# Development and validation of the EUROLIGHT questionnaire to evaluate the burden of primary headache disorders in Europe

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Cephalalgia

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#### Abstract

We developed a 103-item self-reporting questionnaire to assess the burden of primary headache disorders on those affected by them, including headache characteristics, associated disability, co-morbidities, disease-management and quality of life. We validated the questionnaire in five languages with 426 participants (131 in UK, 60 in Italy, 107 in Spain, 83 in Germany/Austria, and 45 in France). After a linguistic and a face-content validation, we tested the questionnaire for comprehensibility, internal consistency and test-retest reliability at an interval of one month. In the different countries, response rates were between 73% and 100%. Test-retest reliability varied between -0.27 to 1.0 depending of the nature of the expected agreement. The internal consistency was between 0.69 and 0.91. The EUROLIGHT questionnaire is suitable for evaluating the burden of primary headache disorders, and can be used in English, German, French, Italian and Spanish.

#### **Keywords**

headache, questionnaire, burden, validation

Date received: 2 June 2009; revised: 29 September 2009; accepted: 7 October2009

### Introduction

Headache disorders, including migraine, are common disabling (1) but under-recognised and and under-treated (2,3). Consequently, they impose a substantial population burden of ill-health. It is well documented that migraine impairs work and social activities (4,5). The World Health Report 2001 (3) ranks migraine twelfth in women and nineteenth overall amongst all causes of disability in the world. Less is known about other primary headache disorders, but tension-type headache (TTH), being more prevalent, may impose an even higher population disability burden than migraine (6). Yet this is poorly acknowledged, along with the physical and emotional impact of headache on those directly affected, their carers, family and colleagues, and the socio-economic burden of headache. For example, fewer than half of people with migraine are correctly diagnosed, a prerequisite

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for receiving adequate treatment (7–11). In comparison with other, less prevalent, neurological disorders, head-ache attracts little attention and is generally accorded low priority (10,12–14).

The EUROLIGHT project (<www.eurolight-online. eu>) is an initiative supported by the EC Public Health Executive Agency and a partnership activity within *Lifting The Burden: The Global Campaign to Reduce the Burden of Headache Worldwide.* One of its main objectives is to gather up-to-date and reliable knowledge of the prevalence and impact of migraine, TTH and chronic daily headache across Europe. There is no validated instrument for collecting the data that will achieve this. Therefore, the EUROLIGHT questionnaire has been developed.

This instrument is based largely on the BURMIG questionnaire, and has additions from instruments developed by Lifting The Burden (15). The BURMIG questionnaire was developed in 2004 for а population-based survey of the burden of migraine in the Grand Duchy of Luxembourg. It incorporated previously validated tools for diagnosis, disability assessment and recognition of depression, and added questions on disease management and impact on quality of life (16). It proved to be consistent and reliable for the Luxembourg population. In order to develop the EUROLIGHT questionnaire for use in different European countries, and also to encompass other headache disorders, the BURMIG questionnaire was revised. We integrated sections to assess disability burden, measure general and disease-specific quality of life (QoL), detect anxiety and depression, and enquire into disease management.

The aim of the present study was to assess the testretest reliability and validity of the EUROLIGHT questionnaire for use throughout Europe. A pilot validation study in the UK was followed by a multicountry study in France, Luxembourg, Germany, Austria, Italy and Spain.

## **Materials and methods**

#### Questionnaire development

The content of the BURMIG questionnaire was reviewed and thoroughly revised by the steering committee of the EUROLIGHT project. Priority areas for revision had been defined in a pilot study (16), with support from several patient organisations (Migraine Action Association UK. Switzerland and Luxembourg), international headache experts (see Acknowledgements) and the Luxembourg Ministry of Health. The additional or amended items were incorporated into the EUROLIGHT questionnaire after a full literature review of studies on headache burden (17).

The EUROLIGHT questionnaire final (see Appendix) contains 103 items, 7% of which are open questions, 15% numerical questions (i.e. requesting a number for the answer) and 78% categorical (requesting the respondent to place a tick in a box). The first section is biographical (age, gender, language and employment). Next are screening questions for headache (life-time and 1-year prevalence), followed by a section on chronic daily headache. The following questions diagnose the headache that the patient considers to be the most bothersome (if more than one headache type is identified). This approach recognised the virtual impossibility of accurately diagnosing, by self-administered questionnaire, more than one headache type in the same individual. The diagnostic questions, for migraine and TTH, were based on the criteria the International Classification of Headache of Disorders, 2nd edition (ICHD-II) (18). Further questions relate to age at onset and frequency of headache during the previous 3 months. This section is followed by questions about headache yesterday (point prevalence), and then by sections on the use of healthcare resources (medicines, investigations, consultations, etc.) and the impact of headache on work, family life and social activities (including the Headache-Attributed Lost Time [HALT] Index (19)), both for those with headache and for their household partners. A set of questions determined body mass index (BMI), a risk factor if high, for frequent headache. Finally, there were questions on general health derived from the World Health Organization Quality of Life BREF (WHO QoL -BREF) (20) and the Hospital Anxiety and Depression Scale (HADS) (21).

## Evaluation of the questionnaire

The EUROLIGHT questionnaire was assessed for: (i) face, content and language validity; (ii) test-retest reliability over one month, a period of time during which little or no change in the respondent's headache is expected; (iii) the extent to which it could discriminate between respondents with more or less severe disease (construct validity); and (iv) the extent to which individual items correlated with other items relating to the particular area of enquiry (internal consistency). The respective methods are detailed below.

All parts of the study conformed to the ethical standards described in the Declaration of Helsinki. Ethics committee approval was obtained from the National Ethics and Research Board of Luxembourg.

**Study population:** People with headache were recruited by different means in five countries. In England, they were recruited from the members of Migraine Action UK. In France, consecutive patients

were recruited in the Department of Evaluation and Treatment of Pain within the Neurosciences Clinic, University Hospital, Nice. In Luxembourg, people with headache were recruited from the French-speaking employees of CRP-Santé by email. The subjects from Luxembourg and France participated in the evaluation of construct validity. The sample from Germany was derived from an existing data bank of the German Headache Consortium, University Hospital of Essen, a population-based cohort including people with and without headache. In Austria, consecutive patients were recruited in the Department of Neurology and Pain Medicine, Konventhospital Barmherzige Brüder, Linz; healthy subjects were enrolled from the personnel working at the hospital and their families. In Italy, 50% of subjects with headache came from the waiting list of the Applied Neurological Research Centre of the C Mondino Foundation and 50% were members of the headache patient organization, AI.Ce. Healthy subjects were enrolled from the staff of the research centre. In Spain, respondents with or without headache were recruited from people attending general practitioners for reasons other than headache.

Face, content and language validity: Initial content validity was explored through systematic review by experts, and face validity was tested by pre-piloting with 23 volunteers. All questions not used previously in validated questionnaires in a particular language were forward-and-back translated by two native translators, with reconciliation by a bilingual headache expert. Comprehensibility was tested by native language-speaking volunteers.

**Test–retest reliability:** Questions were categorized by the amount of change expected within the relevant time frame, as described previously for the development of a comparable questionnaire (22), as follows: 'no change expected'; 'change unlikely'; 'up to 1 unit change expected'; 'up to 2 units change expected'; and 'up to 3 units change expected'. Respondents in this study completed the questionnaire twice, the second time after an interval of 1 month. At retest, they were blinded (beyond what they might have recalled) to their responses on the first occasion.

To assess test-retest reliability, the two sets of answers were compared. For categorical data, agreement measures were the percentage agreement rate, Kappa values, McNemar's S-test and Bowker's S-test. Percentage agreement measures absolute within-patient agreement. The Kappa coefficient indicates whether this agreement exceeds what might be expected by chance: a value >0.6 is generally considered acceptable. For the questions with discrete integer data, the Cephalalgia 30(9)

Construct validity and internal consistency: Construct validity was intended to be assessed partly by comparing headache-free participants with headache sufferers and partly by measuring the internal consistency of answers to related questions. In the course of this part of the study, it transpired that some participants recruited as 'healthy' were, in fact, reporting occasional headaches. Construct validity assessment was, therefore, based on headache frequency rather than presence or absence (low frequency = 0-3 and high frequency > 3headache-days per month). Comparisons between low-frequency and high-frequency headache sufferers were made for the total scores of the WHOQoL, HALT index and HADS. Comparisons between categorical scores of those diagnosed with migraine, other episodic headache and chronic daily headache were performed by chi-squared test. Continuous scores were compared by one way-ANOVA, with the score as dependent variable. Normality was assessed by Kolmogorov-Smirnov test; if this was significant, data were log-transformed and re-analysed if normally distributed; otherwise the Kruskall-Wallis test was used.

using a 2-way random effects model for agreement.

Where appropriate, cross-tabulations were used to check for internal consistency. Blocks of questions corresponding to the ICHD-II criteria, WHO QoL, HALT index and HADS were explored for consistency using Cronbach's alpha coefficient: the larger this coefficient, the more likely it was that items contributed consistently to a scale, with a value of >0.70 suggesting acceptable consistency. Recalculating the alpha coefficient after deleting each question within a set determined how each contributed to the reliability of the scale: when the coefficient increased after a question was deleted, its responses were not highly correlated with those to other questions in the set; conversely, if the coefficient decreased, they were highly correlated.

Sample size calculation: To our knowledge, there is no method to calculate the sample size needed to assess face content, language validity, construct validity and internal consistency in a questionnaire validation study. Therefore, the sample size calculation was based on the test–retest reliability. Assuming an absolute Kappa precision of 0.18 (based on parts of the BURMIG questionnaire that had been validated previously), we estimated that 73 responses to the main questions in the second test would enable a Kappa value of  $\geq 0.5$ to be detected with a power of 0.95 (two-tailed  $\alpha =$ 0.05). Thus allowing for a 60% response rate, 135 subjects were considered necessary.

#### Results

#### UK pilot study

Before translations, the English version of the questionnaire was tested in a pilot study of 200 members of Migraine Action UK; 136 questionnaires were returned of which five were deleted from the database because they were duplicated or incomplete. Thus the response rate was 65%. Of the 131 included respondents, 83 answered a second questionnaire 1 month later, but 10 of these were excluded because incomplete identification details to link the second questionnaire to the previously completed questionnaire. Therefore the response rate for retest was 63% (Table 1).

Completion rates were  $\geq 90\%$  for 86% of single questions at both test and retest. Questions with < 90% completion rate were those related to income, questions from the HALT Index and those related to impact on children. One question about the 'level of control' over headaches seemed especially difficult to answer, with completion rates of 49% and 55% at test and retest. A question on preventative medications had three response fields (name of medication and how long it had been taken in weeks or months); the first field had completion rates of 45% and 40% for test and retest, respectively, while the two other fields fell below 10%. Questions on investigations such as magnetic resonance imaging (MRI) and computed tomography (CT) also showed completion rates below 10%.

Of the 188 questions and sub-questions of the questionnaire, 79 were analyzed by Kappa coefficient, 55 by ICC, 20 by McNemar test and 59 by Bowker S-test to evaluate the reliability (Table 2). Because of the nature of responses, and the high likelihood of change between test and retest, the reliability of the open-text-field questions could not be quantified.

Among the questions categorized as 'no change expected', two of those analyzed by Kappa coefficient were responsible for lowering the rate of agreement (< 30%) while all others analyzed in this way showed test-retest agreements of 40–100% (Table 2). The Kappa coefficient varied from 0.26 to 1, with questions from the HADS contributing most (from 0.36 to 0.55) to a low value. For questions with quantitative responses, analyzed by ICC, the rate of agreement varied from 1% to 74%, with the extreme low value due to a diagnostic question asking the number of days with headache (Appendix 1, Question 18). Most of these questions were in the range 20–25%. The ICC was good for these questions.

For the questions categorized as 'up to 1 unit change expected', only a third had agreement rates of <60%. Age had the highest value (98%). These questions were also associated with low Kappa coefficients: only one quarter of them had coefficients >0.5.

Only two questions were categorized 'up to 2 units change expected'; these had 12% and 100% agreement rates with Kappa coefficients of 0.16 and 0.66. Six questions were categorized 'up to 3 units change expected': one had an agreement rate of 36%, with a Kappa coefficient of 0.21, which is not a good result, and 5 HALT Index questions showed agreement rates of 25–52%, with an ICC varying from 0.83 to 0.92, which is a good result.

For questions with two response options, McNemar's S-test showed a significant difference for one question, which asked whether the respondent had a headache yesterday (Appendix 1, Question 32). A change of response to all questions about headache yesterday is expected between test and retest. Only three items were significant (P < 0.05) on Bowker's S-test: no agreement was observed for questions attempting to measure lost work due to headache (Appendix 1, Questions 36 and 37) and the question about how headache was accepted at work (Appendix 1, Question 53).

Internal consistency was evaluated independently for the blocks of questions derived from WHO QoL, the HALT index and HADS. The standardized values of Cronbach's alpha were, respectively, 0.93, 0.88 and 0.90.

Following this pilot study, the phrasing and the response options of some questions were modified. In general, however, the pilot study showed that the questionnaire was well understood and yielded satisfactory completion rates; therefore, no questions were deleted or added.

#### Validation study in other countries

The slightly amended questionnaire was translated for validation in the other countries.

#### **Populations**

The numbers of subjects participating in each country is given in Table 1. There was a female preponderance in all countries. Most respondents were full- or part-time employed or self-employed, while students, unemployed and retired people accounted for 10–20%. Average age was 40 years except in France where it was 50 years.

#### Response rates

Numbers of responders in each country are given in Table 1, varying between 66% and 100%. In Spain, one questionnaire was deleted from the database as it was incomplete.

	NK		Italy		Spain		Germany/Austria	ia	France	
	Test	Retest	Test	Retest	Test	Retest	Test	Retest	Test	Retest
Age Year (mean ±SD)	49.9 土 11.5	51.3 ±11.3	38.18 + 11.67	38.18 + 11.67	40.44 + 11 11	40.71 + 11.01	41.10 + 11.08	39.43 + 11 69	50.14 + 11.75	50.98 + 11.08
L	131	83	60	÷	107	± 1.07	83	÷	45	43
Gender M/F (n)	21/110	17/65	17/42	18/42	28/79	28/76	29/53	19/41	9/35	8/35
Work status(%)										
Full-time	45.9	40.0	68.33	68.33	79.44	78.85	56.25	53.33	68.89	65.12
	787	75 D	5 00	5 00	841	8 4E	77 E.O	22 22	7 67	465
earning	7.07	0.07	00.0	00.0	- L.O	60.0	00.77	CC.C7	10.0	
Eull-time	2.3	I	16.67	16.67	7.48	8.65	10.00	13.33	4.44	2.33
student										
Unemployed but seeking employment	I.5	3.7	5.00	6.67	0.93	I	2.50	1.67	6.67	11.63
Unemployed and not	7.0	3.7	5.00	3.33	3.74	3.85	6.25	8.33	13.33	16.28
seeking employment										
Retired	18.6	27.5	$21.55\pm4.86$	$21.47 \pm 4.78$	$\textbf{20.60} \pm \textbf{3.84}$	$\textbf{20.65} \pm \textbf{3.86}$	2.50	$19.65 \pm 3.51$	$19.78 \pm 3.37$	
Age of finishing education										
Year (mean + SD)	l9.8± 5.5	20.5± 7.0					16.00 土 1.97	$15.98 \pm 2.28$		
Income										
GB/year (mean ± SD)	40524 土 78018	37379 土 24609	98.11	13.56	8.05	10.23	28324 ± 27338	29617 ±26201	21.21	20.59
			42.37	38.98	33.33	31.82			24.24	23.53
Partner(%)	81.5	85.4	33.90	37.29	28.74	23.86	62.65	65.57	18.18	26.47
			6.78	5.08	11.49	15.91			36.36	29.41
Headache frequency										
days/month (%)			5.09	5.08	18.39	18.18				
	I.5%	3.7%					15.38	10.42	70.45	70.73
I3	12.2%	17.1%	86.67	86.67	66.36	68.57	50.77	50.00		
49	34.3%	33.9%					16.92	27.08		
10-14	25.9%	23.2%					7.69	6.25	2.27	2.56
<ul> <li>15</li> </ul>	25.9%	23.2%	8.89	60.6	11.90	10.00	9.23	6.25	15.91	12.82

	Я			Italy			Spain			Germany/Austria	ıstria		France/Luxembourg	nbourg	
	% Agreement	Kappa	P-value	% Agreement	Kappa	P-value	% Agreement	Kappa	P-value	% Agreement	Карра	P-value	% Agreement	Карра	P-value
No change	2–99	0.26–1	<0.0001-0.0004	2–100	0.65-1.00 <0.001	<0.001	I–98	-0.01 to 1.00	<0.0001-0.0091	2–97	-0.07 to 1.00	-0.07 to 1.00 <0.0001-0.0087	2–98	-0.06 to 1.00	-0.06 to 1.00 <0.0001-0.71
expected ±1 unit change 1–100 expected	e 1–100	-0.03 to 0.95	-0.03 to 0.95 < 0.0001–7894	2-100	— I.04	<0.0001-0.74	I-100	-0.19 to 1.00	<0.0001-0.90	2-100	-0.27 to 1.00	-0.27 to 1.00 < 0.0001-0.87	2-100	-0.14 to 1.00	<0.0001-0.80
±2 unit change expected	a 12–100	0.16-0.66	<0.0001-0.0155	13	I	I	13	0.35	<0.0001	01	0.47	< 0.0001	33	0.27	0.0096
±3 unit change expected	e 36	0.21	0.0002	13	0.46	<0.0001	12	0.28	<0.0001	01	I	I	30	0.17	0.0807
	% Agreement ICC	t ICC	P-value	% Agreement ICC		P-value	% Agreement ICC	it ICC	P-value	% Agreement ICC	it ICC	P-value	% Agreement ICC	t ICC	P-value
No change expected	1–73	0.76-0.097	0.05-0.80	3–95	0.16-0.99 0.02-0.72	0.02-0.72	7–86	-0.06 to 0.99	0.06-0.56	2–85	0.13-0.99	0.14-1.00	2–93	0.72–0.99	0.0781-0.8118
±1 unit change	98	0.99	<0.0001	100	_	I	26	0.99	0.1	97	0.89	0.95	001	0.99	0.0272
expected $\pm 2$ unit change	l	I	I	58-65	0.60-0.97 0.03-0.69	0.03-0.69	5560	0.89–0.95	0.05-0.85	23–38	0.55-0.94	0.14-0.96	23–33	0.58-0.94	0.0409-0.4332
expected ±3 unit change	e 23–52	0.83-0.99	<0.0001–0.66	65	0.83-0.93 0.10-0.01	0.10-0.01	8-69	0.80-0.83	0.12-0.28	8–64	0.89-0.99	0.15-0.21	1665	0.80-0.86	0.0348-0.4198
expected Change likely	I-31	0.55-0.99	0.32-0.93	2-100	-3.55	0.01-1.00	I-100	-27.15 to 0.99 0.06-1.00	0.06-1.00	2-100	-3.24	0.13-0.87	2-100	-6.64 to 0.99	-6.64 to 0.99 0.0004-0.8790
	Not significant	nt	Significant	Not significant	ıt	Significant	Not significant	nt	Significant	Not significant	Int	Significant	Not significant	nt	Significant
	Statistic	P-value	Statistic <i>P</i> -value	Statistic	P-value	Statistic <i>P</i> -value	Statistic	P-value	Statistic P-value	e Statistic	P-value	Statistic P-value	Statistic	P-value	Statistic P-value
McNemar's coefficient	I	I	1	0-3	I-0.1025	4-14 0.0455-0.0002 0-4	2 0-4	I-0.0588	I	03	I-0.0.083	1	02	I–0.1573	46 0.0455-0.0143
Bowker's coefficient	I	I	I	9-6	I=0.81	8 0.0002–0.046	60	I-0.5	54.8-64.8 <0.0001 0.3-10	01 0.3-10	0.95-0.12	31.36–35 <0.0001 0–9	6-0	1-0.17	22 0.0012
Intraclass correlation	0.6–1	0.32-0.63	0.89-0.99 0.048-<0.0001 -3 to 1	01 -3 to	0.42-0.90 0.93-0.97	0.93-0.97 0.013-0.034	-27.1	0.061-0.18	0.88 0.046	-2.1	0.87–1	I	-7 to	0.52-0.74	0.84-0.99 0.0004-0.041

Table 2. Test-retest reliability of questionnaire (percentage agreement; Kappa values and intraclass correlation coefficient [ICC] values for variables of two modalities; McNemar's coefficient for

#### Completion rates

Completion rates for each question were adjusted according to expectation. A rate > 100% meant that the participant was not expected to answer a particular question but nevertheless did: for example, some respondents answered that they had not had headache yesterday, but still had taken medicines to relieve headaches on that day. Per country, the percentages of respondents with completion rates over 90% were: Germany-Austria, 69%; Spain, 75%; Italy, 65%; and France, 82%.

Certain questions had low completion rates. For the question on duration of use of preventative drugs (Appendix 1, Question 45), the rate was < 30% in Italy and < 10% in the other countries. The questions concerning MRI and CT scans had completion rates of < 10% in Italy, < 30% in Spain and < 20% in Germany/Austria. The HALT-Index questions had low completion rates in France, ranging from 52% to 61%.

#### Test-retest reliability

In Italy, 141 questions (including some sub-questions) were used to assess reliability (open questions were excluded, as they could not be quantified). Of these, 42% (n = 59) showed > 80% agreement, 10% (n = 14) ranged from 40–80% and 48% (n = 66) had < 40% agreement (Table 2). In Spain, 149 questions were used (again including sub-questions and excluding the open questions). Of these, 46% (n = 69) had > 80% agreement, 16% (n = 23) ranged between 40–80% and 38% (n = 57) had < 40% agreement. In Germany/Austria and in France, 116 questions were used (including sub-questions), of which 36% (n = 42) showed > 80% agreement, 21% (n = 24) ranged between 40–80% and 43% (n = 50) had < 40% agreement.

Two 'no change expected' questions were identified as largely responsible for lowering the rate of agreement below 40%. The first (Appendix 1, Question 15) asked for the medication usually taken to treat chronic daily headache; some participants may not have understood well enough the accompanying text to the question. The second (Appendix 1, Question 56) question asked how well subjects were able to control their headache. In this category, two other questions had low reliability scores. The first asked for the number of days with headache (Appendix 1, Question 18), giving respondents the reply options of 'every day' or stating the number of 'days/month' or 'days/year'. The second asked the duration of headache in minutes, hours or days (Appendix 1, Question 20).

Of 'up to 1 unit change expected' questions, 26 out of 48 in Italy had agreement rates of < 60% (only 11

having Kappa coefficients of > 0.5). Corresponding numbers were 29 of 48 in Spain, 24 of 46 in Germany/Austria and 22 of 48 in France; in all countries these questions accounted for the low Kappa coefficients. The question about investigations (MRI, CT, etc.; Appendix 1, Question 48) unsurprisingly also had low agreement rates. Questions on the effects of headache on education, career and family planning (Appendix 1, Questions 50-76), with 4-6 possible response options, had agreement rates of < 10% in Italy. As multiple responses could be chosen, completion rate was calculated for each possibility. As a consequence, percentage changes were very low for all responses other than 'no'. Three questions of the WHO OoL and one from the HADS showed significant Bowker S-tests in Germany/Austria, Spain and France, meaning that there was lack of reliability over time.

There was one question with 'up to 2 units change expected', and this had very low agreement rates: Italy 13%; Germany/Austria 10% with Kappa = 0.47; France 33% with Kappa = 0.27; and Spain PA = 13% with Kappa = 0.35.

Of questions in the category 'up to 3 units change expected', only one had low agreement rates: in Italy (3%, Kappa = 0.46), Spain (12%, Kappa = 0.28) and France (30%, Kappa = 0.17). However, the poorest agreement was for the HALT Index, the reliability of which was measured by the ICC associated with the percentage agreement rate: in Italy, 58–65% with ICC = 0.60–0.97; in Spain 90–100% with ICC = 0.88–0.95; in Germany/Austria 28–38% with ICC = 0.55–0.94 and in France 23–36% with ICC = 0.58–0.94.

#### Construct validity and internal consistency

The four populations were relatively similar overall with respect to age, gender and employment status. However, there were significant differences in each country between headache sufferers and participants without headache (Table 3). Age was higher in the French speaking sample with high headache frequency. Males were more frequent amongst the 'headache-free' participants, except in Italy. There were more employed persons amongst people with headache in Italy and Germany/Austria compared with Spain and France/ Luxembourg (significantly for France/Luxembourg).

Internal consistency was evaluated independently for each block of questions derived from WHO QoL, HALT Index and HADS. The standardized values of Cronbach's alpha were high in all cases, indicating excellent consistency (Table 4. Internal consistency of question blocks (WHO QoL, HALT, HADS).

It is indicative of good construct validity that the mean scores for WHOQoL, HADS overall, HADS anxiety (HADS-A) and HADS-depression (HADS-D)

	, ,			,	
	UK	Italy	Spain	Germany/Austria	France/Luxembourg
WHO QoL	0.93	0.86	0.86	0.9	0.82
HALT Index	0.88	0.81	0.86	0.91	0.69
HADS	0.9	0.88	0.89	0.91	0.78

Table 3. Internal consistency of question blocks (WHO QoL, HALT, HADS)

Standardized values of Cronbach's alpha.

	Country	Headache	No headache	All	P-value
Age (years) (mean $\pm$ SD)	Italy	$\textbf{38.5} \pm \textbf{10.9}$	$\textbf{37.4} \pm \textbf{I3.4}$	$\textbf{38.2} \pm \textbf{11.7}$	0.4692
	Spain	$\textbf{39.4} \pm \textbf{10.9}$	$\textbf{42.9} \pm \textbf{11.4}$	$40.4\pm11.1$	0.119
	Germany/Austria	$\textbf{42.9} \pm \textbf{9.9}$	$\textbf{37.8} \pm \textbf{12.5}$	$41.1 \pm 11.1$	0.0597
	France/Luxembourg	$47.8\pm13.1$	$\textbf{37.1} \pm \textbf{11.8}$	$41.8\pm13.4$	< 0.0001
Gender (males) (%)	Italy	25	36.8	28.8	0.34
	Spain	16.2	48.5	26.2	0.0005
	Germany/Austria	26.4	51.7	35.4	0.0219
	France/Luxembourg	17.1	37.2	28.3	0.0326
Economic workers (%)	Italy	73.2	57.9	68.3	0.24
	Spain	75.7	87.9	79.4	0.1492
	Germany/Austria	82.7	71.4	78.8	0.2401
	France/Luxembourg	68.3	86.6	78.5	0.0335
WHO QoL (mean $\pm$ SD)	Italy	$27.5\pm4.6$	$\textbf{32.6} \pm \textbf{3.2}$	$\textbf{29.1} \pm \textbf{4.9}$	<0.0001
	Spain	$\textbf{28.1} \pm \textbf{5.2}$	$30.2\pm4.7$	$\textbf{28.8} \pm \textbf{5.1}$	0.0382
	Germany/Austria	$\textbf{30.3} \pm \textbf{5.9}$	$34.0\pm4.6$	$31.5\pm5.8$	0.012
	France/Luxembourg	$\textbf{27.7} \pm \textbf{5.2}$	$\textbf{32.2}\pm\textbf{3.7}$	$\textbf{30.3} \pm \textbf{4.9}$	<0.0001
HADS (mean $\pm$ SD)	Italy	$13.3\pm6.3$	$\textbf{4.3}\pm\textbf{3.7}$	$10.4\pm7.0$	< 0.0001
	Spain	$12.5\pm6.9$	$\textbf{8.5} \pm \textbf{7.0}$	$11.2\pm7.2$	0.0047
	Germany/Austria	$12.4\pm7.8$	$\textbf{6.1} \pm \textbf{6.3}$	$10.3\pm7.0$	0.0003
	France/Luxembourg	$17.4\pm6.5$	$11.6\pm6.5$	$14.2\pm7.1$	< 0.0001
HADS Anxiety (mean $\pm$ SD)	Italy	6.9 ± 3.7	$\textbf{2.4} \pm \textbf{2.4}$	$\textbf{5.5} \pm \textbf{3.9}$	< 0.0001
	Spain	$\textbf{6.7} \pm \textbf{4.0}$	$\textbf{4.1} \pm \textbf{4.0}$	$5.9\pm4.2$	0.0005
	Germany/Austria	$7.3\pm4.0$	$3.4\pm3.4$	$5.9\pm4.2$	< 0.0001
	France/Luxembourg	$\textbf{9.9}\pm\textbf{3.6}$	$\textbf{7.1} \pm \textbf{3.7}$	$\textbf{8.3}\pm\textbf{3.9}$	0.0003
HADS Depression (mean $\pm$ SD)	Italy	6.2 ± 3.6	ʻI.9±I.8	4.8±3.8	< 0.0001
	Spain	$5.7\pm3.8$	$\textbf{4.4} \pm \textbf{3.5}$	$5.3\pm3.7$	0.095
	Germany/Austria	$5.1\pm4.6$	$\textbf{2.6} \pm \textbf{3.2}$	$\textbf{4.3} \pm \textbf{4.3}$	0.0091
	France/Luxembourg	$\textbf{7.5}\pm\textbf{3.6}$	$4.7\pm3.8$	$5.9\pm3.9$	0.0005
HALT Index (mean $\pm$ SD)	Italy Spain	$28.7\pm65.7$	$1.9\pm3.5$	9.5±36.3<	0.0001
	Germany/Austria France/Luxembourg				
*HALT Index (mean $\pm$ SD)	Italy Spain	12.1±14.2	$1.9\pm3.5$	4.7 ± 9.0	< 0.0001
	Germany/Austria France/Luxembourg				

\*One subject was excluded due to a high score of 261.

		Ital	у			Spa	in				rmany Istria			Fra	nce		
Variable		n	Mean	SD	P-value	n	Mean	SD	P-value	n	Mean	SD	P-value	n	Mean	SD	P-value
WHO QoL	Other headaches	20	30	3.9	0.0031	47	30	4.7	0.0182	41	32	3.7	0.0041	12	25	5.4	0.0285
	Migraine	12	30	5.I		25	27	5.3		9	24	7.8		16	30	4.8	
	Chronic daily headaches	15	25	3.7		9	25	3.7		6	28	8.1		П	27	3.4	
HADS	Other headaches	19	9	6.1	0.0118	47	11	6.7	0.5368	44	10	6.7	0.0169	12	23	4.8	0.0038
	Migraine	12	12	7.7		24	12	6.8		10	18	6.7		15	16	6.3	
	Chronic daily headaches	16	16	4.7		8	15	8.6		6	16	11.0		12	18	4.9	
IADS-A	Other headaches	20	5	3.7	0.0293	47	6	4.3	0.3914	45	6	3.8	0.0738	12	12	3.1	0.0372
	Migraine	12	7	4.6		25	6	3.6		10	9	3.3		16	9	3.4	
	Chronic daily headaches	16	8	2.7		8	8	3.8		6	8	5.5		12	10	3.3	
IADS-D	Other headaches	19	4	2.8	0.0122	47	5	3.4	0.6366	44	4	3.4	0.013	13	10	2.4	0.0047
	Migraine	12	6	4.2		24	6	3.6		10	8	4.3		16	6	3.3	
	Chronic daily headaches	16	8	3.2		9	7	5.2		6	8	7.4		13	8	2.8	
HALT	Other headaches	17	16	34.2	0.0004	35	8	13.7	< 0.0001	24	2	3.2	0.0003	4	27	18.7	0.121
	Migraine	12	19	11.3		23	16	16.9		7	35	54.8		6	8	5.4	
	Chronic daily headaches	16	67	61.6		9	50	34.3		2	72	53.7		4	68	128.9	

Table 5. Construct validity for WHO QoL, HADS and HALT in relation to headache diagnoses

HADS, Hospital Anxiety and Depression scale; HADS-A, HADS-anxiety; HADS-D, HADS-depression.

were significantly different between those with and those without headache in each country. In addition, the HALT index, used to compare groups with low and high headache frequencies in France/Luxembourg, showed significantly higher scores in the latter.

We further investigated construct validity by comparing those with different types of headaches (migraine, other episodic headache or chronic daily headache; Table 5). The mean scores of WHO QoL were significantly different between these in each country. The mean HADS, HADS-A and HADS-D scores were significantly different between these in each country except Spain. The mean scores of the HALT Index were significantly different in each country except France/Luxembourg.

## Discussion

This paper describes the development and testing of the EUROLIGHT questionnaire to evaluate the burden of headache disorders in different European populations. The questionnaire originated in the BURMIG questionnaire, and was revised after a systematic literature

review and discussions among headache experts and lay persons in the EUROLIGHT steering committee. The English version was tested in a UK pilot study and, after some minor amendments, the resulting questionnaire was translated and tested in a German version in Austria and Germany, a French version in France and Luxembourg, a Spanish version in Spain and an Italian version in Italy.

As to test-retest reliability, good response rates were achieved, and completion rates for each question were generally good with the majority (65–80%) above 90%. A small number of questions required modification in the light of likely causes for low completion rates. Sub-questions asking for the total number of days or occasions were deleted as they were not completed by respondents. Questions with text field for respondents to fill in also had to be avoided. Questions from WHOQoL and HADS showed good completion rates, and good reliability. This was not the case for the HALT Index, especially in France.

For methodological purposes, we had defined the amount of change expected for each question before administering the questionnaire. Questions where a change had been expected did show higher amounts of change, indicating that these items were understood correctly and, therefore, can be used as part of the EUROLIGHT questionnaire.

The reliability coefficients also showed convincing results. Kappa and ICC showed values above the defined significance threshold (see Materials and methods). However a small number of questions needed to be modified to increase the reliability of the questionnaire.

Internal consistency was found to be excellent for WHOQoL, HADS, HADS-A, HADS-D and the HALT Index.

Construct validity was found to be acceptable in different countries as the relevant questions were able to discriminate between groups of respondents with different headache frequencies and diagnoses. The tools WHO QoL, HADS and HALT Index used within the questionnaire discriminated well between those with and those without headache. In headache sufferers alone, questions from the HADS showed a low discrimination between headache types, which is unsurprising, as co-morbidity is known to differ little between headache types but more depending on headache frequency (23–25). The headache-specific tool HALT showed good discriminative power in most counties, although not in France and Luxembourg.

For questions on disease management, test-retest agreements ranged from 77% to 98% (except for questions with multiple response options). Kappa coefficients ranged from 0.68 (0.62 for questions with multiple response options) to 1.00, which indicates good agreement.

The majority of questions about private and social impact were of the type with several response options, and these scored poorly in terms of agreement rate (10–30%) but had a good test-retest reliability (Kappa coefficients ranging from 0.52 to 0.97). As the responses to these questions were stable over time, we believe that they truly reflected the headache impact on patients' lives over a certain period and not only how they perceived it on that day.

It is a weakness in the development of the questionnaire that the diagnostic questions have not yet been validated against a gold standard method for diagnosing headaches (interview and examination by a headache expert), which is mandatory when diagnostic accuracy is of paramount importance (26). Diagnostic validation should be done in the population to be studied and, since the present study was mostly performed among headache patients who had already been diagnosed and treated, this was not done. When the population-based studies with the EUROLIGHT questionnaire are performed, some sort of validation in the different countries is planned in order to assess the diagnostic precision of the questionnaire.

## Conclusions

The EUROLIGHT questionnaire was developed in order to estimate the burden of headache disorders in Europe. Established and recently validated tools for diagnosis, disability and co-morbidity were supplemented with more detailed questions on disease management and impact on school, work, family, social life and quality of life. The resulting questionnaire was tested in UK, Italy, Spain, Germany, Austria, France and partly in the Grand Duchy of Luxembourg. Reliability and consistency were found to be comparable to those of previously published questionnaires (16,22). The validation process resulted in relatively minor changes. We believe the final EUROLIGHT questionnaire, at least in the five languages that have been tested, will give a reliable and valid picture of the impact and burden of primary headache disorders in European populations and offer additional valuable information to the results of the American Migraine Prevalence and Prevention (AMPP) questionnaire (27–29).

Since headache is a considerable burden for people everywhere, we hope that the questionnaire can be adapted for use in many other countries and cultures.

#### Acknowledgements

The authors are indebted to patient organizations within the World Headache Alliance for their contributions to this study, and are especially grateful for the help offered by S Chatterji, R Lipton, J Schoenen and A MacGregor.

EUROLIGHT is a European initiative supported by a grant from the EC, Executive Agency for Health and Consumers (EAHC) and promoted by the Centre of Public Research, Luxembourg.

JB, MLL and MV are staff members of the CRP-Santé; the authors alone are responsible for the views expressed in this publication and they do not necessarily represent the decisions, policy or views of the CRP-Santé.

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#### Appendix 1 EUROLIGHT Questionnaire

1	Please enter today's date	Day/month/year
2	What is your age?	years
3	What is your gender? (Please tick)	Male Female
Socia	l situation questions	
4	Which of these is closest to your personal situation? (Please tick)	<ul> <li>Employed or self-employed</li> <li>Homemaker or housewife student</li> <li>Unemployed</li> <li>Retired</li> </ul>
5	Are you now married or living with a household partner? (Please tick)	NoYes
6	What is your total net household income per year? (Please tick)	$ \begin{array}{c} - < \epsilon 18,000 \\ - \epsilon 18,000 - 29,999 \\ - \epsilon 30,000 - 41,999 \\ - \epsilon 42,000 - 59,999 \\ - > \epsilon 59,999 \end{array} $
7	How old were you when you left full-time education?	years
8	What is your native language? (The language you first learned to speak)	Still in process Enter name of language
9	What language do you usually speak in your own home?	Enter name of language
Scree	n questions	
10	Have you ever had a headache? (Please tick)	NoYes
11	(If no, go directly to Question 74) Have you had a headache during the last year? (Please tick)	NoYes
12	(If no, go directly to Question 74) During the last 30 days, on how many of these days did you have a headache? (please enter number of days between 0 and 30) If you answered 15 or more, please continue with Questions 13–16. Otherwise, go directly to Question 17	days
Daily	headache questions	
You I 13	have said that you had headache on 15 or more days in the last month. Please th How long, during each day, do these headaches usually last? (Please enter th number of minutes or hours)	
14	Do you usually take any medication to treat these headaches? (Please tick) (Please note that this question is about treatment to relieve the headache, not daily treatment to prevent headache)	NoYes (if no, go directly to Question 17)
15	What medications do you use most to treat these headaches? (please note that this question is only about treatment to relieve headache)	None
	(if you use no medications at all for these headaches, please tick the box)	Name the most-used medications
16	Altogether, on how many days in the last 30 days did you take these medications?	days
	(Please enter number of days between 0 and 30)	
Thes	st bothersome headache' questions se are questions on the headaches that interfere most with your life. These heads have just described, or they may be different headaches if you have more than of Please think about your headaches. Do you think they are all of one type, or are they of more than one type? (Please tick) If you answered one, the next questions are to diagnose this headache. Pleas If you answered more than one, please start also at Question 18 but from no that on the whole bothers you most (i.e. interferes most with your life)	one type of headache r One More than one se start at Question 18.

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Diag	nostic questions	
18	How often do you have this type of headache?	Every day
	(Please tick or enter the number of days per month or per year)	days/month
		days/year
19		min
19	How long does this type of headache usually last? (Please enter the number of minutes, hours or days)	hours
	(Flease effet the number of minutes, nours of days)	days
20	Is your last answer (to Question 19) with or without having taken medication?	With
	(Please tick)	Without
	(If you answered without medication, please go to Question 22)	
21	How long would it last if you did not take medication?	min
	(Please enter the number of minutes, hours or days)	hours
		days
22	How bad is this headache usually?	Not bad
	(Please tick)	Bad
		Very bad
23	There are many ways of describing a headache, but most headaches are either	Throbbing or pulsating
	throbbing or pressing.	Pressing, squeezing or
	Thinking still of this type of headache, which best describes the pain? (Please	tightening
	tick)	
	Throbbing means varying in time with the heart beat	
24	Is the pain of this headache usually on only one side of the head? (Please tick)	NoYes
25	Does exercise (like walking or climbing stairs) tend to make it worse?(Please	NoYes
	tick)	
26	Thinking still of this type of headache, how does it affect your ability to do	Can do everything as normal
	day-to-day activities?	Cannot do some things
	(Please tick)	Can do nothing
27	With this headache, do you usually feel sick (as though you may throw up)?	NoYes
20	(Please tick)	N. N.
28	With this headache, are you usually actually sick (do you throw up)? (Please	NoYes
20	tick)	N. N.
29	When you have this type of headache, does daylight or other lighting bother	NoYes
	you? In other words, do you prefer to be in the dark? (Please tick) This	
20	question refers to ordinary levels of light, not bright lightning	N. N.
30	When you have this type of headache, does noise bother you? In other words,	NoYes
	do you prefer to be in the quiet? (Please tick) This question refers to ordinary levels of noise, not very loud noise	
	This question refers to ordinary levels of holse, not very four holse	No. Voc
31	Has a doctor ever given you a diagnosis for this headache?	No Yes If yes, please write the diagnosi
	(Please tick and, if applicable, enter the diagnosis)	If yes, please write the diagnosi
The r	next series of questions are specifically about any headache you had yesterday (the	day before you fill in your answers)
	may be the same headache as the one you have just been describing, or it may be a	
	more than one type.	
	very important that the answers you give are about yesterday and not any other day	
-	tions about yesterday	NoYes
32	Did you have a headache yesterday? (Please tick)	(If no, go directly to Question
		44)
33	Was this the type of headache you have just been describing? (Please tick)	NoYes
		< 1 hour
24		1_4 hours
34	Please now think about the headache you had yesterday. How long did it last?	5–12 hours
	(Please tick)	> 12 hours
		_
25	How had was your baddada yastarday?	Not bad
35	How bad was your headache yesterday?	Bad
	(Please tick)	Very bad
		Nothing
36	Please now think about everything you wanted to do yesterday if you had not	Less than half
	had a headache.	More than half
	How much of this did you actually do? (Please tick)	Everything
37	Was yesterday a workday (either at your job or at school)? (Please tick)	Everything No Yes
51	(If no, go directly to Question 41)	
	(11 no, go directly to Question 41)	No
		Absent less than half the day
		Absent less than half the day
		day
20	Pageusa of your baddaba, ware you absent from work or school vesterday?	uuy

day Absent the whole day

38 Because of your headache, were you absent from work or school yesterday? (If absent the whole day please go to Question 40)

		Nothing
39	If you went to work or school with your headache yesterday, how much of your	Less than half
	work did you get done? (Please tick)	More than half
	(If everything, please go to Question 41)	Everything
40	Will you be able to make up for this today or later?	NoYes
	(Please tick)	
41	This question is about household work or general chores that you wanted to do	Nothing
	yesterday if you had not had headache.	Less than half
	How much of this did you actually do?	More than half
	(Please tick)	Everything
		Nothing
42	This question is about leisure and social activities that you wanted to do	Less than half
	yesterday if you had not had headache. How much of this did you actually do?	More than half
	(Please tick)	Everything
43	What treatment did you take for the headache you had yesterday?	Nothing at all
	(Please tick the box if you took nothing; otherwise, please list the names and	List medications:
	amounts of all medications taken yesterday)	How many times you took each
	(Please list medications for headache, not for any other illnesses)	yesterday
	(i lease list medications for neadache, not for any other milesses)	yesterday
Heal	thcare questions	
	-	
	im of the following questions is to help us know how much healthcare should be av	vailable to meet the needs of people
	headache	
44	Many different medications may be used to treat headache. This question is	
	about any of these medications you may have taken for headache in the last 30	Not used
	days	
	Please tick the first box if you took nothing at all in the last 30 days.	
	Otherwise, please look at these lists, and think about which of these you have	
	used in the last 30 days.	
	Please tick one box by each medication.	
	Almotriptan (Almigran)	
	Eletriptan (Relert)	
	Naratriptan (Naramig)	
	Rizatriptan (Maxalt)	Once>Once
	Sumatriptan, Imitrex, Merck-sumatriptan (Finigraine)	Once>Once
	zolmitriptan (Zomig)	Once>Once
	Ergotamine Dihydergot, Dystonal (Cafergot)	Once>Once
	Domperidone Motilium (Zilium)	Once>Once
	Metoclopramide Primperan, (Docmetoclo, Dibertil)	
	Aspirine Acetylsalicylique acide (Sedergine, Dispril)	Once>Once
	Diclofenac Voltaren, Motifene	Once>Once
	Ibuprofene Brufen, Nurofen, Spidifen, (Advil-mono)	Once>Once
	Ketoprofene Rofenid	Once>Once
	Naproxene Aleve, Apranax (Naprosyne)	
	Paracetamol Dafalgan, Panadol, Perdolan (Dolprone)	Once>Once
	Proprietary combination drugs:	
	Migpriv (acetylsalicylate lysine, metoclopramide HCI)	Once>Once
	Please list any other medications you have used to treat your headache in the	Once>Once
	last month?	
	Name(s) of medication(s):	Once>Once
	(Please list medications for headache, not for any other illnesses)	Once>Once
		Once>Once
		Once>Once
		Name(s) of medication(s):
45	Medications to prevent headaches are usually taken daily. Are you taking any	runne(s) or methedulon(s).
	of these?	
	Please enter the name(s) and, by each one, for how long in weeks or months	weeks
	you have been taking it	weeks
	you have been taking it	
46	Botulinum toxin (Botox or Dysport) is used sometimes as a treatment for	NoYes
	headaches, although it is not proven to be helpful.	
	Have you been treated with Botulinum toxin for your headaches in the last	
	year?	
	you .	

		No-one Nurse Physical therapist
47	Many people with headache treat themselves, but others need professional advice. Have you had professional advice about your headaches in the last year? Who	(physiotherapist, osteopath, chiropractor) Primary-care doctor (GP)
	from, and how many times? (Please tick all boxes that apply; for each ticked box, enter the number of times in the last year)	Headache specialist Hospital emergency room Other (please specify):
48	Most people with headache do not require any investigations, but occasionally these tests are done. Because of your headaches, have you had any of these tests in the last year? (Please tick all that apply)	MRI brain scan CT brain scan X-rays of the neck Eye tests (for glasses) Blood tests Other (please specify):
		None No Yes
49	Have you, in the last year, been admitted to hospital because of your headaches? (Please tick the no or yes box and, if yes, also tick the box to indicate the total number of days you spent in hospital)	If yes, how many days: 1 2 3-7 >7
Impa	ct questions	
The n	ext questions are about the effects your headaches are having or have had on your	
50	Have your headaches interfered with your education? (Please tick all boxes that apply because of your headaches)	No Yes, I did less well Yes, I gave up early
51	Do you believe your headaches have made you less successful in your career? (Please tick all boxes that apply because of your headaches) (If this question is not applicable to you, please tick 'no' and go directly to Question 54)	<ul> <li>No</li> <li>Yes, I have done less well</li> <li>Yes, I have taken an easier job</li> <li>Yes, I have taken long-term sick leave</li> <li>Yes, I have retired early</li> <li>Yes, I am on a disability pension</li> </ul>
52	Have your headaches resulted in reduced earnings?	pension
	(Please tick) (If this question is not applicable to you, please tick 'no' and go directly to Question 54)	NoYes
53	Do you feel that your employer and work colleagues understand and accept your headaches? (Please tick)	NoYes Not applicable
54	Do you feel that your family and friends understand and accept your headaches? (Please tick)	NoYes
55	Do you avoid telling people that you have headaches? (Please tick)	NoYes
56	Taking into account everything you do to treat your headaches, do you feel you are in control of your headaches? (Please tick)	Always Often Sometimes Rarely Never

The	next questions are about lost time because of your headaches	
57	On how many days in the last 3 months could you not go to work or school because of your headaches?	days
58	(Please enter the number of days missed completely during the last 3 months) On how many days in the last 3 months could you do less than half your usual amount in your job or schoolwork because of your headaches? (Please enter the number of days; do not include days you counted in Question	days
	57 where you missed work or school)	
59	On how many days in the last 3 months could you not do any household work because of your headaches?	days
	(Please enter the number of days lost completely during the last 3 months)	
60	On how many days in the last 3 months could you do less than half your usual amount of household work because of your headaches? (Please enter the number of days; do not include days you counted in Question	days
	59 where you did not do any household work)	
61	On how many days in the last 3 months did you miss family, social or leisure activities because of your headaches? (Please enter the number of days)	days
	following questions aim to understand how much your headaches affect you ev	ven when you do not actually have
an at		
Pleas 62	se think carefully about the last day when you did not have a headache On that day, were you anxious or worried about your next headache episode? (Please tick)	NoYes
63	On that day, was there anything you could not do or did not do because you wanted to avoid getting a headache? (Please tick)	NoYes
64	On that day, did you feel completely free from all headache-related symptoms?	NoYes
	(Please tick)	
plan	next three questions are about the effects your headaches have on your relation ning	nships, love life and family
<b>plan</b> Pleas	next three questions are about the effects your headaches have on your relation ning se answer no to any that do not apply.	No
plan	next three questions are about the effects your headaches have on your relation ning	No
plan Pleas 65	next three questions are about the effects your headaches have on your relation ning se answer no to any that do not apply. Have your headaches affected your family planning? (Please tick all boxes that apply because of your headaches)	<ul> <li>No</li> <li>Yes, I have had fewer children</li> <li>Yes, I have avoided having</li> </ul>
<b>plan</b> Pleas	next three questions are about the effects your headaches have on your relation ning se answer no to any that do not apply. Have your headaches affected your family planning? (Please tick all boxes that	<ul> <li>No</li> <li>Yes, I have had fewer children</li> <li>Yes, I have avoided having children</li> <li>Yes, I have avoided oral</li> </ul>
plan: Pleas 65 66	<ul> <li>next three questions are about the effects your headaches have on your relation ning</li> <li>se answer no to any that do not apply.</li> <li>Have your headaches affected your family planning? (Please tick all boxes that apply because of your headaches)</li> <li>During the last 3 months, have your headaches caused difficulties in your love life? (Please tick)</li> </ul>	<ul> <li>No</li> <li>Yes, I have had fewer children</li> <li>Yes, I have avoided having children</li> <li>Yes, I have avoided oral contraception (women only)</li> <li>No _Yes</li> <li>No</li> </ul>
plan Pleas 65	<ul> <li>next three questions are about the effects your headaches have on your relation ning</li> <li>se answer no to any that do not apply.</li> <li>Have your headaches affected your family planning? (Please tick all boxes that apply because of your headaches)</li> <li>During the last 3 months, have your headaches caused difficulties in your love life?</li> </ul>	<ul> <li>No</li> <li>Yes, I have had fewer children</li> <li>Yes, I have avoided having children</li> <li>Yes, I have avoided oral contraception (women only)</li> <li>No _Yes</li> <li>No _Yes</li> <li>No _Yes, they have caused separation</li> </ul>
plan: Pleas 65 66	<ul> <li>next three questions are about the effects your headaches have on your relationing</li> <li>se answer no to any that do not apply.</li> <li>Have your headaches affected your family planning? (Please tick all boxes that apply because of your headaches)</li> <li>During the last 3 months, have your headaches caused difficulties in your love life? (Please tick)</li> <li>Have your headaches caused a relationship to break down? (Please tick one</li> </ul>	<ul> <li>No</li> <li>Yes, I have had fewer children</li> <li>Yes, I have avoided having children</li> <li>Yes, I have avoided oral contraception (women only)</li> <li>NoYes</li> <li>NoYes</li> <li>NoYes, they have caused separation</li> <li>Yes, they have caused divorce</li> <li>NoYes</li> </ul>
<b>plan</b> Pleas 65 66 67	<ul> <li>next three questions are about the effects your headaches have on your relationing</li> <li>se answer no to any that do not apply.</li> <li>Have your headaches affected your family planning? (Please tick all boxes that apply because of your headaches)</li> <li>During the last 3 months, have your headaches caused difficulties in your love life? (Please tick)</li> <li>Have your headaches caused a relationship to break down? (Please tick one box)</li> <li>Do you have children of school age (Please tick one box)</li> </ul>	<ul> <li>No</li> <li>Yes, I have had fewer children</li> <li>Yes, I have avoided having children</li> <li>Yes, I have avoided oral contraception (women only)</li> <li>No Yes</li> <li>No Yes</li> <li>No Yes</li> <li>Yes, they have caused separation</li> <li>Yes, they have caused divorce</li> <li>No Yes</li> <li>_ No Yes</li> <li>_ No Yes</li> <li>_ No Yes</li> <li>If 'yes', estimate the total number of missed days:</li> </ul>
plan:           Pleas           65           66           67           68	<ul> <li>next three questions are about the effects your headaches have on your relationing</li> <li>se answer no to any that do not apply.</li> <li>Have your headaches affected your family planning? (Please tick all boxes that apply because of your headaches)</li> <li>During the last 3 months, have your headaches caused difficulties in your love life? (Please tick)</li> <li>Have your headaches caused a relationship to break down? (Please tick one box)</li> <li>Do you have children of school age (Please tick one box)</li> <li>If you ticked 'no', please go directly to Question 71</li> <li>During the last 3 months, have your headaches caused one or more of your</li> </ul>	<ul> <li>No</li> <li>Yes, I have had fewer children</li> <li>Yes, I have avoided having children</li> <li>Yes, I have avoided oral contraception (women only)</li> <li>NoYes</li> <li>NoYes</li> <li>NoYes, they have caused separation</li> <li>Yes, they have caused divorce</li> <li>NoYes</li> <li>NoYes</li> <li>NoYes</li> <li>NoYes</li> <li>If 'yes', estimate the total number</li> </ul>
plan           Pleas           65           66           67           68           69	<ul> <li>next three questions are about the effects your headaches have on your relationing</li> <li>se answer no to any that do not apply.</li> <li>Have your headaches affected your family planning? (Please tick all boxes that apply because of your headaches)</li> <li>During the last 3 months, have your headaches caused difficulties in your love life? (Please tick)</li> <li>Have your headaches caused a relationship to break down? (Please tick one box)</li> <li>Do you have children of school age (Please tick one box)</li> <li>If you ticked 'no', please go directly to Question 71</li> <li>During the last 3 months, have your headaches caused one or more of your children to miss school? (Please tick)</li> </ul>	<ul> <li>No</li> <li>Yes, I have had fewer childrer</li> <li>Yes, I have avoided having children</li> <li>Yes, I have avoided oral contraception (women only)</li> <li>NoYes</li> <li>NoYes</li> <li>_NoYes</li> <li>_NoYes</li> <li>_NoYes</li> <li>_NoYes</li> <li>_NoYes</li> <li>If 'yes', estimate the total number of missed days:</li> <li>_NoOnce</li> <li>_More than once</li> <li>_NoYes</li> </ul>
plan.           Pleas           65           66           67           68           69           70	<ul> <li>next three questions are about the effects your headaches have on your relationing</li> <li>se answer no to any that do not apply.</li> <li>Have your headaches affected your family planning? (Please tick all boxes that apply because of your headaches)</li> <li>During the last 3 months, have your headaches caused difficulties in your love life? (Please tick)</li> <li>Have your headaches caused a relationship to break down? (Please tick one box)</li> <li>Do you have children of school age (Please tick one box) If you ticked 'no', please go directly to Question 71</li> <li>During the last 3 months, have your headaches caused one or more of your children to miss school? (Please tick)</li> <li>During the last 3 months, have your headaches prevented you from caring for your children? (Please tick)</li> <li>Are you currently living with a partner? (Please tick)</li> <li>If you are not now living with a partner? (Please tick)</li> <li>If you are not now living with a partner, please go directly to Question 79</li> <li>During the last 3 months, have your headaches caused your partner to lose time from work?</li> </ul>	<ul> <li>No</li> <li>Yes, I have had fewer childrer</li> <li>Yes, I have avoided having children</li> <li>Yes, I have avoided oral contraception (women only)</li> <li>NoYes</li> <li>NoYes</li> <li>NoYes</li> <li>NoYes, they have caused separation</li> <li>Yes, they have caused divorce</li> <li>NoYes</li> <li>NoYes</li> <li>NoYes</li> <li>If 'yes', estimate the total number of missed days:</li> <li>NoOnce</li> <li>More than once</li> <li>NoYes</li> <li>NoYes</li> <li>NoYes</li> <li>NoYes</li> </ul>
plan           Pleas           65           66           67           68           69           70           71	<ul> <li>next three questions are about the effects your headaches have on your relationing</li> <li>se answer no to any that do not apply.</li> <li>Have your headaches affected your family planning? (Please tick all boxes that apply because of your headaches)</li> <li>During the last 3 months, have your headaches caused difficulties in your love life? (Please tick)</li> <li>Have your headaches caused a relationship to break down? (Please tick one box)</li> <li>Do you have children of school age (Please tick one box) If you ticked 'no', please go directly to Question 71</li> <li>During the last 3 months, have your headaches caused one or more of your children to miss school? (Please tick)</li> <li>Are you currently living with a partner? (Please tick)</li> <li>If you are not now living with a partner, please go directly to Question 79</li> <li>During the last 3 months, have your headaches caused your partner to lose</li> </ul>	<ul> <li>No</li> <li>Yes, I have had fewer children</li> <li>Yes, I have avoided having children</li> <li>Yes, I have avoided oral contraception (women only)</li> <li>No Yes</li> <li>No Yes</li> <li>No Yes</li> <li>No Yes</li> <li>No Yes</li> <li>If 'yes', estimate the total number of missed days:</li> <li>No Yes</li> <li>_ No Yes</li> <li>_ No Yes</li> <li>_ No Yes</li> <li>_ Mo Yes</li> <li>_ No Yes</li> <li>_ If 'yes', enter the total number of days lost:</li> </ul>
plan           Pleas           65           66           67           68           69           70           71	<ul> <li>next three questions are about the effects your headaches have on your relationing</li> <li>se answer no to any that do not apply.</li> <li>Have your headaches affected your family planning? (Please tick all boxes that apply because of your headaches)</li> <li>During the last 3 months, have your headaches caused difficulties in your love life? (Please tick)</li> <li>Have your headaches caused a relationship to break down? (Please tick one box)</li> <li>Do you have children of school age (Please tick one box) If you ticked 'no', please go directly to Question 71</li> <li>During the last 3 months, have your headaches caused one or more of your children to miss school? (Please tick)</li> <li>During the last 3 months, have your headaches prevented you from caring for your children? (Please tick)</li> <li>Are you currently living with a partner? (Please tick)</li> <li>If you are not now living with a partner? (Please tick)</li> <li>If you are not now living with a partner, please go directly to Question 79</li> <li>During the last 3 months, have your headaches caused your partner to lose time from work?</li> </ul>	<ul> <li>No</li> <li>Yes, I have had fewer childrer</li> <li>Yes, I have avoided having children</li> <li>Yes, I have avoided oral contraception (women only)</li> <li>No Yes</li> <li>No Yes</li> <li>No Yes</li> <li>No Yes</li> <li>No Yes</li> <li>If 'yes', estimate the total number of missed days:</li> <li>No Yes</li> <li>_ No Yes</li> <li>_ No Yes</li> <li>_ No Yes</li> <li>_ More than once</li> <li>_ No Yes</li> <li>If 'yes', enter the total number of</li> </ul>

affect 74	t your life. Has your partner had a headache in the last year? (Please tick one box)	NoYes
75	If not applicable, go directly to Question 77 During the last 30 days, on how many days did he/she have a headache? (Please enter the number of days between 0 and 30)	Not applicable days
76	During the last 3 months, have your partner's headaches caused you to lose time from work? (Please tick)	No Once More than once
77	During the last 3 months, have your partner's headaches caused you to miss social activities? (Please tick)	No Once More than once
78	During the last 3 months, have your partner's headaches caused difficulties in your love life? (Please tick) The next three series of questions are general, to be answered by everyone,	NoYes
	Body mass index questions Your answers to these questions will give an indication of your level of fitness	with or without headacnes
79	What is your weight?	kg
.)	(Please enter your weight in kilograms or in stones and pounds)	kg st lb
80	What is you height?	cm
	(Please enter your height in centimetres or in feet and inches)	ft in
81	What is your waist measurement?	cm
	(Please enter the measurement in centimetres or in inches) Please take a tape measure and put it around your waist or take a string put it around your waist and then measure the length of the string with a ruler	in
This s or no The q optio	ity of life questions (WHO QoL) set of eight questions, developed by the World Health Organization, are for everyb at. They will help us compare people with headaches and people without. questions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in t	life. Each question has five respon. the appropriate column. If you are
This s or no The q optios unsur	set of eight questions, developed by the World Health Organization, are for everyb t. They will help us compare people with headaches and people without. questions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in 1 re about which response to give to a question, the first response you think of is ofte se keep in mind your standards, hopes, pleasures and concerns. We ask that you th	life. Each question has five respon the appropriate column. If you are on the best one. ink about your life in the last 4
This s or no The q optio unsur Pleas week.	set of eight questions, developed by the World Health Organization, are for everyb th. They will help us compare people with headaches and people without. questions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the re about which response to give to a question, the first response you think of is often se keep in mind your standards, hopes, pleasures and concerns. We ask that you the s.	life. Each question has five respon the appropriate column. If you are in the best one. ink about your life in the last 4 
This s or no The q optio unsur Pleas	set of eight questions, developed by the World Health Organization, are for everyb t. They will help us compare people with headaches and people without. questions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in 1 re about which response to give to a question, the first response you think of is ofte se keep in mind your standards, hopes, pleasures and concerns. We ask that you th	life. Each question has five respon- the appropriate column. If you are in the best one. ink about your life in the last 4 
This s or no The q optio unsur Pleas week.	set of eight questions, developed by the World Health Organization, are for everyb th. They will help us compare people with headaches and people without. questions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the re about which response to give to a question, the first response you think of is often se keep in mind your standards, hopes, pleasures and concerns. We ask that you the s.	life. Each question has five respon. the appropriate column. If you are in the best one. ink about your life in the last 4 Very poor Poor Neither poor nor good Good Very good
This s or no The q optio unsur Pleas week.	set of eight questions, developed by the World Health Organization, are for everyb th. They will help us compare people with headaches and people without. questions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the re about which response to give to a question, the first response you think of is often se keep in mind your standards, hopes, pleasures and concerns. We ask that you the s.	life. Each question has five respon. the appropriate column. If you are in the best one. ink about your life in the last 4 
This s or no The q optio. unsur Pleas week.	est of eight questions, developed by the World Health Organization, are for everyb t. They will help us compare people with headaches and people without. puestions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the re about which response to give to a question, the first response you think of is often the keep in mind your standards, hopes, pleasures and concerns. We ask that you the s. How would you rate your quality of life?	life. Each question has five respon. the appropriate column. If you are in the best one. ink about your life in the last 4 Very poor Poor Neither poor nor good Good Very good
This S or no The q optio. unsur Pleas week.	set of eight questions, developed by the World Health Organization, are for everyb th. They will help us compare people with headaches and people without. questions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the re about which response to give to a question, the first response you think of is often se keep in mind your standards, hopes, pleasures and concerns. We ask that you the s.	life. Each question has five respon- the appropriate column. If you are in the best one. ink about your life in the last 4 
This s or no The q optio. unsur Pleas week.	est of eight questions, developed by the World Health Organization, are for everyb t. They will help us compare people with headaches and people without. puestions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the re about which response to give to a question, the first response you think of is often the keep in mind your standards, hopes, pleasures and concerns. We ask that you the s. How would you rate your quality of life?	life. Each question has five respon. the appropriate column. If you are in the best one. ink about your life in the last 4 
This s or no The q optio. unsur Pleas week.	est of eight questions, developed by the World Health Organization, are for everyb t. They will help us compare people with headaches and people without. puestions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the re about which response to give to a question, the first response you think of is often the keep in mind your standards, hopes, pleasures and concerns. We ask that you the s. How would you rate your quality of life?	life. Each question has five respon- the appropriate column. If you are in the best one. ink about your life in the last 4 
This : First : For no Fire q optio. Unsur Pleas veek. 32	<ul> <li>bet of eight questions, developed by the World Health Organization, are for everyby the theory will help us compare people with headaches and people without.</li> <li>puestions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the reabout which response to give to a question, the first response you think of is often se keep in mind your standards, hopes, pleasures and concerns. We ask that you the set her would you rate your quality of life?</li> <li>How would you rate your quality of life?</li> <li>How satisfied are you with your health?</li> </ul>	life. Each question has five respon- the appropriate column. If you are in the best one. ink about your life in the last 4 
This : First : For no Fire q optio. Unsur Pleas veek. 32	est of eight questions, developed by the World Health Organization, are for everyb t. They will help us compare people with headaches and people without. puestions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the re about which response to give to a question, the first response you think of is often the keep in mind your standards, hopes, pleasures and concerns. We ask that you the s. How would you rate your quality of life?	life. Each question has five respon- the appropriate column. If you are in the best one. ink about your life in the last 4 
This : First : For no Fire q optio. Unsur Pleas veek. 32	<ul> <li>bet of eight questions, developed by the World Health Organization, are for everyby the theory will help us compare people with headaches and people without.</li> <li>puestions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the reabout which response to give to a question, the first response you think of is often se keep in mind your standards, hopes, pleasures and concerns. We ask that you the set her would you rate your quality of life?</li> <li>How would you rate your quality of life?</li> <li>How satisfied are you with your health?</li> </ul>	life. Each question has five respon- the appropriate column. If you are in the best one. ink about your life in the last 4 
This : for no pptio. unsur Pleas week. 82	<ul> <li>bet of eight questions, developed by the World Health Organization, are for everyby the theory will help us compare people with headaches and people without.</li> <li>puestions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the reabout which response to give to a question, the first response you think of is often se keep in mind your standards, hopes, pleasures and concerns. We ask that you the set her would you rate your quality of life?</li> <li>How would you rate your quality of life?</li> <li>How satisfied are you with your health?</li> </ul>	life. Each question has five respon- the appropriate column. If you are in the best one. ink about your life in the last 4 
This : for no pptio. unsur Pleas week. 82	<ul> <li>bet of eight questions, developed by the World Health Organization, are for everyby the theory will help us compare people with headaches and people without.</li> <li>puestions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the reabout which response to give to a question, the first response you think of is often se keep in mind your standards, hopes, pleasures and concerns. We ask that you the set her would you rate your quality of life?</li> <li>How would you rate your quality of life?</li> <li>How satisfied are you with your health?</li> </ul>	life. Each question has five respon. the appropriate column. If you are in the best one. ink about your life in the last 4 
This : Fris : Or no Optio. Unsur Pleas Week. 32	<ul> <li>bet of eight questions, developed by the World Health Organization, are for everyby the theory will help us compare people with headaches and people without.</li> <li>puestions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the reabout which response to give to a question, the first response you think of is often se keep in mind your standards, hopes, pleasures and concerns. We ask that you the set her would you rate your quality of life?</li> <li>How would you rate your quality of life?</li> <li>How satisfied are you with your health?</li> </ul>	life. Each question has five respon. the appropriate column. If you are in the best one. ink about your life in the last 4 
Normal Science	<ul> <li>bet of eight questions, developed by the World Health Organization, are for everyby the theory will help us compare people with headaches and people without.</li> <li>puestions ask how you feel about your quality of life, health or other areas of your ns. Please choose the answer that appears most appropriate by ticking the box in the reabout which response to give to a question, the first response you think of is often se keep in mind your standards, hopes, pleasures and concerns. We ask that you the set her would you rate your quality of life?</li> <li>How would you rate your quality of life?</li> <li>How satisfied are you with your health?</li> </ul>	life. Each question has five respon- the appropriate column. If you are in the best one. ink about your life in the last 4 
This s or no The q optio unsur Pleas week.	<ul> <li>New York of the set of eight questions, developed by the World Health Organization, are for everyby the theory will help us compare people with headaches and people without. They will help us compare people with headaches and people without. They will help us compare people with headaches and people without. They will help us compare people with appears most appropriate by ticking the box in the readout which response to give to a question, the first response you think of is often the about your standards, hopes, pleasures and concerns. We ask that you the set keep in mind your standards, hopes, pleasures and concerns. We ask that you the set would you rate your quality of life?</li> <li>How would you rate your quality of life?</li> <li>How satisfied are you with your health?</li> </ul>	life. Each question has five respon the appropriate column. If you are in the best one. ink about your life in the last 4 

86	How satisfied are you with your personal relationships?	<ul> <li>Very dissatisfied</li> <li>Dissatisfied</li> <li>Neither satisfied nor dissatisfied</li> <li>Satisfied</li> <li>Very satisfied</li> </ul>		
87	How satisfied are you with the conditions of your living place?	<ul> <li>Very dissatisfied</li> <li>Dissatisfied</li> <li>Neither satisfied nor dissatisfied</li> <li>Satisfied</li> <li>Very satisfied</li> </ul>		
88	Do you have enough energy for everyday life?	Not at all A little Moderately Mostly Completely		
89	Have you enough money to meet your needs?	Not at all A little Moderately Mostly Completely		
Depression and anxiety questions (HADS)				

The final series of questions ask about depression and anxiety, both of which are common in the general population. Please read each item and place a firm tick in the box-circle the number which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response

90	I feel tense or 'wound up'	<ul> <li>Most of the time</li> <li>A lot of the time</li> <li>Time to time</li> <li>Occasionally</li> <li>Not at all</li> </ul>
91	I feel as if I am slowed down	<ul> <li>Nearly all of the time</li> <li>Very often</li> <li>Sometimes</li> <li>Not at all</li> </ul>
92	I still enjoy the things I used to enjoy	Definitely as much Not quite so much Only a little Not at all
93	I get a sort of frightened feeling like 'butterflies in the stomach'	Not at all Occasionally Quite often Very often
94	I get a sort of frightened feeling like something awful is about to happen	<ul> <li>Very definitely and quite badly</li> <li>Yes, but not too badly</li> <li>A little, but it doesn't worry</li> <li>me</li> <li>Not at all</li> </ul>
95	I have lost interest in my appearance	<ul> <li>Definitely</li> <li>I don't take as much care as I should</li> <li>I may not take quite as much care</li> <li>I take just as much care as ever</li> </ul>
96	I can laugh and see the funny side of things	As much as I always could Not quite so much now Definitely not so much now Not al all
97	I feel restless as if I have to be on the move	Very much indeed Quite a lot Not very much Not at all

98	Worrying thoughts go through my mind	<ul> <li>A great deal of the time</li> <li>A lot of the time</li> <li>From time to time but not too often</li> <li>Only occasionally</li> </ul>
99	I look forward with enjoyment to things	A much as I ever did Rather less than I used to Definitely less than I used to Hardly at all
100	I feel cheerful	Not at all Not often Sometimes Most of the time
101	I get sudden feelings of panic	Very often indeed Quite often Not very often Not at all
102	I can sit at ease and feel relaxed	Definitely Usually Not often Not at all
103	I can enjoy a good book or radio or TV programme	Often Sometimes Not often Very seldom