GB

Migraine-Headaches?
Don't suffer in silence!

QUESTIONNAIRE

Assessment of the impact of headaches and migraines in Luxembourg

A STUDY OF THE CRP-SANTÉ

with the support of the Directorate of Health, the National Fund for Research, the Syndicate of Luxembourg Pharmacists, the Health Service for Multi-sector Employment, the Social Security Medical Control, the 'Patientevertriedung', several hospital neurologists and specialists in the treatment and prevention of pain, the Association of General Practitioners and other doctors involved as well as the 'Swiss Migraine Trust' Foundation.

Information letter to participants in the study

DEAR SIR/MADAM,

Headache pain is familiar to most of us, a lot of people get headaches regularly. The national research study: ***Prevalence, burden and impact of migraine in the Grand Duchy of Luxembourg: a pilot study for an European survey****, is being carried out by the Research Centre for Public Health with the support of the Directorate of Health, the National Fund for Research, the Syndicate of Luxembourg Pharmacists, the Health Service for Multi-sector Employment, the Social Security Medical Control, the 'Patientevertriedung', several hospital neurologists and specialists in the treatment and prevention of pain, the Association of General Practitioners and other doctors involved as well as the 'Swiss Migraine Trust' Foundation.*

What is the purpose of the study?

The study aims to estimate the prevalence of migraine at national level, to evaluate the physical, emotional, socio-economic impact of migraine as well as patient satisfaction and needs.

The results of the study will help to have a better understanding of headache as a serious health problem and to assess the burden of headache on people's life. The obtained information should contribute to determine ways to improve their quality of life and evaluate the needs for an optimal disease management.

To whom is the study addressed?

If you are suffering from headaches you will help by completing the questionnaire or if you know someone suffering from headache you can hand him/her the questionnaire to fill in. Only headache sufferers can give us information about the real impact of regular headaches on their own life, that's why it is important that headache sufferers answer this questionnaire.

What do you have to do?

You are invited to complete the questionnaire or to propose it to someone who suffers from headaches to fill in. The questionnaire will take about 20 minutes to fill in. After the questionnaire has been completed, please return it with the **prepaid and addressed envelope** as soon as possible.

IMPORTANT: You can fill in this questionnaire **only once** yourself.

What is the level of privacy?

The Research Centre for Public Health 'CRP-Santé' which will process the answers given by participants in the study will not have access to your personal details as this is an anonymous study. Your answers will only be used within the framework of this study and will be treated as strictly anonymous and confidential and processed as statistics along with all the other answers obtained. At no point will your answers feature on a public document or be used by other institutions.

To ensure your anonymity, the questionnaire is not individualized. The questionnaire you complete will be anonymously encoded on the computer system and then destroyed at the end of the study. Before being destroyed, it will be stored in a locked location at the Research Centre for Public Health for which the project manager will be responsible. The computer file of the data will be stored for 10 years in a secure location at the Research Centre for Public Health 'CRP-Santé'.

You cannot be granted access to the data concerning you, which will be registered by the CRP-Santé, as there exists no way to retrieve individual data.

Financial aspect

Your participation in this study is on voluntary basis, no remuneration will be proposed.

Do you require further information?

If you need more information about the study or if you If you don't understand a question and need it explaining, you can call 45-32-13-34 between 8am and 4pm, from Monday to Friday.

We greatly appreciate your participation in this research.
Your responses are highly valuable to us.

ASSESSMENT OF THE IMPACT OF HEADACHES AND MIGRAINES IN LUXEMBOURG

This questionnaire is aimed only at people who **suffer from headaches or migraine**.
Please only fill in this questionnaire **if you live in Luxembourg**.

INSTRUCTIONS

If you do decide to participate in this survey by filling in the questionnaire, it is important that you try to answer as many questions as possible. If you don't understand a question and need it explaining, you can call 45-32-13-34 between 8am and 4pm, from Monday to Friday.

Parents of children under the age of 18 may complete the questionnaire on the child's behalf if the child suffers from headaches or migraine. It is important for this study that each participant consents to participate and to **only fill in the questionnaire once**.

I declare that I have read and understood the information contained in the information to participants and give my written consent to my data being processed by the Research Centre for Public Health in accordance with the objectives described in this information.

Please tick the following box and sign to confirm your agreement:

☐ By ticking this box, I agree to complete only one copy of this questionnaire.

Signature of the respondent or of the legal, juristic or statuary representative of the respondent.

Please sign here: .....(signature)

If you have signed and ticked the box above, please return the completed questionnaire in the stamped addressed envelope provided.

GENERAL INFORMATION (please tick the correspondent cases)

Question 1: **What is your age**: ..... (years)

Question 2: **Gender**: ☐ male ☐ female

Question 3: **What language do you speak at home?**
(Please tick the one you speak mostly at home):

☐ Luxembourgish ☐ French ☐ German
☐ Portuguese ☐ English ☐ Other: .....

Question 4: **What is your actual working situation?** (Please tick all applicable):

☐ Full time employed ☐ Self-employed ☐ Retired ☐ Other
☐ Part-time employed ☐ Student/school ☐ Housekeeping ☐ Unemployed

ABOUT HEADACHE

Question 5: **At what age did you start getting headaches:** ..... (years)

Question 6: **What is the average number of days per month on which you suffered from headaches during the last 3 months:**

☐ less than 1day per month ☐ 1-3 days per month ☐ 4-9 days per month
☐ 10-14 days per month ☐ 15 days or more per month

Question 7: **Think about the last 3 months:**

- Are you nauseated or sick to your stomach when you have a headache?

☐ Yes ☐ No

- Does light bother you when you have a headache?

☐ Yes ☐ No

- Has a headache limited your activities for a day or more?

☐ Yes ☐ No

Question 8: **Do you experience problems before, during or after your headache:**

☐ Yes, **before** my headache: duration: ..... hours (e.g. 2 days = 48 hours)

☐ Yes, **during** my headache: duration: ..... hours

☐ Yes, **after** my headache: duration: ..... hours

☐ No

If yes please tick which ones:	before	during	after
☐ Feeling tired	☐	☐	☐
☐ Feeling dizzy	☐	☐	☐
☐ Speech difficulty	☐	☐	☐
☐ Unusual hunger	☐	☐	☐
☐ Visual disturbances (Blurred or altered vision)	☐	☐	☐
☐ Mood changes	☐	☐	☐
☐ Swollen limbs	☐	☐	☐
☐ Other(s):	☐	☐	☐

HEALTH AND LIFE (World Health Organization Disability Assessment Schedule II)

Question 9: **How do you rate your overall health in the past 30 days?**

☐ Very good ☐ Good ☐ Moderate ☐ Bad ☐ Very Bad

The questions in this section ask about difficulties due to health conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs.

Think back over the last 30 days and answer these questions thinking about how much difficulty you had because of your headache doing the following activities you usually do them. For each question, please tick only one response.

Question 10: **In the last 30 days, how much difficulty did you have in:**

	None	Mild	Moderate	Severe	Extreme/cannot do
Standing for long periods such as 30 minutes?					
Taking care of your household responsibilities?					
Learning a new task, for example, learning how to get to a new place?					
How much of a problem did you have joining in community activities (for example, festivities, religious or other) in the same way as anyone else can?					
How much have you been emotionally affected by your health problems?					
Concentrating on doing something for ten minutes?					
Walking a long distance such as a kilometre [or equivalent]?					
Washing your whole body?					
Getting dressed?					
Dealing with people you do not know?					
Maintaining a friendship?					
Your day to day work?					
Overall, how much did these difficulties interfere with your life?					

Question 11 **Overall, in the past 30 days, how many days were these difficulties present?**

Record number of days: .....

Question 12: **In the past 30 days, for how many days were you totally unable to carry out your usual activities or work because of any health condition?**

Record number of days: .....

Question 13: **In the past 30 days, not counting the days that you were totally unable, for how many days did you cut back or reduce your usual activities or work because of any health condition?**

Record number of days: .....

Please answer the questions 14-19 about all the headaches you have had over the last three months.

Write the answer on the line next to each question.

Write zero if you they did not do the activity in the last 3 months.

Question 14: **On how many days in the last 3 months did you miss work or school (because of your headaches)?**

Record number of days: .....

Question 15: **How many days in the last 3 months was your productivity at work or school reduced by half or more (because of your headaches)? (Do not include days you counted in question 14 where you missed work or school)**

Record number of days: .....

Question 16: **On how many days in the last 3 months did you not do household work (because of your headaches)?**

Record number of days: .....

Question 17: **How many days in the last 3 months was your productivity in household work reduced by half or more because of your headaches? (Do not include days you counted in question 16 where you did not do household work)**

Record number of days: .....

Question 18: **On how many days in the last three months did you miss family, social or leisure activities (because of your headaches)?**

Record number of days: .....

Question 19: **On how many days in the last 3 months did you have a headache?**
(If a headache lasted more than 1 day, count each day)

Record number of days: .....

Question 20: **Over the last 2 weeks, how often have you been bothered by any of the following problems?**

Please answer question 20 not only in relation to your headache but how you felt in general the last 2 weeks.

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things				
Feeling down, depressed, or without hope				
Trouble falling/staying asleep, sleeping too much				
Feeling tired or having little energy				
Poor appetite or overeating				
Feeling bad about yourself - or that you are a failure or have let yourself or your family down				
Trouble concentrating on things, such as reading the newspaper or watching television				
Moving or speaking so slowly that other people could have noticed or the opposite - being so fidgety or restless that you have been moving around a lot more than usual				
Thoughts that you would be better off dead or of hurting yourself in some way				

DISEASE MANAGEMENT

Question 21: **Have you consulted a medical doctor for one of the following reasons since your headaches started:**

Please tick **all** that are applicable:

☐ Head trauma ☐ Hypertension ☐ Sleeping problems
☐ Depression ☐ Anxiety or Panic disorder ☐ Allergies
☐ Eating problems ☐ Asthma
☐ Other: ..... ☐ No other reason

Question 22: **How many doctors have you already consulted because of your headaches?**

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ more

Question 23: **If you have already consulted a doctor because of your headaches, did the doctor tell you what kind of headache you suffer from?**

☐ Yes ☐ No

If yes, what kind:

☐ Migraine ☐ Tension headache ☐ Cluster ☐ Stress
☐ Neck problems ☐ Other ☐ I do not remember

Question 24: **How many doctors have you consulted because of your headaches during the last 12 months?**

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ more

If you have not consulted a doctor because of your headaches during the last 12 months, why not:

☐ my headache improved
☐ my headache did not get better despite a prior medical consultation more than 12 months ago
☐ other reasons: .....

Question 25: **Have you ever been given any tests to investigate your headaches?**

☐ Yes ☐ No

If Yes, which one(s):

	How many? (number)	Year (if possible)
☐ MRI of my head	.....	.....
☐ EEG	.....	.....
☐ CT scan of my head	.....	.....
☐ In depth interview about my headache	.....	.....
☐ Other:	.....	.....

Question 26: **Do you currently take any drugs to relieve your headache once it has started?**

☐ Yes ☐ No

If Yes, please indicate what drug(s) you are currently taking to relieve your headache:
(Please tick all that are applicable, more than one tick possible)

☐ Aspirine, Aspro, Aspégic
☐ Dafalgan
☐ Ibuprofen, Brufen, Nurofen
☐ Imitrex
☐ Maxalt
☐ Motilium
☐ Naramig
☐ Panadol
☐ Panadol + Codéine
☐ Primpéran
☐ Relert
☐ Zomig
☐ Family recipe
☐ I do not remember
☐ Other(s) .....
.....
.....

Question 27: **Looking back at the last three months, on how many days each month did you take medication to relieve your headaches?**

☐ less than 1day per month ☐ 1-3 days per month ☐ 4-9 days per month
☐ 10-14 days per month ☐ 15 days or more per month

Question 28: **How many different drugs have you ever tried to relieve your headaches?**

☐ none ☐ one ☐ 2-4 ☐ 5-7 ☐ more

Question 29: **If there was a drug which would relieve your headaches, how much do you think it would change your quality of life?**

☐ no change at all ☐ slight change ☐ complete new life

Question 30: **Do you currently use a treatment (medication on a daily base or alternative/ complementary therapies) to prevent you from getting a headache?**

☐ Yes ☐ No

If Yes, which one(s): .....
.....

Question 31: **How many different treatments (medication on a daily base or alternative/ complementary therapies) have you ever tried to prevent you from getting a headache:**

☐ none ☐ one ☐ 2-4 ☐ 5-7 ☐ more

If applicable, how successful do rate these treatments to prevent you from getting a headache

Treatment:

..... ☐ not at all ☐ a little ☐ fair ☐ very
..... ☐ not at all ☐ a little ☐ fair ☐ very
..... ☐ not at all ☐ a little ☐ fair ☐ very
..... ☐ not at all ☐ a little ☐ fair ☐ very

Question 32: **Have you ever controlled or do you currently control your headaches using one of the following self-management techniques?**

☐ Diet/healthay life style ☐ Sports ☐ Food supplements

☐ Meditation/relaxation ☐ Other method(s) of self-management .....

☐ None of the above .....

If applicable, how successful do rate the methods?

Method:

.....	☐ not at all	☐ a little	☐ fair	☐ very
.....	☐ not at all	☐ a little	☐ fair	☐ very
.....	☐ not at all	☐ a little	☐ fair	☐ very
.....	☐ not at all	☐ a little	☐ fair	☐ very

Question 33: **Taking into account everything you do to treat your headache, how well do you think you control your headache?**

☐ not at all ☐ a little bit ☐ quite well ☐ completely under control

Question 34: **Please tick of the following services those which you would appreciate to be present to improve your headache:**

Education for the patient ☐

Consultation with a health professional with specialist knowledge of headache ☐

Individualised care ☐

Telephone Helpline ☐

Written information, brochures ☐

Self management courses ☐

Help with medication 'withdrawel' and rehabilitation support ☐

Internet website ☐

self-help group meetings ☐

Public forum ☐

Information in the press media ☐

Books ☐

Research studies ☐

Other suggestions: .....

.....

.....

.....

PRIVATE AND SOCIAL IMPACT

Question 35: **Have headaches ever influenced your job situation/career, school choice, job choice?**

☐ Yes ☐ No

If Yes, tick all that are applicable:

☐ Less chance /missed promotion

☐ Restricted my job's choice

☐ Afraid of losing my job

☐ Lost my job

☐ Could not pass my exams

☐ Other: .....

☐ Had to change my workplace

☐ Less opportunity to get a job

☐ Had to change school

☐ Bullying

☐ Reduce my working time

Question 36: **At your working place do you encounter situations which worsen your headache, like: (Skip this question if not applicable)**

☐ Light

☐ Air conditioning

☐ Computer screen

☐ Noise

☐ Working positions(e.g. uncomfortable or badly positioned chairs, standing too long etc.)

☐ No relaxation facilities or opportunities

☐ Other: .....

Question 37: **When you talk about your headache do you feel that others understand?**

Your family	☐ No	☐ to some extent	☐ Yes
Your friends	☐ No	☐ to some extent	☐ Yes
Your work colleagues	☐ No	☐ to some extent	☐ Yes
Your employer	☐ No	☐ to some extent	☐ Yes

Most people know about my headache:

☐ Yes ☐ No

Question 38: **Have headaches ever influenced your family situation/partnership?**

☐ Yes ☐ No

If Yes, tick all that are applicable:

☐ Arguing ☐ Feeling guilty

☐ Isolation ☐ Divorce

☐ Frustration ☐ Breaking up

☐ Other: .....

Question 39: **Are there any hobbies/social activities which you enjoy doing/participating in, but which you had to limit or which you had to give up/could not participate in because of headache?**

☐ Yes ☐ No

If yes, which ones: .....

.....

Question 40: **Do you feel that your social life is constrained because of headache?**

☐ not at all ☐ to some extent ☐ completely constrained

Question 41: **Please tick any popular myths or misconception about headache you are confronted with:**

None ☐

Headache just hurts, you should be able to cope with it easily ☐

Headache only affects weak people ☐

Headache affects people who can't cope with stress ☐

Headache is just putting it up, is just all in the mind ☐

Headache is just an excuse ☐

Only women get headaches ☐

Other: ..... ☐

Thank you for having accepted to fill in this questionnaire!