

# The EUROLIGHT Project: Highlighting the impact of primary headache disorders in Europe - Description of methods



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## BACKGROUND

The purposes of the Eurolight Project, a collaborative data-collection exercise in ten countries of Europe initiated by the Center of Public Health Research (CRP-Santé) Luxembourg, were to estimate the prevalence and impact of headache disorders (migraine, tension-type headache (TTH) and chronic headache disorders occurring on  $\geq 15$  days/month) in Europe.

## AIM

The project took the form of surveys by structured questionnaire, conducted from November 2008 to August 2009, of population samples from ten countries of Europe representing 60% of the adult population of the European Union: Austria, France, Germany, Ireland, Italy, Lithuania, Luxembourg, Netherlands, Spain and UK. The Eurolight questionnaire was based on the BURMIG questionnaire, which itself was developed for the BURMIG (burden of migraine) study, a Eurolight pilot study in Luxembourg [4]. Modifications were made in the light of the results of that study, and some elements were imported from other validated sources. The Eurolight questionnaire (together totalling 103 items) was translated into Dutch, French, German, Italian, Lithuanian, Luxembourgish, Portuguese (for part of the population in Luxembourg) and Spanish.

## DIAGNOSIS OF HEADACHE, ASSESSMENT OF IMPACT, DATA ENTRY AND QUALITY CONTROL

Only one headache type was diagnosed in each respondent. Diagnoses in respondents with headache on  $< 15$  days/month (episodic headache) were derived, from the responses to these questions, by means of a computerized algorithm constructed by LTB for this question set and applying ICHD-II criteria [7]) for, in order, migraine, TTH, probable migraine and probable TTH. Further questions enquired into frequency, intensity and duration of headache, use of health-care resources (medication, consultations, investigations and hospitalizations) and effects of headache on school, work, career, income, family life, children and household partner. Additionally there were standard questionnaires on lost time (HALT index [10]), quality of life (WHOQOL-8 [11]) and anxiety and depression (HADS [12]). Independent double data-entry was performed in all cases. CRP-Santé supervised data entry and developed a database and means of electronic transfer via a secure web application to the central collecting point. All hard-copy completed questionnaires were also sent to CRP-Santé.

Table 1. Summarized methodological description of the surveys in ten countries

Survey	Target population and mode of distribution of questionnaire
<b>Studies with a general-population basis or conducted in health-care settings</b>	
Austria	Consecutive patients consulting GPs or neurologists for any reason, questionnaire handed directly
France	Consecutive patients consulting GPs for any reason, questionnaire handed directly
Germany	Random general-population sample from urban and rural areas, contacted by regular post
Italy	Stratified general-population sample from urban and rural areas, contacted by regular post
Lithuania	General population sample in and around Kaunas (urban and rural), contacted by door-to-door cold-calling and personally interviewed by trained medical students
Luxembourg	Stratified general-population sample contacted by regular post
Netherlands-population	Stratified general-population sample contacted by internet
Spain-workplace	Stratified sample of employees of the tertiary sector of the Postal Services contacted by internal post by occupational health physicians
UK	Consecutive patients attending GPs for any reason; questionnaire handed directly
<b>Studies among members of headache patients' organization</b>	
Ireland	Members of MAI and their non-biological relatives, contacted by regular post
Netherlands-patient	Random sample of members of NVvH <sup>2</sup> and (where existing) their non-headache-affected partners, contacted by regular post
Spain-patient	Members of AEPAC and their family, questionnaire distributed by hand via helpers of AEPAC
<b>Studies among non-responders</b>	
Germany-nr	Telephone interview
Italy-nr	Telephone interview
Luxembourg-nr	Telephone interview
Netherlands-nr	Telephone interview

Table 2. Responder-rates, gender distribution and mean age of samples in each survey

Survey	Denominator (n)	Responders (n)	Responder-rate (%)	Gender (% female)	Age (yr) mean (SD)
Austria	6,000	646	10.8	70	48.8 (16.0)
France	2,400	876	36.5	68	50.2 (16.7)
Germany	3,000	338	11.3	57	44.6 (12.5)
Ireland	members 1,500 relatives unknown	195 73	13.0 incalculable	66	49.4 (14.0)
Italy	3,500	500	14.3	58	43.4 (12.6)
Lithuania	1,137	616	54.2	59	40.9 (13.8)
Luxembourg	6,498	2,023	31.1	58	40.5 (12.7)
Netherlands-population	unknown	2,414	incalculable	50	42.6 (13.2)
Netherlands-patient	members 500 partners unknown	337 115	67.4 incalculable	57	48.6 (10.6)
Spain-workplace	1,700	999	58.8	59	42.7 (11.9)
Spain-patient	300	272	90.7	62	41.6 (11.4)
UK	720	128	17.8*	65	48.0 (18.3)
<b>Non-responder studies</b>					
Germany-nr		260		55	unknown
Italy-nr		202		70	39.4
Luxembourg-nr		357		50	unknown
Netherlands-nr		188		52	38.9

## Discussion

1. EUROLIGHT will provide robust data revealing the amount of public ill-health that results from headache in Europe.
2. The different sampling methods adopted in these ten countries worked with differing degrees of effectiveness, as evidenced by the responder-rates, which varied from 10.8% to 90.7%
3. The samples were mostly of employed people, married or living with household partners. Good opportunities were created, therefore, to assess impact of headache beyond its effects on people with it: on work and productivity, and on family.
4. EUROLIGHT carries a very important message to health policy-makers.