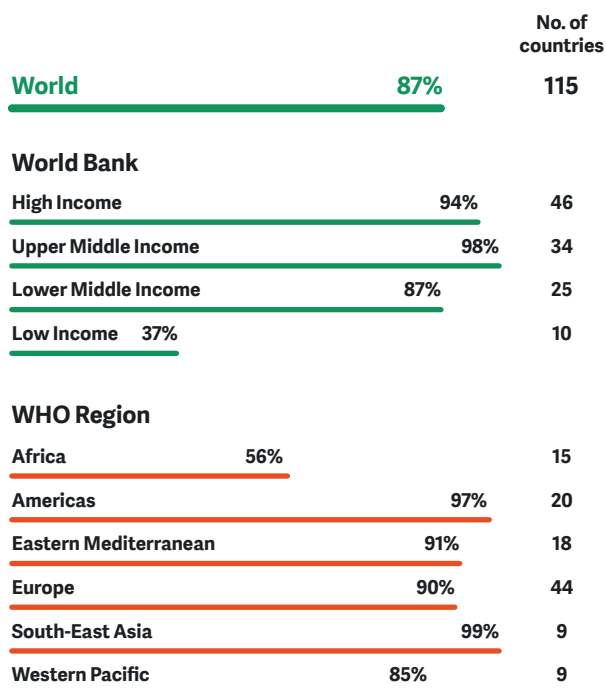
A high proportion of the population was represented within each of the World Bank Income categories and the WHO regions with the exception of the African region and the low income countries.

Positively we also see a trend of increased reporting for most epidemiology statistics compared to 2013.
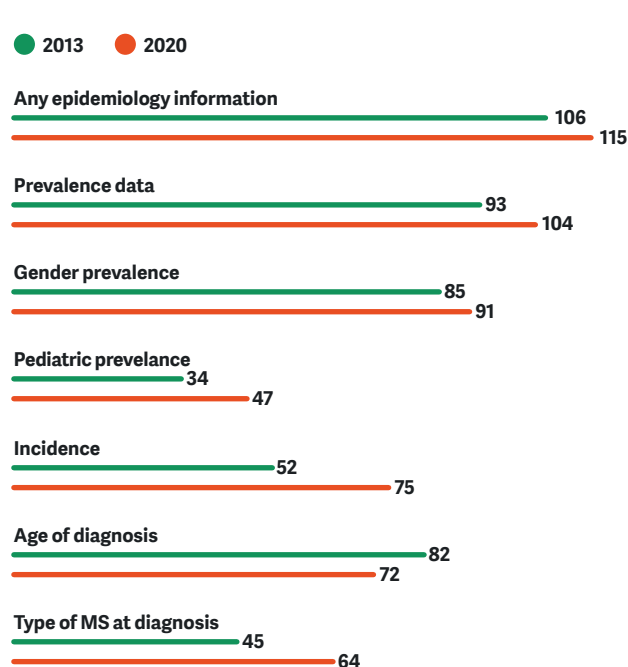
The largest uplifts are for pediatric prevalence, incidence and type of MS at diagnosis.

The only exception is for the average age of diagnosis where the number of reporting countries has gone down.

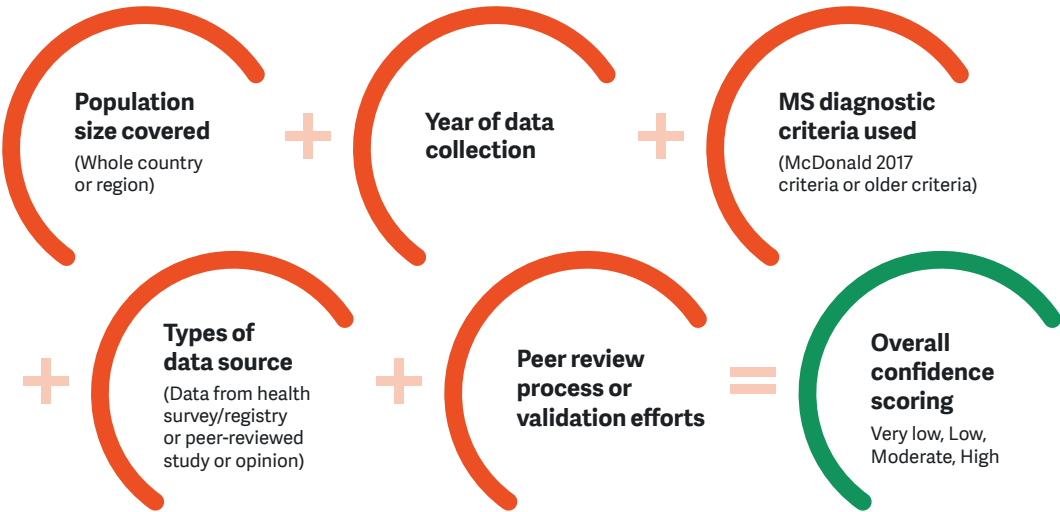## Proportion of population covered by countries providing data

		No. of countries
World	**87%**	**115**
World Bank		
High Income	94%	46
Upper Middle Income	98%	34
Lower Middle Income	87%	25
Low Income	37%	10
WHO Region		
Africa	56%	15
Americas	97%	20
Eastern Mediterranean	91%	18
Europe	90%	44
South-East Asia	99%	9
Western Pacific	85%	9

Number of countries providing each type of data

● 2013   ● 2020

	2013	2020
Any epidemiology information	106	115
Prevalence data	93	104
Gender prevalence	85	91
Pediatric prevalence	34	47
Incidence	52	75
Age of diagnosis	82	72
Type of MS at diagnosis	45	64

The **quality** of the data provided has also improved. Experts in 84% of countries provided evidence to support their prevalence data compared to 71% in 2013. Positively, 57% cited the gold standard of a peer-reviewed academic study (an uplift on the 51% seen in 2013). Additionally, experts in most countries (67%) referenced data collected recently (2017-2019) with 2019 being the most common year cited.

Despite the significant improvements, however, there are still substantial gaps in our knowledge, which need to be addressed to understand the true dimensions of MS. In order to measure the availability of high quality epidemiological evidence around the globe, we developed a confidence tool to assess the strength of the data sources, rating them as either very low, low, moderate or high. This helps to highlight where there are data inadequacies and to encourage systematic data gathering and surveillance in all countries across the globe.

The factors driving the confidence scoring are shown below:

Population size covered
(Whole country or region)

+

Year of data collection

+

MS diagnostic criteria used
(McDonald 2017 criteria or older criteria)

+

Types of data source
(Data from health survey/registry or peer-reviewed study or opinion)

+

Peer review process or validation efforts

=

Overall confidence scoring
Very low, Low, Moderate, High

Globally, 54% of the experts had access to prevalence source evidence that rated as high (20%) or moderate (34%) on our confidence tool. 29% referenced sources rated as low (23%) or very low (6%), whilst 8% lacked prevalence evidence and 10% were unable to provide prevalence data.

There was limited access to evidence in the African and South-East Asia regions, with 33% and 56% of the country experts in these regions saying there was no prevalence data available.
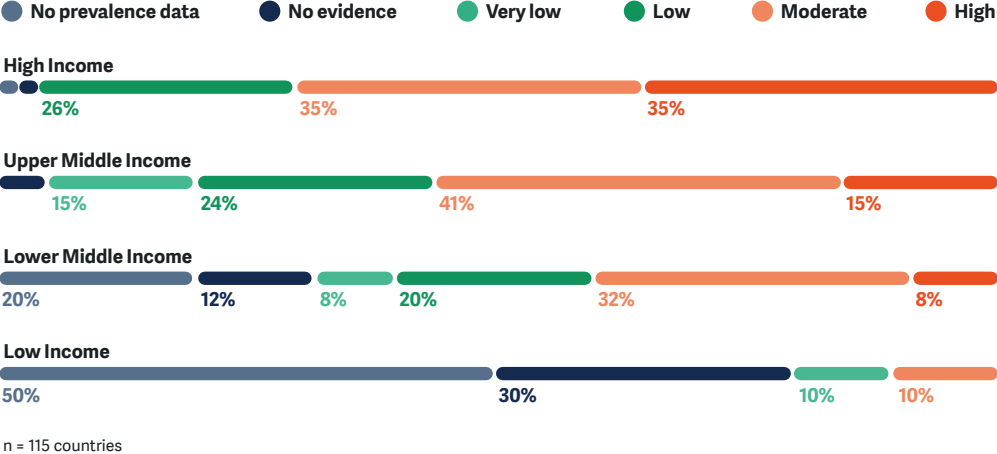
Prevalence evidence confidence coding - WHO region

● No prevalence data   ● No evidence   ● Very low   ● Low   ● Moderate   ● High

Western Pacific
22%   56%   22%

Eastern Mediterranean
17%   6%   6%   44%   28%

Americas
5%   5%   20%   50%   20%

Europe
9%   34%   27%   25%

South-East Asia
56%   22%   11%   11%

Africa
33%   27%   7%   13%   20%

n = 115 countries

14

Looking at this by World Bank income levels, there is a clear trend towards more and higher quality data sources as you move from low through to high income countries.

Prevelence evidence confidence coding - World Bank Income

● No prevalence data ● No evidence ● Very low ● Low ● Moderate ● High

High Income

26% 35% 35%

Upper Middle Income

15% 24% 41% 15%

Lower Middle Income

20% 12% 8% 20% 32% 8%

Low Income

50% 30% 10% 10%

n = 115 countries

On average, prevalence sources scored higher on the confidence tool than sources providing incidence and other epidemiological data.

The gaps in evidence make it difficult to fully understand how MS varies across the globe. The MSIF movement calls on governments, health professionals, patient organisations and others to improve the collection of MS data. This evidence is important to inform healthcare provision, pharmacovigilance, and legislation and help to demonstrate the true global burden of MS.

A new methodology for calculating the global prevalence number

To calculate the worldwide prevalence estimate, prevalence data was required from each country and population in the world. In total, 218 countries were recognised by this project, and an additional 20 populations/territories were identified to account for the 2019 world population of 7.7 billion. The additional populations included transient populations such as expats and refugees in Qatar and Lebanon, as well as small territories such as Martinique, Réunion and Guadeloupe.

Experts in 104 countries, representing 83% of the global population, reported prevalence data, an increase from 92 countries (79%) in 2013. Combining the data submitted from these countries provided a global total of 2.6 million people with MS. However, we were missing data from countries representing 17% of the global population. In order to fill the gaps we searched for published data available for the missing countries

Literature review
(16 countries)

+

Consulted the 2013 Atlas
(3 countries)

=

Generated data for another 19 countries
(2% of the global population)

After completing a literature review for published data sources and consulting the 2013 Atlas, we still had prevalence data missing for 95 countries and 20 populations representing 15% of the global population. Recognising that most of these data gaps were from regions of the world that had lower MS prevalence, we factored this into our calculation methods, thereby improving the accuracy of our estimation.

In our analysis, we grouped the 123 countries, where experts had provided prevalence data or where we had found the data, into 15 geographically diverse sub-regions, based on the Global Health Data Exchange (GHDx)[6]. The prevalence data from these 123 countries was used to calculate the number of people with MS per 100,000 for each sub-region. The appropriate sub-region prevalence was applied to the missing countries/populations to determine an estimated number of people with MS for each of the countries/populations where we had gaps.

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[6] The GHDx consists of 21 sub-regions. We combined some of these due to lack of data. We used 15 regions, grouping the 4 Sub-Saharan African regions together (Western, Southern, Eastern and Central) and created a new Western Pacific sub-region, which combined Australasia, High Income Asia Pacific and South-East Asia

The estimated number of people with MS in populations where data was missing were added to the 2.6 million figure calculated from the 123 countries where data was reported or gathered. This provided a global estimate of **2.8 million** people with MS.

Prevalence data was used to calculate the number of people with MS per 100,000 for each sub-region

Sub-region prevalance applied to the missing populations to determine the number of people with MS in populations /countries where data was not available

The missing population estimates were added to the 2.6 million figure calcuated from the reported/gathered data from 123 countries, providing a global estimate of **2.8 million people**

A snapshot of some of the people with MS from around the world who feature in the 'Global faces of MS' video.

Limitations

The Atlas of MS is one of the most accurate global data sources on the epidemiology of MS, but it still has some limitations.

In the majority of countries, the data was provided by a single contact:

- In 71 countries out of the 115 answering the epidemiology survey, a single key person provided the information. Although most people had access to numerous official and unofficial sources of information and were able to consult other experts in the country, others were only able to provide best estimates.

- In spite of these limitations, the data should be still be considered as reasonably, but not completely, reliable and accurate.

- We developed a confidence-coding tool to measure the strength of the evidence provided and to improve confidence in the reported data.

Direct comparisons with previous data are difficult:

- Our global prevalence calculation methods have varied across editions as we strive to improve the accuracy.

- The number of countries participating varies, as does the proportion of the population covered in each region/income band.

Although there are improvements in the number of countries providing data, there are still significant gaps in our knowledge. We hope that the Atlas of MS will stimulate new and rigorous surveillance within countries and across the globe.

- The Atlas of MS lacks data from the African region and low income countries.

- Not all responding countries were able to provide the key data; the largest gaps centre around data for incidence, disease type and pediatric data – but even for prevalence, where we had the most comprehensive data reported, only 104 countries out of 115 responding countries provided data.

- The quality of the data is also variable. Some countries have limited information – or only have fragmented data (by region, or hospital/clinic) or lack up-to-date statistics. Methodologies for epidemiology studies also vary which makes comparison between countries and regions difficult.

- Even within countries, studies calculating prevalence and incidence are not always conducted with consistent methodologies or over the same time period, which can make it difficult to compare.

Main findings

The number of people with MS around the world (prevalence of MS)

2.8m

There are **2.8 million** people living with MS in the world

1 in 3,000

This means that **1 in every 3,000** people worldwide has MS

2.3m ↑

Global prevalence has increased since the estimate of **2.3 million in 2013**

↑

Prevalence has increased in **all WHO regions** since 2013
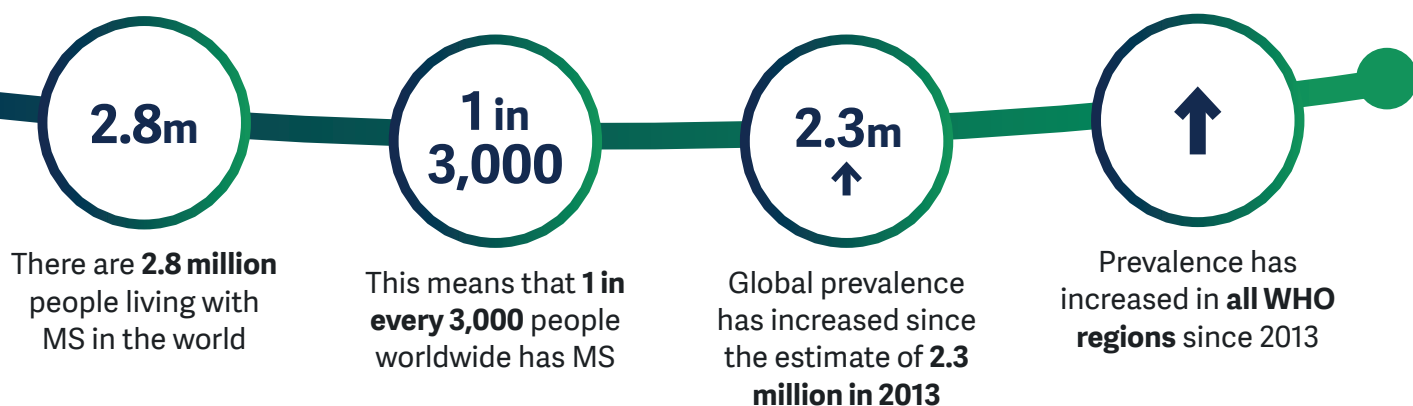
The global prevalence of MS is estimated at 36 people per 100,000[7] people, which means there are 2.8 million people living with MS worldwide. This equates to 1 in every 3,000 people living with the disease.

This global estimate has increased from 2.3 million people in 2013, which is consistent with stated increases in national prevalence in some countries[8] over this time.

The literature points to several factors that are likely to play an important role in explaining the increase, including improvements in counting methods nationally and globally since 2013, as well as better diagnosis[9], people with MS living longer[10] and global population growth (9%[11] since 2013).

These factors are supported by the country experts who were asked to indicate possible causes for change in their prevalence estimates since 2013. The three most common reasons provided by 73 country experts were:

- **An improvement in MS diagnosis (60%)**

- **Improved MS treatment and support (56%)**

- **Improved ability to count the numbers of people with MS (53%)**

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7   A 95% confidence interval was calculated around our estimated prevalence figure of 35.91 and we can be 95% confident that the estimated prevalence is between 35.87 and 35.95 per 100,000

8   A UK study in 2018, showed an increase of 30% - MS Society UK, MS Prevalence Report January 2020. URL: www.mssociety.org.uk/care-and-support/resources-and-publications/publications-search/ms-in-the-uk and a US study has shown estimates double: Wallin M, et al, The prevalence of MS in the United States - A population-based estimate using health claims data, Neurology. March 2019, 92 (10) e1029-e1040; doi: 10.1212/WNL.0000000000007035 https://n.neurology.org/content/92/10/e1029. Additionally, the EMSP's European Multiple Sclerosis' Barometer of MS has reported interim results showing a 35% increase in the number of people with MS in Europe since 2017. The data when finalised will be published here: www.emsp.org/projects/ms-barometer

9   Schwenkenbecher P, Wurster U, Konen FF, et al. Impact of the McDonald Criteria 2017 on Early Diagnosis of Relapsing-Remitting Multiple Sclerosis. Front Neurol. March 2019:10:188. doi:10.3389/fneur.2019.00188

10 Kingwell E, Leray E, Zhu F, Petkau J, Edan J, Oger J, Tremlett H, Multiple sclerosis: effect of beta interferon treatment on survival, Brain, Volume 142, Issue 5, May 2019:1324–1333, https://doi.org/10.1093/brain/awz055

11 Global population used in the 2013 Atlas was 7,080,072,000 (UN projections for 2013 medium growth) vs. 7,713,468,205 (2019 UN population prospects)

Comparing the global number with the 2013 estimate

In 2013, the global estimate of 2.3 million people was derived from a more simplistic calculation. The median prevalence per 100,000 people for the world was calculated from the country data provided, and was used to estimate the number of people with MS living in countries where prevalence data was missing.

If we were to use this same methodology for 2020 we would estimate 3 million people to be living with MS globally; an increase of 30% since 2013. This figure is higher than our current estimate, because our new calculation takes into account that the gaps in our data collection centre around lower prevalence regions such as Central Asia and Africa. Applying the median prevalence to these countries would therefore inflate the estimates.

It is important to recognise that whatever calculation method is used to determine the global number of people with MS, it is likely to be an underestimate due to the lack of up-to-date or complete surveillance data, the complexities of diagnosis and other inequalities and barriers to accessing healthcare.
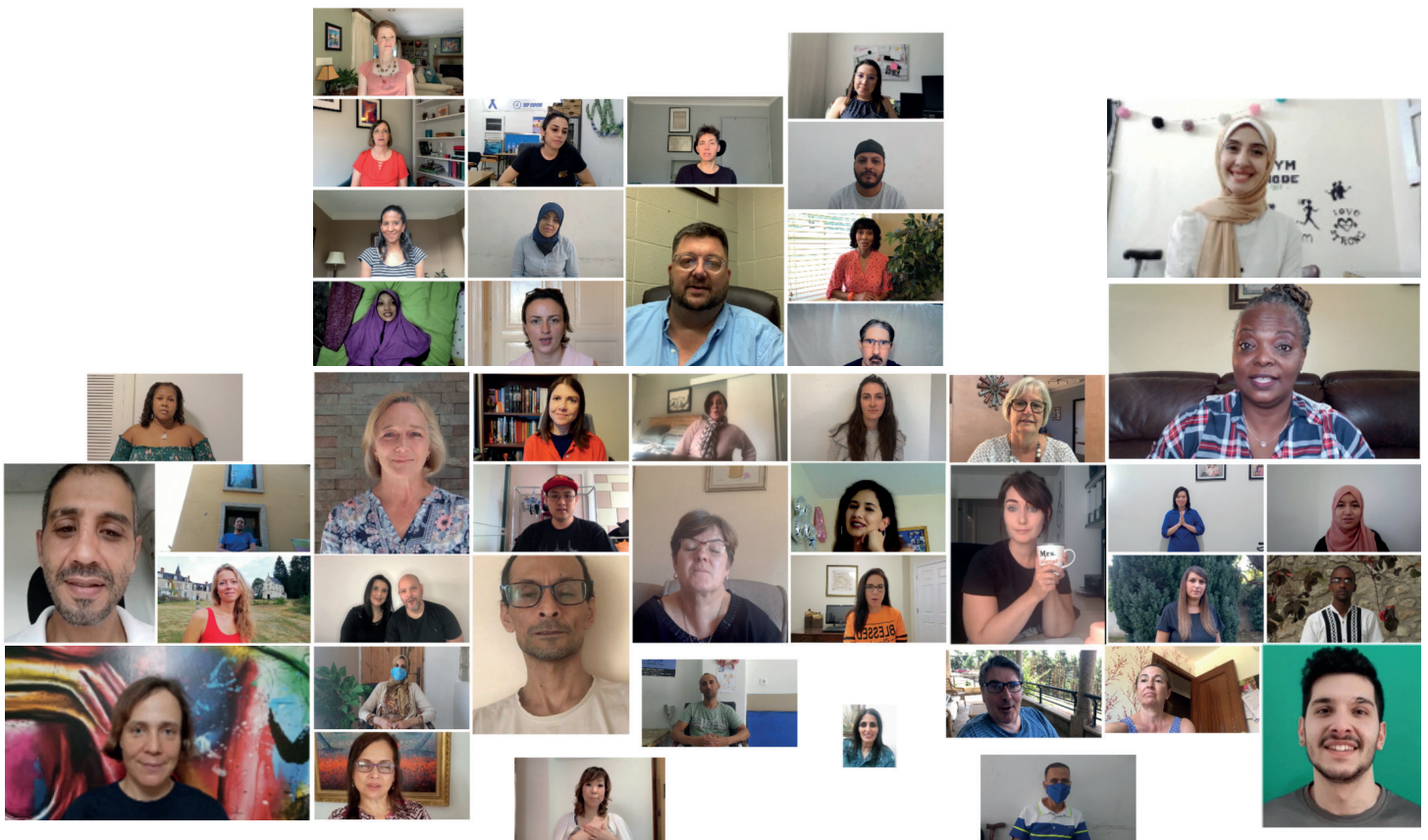
A snapshot of some of the people with MS from around the world who feature in the 'Global faces of MS' video.

The prevalence of MS varies considerably around the world

We have calculated the number of people living with MS as a prevalence number per 100,000 people. This allows comparison between nations and regions irrespective of their population size. The estimate of 2.8 million people living with MS around the world is represented by the prevalence of 36 per 100,000 people.

In line with previous editions of the Atlas, MS is present in all regions of the world but is noticeably higher in the European and Americas regions.

There are some limitations in being able to compare prevalence across diverse and different populations with confidence. Nevertheless, prevalence clearly varies considerably within regions. For example, in the European region, San Marino (337 per 100,000), Germany (303 per 100,000) and Denmark (282 per 100,000) have the highest levels of people with MS. In fact San Marino and Germany have the highest prevalence in the world, followed by the USA (288 per 100,000). In contrast, there are several countries with prevalence figures below 40 per 100,000 in the European region.

Number of people with MS (per 100,000) - WHO region

Region	
Europe	**133**
Americas	**112**
Eastern Mediterranean	**30**
South-East Asia	**9**
Africa	**5**
Western Pacific	**5**

Global = 36

Limitations of comparing prevalence are due to a multitude of factors including: different ethnic and demographic profiles of countries as well as barriers to diagnosis, differences in the epidemiological study methodologies (choice of diagnostic criteria, year of collection and the size of the population included in the study).

When we compare a sub-set of our data focusing on the 81 countries from which prevalence data was provided in both the 2013 and 2020 editions of the Atlas, we see increasing prevalence in all 6 WHO regions. The greatest uplift is in the Americas region, which has almost doubled. In fact, 86% of the 81 countries reporting at both time points have increasing prevalence. Supporting this finding, many countries have published new epidemiological studies that have uncovered increases in the prevalence of MS, primarily due to better counting methods, increased awareness and improved diagnosis.

A few notable examples where the reported prevalence has doubled or even tripled include: Argentina, China, Egypt, Germany, Iraq, Israel, Libya, the Palestinian Authority, Serbia, Sri-Lanka, Thailand and the United States.

Number of people with MS (per 100,000) - comparison of a sub-set of countries from which data was provided at both time-points

● 2013   ● 2020

Global
29
44

Europe
108
143

Americas
63
118

Eastern Mediterranean
24
33

South-East Asia
5
9

Africa
6
9

Western Pacific
4
5

Data based on 81 countries that provided prevalence data for both 2013 and 2020

Several studies have shown the prevalence of MS has a link with latitude[12], with people living in countries closer to the equator being at lower risk of MS, whilst those living in countries at higher latitudes (closer to the north/south poles) being at greater risk. It is thought that people who live in higher geographical latitudes may receive lower levels of sunlight, and therefore have lower vitamin D levels, which may explain the latitude relationship. The data reported to the Atlas and shown visually in the map below supports this.

Number of people with MS - prevalence per 100,000 people

Number of people with MS, Prevalence per 100,000 people

- Unknown
- 0 - 25
- 26 - 50
- 51 - 100
- 101 - 200
- > 200
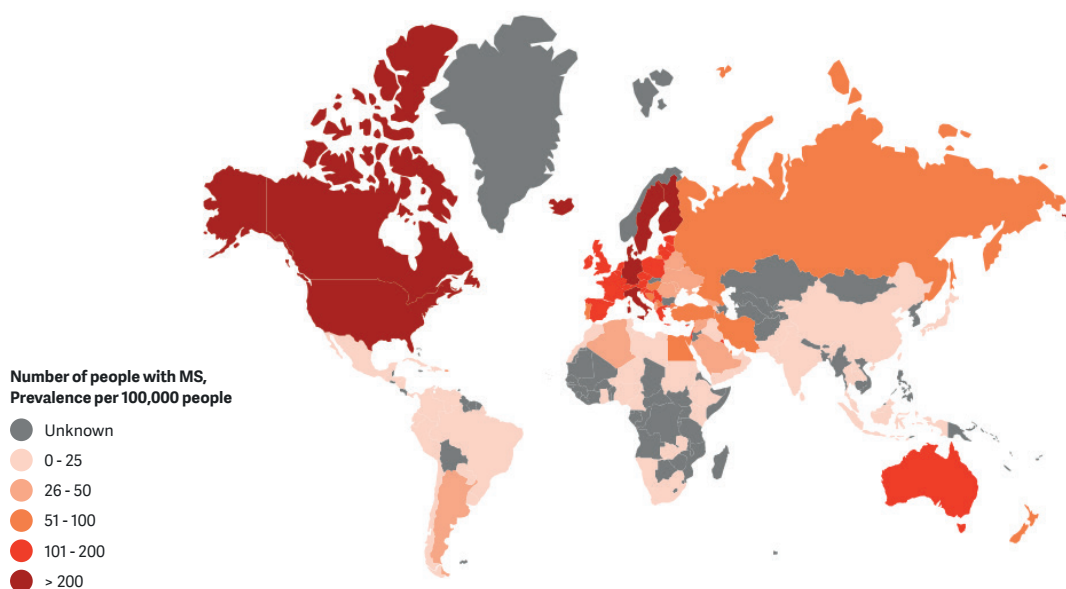
This latitude effect is also seen within many countries. For example, in Australia[13], people living in the southern most part of the country (and furthest away from the equator) - Tasmania - are almost twice as likely to develop MS than those in the northern state of Queensland (139 per 100,000 people in Tasmania compared with 75 per 100,000 for Queensland).

12 Simpson S Jr, Wang W, Otahal P, Blizzard L, van der Mei IAF, Taylor BV. Latitude continues to be significantly associated with the prevalence of multiple sclerosis: an updated meta-analysis. J Neurol Neurosurg Psychiatry. 2019: 90(11):1193-1200. doi:10.1136/jnnp-2018-320189 https://pubmed.ncbi.nlm.nih.gov/31217172/

Tao C, Simpson S, van der Mei I on behalf of the MSBase Study Group, et al, Higher latitude is significantly associated with an earlier age of disease onset in multiple sclerosis. Journal of Neurology, Neurosurgery & Psychiatry. 2016:87:1343-1349. http://dx.org/10.1136/jnnp-2016-314013

13 MS Research Australia, Health Economic Impact of MS in Australia 2017. 2017:15. URL: www.msra.org.au/wp-content/uploads/2018/08/health-economic-impact-of-ms-in-australia-in-2017_ms-research-australia_web.pdf

Who gets MS and how does this vary across the globe?

Gender

As shown in the previous Atlas editions, there are **at least twice as many females** (69%) with MS as there are males (31%).

This skew towards females is even greater in the Western Pacific and South-East Asia regions where there are more than three times as many females to males.

Within regions, there is variation in the gender ratio. For example in the Eastern Mediterranean region, the average ratio is 2 females to every male but there are several countries where females with MS outnumber males on a ratio of 3 or even 4 to 1. Examples include: Egypt, Iran, the Palestinian Authority and Sudan.

In some countries, this gender skew is increasing. For example, in Egypt and the Palestinian Authority, the proportion of females has doubled since reporting in 2013.

Percentage of people with MS who are female - WHO region

Region	Percentage
Western Pacific	**78%**
South-East Asia	**76%**
Americas	**71%**
Europe	**69%**
Africa	**67%**
Eastern Mediterranean	**66%**

n = 91 countries,
% of population represented by reporting countries (Western Pacific 85%, SE Asia 89%, Americas 96%, Europe 85%, Africa 31%, Eastern Mediterranean 60%)

The reasons for the difference in risk between males and females are unknown but a variety of factors are likely to be influencing it such as hormonal[14] and genetic[15] differences, as well as differing social, lifestyle and environmental exposures between the sexes.

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[14] Russi AE, Ebel ME, Yang Y, Brown MA, IL-33 and sex-dimorphic immune responses. Proceedings of the National Academy of Sciences. Feb 2018:115 (7) E1520-E1529; doi: 10.1073/pnas.1710401115 https://www.pnas.org/content/115/7/E1520.short?rss=1

[15] Voskuhl RR, Sawalha AH, Itoh Y. Sex chromosome contributions to sex differences in multiple sclerosis susceptibility and progression. Multiple Sclerosis. 2018:24(1):22-31. doi:10.1177/1352458517737394 https://pubmed.ncbi.nlm.nih.gov/29307297

- More research is needed to understand how genetics, environment and other factors increase a woman's chances of developing MS - this could potentially reveal new ways to treat or even prevent MS.

- It is important that national healthcare systems, registries, researchers and MS organisations collect data by gender to help provide real-world evidence on these differences.

- It is vital that if any gender inequalities and barriers[16] to accessing healthcare within countries exist, they are reviewed to ensure that females have access to prompt and affordable diagnosis and treatment.

Age

MS can occur at any age, but the average age of an MS diagnosis globally is 32 years. There is no cure for MS, which means that people are living with the disease for many decades. This differentiates MS from other neurological conditions such as dementia and stroke, which predominantly affect people later in their lives (aged 65 years or more[17]). MS is the most common neurological cause of disability for young adults.

The average age of diagnosis is relatively consistent across the regions of the world (ranging from 30-33 years across the six WHO regions). However, we see greater variation in the average age of diagnosis across individual countries, ranging from 20 years up to 50 years. This is another aspect where data is lacking, with only 72 countries providing data.

- As this is an age where many people might be finding a long-term partner, having children, and forging careers, it is important that support mechanisms are available (financial, social, legislation) to enable people with MS to achieve good quality of life.

- It is important that governments, national healthcare systems, employers and legislation enable people with MS to achieve a quality of life. This includes diagnosing and treating the disease early to stave off relapses, and prevent progression of disability, alongside protective legislation to enable people to access affordable treatment as well as remain in employment.

[16] Gender inequalities in accessing healthcare exist in many countries as illustrated by these two different examples: 1) Socías ME, Koehoorn M, Shoveller J, Gender Inequalities in Access to Health Care among Adults Living in British Columbia, Canada. Women's Health Issues. Sept 2015. https://doi.org/10.1016/j.whi.2015.08.001, 2) Kapoor M, Agrawal D, Ravi S, et al Missing female patients: an observational analysis of sex ratio among outpatients in a referral tertiary care public hospital in India. BMJ Open. 2019;9:e026850. doi: 10.1136/bmjopen-2018-026850 https://www.bmj.com/company/newsroom/extensive-gender-discrimination-in-healthcare-access-for-women-in-india/

[17] https://www.alz.co.uk/info/faq#:~:text=Up%20to%20the%20age%20of,to%201%20person%20in%205. Dementia primarily affects older people. Up to the age of 65, dementia develops in only about 1 person in 1000. The chance of having the condition rises sharply with age to 1 person in 20 over the age of 65. Over the age of 80, this figure increases to 1 person in 5. https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2017_final_1.pdf In England, Wales & Northern Ireland the average age for men to have a stroke is 74 and the average age for women to have a stroke is 80

Children and MS

MS not only affects adults; at least **30,000 children and teenagers** under the age of 18 years are living with MS (1.5% of the total number of people with MS in the countries reporting pediatric prevalence data).

Although this is likely to be an underestimate due to a high proportion of countries being unable to provide data, this is an increase on the 7,000 reported in 2013. This is likely to be a reflection of a number of childhood prevalence studies[18] published since the previous Atlas edition.

Recognition and surveillance of pediatric MS appears to be increasing, with experts in 47 countries reporting this data compared to only 34 countries in 2013. However, there are still significant gaps in our understanding; only 20 experts were able to provide the pediatric prevalence per 100,000 people for their country. Calculating the number of children with MS brings additional challenges as they transition to become adults. Some children included in the reported prevalence figures may well now be over 18 years.

- These gaps in data need to be addressed to ensure we can more accurately estimate and understand the prevalence of MS amongst children and teenagers in the future.

Diagnosing MS in children is more challenging than in adults due to the frequency of other childhood disorders with similar symptoms and characteristics. Pediatricians may not be familiar with MS because they are not expecting to see it in children. Furthermore, under 18s have different treatment and support needs. The International Pediatric Multiple Sclerosis Study Group (IPMSSG) www.ipmssg.org is a network of adult and pediatric neurologists, researchers, and others. The group – which was funded by MSIF and our members for many years – aims to improve diagnosis and treatment of pediatric MS.

- We call on MS organisations, governments, and health systems to increase awareness of pediatric MS amongst the general public and healthcare professionals to enable prompt diagnosis and treatment as well as ensure that people under 18 with MS are not disadvantaged.

[18] Some example new studies include: a) Alroughani R, Akhtar S, Ahmed SF, Behbehani R, Al-Abkal J, Al-Hashel J. Incidence and prevalence of pediatric onset multiple sclerosis in Kuwait: 1994-2013. J Neurol Sci. 2015:353(1-2):107-110. doi:10.1016/j.jns.2015.04.025 b) Marrie RA, O'Mahony J, Maxwell C, Ling V, Yeh EA, Arnold DL, Bar-Or A, Banwell B, Incidence and prevalence of MS in children, A population-based study in Ontario, Canada, for the Canadian Pediatric Demyelinating Disease Network, Neurology Oct 2018, 91 (17) e1579-e1590; doi: 10.1212/WNL.0000000000006395

Types of MS

85% of people with MS around the globe are initially diagnosed with relapsing-remitting MS and 12% with progressive MS. The remaining 3% are given an unknown disease type on diagnosis. This pattern is consistent with that seen in the 2013 Atlas. Given the low number of experts providing this information (64 countries) and particularly the gaps in the African and Western Pacific regions (data only represents 11% and 5% of these populations respectively) it is not possible to comment on regional differences.

The International Advisory Committee on Clinical Trials of MS published a paper in 2013[19] highlighting the need to include descriptors to describe the 'activity' and 'progression' within the different types of MS. Neurologists in two-thirds (66%) of the 98 countries providing data, were using these additional descriptors. There was considerable variation by region however, with less than half of the reporting countries in the Americas and African regions using the descriptors, compared to almost universal use in the Eastern Mediterranean region.

Percentage of countries in each region where neurologists classify MS by activity and progression

Eastern Mediterranean **88%**

Europe **77%**

Western Pacific **67%**

South-East Asia **57%**

Americas **47%**
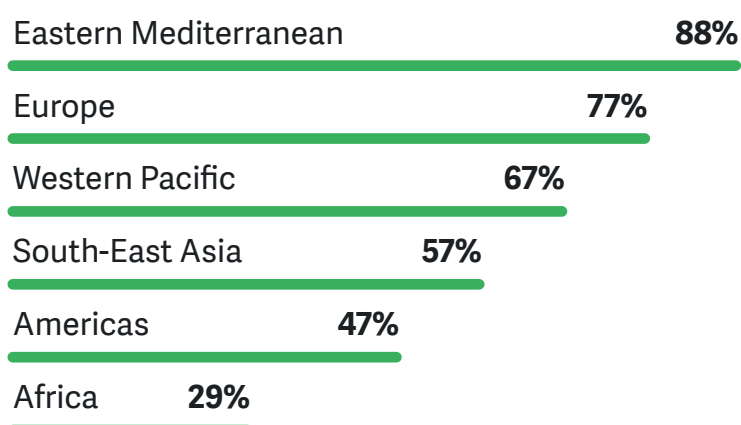
Africa **29%**

n = 98 countries,
% of population represented by reporting countries (Eastern Mediterranean 84%, Europe 71%, Western Pacific 85%, SE Asia 99%, Americas 96%, Africa 15%)

[19] Lublin FD, Reingold SC, Cohen JA, et al. Defining the clinical course of multiple sclerosis: the 2013 revisions. Neurology. 2014;83(3):278-286. doi:10.1212/WNL.0000000000000560. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4117366/

The number of new cases of MS diagnosed each year (incidence)

Incidence data is lacking in many countries across the globe – experts in only 75 countries were able to provide this data (65% of the 115 responding countries). Incidence data measures the number of new cases diagnosed in the country over a year and is therefore vital to help us understand if the risk of MS is increasing over time.

EVERY 5 minutes **someone, somewhere is diagnosed with MS**

107,000 people were diagnosed with MS per year across the 75 reporting countries. This equates to almost 300 people diagnosed each day, which means that every 5 minutes, someone, somewhere in the world is diagnosed with MS.

This incidence number is an underestimate, as we do not have data from every single country.

An average incidence rate of 2.1 per 100,000 people per year was calculated across the 75 reporting countries. This rate cannot be applied to the total global population due to the gaps in the data and the fact that incidence data is more likely to be reported in high-income and higher prevalence countries.

Positively, the number of countries with incidence statistics has increased since 2013 when experts in only 52 countries provided data. However, the inconsistency in the reporting countries, together with the lack of data in some regions, means that we cannot compare global incidence data over time. Additionally, incidence data has similar limitations to prevalence data, making it difficult to compare across countries or regions with confidence.

How common are national registries?

A new objective for the 3rd edition of the Atlas was to ascertain the availability of MS registries. The following descriptor was used to define registries: *'A registry is a systematic, ongoing collection of data to evaluate specified outcomes for a defined population in order to serve one or more predetermined scientific, clinical or policy purposes. Registries differ from studies in that the collection of data is ongoing rather than time-limited. However the data collected as part of registries may be utilised for individual studies.'*

37% of the 102 countries in which this question was answered, had a national registry covering the whole country, a further 14% had a registry covering a regional or local population. It must be noted that a national register does not necessarily include the whole population of people with MS in the country.

Perhaps not unexpectedly, registries are more prevalent in high-income countries. 52% had a national registry compared with 35% of upper middle income, 20% of lower middle income and 0% of the low income countries.

Across the regions, none of the countries in the South-East Asia region had registries compared to 20% and 22% of the African and Western Pacific regions. The regions with the highest proportion of countries with registries are the Americas (47%), Europe (46%) and Eastern Mediterranean (38%).

Percentage of countries in each category who have a national MS registry

Global   **37%**

World Bank

High Income   52%

Upper Middle Income   35%

Lower Middle Income   20%

Low Income   0%

WHO Region

Americas   47%

Europe   46%

Eastern Mediterranean   38%

Western Pacific   22%

Africa   20%

South-East Asia   0%
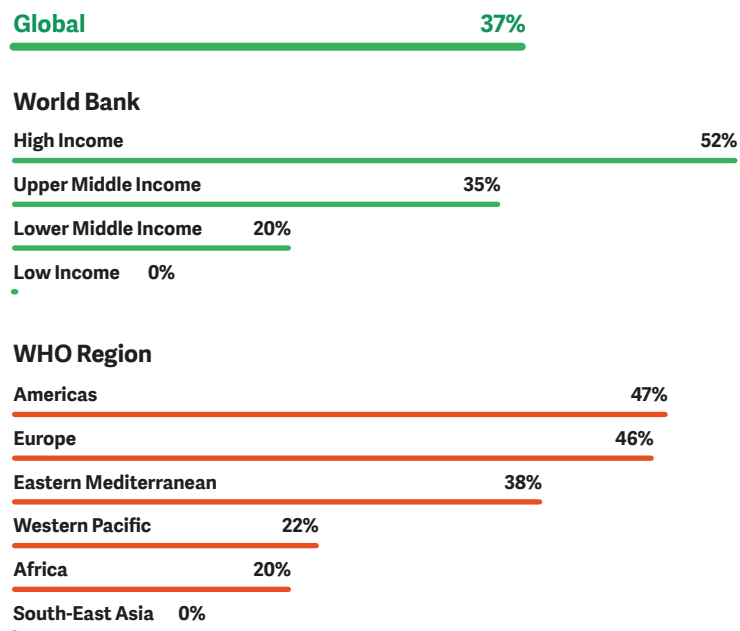
n = 102 countries,
% of population represented by reporting countries (High income 93%, Upper middle income 91%, Lower middle income 80%, Low income 15%, SE Asia 99%, America 96%, Western Pacific 85%, Eastern Mediterranean 84%, Europe 73%, Africa 19%)

Concluding remarks

The 3rd edition of the Atlas of MS brings increased rigour to the estimates of the number of people with MS around the world. Although we have seen improvements in the number of countries able to provide epidemiological data, we still have large gaps, particularly around incidence, pediatric data and in low income and African countries. This data is vital to help us understand whether MS is increasing and to have a better picture of how MS varies across the globe.

Additionally, robust epidemiological data is vital evidence to inform decision making regarding policies and healthcare interventions to best meet the needs of people with MS. It's also crucial for monitoring these interventions, such as the impact of new disease modifying therapies on disease progression.

We hope that the MS movement will use the data from the Atlas of MS to uncover new insights and to evidence advocacy efforts to ensure that people affected by MS can achieve good quality of life.

Our next report on the clinical management of MS looks at access to diagnosis, healthcare professionals and disease modifying treatments. We look forward to sharing this with you in early 2021. You can sign up to receive notifications of its release on the website (www.atlasofms.org).

Collaborators and acknowledgements

The Atlas of MS relies on extensive collaboration and support from MS organisations, clinicians, researchers, people affected by MS and other experts from around the world.

We are thankful to the Atlas of MS working group and expert advisors, who have been instrumental in guiding the development of the project, including the questionnaire, analysis and reporting:

Working Group

- María José Wuille-Bille (Argentina)
- Andrew Giles (Australia)
- Nora Kriauzaitè (Belgium)
- Benjamin Davis (Canada)
- Lasse Skovgaard (Denmark)
- Anna-Lena Roper (Germany)
- Renuka Malaker (India)
- Aoife Kirwan (Ireland)
- Prof. Mario Battaglia (Italy)
- Magdalena Fac-Skhirtladze & Marta Szantroch (Poland)
- Prof. Riadh Gouider (Tunisia)
- Arwenna Davis (UK)
- Dr. Tim Coetzee (USA)

Expert Advisors

- Prof. Ingrid van Der Mei (Australia)
- Prof. Ruth Ann Marrie (Canada)
- Prof. Emmanuelle Leray (France)
- Dr. Joanna Laurson-Doube (Hong Kong)
- Prof. Kazuo Fujihara (Japan)
- Prof. Bernard Uitdehaag (Netherlands)
- Dr. Mona Alkhawajah (Saudi Arabia)
- Prof. Neil Robertson (UK)
- Dr. Nick La Rocca (USA)
- Dr. Mitchell T Wallin (USA)

We would also like to thank epidemiology experts: Dr. Wendy Kaye and Dr. Lindsay Rechtman of McKing Consulting Corporation, in helping us administer the survey, conduct the analysis and in aiding our endeavours to improve the robustness and quality of the data.

The key MS International Federation staff who contributed to the Atlas project were: Rachel King, Peer Baneke, Nick Rijke, Ceri Angood Napier, Clare Walton, Anne Helme, Victoria Gilbert, Zoe Burr and Sarah Dobson

MSIF extends its thanks to the World Health Organization and the European MS Platform (EMSP) for their contribution to the initial edition of the Atlas of MS.

We are also grateful to Red Bullet for the website/analytical tool and Osomi for the design of the logo, report and social media materials.

Lebanon	Dr. Bassem Yamout, Dr. Maya Zeineddine	San Marino	Dr. Susanna Guttmann
Libya	Dr. Souad Ahmad Zoubi	Saudi Arabia	Prof. Mohammed Al Jumah
Lithuania	Prof. Rasa Kizlaitiene	Serbia	Prof. Tatjana Pekmezovic, Prof. Jelena Drulovic
Malawi	Dr. Yohane Gadama	Singapore	Ass. Prof. Kevin Tan, Ass. Prof. Terrence Thomas, Ass. Prof. Simon Robert Ling, Dr Derek Soon Tuck Loong, Dr Amy Quek May Lin, Dr Furene Wang Sijia, Dr Yong Kok Pin
Malaysia	Dr. Shanthi Viswanathan		
Malta	Dr. Josanne Aquilina		
Mexico	Prof. Jose Flores-Rivera, Dr. Veronica Rica-Alonso		
Moldova, Republic of	Prof. Vitalie Lisnic, Dr. Olesea Odainic		
Montenegro	Dr. Jevto Erakovic, Dr. Ljiljana Radulovic	Slovenia	Dr. Beatrika Končan Vračko
		South Africa	Dr. Dominic Giampaolo
Myanmar	Dr. Ohnmar Ohnmar, Dr. Htet Htet Lin, Khine Yee Mon, Kyawt Oo Kay Thi Htay, Chaw Su Hlaing	Spain	Dr. Alfredo Rodriguez Antigüedad, Pedro Carrascal
		Sri Lanka	Dr. Bimsara Senanayake
Nepal	Dr. Raju Paudel	Sudan	Dr. Mohammed Gasm Elseed Mohammed Elmahal, Dr. Eetidal Ahmed
Netherlands	Dr. Rinze F. Neuteboom		
New Zealand	Dr. Deborah F Mason	Sweden	Kelsi Alexandra Smith, , Prof Scott Montgomery, Peter Alping, Leszek Stawiarz, Jan Hillert
Nicaragua	Dr. Jorge Alberto Martínez Cerrato, Dr. Luis Garcia Valle, Dr. José Giroud Benitez		
		Switzerland	Dr. Viktor von Wyl, Marco Kaufmann
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		United States of America	Dr. Nicholas G. LaRocca, Dr. Mitchell Wallin, Prof. Ruth Ann Marrie, Dr. Annette M. Langer-Gould, Dr. Timothy Coetzee
Poland	Prof. Brola W.		
Portugal	Prof. Ana Martins da Silva		
Puerto Rico	Dr. Angel R. Chinea, Dr. Ivonne Vicente, Astrid Diaz, Lourdes Fernandez, Carlos Rios-Bedoya, Cristina Rubi		
		Uruguay	Prof. Carlos N. Ketzoian, Prof. Carlos Oehninger
		Venezuela	Dr. Miguel Ángel Romero C., Dr. Geraldine Orozco Escobar
Romania	Prof. Ovidiu Alexandru Bajenaru		
		Yemen	Giyab Ali Abdullah Al-Ghalabi
Russian Federation	Prof. Alexey Boyko		
		Zambia	Dr. Deanna Saylor

We would also like to thank those coordinators who provided data but who wished to remain anonymous.

Sponsors

About the Multiple Sclerosis International Federation (MSIF)

- The world's only **global network** of MS organisations.
- **48 member** organisations from around the globe, with links to many other organisations.

- **Together we lead the fight against MS** and work to improve the quality of life of people affected by MS wherever they live.
- Together, we campaign for increased international awareness of MS, provide information and support to people affected by MS, and support international research to discover better treatments and ways to manage the disease.

- **Our vision** is a world without MS.
- **Our mission** is to lead the global MS movement to improve the quality of life of people affected by MS and to support better understanding of the treatment of MS by facilitating international cooperation between MS societies, the international research community and other stakeholders.

Some examples of our work include:

- **COVID-19 and MS global data sharing initiative:** Together with our members and the MS Data Alliance, we are spearheading a global data sharing initiative to meet the demand for data on the impact of the novel coronavirus on people with multiple sclerosis (MS). This information is crucial for people with MS and clinicians to make evidence-based decisions on how to manage their condition during the pandemic.

- **Patient Reported Outcomes initiative for people with MS (PROMS):** This initiative brings together the global MS community, people with and affected by MS, researchers, the healthcare industry and many more, to enable patient input in research, clinical trials of new therapies, and the design of healthcare systems. Through this exciting project, we will see an aligned global view on Patient Reported Outcomes (PROs) for MS for healthcare providers, regulatory agencies and healthcare technology assessment agencies (HTAs).

- **The International Progressive MS Alliance** is an unprecedented global collaboration of MS organisations, researchers, clinicians, pharmaceutical companies, and people with progressive MS, transforming the landscape for people with progressive MS. The Alliance's strategic objectives are to make progressive MS a global research priority, to secure resources and global funding to enable research, to stimulate awareness, engagement and active support of priority stakeholders in the MS community to end progressive MS.

Find out more at **www.msif.org**