

Atlas

COUNTRY RESOURCES
FOR NEUROLOGICAL
DISORDERS
2004



World Health Organization
Geneva



World Federation of Neurology
London

Atlas

**COUNTRY RESOURCES
FOR NEUROLOGICAL
DISORDERS
2004**

Results of a collaborative study of the World Health Organization
and the World Federation of Neurology



Programme for Neurological Diseases and Neuroscience
Department of Mental Health and Substance Abuse
World Health Organization

Geneva

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For further details on this project or to submit updated information, please contact:

Dr L. Prilipko
Programme Leader
Neurological Diseases and Neuroscience
Department of Mental Health and Substance Abuse
World Health Organization
Avenue Appia 20, CH-1211 Geneva 27, Switzerland
Tel: +41 22-791 36 21, Fax: +41 22-791 4160, e-mail: prilipkol@who.int

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Tel: +41 22-791 36 21, Fax: +41 22-791 4160, e-mail: prilipkol@who.int

Neurological disorders constitute a large and increasing share of the global burden of disease. Stroke, dementia, epilepsy and Parkinson's disease are important factors determining mortality and morbidity in all societies. However, the resources and services for dealing with these disorders are disproportionately scarce, particularly in developing countries. While neurological service in Western countries varies from 1 to 10 neurologists per 100 000 inhabitants, neurology either does not exist or is only marginally present in major parts of the world.

Over the years, programmes, projects and other activities of the World Health Organization (WHO) in the areas of mental health and neurological disorders have been closely linked. During the past decade WHO has launched a number of global public health projects, including the Global Initiative on Neurology and Public Health, in order to increase professional and public awareness of the global burden of neurological disorders and to emphasize the need for provision of neurological care in first-level and referral health facilities. The outcomes of these endeavours have revealed a paucity of information regarding national and subnational policies, programmes and resources for the treatment and management of neurological disorders.

WHO is responsible for providing technical information and advice to its Member States to help them to improve the health of their citizens. This task is facilitated by collaboration with various scientific and professional groups that have similar goals. The study of country resources for

neurological disorders represents a unique collaborative effort between WHO and the World Federation of Neurology (WFN), which is committed to improving human health worldwide by promoting prevention and care of persons with nervous system disorders. WHO and WFN have been working closely for many years on activities related to prevention and control of noncommunicable and communicable neurological diseases. This publication is another product of their close collaboration.

The results obtained from the study of country resources for neurological disorders confirm that the available resources for neurological services in most countries of the world are insufficient compared with the global need for neurological care. The Neurology Atlas presents the facts and figures and highlights the large inequalities across regions and countries, with low-income countries having extremely meagre resources.

The availability of information will lead to greater awareness among policy-makers of the gaps in resources for neurological care. It will assist health planners and policy-makers to identify areas that need urgent attention and to plan the upgrading of resources in those areas. The data also serve as a baseline for monitoring the improvement in availability of resources for neurological care. We hope that personnel involved in caring for people with neurological disorders, including health professionals and nongovernmental organizations, will use the Neurology Atlas data in their advocacy efforts for more and better resources for neurological care.

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

Dr Johan A. Aarli
First Vice-President
World Federation of Neurology

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◆ The Atlas of Country Resources for Neurological Disorders is a project of WHO headquarters, Geneva, supervised and coordinated by Dr Leonid Prilipko and Dr Shekhar Saxena. Dr Benedetto Saraceno provided vision and guidance to the project. The project was carried out in close collaboration with the World Federation of Neurology (WFN) coordinated by its First Vice-President Dr Johan A. Aarli. Dr Aleksandar Janca provided technical guidance and supervision and was involved in the development of the survey design and questionnaire, data collection and project management. Dr Tarun Dua was responsible for completion of the data collection, data analyses and overall project management beginning 2004. Dr Dua also took the primary responsibility of writing this report. Kathy Fontanilla helped in data management and provided administrative support. Technical and methodological support was kindly provided by Dr Pratap Sharan and Dr Pallab Maulik.

Key collaborators from WHO regional offices include: Dr Custodia Mandlhate and Dr Therèse Agossou, African Regional Office; Dr Claudio Miranda and Dr Jose Miguel Caldas de Almeida, Regional Office of the Americas; Dr Ahmed Mohit and Dr R. Srinivasa Murthy, Eastern Mediterranean Regional Office; Dr Wolfgang Rutz and Dr Matthijs Muijen, European Regional Office; Dr Vijay Chandra, South-East Asia Regional Office; and Dr Helen Hermann and Dr Xiangdong Wang, Western Pacific Regional Office, all of whom made significant contributions during the development of the project, the identification of focal experts in the area of neurology in Member States, and the review of the results.

The information from various countries, areas and territories was provided by key persons working in the field of neurology identified by WFN, WHO regional offices and the offices of WHO Representatives. The respondents also

handled the many requests for clarification arising from the data. The list of the respondents is included at the end of the Atlas.

A number of leading experts in the field of neurology reviewed the project report and provided comments. They include Dr Leontino Battistin, Dr Donna C. Bergen, Mrs Hanneke de Boer, Dr Pedro Chana, Dr Amadou Gallo Diop, Dr M. Gourie-Devi, Dr Jin-Soo Kim, Dr Ashraf Kurdi, Dr Najoua Miladi, Dr Elisabeth Müller, Dr Michael Piradov, Dr Donald Silberberg and Dr Wenzhi Wang. Various specialists contributed short reviews of selected areas in relation to neurology, as follows. Epilepsy: Dr Jerome Engel Jr; Cerebrovascular diseases: Dr B. Piechowski-Jozwiak and Dr J. Bogousslavsky; Headache: Dr Timothy J. Steiner; Parkinson's disease: Dr Bhim S. Singhal; Dementia: Dr Martin Prince; Multiple sclerosis: Dr Jürg Kesselring; Training in neurology: Dr Donna C. Bergen.

A number of colleagues at WHO gave advice and guidance during the course of the project, in particular Dr José Bertolote, Dr Michelle Funk and Dr Vladimir Poznyak.

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

Assistance in preparing the Atlas for publication was received from Tushita Bosonet (graphic design), Steve Ewart (maps) and Barbara Campanini (editing).

There is considerable information available that the global burden of neurological disorders is large and increasing. Very little is known, however, about the resources available within countries to meet this burden. Most information about resources for the care of people with neurological disorders pertains to a few developed countries; little is known at present about the situation in the vast majority of countries, and the information that is available is not comparable across different countries or over time.

To fill this knowledge gap, Project Atlas was launched by WHO in 2000 with the object of collecting, compiling and disseminating relevant information on health-care resources in countries. The first publication of the project provided regional and world figures on mental health resources in an illustrated Atlas of Mental Health Resources in the World 2001. WHO decided to expand the Atlas project into the area of neurology and neurological services, as the next logical step in the work of WHO in assessing country resources – and consequently country needs – to control mental and neurological disorders.

All information and data contained in the Atlas of Country Resources for Neurological Disorders (the Neurology Atlas) were collected from a large international study carried out in 2001–2003, which included 109 countries spanning all six WHO regions and covering over 90% of the world population. The World Federation of Neurology (WFN) collaborated closely in the collection and analysis of the data and the development of the Neurology Atlas, with the active participation of leading experts in neurology all over the world and valuable assistance from WHO regional advisers and WHO country representatives.

Dr Leonid Prilipko
Programme Leader
Neurological Diseases and Neuroscience
Department of Mental Health and Substance Abuse
World Health Organization

The Neurology Atlas illustrates the current status of neurological services and provision of neurological care in various parts of the world. In general, results obtained objectively confirm that the available resources for neurological disorders in most countries of the world are insufficient compared with the known significant burden associated with these disorders. In addition, there are large inequalities across regions and income groups of countries, with low-income countries having extremely scanty resources.

We believe that the information presented in this volume will be useful for a large range of readers including policy-makers, health planners and specialists on international as well as national level. The results of the Neurology Atlas clearly establish the need for substantial increase in the neurology services especially in low and low-middle income countries to decrease the inequity. This would only be possible with significant increase in allocation of financial resources for these services. The data also demonstrate the role of international collaboration and partnerships in making a concerted effort to improve the neurological care.

At the country level, the data summarized in the Neurology Atlas may be used for building up national programmes and development of strategies to improve control of neurological disorders, as well as their implementation at country level. In addition, the Neurology Atlas provides the opportunity for comparative analysis of available resources for neurological disorders across geographical regions and countries.

The material presented is a first snapshot of the actual global situation, and we are aware of gaps in information and possible inaccuracies. We are planning to continue our work in this direction to provide more complete, accurate and comparable information in the coming years.

Dr Shekhar Saxena
Coordinator
Mental Health: Evidence and Research
Department of Mental Health and Substance Abuse
World Health Organization

Very little information exists regarding the country resources available to cope with the known burden of neurological disorders, which is large by all accounts. To fill this knowledge gap, some important information was collected by the headquarters of the World Health Organization (WHO) working in close collaboration with its regional offices and the World Federation of Neurology (WFN). This work was undertaken under WHO's Project Atlas, ongoing since 2000. The Atlas of Country Resources for Neurological Disorders (the Neurology Atlas) describes the global and regional analyses of the country resources for neurological disorders from 106 Member States of WHO, one Associate Member (Puerto Rico), one Special Administrative Region (Hong Kong, China) and one territory (West Bank and Gaza Strip), covering 90.1% of the world population. The information is primarily gathered from key experts in the area of neurology in each country identified by WFN as their official delegates and, in some cases, by WHO regional offices. It is one of the most comprehensive compilations of neurological resources ever attempted. Limitations are to be kept in mind, however, when interpreting the data and their analyses. The key persons were among the most knowledgeable persons in their countries, but the possibility remains of the data being incomplete and in certain areas even inaccurate. The draft report was reviewed by leading experts in the field of neurology and regional advisers of the six WHO regions, and their comments were incorporated. The available literature regarding some of the themes was also reviewed, and the evidence is summarized.

The analyses of the reported frequency of neurological disorders showed that epilepsy, cerebrovascular diseases and headache are among the most common neurological conditions encountered in both specialist and primary care settings globally, as well as in all WHO regions. The other neurological disorders reported frequently include Parkinson's disease, neuroinfections, neuropathies and neurological problems attributable to vertebral disorders. Alzheimer's disease and other dementias were also among the most frequent neurological conditions encountered by neurologists in high-income countries. The programmes dealing with prevention, health care, training of personnel and research in the countries need to be based on locally prevalent disorders.

An important resource is the availability of hospital beds for neurological disorders. Designated neurological beds, though not essential, are an important indicator of the level of organization of neurological services in a country. The median number of neurological beds available in the responding countries is 0.36 per 10 000 population. Two thirds of the responding countries have access to less than one neurological bed per 10 000 population. In terms of population covered, only 8.8% have access to more than one neurological bed per 10 000 population. Neurological beds are particularly deficient in the African and South-East Asia Regions. The median number of neurological beds per 10 000 population in low-income countries (0.03) is much lower than in high-income countries (0.73). Separate neurological hospitals with a large number of beds may not be desirable, but a neurologi-

cal inpatient facility as a part of general hospital is, however, needed to provide comprehensive neurological management.

Specialized services and personnel are essential to provide comprehensive neurological care. They are also important for providing training, support and supervision to primary health-care providers in neurological care. The median number of neurologists is 0.91 per 100 000 population in the responding countries. This deficiency is particularly evident in the African, South-East Asia, Eastern Mediterranean and Western Pacific Regions. In terms of the population covered, only one quarter has access to more than one neurologist per 100 000 population. The median number of neurologists per 100 000 population is also much lower for low-income countries (0.03) compared with high-income countries (2.96). Recommendations regarding the required number of neurologists in a country are available from countries in the European Region and the Region of the Americas, varying between 1 and 5 per 100 000 population. The number of available neurologists in the low-income countries is very much lower than any of these recommendations.

The availability of other types of highly specialized personnel is also limited, with median numbers for neuropaediatricians and neurosurgeons being 0.10 and 0.56 per 100 000 population, respectively. Again, this deficiency is particularly evident in Africa, South-East Asia, the Eastern Mediterranean and the Western Pacific. In terms of population covered, more than one neuropaediatrician and neurosurgeon per 100 000 population are available for only 2.2% and 15.1% of the population, respectively. Such a situation is particularly evident in low-income countries, with only 0.002 neuropaediatricians and 0.03 neurosurgeons available per 100 000 population.

Neurological nursing does not exist as a specialty in 41% of the responding countries. Three quarters of the responding countries have access to less than one neurological nurse per 100 000 population. The median number of neurological nurses in the responding countries per 100 000 population is 0.11. While training for neurologists is being pursued, specialized neurological nursing training has been neglected even in developed countries.

The presence of subspecialized neurological services indicates the level of organization and development of neurology in a country. Subspecialized neurological services are important, because many neurological disorders require highly specialized skills for appropriate diagnosis and management. Such services also provide the basis for conducting research and training for various neurological disorders. The respondents reported availability of subspecialized neurological services (paediatric neurology, neurological rehabilitation, neuroradiology and stroke units) in at least two thirds of the responding countries for each of these areas. All the subspecialized services are especially deficient in the African Region, while stroke units are also deficient in the Eastern Mediterranean Region. Like all other neurological resources, the availability of subspecialized services is much lower for the low-income countries. In interpreting these data, however, an important limitation should be kept in mind: respondents may have replied posi-



Fostering cooperation among scientific and professional groups that contribute to the advancement of health is one of the key constitutional responsibilities of the World Health Organization (WHO) (1). In order to fulfil its constitutional obligation, WHO has been collaborating with numerous governmental and nongovernmental organizations and launched a number of international projects that helped health professionals and policy-makers prioritize health needs and design evidence-based health programmes all over the world.

One of the most remarkable collaborative endeavours was the Global Burden of Disease study, which was a result of the coordinated effort of WHO, the World Bank and Harvard School of Public Health. The Global Burden of Disease report drew the attention of the international health community to the fact that the burden of mental and neurological disorders had been seriously underestimated by traditional epidemiological methods that took into account only mortality, not disability rates. This report specifically showed that while mental and neurological disorders are responsible for about 1% of deaths, they account for almost 11% of disease burden worldwide (2).

As the world became aware of the massive burden associated with mental and neurological disorders, it also recognized that the resources and services for these disorders were disproportionately scarce, particularly in developing countries. Furthermore, there has been a large body of evidence showing that, in the years to come, policy-makers and health-care providers in developed and developing countries alike may be unprepared to cope with the predicted rise of the prevalence of mental and neurological disorders and the disability associated with them. In order to respond to this worrisome fact, in 2001 WHO coordinated a large international project aimed at collecting, compiling and disseminating information and data on the existing resources and services for people suffering from mental disorders. This project was carried out by WHO headquarters and involved all six WHO regional offices as well as 191 WHO Member States. The main outcome of the project was the publication of the *Atlas: Mental Health Resources in the World* (http://www.who.int/mental_health_evidence/atlas/) that mapped mental health services around the world and provided a snapshot of the situation on the ground regarding this important public health matter (3).

Over the years, WHO programmes, projects and activities in the areas of mental and neurological disorders have been closely linked. Many such disorders are chronic and progressive in nature and fulfil criteria to be recognized as a global public health problem; moreover, they are frequent and disabling, and they represent a significant burden on communities and societies all over the world. The extension of life expectancy and the ageing of the general populations in both developed and developing countries are likely to increase the prevalence of many chronic and progressive physical and mental conditions, including neurological disorders. However, the increasing capacity of modern medicine to prevent death, and the development of new, more effective treatments have changed the frequency and severity of impairment attribut-

able to neurological disorders and raised the issue of restoring or creating life of acceptable quality for people who suffer from their consequences.

In order to increase professional and public awareness of the frequency, severity and costs of neurological disorders and to emphasize the need for provision of neurological care at all levels including primary health care, over the past decade WHO launched a number of global public health projects including the Global Initiative on Neurology and Public Health (4). The outcomes of this large international endeavour, which involved health professionals in numerous countries all over the world, clearly indicated that there was a paucity of information on the prevalence of neurological disorders as well as a lack of policies, programmes and resources for their treatment and management.

In view of these findings and in order to fill the information gap in the area of neurological disorders and services, in 2001 WHO decided to expand the Atlas Project into the area of neurology and to conduct a study of Country Resources for Neurological Disorders. The main objectives of this large international study were to obtain the following expert information:

- ◆ the most common neurological conditions and their distribution in primary care and specialist settings;
- ◆ availability of neurological procedures, treatments and services;
- ◆ number and types of health professionals involved in the delivery of neurological care;
- ◆ characteristics of postgraduate teaching in neurology;
- ◆ budget for and financing of neurological care, including the types of health insurance and disability benefits;
- ◆ availability, role and involvement of national neurological associations and other nongovernmental organizations in advocacy to raise public and professional awareness of neurological disorders and their participation in the treatment, rehabilitation and prevention of neurological disorders.

The study of Country Resources for Neurological Disorders represents a unique collaborative effort, which involved WHO headquarters and regional offices and the World Federation of Neurology (WFN). Although launched under severe staff and budgetary constraints in both WHO and WFN, the project created much enthusiasm and mobilized more than 100 WHO Member States and WFN member societies. The main outcome of the project is the present *Atlas of Country Resources for Neurological Disorders* (the *Neurology Atlas*), which provides an illustrative presentation of data and information on the current status of neurological services and neurological care in different parts of the world. It is hoped that the *Neurology Atlas* will serve as a useful reference guide to both health professionals and policy-makers and assist them in planning, developing and providing better health care and services to people suffering from neurological disorders throughout the world.

◆ All the information and data contained in the Neurology Atlas have been collected in a large international study which was carried out in the period 2001–2003 and included more than 100 countries spanning all WHO regions and continents.

Data collection

The Neurology Atlas is based on the information and data collected by WHO and WFN. At WHO, the work was led by headquarters in close collaboration with the regional offices. The first step in the development of the Neurology Atlas was to identify specific areas where information related to neurological resources and services was lacking. In order to obtain this information, a questionnaire was drafted in English in consultation with a group of WHO and WFN consultants. A glossary of terms used in the questionnaire was also prepared in order 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 questionnaire was piloted in one developed and one developing country and some necessary changes were made. The questionnaire and the glossary were then translated into some of the other official languages of WHO – Arabic, French, Russian and Spanish.

The questionnaire and glossary were sent to the official delegates of all the 90 member societies of WFN. In addition, WHO regional offices were also asked to identify a key person working in the field of neurology in those countries where the WFN liaison person was not available or not responsive. The key persons were requested to complete the questionnaire based on all possible sources of information available to them. All respondents were asked to follow closely the glossary definitions, in order to maintain uniformity and comparability of received information. The Neurology Atlas project team responded to questions and requests for clarification. Repeat requests were sent to the key persons in cases where there was delay in procuring 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.

Received data were entered into an electronic database system using suitable codes and analysed using Stata (special edition) version 8 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. Countries were grouped into the six WHO regions (Africa, the Americas, Eastern Mediterranean, Europe, South-East Asia and Western Pacific) and four World Bank income categories according to 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\$ 735 or less), lower middle-income (US\$ 736–2935), upper middle-income (US\$ 2936–9075) and high-income (US\$ 9076 or

more) (5). The countries were also categorized according to the population figures published in The World Health Report 2003 (population data 2002) as: Category I (0–1 million), Category II (1–10 million), Category III (10–100 million) and Category IV (>100 million) (6). 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 neurology and regional advisers of the six WHO regions, and their comments were incorporated.

Representativeness of data collected

Completed questionnaires were received from various WHO Member States, areas and territories: 106 Member States, one Associate Member (Puerto Rico), one Special Administrative Region (Hong Kong, China) and one territory (West Bank and Gaza Strip), which are henceforth referred to as countries for the sake of convenience. The data were collected from 16 countries in the African Region (34.8%), 14 countries in the Region of the Americas (40%), 18 countries in the Eastern Mediterranean Region (85.7%), 43 countries in the European Region (82.7%), 6 countries in the South-East Asia Region (54.5%) and 9 countries in the Western Pacific Region (33.3%). In terms of population covered, the data pertain to 90.1% of the world population; 52.3% of the population in Africa, 89.3% in the Americas, 84.1% in the Eastern Mediterranean, 97.2% in Europe, 96.8% in South-East Asia and 97.1% in the Western Pacific.

Limitations

- ◆ The most important limitation of the dataset is that only one key person in each country was the source of all information. Although the respondent was a WFN liaison officer and had access to numerous official and unofficial sources of information and was able to consult other neurologists within the country, the received data 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 Neurology Atlas is the most comprehensive compilation of neurological resources in the world ever attempted.
- ◆ Because the sources of information in most countries were the key persons working in the field of neurology, the dataset mainly covers countries where there are neurologists or other experts with an interest in neurology. It is therefore likely that the Neurology Atlas gives an overly positive view of neurological resources in the world.
- ◆ While attempts have been made to obtain all the required information from all countries, in some countries it was not available. Hence, the denominator for various themes is different and this has been indicated with each theme. The most common reason for missing data was the non-availability of the information in the country.

- ◆ The data regarding reported frequency of neurological disorders in various settings represents an estimate and has not been collected and calculated using stringent epidemiological research methods as for prevalence studies. The data were compared with the published evidence available from various countries and the results of this literature review have been incorporated as separate boxes.
- ◆ Certain questions, especially in relation to neurological resources, were framed in such a way that responses could be "yes" or "no". Although this facilitated a rapid gathering of information, it failed to take account of differences in coverage and quality. Respondents may have replied positively to the question of availability of neurological services in the country even if only a very limited number of such facilities were available in a few large cities. Also, 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. The definitions regarding various human resources, for example, may need to be amended and expanded in future.
- ◆ 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 Neurology Atlas are organized in 15 broad themes. The pages on the right-hand side give a graphic presentation of the data and facing pages on the left provide related text. The graphic displays include maps of the world with colour codings of 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. Atlas pages also contain definitions of the terms used in the process of collecting the data. Selected findings from analysis of 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 data analyses presented. Limitations specific to each theme are to be kept in mind when interpreting the data and their analyses. It should be noted that some implications of the findings for further development of resources for neurological disorders are highlighted.

In addition to the information collected as a part of the Atlas project, the Neurology Atlas also provides some data that were obtained from a review of selected literature under some of the themes. No attempt has been made, however, to provide a comprehensive literature review. This additional information is presented in separate boxes and is shown in a different colour. Brief review of selected topics related to neurology by leading experts is also provided in a separate section.