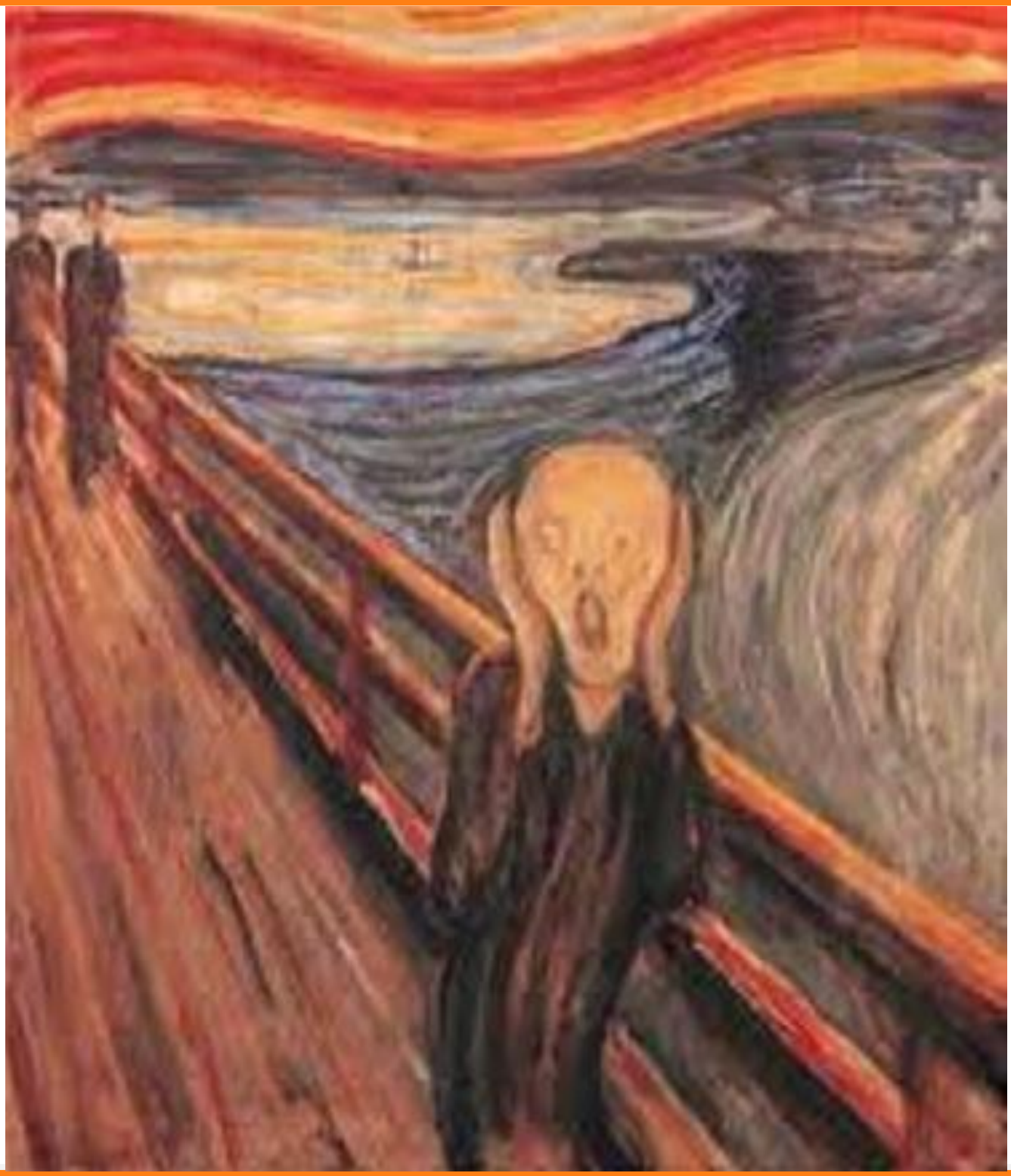
Health Consumer Powerhouse



Euro Headache Index 2012

Health Consumer Powerhouse

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2012

Report

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Health Consumer Powerhouse

2012-03-13

Number of pages: 49

ISBN 978-91-977879-8-7

Front cover picture, "The Scream" by
Edvard Munch, 1893.

Contents

Time for 50 million Europeans with headache to come out of the twilight!

As many as 50 million people around Europe suffer from a headache condition, more or less frequently. Though a severe migraine attack – to mention just one of many possible expressions of headache-related diseases – can be intolerable and even a matter of life and death to the sufferer, this huge group of conditions still exists in a kind of twilight. In spite of the number of sufferers and the severe conditions, headache is looked upon with a different mindset.

It is high time to deal with this dilemma!

Why is headache still less recognized as an illness? Why can headache be described as a "minor ailment" in a group of diseases containing also dandruff, acne or threadworm? There are possible explanations – at the same time indicating what needs to be done to move forward the perception and position of headache diseases.

There are no diagnostic tests giving numbers or other "hard facts" on whether a patient suffers from headache disorders. The basic headache diagnostic remains "asking questions to the patient". For this reason, there is a shortage of actual headache outcomes data to tell what are the best therapies and if prevention matters compared to other large diseases. This very first Euro Headache Index (EHI) tries to bring together many indicators, measuring how well – or bad – 29 European countries (the whole of EU adding Norway and Switzerland) handle the challenge from migraine and headache. Our extensive research points to a general lack of data and accepted definitions of headache-related attitudes, treatment and prevention.

The data shortage is quite evident when it comes to medical outcomes. No more than three out of 29 countries have organized some kind of national registry of headache, to support documentation and assessment of successful practices. Lack of such data is proven to hinder the development of national best practice and treatment programs. There is a clear connection between the lack of recognized guidelines and the perception of a disease.

The EHI project aims to raise awareness of headache in Europe. One basic strategy is to research if a "European standard" would be feasible, measuring to what extent certain qualities of care are available and what remains to be done to design a system for assessment and further policy development. We hope that this initial attempt will generate debate and contribute to more spotlight on these diseases, of vital, direct interest to not only many millions of Europeans but as well to health systems and to tax payers.

Since 2004, HCP has published more than 40 health consumer indices. They are all funded by unrestricted grants from various stakeholders. For the 2012 EHI HCP is gratefully acknowledging an unconditional educational grant from the European Headache Alliance.

Stockholm in March, 2012

Johan Hjertqvist

Founder & President
Health Consumer Powerhouse

1. Summary

Though severe headache-related conditions are not only very frequent but can also be devastating to sufferers and costly to society, there is a blatant lack of data around Europe to measure outcomes of prevention and treatment. The fundamental reason for this is that headache disorders lack diagnostic methods giving firm numerical data. The main diagnostic tool remains "asking questions to the patient".

The data shortage is so serious that this inaugural Euro Headache Index (EHI) - contrary to HCP methodology tradition – has been constructed mainly from the quality processes and procedures in each country, without any true outcomes indicators.

This means that the EHI is a somewhat different kind of benchmark, providing a snapshot of how headache is looked upon around our continent and how well –or bad – not only the healthcare systems but society as a whole adjusts to the needs of people with headache conditions.

Given this lack of Outcomes data, otherwise normally essential for a HCP Index, not only the data mining but the identification and terminology issues have been quite a challenge to the EHI project. Working out what type of indicators to present in order to understand what is really offered to patients or citizens suffering from headache or migraines proved a tough task (for instance, creating a universal interpretation of basic terms such as "headache clinic").

The 2012 EHI report takes its readers through the main elements of the Index such as the background, the countries involved, the results of the Index, the evolution of the index itself and the way it was built.

The overall picture provided by this very first EHI? Some highlights:

- Headache sufferers often have a weak position in spite of being generally supported by patients' rights, as quality information about therapies and care providers is rare and severe headache seldom seems to be a recognized condition for a disability pension.
- The education and training of doctors in most countries seems to pay no or little attention to headache and migraine. The awareness of the severity of these conditions is reported to be weak in many countries. National registries for headache are in reality non-existent.
- There are huge variations around Europe when it comes to the number of neurology specialists and whether patients can count on an easy referral by their GP.
- There is evidently no pan-European best practice on the use of pharmaceuticals for therapy, with dramatic variations in prescription of what should be regarded standard medication.
- There seems to be interesting correlations between the prevalence of headache diseases and "quality of life"-indicators such as unemployment rates and work-related stress.

How do the 29 compared countries come out of the 2012 EHI ranking? The Netherlands emerges as the overall winner, with a score of 845 points (out of potentially 1 000 points). Alongside with Germany (825 points) and Denmark (817), followed by Austria (793), France (792), Sweden (769), and Switzerland (769), the Netherlands provide the best headache provision for its citizens in terms of information, patient rights access, professional awareness, treatment and prevention.

Among patient rights, information and e-health in the field of headache and migraine, the top countries were the UK, Switzerland, Netherlands, Hungary, Finland and a few other countries. As for the sub-discipline on professional awareness and education, France is ranked highest with 150 points, followed by Germany and Denmark (136 for both countries). The top three countries scoring the highest in terms of access to headache or migraine-related healthcare are Austria, Bulgaria and Germany. These countries scored 204 in this sub-discipline. They were closely followed by the Netherlands, Hungary, Italy and Belgium.

On the sub-discipline "Medication / Treatment", with indicators such as the sales of Triptans (the standard drugs to shorten the duration of migraine attacks), the availability of prophylactic drugs (and their co-payment), prevalence of medication over-use-induced headache and detoxification – the UK scored the highest (260 points), followed by the Netherlands, Denmark and Switzerland.

And for the last set of indicators under the sub-discipline "Prevention", the countries that score highest are the ones already mentioned above: The Netherlands as the winner of the sub-discipline, followed by Austria, Sweden and Norway. Most of these countries are those with low unemployment rates and are also ranked as "happy" nations, with comparatively lower work-related stress.

2. Background

2.1 The impact of headache in Europe

Headache is the most prevalent neurological symptom and is experienced by almost everyone. Headache can be a symptom of a serious life-threatening disease, such as a brain tumour, but in most cases it is a benign disorder that comprises a primary headache such as migraine or tension-type headache (TTH). Nevertheless, migraine and TTH can cause substantial levels of disability, not only to patients and their families but also to society as a whole owing to its high prevalence in the general population.

Unfortunately, the scope and scale of the burden of headache is underestimated, and headache disorders are universally under-recognized and undertreated.[1] An important initiative, ***Lifting the Burden: The Global Campaign to Reduce the Burden of Headache,*** focuses on these widespread aspects of headache and is a collaboration between multinational health-care organisations and professionals to raise awareness of headache disorders in general. Another initiative, ***Cost of the Brain Disorders in Europe***, includes migraine as a separate neurological disorder that ranks as number nine on the list of the most costly neurological disorders in both sexes, and as number three in women. TTH is the most common form of headache and is often thought of as a "normal" headache, in contrast to debilitating and characteristic migraine attacks or cluster headaches. Owing to its high prevalence, disability due to TTH is greater than that for migraine at the population level.[3] Headache is among the ten most disabling disorders for both sexes and, if the burden of TTH is taken into account, among the five most disabling disorders for women, in accordance with the WHO's ranking of the most disabling disorders[2].

Limited data is available so far on headache disorders. In 2004 WHO identified **headache** as the **most frequently reported neurological disorder** in primary care in Europe. Primary headaches are **highly prevalent, disabling**, **underestimated**: up to one adult in 25 has headache every or nearly every day. WHO classified migraine alone as 19th century among all causes of years lived with disability (YLD). All **headache disorders** together are possibly in the **top five causes of disability worldwide.** The ECHI (European Community Health Indicators) project, funded by the EU Public Health Programme, has compiled generic data on migraine or frequent headaches only including 12-month prevalence, by gender, age, region, SES (Socio Economic Status) and the WHO Atlas on Country resources has focused on the compilation of data on the frequency of primary and secondary care of headache in Europe. To date only pharmaceutical companies have drawn-up some evaluation on parts of the global burden of headache. There is **no data at European level on prevalence and global impact of headache[3]**.

Headache disorders vary in severity, incidence and duration with a lack of public/ professional awareness of their epidemiology (burden/risk) and impact on sufferers, carers, family, colleagues and society. Headache, particularly chronic and recurrent headaches are a major liability in the quality of life in Europe. Over 12 percent of the general population (2/3 females) have regular migraine attacks. People with migraine score high on scales of general physical and mental-ill health. According to the WHO disability assessment, the disability of a day with severe migraine is in the highest disability category, the same disability category than quadriplegia (i.e. paralysis from the shoulders and below). Social and work capacities are reduced in almost all migraine sufferers and in 60 percent of the TTH sufferers. Migraine costs alone are estimated in EU-25, Norway, Iceland and Switzerland at EUR 27 billion (2004 "Cost of disorders of the Brain", European Brain Council (EBC).

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[1] Rigmor Jensen, Lars J Stovner, ***Lancet Neurol* 2008; 7:** 354–61.

[2] Stovner L, Hagen K, Jensen R, et al. The global burden of headache: a documentation of headache prevalence and disability worldwide. ***Cephalalgia* 2007; 27:** 193–210.

[3] EUROLIGHT; key project document (http://www.eurolight-online.eu/, last accessed 14 September 2012)

2.2 Headache/migraine as "minor complaints"

The public and majority of healthcare professionals perceive headache as a minor complaint, an excuse for absenteeism and that simple analgesics suffice. Headache predominates in women and sufferers have a normal life expectancy: this may explain that headache patients perceive less attention in resources than deserved and that physical, emotional, social and economic burdens of headache are poorly acknowledged compared to less prevalent neurological disorders.

Another reason why headache is perceived as a minor complaint is that there are few "objective" diagnostics such as X-ray images or laboratory tests to diagnose headache disorders. The main diagnostic tool remains "asking questions to the patient", which gives less conclusive results and, unfortunately, more room for derision of sufferers. As indicated by the EHI, there are evident risks that the lack of "hard" outcomes data affects the perception of the severity of headache conditions and offers opportunities to downgrade the consequences of these diseases, as the following example suggests:

The slides shown below are from a study commissioned by a national healthcare body in a major EU member state. They have been anonymised, as the purpose of including them is not to stigmatise a particular country, but rather to illustrate an endemic problem for headache/migraine sufferers: these conditions can be severely debilitating! To then find them listed in company with, among others, dandruff and fungal nail infections proves that headache conditions are associated with a serious communication problem. If not bagatellised, headaches/migraines are seen as cost problems, as is illustrated by the following slides (figure 1 – 3) from the same study.

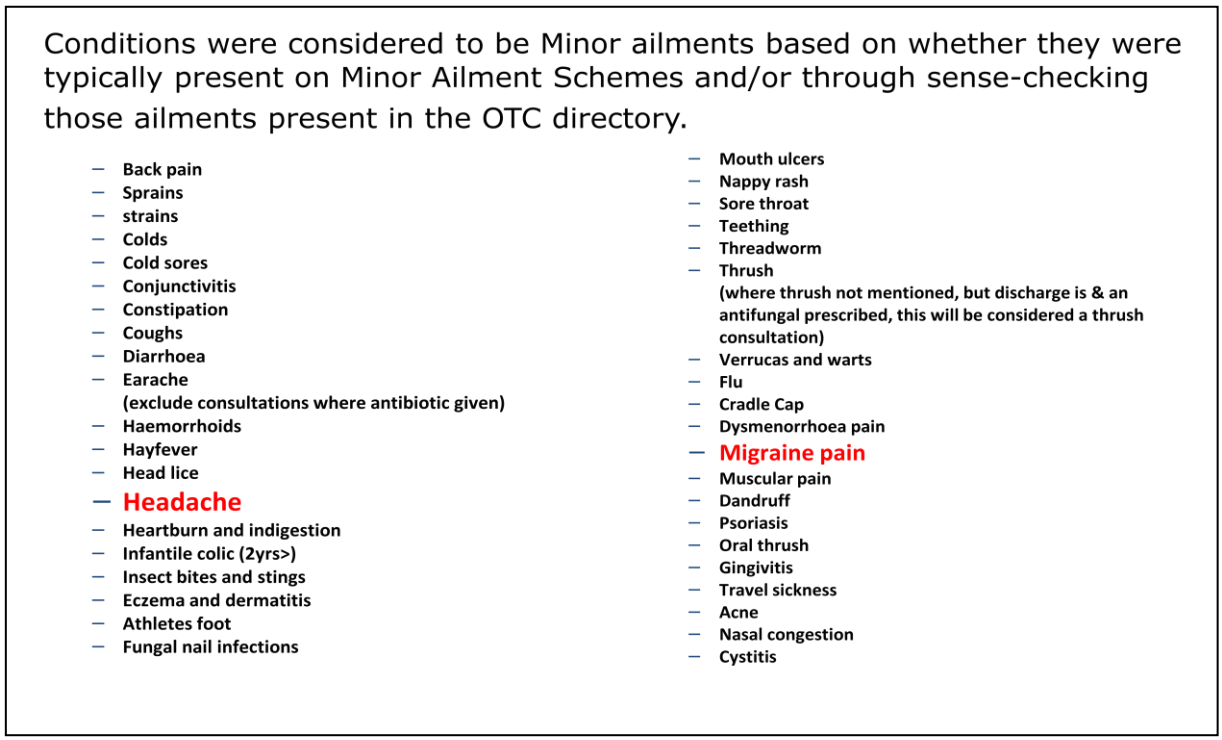


Figure 1: The Minor Ailment List (IMS presentation, PAGB: Driving Self Care, 23 March 2010)

The top 10 Minor Ailments are responsible for over 75% of all minor ailment consultations

MA	Total consultations (millions)
Back Pain	8.4
Dermatitis*	6.8
Heartburn and indigestion	6.8
Nasal Congestion	5.3
Constipation	4.3
Migraine	2.7
Cough	2.6
Acne	2.4
Sprains and Strains	2.2
Headache	1.8
Earache	1.7
Psoriasis	1.7
Conjunctivitis	1.3
Sore Throat	1.2
Diarrhoea	1.2
Haemorrhoids	0.9
Cystitis	0.7
Hay Fever	0.7

Warts and Verrucas	0.6
Nail Infections	0.4
Common Cold	0.4
Influenza	0.3
Dysmenorrhoea	0.3
Thrush	0.3
Infantile Colic	0.2
Insect bites	0.2
Mouth Ulcers	0.2
Athlete's Foot	0.2
Muscular Pain	0.2
Oral Thrush	0.2
Threadworm	0.1
Nappy Rash	0.1
Head Lice	0.1
Gingivitis	0.04
Dandruff	0.04
Cold Sores	0.04
Cradle Cap	0.02
Travel Sickness	0.02
Teething	0.02

- Through focusing on the 'major' MA categories, a large number of GP consultations could be saved

Figure 2: The Top 10 Minor Ailments (IMS presentation, PAGB: Driving Self Care, 23 March 2010)

Minor Ailments with the most consultations are also largely responsible for th greatest cost in terms of prescriptions

MA	Total Rx cost (millions)	Total Rx (millions)	Average Rx cost	Total consultations (millions)
Back Pain	£64.0	7.8	* £8.23	8.4
Heartburn and indigestion	£54.0	6.7	£8.07	6.8
Migraine	£51.9	2.6	£19.68	2.7
Dermatitis	£35.3	6.7	£5.30	6.8
Acne	£25.7	2.3	£10.96	2.4
Psoriasis	£22.2	1.6	£13.70	1.7
Constipation	£22.2	4.2	£5.31	4.3
Nasal Congestion	£17.4	5.2	£3.36	5.3
Sprains and Strains	£12.1	1.8	£6.86	2.2
Headache	£11.7	1.5	* £8.03	1.8
Cough	£9.0	2.2	£4.18	2.6
Nail Infections	£4.7	0.4	£12.92	0.4
Haemorrhoids	£4.6	0.8	£5.59	0.9
Diarrhoea	£4.4	0.8	£5.25	1.2
Cystitis	£3.6	0.7	£5.28	0.7
Sore Throat	£3.6	0.9	£3.91	1.2
Conjunctivitis	£3.4	1.2	£2.81	1.3
Earache	£3.3	1.2	£2.74	1.7
Hay Fever	£2.3	0.7	£3.37	0.7

- **Migraine and psoriasis products are particularly expensive when compared to products prescribed for othe MAs**
- **The prescription costs of cough treatments are relatively low when compared to the other 'major' MAs**

*The high average Rx cost for headaches is due to prescribing of triptans under "headache" consultations, and significant use more expensive items such as; Paramax, Paracetamol soluble, co-codamol 30mg, propranolol etc.
Back pain has a high average Rx cost due to significant usage of slow release & combination NSAID products e.g. Arthrotec

Figure 3: Minor Ailments with the most consultations (IMS presentation, PAGB: Driving Self Care, 23 March 2010). *Dermatitis includes all forms of dermatitis (e.g.contact, atopic, ingestion, seborrhoeic) and eczema (e.g. atopic, dry, and infantile)

2.3 Purpose of the Euro Headache Index 2012

There are several purposes for researching headache provision throughout the EU, Norway and Switzerland. The main objectives have been:

- Provide a reality check of migraine and headache treatment conditions around Europe
- Build awareness and understanding among European stakeholders of headache disorders to increase the priority given to treatment of these illnesses
- Boost research of actual outcomes data
- Improve access to appropriate treatment and care – many sufferers do not seek medical assistance:
    - Increase the percentage of migraine patients in the care of a physician
    - Increase the number of patients receiving effective therapy for acute migraine attacks
    - Increase the access to migraine prevention therapy
    - Promote information and education of sufferers, the public and physicians through open headache treatment policy benchmarks
    - Promote research on headache and migraine and related areas
- Adding to the existing platform for cooperation, aligning the efforts of national migraine patient groups in Europe.

2.4 Countries involved

This research study encompassed all EU countries (27) and two well-off reference countries: Norway and Switzerland, adding up to 29 countries in all.

3. Results of the Euro Headache Index 2012

Euro Headache Index 2012

Sub-discipline	Indicator	Austria	Belgium	Bulgaria	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy	Latvia
1. Patient rights and information & E-Health	1.1 Existence of a headache* patient organization															
	1.2 Right of patient organizations co-determination															
	1.3 Can pharma companies inform direct to patients about Rx drugs															
	1.4 Patient headache diaries downloadable															
	1.5 Access to reliable, accurate headache information															
	1.6 Right to choose among providers in country of residence															
	1.7 Quality information about headache care providers (hospitals/clinics/centers)?															
	1.8 Compensation for absenteeism due to headache*?						n.a.							n.a.		
	1.9 Is headache* a recognized condition for getting a disability pension?						n.a.							n.a.		
	Weighted sub-discipline score	170	163	104	104	141	170	141	178	163	170	141	178	133	141	141
2. PROFESSIONAL AWARENESS AND EDUCATION	2.1 Existence of a National Registry for Headache?															
	2.2 Availability of reliable national epidemiological data on the prevalence of headache disorders*															
	2.3 Is there a national headache society (for doctors)?															
	2.4 Is there an official set of national guidelines for headache															
	2.5 Is there a fixed set of diagnostic criteria (IHS) available to healthcare professionals? Is it available in the national															
	2.6 Existence of a module in headache/migraine care in medical school (pregraduate) training curricula (before															
	2.7 Existence of a module in headache/migraine care in neurological specialist training															
	Weighted sub-discipline score	107	93	100	79	121	136	93	100	150	136	114	100	93	121	100
3. ACCESS TO HEALTHCARE	3.1 # of specialized centers for headache p.m.p.				n.a.			n.a.								
	3.2 # of members of national headache society(-ies) p.m.p.								n.a.	n.a.				n.a.		n.a.
	3.3 Neurology specialists p.m.p.															
	3.4 Modalities of access to a headache specialist (w or w/o referral; "GP gatekeeping")															
	3.5 Is there a special unit for detoxification?															
	3.6 Mode of admission for detoxification?															
	3.7 Emergency room visits for headache*															
	3.8 Availablility of specialist headache* nurses															
	3.9 Waiting time for accessing a headache* specialist or neurologist on the secondary level				n.a.											
	Weighted sub-discipline score	204	194	204	139	167	176	130	167	176	204	167	194	148	194	167
4. MEDICATION / TREATMENT	4.1 TRIPTANS (sales per capita)				n.a.			n.a.								n.a.
	4.2 Availablity of prophylactic drugs				n.a.											
	4.3 Co-payment for prophylactics?				n.a.					n.a.						
	4.4 Is "medication over-use" an approved indication for referral for detoxification?				n.a.		n.a.							n.a.		
	4.5 Prevalence of Medication Over-use-induced Headache															
	Weighted sub-discipline score	220	240	180	100	240	260	140	220	220	240	180	180	160	200	140
5. Prevention	5.1 Work-related stress															
	5.2 Unemployment rate															
	5.3 Happy-Life Years															
	5.4 Hard liquor consumption per capita															
	Weighted sub-discipline score	92	67	75	58	67	75	33	67	83	75	58	50	67	75	33
	Total Score	793	757	662	479	736	817	537	731	792	825	660	702	601	732	581
	Rank	4	9	17	29	11	3	26	13	5	2	18	14	23	12	24

Euro Headache Index 2012

Sub-discipline	Indicator	Austria	Lithuania	Luxembourg	Malta	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	United Kingdom
1. Patient rights and information & E-Health	1.1 Existence of a headache* patient organization															
	1.2 Right of patient organizations co-determination															
	1.3 Can pharma companies inform direct to patients about Rx drugs															
	1.4 Patient headache diaries downloadable															
	1.5 Access to reliable, accurate headache information						n.a.									
	1.6 Right to choose among providers in country of residence															
	1.7 Quality information about headache care providers (hospitals/clinics/centers)?															
	1.8 Compensation for absenteeism due to headache*?												n.a.			
	1.9 Is headache* a recognized condition for getting a disability pension?						n.a.						n.a.			
	Weighted sub-discipline score	170	96	119	133	178	148	163	141	119	178	170	119	170	185	185
2. PROFESSIONAL AWARENESS AND EDUCATION	2.1 Existence of a National Registry for Headache?						n.a.									
	2.2 Availability of reliable national epidemiological data on the prevalence of headache disorders*						n.a.									
	2.3 Is there a national headache society (for doctors)?															
	2.4 Is there an official set of national guidelines for headache						n.a.									
	2.5 Is there a fixed set of diagnostic criteria (IHS) available to healthcare professionals? Is it available in the national						n.a.									
	2.6 Existence of a module in headache/migraine care in medical school (pregraduate) training curricula (before						n.a.						n.a.			
	2.7 Existence of a module in headache/migraine care in neurological specialist training						n.a.						n.a.			
	Weighted sub-discipline score	107	86	79	100	121	64	100	129	100	136	100	100	121	100	121
3. ACCESS TO HEALTHCARE	3.1 # of specialized centers for headache p.m.p.			n.a.	n.a.		n.a.				n.a.	n.a.	n.a.			
	3.2 # of members of national headache society(-ies) p.m.p.		n.a.						n.a.				n.a.			
	3.3 Neurology specialists p.m.p.												n.a.			
	3.4 Modalities of access to a headache specialist (w or w/o referral; "GP gatekeeping")															
	3.5 Is there a special unit for detoxification?						n.a.									
	3.6 Mode of admission for detoxification?						n.a.						n.a.			
	3.7 Emergency room visits for headache*															
	3.8 Availablility of specialist headache* nurses						n.a.									
	3.9 Waiting time for accessing a headache* specialist or neurologist on the secondary level						n.a.						n.a.			
	Weighted sub-discipline score	204	185	167	148	194	120	157	130	130	204	157	111	157	185	117
4. MEDICATION / TREATMENT	4.1 TRIPTANS (sales per capita)		n.a.		n.a.						n.a.	n.a.				
	4.2 Availablity of prophylactic drugs												n.a.			
	4.3 Co-payment for prophylactics?												n.a.			
	4.4 Is "medication over-use" an approved indication for referral for detoxification?						n.a.		n.a.				n.a.			
	4.5 Prevalence of Medication Over-use-induced Headache															
	Weighted sub-discipline score	220	120	180	160	260	200	180	160	140	180	180	120	240	240	260
5. Prevention	5.1 Work-related stress						n.a.								n.a.	
	5.2 Unemployment rate														n.a.	
	5.3 Happy-Life Years															
	5.4 Hard liquor consumption per capita															
	Weighted sub-discipline score	92	33	83	83	92	83	67	58	67	42	67	67	83	58	75
	Total Score	793	521	627	625	845	616	667	617	555	739	674	516	773	769	758
	Rank	4	27	19	20	1	22	16	21	25	10	15	28	6	7	8

3.1 Summary of Results: The Total Scores

The scoring has intentionally been done in such a way that the likelihood that two states should end up sharing a position in the ranking is almost zero. It must therefore be noted that great efforts should not be spent on in-depth analysis of why one country is in the 14th place, and another in the 21st. Very subtle changes in single cores can modify the internal order of countries, particularly in the middle of the ranking.

The EHI 2012 total ranking of countries shows a victory for The Netherlands, scoring 845 out of 1000, 20 points ahead of runners-up Germany, scoring 825 points, closely followed by Denmark, 817 points, Austria, 793 points, France, 792 points, Sweden 773, Switzerland 769 points, and so on.

The Netherlands and Germany seem to have seriously tackled the issue of headache and migraine in their countries and have worked out the best way to provide care provision to its sufferers. The situation is similar in the countries that score high on the HCP scale.

The other countries fall behind for various reasons as described under each indicator. One of the main reasons is that there are no "real" headache centers.

In a medical speciality with weak methodology and guidelines, even defining what a "headache center" is and how different nations interpret the meaning of a "headache specialist" (when one can hardly specialize in this domain), the need for a common infrastructure and set of values and perceptions is vital. HCP has noted that there are numerous activities in the direction of universally accepted definitions of headache centers, headache nurses and education, largely described and presented by renowned European Headache Specialists and EU Projects on Headache, as noted already in the Background section of this report.

In many of the countries headache sufferers would normally see a neurologist, who oftentimes is too busy with "more serious illnesses or those that bring in money to the hospitals". It is rare a patient with headache would be kept overnight on a hospital bed. Many headache cases are treated on the GP level and / or in an outpatient clinic. It is also quite common that headache sufferers do not take their symptoms seriously enough but would seek real medical help after suffering even ten years in average. Headache is a major problem of the modern society and is closely linked to stress, different types of foods, menstrual cycles and so on.

What is interesting is that those countries that scored high on the Happy-life Years indicator also use less medication and have a lower unemployment rate. These countries are mainly the ones that have the highest over-all scores in the EHI.

Germany, the runner-up, is famous for its "pains clinics" where headache and migraine patients are treated. Germany does really well in terms of "Professional awareness and education", finishing right behind the winner of this sub-discipline, France. Italy, the country with the highest number of Headache Centers according to the EHI definition, takes up the 5th position after Germany, Bulgaria, Austria and the Netherlands. Bulgaria in this sub-discipline comes right along the same level as Germany and Austria (204 points each country). In terms of prevention, Austria and The Netherlands share the gold medal.

There are some other interesting countries in this Index – for instance, Lithuania has the highest number of neurologists per capita (as one of the indicators under the sub-discipline Access to Healthcare) but scores poorly on almost all other indicators. After some research, the HCP was told that not all registered neurologists work as physicians; that mainly the reason for such a high number was due to the Soviet-time educational system.

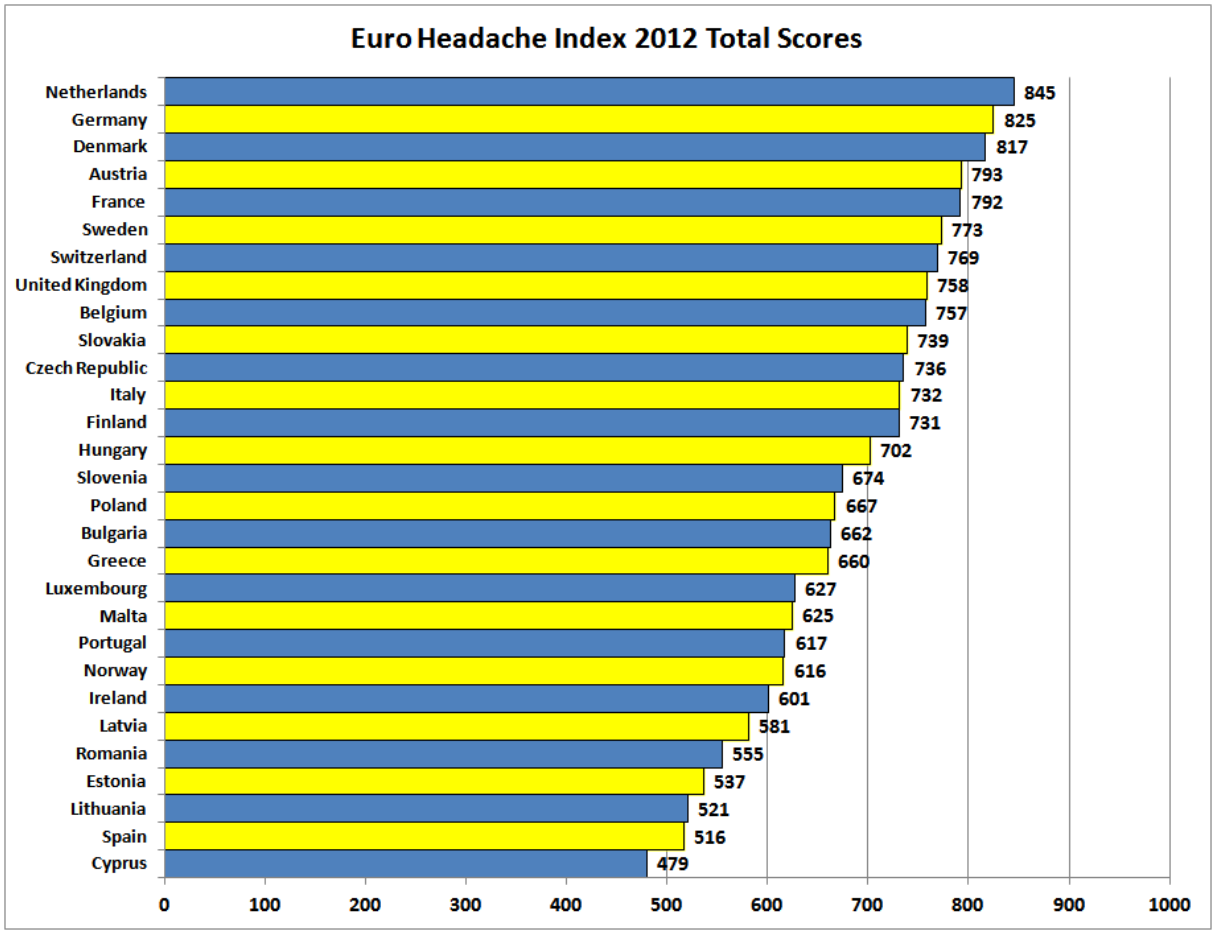


Figure 4: Euro Headache Index 2012: Total Scores

3.1.1 Country Scores

In a typical European Index[4], there are no countries, which excel across the entire range of indicators. In most cases, the national scores will reflect the national and organisational cultures and attitudes rather than mirroring the amount of resources the country spends, namely their total health expenditures. The professional cultures within a healthcare system have historical roots. The results of the EHI 2012 convey the impression that a limited number of countries, such as the Netherlands, Germany, Belgium, Sweden and the United Kingdom, have engaged in putting more attention and provide more structured care provision for people living with headache/migraine.

3.1.2 Results in the "Pentathlon"

The EHI 2012 is composed of five sub-disciplines. Most frequently in HCP Indexes, no country excels across all aspects of measuring a healthcare system. It can therefore be of interest to study how the 29 countries rank in each of the five parts of the "pentathlon". The scores within each sub-discipline are summarised in the table below:

[4] Published on http://www.healthpowerhouse.com

Sub-discipline	Austria	Belgium	Bulgaria	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	United Kingdom
1. Patient rights, information and e-health	170	163	104	104	141	170	141	178	163	170	141	178	133	141	141	96	119	133	178	148	163	141	119	178	170	119	170	185	185
2. Professional awareness and education	107	93	100	79	121	136	93	100	150	136	114	100	93	121	100	86	79	100	121	64	100	129	100	136	100	100	121	100	121
3. Access to healthcare	204	194	204	139	167	176	130	167	176	204	167	194	148	194	167	185	167	148	194	120	157	130	130	204	157	111	157	185	117
4. Medication / treatment	220	240	180	100	240	260	140	220	220	240	180	180	160	200	140	120	180	160	260	200	180	160	140	180	180	120	240	240	260
5. Prevention	92	67	75	58	67	75	33	67	83	75	58	50	67	75	33	33	83	83	92	83	67	58	67	42	67	67	83	58	75
Total score	793	757	662	479	736	817	537	731	792	825	660	702	601	732	581	521	627	625	845	616	667	617	555	739	674	516	773	769	758
Rank	4	9	17	29	11	3	26	13	5	2	18	14	23	12	24	27	19	20	1	22	16	21	25	10	15	28	6	7	8

Table: Result of the EHI 2012 Pentathlon

The top countries show an unusually even performance. The Netherlands seizes the victory mainly through an even all-over performance; France for scoring all Greens in the sub-discipline of "Professional Awareness and education"; use of Triptans and availability of prophylactic drugs and their rate of subsidy in the UK, the Netherlands and Denmark. The Netherlands and Austria score low or medium rates of work-related stress, low rate of unemployment, high rate of Happy-life years and seemingly regular lifestyle habits.

Sub-disciplines	Top countries	Score	Maximum score
1. Patient rights and information & e-Health	Switzerland, UK	185	200
2. Professional awareness and education	France	150	150
3. Access to healthcare	Austria, Bulgaria, Germany, Slovakia	204	250
4. Medication /Treatment	Denmark, The Netherlands, UK	260	300
5. Prevention	Austria, The Netherlands	92	100

Table: The winners of the sub-disciplines

4. How to interpret the Index results?

The first and most important consideration on how to treat the results is: WITH CAUTION!

The Euro Headache Index 2012 attempts to measure and rank how well the 29 European countries tackle the well spread issue of headache and migraine in terms of providing healthcare provision to the sufferers. The results definitely contain information quality problems. There is a shortage of pan-European and uniform set procedures for data gathering in this field.

The HCP finds it far better to present the results to the public and to promote constructive discussions rather than abiding by the only too common opinion that "as long as healthcare information is not a hundred percent complete it should be kept in the closet". It is important to emphasize that the Index displays **consumer information** and not data that is medically sensitive or sensitive on the level of the individual user of the healthcare system.

Experience tells us that merely publishing performance data on healthcare increases awareness and drives the reporting, even if our data are far from complete.

While the HCP by no means claims that the Euro Headache Index 2012 results are of dissertation quality, the findings should not be regarded as random findings. On the contrary, previous experience from the main HCP product, the Euro Health Consumer Index, reflects and illustrates that ranking by similar indicators is an important tool to display the quality of services provided within a national healthcare system.

The HCP hopes that the EHI 2012 results can serve as an inspiration for how and where headache/migraine treatment can be improved within the range of patient rights, information and e-Health; professional awareness and education; access to headache/migraine care; medication and treatment, and prevention.

4.1 Data shortage in Europe

There is an abundance of statistics on input of resources but a traditional scarcity of data on quantitative and / or qualitative output.

Organisations such as the WHO and OECD publish easily accessible and frequently updated statistics on rates, indicators, and the like in different areas, such as:

- Health status (mortalities, …)
- Quality of Care (avoidable admissions, screenings, vaccinations, …)
- Non-medical Determinants of Health (tobacco consumption, obesity, …)
- Healthcare Activities (hospital beds, hospital discharges, …)
- Health Workforce (number of doctors, nurses, …)
- Access to care (waiting times, burden of out-of-pocket health expenditure, …)
- Healthcare Expenditure and Financing (Health expenditure in relation to GDP, per capita, …)
- Long-term Care (Life expectancy and healthy life expectancy at age 65, Long-term care beds in institutions and hospitals, …)

Healthcare systems with a history of funding structures based on grant schemes and global budgeting often exhibit a management culture, where monitoring and follow-up is more or less entirely on input factors. Such factors can be number of staff, various costs (though not usually related to output factors) and other factors as listed above.

Public healthcare systems operating more on an industrial basis have a natural inculcation to focus monitoring on outputs rather than inputs. The relation between the measurements of costs to output factors in order to measure productivity, cost-effectiveness and quality is much more obvious.

The EHI 2012 project team's aim was to obtain data on the output of headache care provision efforts. By keeping this as the main focus of the project, the ambition was to remain concentrated on those indicators where the major factor lied within the following notion: *"the contribution of somebody actually having done or doing something".*

5. Evolution of the Euro Headache Index 2012

The evolution of the Euro Headache Index 2012 was the effort of consensuses and discussions among the members of Experts Panel for the Index and the HCP team. It combined the HCP know-how, the expertise of health system experts and medical experience (mainly neurologists with exhaustive scientific knowledge in the area of headache/migraine).

5.1 Indicators introduced for EHI 2012

In the design and selection of indicators, the HCP team has been working on the following three principles since the first HCP Euro Health Consumer Index indicator in 2005:

1. Relevance
2. Scientific soundness
3. Feasibility (i.e. can data be obtained?)

Incidentally, these are the same three principles that are also governing the German quality indicators projects at the BQS[5] Institute (The German Institute for Quality and Patient Safety).

As for any other HCP index, the Experts' Panel for the Headache Index after long discussions and consensus meetings came up with a list of indicators. Going from the initial brainstorming session to the fine-tuning of indicators was in this particular Index a major exercise and took almost over a year. In the process some indicators had to be dropped. For instance, initially there were great pressures to find out how many "tertiary headache centers" existed in the EU. The definition of what a tertiary headache center or "Academic headache center" was, was provided by EHF[6] and it states:

"Level 3 should:

- Provide specialist advanced care to 10% of patients seen at level 2 who are referred to level 3
- Provide support to emergency or acute treatment services for patients presenting with headache

Therefore, 1 full-time equivalent physician can provide headache care at level 3 for no more than 2,000,000 populations." (Organization and standards of headache services in Europe: A proposal for stakeholder consultation prepared by a joint working group of the EHF and Lifting the Burden, Presentation by EHF, 2010)

However, it turned out after intensive field research that hardly any country abode by this definition and so it was close to impossible to find out the number of these academic headache centers. Mainly, this is what EHF's wish but the reality within most countries was different and so the final consensus was to drop this particular indicator. Instead, at the last stage of the project a new indicator was inserted that gave to some extent relevant information in terms of access of care. This indicator is called: the number of members of national headache societies per million populations.

A detailed description of the content of the indicators is provided under heading **6.2 Content of indicators in the Euro Headache Index 2012.**

5.1.1 The sub-disciplines (indicator sections)

As all European HCP Indexes the EHI 2012 encompasses indicators grouped in sub-disciplines. After having surrendered to the "lack of statistics syndrome" and the scrutiny by the Experts on the panel, 34 indicators "survived" into the EHI 2012 in the following so-called sub-disciplines:

Sub-discipline	Number of indicators
1. Patient rights, information and e-Health	9
2. Professional awareness and education	6
3. Access to healthcare	8
4. Medication and / or treatment	5
5. Prevention	4

[5] BQS Institute (http://www.bqs-institut.de/, last accessed 12 December 2012)

[6] EHF stands for European Headache Federation (http://www.ehf-org.org/Pages/default.aspx, last accessed 10 November 2012)

5.1.2 Scoring the EHI 2012

The performance of the respective countries is graded on a three-grade scale for each indicator.

The color and the direction of the hands symbols indicate HIGH or GOOD (green and thumb up), MEDIUM or SO-SO (orange and leveled thumb) and LOW or NOT-SO-GOOD or Not Available (n.a.) (red and thumb down) weight indicators. A Green score earns 3 points, a Yellow 2 points, and a Red score earns 1 point as the weight to a specific indicator. A "not available" (**n.a.**) counts equal to a Red score.

Since the EHCI 2006, the same methodology has been used at HCP. For each of the sub-disciplines, the country score is calculated as a percentage of the maximum possible. Thereafter, the sub-discipline scores are multiplied by the weight coefficients given in the following section and added up to make up the final country score. These percentages are then multiplied by 100 and rounded to a three-digit integer so that an "all Green" score on the 34 indicators would yield 1000 points.

5.1.3 Weight coefficients

The possibility of introducing weight coefficients was discussed already for the EHCI 2005, i.e. selecting certain indicator sections or areas as being more important than others and multiplying their scores by numbers other than 1.

For the EHCI 2006, explicit weight coefficients for the five sub-disciplines were introduced after a careful consideration of which indicators should be considered for higher weight. The accessibility and outcomes sub-disciplines were decided as the main candidates for higher weight coefficients based mainly on discussions with expert panels and experience from number of patient survey studies. The HCP is welcome to discussions and welcomes constructive inputs on improving the "how" of the Index methodology[7].

In EHI 2012, the scores for the five sub-disciplines were given the following weights:

Sub-discipline	Relative weight ("all **Green**" score contribution to total maximum score of 1000)	Points for a **Green** score on an indicator in each sub-discipline
1. Patient rights, information and e-Health	200	22.22
2. Professional awareness and education	150	21.43
3. Access to healthcare	250	27.77
4. Medication and / or treatment	300	60
5. Prevention	100	25

Consequently, as the percentages of full scores are added and multiplied by (1000/Total sum of weights), the maximum theoretical score attainable for a country in the Index is 1000, and the lowest possible score is 333.

It should be noted that, as there are not many examples of countries that excel in one sub-discipline but do very poorly in others, the final ranking of countries presented by the EHI 2012 is stable if the weight coefficients are varied within wide limits.

[7] For any suggestions, feel free to contact Dr. Arne Bjornberg via email at arne.bjornberg@healthpowerhouse.com

5.1.4 Regional differences within European states

The HCP is well aware that many European countries have various models of decentralized healthcare systems. Not least for the United Kingdom (UK) it is often argued that "Scotland and Wales have separate NHS services, and should be ranked separately".

The uniformity among different parts of the UK is probably higher than among regions within Spain or Italy, Bundesländer in Germany and possible even within counties in the tiny 9 million population of Sweden.

Grading European countries does present a certain risk of encountering the syndrome of "if you stand with one foot in an ice-bucket and the other on the hot plate, on average you are pretty comfortable." This problem would be quite pronounced if there were ambitions to include the USA as one country in an HCP Index.

Since equity in healthcare has traditionally been high on the agendas of European countries, it has been judged that regional differences are small enough so as to make relevant and meaningful statements about the national levels of healthcare services.

5.1.5 Indicator definitions, explanations and data sources for the EHI 2012

Sub-discipline	Indicator	Explanatory comment	Score 3	Score 2	Score 1	Main Information Sources
1. Patient rights and information	**1.1 Headache* patient organisation(s)**		YES, active.	Yes, but no website available.	None.	EHA (European Headache Alliance); websites such as: http://www.migraine.org.uk/, http://www.migraine.ie/, http://www.migrene.no/, http://www.hovedpineforeningen.dk/, http://www.hortonforeningen.dk/english, http://www.migran.org/news.php, http://www.dmkg.de/, http://www.glavobol.com, http://www.migraine-action.ch; PatientView (Survey commissioned by HCP), interviews with national headache specialist representatives
	1.2 Patient organisations co-determination	EHCI 2009	Yes, visibly active (actions and strategies are published on patient organisation sites).	Active to a very limited extent.	No active headache organisation to put pressure on policy-makers.	Interviews with National Representatives, EHA (European Headache Alliance)
	1.3 Information direct to patients about Rx drugs	Medicinal drugs description available on internet	YES, at least the same information as on package leaflet available from identifiable industry source	In principle the same information as on package leaflet available, but source difficult to verify	No available access	Official websites, such as www.zdravila.net,www.raviminfo.ee, medicin.dk - see section 6 in the Report for a more exhaustive list; Websites, interviews with National Representatives (Medical Product Agencies)
	1.4 Patient headache diaries downloadable		YES, and also provided by Headache Specialist	Yes, provided by specialist only.	Nothing available in national language	Interviews with National Headache/Neurology society and/or websites, Patient Organisations websites; PatientView (survey commissioned by HCP)
	1.5 Reliable, accurate headache information		YES, source clearly provided	YES, no source provided or source's reliability difficult to assess.	NO, nothing in national language.	Interviews with National Representatives and National Headache Specialists; PatientView survey commissioned by HCP
	1.6 Right to choose among care providers	In country of residence	YES, possible to do so throughout the country (regardless whether through the public healthcare system or private).	To a certain extent, within your assigned region	NO, you must see provider assigned to your place of residency	Interviews with National Representatives
	1.7 Quality information about headache care providers	Hospitals/clinics/ centers	YES, accessible free of charge to all.	YES, accessible to healthcare professionals and authorities only.	NO.	Interviews with National Representatives and National Headache Specialists; PatientView survey commissioned by HCP

Sub-discipline	Indicator	Explanatory comment	Score 3	Score 2	Score 1	Main Information Sources
	1.8 Compensation for absenteeism due to headache*	As compared with compensation for other causes	YES, compensation provided (same level as for other causes).	YES, but at a lower level of compensation and depending on the medical board.	No, not at all.	Interviews with National Representatives and National Headache Specialists
	1.9 Headache* a recognized condition for disability pension	As compared with compensation for other causes	YES, fully recognized condition.	YES, but only partly.	NO, lots of hurdles or not at all	Interviews with National Representatives and National Headache Specialists, Health Insurance websites
2. Profes-sional awareness and education	**2.1 National Registry for Headache**		YES, continuously updated on annual basis.	Only Regional Registries available.	NO.	Interviews with National Headache/Neurology representatives
	2.2 National epidemiological prevalence data	Availability of reliable national epidemiological data on the prevalence of headache disorders*	YES, it is set within a National Agency and openly available.	YES, but no access for the public.	NO.	Interviews with National Headache Specialists, Alpay et al. (2010), Dahlof et al. (2001), Diaz-Insa et al. (2011), Duru et al. (2004), Eurolight-online.eu, Fendrich et al. (2007), Gerardy et al. (2008), Grande et al. (2008), Kristiansen et al. (2011), Kroner-Herwig et al (2007), Lampl et al. (2003), Lanteri-Minet et al. (2003, 2005, 2007, 2010), Laurell et al. (2004), Leonardi et al. (2005), Lucas et al. (2006), Lyngberg et al. (2005), Lyngberg et al. (2005a), Markova (2009), Matias-Guiu et al. (2011), Mitsikostas et al. (2010), Purina et al. (2010), Russell et al. (2007), Steiner et al. (1998, 2000, 2002, 2003, 2005), Stovner et al. (2007), Straube et al. (2010), Strgar-Hladnik et al. (2008), Wiendels et al. (2006), Wilkinson et al. (1995), Zwart et al. (2004), www.l-t-b.org
	2.3 National headache professional society	Is there a national headache society (for doctors)?	YES, and it is stand-alone	YES, part of a Neurological Society.	NO.	Interviews with National Representatives and National Headache Specialists, EHF (European Headache Federation)
	2.4 National guidelines for headache	Not older than 10 years	YES, accessible to anyone (on the Internet).	YES, accessible to healthcare professionals only.	NO.	Interviews with National Headache Specialists, Scientific Papers or guidelines: BASH (2011), Bendtsen et al. (2010), EFNS (2011), Evers et al. (2009), Headache Classification Subcommittee of the International Society (2004), Pfaffenrath et al. (2009), Steiner et al. (2010)
	2.5 Fixed set of diagnostic criteria (IHS)	Is there a fixed set of diagnostic criteria (IHS) available to healthcare professionals? Is it available in the national language?	YES, accessible to anyone (on the Internet).	YES, accessible to healthcare professionals only.	NO.	Interviews with National Headache Specialists, Scientific Papers or guidelines: BASH (2011), Bendtsen et al. (2010), EFNS (2011), Evers et al. (2009), Headache Classification Subcommittee of the International Society (2004), Pfaffenrath et al. (2009), Steiner et al. (2010)
	2.6 Module of headache/migraine care in pre-graduate medical school	Existence of a module in headache/migraine care in medical school	YES, intrinsic compulsory part of doctors' training	YES, voluntary part of doctors' training	NO.	Interviews with National Headache Specialists, Medical Faculty Curricula; CEEAM (2011)

Sub-discipline	Indicator	Explanatory comment	Score 3	Score 2	Score 1	Main Information Sources
		(pregraduate) training curricula (before reaching specialist training)				
	2.7 Module of headache/migraine care in neurological specialist training	Existence of a module in headache/migraine care in neurological specialist training	YES, modules are provided annually.	YES, modules are provided sporadically.	NO.	Interviews with National Headache Specialists, Medical Faculty Curricula; CEEAM (2011) www.ceeam.info last accessed 3 June 2011, Diener et al. (2006), European Neurological Societies (2011), Facheris et al. (2005), Fumal et al. (2008); but future prospects discussed in: Antonaci et al. (2005, 2008), Jensen et al. (2010, 2010a), Russell et al. (2007), Steiner et al. (2011).
3. Access to healthcare	**3.1 # of specialised centers for headache**	# of specialised centres for headache p.m.p., with reference to the EHF	> 1 p.m.p.	1 - 0.5 p.m.p.	< 0.5 p.m.p.	Interviews with National Headache Experts; www.dmkg.de (last accessed 5 Sept 2011), Danish Headache Center, London Headache Center,
	3.2 # of members of national headache societies	# of members of national headache societies p.m.p	> 10 p.m.p.	10 - 5 p.m.p.	< 5 p.m.p.	Interviews with National Representatives and National Headache Specialists,http://www.ehf-org.org/ehf_membership/Pages/Membership.aspx (last accessed 5 Jan 2012)
	3.3 Neurology specialists p.m.p.		> 80 p.m.p.	80 - 40 p.m.p.	< 40 p.m.p.	Svenska neurologforeningen (2010), Grisold et al. (2007), EFNS Directory (2010-2011), Lisnic et al. (2008), interviews with National Headache Specialists / Neurologists
	3.4 Direct access to headache specialist	Modalities of access to a headache specialist (w or w/o referral; "GP gatekeeping")	Without referral.	With referral but to any specialist of the patient's choice.	With referral only to a designated specialist.	PatientView Survey, interviews with National Representatives and National Headache Specialists
	3.5 Special unit for detoxification?	Particularly for medication overuse!	YES, special units for medication-overuse detoxification exist in headache centres / hospitals	YES, it is outpatient-based.	NO. Normally the patient is referred to the Narcology Unit or Psychiatric Unit, or the like.	Interviews with National Headache Specialists
	3.6 Mode of admission for detoxification?		YES, with no referral.	YES, with referral.	Not possible to admit for detoxification, very rarely admitted.	Interviews with National Headache Specialists
	3.7 Emergency room visits for headache*		YES, patients with severe headache are admitted.	Yes, for several hours ONLY.	NO, after triage, even if severe headache, patient is sent home.	Interviews with National Headache Specialists, Martelleti et al. (2008)

Sub-discipline	Indicator	Explanatory comment	Score 3	Score 2	Score 1	Main Information Sources
	3.8 Availability of specialist headache* nurses		YES, on all levels.	YES, on tertiary level only.	NO	Interviews with National Headache Specialists
	3.9 Waiting time to see headache* specialist	Waiting time for accessing a headache* specialist or neurologist on the secondary level	Less than 1 month.	Between 1 and 3 months.	More than 3 months.	Interviews with National Representatives and National Headache Specialists
4. Medication / Treatment	**4.1 Triptan deployment**	ATC code N02CC, DDD per capita/year	> 10	10 - 5	< 5	IMS data
	4.2 Availablity of prophylactic drugs	flunarizine, pizotifen, topiramate, sodium valproate, amitriptyline, cinnarizine, propranolol registered for sale	Yes, all 7 available.	5 -6 available (incl. flunarizine or pizotifen)	< 5 available, or flunarizine and pizotifen both missing	Interviews with National Representatives; National Specialists; Edameads (2006), Pradalier et al. (20049, official national websites for medicinal products (such as www.onmeda.de, www.ogyi.hu/drug_database, www.inami.fgov.be/drug, www.raviminfo.ee, http://www.mz.gov.pl/wwwmz/index?mr=b4&ms=300&ml=pl&mi=300&mx=0&ma=16030, …),
	4.3 Co-payment for prophylactics?		YES, full subsidy as any other vital Rx medication	YES, but subsidised at a lower rate than the maximum subsidy rate	Not at all.	Interviews with National Officials and National Headache Specialists, websites of official medicinal agencies (as noted above and in the report)
	4.4 "Medication over-use" an approved indication for detoxification?	Is "medication over-use" an approved indication for referral for detoxification?	Yes, it is, protocols are in place.	Partly, depending on the provider	Not at all.	Interviews with National Headache Specialists
	4.5 Prevalence of Medication Over-use-induced Headache	Prevalence data available	YES, available (from 2000 onwards)	Yes, available from pre-2000	No data available	Interviews with National Headache Specialists, Grande et al. (2011), Haag et al. (2010, 2011), Markova (2009), Lucas et al. (2004, 2005), Paemeleire et al. (2006, 2008), Russell (2011), Schoenen et al. (2006), Van Alboom et al. (2009)
5. Prevention	**5.1 Work-related stress**					European Foundation for the Improvement of Living and Working Conditions, *Fourth European Working Conditions Survey*, Office for Official Publications of the European Communities, Luxembourg, 2006. http://www.eurofound.europa.eu/
	5.2 Unemployment rate					Eurostat, 2010: http://epp.eurostat.ec.europa.eu/statistics_explained/index.php?title=File:Table_unemployment_rates_by_age_and_gender.PNG&filetimestamp=20110504125603, last accessed 29 Jan 2012.

Sub-discipline	Indicator	Explanatory comment	Score 3	Score 2	Score 1	Main Information Sources
	5.3 Happy-Life Years					Veenhoven. R.. Happy Life Years in 149 nations 2000-2009. World Database of Happiness. Rankreport Happy Life Years. Internet: worlddatabaseofhappiness.eur.nl/hap_nat/findingreports/RankReport_HappyLifeYears.php
	5.4 Hard liquor consumption per capita	Adjusted for irregular consumption; Index weighted 0.33*males + 0.67*females	Low	Medium	High	Special Eurobarometer 272, WHO HfA

5.1.6 Additional data gathering – feedback from National Ministries and Agencies

In September of 2011, preliminary so-called Country Score Sheets were sent out to officials at National Ministries and / or Agencies of all 29 countries to give the opportunity to supply more recent data and / or better quality data than what is available in the public domain.

Prior to sending out these Country Score Sheets for review and feedback purposes, the HCP team spent almost a year searching and collecting data in the public domain (from the Internet, websites of scientific journals related to headache[8] and other browsers such as for example PubMed and so on); personal visits were carried out to officials in their countries and extensively communicated via telephone and e-mails with different national experts. The PatientView organization was commissioned to carry out online surveys throughout Europe on the provision of care for headache sufferers. The questionnaires were translated into French, German and Spanish.

Once the data was collected, analyzed and prepared to feed the specific indicators, the country score sheets were completed and then sent to the respective Ministries and / or Agencies for feedback.

Corrections were accepted only in the form of actual data, not by national agencies just changing the scores (frequently, from Red to something better, but surprisingly often honesty prevailed and scores were revised downwards).

In addition, in the case where the EHI 2012 team was left with an outstanding score(s), direct contact with national bodies followed to validate the score(s) on one or more indicators.

5.1.7 Threshold value settings

At HCP, the ambition to establish a global, scientifically based principle of threshold values to score green, orange of red on the different indicators has never been present. The threshold levels have been set after studying the actual parameter value spreads, in order to avoid having indicators showing "all Green" or totally Red".

Setting threshold values is typically done by studying a bar graph of country data values on an indicator sorted in ascending order. The usual "S"-shaped curve yielded by that is studied for notches in the curve, which can distinguish clusters of states, and such notches are often taken as starting values for scores. A slight preference is also given to threshold values with even numbers.

5.1.8 "CUTS" data sources

A "CUTS" is a terms coined by the HCP. A CUTS stands for **C**omprehensive **U**niform **T**rustworthy **S**ource. So wherever and whenever possible, research on data for individual indicators has endeavored to find a so-called CUTS.

If data on the underlying parameter behind an indicator is available for all or most of the 29 countries from one singe and reasonably reliable source, then there is a definitive preference to base the score on the CUTS. Examples considered as CUTS are normally found in: WHO databases, OECD Health Data, Special Eurobarometer reports, and even scientific papers using well-defined and established methodology.

Apart from the sheer effectiveness of the approach, the basic reason for the concentration on CUTS when available is that data collection primarily based on information obtained from 29 national sources, even if those sources are official bodies such as Ministries of Health or national bodies for health statistics, they generally yield a high noise level. It is notoriously difficult to obtain precise answers from many sources even when these sources are all answering the same question. For example, in the Euro Consumer Diabetes Index 2008, it was a challenge to find answers to indicators such as "Do you have nurse practitioners in your country?" or "Is diabetes foot (podiatrist) a recognized sub-specialty in your country?". The reason is very simple: the definition of what is a diabetes nurse or a diabetes podiatrist and the amount of education and training required to qualify are different from country to country. The HCP team for the EHI 2012 faced a similar problem when

[8] Cephalalgia (http://cep.sagepub.com/)

trying to locate the number of headache clinics in each country. This very indicator was dropped, for reasons of a lack of a uniform European definition of what a headache clinic is.

It needs to be pointed out that even when a CUTS for a specific indicator is identified, the data is reviewed and validated through various cross-check procedures (by presenting the issue to the Panel of Experts or National Officials or through further research in the matter) as there have oftentimes been occasions where national sources or scientific papers have been able to supply more recent and /or better quality of data.

Another reason for preferring the use of CUTS whenever possible lies within the same reasons why Rolls-Royce (in their pre-BMW days) did not build their own gearboxes. The reason was stated as "we simply cannot build a better gearbox than those we can get from outside suppliers, and therefore we do not make them ourselves". For the small size HCP organization, this same circumstance is true for an indicator where a Eurobarometer question, or WHO HfA database or any other CUTS happens to cover a specific indicator.

5.2 Content of indicators in the Euro Headache Index 2012

The research team of the EHI 2012 collected data on 33 indicators, structured in a framework of five sub-disciplines. Each of these sub-disciplines reflects a certain logical entity: Patient rights, information and e-Health; professional awareness and education, access to healthcare, medication and treatment, prevention and outcomes.

This is the first HCP Index, where it proved to be impossible to construct even a single indicator measuring actual outcomes.

One thing to keep in mind while reading the following passages is that under the term "HEADACHE" we are also referring to "MIGRAINE and OTHER HEADACHE DISORDERS"[9].

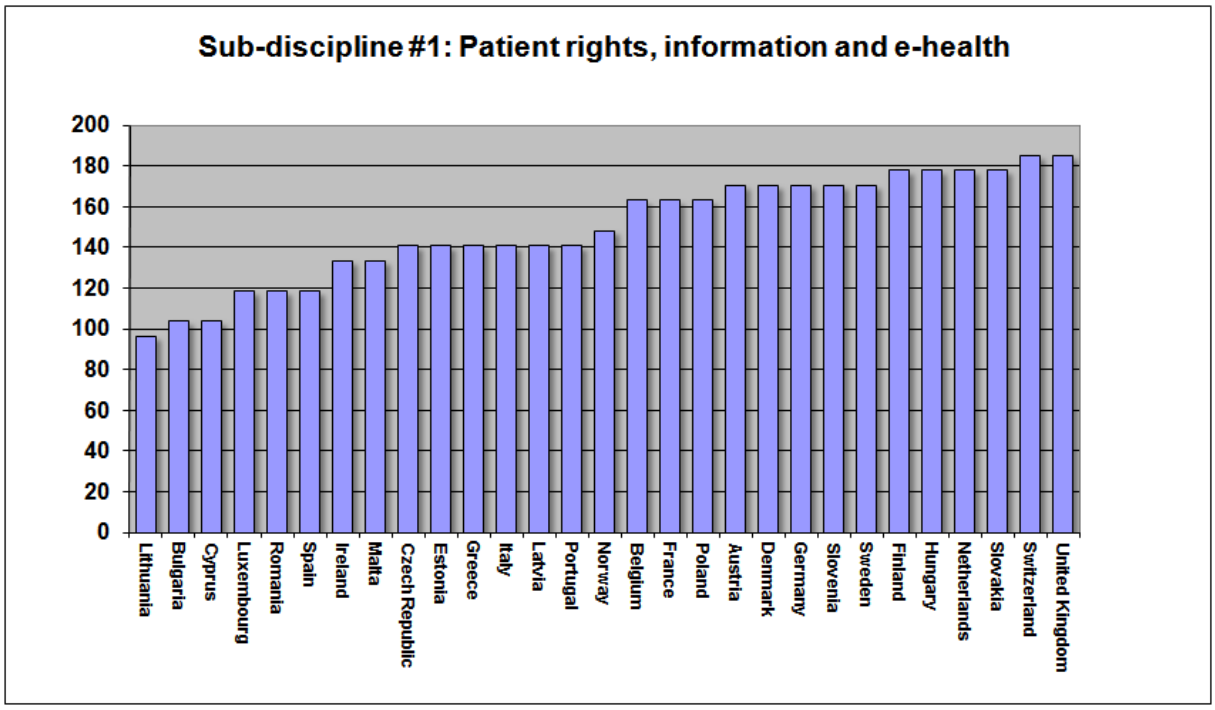
The indicators come numbered in the report, to provide more reader-friendliness and clarity.

Where possible, CUTS - Comprehensive Uniform Trustworthy Sources - were used; see section "CUTS Data Sources" for more information on this approach, typical for HCP research work.

5.2.1 Patient rights, information and e-Health

Countries that score really high are Finland, the Netherlands, Switzerland and the United Kingdom. On the other side of the spectrum, where patient rights, information and e-health are limited are countries such as Lithuania, Spain and Greece.

[9] The Euro Headache 2012 Experts Panel suggested using the term "headache" in general and emphasizing the fact that we are actually referring to "migraine and other headache disorders".



Graph: Patient rights, information and e-Health – final results

*There are **nine** indicators in this sub-discipline:*

5.2.1.1 Existence of a headache patient organisation

The number of headache patient organizations is on the rise depending on the awareness of headache-related issues within a country. The existence of a headache patient organisation gives way to establish proper grounds for exchange of information among headache-suffering citizens and health professionals. The existence of headache patient organisations presents an indicator of whether there is a platform for headache-related issues and their cures. Some patient organisations are far more active than the other. Active patient organisations are the ones with established websites and updated information and those providing support to their members. In some countries the website is uploaded but not maintained. In some countries there are no websites at all. And given the 21st centuries some countries may have a headache patient organisation but no website which is in HCP terms considered close to non-existent.

SOURCE: EHA (European Headache Alliance); websites such as: http://www.migraine.org.uk/, http://www.migraine.ie/, http://www.migrene.no/, http://www.hovedpineforeningen.dk/, http://www.hortonforeningen.dk/english, http://www.migran.org/news.php, http://www.dmkg.de/, http://www.glavobol.com, http://www.migraine-action.ch; PatientView (Survey commissioned by HCP), interviews with national headache specialist representative

5.2.1.2 Right of patient organisations co-determination

This indicator is based on the Euro Health Consumer Index 2009 with minor updates. It goes without saying that those patient organisations with visible actions lines and strategies published on their websites are those organisations that most likely are determined to play a role in co-determination in healthcare policies of their country. In some other countries these patient organisations are active to a limited extend. In other countries where the patient organisations are not active or present, co-determination on headache policies are not available but there may be some level of co-determination for disease areas where there are organisations.

SOURCE: Interviews with National Representatives, EHA (European Headache Alliance)

5.2.1.3 Can pharmaceutical companies inform directly to patients about prescription drugs?

This is a tricky indicator. At first it sounds as an easily understood indicator as the first thing that comes to anyone's mind is the EU law on the advertisement of pharmaceutical drugs What HCP tried to study was the medicinal drugs description available on the internet and the source of this internet is a reliable one, preferably backed by a national agency or identifiable source. In some countries medicinal drugs description are not available at all. In some other countries, one could easily find all the needed information about a medicinal drug (same information as on the package leaflet) from an identifiable industry source. In the third case, one could in principle find the description of the medicinal drug on the internet but it was very difficult to verify the source or the source was not provided.

Table: Websites with comprehensive information about registered pharmaceuticals: OTC and Rx

Country	**Links** (accessed in 2011 and 2012)
Austria	www.austriacodex.at/avmain/
Czech Republic	www.zdravotnickenoviny.cz/scripts/modules/catalogue/search.php?catalogueID=2
Denmark	http://medicin.dk/
Estonia	www.raviminfo.ee
Finland	www.fimea.fi/lakemedel/produktresumeer/humpl
France	www.doctissimo.fr
Germany	www.onmeda.de
Hungary	www.ogyi.hu/drug_database/
Italy	www.prontuariofarmaci.com
Malta	http://medicinesauthority.gov.mt/products/search.htm
Netherlands	www.cbg-meb.nl/CBG/en/human-medicines/geneesmiddeleninformatiebank/default.htm
Norway	www.legemiddelverket.no/custom/templates/gzInterIFrame_1548.aspx
Poland	http://www.mz.gov.pl/wwwmz/index?mr=b4&ms=300&ml=pl&mi=300&mx=0&ma=16030
Portugal	www.infarmed.pt/infomed/inicio.php
Romania	www.anm.ro/en/html/pharmacopoeia.html
Slovakia	www.liekinfo.sk
Slovenia	www.zdravila.net
Sweden	www.fass.se
Switzerland	www.kompendium.ch
United Kingdom	http://emc.medicines.org.uk/

SOURCE: Official websites, such as www.zdravila.net,www.raviminfo.ee, medicin.dk - see section 6 in the Report for a more exhaustive list; Websites, interviews with National Representatives (Medical Product Agencies

5.2.1.4 Downloadable patient headache diaries

For headache sufferers it is crucial that the patterns of headache emergence and mode of emergence and so on is tracked. In many countries we found out that patient headache diaries are downloadable and are also provided by the physicians. In some countries, these headache diaries are provided by the physicians only; whereas in only very few countries there such diaries are not available.

Diary examples:

- http://www.relieve-migraine-headache.com/diary-headache-migraine.html
- http://www.migraine.ie/index.php?id=99
- http://www.headaches.org/For_Professionals/Headache_Diary
- http://www.headaches.org/Free_Download_iHeadache_Electronic_Diary_App
- http://www.slideshare.net/mzk/vodi-za-uinkovito-obvladovanje-migrene-in-dnevnik-migrenskih-glavobolov
- E-diary for iphones: http://itunes.apple.com/us/app/iheadache-headache-migraine/id319801270?mt=8
- And more…

SOURCE: Interviews with National Headache/Neurology society and/or websites, Patient Organizations websites; PatientView (survey commissioned by

5.2.1.5 Access to reliable, accurate headache information

This is a straightforward indicator. However, most importantly, the countries with easily accessible (via Internet) reliable and accurate headache information in the national language scored the highest. Some countries provide information in their local language however the source is oftentimes not available. Those countries that do not provide information in their local language scored Red.

SOURCE: Interviews with National Representatives and National Headache Specialists; PatientView survey commissioned by HCP

5.2.1.6 The right to choose among providers within the country

This is an indicator that appears in most HCP EU Indices. It is also an indicator that for some countries has changed over the years. Namely, HCP favors countries, where regardless whether private or public, provides its citizens the possibility to be treated anywhere within their national country. Those scoring an average are those countries where it is possible to choose your own physician or clinic within your assigned region. The countries with the lowest scores are the ones where the citizen has no choice but is obligated to visit a particular physician within a particular establishment of his/her residential area.

SOURCE: Interviews with National Representatives, PatientView

5.2.1.7 Quality information about headache care providers

Except for two countries in the EU, Denmark and the UK, no other country provides openly and transparently quality information about headache care providers and is accessible to anyone. Some countries within professionals associations keep track of quality information but it is kept confidential. It is basically accessible to healthcare authorities and professionals only. The majority of countries do not make quality information about headache care provides available to the public.

SOURCE: Websites such as: www.sundhedskvalitet.dk , www.drfosterhealth.co.uk, interviews with National Representatives and National Headache Specialists; PatientView survey commissioned by HCP.

5.2.1.8 Availability of compensation for absenteeism due to headache

As compared with compensations provided for other causes, there was a mixture of information available for this indicator. In a third of EU countries, absenteeism due to headache is compensated at the same level as for any other condition or cause; in other countries, compensation will depend on the medical board and will in most cases be granted at a lower compensation rate. In some countries, one cannot get any compensation for being absent due to headache-related issues.

SOURCE: Interviews with National Representatives and National Headache Specialists

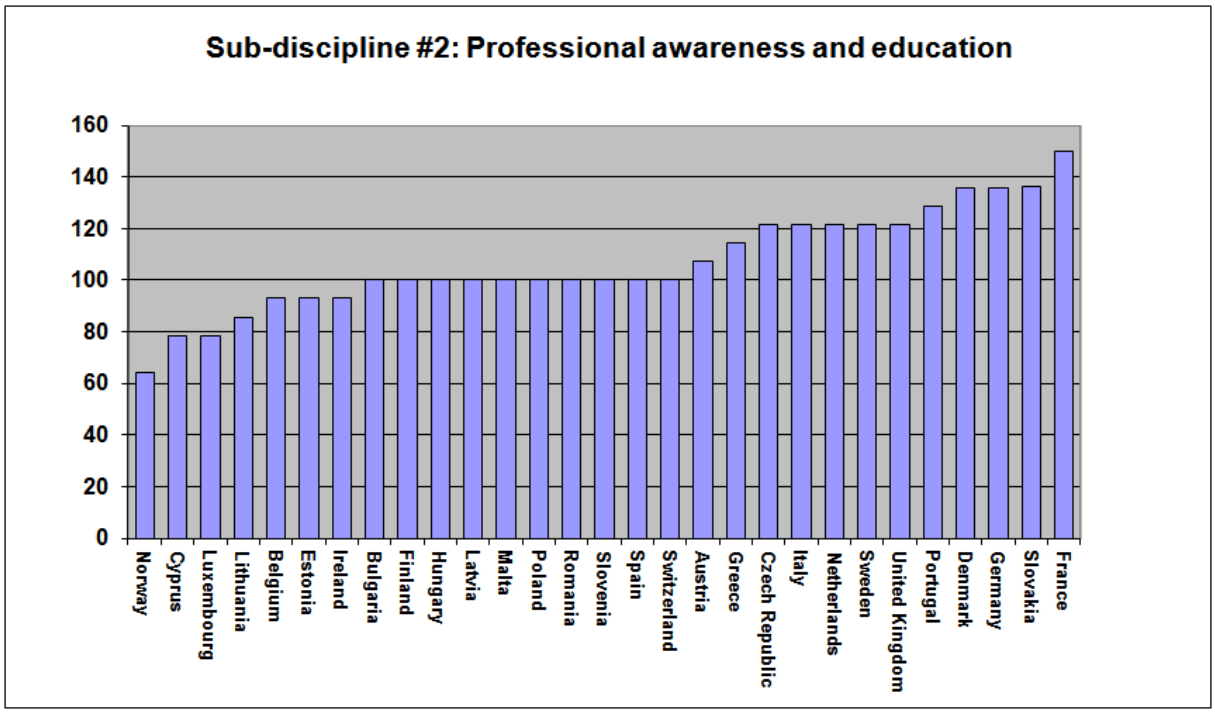
5.2.1.9 Is headache a recognized condition for getting disability pension?

Finding a black-on-white response presented a challenge; and when discussing this topic with a number of national representatives, this question came to them as a surprise and the usual response was that headache was considered just as any other conditions for getting disability pension. However, we wanted to know to which extend headache was recognized for getting disability pension. In some countries it was fully recognized, in some other, headache was recognized only partly. In the remaining countries headache was not recognized at all or only to a very limited extend but through lots of hurdles for headache-sufferers to overcome.

SOURCE: Interviews with National Representatives and National Headache Specialists, Health Insurance websites

5.2.2 Professional awareness and education

Under this sub-discipline we were interested to find out to which extend specialists in headache and migraine, physicians or neurologists are aware of the burden of headache within their society and what type of educational support is provided to them especially through their training or in the form of continuous education; whether clinical guidelines are available and what type of diagnostic criteria is available to headache specialists, if at all. France and Germany score relatively high in comparison to most other countries. Surprisingly it was difficult to get any information from the Norwegian authorities or their websites and for this Norway falls lowest on this scale.



Graph: Professional awareness and education – final results

*There are **seven** indicators in this sub-discipline*:

5.2.2.1 Existence of a National Registry for Headache

National Registries are systematic collections of data about headache diseases. Hardly any EU country has a National Registry for Headache. It is but a few headache specialists in EU countries that in one way or the other report data for research purposes and is most of the time available on the regional level (?). France is the only country to have set up a proper national registry for headache which is continuously updated.

SOURCE: Interviews with National Headache/Neurology representative

5.2.2.2 Availability of reliable national epidemiological data on headache

We ran a search within PubMed and a very few papers presented any kind of national epidemiological data on headache.

SOURCE: Interviews with National Headache Specialists, Scientific papers: Alpay et al. (2010), Dahlof et al. (2001), Diaz-Insa et al. (2011), Duru et al. (2004), Eurolight-online.eu, Fendrich et al. (2007), Gerardy et al. (2008), Grande et al. (2008), Kristiansen et al. (2011), Kroner-Herwig et al (2007), Lampl et al. (2003), Lanteri-Minet et al. (2003, 2005, 2007, 2010), Laurell et al. (2004), Leonardi et al. (2005), Lucas et al. (2006), Lyngberg et al. (2005), Lyngberg et al. (2005a), Markova (2009), Matias-Guiu et al. (2011), Mitsikostas et al. (2010), Russell et al. (2007), Steiner et al. (1998, 2000, 2002, 2003, 2005), Stovner et al. (2007), Straube et al. (2010), Strgar-Hladnik et al. (2008), Wiendels et al. (2006), Wilkinson et al. (1995), Zwart et al. (2004), Lifting the Burden : www.l-t-b.org (last accessed 23 Dec 2011)

5.2.2.3 Availability of a national headache society (for doctors)

This indicator was rather straightforward. By browsing the internet, we came across various national headache societies oftentimes as part of the national neurological society. In some cases, these national headache societies were stand-alone ones. The smaller countries such as Cyprus, Malta, Luxemburg and Ireland do not present and websites or links to (stand-alone) headache societies (at least at the time of research).

SOURCES: Interviews with National Representatives and National Headache Specialists, EHF (European Headache Federation)

5.2.2.4 Availability of an official set of national guidelines for headache

One of the criteria for this indicator is that if a certain country used an official set of national guidelines for headache it could be as old as 10 years. Any type of guideline older than 10 years was not taken into consideration. For a country to score a green, the guideline for headache is supposed to be in the local language and accessible to anyone via the internet. Those countries that kept these guidelines within the realm of the professional societies received a yellow score. Many of the countries do not have national guidelines in their local language and borrow the guidelines from other countries or have no guidelines at all. These countries scored red.

SOURCES: Interviews with National Headache Specialists, Scientific Papers or guidelines: BASH (2011), Bendtsen et al. (2010), EFNS (2011), Evers et al. (2009), Headache Classification Subcommittee of the International Society (2004), Pfaffenrath et al. (2009), Steiner et al. (2010)

5.2.2.5 Availability of a fixed set of diagnostic criteria (IHS10) available to healthcare professionals in the national language

This indicator is similar to the one above. IHS has defined a fixed set of diagnostic criteria and the main questions were whether this set has been translated in the local language of the country, published on the Internet and used in practice. This is one of the two indicators where not a single EU country scored a red (the other indicator with almost all green scores is the one on "Emergency room visits for headache".

SOURCES: Interviews with National Headache Specialists, Scientific Papers or guidelines: BASH (2011), Bendtsen et al. (2010), EFNS (2011), Evers et al. (2009), Headache Classification Subcommittee of the International Society (2004), Pfaffenrath et al. (2009), Steiner et al. (2010), National Societies Websites

5.2.2.6 Existence of a module in headache care in medical school (pre-graduate) training curricula (before reaching specialist training)

It was interesting to hear or read that within some countries there were no modules in headache care in the medical schools on the pre-graduate level curricula. In some countries the specialists we interviewed pointed out that there were 2 to 4 hours of lectures on headache as an intrinsic compulsory curriculum but under the heading of neurology. In some other countries, students can assign themselves to elective and fairly short courses or lectures on headache.

SOURCES: Interviews with National Headache Specialists, Medical Faculty Curricula.

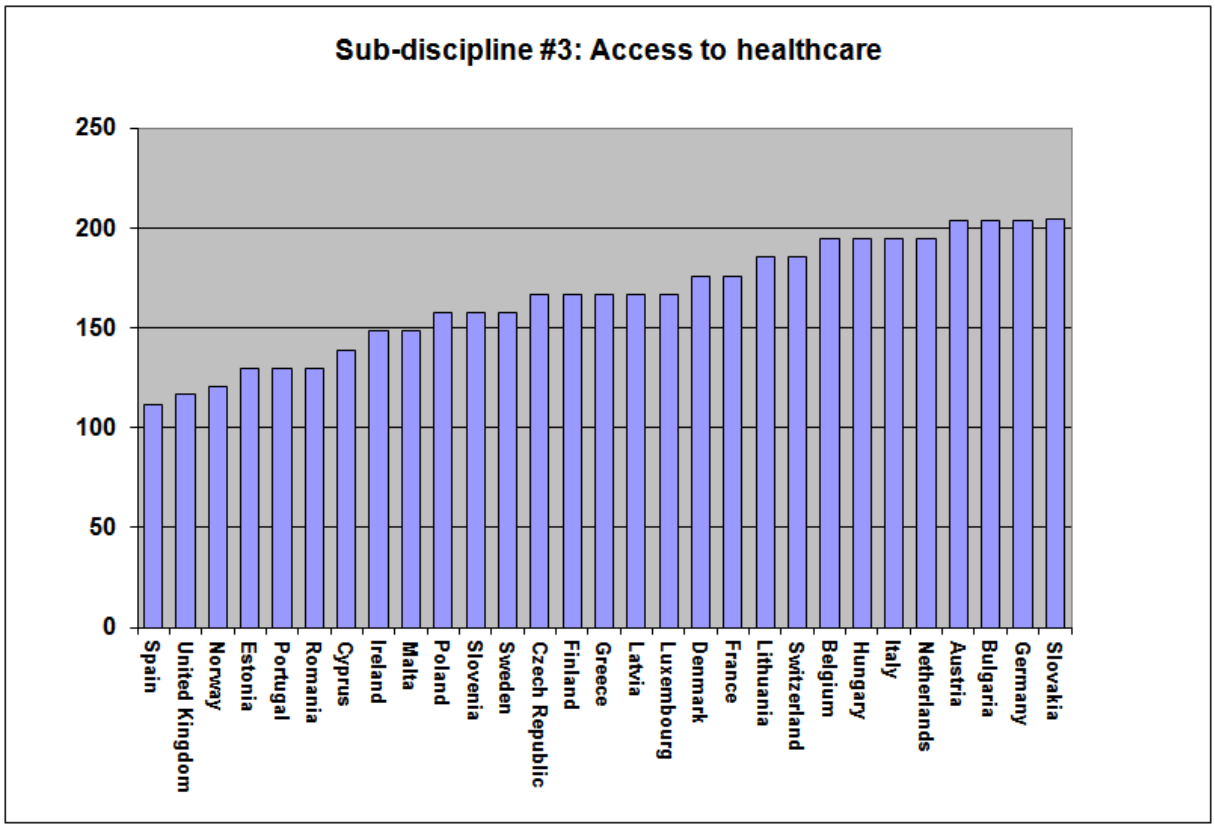
5.2.2.7 Existence of a module in headache care in neurological specialist training

It comes as a surprise, given the burden of headache throughout the EU, that in most countries modules in headache care are offered sporadically. Some countries offer them on continuous basis: annually. Several countries provide no training at all and depend on knowledge acquired at conference or self-education.

SOURCES: Interviews with National Headache Specialists, Medical Faculty Curricula; CEEAM (2011) www.ceeam.info last accessed 3 June 2011, Diener et al. (2006), European Neurological Societies (2011), Facheris et al. (2005), Fumal et al. (2008); but future prospects discussed in: Antonaci et al. (2005, 2008), Jensen et al. (2010, 2010a), Steiner et al. (2011).

[10] IHS stands for the International Headache Society (http://www.i-h-s.org/, last accessed August 2011)

5.2.3 Access to healthcare



Graph: Access to healthcare – final results

This sub-discipline was a relatively easy one to define until we reached the challenge of different definitions and understanding of healthcare systems. Namely, every country defines the primary, secondary and tertiary level in a slightly different manner; and then there was the issue of who exactly is a neurologist – take for instance the number of neurologists in Lithuania – is it really possible that the number is X times higher than the number of neurologists p.m.p. in Denmark? How is a unit of detoxification defined? The question and longest discussions that we had among ourselves and the Experts Panel is the definition of Headache Clinics as defined in the Danish healthcare system. For example, Germany does not have Headache Clinics but rather "Pains Clinic" where headaches are treated. At the end of the day we decided to follow the EHF definitions provided on their website http://www.l-t-b.org/index.cfm/spKey/newsletter.august_2008.headache_services_europe.html (last accessed 3 November 2011)

Interestingly, countries that scored the highest overall for this sub-discipline are: Austria, Bulgaria, Germany, and Slovakia. The lowest scores were attributed to Spain, Norway and the United Kingdom.

*There are **nine** indicators in this sub-discipline*:

5.2.3.1 Number of specialized centers for headache p.m.p.

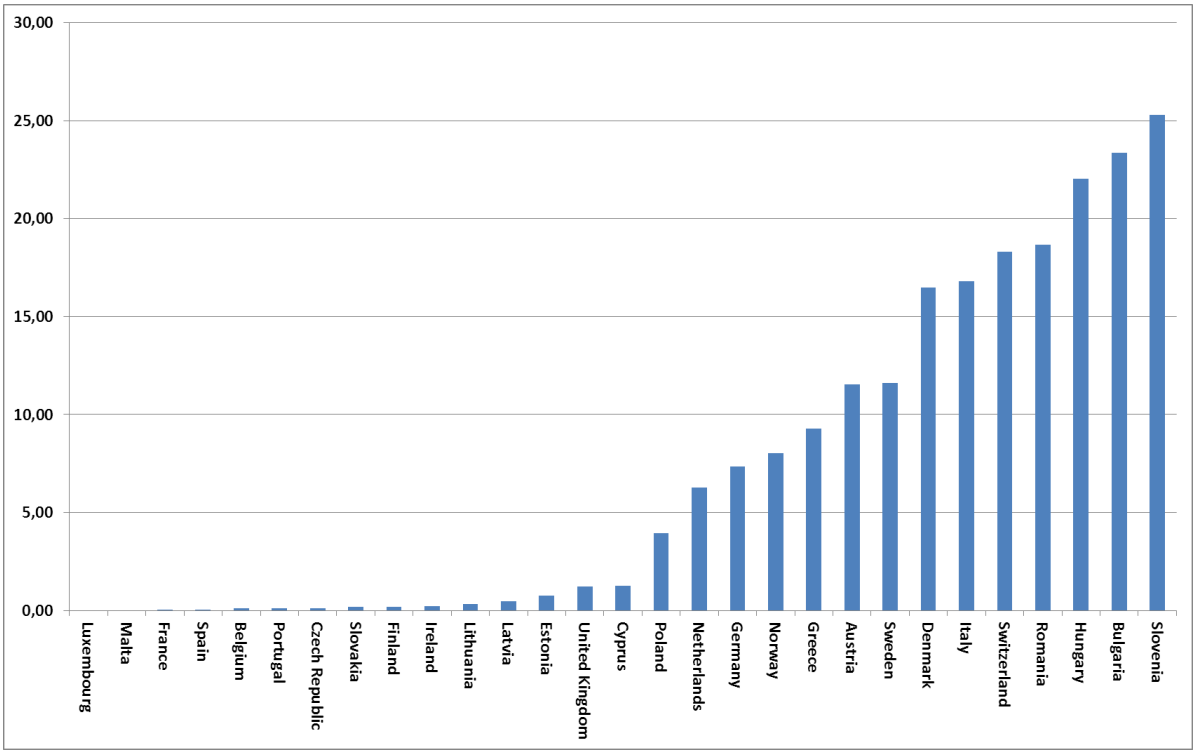
A rather unclear indicator in terms of what the meaning behind "specialized or specialist centers for headache" is. It confused lots of interviewees and there when doing literature research the terms were rather inconsistent. Basically, throughout the EU there is not common understanding and definition of "specialized or specialist centers for headache". However we managed to get some information for most countries through discussions with national headache specialists. For instance, the United

Kingdom and Denmark score a red on this particular indicator, whereas countries like Italy, Bulgaria and the Netherlands score a green.

SOURCES: Interviews with National Headache Experts; www.dmkg.de (last accessed 5 Sept 2011), Danish Headache Center, London Headache Center

5.2.3.2 Number of members of national headache societies p.m.p.

Under this indicator the HCP team wanted to find out what was the number of members of national headache societies per million populations within their countries. The results were available through a CUTS from the European Headache Federation (http://www.ehf-org.org/Pages/default.aspx, last accessed December 2012). Some countries do not report these numbers to the Federation and these are: Finland, France, Ireland, Latvia, Lithuania, Portugal, Slovakia and Spain.



Graph: Number of members of national headache societies p.m.p.

SOURCES: European Headache Federation (http://www.ehf-org.org/ehf_membership/Pages/Membership.aspx, last accessed 29 Jan 2012) and other National Representatives

5.2.3.3 Number of neurology specialists p.m.p.

It was a rather difficult to work out who exactly a headache specialist is and for this reason the most obvious thing to do was to take note of neurology specialist. A straightforward indicator is the number of neurology specialists on the national level. This was readily available through a CUTS.

SOURCES: Reflex Special 2010 - Svenska Neurologföreningen (2010), Grisold et al. (2007), EFNS Directory (2010-2011), Lisnic et al. (2008), interviews with National Headache Specialists

5.2.3.4 Modalities of access to a headache specialist (with or without referral)

In the case where a patient or citizen would need a referral letter to see any headache specialist, this country scored a Yellow; if no referral needed, meaning that one could directly see a headache

specialist then a green was attributed. HCP gave a red to those countries where one would need a referral and was designated to see a specific headache specialist.

SOURCE: PatientView Survey, interviews with National Representatives and National Headache Specialists

5.2.3.5 Availability of special units for detoxification

For this indicator, HCP and the Experts' Panel wanted to find out whether a citizen or patient suffering from headache could be admitted to a special unit for detoxification (*what is meant by detoxification in this case is detoxification from enjoying a mixture for medicinal drugs that led to headache)* . Countries with available special units for medication over-use detoxification exist in headache centers or hospitals scored a green; if outpatient-based a Yellow; and in the case there were no such units available a red was attributed. In these countries the patient is normally sent (if at all) to a narcology unit or the like.

SOURCE: Interviews with National Headache Specialists

5.2.3.6 Mode of admission for detoxification

Similarly to the indicator on "modalities of access to a headache specialist", red was attributed to those countries where admission for detoxification was not possible or admission for such a problem was a very rare occurrence, green for an immediate admission (without referral) to the detoxification unit or program. The general tendency for most countries was an orange, indicating that there were no strict policies or rules in place and it was a matter of professional opinion. The only country where one cannot be admitted for detoxification was Romania.

SOURCE: Specialists, National Representatives, National Societies

5.2.3.7 Emergency room visits for headache

This is the sole indicator where all countries scored a green.

SOURCES: Interviews with National Headache Specialists, Martelleti et al. (2008), PatientView

5.2.3.8 Availability of specialist headache nurses

This indicator was another such indicator where most interviewees were concerned about the definition and / or the existence of such "post" within their healthcare system and the type of education these nurses would be exposed to in relation to headache. The only three countries that had "specialist headache nurses" institutionalized are Belgium, Germany and the Netherlands.

SOURCES: Interviews with National Headache Specialists

5.2.3.9 Waiting time for accessing a headache specialist or neurologist on the secondary level

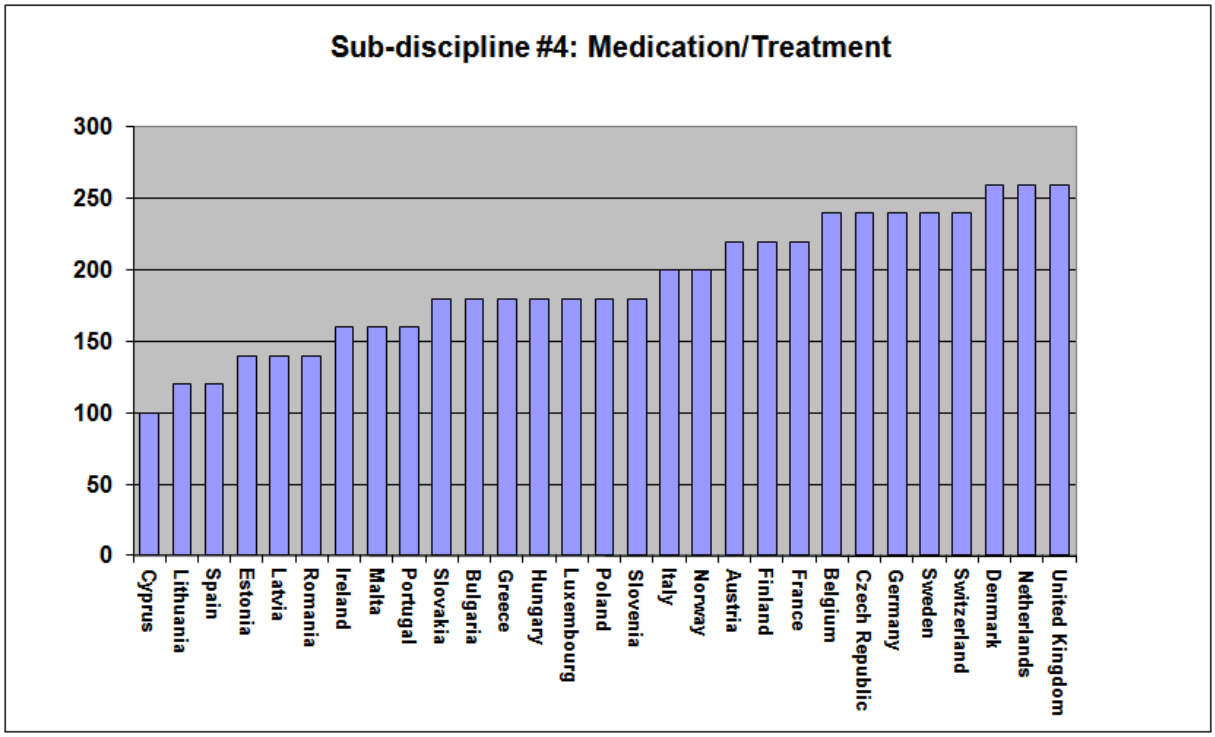
In the Czech Republic, Estonia, Ireland and Romania, a citizen suffering from headache ailments could wait over 3 months to see a headache specialist. Otherwise in most other countries one would wait less than a month to see a specialist. These countries scored a green.

SOURCES: Interviews with National Representatives and National Headache Specialists

5.2.4 Medication and/or treatment

In this sub-discipline there were also several hurdles to overcome. The easiest indicator to complete was the one on the sales per capita for Triptans and the one on the availability of prophylactic drugs.

As for co-payments searching for information with this information for each country was a painful exercise. Some countries positively surprised the team with the availability of data on official national websites provided in the national language but still resourceful.



Graph: Medication / Treatment – final results

*There are **five** indicators in this sub-discipline*:

5.2.4.1 Triptans sales p.m.p.

The ATC (Anatomical Therapeutic Chemical) code studied is N02CC. HCP was provided by IMS the data on the sales of triptans by countries which could be considered a straightforward CUTS. SOURCE: IMS data, interviews with National Representatives (Medicinal Agencies)

5.2.4.2 Availability of prophylactic drugs

In terms of prophylactic drugs, HCP wanted to find out which of the following drugs are registered (available) in each and every country: flunarizine, pizotifen, topiramate, sodium alproate, amitriptyline, cinnarizine, and / or propranolol. According to the Experts, all of these drugs should be available for headache treatment and from the scientific point of view, it is crucial the country offers flunarizine and / or pizotifen (drugs that renowned for their positive effects). So, those countries that offered all these drugs received a green; countries where 5 to 6 of these drugs are offered (incl. flunarizine and / or pizotifen) scored a Yellow, and those countries that had 5 or less of these drugs available out of which flunarizine and or pizotifen were both missing scored a red.

SOURCE: E-mail exchanges with the Info functions of national Medical Products Agencies, Interviews with National Representatives; National Specialists; Edameads (2006), Pradalier et al. (20049, official national websites for medicinal products (such as www.onmeda.de, www.ogyi.hu/drug_database, www.inami.fgov.be/drug, www.raviminfo.ee, http://www.mz.gov.pl/wwwmz/index?mr=b4&ms=300&ml=pl&mi=300&mx=0&ma=16030, …), National drugs databases

5.2.4.3 Share of co-payment for prophylactics

For this indicator, the HCP team spent on average more time than for most of the other indicators in this sub-discipline as the sources to find out the share of co-payment for prophylactic drugs was available through various open sources, if at all. In the cases where the HCP could not find the information in the literature or on national official websites, information was provided through national representatives. Interestingly, for some countries the data was just not available or by discussing it with different interviewees the data was totally different (thus a red score was attributed) or simply not subsidized at all (for example, in Malta). However, in most cases, countries would subsidy at a lower rate than the maximum subsidy rate or would be fully subsidized (green scores).

Also, several countries (including Germany, the UK, Sweden and many more) do not have a system to distinguish between different reasons of prescribing. In those countries a medication is either subsidized or not, which means that "medication for headache prophylaxis" is a non-issue, if the drugs in question are included in pharmacy benefits systems.

SOURCE: Interviews with National Officials and National Headache Specialists, websites of official medicinal agencies (as noted above and in the report), Official National Websites (Ministry, National Payer, Drugs Agency, Insurer), such as www.inami.fgov.be/drug

5.2.4.4 Is "medication over-use" an approved indication for referral for detoxification?

If the response or the data towards this indicator was that the protocols are in place, the countries scored a green (most old EU countries); if however it depended on the provider, the country scored a yellow; and if medication over-use was not all an approved indication for referral for detoxification then it scored a red (Estonia, Lithuania and Romania).

SOURCE: Interviews with National Headache Specialists

5.2.4.5 Prevalence of medication over-use-induced headache

It is rather a few countries that keep track of the prevalence of medication over-use-induced headache. These are Denmark, France, the Netherlands and the United Kingdom where the prevalence of medication over-use-induced headache is recorded and is openly available from year 2000. Some but very few countries have some data available but it is outdated and presents the prevalence from pre-2000. The most common answer was: "no data available".

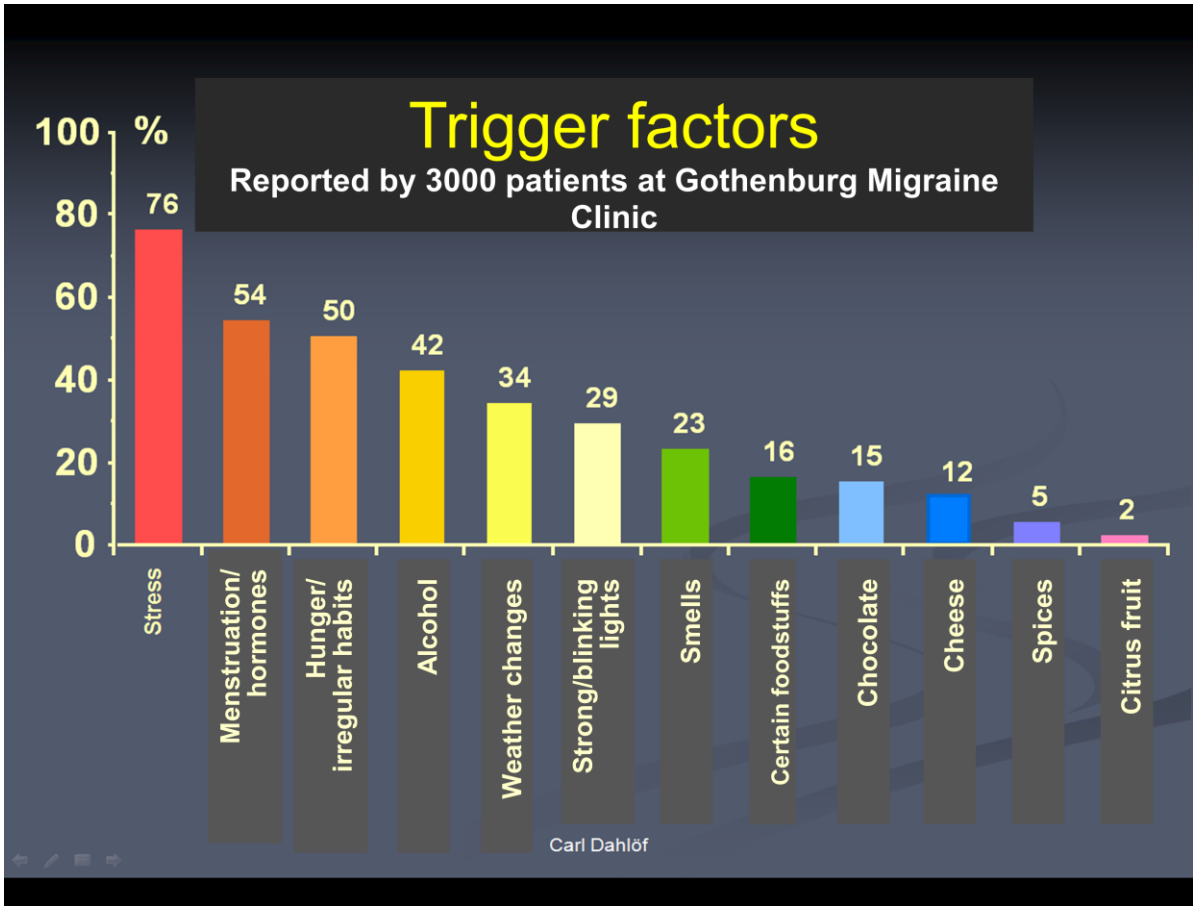
SOURCE: Interviews with National Headache Specialists, Grande et al. (2011), Haag et al. (2010, 2011), Markova (2009), Lucas et al. (2004, 2005), Paemeleire et al. (2006, 2008), Russell (2011), Schoenen et al. (2006), Van Alboom et al. (2009)

5.2.5 Prevention

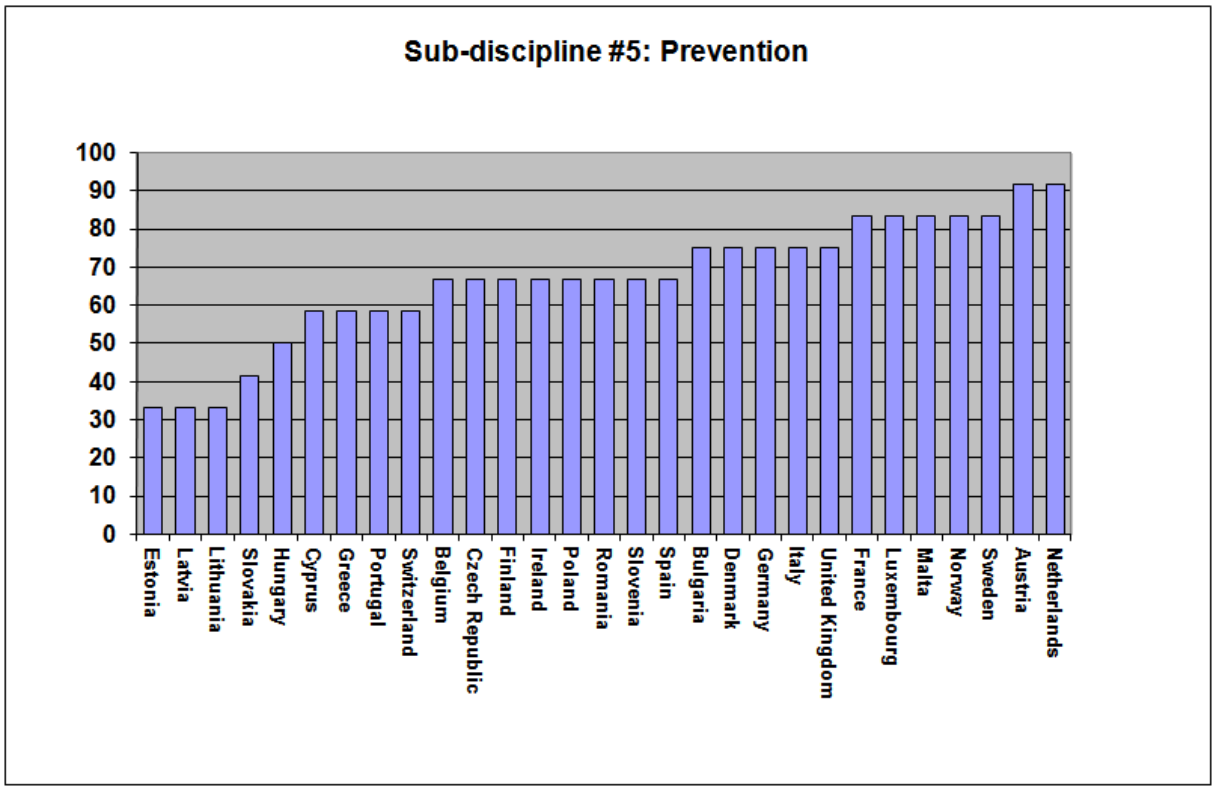
Under this sub-discipline one can see correlations between some of the above-mentioned indicators such as prevalence of headache disorders, sales of triptans, availability of prophylaxis drugs and so on.

Unlike for heart disease or diabetes, for headache/migraine there seem to be no lifestyle factors such as smoking, obesity, lack of exercise or eating certain foodstuffs (*e.g.* vegetables) which could be turned into preventive measures.

Apart from hormonal factors (particularly in women) stress, alcohol and irregular lifestyle in general seem to be the most important trigger factors for migraine. For this reason, HCP selected four "trigger avoidance indicators" as measures on the migraine preventive capacity of a society.



Graph: Dahlof C.: Headache Trigger factors.



Graph: Prevention – final results

The winner in this sub-discipline is the Netherlands, followed by Austria and Sweden – namely these countries have the lowest rates of unemployment, lowest rates in work-related stress, high rate in Happy-life years and moderate or low liquor consumption, particularly when adjusted for uneven consumption patterns.

There are **four** indicators to this sub-discipline:

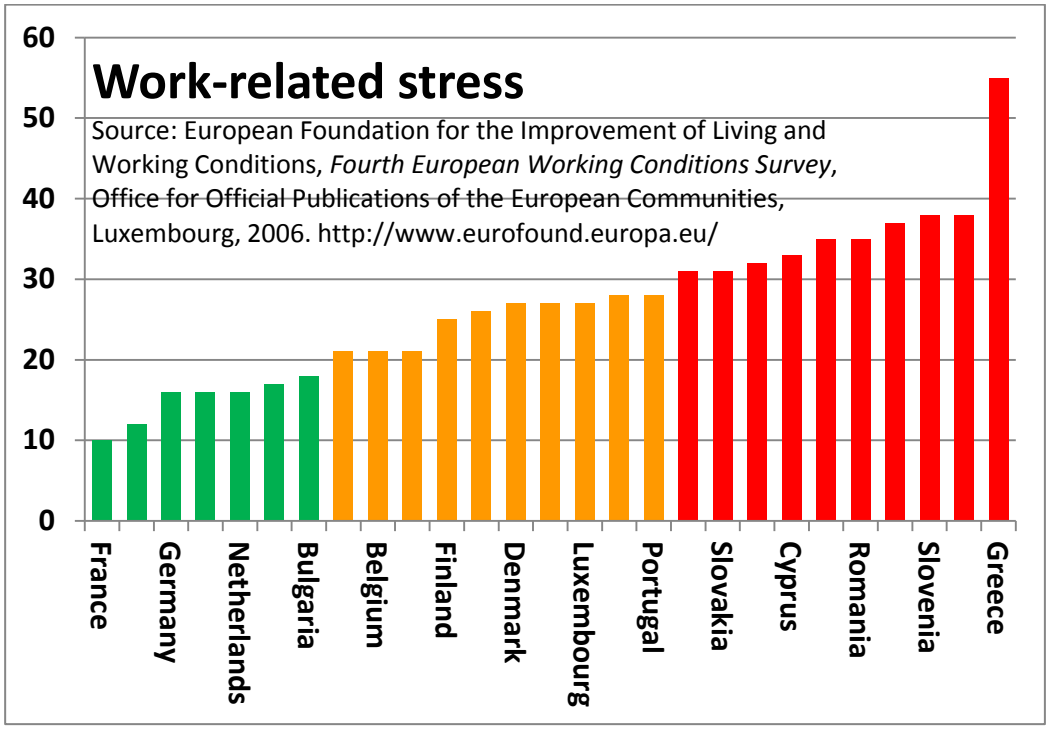
5.2.5.1 Work-related stress

As stated in the European Risk Observatory Report (http://osha.europa.eu/en/riskobservatory/index_html , last accessed 4 Jan 2012) »one of the major reasons for headache is stress. Stress prevalence in the new Member States (EU10) is markedly higher than in the old Member States (EU15). Work-related stress was reported by 20% of workers from EU15, 30% of workers from EU10. The highest level of stress was reported in Greece (55%), and then in Slovenia, Sweden (38%), and Latvia (37%). Lowest stress levels were noted in the United Kingdom (12%), Germany, Ireland, and the Netherlands (16%), in the Czech Republic (17%), and in France and Bulgaria (18%).

Other stress-related outcomes (except for anxiety) are also at higher levels in the new EU countries[11]. In 2005, overall *fatigue* was reported by 18% of workers from EU15, 41% from EU10; **headaches**, 13% and 24% respectively; backache 21%, and 39% in EU10; sleeping problems by 8%, 12%, and 16% of workers respectively. Substantial differences were also noted in heart disease figures. This problem was reported by 1.4% of workers from EU15, 5.6% from EU10. The level of irritability, and anxiety was similar in all groups of countries - 10-12% reporting irritability and 7-9% reporting anxiety."

According to the Fourth European Working Conditions Survey in 2005 stress was experienced on average by 22% of workers from 25 Member States (EU 27 from January 2007) as presented in the graph below (no data was available for Norway nor Switzerland). The green bars represent countries where the work-force is least stressed, the red bars most stressed (Greece having the highest level of stress, and France the lowest).

[11] The statistical analysis of the results of the 3rd EWCS carried out by Daniels, indicated that items such as "anxiety", "irritability", "sleeping problems", "stomach ache", "headaches", and "overall fatigue" are closely related to the item "stress". All of these items formed a coherent scale with the level of reliability (*alpha*) = 0.73.



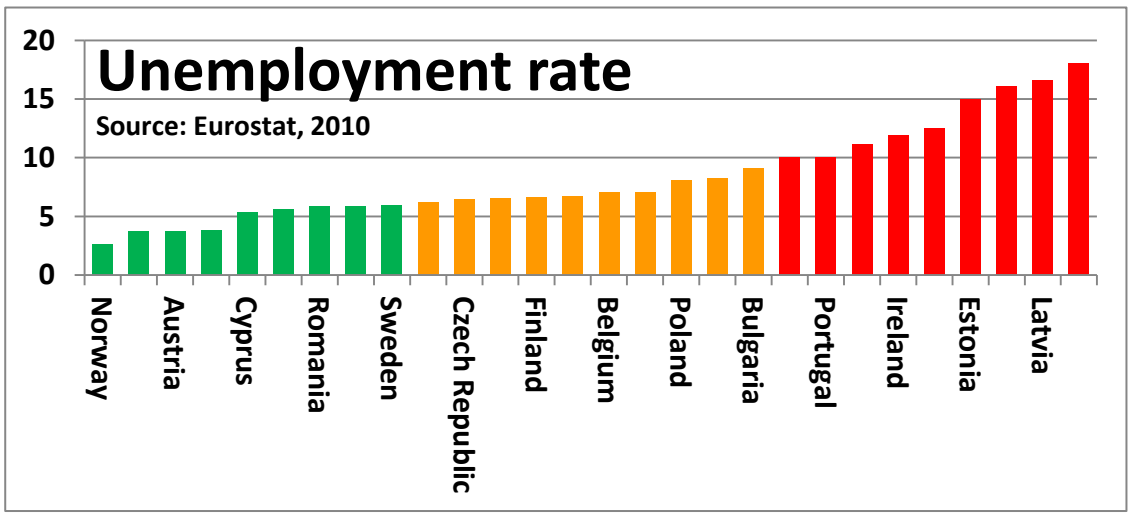
Graph: Work-related stress

SOURCE: European Foundation for the Improvement of Living and Working Conditions, *Fourth European Working Conditions Survey*, Office for Official Publications of the European Communities, Luxembourg, 2006. http://www.eurofound.europa.eu/ewco/surveys/EWCS2005/index.htm in European Risk Observatory Report - OSH in figures: stress at work — facts and figures. European Agency for Safety and Health at Work: 2009.

5.2.5.2 Unemployment rate

The graph below represents the data for unemployment rate in 2010 by Eurostat (a pure CUTS). It goes without saying that unemployment is a serious stress factor that ultimately can lead to headache ailments as suggested by many headache specialists and scientist.

Graph: Unemployment rates for 2010, 25-74 years, female and male population

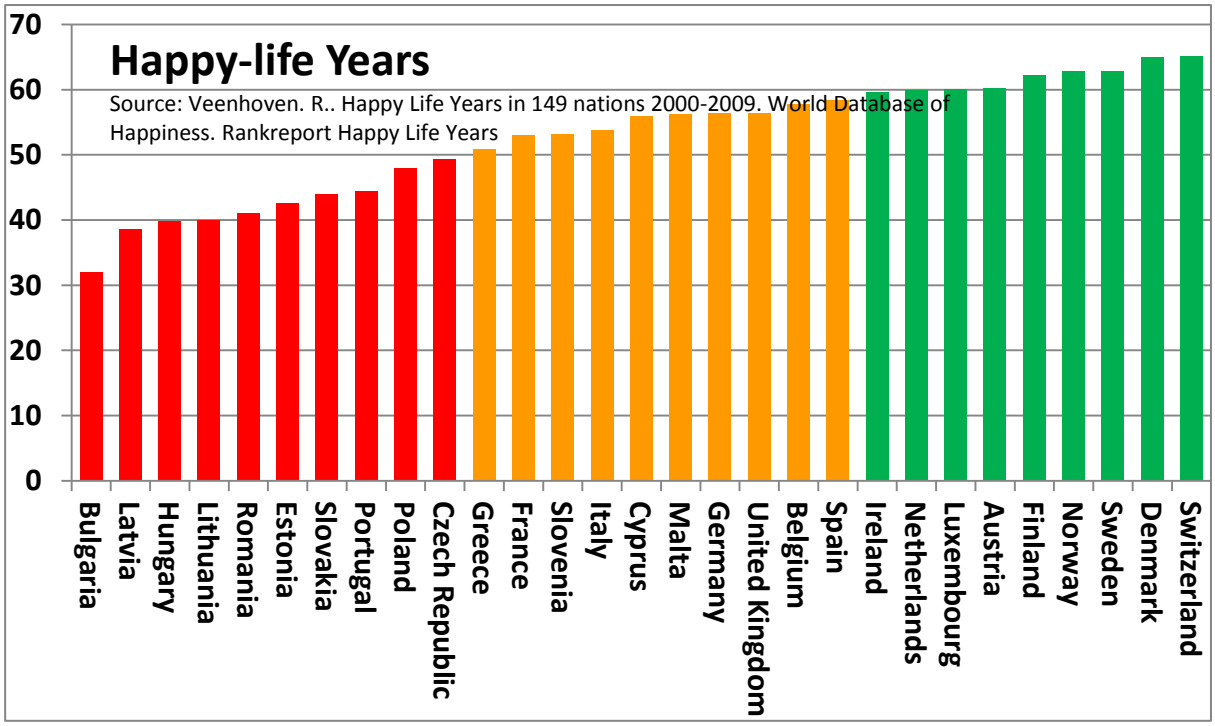


SOURCE: Eurostat 2010
(http://epp.eurostat.ec.europa.eu/statistics_explained/index.php?title=File:Table_unemployme

nt_rates_by_age_and_gender.PNG&filetimestamp=20110504125603, last accessed 29 January 2012)

5.2.5.3 Happy-life Years (HLY)

According to Veenhoven, "Happy-life Years" is an estimate of how long and happy the average citizen will live in that nation in this era. Computation: 0-1 enjoyment of life multiplied by expected length of life. On the basis of a CUTS, one can say that one third (almost to the point) of the EU nations live longest and happiest on average and are the ones marked in green. The Swiss and the Danes are to live around 60 happy life years whereas Bulgarians a little above 30 happy life years.



Source: Veenhoven. R.. Happy Life Years in 149 nations 2000-2009. World Database of Happiness. Rankreport Happy Life Years. Internet:

worlddatabaseofhappiness.eur.nl/hap_nat/findingreports/RankReport_HappyLifeYears.php

5.2.5.4 Hard liquor consumption per capita

The second most common reason or explanation for headache is alcohol consumption. It could range from drinking a sip of red wine to binge-drinking. For the purpose of this Index HCP looked at the hard liquor consumption per capita per country. This indicator was fed by a CUTS (WHO HfA) and has been adjusted for irregular consumption in the following way;

National hard liquor consumption pattern	**Adjustment factor used to multiply nominal per capita consumption**
Significantly more irregular than EU average	1.0
Irregularity close to EU average, but still more irregular	0.8
Regular consumption over the week	0.6

Index weighted 0.33*males + 0.67*females, as females account for a higher share of headache disorders.

SOURCE: Special Eurobarometer 272, WHO HfA, A. Björnberg, A-M. Yazbeck, A. Odén: *Which European country has the best cardiac care: Risk factor based expected heart disease death rates vs. actual observed death rates in 29 European countries***.** Poster, European Society of Cardiology Congress, Munch 2008.

6. How was the Euro Headache Index 2012 built?

The Index does not take into account whether national systems are publicly or privately funded and/or operated. The purpose is citizen empowerment, not the promotion of political ideology. Aiming for dialogue and co-operation, the ambition of HCP is to be looked upon as a partner in developing healthcare-related issues around Europe.

6.1 HCP Background

Since 2004 the HCP has been publishing a wide range of comparative publications on healthcare in various countries, first, the Swedish Health Consumer Index in 2004. By ranking the 21 county councils by 12 basic indicators concerning the design of ”systems policy”, consumer choice, service level and access to information we introduced benchmarking as an element in consumer empowerment. In two years time this initiative had inspired – or provoked – the Swedish Association of Local Authorities and Regions together with the National Board of Health and Welfare to start a similar ranking, making public comparisons an essential Swedish instrument for change.

For the pan-European indexes in 2005 – 2008, HCP followed basically the same approach, *i.e.* selecting a number of indicators describing to what extent the national healthcare systems are “user-friendly”, thus providing a basis for comparing different national systems.

Furthermore, since 2008 the HCP has enlarged the existing benchmarking program considerably:

- In January 2008, the Frontier Centre and HCP released the first Euro-Canada Health Consumer Index, which compared the health care systems in Canada and 29 European countries. The 2009 edition was released in May, 2009.
- The Euro Consumer Heart Index, launched in July 2008, compares 29 European cardiovascular healthcare systems in five categories, covering 28 performance indicators.
- The Canada Health Consumer Index was released in September 2008, and again in May 2010 in co-operation with Frontier Centre for Public Policy, examining healthcare from the perspective of the consumer at the provincial level.
- The first Euro Consumer Diabetes Index, launched in September 2008, provides the first ranking of European diabetes healthcare services across five key areas: Information, Consumer Rights and Choice; Generosity, Prevention; Access to Procedures and Outcomes.
- The Euro HIV Index was published in October 2010, analyzing how 29 European countries are performing on HIV care and conditions for People Living With HIV (PLWH).

Though still a somewhat controversial standpoint, HCP advocates that quality comparisons on healthcare-related issues is a true win-win situation. To the consumer, who will have a better platform for informed choice and action. To governments, authorities and providers, the sharpened focus on

quality outcomes will support change. To media, the ranking offers clear-cut facts for consumer journalism with some drama into it. This goes not only for evidence of shortcomings and method flaws but also illustrates the potential for improvement. With such a view the THPI is designed to become an important benchmark system supporting interactive assessment and improvement.

As we heard one of the Ministers of health saying when seeing his country's preliminary results: "It´s good to have someone still telling you: you could do better."

6.2 About the authors

Project Management for the EHI 2012 has been executed by Arne Björnberg, Ph.D.

Dr. Björnberg has previous experience from Research Director positions in Swedish industry. His experience includes having served as CEO of the Swedish National Pharmacy Corporation ("Apoteket AB"), Director of Healthcare & Network Solutions for IBM Europe Middle East & Africa, and CEO of the University Hospital of Northern Sweden ("Norrlands Universitetssjukhus", Umeå).

Dr. Björnberg was also the project manager for the EHCI 2005 – 2012 projects, the Euro Consumer Heart Index 2008 and numerous other Index projects.

Anne-Marie Yazbeck, MSc, co-authored with Dr Bjornberg the Euro Heart Index 2008. She works in the field of health system development and public hospital financing on the national level in Slovenia. She worked at the Ministry of Health of Slovenia and WHO. She is also presently finishing up her doctorate thesis in the field of public hospital reorganizations and work processes at the Faculty of Economics of Ljubljana in Slovenia.

6.3 The HCP Flagship product: Euro Health Consumer Index

6.3.1 Scope and content of EHCI 2005 - 2012

Countries included in the EHCI 2005 were: Belgium, Estonia, France, Germany, Hungary, Italy, the Netherlands, Poland, Spain, Sweden, the United Kingdom and, for comparison, Switzerland.

To include all 25 member states right from the start would have been a very difficult task, particularly as many memberships were recent, and would present dramatic methodological and statistic difficulties

The EHCI 2005 was seeking a representative sample of large and small, long-standing and recent EU membership states.

The selection was influenced by a desire to include all member states with a population of ~40 million and above, along with the above-mentioned mix of size and longevity of EU membership standing. As the Nordic countries have fairly similar healthcare systems, Sweden was selected to represent the Nordic family, purely because the project team members had a profound knowledge of the Swedish healthcare system.

As already indicated, the selection criteria had nothing to do with healthcare being publicly or privately financed and/or provided. For example, the element of private providers is specifically not at all looked into (other than potentially affecting access in time or care outcomes).

One important conclusion from the work on EHCI 2005 was that it is indeed possible to construct and obtain data for an index comparing and ranking national healthcare systems seen from the consumer/patient's viewpoint.

The EHCI 2006 included all the 25 EU member states of that time, plus Switzerland using essentially the same methodology as in 2005.

The number of indicators was also increased, from 20 in the EHCI 2005 to 28 in the 2006 issue. The number of sub-disciplines was kept at five; with the change that the "Customer Friendliness" sub-discipline was merged into "Patient Rights and Information". The new sub-discipline "Generosity"

(What is included in the public healthcare offering?) was introduced, as it was commented from a number of observers, not least healthcare politicians in countries having pronounced waiting time problems, that absence of waiting times could be a result of "meanness" – national healthcare systems being restrictive on who gets certain operations could naturally be expected to have less waiting list problems.

In order to test this, the new sub discipline "Generosity" of public healthcare systems, in 2009 calles "Range and reach of services". A problem with this sub discipline is that it is only too easy to land in a situation, where an indicator becomes just another way of measuring national wealth (GDP/capita). The indicator "Number of hip joint replacements per 100 000 inhabitants" is one prominent example of this. The cost per operation of a hip joint is in the neighbourhood of € 7000 (can be slightly more in Western Europe – less in states with low salaries for healthcare staff). That cost, for a condition that might be crippling but not life-threatening, results in Provision levels being very closely correlated to GDP/capita.

Cataract operations seem a better and less GDP-correlated indicator on the Generosity of public healthcare systems. The cost per operation is only one tenth of that for a hip joint and thus much more affordable in less affluent countries. Interestingly, Belgium – a country with minimal waiting list problems, and which was most often to us accused of achieving this through restrictiveness, by far has (along with Canada) the highest provision levels for cataract operations in the OECD.

To achieve a higher level of reliability of information, one essential work ingredient has been to establish a net of contacts directly with national healthcare authorities in a more systematic way than was the case for previous EHCI editions. The weaknesses in European healthcare statistics described in previous EHCI reports can only be offset by in-depth discussions with key personnel at a national healthcare authority level.

In general, the responsiveness from Health Ministries, or their state agencies in charge of supervision and/or Quality Assurance of healthcare services, was good in 2006 – 2008. Written responses were received from 19 EU member states. This situation greatly improved in 2009.

The project work on the Index is a compromise between which indicators were judged to be most significant for providing information about the different national healthcare systems from a user/consumer's viewpoint, and the availability of data for these indicators. This is a version of the classical problem "Should we be looking for the 100-dollar bill in the dark alley, or for the dime under the lamppost?"

It has been deemed important to have a mix of indicators in different fields; areas of service attitude and customer orientation as well as indicators of a "hard facts" nature showing healthcare quality in outcome terms. It was also decided to search for indicators on actual results in the form of outcomes rather than indicators depicting procedures, such as "needle time" (time between patient arrival to an A&E department and trombolytic injection), percentage of heart patients trombolysed or stented, etcetera.

Intentionally de-selected were indicators measuring public health status, such as life expectancy, lung cancer mortality, total heart disease mortality, diabetes incidence, etc. Such indicators tend to be primarily dependent on lifestyle or environmental factors rather than healthcare system performance. They generally offer very little information to the consumer wanting to choose among therapies or care providers, waiting in line for planned surgery, or worrying about the risk of having a post-treatment complication or the consumer who is dissatisfied with the restricted information.

6.4 Other HCP Indexes

In addition to the EHCI editions, the HCP has also published special indexes constructed along the same principles. Among these are:

- The Euro Consumer Heart Index 2008; http://www.healthpowerhouse.com/files/euro-heart-index-2008.pdf

- The Euro Consumer Diabetes Index 2008; http://www.healthpowerhouse.com/files/edi-2008/2008-euro-diabetes-index-report.pdf
- The Euro HIV Index 2009; http://www.healthpowerhouse.com/files/Report%20Euro%20HIV%20index%20091008-3.pdf

All the indexes are built along the same principles. The sub-disciplines and indicators are similar but different depending on the issue at hand.

6.5 Index production phases

The Euro Headache Index 2012 was constructed under the following project plan.

6.5.1 Phase 1

Normally, in the first phase there is a kick-off meeting of the project with the Experts Panel where the mapping of existing data and possible indicators is rolled out. The composition of the Experts Panel can be found in the section XX. Following this meeting, the researchers spend about 1 to 3 months to collect data.

The major activities of Phase 1 is to evaluate to what extent relevant information is available and accessible for the selected countries. The basic methods are:

- Web search, journal search
- Telephone and e-mail interviews with key individuals, and
- Personal visits when required.

Web search:

- Relevant byelaws and policy documents
- Actual outcome data in relation to policies
- Scientific browsers and journals
- Any websites related to professional societies in the field of research
- Any websites related to patient organizations in the field of research

Contacting information providers in various areas:

- National and Regional Health Authorities
- Miscellaneous organizations (University clinics, International bodies in the field of research such as for example European Federations, Societies and so on)
- Private enterprises (IMS Health, pharmaceutical industry, others)

Involvement of Patient View:

HCP has several times involved the Patient View organization who disseminated in various languages online questionnaires relevant to the topic of the Index. This is a crucial exercise and contribution to the Index as it provides feedback from patient organization who are the prime users of the healthcare system and are most affected by the provided provisions of care within their countries.

Interviews with national representatives to evaluate findings from earlier sources, particularly to verify the real outcomes of policy decisions through various means:

- Telephone and e-mail

- Personal visits to key information providers

6.5.2 Phase 2

There are several stages of development that take place in Phase 2 of the production of the Index. This phase can last between 3 to 9 months:

- Analysis of collected data and preparation of this data to feed the indicator of the Index.
- Identification of vital areas where additional information is needed to be revisited recollected through a different medium.
- Collection of any other relevant data to contribute towards reliable information.
- A round of personal visits by the researchers to Health Ministries and/or State Agencies for supervision and/or quality assurance of healthcare service provision in the field under discussion.
- Regular communication via e-mail or telephone with the members of the Experts Panel to discuss the development of the Index. When need be, discuss particular indicators, redefine the criteria, and sort out the problems of acquiring data.
- Second meeting with the Experts Panel to discuss in detail each of the indicators, including those that could not be included in the Index due to lack of data and examine the discrepancies between data from different sources. In addition, the indicator and sub-discipline relative weights are normally also discussed and set within this meeting.

6.5.3 Phase 3

Normally, in month 10 of the project, the countries (their National Ministries or Agencies) involved in the research receive their respective preliminary country score sheet (with no reference to other country's scores) via email and are asked to provide updates and / or corrections within a period of six weeks. Corrective feedback from the countries are then noted and reexamined by the researchers and the Experts Panel. For this Index the list of countries providing feedback is noted under section 3 above.

6.5.4 Phase 4

Phase 4 is the report writing phase that can last about two months. The final report is then officially launched on the HCP website: www.healthpowerhouse.com.

6.6 External reference Panel of Experts

As is the standard working mode for all HCP Indexes, an external Experts Panel is recruited. The Panel for the Euro Headache Index 2012 met for three times for 6-hour meeting in the course of the project. The members of the panel received working material in advance and were invited to contribute according to their line of expertise. The following persons took part in different stages of the Experts Panel work for the Euro Headache Index 2012:

Name	**Affiliation**
Dr Emile Couturier	Headache Specialist, EHF Country Representative
Mrs Audrey Craven	European Headache Alliance, Ireland
Dr Rigmor Jensen	Danish Headache Center, Department of Neurology, Glostrup Hospital, Denmark
Dr Michel Lanteri-Minet	Département d'Evaluation et Traitement de la Douleur,CHU de Nice - Hôpital Pasteur, France

Dr Diana Obelieniene	Head of Neurological Department of Kaunas Medical University, Lithuania
Dr Jes Olesen	Department of Neurology, University of Copenhagen, Glostrup Hospital, Denmark
Dr Koen Paemeleire	Headache Specialist, EHF Country Representative
Dr Cristina Tassorelli	National Neurological Institute C. Mondino Foundation, Italy
Dr Maria Magdalena Wysocka-Bąkowska	President, Polish Headache Society

The Experts Panel for a HCP Index has two core tasks:

1. Assist in the design and selection of sub-disciplines and indicators. This is obviously of vital importance for an Index, if the ambition is to be able to say that a state scoring well can truly be considered to have good, consumer-friendly public health services.
2. Review the final results of research undertaken by HCP researchers before the final scores are set and presented publicly. If the information obtained seems to clash too violently with the many decades of headache care experience represented by the panel members, this has been taken as a strong signal to do an extra review of the results.

The HCP wishes to extend its sincere thanks to the members of the panel for their fundamentally important contribution to the Index work, and for very valuable discussions.

7. References

Aside from the stated sources and references in the body of the report the HCP team also referred to the following references and resources and found evidence that led to the final results of this Euro Headache Index 2012. The main sources of input for the various indicators are given in Table X under section X. For most of the indicators the information has been supplemented by interviews, correspondence and discussions with public health officials and professional societies in the field.

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