# ATLAS

# OF HEADACHE DISORDERS AND RESOURCES IN THE WORLD 2011

A collaborative project of World Health Organization and *Lifting The Burden* 





The Global Campaign against Headache

# FOREWORD

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Headache disorders are among the most common disorders of the nervous system, causing substantial ill-health and disability in populations throughout the world. Despite this, they are underestimated in scope and scale, and there is little recognition of their public-health impact. It is not known how, or how effectively, health-care and other resources are utilized to mitigate their effects.

WHO has a number of important initiatives in the field of clinical neuroscience designed to promote international collaboration, enhance research capacity and, above all, develop programmes to benefit communities worldwide affected by neurological disorders. Among them is *Project Atlas*, a series of publications now including the *Atlas of Headache Disorders*, the result of a collaborative study by WHO and the nongovernmental organization, *Lifting The Burden*: the Global Campaign against Headache. The Global Campaign involves multiple nongovernmental organizations, academic institutions and individuals worldwide, with objectives not only of better professional, public and political awareness of the global burden of headache but also of solutions to it.

It might appear that production of an Atlas would be difficult in relation to headache disorders, but this publication, carefully and expertly designed and covering, as it does, very important causes of population ill-health and disability, is highly appropriate and timely. Its introduction provides a clear description of its purpose, definitions and descriptions of the principal headache disorders and an account of barriers to care that must be overcome if these are to be managed effectively. The results, gathered from respondents from more than half the world's countries, are set out in themes: epidemiology, the impact of headache disorders on society, health-care utilization, diagnosis, assessment and treatment, professional training and the importance of national professional organizations are all given full consideration.

The key messages derived from this project can be expected to have major influence upon the recognition and management of headache disorders across the world. This publication is likely to be widely read; it is an important resource for doctors and others interested in headache disorders or concerned with their management, especially policy-makers.

#### Lord Walton of Detchant, Kt TD MA MD DSc FRCP FMedSci

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# PREFACE

### PROJECT TEAM AND PARTNERS

The *Atlas of Headache Disorders* is a project of WHO headquarters, Geneva, supervised and coordinated by Dr Shekhar Saxena and Dr Tarun Dua. Dr Benedetto Saraceno provided guidance and Dr Colin Mathers gave technical input.

The project was carried out in close collaboration with Lifting The Burden as a key component of the Global Campaign against Headache, directed by Professor Timothy Steiner. Professor Lars Jacob Stovner and Professor Steiner provided expert support, and they and Dr Dua designed the survey methods and guestionnaire. Professor Steiner, assisted by Mrs Ulla Schultz, was responsible for project management on a practical level. Respondents were found with help from the International Headache Society, European Headache Federation, World Headache Alliance and World Federation of Neurology. Professor Stovner and Ms Gøril Gravdahl, supported by the Norwegian University of Science and Technology, undertook questionnaire distribution, query resolution and data collection and management. Dr Dua and Dr Nelly Huynh conducted the analyses. Professor Steiner, with assistance from Dr Huynh, took primary responsibility for writing this report.

The information from various countries, areas and territories was provided by neurologists, headache specialists, general practitioners and patients' representatives identified from multiple sources by Professor Steiner, Mrs Schultz and Ms Gravdahl. The list of the respondents is included at the end of the Atlas.

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

Ms Adeline Loo provided administrative support in the preparation and production of the document. Assistance in preparing the Atlas for publication was received from Ms Erica Lefstad and Mr Christian Bäuerle (graphic design) and from Mr Christophe Francois A Grangier (map design). Professor Paolo Martelletti supported production through Sapienza University of Rome and the Italian League of Headache Patients. Dr Shekhar Saxena, Dr Tarun Dua, Dr Benedetto Saraceno and Dr Colin Mathers:

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Italian League of Headache Patients (LIC – ONLUS), Rome, Italy Headache is felt, at some time, by nearly everybody, and almost half the world's adults at any one time have recent personal experience of one or more headache disorders. In the Global Burden of Disease Study, updated in 2004, migraine on its own was found to account for 1.3% of all years of life lost to disability worldwide. Other headache disorders, collectively, may be responsible for a similar burden.

Yet, much is unknown about the public-health impact of these conditions. While our view of the global burden attributable to headache disorders is incomplete, and our knowledge of health-care resource allocation to headache is scant, there is good evidence that very large numbers of people disabled by headache do not receive effective health care. The barriers responsible for this vary throughout the world, but poor awareness in a context of limited resources generally – and in health care in particular – is undoubtedly high among them everywhere.

The World Health Organization (WHO) initiated *Project Atlas* with the objective of collecting, compiling and disseminating relevant information on health-care resources in countries. Within *Project Atlas*, information has been collected for various domains of mental and neurological services and conditions of public-health priority. The *Atlas of Headache Disorders* is an important addition to this series. The *Atlas of Headache Disorders* presents the results of the survey carried out by WHO in collaboration with the nongovernmental organization, *Lifting The Burden*, in order to collect and disseminate

#### Dr Shekhar Saxena

Director, Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland information on the burden of headache disorders and the resources available to reduce them. The facts and figures presented within it illuminate the worldwide neglect of a major cause of public ill-health and reveal the inadequacies of responses to it in countries throughout the world.

The findings of the *Atlas of Headache Disorders* have specific implications for the work of public-health professionals, academicians, service user groups, health planners and other stakeholders. We are aware of severe limitations in the data presented in this Atlas and welcome suggestions to improve the quantity and quality of data, especially for countries where no information is available or it is scarce.

The eventual objective of the project is to use the information collected through the *Atlas of Headache Disorders* to enhance global and national awareness and improve care and services for people with headache disorders. We hope it will assist health planners and policy-makers as well as professionals at every level involved in caring for people with headache disorders, and that nongovernmental organizations, wherever they exist, will use the *Atlas of Headache Disorders* in their advocacy efforts for more and better headache care.

#### Professor Timothy J Steiner

Global Campaign Director, *Lifting The Burden*, London, UK; Professor of Medicine (Headache and Global Public Health), Norwegian University of Science and Technology, Trondheim, Norway

# EXECUTIVE SUMMARY

### **KEY MESSAGES**

- issue impeding good management of headache;

Despite that headache is felt at some time by nearly everybody, and almost half the world's adults at any one time have recent personal experience of one or more of the three very common headache disorders, much is unknown about the public-health impact of these conditions. It is not known how, or how much, they affect many of the populations of the world, or how healthcare and other resources are utilized to mitigate their effects.

This first global enquiry into these matters illuminates the worldwide neglect of a major public-health problem, and reveals the inadequacies of responses to it in countries throughout the world.

- illness that could be relieved is not, and burdens,

- better professional education ranks far above all
- effectively may well be cost-saving overall.

#### METHODS

Global Campaign.

The Atlas of Headache Disorders presents data acquired by WHO in collaboration with Lifting The Burden: the Global Campaign against Headache. Most of the information was collected in a questionnaire survey of neurologists, general practitioners and patients' representatives from 101 countries, performed from October 2006 until March 2009. Epidemiological data were compiled from published studies through a systematic review, and supplemented by data gathered in population-based studies undertaken within the

# EXECUTIVE SUMMARY

#### ATLAS OF HEADACHE DISORDERS AND RESOURCES IN THE WORLD 2011

#### **KEY FINDINGS**

#### The burden of headache

- Headache disorders, including migraine and tension-type headache, are among the most prevalent disorders of mankind.
- The prevalence studies estimate that half to three quarters of adults aged 18-65 years in the world have had headache in the last year.
- According to these studies, over 10% have migraine, and 1.7-4% of the adult population are affected by headache on 15 or more days every month.
- Information on the societal impact of headache exists in only 18% of countries that responded.
- Headache disorders are included in an annual health reporting system in only 12% and in national expenditure surveys in only 7 % of countries that responded.

#### **Diagnosis of headache**

- A minority of people with headache disorders worldwide are professionally diagnosed.
- The rates for migraine and tension-type headache are about 40%; for medication-overuse headache only 10%.
- Specialists use International Headache Society diagnostic criteria to support diagnosis in 56% of countries that responded. Usage is lower in Africa, the Eastern Mediterranean and South-East Asia and very low in lowincome countries generally. Little is done to encourage their use in low-income countries.
- Investigation rates, mainly for diagnostic purposes, are high, despite that investigations are usually not needed to support diagnosis.
- Instruments to assess impact of headache are used routinely in only 24% of countries that responded, and very little in lower middle- or low-income countries.

#### Management of headache

- Worldwide, about 50 % of people with headache are estimated to be primarily self-treating, without contact with health professionals.
- Up to 10% are treated by neurologists, although fewer in Africa and South-East Asia.
- The top three causes of consultation for headache, in both primary and specialist care, are migraine, tension-type headache and the combination of these.
- · Medication-overuse headache as a cause of specialist consultation (1 - 10%) is related to country income.
- · Other secondary headaches as a cause of specialist consultation (5-12%) are inversely related to country income.
- Management guidelines are in routine use in 55 % of responding countries worldwide. Usage is much less common in low-income countries.
- There are many widely available drugs for use against headache, generally reflecting their efficacy. They offer an adequate range, but with some obvious limitations.
- Among specific anti-migraine drugs, ergotamine is more widely available than triptans. The latter are more efficacious and less toxic, but more expensive.
- Drugs for use against headache are fully reimbursed in fewer than half of countries, with partial reimbursement for most in up to two thirds of countries.
- · Countries in all income categories identify non-availability of appropriate medication as a barrier to best management. This probably refers to limited reimbursement.
- Among alternative and complementary therapies, physical therapy, acupuncture and naturopathy are clear preferences, at least one of these being in the top three such therapies in all regions and all income categories.

#### Organization of headache services

A third of responding countries recommend, as a proposal for change, improved organization and delivery of health care for headache.

#### Education in headache

- Worldwide, just four hours are committed to headache disorders in formal undergraduate medical training, and 10 hours in specialist training.
- Better professional education ranks far above all other proposals for change (75% of countries that responded), and lack of education is seen as the key issue impeding good management of headache.

#### National professional headache organizations

- A national professional organization for headache disorders (or headache chapter in another organization) exists in two thirds of countries that responded. There is a very marked difference between high- and upper middle-income (71-76%) and low-income countries (16%).
- . The true figures may be much lower, as respondents were much more readily identified in countries where such organizations exist.
- Over one third of professional headache organizations arrange conferences, raise awareness of headache-related issues or are involved in setting guidelines in the management of headache disorders.
- · These are the top three activities in all regions and income categories.
- Fewer professional headache organizations (20%) participate in the construction of postgraduate training curricula, and only 10% do so in the development of undergraduate curricula on headache.

### CONCLUSIONS

Headache disorders are ubiquitous, prevalent, disabling and largely treatable, but under-recognized, under-diagnosed and under-treated. Illness that could be relieved is not, and burdens, both individual and societal, persist. Financial costs to society through lost productivity are enormous – far greater than the health-care expenditure on headache in any country.

Health care for headache must be improved, and education is required at multiple levels to achieve this. Most importantly, health-care providers need better knowledge of how to diagnose and treat the small number of headache disorders that contribute substantially to public ill-health. Given the very high indirect costs of headache, greater investment in health care that treats headache effectively, through well-organized health services and supported by education, may well be cost-saving overall.

# INTRODUCTION

Despite that headache is felt, at some time, by nearly everybody, and almost half the world's adults at any one time have recent personal experience of one or more of the three very common headache disorders (1), much is unknown about the public-health impact of these conditions. It is not known how, or how much, they affect many of the populations of the world, or how healthcare and other resources are utilized to mitigate their effects.

This first global enquiry into these matters, consulting specialist and general physicians and people who have headache, is an attempt to document from country to country, region to region, the responses to a public-health priority.

# **HEADACHE DISORDERS**

Headache is a painful feature of a number of primary headache disorders, two of which - migraine and tension-type headache are widespread, prevalent and often life-long conditions. These, together with medication-overuse headache, are disorders of substantial public-health importance because, collectively, they are the cause of much disability in populations throughout the world.

#### MIGRAINE

This is a disorder that almost certainly has a genetic basis (2), but environmental factors play a significant role in how it affects those who have it. Pathophysiologically, activation of a mechanism deep in the brain causes release of pain-producing inflammatory substances around the nerves and blood vessels of the head. Why this happens periodically in migraine attacks, and what brings the process to an end in spontaneous resolution of these attacks, are uncertain.

Usually starting at puberty, migraine is recurrent – in many cases throughout life. Adults with migraine describe episodic disabling attacks in which headache and nausea are the most characteristic features; others are vomiting and/or dislike or intolerance of normal levels of light and sound. Headache is typically moderate or severe in intensity, one-sided and/or pulsating, and aggravated by routine physical activity; it lasts for hours up to 2–3 days. Attack frequency is, on average, once or twice a month but can be anywhere between once a year and once a week, often subject to lifestyle and environmental factors that suggest people with migraine react adversely to changes in routine.

#### **TENSION-TYPE HEADACHE**

The mechanism of tension-type headache is poorly understood. It has long been regarded as a headache with muscular origins, but this may not be entirely correct (3). It may be stress-related or associated with musculoskeletal problems in the neck.

Tension-type headache pursues a highly variable course, often beginning during the teenage years and reaching peak levels in the 30s. Headache is usually mild or moderate, and generalized, described as pressure or tightness, like a band around the head, sometimes spreading into or from the neck. It lacks the specific features and associated symptoms of migraine. There are distinct sub-types although, in any individual, one may give way to the other. As experienced by very large numbers of people, episodic tension-type headache occurs, like migraine, in attack-like episodes. These usually last no more than a few hours but can persist for several days. Chronic tension-type headache is less common but, occurring by definition on 15 or more days every month, and sometimes unremitting over long periods, this variant is much more disabling.

### MEDICATION-OVERUSE HEADACHE

Chronic excessive use of medication to *treat* headache is the cause of this disorder (4), which also manifests as headache on 15 or more days every month. It is therefore wholly avoidable. All medications for the acute or symptomatic treatment of headache, in overuse, are associated with this problem, although the mechanism through which it develops undoubtedly varies between different drug classes. Frequency of use is important: even when the total quantities are similar, low daily doses carry greater risk than larger weekly doses.

Medication-overuse headache is oppressive, persistent and often at its worst on awakening in the morning. A typical history begins with episodic headache - migraine or tensiontype headache. The condition is treated with an analgesic or other medication for each attack. Over time, headache episodes become more frequent, as does medication intake. In the endstage, which not all patients reach, headache persists all day, fluctuating with medication use repeated every few hours. This evolution occurs over a few weeks or much, much longer. A common and probably key factor at some stage in the development of medication-overuse headache is a switch to pre-emptive use of medication, in anticipation of headache and with a wish to prevent it and its undesired consequences.

# INTRODUCTION

# **EPIDEMIOLOGY AND BURDEN**

Although headache disorders are among the most common of all health disorders (5), their epidemiology is only partly documented. Population-based studies have mostly focused on migraine which, although the most frequently studied, is not the most common headache disorder. Tension-type headache is more prevalent, while the group of headaches occurring on 15 or more days every month are generally more disabling, but both of these have received less attention. Furthermore, relatively few population-based studies exist for resource-poor countries. In these countries, limited funding and often largely rural (and therefore less accessible) populations, coupled with the low profile of headache disorders compared with communicable diseases, stand in the way of systematic collection of information.

Nevertheless, despite regional variations, there can be no doubt that headache disorders are highly prevalent everywhere, affecting people of all ages, races, income levels and geographical areas. Population-based data are in the process of being gathered, filling the knowledge gaps that exist in many of the world's regions. Present knowledge informs us meanwhile that migraine affects 11% of adults worldwide (1), with a three-times higher rate in women, which is hormonally-driven. Migraine is less common in children and in the elderly. Extrapolation from figures for migraine prevalence and attack incidence suggests that 3,000 migraine attacks occur every day for each million of the general population (6).

Episodic tension-type headache is the most common headache disorder, reported by over 70% of some populations (7). Worldwide its 1-year prevalence appears to vary greatly, with an average of 42% in adults (1), rather higher in women than in men. Chronic tension-type headache affects 1-3% of adults (1).

In terms of prevalence, medication-overuse headache far outweighs all other secondary headaches (8). This iatrogenic disorder affects more than 1 % of some populations (9), women more than men, and some children also.

Overall, the global prevalence among adults of current headache disorder (symptomatic at least once within the last year) is 47 % (1).

No significant mortality is associated with headache disorders, which is one reason why they are so poorly acknowledged. On the other hand, among the recognizable burdens imposed on people affected by headache disorders are pain and personal suffering, which may be substantial, impaired guality of life and financial cost. Above all, headache disorders are disabling: worldwide, migraine on its own is the cause of 1.3 % of all years of life lost to disability (YLDs) (10). Together, all headache disorders probably account for double this burden (1). Repeated headache attacks, and often the constant fear of the next, damage family life, social life and employment (11). Headache often results in the cancellation of social activities while, at work, people who suffer frequent attacks are likely to be seen as unreliable – which they may be – or unable to cope. This can reduce the likelihood of promotion and undermine career and financial prospects.

While those actually affected by headache disorders bear much of their burden, they do not carry it all. Employers, fellow workers, family and friends may be required to take on work and duties abandoned by headache sufferers. Because headache disorders are most troublesome in the productive vears (late teens to 50s), estimates of their financial cost to society - principally from lost working hours and reduced productivity due to impaired working effectiveness (12) - are enormous. In the United Kingdom, for example, some 25 million working- or school-days are lost every year because of migraine alone (6).

Therefore, while headache rarely signals serious underlying illness, the public-health importance of these headache disorders lies in their causal association with these personal and societal burdens of pain, disability, damaged quality of life and financial cost.

# **BARRIERS TO CARE**

Not surprisingly, headache is high among causes of consulting both general practitioners and neurologists (13, 14). One in six patients aged 16–65 years in a large United Kingdom general practice consulted at least once because of headache over an observed period of 5 years, and almost one tenth of these were referred to secondary care (15). A survey of neurologists found that up to a third of all their patients consulted because of headache – more than for any other single complaint (16). Far less is known about the public-health aspects of headache disorders in resource-poor countries. Indirect financial costs to society may not be so dominant where labour costs are lower, but the consequences to individuals of being unable to work or care for children can be severe. There is no reason to believe that the burden of headache in its humanistic elements weighs any less heavily where resources are limited, or where other diseases are also prevalent.

Yet there is good evidence that very large numbers of people troubled, even disabled, by headache do not receive effective health care (17). For example, in representative samples of the general populations of the United States of America (USA) and of the United Kingdom, only half of those identified with migraine had seen a doctor for headache-related reasons in the last twelve months and only two thirds had been correctly diagnosed (18). Most were reliant solely on over-the-counter medications, without access to prescription drugs. In a separate United Kingdom general-population questionnaire survey, two thirds of respondents with migraine were searching for better treatment than their current medication (19). In Japan, awareness of migraine and rates of consultation by those with migraine were found to be noticeably lower (20). Over 80 % of Danish tensiontype headache sufferers had never consulted a doctor for headache (21). It is highly unlikely that people with headache fare any better in resource-poor countries.

The barriers responsible for this vary throughout the world, but they may be classified as clinical, social or political/economic.

#### **CLINICAL BARRIERS**

Lack of knowledge among health-care providers is the principal clinical barrier to effective headache management. This problem begins in medical schools where there is limited teaching on the subject, a consequence of the low priority accorded to it. It is likely to be even more pronounced in countries with fewer resources and, as a result, more limited access generally to doctors and to effective treatments.

### SOCIAL BARRIERS

Poor awareness of headache extends similarly to the general public. Headache disorders are not perceived by the public as serious since they are mostly episodic, do not cause death and are not contagious. In fact, headaches are often trivialized as "normal", a minor annoyance or an excuse to avoid responsibility. These important social barriers inhibit people who might otherwise seek help from doctors, despite what may be high levels of pain and disability.

Surprisingly, poor awareness of headache disorders exists among people who are directly affected by them. A Japanese study found, for example, that many patients were unaware that their headaches were migraine, or that this was a specific illness requiring medical care (20). The low consultation rates in developed countries may indicate that many headache sufferers are unaware that effective treatments exist. Again, the situation is unlikely to be better where resources are more limited.

### POLITICAL/ECONOMIC BARRIERS

Many governments do not acknowledge the substantial burden of headache on society - and may even be unaware of it. They fail to recognize that the direct costs of treating headache are small in comparison with the huge indirect-cost savings that might be made (e.g. by reducing lost working days) if resources were allocated to treat headache disorders appropriately.

### PURPOSE OF THE ATLAS OF HEADACHE DISORDERS

Our view of the global burden attributable to headache disorders is incomplete, whilst our knowledge of health-care resource allocation to headache is scant. The Atlas of Headache Disorders, a project complementary to formal epidemiological studies, is part of defining the problem to be addressed. The purposes are to create awareness and, more importantly, to inform policy so that solutions can be proposed on the basis of knowledge.

This work is a key component of the Global Campaign against Headache (22).

# METHODS

The Atlas of Headache Disorders presents data acquired by WHO in collaboration with Lifting The Burden: the Global Campaign against Headache (22). Most of the information was collected in a large international survey performed from October 2006 until March 2009. Epidemiological data were compiled from published studies through a systematic review of all population-based studies performed up to May 2006 (1) and supplemented by data collected later through Global Campaign door-to-door surveys in China (23), India and the Russian Federation (24). The study by Stovner et al. provides the data sources and methodological details of the systematic review (1). The methods of the Global Campaign door-to-door surveys are described elsewhere (23, 24). Thus, only epidemiological data of sound provenance were accepted: i.e., those supported by peer-reviewed publication or, if not yet published, deriving from surveys of verifiably high quality.

### **QUESTIONNAIRE DEVELOPMENT**

To gather the survey data in a consistent manner from each of the countries, three questionnaires were drafted, in English, by a group of WHO and Lifting The Burden experts. These questionnaires had similar structure but were different in emphasis: one questionnaire was intended for headache specialists or neurologists ("neurology version"), one for primary-care physicians ("GP version") and one for representatives of people with headache ("lay version"). A glossary of terms used in the questionnaires was also prepared to ensure that all respondents would understand the questions in the same way.

The guestionnaires were piloted in one country in each WHO region, and changes made as necessary.

# **IDENTIFICATION OF** RESPONDENTS

A list of respondents was built initially from the International Headache Society's membership register, European Headache Federation member-organization contacts, representatives of World Headache Alliance lay-member organizations, International Headache Congress and European Headache Congress attendance lists, World Federation of Neurology contacts (from national neurological societies) and previous respondents to WHO's data collection exercises for the Atlas of Country Resources for Neurological Disorders and Atlas of Epilepsy Care in the World. A number of geographical gaps remained; to fill these, additional contacts were found during the survey, some through other respondents and some as authors of relevant recently-published articles.

The great majority of contacts located in these ways were headache specialists or neurologists. Each of these was asked to identify, if possible, likely respondents among primary-care physicians and lay representatives known personally to them.

# DATA COLLECTION

The appropriate questionnaire was sent by email, directly by the project team to each person on the respondent list and indirectly by some of these contacts to others.

Respondents were asked to follow closely the glossary definitions, in order to maintain uniformity and comparability of responses. Questions and requests for clarification were answered. Repeat invitations were sent whenever there was delay in procuring the completed questionnaire. When incomplete or internally inconsistent information was submitted, the respondents were asked for further details or clarification.

In cases of non-response after repeated reminders, simplified and shortened versions of the three questionnaires were sent.

# DATA MANAGEMENT AND ANALYSIS

All possible measures were taken to compile, code and interpret the information provided by countries using uniform definitions and criteria.

As they were received, data were entered into an electronic database applying suitable codes using Stata (special edition) version 8 software.

Analyses and group comparisons were made with SPSS 17 software. Values for continuous variables were analysed for frequency distributions and measures of central tendency (means, medians and standard deviations) were calculated as appropriate. Graphics were created using medians because of the skewed distributions of most data and, in some cases, occurrences of outliers.

Countries were grouped into the six WHO regions (African Region [AFR], Region of the Americas [AMR], Eastern Mediterranean Region [EMR], European Region [EUR], South-East Asia Region [SEAR] and Western Pacific Region [WPR]) and four World Bank income categories according to 2009 gross national income (GNI) per capita (low-income: US\$ 995 or less; lower middle-income: US\$ 996-3945; upper middle-income: US\$ 3946-12195; high-income: US\$ 12196 or more) (25).

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# REPRESENTATIVENESS

In full or simplified versions, the neurologist questionnaire was returned from 101 countries (in 65 cases the simplified version), the GP questionnaire from 47 countries (four simplified) and the lay questionnaire from 48 countries (16 simplified).

At least one questionnaire was obtained from each of 101 countries (figure 1.1): 18 in the African Region (39% of all countries in the region), 19 in the Americas (54%), 13 in the Eastern Mediterranean (62%), 38 in the European Region (72%), five in South-East Asia (46%) and eight in the Western Pacific (30%) (figure 1.2). These numbers might suggest less than 50% representation from three regions, but the data in fact pertained to 86% of the world's population: 71% of the population in Africa, 95% in the Americas, 83% in the Eastern Mediterranean, 86% in Europe, 82% in South-East Asia and 93% in the Western Pacific (figure 1.3).



Response rates (i.e., returns per contact made) for the neurologist questionnaire reflected country-income categories: the highest rate (77%) was from high-income countries, with other categories following in order: upper middle- (54%), lower middle- (46%) and low-income (38%). Response rates of GP and lay questionnaires are unknown since these were passed in many cases by neurologist-respondents to contacts known to them.

# RESULTS

# DATA QUALITY



FIG. 1.2 Country-based response rates (% of countries within each WHO region represented [any questionnaire returned] among responses)



FIG. 1.3 Population-based response rates (% of population within each WHO region represented [any questionnaire returned] among responses)

AFR = African Region AMR = Region of the Americas EMR = Eastern Mediterranean Region EUR = European Region SEAR = South-East Asia Region WPR = Western Pacific Region

# LIMITATIONS

No data were obtained from 92 (48%) of the 193 Member States. Although responding countries represented a large majority (86%) of the world's population, some bias was possible. Particularly in low-income countries it was difficult to identify likely respondents; it may therefore be expected that unrepresented countries are those where health services for headache are least developed. If this is so, the most disadvantaged countries are under-reported.

At most, six key persons in each country (but in many countries only one) were the source of all information other than epidemiological data. Many respondents, particularly those from large countries, found it difficult to complete the questionnaire since there might be significant variation from area to area within the country. Hence, answers from one respondent might not be representative of the whole country. Many of the originallyidentified contacts did not respond, and in some countries there was nobody known to work in the field of headache medicine. Hence, the level of headache expertise of respondents might vary considerably.

For other reasons, the quality of responses was probably quite variable. In some countries, some answers could be based on empirical studies (for example, of use of health-care resources for headache), whereas in other countries the questions could be answered only on the basis of clinical experience, or by extrapolation of data from nearby countries. For most countries, the scientific basis of the responses could not be known.

In spite of these limitations, the Atlas of Headache Disorders is the most comprehensive compilation of resources for headache in the world ever attempted.

### DATA ORGANIZATION AND PRESENTATION

The information is organized in eight themes and divided regionally and by income categories within each theme. Data are presented as graphics, world maps and written text. Bar and pie charts illustrate frequencies, medians or means as appropriate. Because the distributions of most of the data are skewed, the median has been used to depict the central tendency of most variables.

It has not been possible to present all the findings from the analyses. Limitations specific to each theme are to be kept in mind when interpreting the data and their analyses.

Implications of the findings for development of resources for headache care are highlighted within each theme.

THEMES

ATLAS OF HEADACHE DISORDERS AND RESOURCES IN THE WORLD 2011

# THEMES - EPIDEMIOLOGY

Epidemiological data were compiled from a systematic review of published literature (1) supplemented by data collected through Global Campaign door-to-door surveys in China (23), India and the Russian Federation (24). Only epidemiological data of sound provenance were accepted for this analysis: i.e., those deriving from surveys of verifiably high quality; expert estimates having no evidence base were not included (see Methods). The enquiry was limited to adults because relatively few data would be available for children and adolescents, and most studies focused on the age-range 18-65 years. Accordingly, the results summarized in table 2.1 are wholly from population-based studies that employed adequate methods, achieved acceptable response rates and used established diagnostic criteria (26, 27). The term "1-year prevalence" means percentage of the population reporting at least one headache episode meeting diagnostic criteria for the relevant headache disorder during the previous 12 months.

SALIENT FINDINGS

- Approximately half to three quarters of adults aged 18–65 years have had headache in the last year in studies from all regions except Africa, where the estimated 1-year prevalence is lower at 22 %.
- Migraine is reported, in these studies, in more than 10% of adults in this age range, except in Africa and Eastern Mediterranean.
- Headache on 15 or more days every month affects 1.7-4% of the world's adult population, according to these studies. Much

	Africa	Americas	Eastern Mediterranean	Europe	South-East Asia	Western Pacific
All headache	21.6	46.5	78.8	56.1	63.9	52.8
	(n = 2)	(n = 1)	(n = 2)	(n = 8)	(n = 1)	(n = 4)
Migraine	4.0	10.6	6.8	14.9	10.9	10.4
	(n = 2)	(n = 1)	(n = 2)	( <b>n</b> = <b>9</b> )	(n = 1)	( <b>n</b> = 6)
Tension-type headache	nr	32.6 (n = 1)	nr	80* (n = 2)	34.8 (n = 1)	19.7 (n = 3)
Medication-overuse headache (MOH)	nr	nr	nr	1.0 (n = 3)	1.2 (n = 1)	nr
Headache on ≥15 days/	1.7	4.0	nr	3.3	1.7	2.1
month (including MOH)	(n = 2)	(n = 1)		(n = 3)	(n = 1)	(n = 3)

TABLE 2.1 Mean 1-year prevalences (%) in adults aged 18-65 years of all headache, migraine, tension-type headache and medication-overuse headache from population-based studies by WHO region

n = Number of studies in the WHO region contributing to the reported mean.

nr = Not reported. This is indicative of lack of relevant studies rather than absence of the disorder. \* The discrepancy between 80% for tension-type headache and 56.1% for all headache arises because these are means of estimates from different studies. Those focusing on the former generally made greater effort to include infrequent tension-type headache (by definition occurring less than once a month), which is commonly unreported; those considering all headache might overlook this.

of this may be medication-overuse headache, but data on this are lacking from most regions.

In many countries, and some regions, the data are uncertain because of a scarcity of good epidemiological studies.

- The findings in table 2.1 confirm that headache disorders, including migraine and tension-type headache, are among the most prevalent disorders of mankind.
- Relatively few studies have included children or adolescents, and data from these are not presented. The focus on adults aged 18-65 years is not inappropriate from a public-health perspective as these are the productive years.
- Worldwide, migraine on its own is the cause of 1.3% of all years of life lost to disability (YLDs) (10). The burden of all headache disorders is substantially higher according to a systematic review of the published literature (1). Health-policy makers everywhere therefore need to be well informed about headache disorders in their countries. Yet, in many countries, and at least four of the six WHO regions, there are gaps in the knowledge needed to inform health-care policy. More high-quality epidemiological studies are required in order to fill these.

# RESULTS

# THEMES - IMPACT ON SOCIETY, AND NATIONAL DATA



# SOCIETAL IMPACT

Respondents were asked whether information was available on the impact of headache on society, including economic impact. In very few countries was this so. The responses are presented in figures 3.1-3.3.

### SALIENT FINDINGS

- Globally, information on the societal impact of headache exists in very few countries: only 18 % of those that responded (figure 3.2).
- Regional variations are marked: Europe has by far the most access to information, but still only in one third (32%) of countries. Following in order are the Americas (16%), Western Pacific (13%), Eastern Mediterranean (8%) and Africa (6%), with none in South-East Asia.
- A huge differential exists between high-income countries (still only one third, at 35 %) and all others (6-10 %) (figure 3.3).



FIG. 3.2 Countries with information on the societal impact of headache, worldwide and by WHO region (% positive responses among those responding)



(% positive responses among those responding)

# RESULTS

# THEMES - IMPACT ON SOCIETY, AND NATIONAL DATA



# NATIONAL HEALTH REPORTING

Respondents were asked whether headache disorders were included in an annual national health-reporting system or national expenditure survey. The results are presented in figures 3.4 and 3.5.

### SALIENT FINDINGS

- Worldwide, headache disorders are included in an annual health-reporting system in only 12% of countries that responded.
- There is variation between regions, but in none is the proportion higher than 18%. There is no consistent trend by income.
- Worldwide, headache is rarely included in national expenditure surveys: only 7 % of responding countries, all of which are within three regions - Eastern Mediterranean (15%), European (11%) and the Americas (5%). None are low-income countries.



FIG. 3.5 Countries including headache disorders in the annual health-reporting system, worldwide and by WHO region (% positive responses among those responding)

- Very few countries have nationally-derived data on impact of headache disorders, upon which adequate health-care provision for headache disorders is dependent.
- Population-based studies, which must be well-conducted if they are to be reliable, are needed in many countries throughout the world, in all regions, but especially in resource-poor countries. Ideally these should be performed in ways that allow comparison with other common and disabling disorders. Many studies are now underway within the Global Campaign against Headache (22).
- It would be highly informative to health policy if accurate information existed within countries on direct and indirect costs attributable to headache, given the huge disparity between the two (28, 29). However, little such information exists worldwide.

# RESULTS

# THEMES - HEALTH-CARE UTILIZATION

### SELF-TREATMENT VERSUS **PROFESSIONAL HEALTH CARE**

Respondents were asked to estimate the percentages of all people with headache who were primarily self-treating or consulting health professionals (primary-care physician [PCP], neurologist, alternative or complementary medicine practitioner or others). Their responses are summarized in figure 4.1.

### SALIENT FINDINGS

Worldwide, about 50 % of people with headache are estimated to be primarily self-treating, without contact with health professionals. However, some 10% are reportedly treated by neurologists, although fewer, as might be expected, in Africa and South-East Asia.

# **CONSULTATION RATES**

Neurologists and primary-care physicians were asked what percentages of consultations for headache in their settings were for each headache disorder. The responses are presented in figures 4.2 and 4.3.



FIG. 4.1 Estimated percentages of people with headache who are primarily self-treating or managed by health professionals, worldwide and by WHO region (medians of responses within regions)



FIG. 4.2 Estimated percentages of all headache consultations for each headache type worldwide (medians of responses, adjusted to total 100%)



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# THEMES - HEALTH-CARE UTILIZATION

FIG. 4.3 Estimated percentages of all headache consultations made for each headache disorder, in primary and specialist care, by WHO region (medians of responses within regions, adjusted to total 100%) (TTH: tension-type headache; M+TTH: combined migraine and TTH; MOH: medication-overuse headache; Other secondary: other secondary headache)

### A. AFRICAN REGION



#### **B. REGION OF THE AMERICAS**



### C. EASTERN MEDITERRANEAN REGION



D. EUROPEAN REGION



E. SOUTH-EAST ASIA REGION



F. WESTERN PACIFIC REGION



**RESULTS | THEMES | HEALTH-CARE UTILIZATION** 

# THEMES - HEALTH-CARE UTILIZATION

SALIENT FINDINGS

- Globally, the top three causes of consultation for headache, in both primary and specialist care, are migraine, tensiontype headache and the combination of these. Tension-type headache is the more prevalent disorder worldwide (see p 25), but consultation frequencies overall for migraine and tensiontype headache only partially reflect this difference. Migraine is associated with a higher probability (per person affected) than tension-type headache of consultation for headache, and more so in specialist than in primary care. Primary-care physicians, almost universally, are consulted more often for tension-type headache, which almost certainly reflects its greater prevalence. Specialists on the other hand see more migraine, probably a reflection of its relative severity (greater individual burden).
- Regionally, migraine is the most frequent cause of consultation for headache in responding countries of the Americas, Europe, South-East Asia and the Western Pacific. This is contrary to relative prevalences (see p 25) and again probably reflects relative individual burdens attributable to migraine and tensiontype headache. Tension-type headache is the more frequent cause for consultation, better reflecting prevalence, in the Regions of Africa and the Eastern Mediterranean.
- By income category, consultations for migraine rise from 20% of all headache consultations in low-income countries to 32 % in high-income countries. Conversely, and reflecting the regional variations noted above, consultations for tensiontype headache make up 25-30% of headache consultations in low- and lower middle-income countries and 18.5-20% in upper middle- and high-income countries. An explanation

does not appear to lie in regional prevalence variations, although epidemiological data are few from African and Eastern Mediterranean Regions and from resource-poor countries generally. Cultural differences may play a part. In addition, there are generally fewer neurologists in resource-poor countries, which may result in different diagnostic practices and, particularly, less usage of standard diagnostic criteria. However, the low denominators (few consultations overall for headache) should be kept in mind.

- Cluster headache is the cause of 1–3.8% of specialist consultations for headache. This is rather consistent across all regions and income categories. Expectation based on the prevalence of this relatively uncommon disorder is much lower than this, and the explanation undoubtedly lies in the extreme severity of this headache, demanding medical attention.
- Medication-overuse headache as the cause of specialist consultation rises from 1% in low-income countries to over 10% in upper middle- and high-income countries.
- Other secondary headaches as a cause of specialist consultation are inversely related to income category: 12% in lowincome countries, falling to 5% in high-income countries.

# **REMEDIABLE RISK FACTORS**

Respondents were asked to identify three treatable risk factors that were, in their view, of greatest importance for headache causation or aggravation.

#### SALIENT FINDINGS

- Globally, four categories of risk factor are rated of highest importance: social (20.8 %), including quality of life, domestic circumstances and life events; other medical conditions (15.8%), including hypertension, depression and infectious diseases; drugs or medications (12.9%), particularly medication overuse; and lifestyle factors (7.9%), for example substance abuse and dietary habits.
- Other medical conditions constitute the top remediable risk factor in low- and lower middle-income categories. This is in line with the finding, reported above, that secondary headaches are more commonly seen in resource-poor countries. Drugs and medications are the top risk factor in upper middleand high-income countries, which is consistent with the higher consultation rates in these countries for medication-overuse headache

- The proportion of people with headache estimated to be selftreating (about 50%) is not unexpected, given that much tension-type headache and some migraine manifests only as infrequent and/or mild attacks. Not everyone with headache would benefit from professional health care.
- This proportion is unlikely to change even with better health care; consequently, education of people with headache about how to treat their headaches effectively and efficiently is of considerable public-health importance. This is particularly relevant to the avoidance of medication overuse and risk of medication-overuse headache.

- On the other hand, if it is correct that about 10% of people with headache are seen by neurologists, this is far too great a proportion (30). These data appear robust, as they were supplied with a high degree of consistency by neurologists, primary-care physicians and lay representatives, but all these groups may have over-estimated numbers seen within the health system. The question specified people with headache, but was perhaps interpreted as patients with headache. Even if this were the case, there is a strong efficiency-based argument for expanding primary-care management of headache (30).
- The principal primary headaches generate most consultations for headache, both primary-care and specialist, in all regions and all income groups. Whilst secondary headaches assume greater importance in resource-poor countries, it is still primarily for migraine and tension-type headache that headache services throughout the world must cater.
- Cluster headache is important not for its prevalence but for its severity. Not all cases are coming to specialist attention. This is indicative of failure of headache services, and is equally true regardless of income category.
- Medication overuse is a behaviour dependent upon unrestricted access to medication. Better-resourced countries are more likely to provide this, and in these countries more medicationoveruse headache is seen. The implications are educational: better public awareness is required.

# RESULTS

# THEMES - DIAGNOSIS AND ASSESSMENT



FIG. 5.1 Estimated percentages of people with specific headache disorders who have been professionally diagnosed, worldwide and by WHO region (medians of individual responses)

# **DIAGNOSTIC RATES**

Respondents were asked to estimate the percentages of patients with migraine, tension-type headache or medicationoveruse headache who had been diagnosed by a health professional. The results are presented in figures 5.1 and 5.2.

#### SALIENT FINDINGS

- Globally, health professionals diagnose migraine and tensiontype headache in only about 40 % of people with these disorders, and medication-overuse headache in a small minority (10%) of cases.
- There are small regional variations: the lowest percentages are in the African Region, which may be a true finding but it is based on a low number of respondents.
- There is a consistent trend whereby the rate of diagnosis of migraine increases with income category, and an almost consistent similar trend for medication-overuse headache. There is no clear trend for tension-type headache.



FIG. 5.2 Estimated percentages of people with specific headache disorders who have been professionally diagnosed, by country-income category (medians of individual responses)

# RESULTS

# THEMES - DIAGNOSIS AND ASSESSMENT



# **USE OF DIAGNOSTIC CRITERIA**

Neurologist respondents were asked whether a set of explicit diagnostic criteria was routinely used, in specialist care, to support the diagnosis of patients with headache. Their responses are presented in figures 5.3-5.5.

### SALIENT FINDINGS

In specialist care, explicit diagnostic criteria are routinely used to support diagnosis of patients with headache in 56 % of countries that responded. The criteria cited were, invariably, International Headache Society criteria (either first (26) or second editions (27)). There is some regional variation, with usage in only a minority of countries that responded in African, Eastern Mediterranean and South-East Asia Regions. Low-income countries mostly do not routinely use explicit diagnostic criteria.



FIG. 5.4 Countries making routine use in specialist care of explicit diagnostic criteria to support headache diagnosis, worldwide and by WHO region (% positive responses among those responding)



FIG. 5.5 Countries making routine use in specialist care of explicit diagnostic criteria to support headache diagnosis, by income category (% positive responses among those responding)

# RESULTS

# THEMES - DIAGNOSIS AND ASSESSMENT

# **USE OF INVESTIGATIONS**

Respondents were asked to estimate the percentages of patients, in their settings, receiving specified investigations as part of the diagnostic or assessment procedures for headache disorders. The results of this are in table 5.6. Respondents were also asked to identify the principal reasons for conducting these investigations.

### SALIENT FINDINGS

- Investigation rates are generally high, more than is expected on the basis that headache disorders mostly do not require investigations either for diagnosis or assessment. This is particularly true of EEG.
- Regional variations are evident, especially for sinus and eye (refractory error) examinations.
- Globally, the most-reported reason for performing investigations in specialist care is to aid diagnosis (70%). This is the mostcited reason (≥55%) in all regions and for all income categories. Reassurance of patients and family members (20%) is less often cited, and frequency varies by region, from 10% in African to 40% in the Western Pacific Regions, and to a lesser extent by income, from 20% in low- and lower middleincome countries to 27.5 % in upper middle- and highincome countries. Also cited is avoidance of litigation (10%).

WHO region	MRI (%)		CT (%)		Sinus examination (%)		EEG (%)		CSF (%)		Refractory errors (%)	
	Ν	PC	N	PC	N	PC	N	PC	N	PC	N	PC
African (n = 17)	0	1	28	5	15	15	5	5	5	5	19	3
Americas (n = 19)	15	8	30	10	10	8	15	28	2	10	13	-
Eastern Mediterranean (n = 12)	10	2	60	10	18	28	13	5	5	5	10	25
Europe (n = 34)	10	3	30	4	10	5	9	1	2	1	5	7
South-East Asia (n = 5)	5	1	30	2	45	8	5	1	5	1	50	35
Western Pacific (n = 8)	23	20	20	64	10	30	13	55	1	15	8	13
World (n = 95)	10	3	30	5	10	10	10	5	3	1	10	8

TABLE 5.6 Estimated percentages of headache patients in specialist and primary care receiving specified investigations (medians of individual responses)

MRI = magnetic resonance imaging; CT = X-ray computed tomography; EEG = electroencephalography; CSF = cerebrospinal fluid examination; N = specialist (neurologist) care; PC = primary care; n = number of countries contributing data

### **USE OF ASSESSMENT INSTRUMENTS**

Neurologists were asked whether assessment instruments, either disease-specific or generic, were routinely used in their setting for quality of life or disability in people with headache. Their responses are shown in figures 5.7-5.9.



#### SALIENT FINDINGS

- Globally, assessment instruments are not widely used routinely in only 24% of countries that responded. The mostcited instruments are the MIDAS questionnaire (31-33) and HIT-6 (34, 35).
- Regionally there are wide variations. Estimates are uncertain because of low numbers of responders, but assessment instruments appear not to be routinely used at all for quality of life or disability in people with headache in the African or South-East Asia Regions.
- Low- and lower middle-income countries use these instruments less (5-12.5%) than upper middle- and highincome countries (29-43%).

# THEMES - DIAGNOSIS AND ASSESSMENT



FIG. 5.8 Countries making routine use in specialist care of an assessment instrument for quality of life or disability in people with headache, worldwide and by WHO region (% positive responses among those responding)



FIG. 5.9 Countries making routine use in specialist care of an assessment instrument for quality of life or disability in people with headache, by income category (% positive responses among those responding)

- To the extent that diagnosis rate reflects quality or reach of headache services, there is much room for improvement in all regions. Both educational and political remedies are needed.
- Low professional diagnostic rates are partially a consequence of poor resources, which may be reflected in lower availability of doctors (or health care more generally) and less usage of explicit diagnostic criteria. But this is far from being the whole cause, since diagnosis rate (as a percentage of prevalence) is higher for tension-type headache than for migraine in resourcepoor countries but the reverse is true in upper middle- and high-income countries. Explanations are speculative. Underdiagnosis of all headache disorders occurs everywhere, but better diagnosis of migraine in high-income countries may be the result of better availability of specific medications, perhaps coupled with pharmaceutical industry awareness campaigns. In some high-income countries, reimbursement policies favouring migraine over tension-type headache lead directly to relative over-diagnosis of migraine (or, rather, increase the likelihood that tension-type headache will not be recorded as a formal diagnosis).
- Medication-overuse headache is both preventable and remediable. As a chronic headache, typically present daily, it is a high cause of disability. It is also unlikely to resolve without medical care. The low diagnosis rate of 10% is a failure of health care that has important adverse health and economic consequences.

- Penetration of International Headache Society diagnostic criteria is high, but their usage is not universal and is low in low-income countries. Little is done to encourage their use in low-income countries. The remedy for this is educational, but this requires policy-support. Part of the problem is likely to be the complexity of ICHD-II, describing 200 headache entities in 160 pages (27). Translation of the full criteria requires considerable commitment of resources, and is unnecessary for management of most headache in primary care: a muchreduced set of criteria for about 15 core diagnoses is sufficient (36).
- Investigation rates may be driven by tradition, culture and expectation rather than clinical need. There is potential for substantial reductions, with resource savings.
- Assessment of impact of headache on an individual should be part of management. This is especially true where resources are limited, in order to direct them efficiently.
- Existing instruments are easy to use, but have very low usage. There is large potential for improvement globally, and particularly in resource-poor countries.
- Two simple instruments are apparently preferred, both of which are appropriate. MIDAS measures time lost to headache (31-33), which reflects disability. A more crossculturally acceptable version of this is the HALT index (37). HIT-6 assesses impact more broadly, including aspects of quality of life (34, 35). There is no reported use of pure quality-of-life instruments such as WHOQoL, and these may not be useful in routine clinical management of people with headache.

ATLAS OF HEADACHE DISORDERS AND RESOURCES IN THE WORLD 2011

# THEMES - TREATMENT



### **GUIDELINES**

Neurologist respondents were asked whether guidelines or recommendations for the management of headache disorders were routinely used in specialist care in their country. Their responses are shown in figures 6.1-6.3.

#### SALIENT FINDINGS

- Globally, guidelines or recommendations are in routine use in headache management in rather more than half (55%) of the responding countries. National guidelines are in use in 26 countries.
- Regional variation is marked: guidelines or recommendations are widely used - in three quarters of countries - in the Americas, Europe and Western Pacific, much less in Africa and barely at all in Eastern Mediterranean and South-East Asia Regions.
- These differences appear to be driven by the low-income countries (figure 6.3), which may be expected. About 40% of the world's population live in low-income countries.



FIG. 6.2 Countries making routine use of management guidelines or recommendations in specialist care of headache, worldwide and by WHO region (% positive responses among those responding)



FIG. 6.3 Countries making routine use of management guidelines or recommendations in specialist care of headache, by income category (% positive responses among those responding)

# THEMES - TREATMENT



FIG. 6.4 Availability of specific anti-migraine drugs worldwide (% positive responses among countries responding)

# AVAILABILITY OF MEDICATIONS

The main classes of drugs to treat headache disorders were listed in the questionnaires: analgesics, anti-emetics, specific anti-migraine drugs and prophylactic medications. Respondents were asked about availability and regulatory status of each, and reimbursement policy.

The listed analgesic drugs were paracetamol (acetaminophen), aspirin, other non-steroidal anti-inflammatory drugs (NSAIDs), barbiturate-containing analgesic compounds, opiates/opioids (including codeine or dihydrocodeine) and opioid-containing analgesic compounds.

The listed anti-emetic drugs were domperidone and metoclopramide, both of which are prokinetic (by enhancing gastric emptying) and particularly appropriate for migraine.

The listed specific anti-migraine drugs were ergots (ergotamine and dihydroergotamine) and triptans (almotriptan, eletriptan, frovatriptan, naratriptan, rizatriptan, sumatriptan and zolmitriptan).

The listed prophylactic drugs were beta-blockers, flunarizine, methysergide, pizotifen, valproate (sodium valproate, valproic acid or divalproex), tricyclic antidepressants and topiramate.

Results are set out in figures 6.4-6.9.



OTC = over-the-counter; GP = GP's prescription needed; SP = specialist's prescription needed FIG. 6.5 Regulatory status of specific anti-migraine drugs worldwide (% of countries responding)



FIG. 6.6 Reimbursement of specific anti-migraine drugs worldwide (% of countries responding)

# THEMES - TREATMENT



FIG. 6.7 Availability of prophylactic drugs worldwide (% positive responses among countries responding)



OTC = over-the-counter; GP = GP's prescription needed; SP = specialist's prescription needed

FIG. 6.8 Regulatory status of prophylactic drugs worldwide (% of countries responding)



FIG. 6.9 Reimbursement of prophylactic drugs worldwide (% of countries responding)

#### SALIENT FINDINGS

#### Analgesics

- Paracetamol and aspirin are available in all countries that responded, in all regions and all income categories. Other NSAIDs are available in two thirds (67 %). These drugs are almost always obtainable over-the-counter.
- Opiates/opioids are available in 65% of countries, barbituratecontaining analgesic compounds in half this number (33%). These drugs are mostly available only on prescription.
- Analgesics are reimbursed in about half of the countries that responded, with variations between drug classes.

#### Anti-emetics

- Metoclopramide is available in all countries (100%), domperidone in most (86 %). A doctor's prescription is usually needed, but purchase over-the-counter is possible in about one third of countries.
- These drugs are reported to be reimbursed in two thirds of countries.

#### Anti-migraine drugs

- The most widely available specific anti-migraine drug is ergotamine (96% of responding countries), closely followed by sumatriptan (93%) (figure 6.4). Of the other triptans, only zolmitriptan (66%) is in more than half of the responding countries. Rizatriptan (47%), eletriptan (45%) and naratriptan (44%) are similarly but less-widely available and almotriptan (22%) and frovatriptan (21%) reach fewer than one guarter of countries.
- All of these drugs are prescription-only (GP or specialist) in most countries, but ergotamine, notably, is obtainable overthe-counter in almost a quarter (23%) (figure 6.5). They are reimbursed at least in part in about two thirds of countries, but in full in only between one third and one half (figure 6.6).

#### Prophylactic drugs

- The most widely available prophylactic drugs are beta-blockers and tricyclic antidepressants (100% of responding countries), followed closely by sodium valproate (98%) and at increasing distance by topiramate (81 %), flunarizine (72 %), pizotifen (57 %) and methysergide (43%) (figure 6.7).
- All these drugs are prescription-only in most countries (figure 6.8). They are reimbursed, at least in part, in about two thirds of countries, but in full in fewer than half (figure 6.9).

# THEMES - TREATMENT



FIG. 6.10 Most preferred analgesic drugs for treatment of acute episodic migraine, worldwide and by WHO region (median % of individual responses)

# **USE OF MEDICATIONS**

Respondents were asked for their preferences among the drugs listed (not frequency of use, since reliable data on this were unlikely to be available).

### SALIENT FINDINGS

#### Migraine

- For treatment of acute episodic migraine, other NSAIDs (than aspirin) are, as a class, the most widely preferred drugs (86% of countries that responded). Paracetamol (69%) and aspirin (52%) follow. Both these drugs are listed by WHO as essential medicines for migraine and probably are the leading preferred single drugs (as opposed to drug classes) in all regions and income categories (figure 6.10).
- Metoclopramide is the preferred anti-emetic drug for acute episodic migraine (71 % of countries), and this held true in all regions except South-East Asia.

- Globally, the equally-preferred specific anti-migraine drugs are ergotamine (34% of countries that responded) and sumatriptan (33%) (figure 6.11). These overall numbers conceal marked regional differences, with ergotamine preferred in all but Europe and the Western Pacific, where sumatriptan leads (with four-fold preference in Europe).
- Beta-blockers are the preferred migraine prophylactic drugs worldwide (85% of countries) and in every region (figure 6.12). Tricyclic antidepressants (56 %) follow, second in all regions except Western Pacific. Sodium valproate (40%), topiramate (34%) and flunarizine (34%) are used less, with regional variations.

### **Tension Type Headache**

• For acute treatment of episodic tension-type headache, other NSAIDs (than aspirin) are, collectively, the most widely preferred drugs (87% of countries that responded). Paracetamol (75%) follows, but is probably the leading single drug in all regions and income categories. Aspirin (45.5%) appears to be less used.



(median % of individual responses)



FIG. 6.12 Most-preferred prophylactic drugs for migraine, worldwide and by WHO region (median % of individual responses)

FIG. 6.11 Ergotamine and sumatriptan are the most preferred specific anti-migraine drugs worldwide and in each WHO region

# THEMES - TREATMENT

# ALTERNATIVE OR **COMPLEMENTARY THERAPIES**

Respondents were asked to identify the three most frequently used alternative or complementary therapies for headache in their country. The responses are summarized in table 6.13.

#### SALIENT FINDINGS

- Physical therapy (44 % of countries that responded), acupuncture (39%) and naturopathy (25%) are the most frequent overall by a clear margin. At least one of these is in the top three such therapies in all regions and all income categories.
- Other alternative or complementary therapies in frequent use in at least some countries are biofeedback/relaxation, herbal preparations, traditional medicine, exercise or yoga, psychological therapies, religious forms of treatment, dietary alterations, Ayuverda, reflexology and aromatherapy.

WHO region	Acupuncture (%)	Naturopathy (%)	Physical therapy (%)
African (n = 18)	22	11	22
Americas (n = 19)	32	26	42
Eastern Mediterranean (n = 13)	31	15	23
Europe (n = 38)	50	32	68
South-East Asia (n = 5)	60	80	0
Western Pacific (n = 8)	38	0	38
World (n = 101)	39	25	44

n = number of countries responding

TABLE 6.13 The three most frequently used alternative or complementary therapies for headache, worldwide and by WHO region (% positive responses among responding countries)

- Guidelines, especially those developed locally and appropriate to local illness patterns, resources and culture, are expected to improve management and outcomes, and this is true at all resource levels. Most low-income countries do not routinely use guidelines, a finding that signals a major and low-cost opportunity for service improvement. However, these countries also have the fewest professional organizations (see pp 58-59) to help raise awareness of, or indeed develop, guidelines and recommendations.
- It is true, of course, that, if people with headache do not consult doctors, headache management guidelines for doctors lose relevance. In such circumstances, guidelines for other healthcare providers such as clinical officers and nurses may be as or more important.
- There are many widely available drugs, generally reflecting their efficacy and offering an adequate range. There is, therefore, good potential for effective management, using these drugs according to guidelines.
- When there is no or only partial reimbursement, a barrier is placed in the way of best management. Generally, the available drugs are fully reimbursed in fewer than half of countries (although at least partial reimbursement is offered for most drugs in up to two thirds of countries). Given the costeffectiveness of most drugs for headache (in that the indirect costs of inadequately-treated headache are very high (6, 12, 28, 29)), policies of wider reimbursement would be advisable.

- The most preferred drugs for acute treatment and prophylaxis of migraine are also the most widely available drugs (in >96% of responding countries), but they are not necessarily the most efficient. A particular example is ergotamine, which remains the most available specific anti-migraine drug worldwide, despite its removal from WHO's essential medicines list in 2005 (38). Ergotamine is low-cost compared with triptans and, although the differential cost has reduced since sumatriptan became available as a generic product, this appears to drive widespread preference for a drug with quite inferior efficacy (39). Furthermore, over-the-counter availability in about one guarter of countries raises concerns in view of its toxicity, accumulation and overuse potential (39). Triptans, especially sumatriptan, should be more widely available and more commonly used.
- Treatment of tension-type headache, when it is treated, is much the same everywhere. It is not known how much of it is treated, or how much needs to be treated: the symptoms of this disorder are, in many cases, mild and infrequent.
- Opiates/opioids are widely available, but do not feature as preferred drugs for either migraine or tension-type headache. This is correct. They are not particularly effective for either disorder, whilst opioid dependence, even with codeine or dihydrocodeine, becomes a clear risk in users of these drugs who have frequent headache episodes.

ATLAS OF HEADACHE DISORDERS AND RESOURCES IN THE WORLD 2011

# THEMES - PROFESSIONAL TRAINING



FIG. 7.1 Estimated numbers of hours of training in headache disorders in the undergraduate medical curriculum and in postgraduate neurology specialist training, worldwide and by WHO region (medians of individual responses)

### **UNDERGRADUATE AND POSTGRADUATE MEDICAL TRAINING**

Physician respondents were asked to estimate the number of hours of training in headache disorders in the formal undergraduate medical curriculum. Neurologists were additionally asked how many hours were spent on headache in postgraduate specialist training. The findings are summarized in figures 7.1 and 7.2.

Respondents were not asked about continuing medical education for primary-care physicians.

#### SALIENT FINDINGS

· Worldwide, just four hours are committed to headache disorders in formal undergraduate medical training, and 10 hours in specialist training. The latter in particular demonstrates regional variations, with more hours committed in the Americas and Europe. However, wide variations are reported between individual countries within all regions and income categories: from 0-20 hours of undergraduate medical training and from 0-720 hours of specialist training. The means (4.8 for undergraduate and 37 for specialist training) suggest the former is not strongly skewed but the latter clearly is. This probably reflects very differently structured training programmes for specialists; it may also reflect what is variably included within the definition of "training" (for example, clinical attachment to a specialist headache service).



FIG. 7.2 Estimated numbers of hours of training in headache disorders in the undergraduate medical curriculum and in postgraduate neurology specialist training, by country-income category (medians of individual responses)

- The key finding is that fewer than five hours of undergraduate training (in a course of 4-6 years' duration) are committed, on average worldwide, to a set of disorders that represent a high proportion of medical practice in both primary care and specialist neurology (40).
- Accordance of low priority to headache is why it is given little educational emphasis, which translates later into ineffective management and poor outcomes. Benefits that would accrue from good management are not seen, which appears to justify and therefore maintains, with a self-sustaining circularity, the initial low priority.
- Instead, better education will improve usage of available treatments and lead to better outcomes and lower overall costs.
- International and regional initiatives on headache education are needed. Because most headache should be treated in primary care, the emphasis should first be on undergraduate training, and then more on continuing medical education for general practitioners than on specialist training.

# RESULTS

# THEMES - NATIONAL PROFESSIONAL **ORGANIZATIONS**



Neurologist respondents were asked whether there was a national professional organization for headache disorders in their country. If there was not, they were asked if a headache chapter existed within another national professional organization (for example, for neurology). In either case, respondents were asked about the size (number of members) of these organizations or chapters and their activities (from a pre-specified list).

The reported results combine the two: there is no crucial difference between them (figures 8.1-8.6).



FIG. 8.2 Countries with either a national professional organization for headache disorders or headache chapter of another national organization, worldwide and by WHO region (% positive responses among those responding)



national organization, by income category (% positive responses among those responding)



FIG. 8.4 Size (number of members) of national professional organizations for headache disorders or headache chapters of other national organizations, by WHO region (medians of individual responses)

FIG. 8.3 Countries with either a national professional organization for headache disorders or headache chapter of another

# THEMES - NATIONAL PROFESSIONAL **ORGANIZATIONS**



FIG. 8.5 Size (number of members) of national professional organizations for headache disorders or headache chapters of other national organizations, by country-income category (medians of individual responses)



FIG. 8.6 Activities of national professional organizations for headache disorders or headache chapters of other national organizations (% positive responses among those responding)

### SALIENT FINDINGS

- A national professional organization for headache disorders, and/or headache chapter in another organization, exists in two thirds (67 %) of the countries that responded.
- Regionally, such organizations are most common in Europe (85% of countries) and the Americas (79%), less so in the Western Pacific (50%) and South-East Asia (40%) and least common in the Eastern Mediterranean (31 %) and Africa (28 %).
- There is a very marked difference between high- to lower middle-income countries (all in the range 71-76%) and lowincome countries (16%).
- Regional variation is apparent also in the size (number of members) of these national professional organizations or chapters. Judged by medians, the largest are in South-East Asia (median 85). Following in order are Europe (median 70), the Western Pacific (median 50), the Eastern Mediterranean (median 36), the Americas (median 30) and Africa (median 18). Large standard deviations in the Americas and Western Pacific indicate wide variations between countries.
- Size appears to correlate with country-income category: low (median 25 members), lower middle (median 21), upper middle (median 50) and high (median 113).
- Over one third of professional headache organizations or chapters arrange meetings or conferences (39%), raise awareness of headache-related issues (36%) or are involved in setting guidelines and/or recommendations for the management of headache disorders (35%). These are the top three activities in all regions and income categories, although not necessarily in that order. Meetings or conferences, as might be expected, are an income-related activity performed in 49% of responding high-income countries, 38% of upper and lower middle-income countries and only 21% of lowincome countries.
- Not so many organizations participate in the construction of postgraduate training curricula (20%), and even fewer do so in the development of undergraduate curricula on headache (0-15% by region, and 10% overall).
- Only 13% lobby governments on headache-related issues (0-25% by region, most commonly in the Western Pacific and Europe). Lobbying is income-related: most likely (16-19%) in high- and upper middle-income countries, less so (8%) in lower middle-income and least (5%) in low-income countries.
- Slightly more organizations (17%) advise governments on these issues (0-32% by region, most commonly in Europe and the Western Pacific).

- Since their top three activities in all regions are conferences, raising awareness of headache and guideline-setting, these organizations probably perform valuable roles in education and maintenance of standards of care, at least in specialist settings.
- National professional organizations also maintain links with international organizations, importing awareness of international standards and guidelines and knowledge of new research conducted worldwide. Almost all national organizations are member societies of the International Headache Society, which has a policy of offering free membership to interested health professionals working in the 100 poorest countries.
- Whilst national professional organizations for headache disorders appear to be common (existing in two thirds of responding countries), a large bias is likely: respondents were much more readily identified in countries where such organizations exist, and countries without them are certainly under-represented in the survey. If the denominator is taken to be all 193 WHO Member States rather than the 101 responding countries, the proportion with such organizations falls to 35 %, which is probably close to the truth. If so, there is considerable potential benefit in raising this to a much higher level, especially in low-income countries.
- Benefits at primary-care level are less certain. National professional organizations apparently have limited roles in promoting headache within formal training curricula but, of course, specialists have a key role in continuing medical education of primary-care physicians.
- Lobbying and advising governments is a minority activity, with an income-relationship that is probably the inverse of what is needed.

# THEMES - ISSUES

# ENCOUNTERED PROBLEMS

Neurologist respondents were asked to list up to five major problems encountered by health professionals involved in the care of people with headache in their setting in their countries. Their free-text responses were placed into 18 categories, shown in figure 9.1.

### SALIENT FINDINGS

• The reported major problems are diverse: at the top of the list are lack of professional education (34% of responding countries), patient-related problems including co-morbidities but excluding medication overuse (33%), headache-specific lack of health-care resources (33%), non-availability of appropriate medications (29%) and lack of public awareness (26%).

- Low- and lower middle-income countries focus more on lack of health resources generally, whilst upper middle- and highincome countries report lack of headache-specific resources.
- All income categories identify non-availability of appropriate medication. This is surprisingly the case in high-income countries, where the various drugs for headache are reported to be widely available within countries (see pp 46-49). Responses may reflect limited reimbursement, which restricts access by individual patients, rather than complete nonavailability. A number of responses refer specifically to high costs of medications. Others comment on lack of efficacy of prophylactics generally.

# SUGGESTED CHANGES

Neurologist and GP respondents were asked to list up to five major changes that would improve the care of people with headache in their countries. The responses, sorted into nine categories, are shown in figure 9.2.

#### SALIENT FINDINGS

- Among changes that would improve the care of people with headache, professional education is by far the highest on the list (75% of countries that responded).
- Next, recommended by almost half (49%) of responding countries, is awareness-raising, reflecting the under-recognition of headache referred to earlier.



FIG. 9.2 Changes suggested by health professionals to improve the care of people with headache disorders (% of countries responding)

# **IMPLICATIONS**

 Most problems encountered by neurologists and headache specialists reflect the low priority given to headache disorders and under-recognition of their impact. The effects of this low priority are seen throughout all sections of this Atlas of Headache Disorders.



(% of countries responding)

- About one third of countries list improved availability of health care (37%) and improved organization and delivery of health care (34 %) for headache.
- Other suggested changes are introduction of management aids, improved reimbursements, creation or support of professional societies, research, advocacy and lobbying, creation of lay support groups and better controls and regulation of medicines.

- Better education ranks far above all other proposals for change, and lack of education is seen as the key issue impeding good management of headache disorders. This issue is addressed above (see pp 54-55).
- In addition, better availability and better organization and delivery of headache services are widely called for.

# THE WAY FORWARD

Headache disorders are ubiquitous, prevalent, disabling and largely treatable, but under-recognized, under-diagnosed and under-treated. Illness that could be relieved is not, and burdens, both individual and societal, persist. Financial costs to society through lost productivity are enormous - far greater than the health-care expenditure on headache in any country.

The following messages, offering guides to the way forward, emerge from the survey reported here.

# POLITICAL WILL IS NEEDED

There is an urgent need for political recognition that the problem exists, and that it demands remedial action. This Atlas of Headache Disorders is intended to have this effect.

### **KNOWLEDGE GAPS MUST BE** FILLED

Knowledge to inform policy is still incomplete. Further wellconducted epidemiological studies, incorporating populationbased measures of individual and societal burdens, are needed in many countries, and especially in resource-poor countries.

# HEALTH CARE FOR HEADACHE MUST BE IMPROVED

It is reasonable that, worldwide, about 50% of people with headache are primarily self-treating, without contact with health professionals: much tension-type headache and some migraine manifests only as infrequent and/or mild attacks.

On the other hand, if diagnosis rate reflects quality and reach of headache services, which is likely, there is much room for improvement in all regions. As an example, medication-overuse headache is a high cause of disability, and both preventable and remediable, but unlikely to resolve without medical care. The low diagnosis rate (10%) is a failure of health care that has important adverse health and economic consequences.

Guidelines for diagnosis and treatment will support better management, particularly by non-experts in primary care. Many exist already; countries that lack them - especially lowincome countries - need only adapt these to be suitable locally. This is a low-cost opportunity for substantial service improvement.

The high rate of investigations to support diagnosis is not expected, since headache disorders mostly do not require investigations, either for diagnosis or assessment. Substantial reductions are possible, with resource savings.

Assessment of impact of headache is part of management, needed especially where resources are limited in order to direct them efficiently. Existing assessment instruments are easy to use. There is a large and low-cost opportunity for improvement through their wider usage, particularly in resourcepoor countries.

Diagnosis is likely to be improved if effective drugs are available and affordable since, arguably, there is little point in diagnosing when the appropriate treatment cannot be offered. In fact, many effective drugs exist, but countries in all income categories identify lack of access to them as a barrier to best management. In particular, triptans need to be more widely available, and used in preference to ergotamine, which not only has inferior efficacy but also raises concerns over toxicity, accumulation and overuse potential (see p 53).

Reimbursement is, for many people, the key to better access to drugs. Reimbursement has obvious cost implications, but these must be considered in full. Given the cost-effectiveness of most drugs for headache, policies of wider reimbursement appear sensible from a societal perspective.

### HEADACHE SERVICES MUST BE ORGANIZED

The disorders that cause most population ill-health are migraine, tension-type headache and medication-overuse headache. It is primarily for these disorders that headache services throughout the world must cater.

Headache services need to be delivered countrywide, efficiently and equitably to very large numbers of people who stand to benefit from them. Organization of services to achieve this is clearly a challenge, perhaps with no single, complete and universally-appropriate solution, but always their basis must be in primary care. This is where the great majority of people with headache are and should be managed. The proportion of 10% currently seen by specialists is far too great: specialist services are required by and should be reserved for only the very small minority who need them.

A strong efficiency-based argument therefore exists for expanding primary-care management of headache, and this is particularly so in countries where health-service reforms are, generally, shifting priority towards primary care.

# THE WAY FORWARD

### EDUCATION IS CENTRAL TO **REMEDIAL ACTION**

Accordance of low priority to headache means it is given little educational emphasis, which translates later into ineffective management and poor outcomes. Change can only follow recognition of the amount of ill-health these disorders cause, and reassessment of priority accordingly.

Education is required at multiple levels. Most importantly, healthcare providers need better knowledge of how to diagnose and treat the small number of headache disorders that are of publichealth importance. This better knowledge will improve usage of available treatments, produce better outcomes, avoid wastage and reduce overall costs.

Because most headache should be treated in primary care, emphasis should first be on undergraduate training, in medical schools, requiring changes to the undergraduate curriculum. Second, it should be on continuing medical education for general practitioners.

Worldwide, about 50% of people with headache are primarily self-treating, without contact with health professionals. Therefore, education of people with headache about how to treat their headaches effectively and efficiently is of considerable publichealth importance. In better-resourced countries especially, one focus of education should be the avoidance of medication overuse and its consequence of medication-overuse headache, itself a high cause of disability.

### NATIONAL PROFESSIONAL **ORGANIZATIONS SHOULD BE** SUPPORTED

National professional headache organizations, where they exist, have clear roles in promoting education, producing locally-relevant management aids, including guidelines, and importing knowledge and international standards through links to international groups.

Support for the establishment and maintenance of national professional organizations appears highly worthwhile.

### **GREATER INVESTMENT IN** HEADACHE SERVICES IS SENSIBLE

Given the very high indirect costs of headache, greater investment in health care that treats headache effectively, through well-organized health services and supported by education, may well be cost-saving overall.

# **KEY MESSAGES**

- Headache disorders are ubiquitous, prevalent and disabling. Yet they are under-recognized, underdiagnosed and under-treated worldwide:
- a minority of people with headache disorders are professionally diagnosed;
- management guidelines are used routinely in 55 % of responding countries, but much less commonly in low-income countries;
- despite there being a range of drugs with efficacy against headache, countries in all income categories identify non-availability of appropriate medication as a barrier to best management;
- worldwide, only four hours are committed to headache disorders in formal undergraduate medical training, and lack of education is seen as the key issue impeding good management of headache;

- illness that could be relieved is not, and burdens. both individual and societal, persist unnecessarily;
- financial costs to society through lost productivity are enormous.
- Among proposals for change:
- better professional education ranks far above all others;
- a third of responding countries also recommend improved organization and delivery of health care for headache.
- Given the very high indirect costs of headache, greater investment in health care that treats headache effectively may well be cost-saving overall.

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#### **Zimbabwe**

Jens Mielke

