Participant ID No: [INSERT DETAILS]

CHESS
Chronic Headache Education and Self-management Study

WARWICK
CLINICAL TRIALS UNIT

CHESS STUDY
Chronic Headache Education and Self-management Study (CHESS)

Baseline Questionnaire

Confidential

Dear participant,

Please can you complete the following questionnaire about yourself and living with frequent headaches. We are aware some of these questions might be repetitive and appreciate the time you take completing the questionnaire. The information that you give us will help us with our research, therefore please answer the questions as accurately as you can.

If you have any difficulties with the questionnaire please contact the study team on: **02476 151 634** or via email: **chess@warwick.ac.uk**

Please use a BLACK or BLUE pen. Please do not use a pencil and check that you have completed all sections.

Please could you tell us the day you completed the questionnaire in the space provided below:

Date completed: | D | D | - | M | M | M | - | Y | Y | Y | Y |

THANK YOU for being part of our study. We look forward to receiving your questionnaire.

CHESS Study Team

This questionnaire presents independent research funded by the National Institute for Health Research (NIHR) under the Programme Grants for Applied Research programme [project number RP-PG-1212-20018]. The views expressed in this questionnaire are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

FUNDED BY NIHR | National Institute for Health Research

Participant ID No: [INSERT DETAILS]

Section 1:

1. Gender Please tick (✓) one

Male ☐ **Female** ☐ **Other** ☐ **Prefer not to say** ☐

2. What is your ethnic group? (please choose **one** section from A to E, then **tick one** box to best describe your ethnic group or background)

A. White

British ☐

Irish ☐

Any other white background (specify below) ☐

_____

B. Black or Black British

Caribbean ☐

African ☐

Any other black background (specify below) ☐

_____

C. Asian or Asian British

Indian ☐

Pakistani ☐

Bangladeshi ☐

Any other Asian background (specify below) ☐

_____

D. Mixed

White & Black Caribbean ☐

White & Black African ☐

White & Asian ☐

Any other mixed background (specify below) ☐

_____

E. Other ethnic group

Please specify: _____

3. Which of the following best describes you? Please tick (✓) one

Employed (full or part time, including self-employment) ☐

Unemployed and looking for work ☐

At school or in full time education ☐

Unable to work due to long term sickness ☐

Looking after your home/family ☐

Retired from paid work ☐

Other (please specify below) ☐

_____

4. How old were you when you left full time education (e.g. school, college or university? Please tick (✓) one

I did not receive a formal education	☐
Age 12 or less	☐
Age 13 to 16	☐
Age 17 to 19	☐
Age 20 or over	☐
I am still in full time education	☐

Section 2:

This questionnaire was designed to help you describe and communicate the way you feel and what you cannot do because of headaches.

To complete, please check (✓) one box for each question.

When you have headaches, how often is the pain severe?

☐ Never ☐ Rarely ☐ Sometimes ☐Very often ☐Always

How often do headaches limit your ability to do usual daily activities including household work, work, college, or social activities?

☐ Never ☐ Rarely ☐Sometimes ☐Very often ☐Always

When you have a headache, how often do you wish you could lie down?

☐ Never ☐ Rarely ☐Sometimes ☐Very often ☐Always

In the past 4 weeks, how often have you felt too tired to do work or daily activities because of your headaches?

☐ Never ☐ Rarely ☐Sometimes ☐Very often ☐Always

In the past 4 weeks, how often have you felt fed up or irritated because of your headaches?

☐ Never ☐ Rarely ☐Sometimes ☐Very often ☐Always

In the past 4 weeks, how often did headaches limit your ability to concentrate on work or daily activities?

☐ Never ☐ Rarely ☐Sometimes ☐Very often ☐Always

Participant ID No: [INSERT DETAILS]

Section 3:

Please fill out this questionnaire. It will help us to understand the effects of headaches on your daily activities. The questionnaire has been designed so that it can be completed quickly and easily.

Please tick (✓) only one answer for each question. You should answer every question.

While answering the following questions, please think about ***all headaches*** you may have had ***in the past 4 weeks***.

1. In the past 4 weeks, how often have headaches **interfered** with how well you dealt with family, friends and others who are close to you? (Select only **one** response.)

   1❑ None of the time
   2❑ A little bit of the time
   3❑ Some of the time
   4❑ A good bit of the time
   5❑ Most of the time
   6❑ All of the time

2. In the past 4 weeks, how often have headaches **interfered** with your leisure time activities, such as reading or exercising? (Select only **one** response.)

   1❑ None of the time
   2❑ A little bit of the time
   3❑ Some of the time
   4❑ A good bit of the time
   5❑ Most of the time
   6❑ All of the time

3. In the past 4 weeks, how often have you had **difficulty** in performing work or daily activities because of headache symptoms? (Select only **one** response.)

   1❑ None of the time
   2❑ A little bit of the time
   3❑ Some of the time
   4❑ A good bit of the time
   5❑ Most of the time
   6❑ All of the time

4. In the past 4 weeks, how often did headaches **keep you** from getting as much done at work or at home? (Select only **one** response.)

1❑ None of the time
2❑ A little bit of the time
3❑ Some of the time
4❑ A good bit of the time
5❑ Most of the time
6❑ All of the time

5. In the past 4 weeks, how often did headaches **limit** your ability to concentrate on work or daily activities? (Select only **one** response.)

1❑ None of the time
2❑ A little bit of the time
3❑ Some of the time
4❑ A good bit of the time
5❑ Most of the time
6❑ All of the time

6. In the past 4 weeks, how often have headaches **left you too tired** to do work or daily activities? (Select only **one** response.)

1❑ None of the time
2❑ A little bit of the time
3❑ Some of the time
4❑ A good bit of the time
5❑ Most of the time
6❑ All of the time

7. In the past 4 weeks, how often have headaches **limited** the number of days you have felt energetic? (Select only **one** response.)

1❑ None of the time
2❑ A little bit of the time
3❑ Some of the time
4❑ A good bit of the time
5❑ Most of the time
6❑ All of the time

8. In the past 4 weeks, how often have you had to **cancel** work or daily activities because you had a headache? (Select only **one** response.)

1❑ None of the time
2❑ A little bit of the time
3❑ Some of the time
4❑ A good bit of the time
5❑ Most of the time
6❑ All of the time

9. In the past 4 weeks, how often did you **need help** in handling routine tasks such as every day household chores, doing necessary business, shopping, or caring for others, when you had a headache? (Select only **one** response.)

1❑ None of the time
2❑ A little bit of the time
3❑ Some of the time
4❑ A good bit of the time
5❑ Most of the time
6❑ All of the time

10. In the past 4 weeks, how often did you have to **stop** work or daily activities to deal with headache symptoms? (Select only **one** response.)

1❑ None of the time
2❑ A little bit of the time
3❑ Some of the time
4❑ A good bit of the time
5❑ Most of the time
6❑ All of the time

11. In the past 4 weeks, how often were you **not able to go** to social activities such as parties, dinner with friends, because you had a headache? (Select only **one** response.)

1❑ None of the time
2❑ A little bit of the time
3❑ Some of the time
4❑ A good bit of the time
5❑ Most of the time
6❑ All of the time

12. In the past 4 weeks, how often have you **felt** fed up or frustrated because of your headaches? (Select only **one** response.)

1❑ None of the time
2❑ A little bit of the time
3❑ Some of the time
4❑ A good bit of the time
5❑ Most of the time
6❑ All of the time

13. In the past 4 weeks, how often have you **felt** like you were a burden on others because of your headaches? (Select only **one** response.)

1❑ None of the time
2❑ A little bit of the time
3❑ Some of the time
4❑ A good bit of the time
5❑ Most of the time
6❑ All of the time

14. In the past 4 weeks, how often have you been **afraid** of letting others down because of your headaches? (Select only **one** response.)

1❑ None of the time
2❑ A little bit of the time
3❑ Some of the time
4❑ A good bit of the time
5❑ Most of the time
6❑ All of the time

Section 4:

1. **On how many days over the last 4 weeks have you had a headache/migraine?**

   Insert number of days ☐☐

2. **Over the last 4 weeks on how many days have you used pain killers or triptans for your headaches/migraine?** *Please do not include drugs used every day to prevent headaches/migraines coming on.*

   Insert number of days ☐☐

3. **On those days you had a headache/migraine, on average how long did they last?**

   Insert number of hours ☐☐

To complete the next questions, please tick (✓) one box for each question.

4. **On those days you had a headache/migraine on average how severe were they?**

☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
0	1	2	3	4	5	6	7	8	9	10
No pain										**Extremely severe pain**

5. **In the past seven days how fatigued were you on average?**

Not at all	**A little bit**	**Somewhat**	**Quite a bit**	**Very much**
☐	☐	☐	☐	☐

6. **In the past seven days my sleep quality was:**

Very poor	**Poor**	**Fair**	**Good**	**Very good**
☐	☐	☐	☐	☐

Section 5:

For the next questions we would like you think about any other bodily pains you may have; i.e. pain that is not your headache

1. **In the past seven days how would you rate your pain (other than your headache) on average?**

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

0 1 2 3 4 5 6 7 8 9 10

No pain **Worst imaginable pain**

2. **During the past month, how troublesome have each of the following symptoms been? (Please mark the appropriate box on each row for each area that you have pain)**

	No pain experienced	Not at all troublesome	Slightly troublesome	Moderately troublesome	Very troublesome	Extremely troublesome
Headache						
Neck pain						
Shoulder pain						
Elbow pain						
Wrist / hand pain						
Chest pain						
Abdominal pain						
Upper back pain						
Lower back pain						
Hip / thigh pain						
Knee pain						
Ankle / foot pain						
Other pains						

Section 6:

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*
For each of the following questions, please tick (✓) the one box that best describes your answer.

In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐

1. The following questions are about activities you might do during a typical day. Does <u>your health now limit you</u> in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
a <u>Moderate activities</u>, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐	☐	☐
b Climbing <u>several</u> flights of stairs	☐	☐	☐

2. During the <u>past 4 weeks</u>, how much of the time have you had any of the following problems with your work or other regular daily activities <u>as a result of your physical health</u>?

3. During the <u>past 4 weeks</u>, how much of the time have you had any of the following problems with your work or other regular daily activities <u>as a result of any emotional problems</u> (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a <u>Accomplished less</u> than you would like	☐	☐	☐	☐	☐
b Did work or other activities less carefully than usual	☐	☐	☐	☐	☐

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Accomplished less than you would like	☐	☐	☐	☐	☐
b Were limited in the <u>kind</u> of work or other activities	☐	☐	☐	☐	☐

4. **During the <u>past 4 weeks</u>, how much did pain interfere with your normal work (including both work outside the home and housework)?**

Not at all	A little bit	Moderately	Quite a bit	Extremely
☐	☐	☐	☐	☐

5. **These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks…</u>**

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
a	Have you felt calm and peaceful?	☐	☐	☐	☐	☐
b	Did you have a lot of energy?	☐	☐	☐	☐	☐
c	Have you felt downhearted and low?	☐	☐	☐	☐	☐

6. **During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting with friends, relatives, etc.)?**

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐	☐	☐	☐	☐

<u>Section 7:</u>

Under each heading, please tick (✓) the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about ☐

I have slight problems in walking about ☐

I have moderate problems in walking about ☐

I have severe problems in walking about ☐

I am unable to walk about ☐

SELF-CARE

I have no problems washing or dressing myself ☐

Participant ID No: [INSERT DETAILS]

I have slight problems washing or dressing myself ☐

I have moderate problems washing or dressing myself ☐

I have severe problems washing or dressing myself ☐

I am unable to wash or dress myself ☐

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ☐

I have slight problems doing my usual activities ☐

I have moderate problems doing my usual activities ☐

I have severe problems doing my usual activities ☐

I am unable to do my usual activities ☐

PAIN / DISCOMFORT

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discomfort ☐

I have severe pain or discomfort ☐

I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

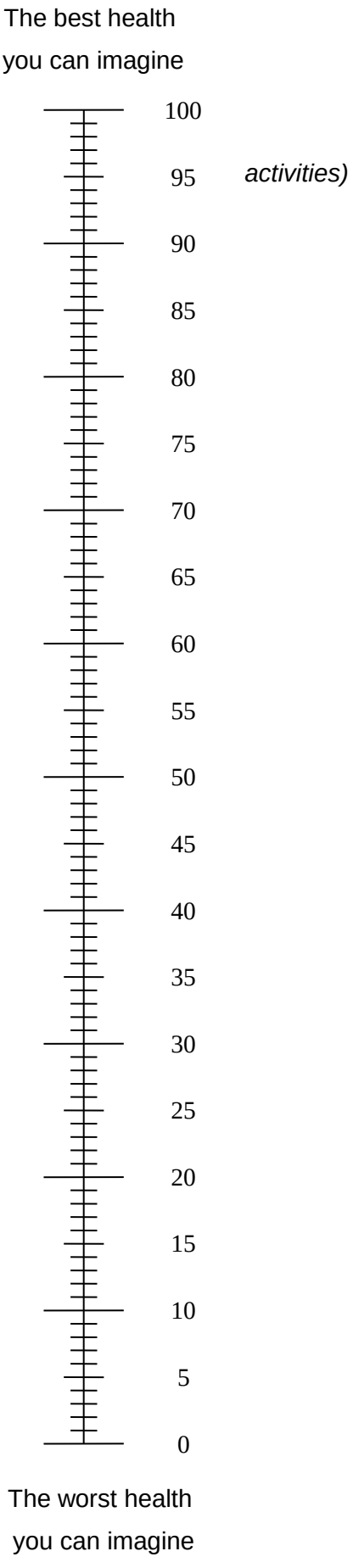
I am moderately anxious or depressed ☐

I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

Your own health state today

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.



YOUR HEALTH TODAY =

Section 8:

Emotions can play an important part in most illnesses, this questionnaire has been designed to help researchers know how you feel. Please tick (✓) the box that comes closest to how you have been feeling in the PAST WEEK.

Do not take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response. Please tick (✓) one box for each question.

I feel tense or "wound up"		**I feel as if I am slowed down**	
Most of the time	☐	**Nearly all the time**	☐
A lot of the time	☐	**Very often**	☐
From time to time, occasionally	☐	**Sometimes**	☐
Not at all	☐	**Not at all**	☐

I still enjoy the things I used to enjoy		**I get a sort of frightened feeling like 'butterflies' in the stomach**	
Definitely as much	☐	**Not at all**	☐
Not quite so much	☐	**Occasionally**	☐
Only a little	☐	**Quite often**	☐
Hardly at all	☐	**Very often**	☐

I get a sort of frightened feeling as if something awful if about to happen		**I have lost interest in my appearance**	
Very definitely and quite badly	☐	**Definitely**	☐
Yes, but not too badly	☐	**I don't take as much care as I should**	☐
A little, but it doesn't worry me	☐	**I may not take quite as much care**	☐
Not at all	☐	**I take just as much care as ever**	☐

I can laugh and see the funny side of things		**I feel restless as if I have to be on the move**	
As much as I always could	☐	**Very much indeed**	☐
Not quite so much now	☐	**Quite a lot**	☐
Definitely not so much now	☐	**Not very much**	☐
Not at all	☐	**Not at all**	☐

Worrying thoughts go through my mind		**I look forward with enjoyment to things**	
A great deal of the time	☐	**As much as I ever did**	☐
A lot of the time	☐	**Rather less than I used to**	☐
Not too often	☐	**Definitely less than I used to**	☐
Very little	☐	**Hardly at all**	☐

I feel cheerful		**I get sudden feelings of panic**	
Never	☐	**Very often indeed**	☐
Not often	☐	**Quite often**	☐
Sometimes	☐	**Not very often**	☐
Most of the time	☐	**Not at all**	☐

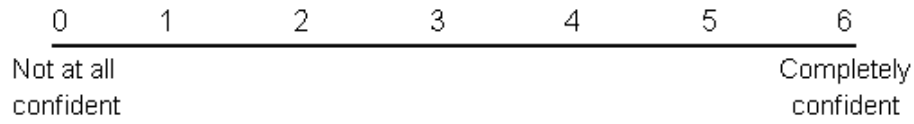
I can sit at ease and feel relaxed		**I can enjoy a good book or radio or television programme**	
Definitely	☐	**Often**	☐
Usually	☐	**Sometimes**	☐
Not often	☐	**Not often**	☐
Not at all	☐	**Very seldom**	☐

Section 9:

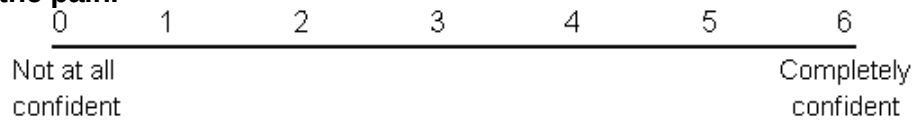
Please rate how **confident** you are that you can do the following things at present, **despite the pain**. To indicate your answer circle one of the number on the scale under each item, where 0 = not all confident and 6 = completely confident.

Remember, this questionnaire is not asking whether or not you have been doing these things, but rather **how confident you are that you can do them at present, despite the pain.**

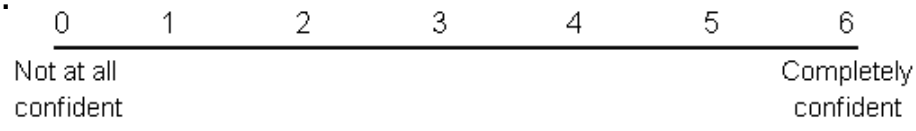
1. I can enjoy things, despite the pain.



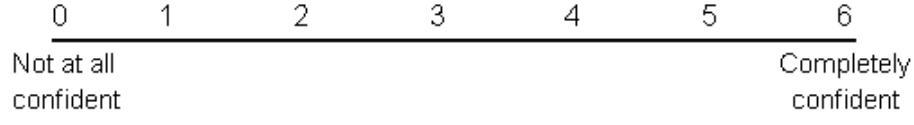
2. I can do most of the household chores (e.g., tidying-up, washing dishes, etc.), despite the pain.



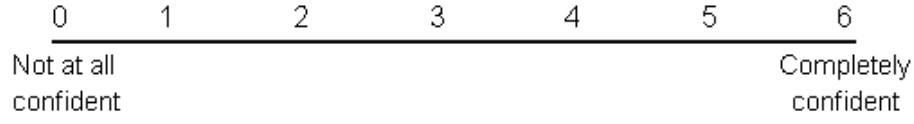
3. I can socialise with friends or family members as often as I used to do, despite the pain.



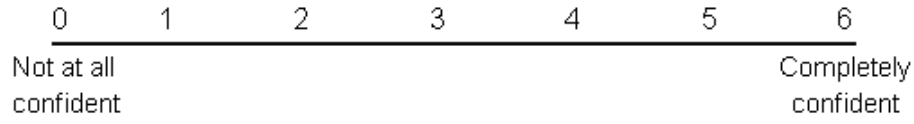
4. I can cope with my pain in most situations.



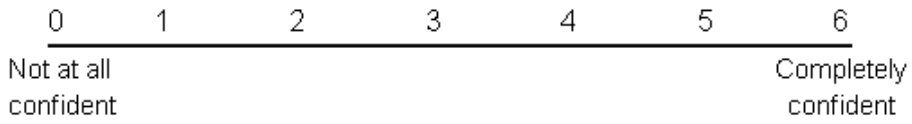
5. I can do some form of work, despite the pain. ("work" includes, housework, paid and unpaid work).



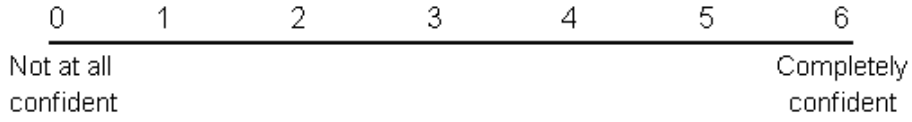
6. I can still do many things I enjoy doing, such as hobbies or leisure activity, despite pain.



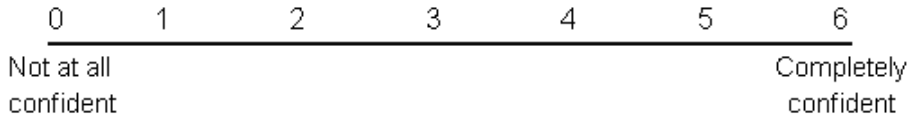
7. I can cope with my pain without medication.



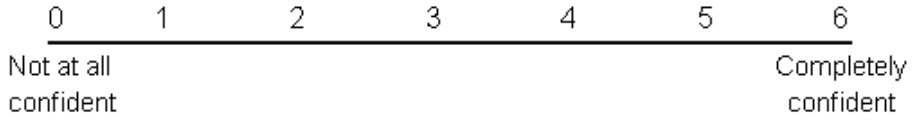
8. I can still accomplish most of my goals in life, despite the pain.



9. I can live a normal lifestyle, despite the pain.



10. I can gradually become more active, despite the pain.



Section 10:

Thank you for taking the time to participate in this survey. There are no right or wrong answers but please make sure that you answer every question the best you can.

Below you will find a list of statements. Please indicate how strongly you agree or disagree with the following statements by checking the response which best describes you now.

Please tick (✓) one box for each question.

1. I am doing interesting things in my life		**2. Most days I am doing some of the things I really enjoy**	
Strongly disagree	☐	**Strongly disagree**	☐
Disagree	☐	**Disagree**	☐
Agree	☐	**Agree**	☐
Strongly agree	☐	**Strongly agree**	☐

3. I try to make the most of my life		**4. I have plans to do enjoyable things for myself over the next few days**	
Strongly disagree	☐	**Strongly disagree**	☐
Disagree	☐	**Disagree**	☐
Agree	☐	**Agree**	☐
Strongly agree	☐	**Strongly agree**	☐

5. I feel like I am actively involved in life	
Strongly disagree	☐
Disagree	☐
Agree	☐
Strongly agree	☐

Section 11:

1. Please can you tell us about all the medications you have taken for your headache over **the last 4 weeks** (tablets, sprays, patches, liquids, injections).

   Paracetamol is given as an example of how we would like you to complete the table. Please remember to include both medications for treating a headache and anything you are using to prevent the headaches coming on.

   You may find it helpful to look on the packaging of your medication for some of the details. If you need to, please continue on the last page of this booklet.

Medication	Usual Dose	Number of times daily	Number of days used
Paracetamol 250mg	*2 tablets*	*2*	*8 days*

Section 12

The following pages contain questions about the expenses you have incurred and the services you have used in **the last 4 months**.

Some questions will seem more relevant than others, but please try to answer all the questions. If you are unsure about any answer then please include as much as you can remember.

1. Inpatient Care

1.1 In **the last 4 months,** have you been admitted to hospital because of your headache/ migraine experiences?

Yes ☐ No ☐ Go to question 2

1.2 **If yes**, please provide details of each hospital admission in the table below. *Heartlands Hospital is given as an example of how we would like you to complete the table.*

Name of hospital	**Private or NHS (please circle)**	**Length of stay** *(if you were admitted as a day case please insert zero)*
Heartlands Hospital	*Private / (NHS)*	*zero nights*
	Private / NHS	nights
	Private / NHS	nights
	Private / NHS	nights

2. Outpatient Care, Community Health and Social Care

2.1 In the **last 4 months,** have you made any visits to hospitals or clinics as an outpatient (for an appointment at a hospital but not admitted), or been in contact with your GP (including any appointments) or any other health/ social care professionals because of your headache/ migraine experiences?

Yes ☐ No ☐ Go to question 3

2.2 **If yes**, please provide details in the table below. *Please include all NHS and private care you paid for yourself or paid through private insurance. If the clinic or specialty is not listed, please feel free to write this in.*

	Have you used this service *Please tick*	**Number of visits** *Please enter the number of NHS and/ or private visits*	
		NHS	**Private**
Hospital emergency department			
Consultant (specialist headache or pain clinic)			
Radiology: MRI Scan			
Radiology: CT, X-Ray, ultrasound			
GP surgery visit			
GP home visit			
Practice nurse			
Occupational Therapist			
Counsellor			
Psychologist			
Social Worker			
Osteopath			
Chiropractor			
Acupuncturist			
Homeopath			
Botox			

Other: *please provide details*			

3. Additional Information

3.1 In the **last 4 months,** have you or your partner, relatives or friends incurred any additional costs as a result of your headache/ migraine experiences?

Yes ☐ No ☐ Go to question 4

If **yes**, please provide details in the following table:

	Additional cost to attend health/social care appointments *(please tick)*	**Cost to you**	**Cost to partner/ relatives/ friends**
Travel costs (e.g. bus fares)		£	£
Child care costs		£	£
Other: *please provide details*			

4. Time off work

4.1 In the **last 4 months**, have you taken any time off work (paid or unpaid) or lost any income because of your headache/ migraine experiences?

Yes ☐ No ☐

If **yes**, please provide details below:

Number of days lost: ☐

Income lost: **£** ☐

THANK YOU FOR FILLING IN THE QUESTIONNAIRE

Please return to the study team using the FREEPOST envelope provided (no postage stamp required)

If you have any difficulties with the questionnaire please contact the study team on: **02476 151 634** or via email: **chess@warwick.ac.uk**

WHAT WILL HAPPEN NEXT?

You will receive a further follow up questionnaires in the post in 4, 8 and 12 months' time. These will be your 4 month, 8 month and 12 month follow up questionnaires.

YOUR CONTACT DETAILS

Please could you contact the CHESS Study team on Tel: **02476 151 634** or via email: **chess@warwick.ac.uk** if any of your contact details have recently changed.