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ATLAS OF MULTIPLE SCLEROSIS 2013: A GROWING GLOBAL PROBLEM WITH WIDESPREAD INEQUITY

Multiple sclerosis (MS) is one of the world's most common neurologic disorders, and in many countries it is the leading cause of nontraumatic neurologic disability in young adults. Despite this, global information on the epidemiology of MS and the availability of resources and services for people with MS is scarce in many regions of the world. The first *Atlas of MS*, published in 2008 as a joint project of the Multiple Sclerosis International Federation (MSIF) and the World Health Organization (WHO),¹ endeavored to fill this knowledge gap with information from 112 countries. Here, we outline important updates in the recently launched *Atlas of MS 2013: Mapping Multiple Sclerosis around the World*.²

Specifically, the goals were to update the information in the *Atlas of MS* Web site (www.atlasofms.org) and to map data, resources, and services by compiling and calculating their distribution by country, by the 6 WHO regions (Europe, Americas, Africa, South-East Asia, Eastern Mediterranean, Western Pacific) and the 4 World Bank income groups (low, lower-middle, upper-middle, high). In addition to improving the robustness of the information in the *Atlas of MS*, the new survey included questions on several new topics, notably pediatric MS, neuromyelitis optica, and access to recently licensed medications. In 2012–2013, the MSIF acquired new data from 104 countries, including 12 countries who submitted data for the first time. Taken together with the existing 2008 data, this represents 87% of the world's population, although there were proportionally fewer countries represented from the WHO Africa region and the World Bank low income group.

The key findings from the 2013 update² include the following:

1. The estimated number of people with MS increased from 2.1 million in 2008 to 2.3 million in 2013.
2. Health care and support services have improved compared to 2008 (increased numbers of neurologists, MRI machines).

3. Inequity in availability of these services continues, with a widening gap between high- and low-income countries.
4. The number of MS groups and organizations worldwide has increased since 2008.

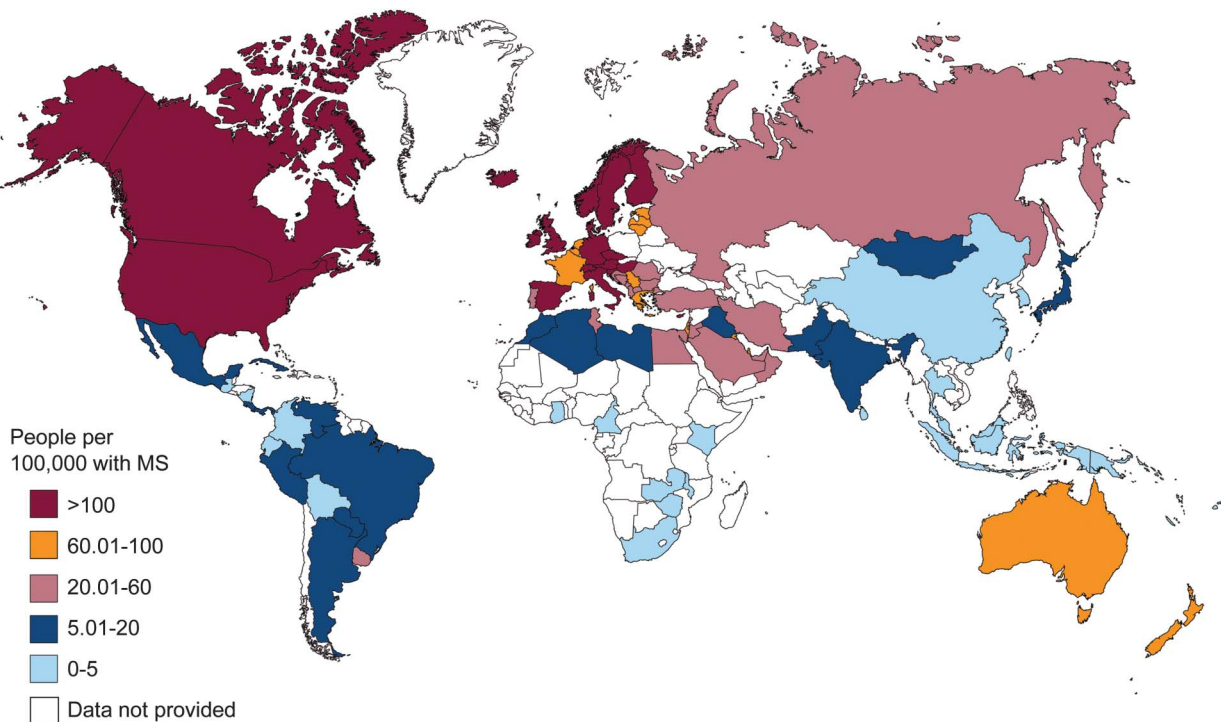
The increase in the reported prevalence of MS between 2008¹ and 2013² (figure) can be attributed in part to increased survival (of both people with MS and the wider general population) and in some countries to increasing MS incidence, but it may also reflect improvements in the diagnosis and reporting of MS and the establishment of clinical registers and publication of new epidemiologic research. The latter is reflected in the observation that just over 50% (47/92) of countries that provided data on MS prevalence cited a peer-reviewed paper in support of their estimate in the 2013 survey,² compared to less than 25% (22/93) in 2008.¹ Incidence, which provides a better measure of changes in MS risk than prevalence, was also found to have increased.² However, fewer countries—52 in total—provided data on the incidence of MS, and only half of these cited a peer-reviewed scientific paper.² Overall there remains a clear need in most countries for improved systems to monitor MS and related disorders.

The 2013 *Atlas of MS* survey² found that while there have been some improvements in health care and support services available to people with MS since the 2008 survey,¹ substantial inequalities remain. For example, while there was an increase of about 30% in the reported number of neurologists, the number ranged from an average of 4.7 per 100,000 in high-income countries to just 0.04 per 100,000 in the low-income countries that participated in the survey.² There was a similar range in the availability of MS nurses, though many countries reported no nurses with this specific expertise. As might be expected, the number of MRI machines available for diagnosis was closely linked to the income category of the country, though here there was more improvement, as the number of MRI machines was reported to have doubled in emerging countries²—those defined as low-to upper-middle income by the World Bank.

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Figure Global prevalence of multiple sclerosis (MS) in 2013



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This pattern of inequity was also seen in the funding of disease-modifying therapies for MS, which were fully or partially funded by government or insurance plans in almost all high-income countries but in none of the low-income countries.² Other key health services such as therapies for relapses and symptoms and rehabilitation were available in almost all countries that took part in the survey, but once again in many countries access to these was severely limited due to inadequate funding or the lack of specialist health care professionals.²

In contrast, the number of countries with MS groups and organizations worldwide was encouraging, with an increase in the number of organizations reported in several regions. In particular, the number of countries with MS organizations in the Eastern Mediterranean increased from 8 to 13, an increase that reflects MSIF's continuing capacity-building program in this region.² However, 1 in 5 countries participating in our survey—predominantly low- or lower-middle income countries—still lacked an MS organization, which is a concern, as the survey found that the presence of MS organizations in a country was associated with increased provision of support and information services for people with MS.

In 2005 MSIF published "*Principles to promote the quality of life of people with multiple sclerosis*,"³ and in 2008 the United Nations Convention on the Rights

of Persons with Disabilities⁴ reaffirmed that people with disabilities have human rights and that they should enjoy them on an equal basis with other people. During the past decade, there have been initiatives across Europe, North America, and Australia/New Zealand to identify the needs of people with MS and the services and expertise required to meet those needs. The findings of the 2013 *Atlas of MS* survey,² along with those of other recent surveys such as the European Multiple Sclerosis Platform *MS Barometer*,⁵ highlight the wide variation in access to treatment and service provision for people with MS both across the globe and within regions. More research is needed at national, regional, and global levels in order to understand the factors that determine the quality of life and experiences of people with MS; measure the indirect costs of MS; understand the sources and causes of inequalities in access to support, health care services, and therapies; and monitor MS and related disorders through epidemiologic studies and the establishment of registries.

The *Atlas of MS* remains the most comprehensive compilation of MS resources around the world and is a powerful tool that carries a truly global message. At a time when increasingly effective therapies are becoming available for relapsing-remitting MS and efforts are being made through international collaboration to develop therapies for progressive MS⁶ (www.endprogressivems.org), it is essential that the *Atlas of MS* is used to its

maximum potential to redress the inadequate and inconsistent services available for people with MS worldwide.²

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

- Ensure improved diagnosis, treatment, information, and resources are available to all who need them, regardless of where they live.
- Call for more research into effective treatments and practical ways to improve quality of life of people with MS and related disorders.
- Raise awareness and general understanding of MS and related disorders among the general public, employers, and health care professionals.
- Support MS-related organizations and patient groups by investing in them and developing their capacity.
- Work together to make treatments more affordable, either directly or through wider reimbursement by insurance or government.

AUTHOR CONTRIBUTIONS

Dr. Paul Browne: design and conceptualization of the manuscript, interpretation of the published data, drafting and critical revision of manuscript. Dr. Dhia Chandraratna: critical revision of the manuscript. Ceri Angood: critical revision of the manuscript. Dr. Helen Tremlett: critical revision of the manuscript. Chris Baker: data analysis and critical revision of manuscript. Professor Bruce Taylor: critical revision of the manuscript. Professor Alan Thompson: drafting and critical revision of the manuscript.

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