



Since headache centres or specialised clinics are vital to effective management of the condition, the survey also looked at how the existence of them is publicised - 56% of the responders knew about them. It took an average 12.8 years from the onset of the headache condition to becoming aware of the existence of a headache centre/clinic!

**Rome Declaration targets 2005 - 2010:**

- The percentage of migraine patients in the care of a physician should increase from the current level of 30% to 50%
- The number of patients receiving effective therapy for acute migraine attacks should increase from the current level of 40% to 70%
- At least 50% of patients requiring migraine prevention therapy should be receiving this treatment

The information gathered in this survey forms the basis of the 2009 European Migraine Day of Action (EMDA) campaign. EHA will endeavour to increase public awareness and influence policy makers at scientific and political level, in order to improve access to care for headache patients and migraineurs in particular.

**By working together, the health professional and patient organisations active in Europe in the field of headache and migraine will:**

- Set up awareness initiatives for the general public in order to create recognition of the need for treatment
- Set up educational programmes for health professionals in order to improve their ability to diagnose and treat
- Produce and disseminate diagnostic aids, management guidelines and instruments for outcome evaluation
- Promote and encourage research

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## ACCESS TO CARE for people with headache and migraine

### A Survey by the European Headache Alliance



Launched in The European Parliament in Brussels on the occasion of the

## European Migraine day of Action

[www.e-h-a.eu](http://www.e-h-a.eu)



**Why this survey?**

Migraine was defined as "a forgotten epidemic" in the joint declaration by European Headache Federation and World Headache Alliance released in Rome in 2005 (*the Rome Declaration*). EHA wanted to take a snapshot of the situation four years on from the release of this declaration. The Access to Care survey was initiated and conducted by EHA in collaboration with its members. Information was collected from both patient organisations and from their members across Europe in order to obtain reliable and representative information on access to care for headache patients.

Two types of questionnaires were used for this purpose. The first questionnaire was intended for the representatives of each patient organisation. The second questionnaire was directed to individual members of patient organisations.

**Heading for a solution**

**- Meeting the aims of the Rome Declaration on Migraine 2005 - 2010<sup>1</sup>**

The survey carried out in nine European countries points out that a majority of headache patients are dissatisfied with their treatment. However, it looks likely that overall the aims of the Rome Declaration may be met.

Perhaps after the five-year time frame of the Rome Declaration expires, another declaration looking at encouraging research, developing treatments, etc. needs to be considered.

It is important that the patient organisations under the EHA umbrella continue to work in partnership with health professionals, policy makers and all possible stakeholders to progress these aims – "unity is strength".

**EHA SURVEY ACCESS TO CARE**

The aims of the two questionnaires employed in this survey were as follows:

- to ascertain the efforts of *patient organisations* to enhance knowledge and information about headaches
- to identify the different patient categories
- to explore the use of health care services by both headache and migraine patients
- to measure the level of satisfaction with health care services and physicians
- to categorise the reasons for satisfaction or dissatisfaction
- to identify how patients obtain information about treatment.

**A. Summary of feedback from the patient organisations**

All the responding member organisations have arranged Headache/Migraine public awareness raising programmes or events in the last five years. Many also have set up education programmes for healthcare providers and all of them have disseminated information on the condition and practical assistance for better management of migraine and other headache disorders. One of the most important tools identified in the survey is the **headache diary**.

Although most responding countries have Specialist Headache Centres or Migraine Clinics, the majority considers access to care inadequate. The reasons differ somewhat, but in general

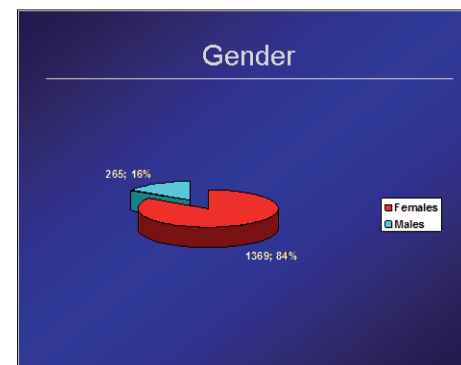
<sup>1</sup>The Rome Declaration is a statement of actions required to improve migraine care and quality of life over a five-year period

they relate to headache and migraine not being accepted as a "real" disease. In many countries migraine has a low profile in primary and in secondary care as well as in education of health professionals, and many GPs (General Practitioners) are not well informed because of this, lacking specialised knowledge about the condition and effective treatments. The high cost of private visits to specialists and expensive medicines also constitute barriers to access.

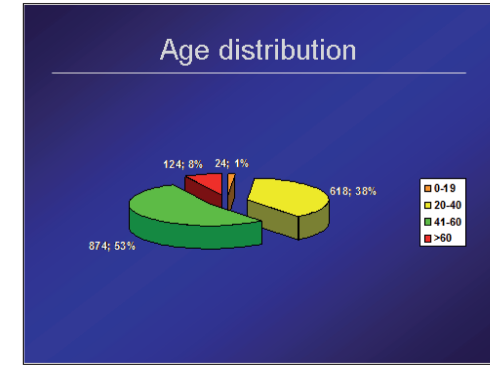
**B. Summary of feedback from migraine and headache sufferers**

As many as 1642 responded to the survey - 84% women and 16% men. The age ranged from 20 to 60 years, the majority being between 40 and 60. The types of headaches represented were migraine (1356 of the responders), tension type, cluster headache and medication overuse.

84% women, 16% men



91% between 40 and 60 years

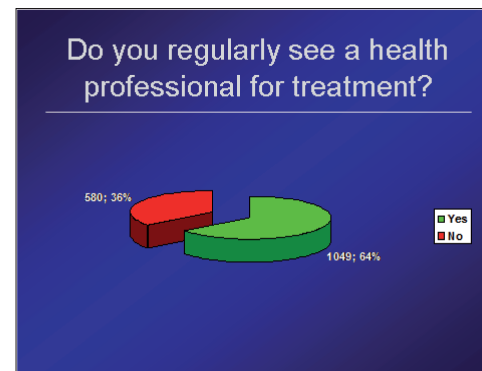


A majority – almost 60% – of the responders was dissatisfied with the management and treatment of the condition. The major reasons for dissatisfaction were:

- ineffective treatment
- difficulties getting to a specialist
- insufficient explanation of the medication and how to use it

EHA believes that headaches should be managed at GP level, and that only refractory cases should be referred to specialists. In this regard it is noteworthy that a low minority of patients (8%) regularly consulted a headache specialist.

64% did see a health professional regularly



Almost 60% are dissatisfied with treatment

