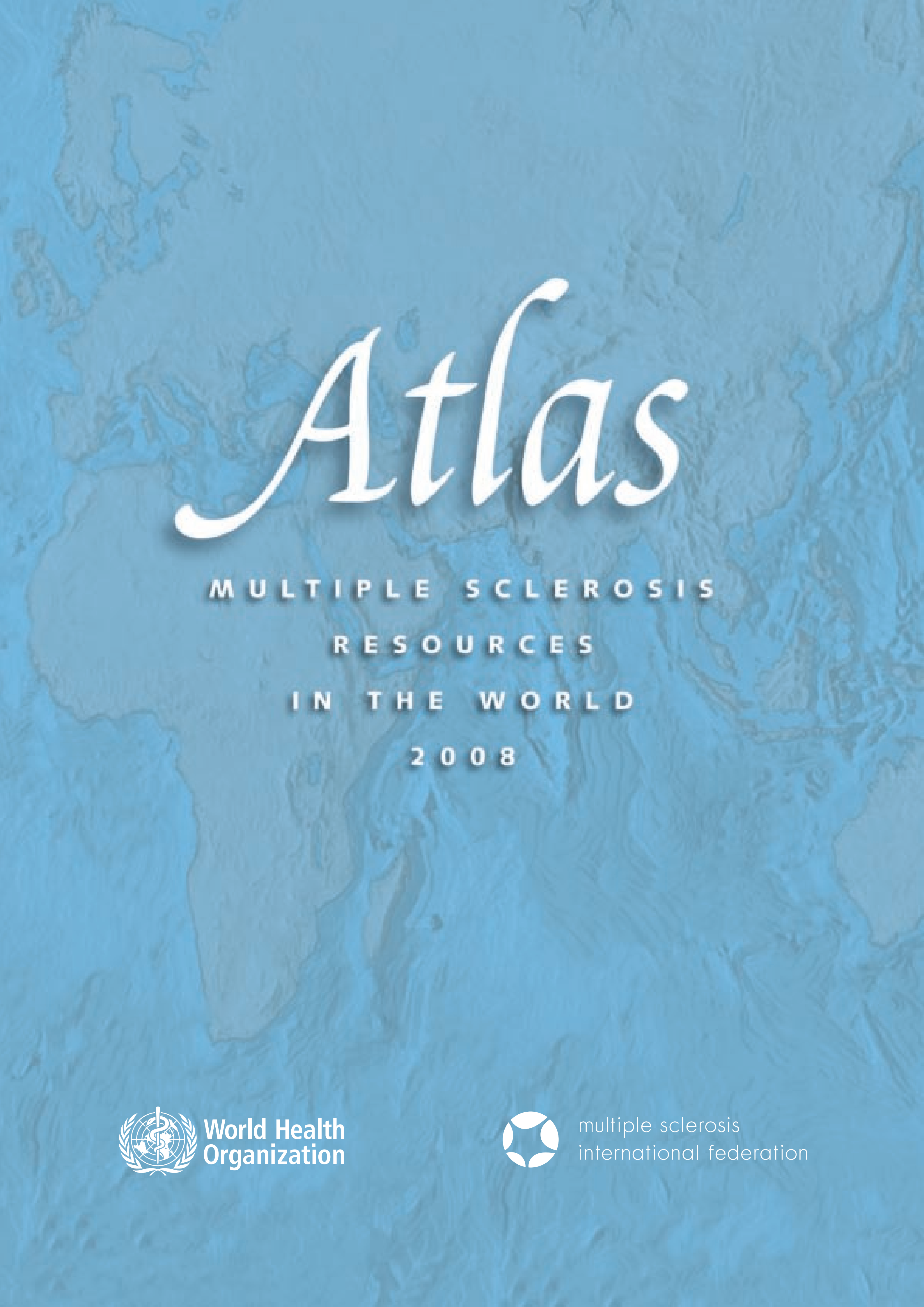
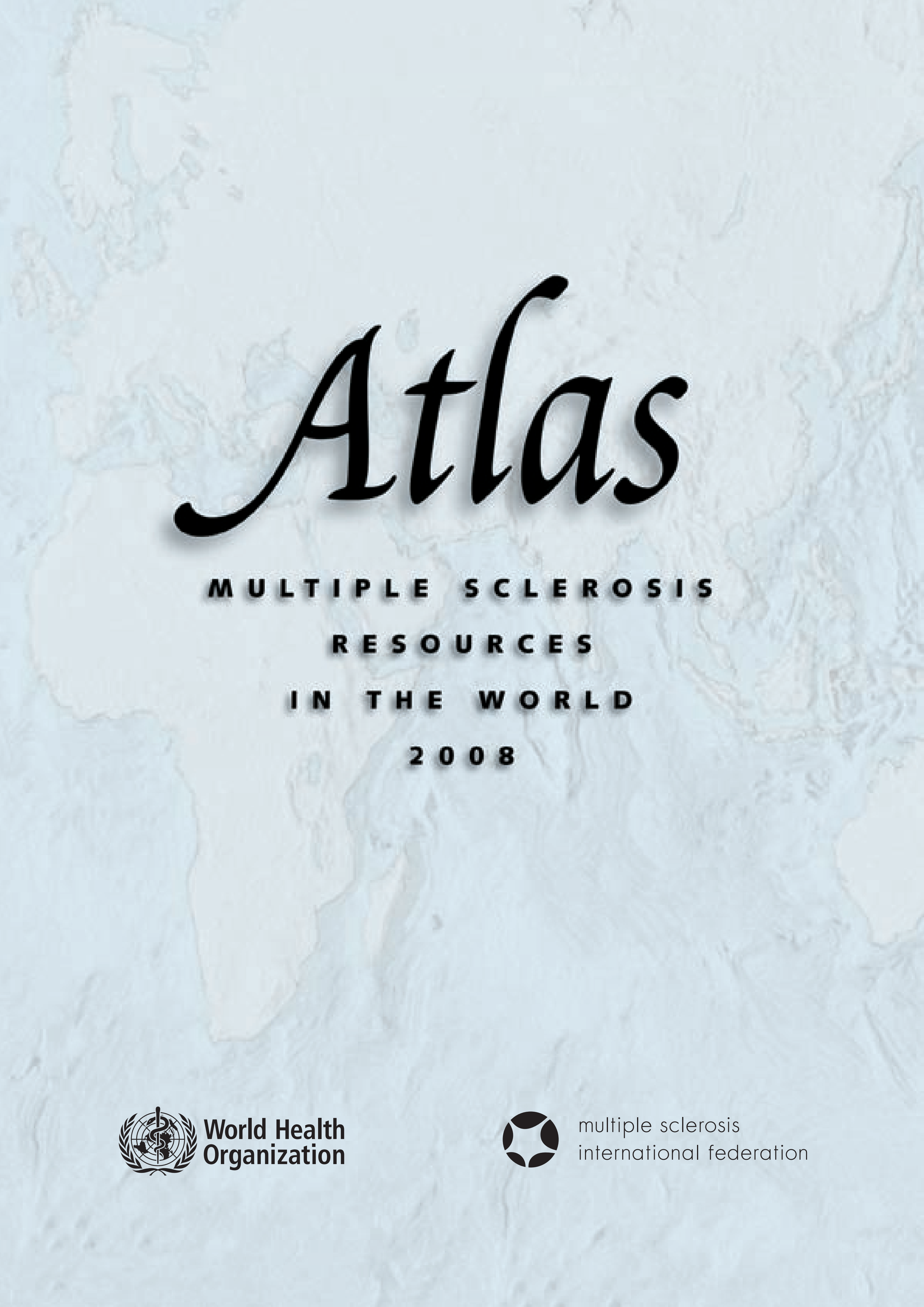


Atlas

MULTIPLE SCLEROSIS
RESOURCES
IN THE WORLD
2008

World Health
Organization

multiple sclerosis
international federation



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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.

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.

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

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.

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.

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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.

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