



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

## **Follow-up Questionnaire at 4 Months**

## 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

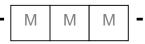
#### Please use a BLACK or BLUE pen. Please do not use a pencil and check that you have completed all sections.

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

Date completed:

D	-	Μ	Μ

D





### 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. IRAS ID: 215304



#### Section 1:

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 tick ( $\checkmark$ ) 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 hav	e a headache, ho	w often do you wis	sh you could lie dov	vn?				
□ Never	□ Rarely	□Sometimes	□Very often	□Always				
In the past 4 w your headache		nave you felt too ti	red to do work or d	aily activities because of				
□ Never	□ Rarely	□Sometimes	□Very often	□Always				
In the past 4 w	eeks, how often h	nave you felt fed u	p or irritated becau	se 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: Section 2:

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 ( $\checkmark$ ) 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*.

- In the <u>past 4 weeks</u>, how often have headaches <u>interfered</u> with how well you dealt with family, friends and others who are close to you? (Select only <u>one</u> response.)
  - $1^{\Box}$  None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5<sup>□</sup> Most of the time
  - 6 All of the time
- In the <u>past 4 weeks</u>, how often have headaches <u>interfered</u> with your leisure time activities, such as reading or exercising? (Select only <u>one</u> response.)
  - $1^{\Box}$  None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}\Box$  Most of the time
  - $_{6}\Box$  All of the time
- 3. In the <u>past 4 weeks</u>, how often have you had <u>difficulty</u> in performing work or daily activities because of headache symptoms? (Select only <u>one</u> response.)
  - $1^{\Box}$  None of the time
  - 2 A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5 Most of the time
  - 6□ All of the time

- In the <u>past 4 weeks</u>, how often did headaches <u>keep you</u> from getting as much done at work or at home? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5 Most of the time
  - $_{6}\Box$  All of the time
- In the <u>past 4 weeks</u>, how often did headaches <u>limit</u> your ability to concentrate on work or daily activities? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}\Box$  Most of the time
  - $_{6}\Box$  All of the time
- 6. In the <u>past 4 weeks</u>, how often have headaches <u>left you too tired</u> to do work or daily activities? (Select only <u>one</u> response.)
  - $1^{\Box}$  None of the time
  - $_{2}\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5□ Most of the time
  - $_{6}\Box$  All of the time

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

- 1 None of the time
- $_2\Box$  A little bit of the time
- $_{3}\Box$  Some of the time
- $_4\Box$  A good bit of the time
- $_{5}$  Most of the time
- 6 All of the time
- 8. In the <u>past 4 weeks</u>, how often have you had to <u>cancel</u> work or daily activities because you had a headache? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}$  Most of the time
  - 6□ All of the time
- In the <u>past 4 weeks</u>, how often did you <u>need help</u> 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 <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - 4 A good bit of the time
  - 5 Most of the time
  - 6 All of the time

- In the <u>past 4 weeks</u>, how often did you have to <u>stop</u> work or daily activities to deal with headache symptoms? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}\Box$  Most of the time
  - 6 All of the time
- 11. In the <u>past 4 weeks</u>, how often were you <u>not able to go</u> to social activities such as parties, dinner with friends, because you had a headache? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}\Box$  Most of the time
  - $6\Box$  All of the time
- In the <u>past 4 weeks</u>, how often have you <u>felt</u> fed up or frustrated because of your headaches? (Select only <u>one</u> response.)
  - $1^{\Box}$  None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5 Most of the time
  - $_{6}\Box$  All of the time

- In the <u>past 4 weeks</u>, how often have you <u>felt</u> like you were a burden on others because of your headaches? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}\Box$  Most of the time
  - $_{6}\Box$  All of the time
- 14. In the <u>past 4 weeks</u>, how often have you been <u>afraid</u> of letting others down because of your headaches? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - 4 A good bit of the time
  - 5 Most of the time
  - $_{6}\Box$  All of the time

#### Section 3:

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 ( $\checkmark$ ) 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

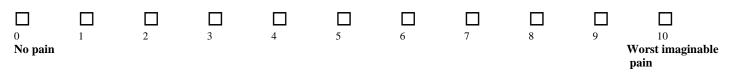
6. In the past seven days my sleep quality was:

Very poor	Poor	Fair	Good	Very good

#### Section 4:

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?



Participant ID No: Section 5:

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 ( $\checkmark$ ) the one box that best describes your answer.

1. In general, would you say your health is:



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

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

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 your physical health</u>?

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
а	Accomplished less than yo					
	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 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</u> <u>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
а	Accomplished less than yo					I
	would like		🗖	🗖	🗖	
b	Did work or other activities					
	less carefully than usual	🗖	🗖	🗖	🗖	

5. 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

6. These questions are about how you feel and how things have been with you <u>during the</u> <u>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
а	Have you felt calm and					I
	peaceful?					
b	Did you have a lot of energ	gy? 🗖				
с	Have you felt downhearted	ł				
	and low?	🗖	🗖		🗖	

7. During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional</u> <u>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

SF-12v2<sup>TM</sup> Health Survey © 1992-2002 by Health Assessment Lab, Medical Outcomes Trust and QualityMetric Incorporated. All rights reserved. SF-12® is a registered trademark of Medical Outcomes Trust. (IOOLA SF-12v2 Standard, English (United Kingdom) 8/02)

### Section 6:

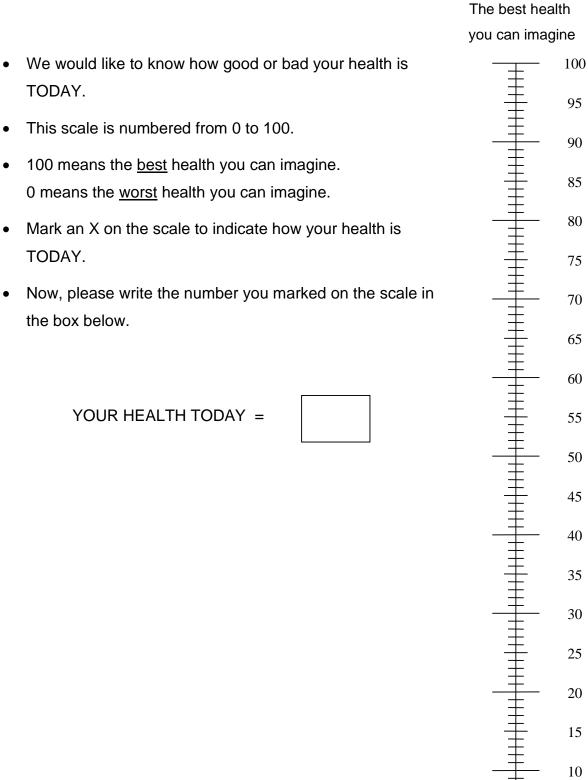
Under each heading, please tick ( $\checkmark$ ) the ONE box that best describes your health <u>TODAY</u>.

#### 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	
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



5 0 The worst health

you can imagine

#### Participant ID No: Section 7:

Only a little

Hardly at all

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

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 ( $\checkmark$ ) one box for each question.

I feel tense or "wound up"		I feel as if I am slowed down	Ì	
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		
-		1		
I still enjoy the things I used to en	joy	I get a sort of frightened feeling like 'butterflies' in the stomach		
Definitely as much		Not at all		
Not quite so much		Occasionally		

Quite often

Very often

I get a sort of frightened feeling as if awful if about to happen	something	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 sid	e 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		

HADS copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994.

Record form items originally published in Acta Psychiatrica Scandinavica 67, 361–70, copyright © Munksgaard International

Publishers Ltd, Copenhagen, 1983.

This edition first published in 1994 by nferNelson Publishing Company Ltd (now GL Assessment Ltd),

389 Chiswick High Road, London W4 4AL

GL Assessment Ltd is part of the Granada Learning Group

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		
l 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		

HADS copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994. Record form items originally published in Acta Psychiatrica Scandinavica 67, 361–70, copyright © Munksgaard International Publishers Ltd, Copenhagen, 1983. This edition first published in 1994 by nferNelson Publishing Company Ltd (now GL Assessment Ltd), 389 Chiswick High Road, London W4 4AL

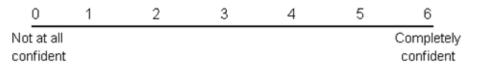
GL Assessment Ltd is part of the Granada Learning Group

#### Section 8:

Please rate how **confident** you are that you can do the following <u>things at present</u>, **despite the pain**. To indicate your answer circle one of the number on the scare 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**, <u>despite the pain</u>.

#### 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.

0	1	2	3	4	5	6
Not at all						Completely
confident						confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all						Completely
confident	t					confident

#### 7. I can cope with my pain without medication.

0	1	2	3	4	5	6
Not at all						Completely
confident						confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

#### Section 9:

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 ticking the response which best describes you now.

Please tick ( $\checkmark$ ) one box for each question.

1. I am doing interesting things in my	' life	2. Most days I am doing some of th really enjoy	ne things I
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 thir over the next few days	ngs for myself
Strongly disagree		Strongly disagree	
Disagree		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 10:

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 11

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?



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?

Go to question 4

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

	Additional cost to attend health/social care appointments <i>(please tick)</i>	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 <u>last 4 months</u>, have you taken any time off work (paid or unpaid) or lost any income because of your headache/ migraine experiences?

Yes		
Vac		
res		

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

£

Number of days lost:

Income	lost:

#### Section 12:

All information that is collected during the study will be kept confidential at all times and held in compliance with the Data Protection Act 1998. Your contact details will be held at Warwick Clinical Trials Unit for the purpose of the study team contacting you regarding the study processes, sending study questionnaires and study related materials.

A member of the study team may contact you if anything on your questionnaire is unclear or missing.

- I give permission for a member of the study team to contact me to discuss any unclear or missing data in the study questionnaires.
- I do not give permission for a member of the study team to contact me to discuss any unclear or missing data in the study questionnaires.

_			
Г			

### 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: <u>chess@warwick.ac.uk</u>

### WHAT WILL HAPPEN NEXT?

You will receive a further follow up questionnaires in the post in 4 and 8 months' time. These will be your 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: <u>chess@warwick.ac.uk</u> if any of your contact details have recently changed.





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

## Follow-up Questionnaire at 8 Months

## 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 compelting 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: <u>chess@warwick.ac.uk</u>

# 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	-	Μ	Μ	

D





### 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. IRAS ID: 215304



#### Section 1:

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 tick ( $\checkmark$ ) one box for each question.

When you hav	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 hav	e a headache, ho	w often do you wis	sh you could lie dov	vn?					
□ Never	□ Rarely	□Sometimes	□Very often	□Always					
In the past 4 w your headache	-	nave you felt too ti	red to do work or d	aily activities because of					
□ Never	□ Rarely	□Sometimes	□Very often	□Always					
In the past 4 w	veeks, how often h	nave you felt fed u	p or irritated becau	se 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					

Headache Impact Test<sup>™</sup> (HIT-6<sup>™</sup>) © 2001, 2015 QualityMetric Incorporated and the GlaxoSmithKline Group of Companies. All rights reserved. HIT-6<sup>™</sup> United States (English) Version

#### Section 2:

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 ( $\checkmark$ ) 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*.

- In the <u>past 4 weeks</u>, how often have headaches <u>interfered</u> with how well you dealt with family, friends and others who are close to you? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}$  Most of the time
  - $6\Box$  All of the time
- In the <u>past 4 weeks</u>, how often have headaches <u>interfered</u> with your leisure time activities, such as reading or exercising? (Select only <u>one</u> response.)
  - $_1 \Box$  None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}\Box$  Most of the time
  - 6 All of the time
- 3. In the <u>past 4 weeks</u>, how often have you had <u>difficulty</u> in performing work or daily activities because of headache symptoms? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - 3 Some of the time
  - $_4\Box$  A good bit of the time
  - 5 Most of the time
  - 6 All of the time

- In the <u>past 4 weeks</u>, how often did headaches <u>keep you</u> from getting as much done at work or at home? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}$  Most of the time
  - 6 All of the time
- In the <u>past 4 weeks</u>, how often did headaches <u>limit</u> your ability to concentrate on work or daily activities? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}$  Most of the time
  - 6 All of the time
- In the <u>past 4 weeks</u>, how often have headaches <u>left you too tired</u> to do work or daily activities? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\square$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5<sup>□</sup> Most of the time
  - 6□ All of the time

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

- 1 None of the time
- $_2\Box$  A little bit of the time
- $_{3}\Box$  Some of the time
- $_4\Box$  A good bit of the time
- $_{5}\Box$  Most of the time
- 6□ All of the time
- 8. In the <u>past 4 weeks</u>, how often have you had to <u>cancel</u> work or daily activities because you had a headache? (Select only <u>one</u> response.)
  - $1^{\Box}$  None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - 4 □ A good bit of the time
  - $_{5}$  Most of the time
  - $_{6}\Box$  All of the time
- In the <u>past 4 weeks</u>, how often did you <u>need help</u> 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 <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}\Box$  Most of the time
  - 6□ All of the time

- 10. In the <u>past 4 weeks</u>, how often did you have to <u>stop</u> work or daily activities to deal with headache symptoms? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}$  Most of the time
  - 6 All of the time
- 11. In the <u>past 4 weeks</u>, how often were you <u>not able to go</u> to social activities such as parties, dinner with friends, because you had a headache? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5<sup>□</sup> Most of the time
  - 6 All of the time
- In the <u>past 4 weeks</u>, how often have you <u>felt</u> fed up or frustrated because of your headaches? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5□ Most of the time
  - 6□ All of the time

- In the <u>past 4 weeks</u>, how often have you <u>felt</u> like you were a burden on others because of your headaches? (Select only <u>one</u> response.)
  - 1 None of the time
  - $2^{\Box}$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}$  Most of the time
  - $_{6}\Box$  All of the time
- 14. In the <u>past 4 weeks</u>, how often have you been <u>afraid</u> of letting others down because of your headaches? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - 3 Some of the time
  - $_4\Box$  A good bit of the time
  - 5<sup>□</sup> Most of the time
  - $_{6}\Box$  All of the time

#### Section 3:

To complete, please tick ( $\checkmark$ ) one box for each question.

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 ( $\checkmark$ ) 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	L

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

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

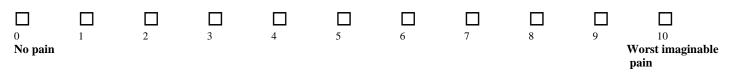
6. In the past seven days my sleep quality was:



#### Section 4:

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?



Participant ID No: Section 5:

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 ( $\checkmark$ ) the one box that best describes your answer.

1. In general, would you say your health is:



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

		Yes, limited a lot	Yes, limited a little	No, not limited at all
а	Moderate activities, such as moving a table, pushi a vacuum cleaner, bowling, or playing golf	° —		
b	Climbing several flights of stairs			

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 your physical health</u>?

		All of the time	Most of the time	Some of the time	A little of the time	None of the time
а	Accomplished less than yo					
	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 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
а	Accomplished less than yo	bu				I
	would like		🗖	🗖	🗖	
b	Did work or other activities					
	less carefully than usual	🗖	🗖	🗖	🗖	

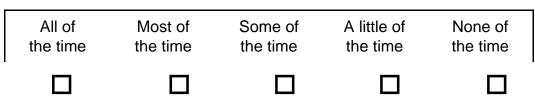
5. During the <u>past 4 weeks</u>, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely

6. These questions are about how you feel and how things have been with you <u>during the</u> <u>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
а	Have you felt calm and					I
	peaceful?	🗖	🗖	🗖	🗖	
b	Did you have a lot of energ	y? 🗖	🗖	🗖	🗖	
С	Have you felt downhearted					
	and low?	🗖	🗖	🗖	🗖	

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



#### Section 6:

Under each heading, please tick ( $\checkmark$ ) the ONE box that best describes your health <u>TODAY</u>.

#### 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	
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	

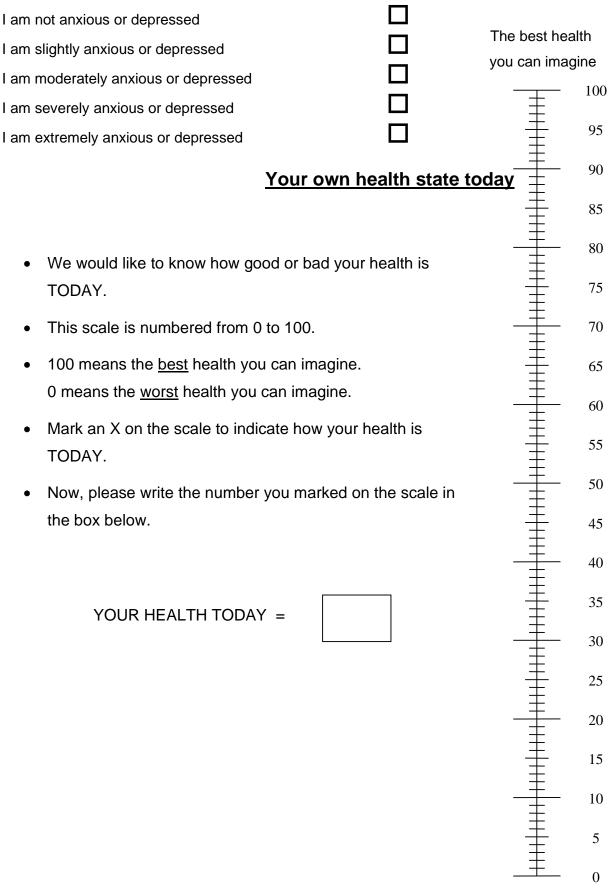
#### **USUAL ACTIVITIES** (e.g. work, study, housework, family or leisure activities)

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	

CHESS \_8 Month QA\_V3.1\_12.Jul.2018 IRAS ID: 215304

#### Participant ID No:





The worst health you can imagine

#### Section 7:

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

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 ( $\checkmark$ ) 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 en	јоу	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 awful if about to happen	something	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 o	of things	I feel restless as if I have to be on the move		
As much as I always could		Very much indeed		

Worrying thoughts go through my m	nind	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		
		1		
I can sit at ease and feel relaxed		I can enjoy a good book or radio or television programme		

	programme	
Definitely	Often	
Usually	Sometimes	
Not often	Not often	
Not at all	Very seldom	
Not quite so much now	Quite a lot	
Definitely not so much now	Not very much	
Not at all	Not at all	

HADS copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994. Record form items originally published in Acta Psychiatrica Scandinavica 67, 361–70, copyright © Munksgaard International Publishers Ltd, Copenhagen, 1983. This edition first published in 1994 by nferNelson Publishing Company Ltd (now GL Assessment Ltd), 389 Chiswick High Road, London W4 4AL GL Assessment Ltd is part of the Granada Learning Group

HADS copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994. Record form items originally published in Acta Psychiatrica Scandinavica 67, 361–70, copyright © Munksgaard International Publishers Ltd, Copenhagen, 1983. This edition first published in 1994 by nferNelson Publishing Company Ltd (now GL Assessment Ltd), 389 Chiswick High Road, London W4 4AL GL Assessment Ltd is part of the Granada Learning Group

#### Section 8:

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 scare 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**, <u>despite the pain</u>.

1. I can enjoy things, despite the pain.

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all						Completely
confident						confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

Participant ID No:

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

#### 7. I can cope with my pain without medication.

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

Participant ID No:

#### Section 9:

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 ticking the response which best describes you now. Please tick ( $\checkmark$ ) one box for each question.

1. I am doing interesting things in my life		2. Most days I am doing some of th really enjoy	ne things I
Strongly disagree		Strongly disagree	
Disagree		Disagree	
Agree		Agree	
Strongly agree		Strongly agree	
		1	
3. I try to make the most of my life		4. I have plans to do enjoyable thin over the next few days	igs for myself
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 10:

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

#### Participant ID No: Section 11

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 C	]

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	
163	

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 ar 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				

Participant ID No:

#### 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 <u>last 4 months</u>, 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: <u>chess@warwick.ac.uk</u>

### WHAT WILL HAPPEN NEXT?

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

### **YOUR CONTACT DETAILS**

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





## Follow-up Questionnaire at 12 Months

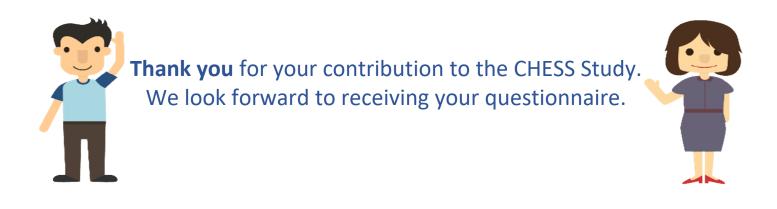
## **Confidential**

Please write the date the questionnaire was completed in the space provided below.



If you have any questions or difficulties with this questionnaire, please contact the CHESS study team on Tel: **02476 151 634** or via email: <u>chess@warwick.ac.uk</u>

CHESS Study Office, Warwick Clinical Trials Unit, University of Warwick, Gibbet Hill Road, Coventry, CV4 7AL



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 letter are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care. Page 1 of 22



Participant ID No: [INSERT DETAILS]								
<u>Section 1:</u> This questionnaire was designed to help you describe and communicate the way you feel and what you cannot do because of headaches.								
To complete, pl	To complete, please tick ( $\checkmark$ ) one box for each question.							
When you hav	e headaches, hov	v often is the pain	severe?					
□ Never	□ Rarely	□ Sometimes	□Very often	□Always				
	headaches limit y bllege, or social ac	-	sual daily activities	including household				
□ Never	□ Rarely	□Sometimes	□Very often	□Always				
When you hav	e a headache, ho	w often do you wis	sh you could lie dov	wn?				
□ Never	□ Rarely	□Sometimes	□Very often	□Always				
In the past 4 w your headache	-	nave you felt too ti	red to do work or d	aily activities because of				
□ 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 w daily activities	-	lid headaches limi	t your ability to cor	ncentrate on work or				
□ Never	□ Rarely	□Sometimes	□Very often	□Always				

Participant ID No: [INSERT DETAILS] Section 2:

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 ( $\checkmark$ ) 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**.

- In the <u>past 4 weeks</u>, how often have headaches <u>interfered</u> with how well you dealt with family, friends and others who are close to you? (Select only <u>one</u> response.)
  - $1^{\Box}$  None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5<sup>□</sup> Most of the time
  - 6 All of the time
- In the <u>past 4 weeks</u>, how often have headaches <u>interfered</u> with your leisure time activities, such as reading or exercising? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}\Box$  Most of the time
  - 6□ All of the time
- 3. In the <u>past 4 weeks</u>, how often have you had <u>difficulty</u> in performing work or daily activities because of headache symptoms? (Select only <u>one</u> response.)
  - $1^{\Box}$  None of the time
  - 2 A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5 Most of the time
  - 6□ All of the time

- In the <u>past 4 weeks</u>, how often did headaches <u>keep you</u> from getting as much done at work or at home? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}$  Most of the time
  - 6 All of the time
- In the <u>past 4 weeks</u>, how often did headaches <u>limit</u> your ability to concentrate on work or daily activities? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5 Most of the time
  - 6 All of the time
- In the <u>past 4 weeks</u>, how often have headaches <u>left you too tired</u> to do work or daily activities? (Select only <u>one</u> response.)
  - 1 None of the time
  - 2 A little bit of the time
  - $_{3}\Box$  Some of the time
  - 4 A good bit of the time
  - 5 Most of the time
  - 6 All of the time

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

- 1 None of the time
- $2^{\Box}$  A little bit of the time
- $_{3}\Box$  Some of the time
- $_4\Box$  A good bit of the time
- $_{5}$  Most of the time
- 6 All of the time
- 8. In the <u>past 4 weeks</u>, how often have you had to <u>cancel</u> work or daily activities because you had a headache? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5 Most of the time
  - 6□ All of the time
- In the <u>past 4 weeks</u>, how often did you <u>need help</u> 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 <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - 4 A good bit of the time
  - 5 Most of the time
  - 6 All of the time

- 10. In the <u>past 4 weeks</u>, how often did you have to <u>stop</u> work or daily activities to deal with headache symptoms? (Select only <u>one</u> response.)
  - 1 None of the time
  - $2^{\Box}$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}$  Most of the time
  - 6 All of the time
- 11. In the <u>past 4 weeks</u>, how often were you <u>not able to go</u> to social activities such as parties, dinner with friends, because you had a headache? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - 4 □ A good bit of the time
  - 5<sup>□</sup> Most of the time
  - 6 All of the time
- In the <u>past 4 weeks</u>, how often have you <u>felt</u> fed up or frustrated because of your headaches? (Select only <u>one</u> response.)
  - 1 None of the time
  - $_2\Box$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5 Most of the time
  - 6 All of the time

- 13. In the <u>past 4 weeks</u>, how often have you <u>felt</u> like you were a burden on others because of your headaches? (Select only <u>one</u> response.)
  - 1 None of the time
  - $2^{\Box}$  A little bit of the time
  - $_{3}\Box$  Some of the time
  - $_4\Box$  A good bit of the time
  - $_{5}$  Most of the time
  - 6□ All of the time
- In the <u>past 4 weeks</u>, how often have you been <u>afraid</u> of letting others down because of your headaches? (Select only <u>one</u> response.)
  - 1 None of the time
  - $2^{\Box}$  A little bit of the time
  - $_{3}\square$  Some of the time
  - $_4\Box$  A good bit of the time
  - 5 Most of the time
  - 6□ All of the time

To complete, please tick ( $\checkmark$ ) one box for each question.

1. Compared to twelve months ago, how would you rate your general health? Please tick the one box that best describes your answer.

Much better	
Somewhat better	
About the same	
Somewhat worse	
Much worse	

2. Compared to twelve months ago, how would you rate your headaches?

Much better	
Somewhat better	
About the same	
Somewhat worse	
Much worse	

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

Insert number of days										
	<b>4. Over the last 4 weeks on how many days have you used pain killers or triptans for your headaches/migraine?</b> Please do not include drugs used every day to prevent headaches/migraines coming on.									
	Insert nun	nber of da	ays							
5. On	those day	s you ha	id a hea	idache/mi	graine, o	n ave	erage how lo	ong did tł	ney la	ast?
	Insert nun	nber of ho	ours							
To con	nplete the ne	ext questio	ons, plea	se tick ( $\checkmark$ )	one box f	or eac	ch question.			
6. On those days you had a headache/migraine on average how severe were they?										
6. On	those days	you had	a heada	che/migra	ine on ave	erage	how severe	were they	?	
6. On 0 No pain	-	-		-		-	how severe w	-	<b>?</b> 9	10 Extremely severe pain
0 No pain	-	2 2	□ 3	4	□ 5	6 6	☐ 7	-		
0 No pain		2 2	□ <sup>3</sup> now fatig	4	D 5 you on av	6 6	☐ 7	-	9	
D No pain 7. In t	□ 1 he past sev	2 en days f A little	☐ 3 now fatiq e bit {	☐ 4 gued were Somewhat	□ ₅ you on av	6 6	□ 7 e?	8	9	
D No pain 7. In t	□ 1 he past sev Not at all	2 en days f A little	☐ 3 e bit s ] s my sle	☐ 4 gued were Somewhat	□ ₅ you on av	6 6	□ 7 e?	8	9	

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?



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 ( $\checkmark$ ) the one box that best describes your answer.

1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor

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

		Yes, limited a lot	Yes, limited a little	No, not limited at all
а	Moderate activities, such as moving a table, pushi a vacuum cleaner, bowling, or playing golf	Ŭ		
b	Climbing several flights of stairs			

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 your physical health</u>?

		All of the time	Most of the time	Some of the time	A little o the time	
а	Accomplished less than yo would like				-	
<b>L</b>						
b	Were limited in the <u>kind</u> of work or other activities					

4. 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</u> <u>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
а	Accomplished less than yo	bu				I
	would like		🗖	🗖	🗖	
b	Did work or other activities	i				
	less carefully than usual	🗖	🗖	🗖	🗖	

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

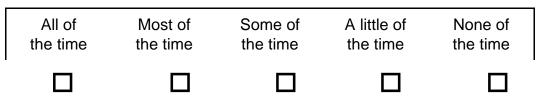
Not at all	A little bit	Moderately	Quite a bit	Extremely

6. These questions are about how you feel and how things have been with you <u>during the</u> <u>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
а	Have you felt calm and					I
	peaceful?	🗖	🗖	🗖	🗖	
b	Did you have a lot of energ	y? 🗖	🗖	🗖	🗖	
С	Have you felt downhearted					
	and low?	🗖	🗖	🗖	🗖	🗖

#### Participant ID No: [INSERT DETAILS]

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



#### Section 6:

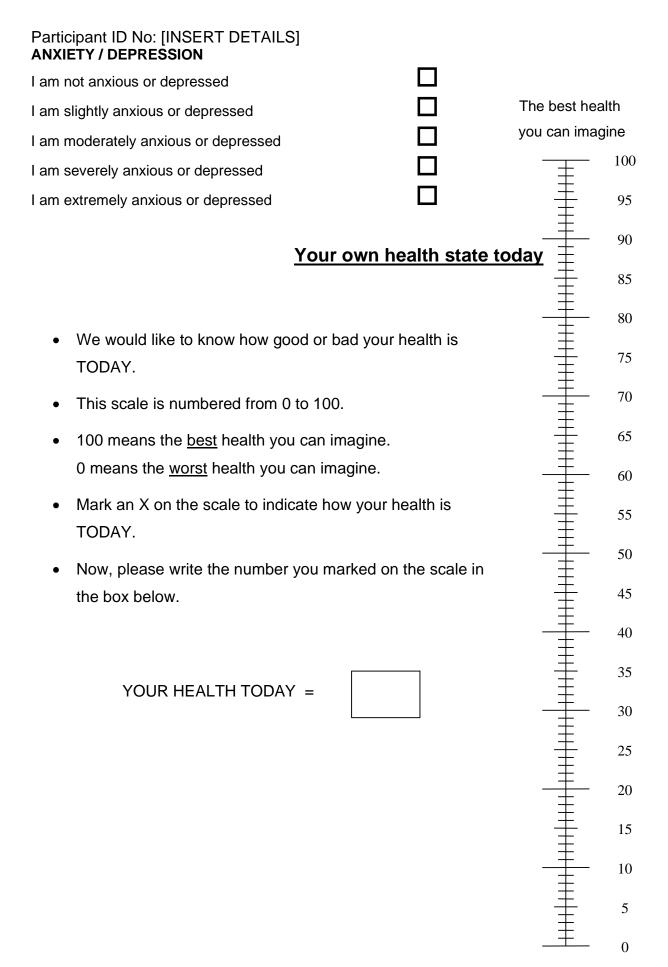
Under each heading, please tick ( $\checkmark$ ) the ONE box that best describes your health <u>TODAY</u>.

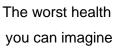
#### MOBILITY

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	
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	





#### Section 7:

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

Do not take too long over your replies: your imm	ediate 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 e	njoy	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 it awful if about to happen	fsomething	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		

Worrying thoughts go through m	y 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 pani	C	
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		
Definitely not so much now		Not very much		
Not at all		Not at all		

HADS copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994. Record form items originally published in Acta Psychiatrica Scandinavica 67, 361–70, copyright © Munksgaard International

Publishers Ltd, Copenhagen, 1983.

This edition first published in 1994 by nferNelson Publishing Company Ltd (now GL Assessment Ltd),

389 Chiswick High Road, London W4 4AL

GL Assessment Ltd is part of the Granada Learning Group

HADS copyright © R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994. Record form items originally published in Acta Psychiatrica Scandinavica 67, 361–70, copyright © Munksgaard International Publishers Ltd, Copenhagen, 1983.

This edition first published in 1994 by nferNelson Publishing Company Ltd (now GL Assessment Ltd),

389 Chiswick High Road, London W4 4AL

GL Assessment Ltd is part of the Granada Learning Group

#### Section 8:

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 scare 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**, <u>despite the pain</u>.

#### 1. I can enjoy things, despite the pain.

0	1	2	3	4	5	6
Not at all						Completely
confident						confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

Participant ID No: [INSERT DETAILS]

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

#### 7. I can cope with my pain without medication.

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

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

0	1	2	3	4	5	6
Not at all						Completely
confident						confident

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

0	1	2	3	4	5	6
Not at all confident						Completely confident

### Section 9:

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 ticking the response which best describes you now.

Please tick ( $\checkmark$ ) one box for each question.

1. I am doing interesting things in my life		2. Most days I am doing some of t really enjoy	he things I
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 the over the next few days	hings for myself
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 10:

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 11

#### 1. Additional costs

In the **last 4 months**, have you or your partner, relatives or friends incurred any additional costs, such as travel costs, to attend health or social care appointments as a result of your headache/ migraine experiences?

Yes	

No 🔲 Go to question 2

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			

#### 2. Time off work

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

No	
----	--

If yes, please provide details below:

£

Number of days lost:	
----------------------	--

		L

CHESS \_12 Month QA\_V3.3 \_19.Sep.2019 IRAS ID: 215304

#### Participant ID No: [INSERT DETAILS] Section 12:

- 1. Thank you for completing a headache diary for the study (either via a Smartphone App or a paper version). If you would like to receive a summary of this information indicate below and we will provide this to you as soon as possible.
  - Yes I would like to receive a summary of the headache diary
  - No I would not like to receive a summary of the headache diary
- 2. We may want to contact you again to find out how you are managing with your headaches. If you are happy for the CHESS team to contact you again please indicate below.
  - I give permission for the study team to contact me again.
  - I do not give permission for the study team to contact me again.
- 3. If you would like to receive a summary of the CHESS Study results please indicate below, we will provide this to you as soon as this information is available.
  - Yes I would like to receive a summary of the CHESS Study results
  - No I would not like to receive a summary of the CHESS Study results

# Many thanks for completing the final questionnaire for the CHESS Study, we greatly appreciate your time in completing the questionnaires for the study.

#### 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: <a href="mailto:chess@warwick.ac.uk">chess@warwick.ac.uk</a>

### YOUR CONTACT DETAILS

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

rv

