



Atlas: Multiple Sclerosis A Questionnaire on Country Resources

Glossary: Definitions and Descriptions of Terms Used

- **Source(s) of information:** refers to the detailed reference of the published or unpublished data used to provide the estimate for prevalence, incidence and risk factors.
- **Prevalence:** refers to 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.
- **Incidence:** refers to 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.
- **Age of onset:** refers to age of appearance of first symptoms.
- **Multiple Sclerosis (MS) Groups and Organizations:** refers to a patient organization that works on issues related to MS in the country. It may also be called an Association, League, Federation, Foundation, Union or other appropriate title, depending upon the regulations and/or practice of the country concerned.
- **Non profit organization:** doesn't return 'profits' to Board, staff, members or shareholders but 'invests' surplus funds back into the activities of the organization.
- **For profit organization:** exists to make profits returned to its Board, staff, members or shareholders.
- **Public organization:** is a government owned or financed entity.
- **Health professionals:** refers to personnel involved in providing care to people with MS like doctors, neurologists, nurses, social workers, physiotherapists, occupational therapists etc.
- **Information:** It refers to communication of knowledge by various channels regarding MS. The information could be regarding epidemiology, symptoms, prognosis, treatment options and their availability, support services, lifestyle, family issues, legislation, research etc.
- **Audio-visual material:** videos, CDs and tapes etc.
- **Advice and advocacy:** a combination of individual and social actions designed to provide advice and gain political commitment, policy support, social acceptance and health systems support for people with MS.
- **Education and training:** to improve the knowledge of patients and their carers, 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.
- **Self Help/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.

- **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, adult day care).
- **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 (Allison & Millar, Schumacher, McAlpine, Rose, Bauer, Poser, McDonald etc)
- **MS neurologist:** refers to a neurologist whose professional interests and activities are related exclusively/specifically to the care of people with MS. He/she runs a clinic or service for MS patients separate from other neurological practice, provides overall management of care, neurologic testing and evaluation, and prescribes medications and monitors their effectiveness.
- **MS nurse:** refers to a licensed/registered nurse whose professional interests and activities are related exclusively/specifically to the care of people with MS either through direct practice, research, education, or administration.
- **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.
- **Clinical Prescription criteria:** Specific clinical guidelines defining eligibility including such factors as type of MS, mobility and number of relapses over specified period of time.
- **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 consumers voluntarily pays to a private insurance company which, in return, pays for part or all of consumers' MS care services; *government* refers to money for health services raised by taxation or through social insurance.
- **Exacerbation:** refers to relapse, an attack or a flare up. One of the most commonly used definitions of an exacerbation is the [sub]acute appearance of a neurologic abnormality that must be present for at least 24 hours in the absence of fever or infection.
- **Complementary/alternative therapies:** refers to a broad set of health care practices that are not integrated into the dominant health care system. It could be a different approach than conventional medicine (alternative) or used along with conventional medicine (complementary). These could be medication or non-medication therapies. Traditional medicine is also used as a term in some countries for these therapies.
- **Disability entitlements:** benefits payable as a part of legal right from public funds in cases of MS that cause physical, mental or intellectual impairment leading to functional limitations.