COSH Delphi Study



Final report - rounds one to three

Clinvivo Limited May 22, 2018

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Methods

1.1 Round one sampling, recruitment, and material

The COSH Delphi study team provided Clinvivo with a list of public participants and health care professionals/academic participants of invitees and e-mail invitation wording (see Appendix). Clinvivo sent this along with a personalised link to the first round of delphi studies on chronic migraine or tension-type headache and episodic migraine or tension-type headache, which ran from January 11, 2018 to January 25, 2018. Public participants were asked to choose whether or not they wanted to complete the round on chronic migraine or tension-type headache, or episodic migraine or tension-type headache, and health care professional/academic participants were asked to complete both chronic and episodic rounds. Reminders to complete the round(s) were sent by Clinvivo on January 18, 2018 and January 24, 2018.

Details of Round 1 as it appeared to panellists, is provided in the appendix. Data from the round were sent directly to a secure SQL database using our software. Once the round had closed we exported these data in CSV format and quantitative data were read into Stata (version 15.0) for analysis. Qualitative data were exported and formatted into an Excel file for examination by the COSH team.

1.2 Statistical analysis

First, histograms were used to show distributions for all ratings in Round 1, for chronic migraine and headache, and separately for episodic. In the histograms the panel's data are all analysed together and then other methods are described that were used to show results separately by sub-panel type (i.e. public participant or clinical/academic participants) as well as together. To assess disagreement and appropriateness within an a panel/sub-panel, we used the Research ANd Development (RAND)/ University of California Los Angeles (UCLA) appropriateness method.¹ This method was initially developed in the mid 1980s as part of the RAND Corporation/UCLA Health Services Utilisation Study to enable the measurement of the overuse and under-use of medical and surgical procedures.^{1,2} It involves calculating the median score, the inter-percentile range (IPR) (30th and 70th), and the inter-percentile range adjusted for symmetry (IPRAS), for each item being rated.

1.2.1 The RAND/UCLA appropriateness method

A brief history of the development of this method is that Fitch *et al* first explored using the IPR alone in an attempt to develop a method that reproduced 'classic' RAND definitions on panels that are multiples of three (which was typical in RAND's early consensus studies), but could also be extended to larger panel sizes. In cases when agreement was good, the IPR should be narrow and in cases where there was disagreement, the IPR should be wide. However, an in-depth examination of the cases of disagreement identified by the IPR led to the discovery that when the ratings were symmetric the IPR required to label an indication as disagreement was smaller than when the ratings were asymmetric with respect to the middle. To overcome this, they developed the IPRAS, which includes a correction factor for asymmetry (equation 1.1).

$$IPRAS = IPRr + (AI \times CFA) \tag{1.1}$$

Where IPRr is the inter-percentile range required for disagreement when perfect symmetry exists, AI is the asymmetry index, and CFA is the correction factor for asymmetry.

The IPRAS is the threshold beyond which the IPR for a particular item indicates disagreement. Using the IPRAS and the IPR to judge disagreement, reproduces 'classic' RAND definitions when applied to panels made up of multiples of three, but can also be applied to panels of any size.¹ Variations on the stringency of definitions of disagreement exist,² but similar examples of Delphi studies in health services research have used the classic definition.^{3–8}

In equation 1.1, the optimal values for IPRr and CFA were derived following empirical work on a 9-point scale.¹ Fitch *et al* found that using values of 2.35 and 1.5 best reproduced the 'classic' definitions of agreement. We used these values in this analysis. We calculated AI as the distance between the central point of the IPR $(\frac{p30+p70}{2})$ and the central point of the scale (*i.e.* 5 on a 1-9 point scale.).

The IPRAS threshold is dependent on the symmetry of ratings about the median. Thus, each item requires a different IPRAS to be calculated. Consequently, the i^{th} indication is rated with disagreement if the $IPR_i > IPRAS_i$. In previous Delphi studies some have calculated the ratio of these: the disagreement index.^{3–5} If the disagreement index is less than 1.0, it indicated there is no disagreement for the item in question. However, this is problematic in terms of interpretation because in the case that the IPR is zero, then the ratio is zero, which can cause confusion. For this reason we present IPR and IPRAS values and simply comment on whether or not there is disagreement (*i.e.* when $IPR_i > IPRAS_i$).

Judgement of appropriateness (or importance) also follows the classic RAND definitions, and this is assessed simply as whether the median rating falls between 1 to 3 (inappropriate/unimportant), 4 and 6 (unsure), or 7 and 9 (appropriate/important).

1.2.2 Alternative methods

We have also calculated and included mean as per your request, but note that you might consider the median more useful as the distributions (as you will see from the histograms) are seldom normal.

In case you would prefer to retain items where more than 70% of the panel have rated an item as 7 or more (as is becoming popular in some other COS Delphi studies) then you may use the p30 statistic for this purpose (*i.e.* the 30th centile; so if the p30 for an item is 7 then 70% of the panel rated the item importance at 7 or more.

1.2.3 Bespoke grading system

Finally, we have included a bespoke grading system as discussed to improve separation and to indicate more easily where participants on a panel who can be grouped by their backgrounds may not see eye-to-eye. Neither the RAND/UCLA method, nor the '70% rating over X' is inherently equipped to take this into account. We hope that you find this an appropriate and useful way to analyse your modified delphi and makes your job of choosing what items to retain in Round 2 somewhat easier. You asked for the data to be analysed as two sub-panel groups: public participants and clinician/academic (i.e. treating the clinicians and academics as the same sub-panel group). Thus, items were graded as follows:

- A^{**} if in both sub-panel groups the median rating is 9;
- A* if in both sub-panel groups $\geq 70\%$ rate an item ≥ 7 ;
- A if in both sub-panel groups the median item rating is ≥ 7 ;

- B if the median rating for an item is ≥ 7 in only one sub-panel group;
- C if the if the whole panel median rating is ≥ 4 and ≤ 6 and no sub-panel group median rating is ≥ 7;
- D if the whole panel median is ≥ 1 and ≤ 3 and no sub-panel group median rating is ≥ 7 ;

We note that this approach was loosely based on one taken by Orbai *et al*, who used a NGT approach to consensus, with modifications made for this project specifically by Haywood and Froud.^{9,10}

1.3 Qualitative analysis

Clinvivo was not contracted to undertake an analysis of qualitative data. The raw qualitative data have been transferred to you.

 $\mathbf{2}$

Round one results

Of the 96 people invited to be public participants, of which a priori 53 were identified to be invited into the chronic round, 40 to the episodic round (and three were given a choice), we received 42 public responses for the chronic part of the round and 34 for the episodic part of the round.

Of the 64 health care professionals who were invited to complete both chronic and episodic parts of the round, we received 33 responses from health care professionals to the chronic part and 31 to the episodic part.

Thus, we received 75 completed responses for the chronic migraine or tension-type headache part in total and 65 completed responses for the episodic migraine or tension-type headache part.

2.1 Demographics

Tables 2.1, 2.2, 2.3, and 2.4 show details of gender, and age in the chronic and episodic parts of the round. Figures 2.1, 2.2, 2.3, and 2.4 show the relative proportions of the participants' countries of origin.

	Professional $(\%)$	Public (%)	Total
Female Male	$\frac{15\ (27.3)}{18\ (90.0)}$	$\begin{array}{c} 40 \ (72.7) \\ 2 \ (10.0) \end{array}$	$55 (100) \\ 20 (100)$
Total	33 (44.0)	42 (56.0)	75 (100)

Table 2.1: Gender in the chronic round, by background

	Professional (%)	Public (%)	Total
Female	15(34.1)	29~(65.9)	44 (100)
Male	16(76.1)	5(23.8)	21 (100)
Total	31 (47.7)	34(52.3)	65(100)

 Table 2.2: Gender in the episodic round, by background

 Table 2.3: Age band in the chronic round, by background

Age band	Professional frequency $(\%)$	Public frequency (%)	Total
18-25	0 (0)	3(7.1)	3(4)
26-35	1(3.0)	9(21.4)	10(13.3)
36-45	5(15.2)	17 (40.5)	22 (29.3)
46-55	19 (57.6)	7(16.7)	26(34.7)
56-65	5(15.2)	4 (9.5)	9(12.0)
≥ 66 years	3(9.1)	2(4.8)	5(6.7)
Total	33 (100)	42 (100)	75(100)

Ageband	Professional frequency $(\%)$	Public frequency $(\%)$	Total
18-25	1(3.2)	1 (2.9)	1(1.5)
26-35	5(16.1)	3(8.8)	4(6.6)
36-45	17(54.8)	5(14.7)	10(15.4)
46-55	6(19.4)	10(29.4)	27 (41.5)
56-65	2(6.5)	11 (32.4)	17(26.1)
≥ 66 years	3(9.1)	4 (11.8)	6(9.2)
Total	31 (100)	34 (100)	65~(100)

 Table 2.4:
 Age band in the episodic round, by background

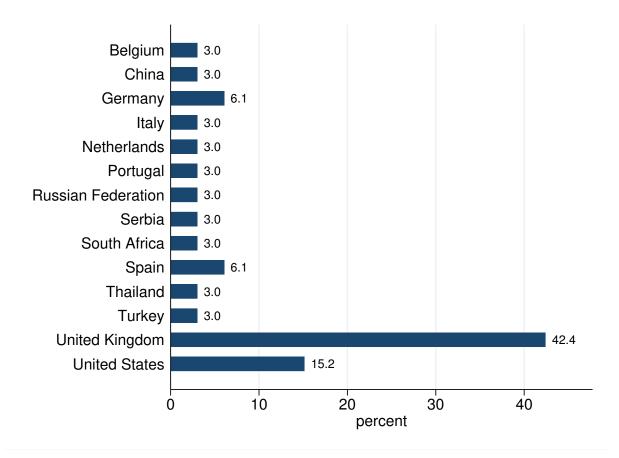


Figure 2.1: Plot of professional participant frequency, by country (chronic) - The figure shows a plot of professional participants country of origin in the chronic round

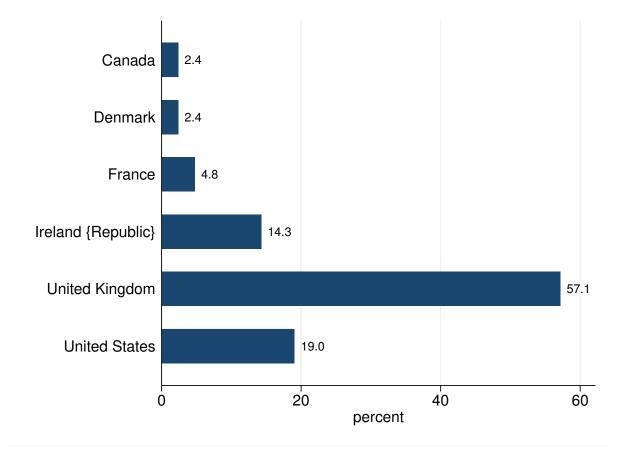


Figure 2.2: Plot of public participant frequency, by country (chronic) - The figure shows a plot of public participants country of origin in the chronic round

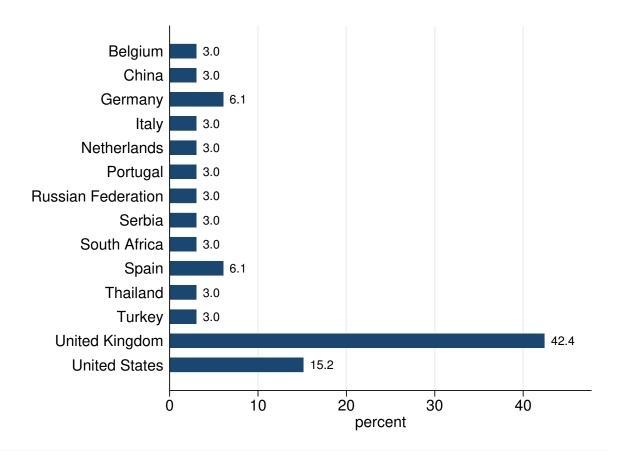


Figure 2.3: Plot of professional participant frequency, by country (episodic) - The figure shows a plot of professional participants country of origin in the chronic round

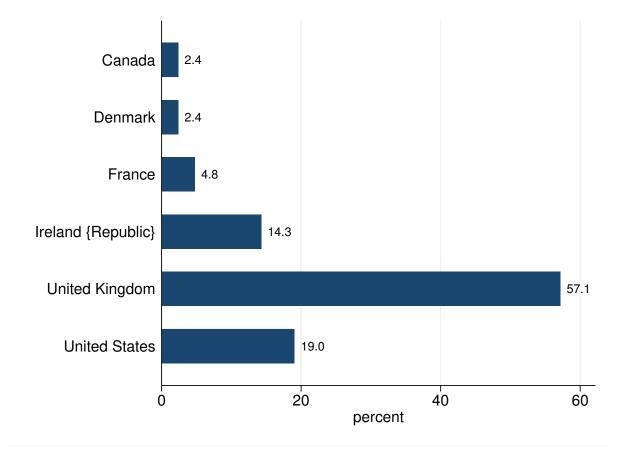


Figure 2.4: Plot of public participant frequency, by country (episodic) - The figure shows a plot of public participants country of origin in the chronic round

Background	Number selecting	Mean service [years] (SD)
Clinician	6	26.2(7.8)
Neurologist	13	20.2(7.0)
Neurologist Special Interest	10	16.0 (9.5)
GP special interest	1	12 (N/A)
Nurse Specialist	4	6.5 (3.7)
Psychologist	0	N/A
Pharmacist	0	N/A
Chiro/Osteo/Physio	2	11.5 (6.3)
Alternative Therapy	0	N/A

 Table 2.5: Professional backgrounds and duration of service for health-care professionals with a specific interest in migraine/headache (chronic round)

Table 2.6: Professional backgrounds and duration of service for health-care professionals with a specific interest in migraine/headache (episodic round)

Background	Number selecting	Mean service [years] (SD)
Clinician	5	26.8(9.9)
Neurologist	12	19.08(6.1)
Neurologist Special Interest	11	15.8 (9.1)
GP special interest	0	0 (N/A)
Nurse Specialist	3	6.3(5.1)
Psychologist	0	N/A
Pharmacist	0	N/A
Chiro/Osteo/Physio	1	7.0 (N/A)
Alternative Therapy	0	N/A

Background	Frequency reporting	Mean service [years] (SD)
Health Economist	2	7.5(3.5)
Clinical Academic	8	16.4(8.0)
Other health professional academic	2	20(21.2)
Clinical Trialist	9	11.5(7.7)
Systematic Reviewer	6	17.3(11.2)
Measurement Expert	7	17.3 (9.1)
Journal editor / member of editorial board	7	10.1 (7.7)
Research - other	7	18.1 (9.6)

Table 2.7: Professional backgrounds and duration of service for health-related research (chronic)

Table 2.8: Professional backgrounds and duration of service for health-related research (episodic)

Background	Frequency reporting	Mean service [years] (SD)
Health Economist	1	10.0 (N/A)
Clinical Academic	9	17.4 (8.5)
Other health professional academic	0	0 (N/A)
Clinical Trialist	8	13.3(7.2)
Systematic Reviewer	5	18.6(13.4)
Measurement Expert	8	17.1 (8.5)
Journal editor / member of editorial board	9	9.2(6.3)
Research - other	10	18.3 (8.6)

Background	Frequency reporting	Mean service [years] (SD)
Contribute to headache-related guideline development	11	9.3 (3.6)
Health service manager/provider/commissioner/	1	2 (N/A)
Member of national funding body	1	10 (N/A)

 Table 2.9:
 Professional backgrounds and duration of service for health policy related activities (chronic)

 Table 2.10:
 Professional backgrounds and duration of service for health policy related activities

 (episodic)
 (episodic)

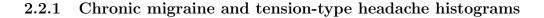
Background	Frequency reporting	Mean service [years] (SD)
Contribute to headache-related guideline development	14	7.4(3.9)
Health service		
manager/provider/commissioner/	2	4.5(3.5)
Member of national funding body	0	0 (N/A)

Tables 2.5, 2.6, 2.7, 2.8, 2.9, and 2.10 shows the frequency of participants identifying with the presented check-boxes regarding background details, and the average duration in role. Please refer to the qualitative data for the qualitative descriptions provided for 'other'. Please note that it appears that this field appearing underneath the heading for 'Health-Related Activities', and this was not identified in piloting. Thus, the qualitative responses provided appear to actually relate to health-related activities rather than to listing other research activities. Please accept our apologies for not spotting this ourselves during in piloting and please consider asking again for details about 'other research' in Round 2.

Please also note that among the qualitative data are the public participants descriptions of their type of headache/migraine (see v107 in the chronic data set, or v106 in the episodic data set. Variables may also be identified through using their field codes, which are printed next to the questions in the appendix).

2.2 Histograms of round one responses

Histograms follow showing the distributions of item ratings by the panel, by round focus (i.e. chronic/episodic) and by domain. You may find it helpful to look at these in conjunction with the print out of the round one as it was seen by participants, which is in the appendix. Item numbers will then be immediately referable.



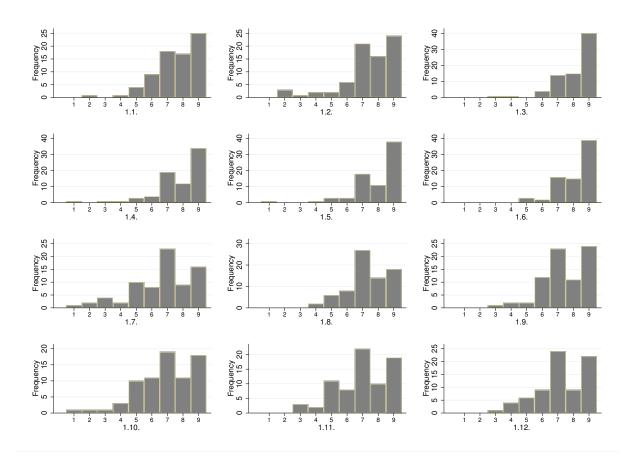


Figure 2.5: Table of histograms for physical symptom items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance

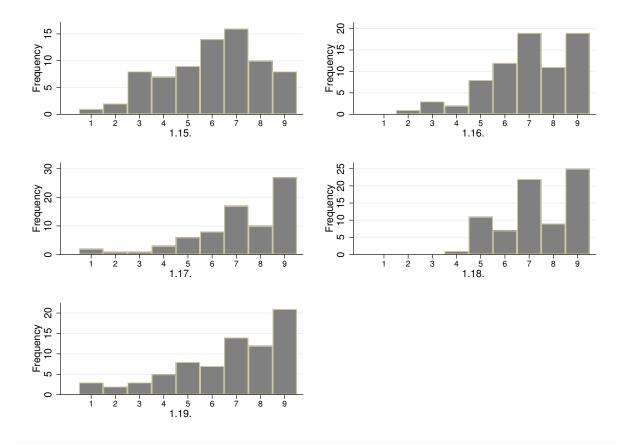


Figure 2.6: Table of histograms for emotional well-being symptom items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance

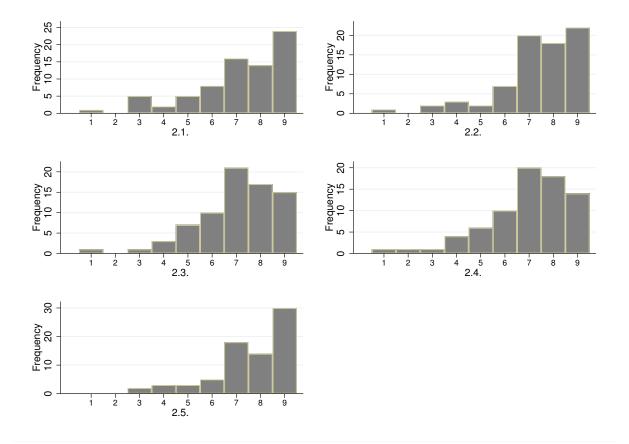


Figure 2.7: Table of histograms for activities of daily living life impact items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance

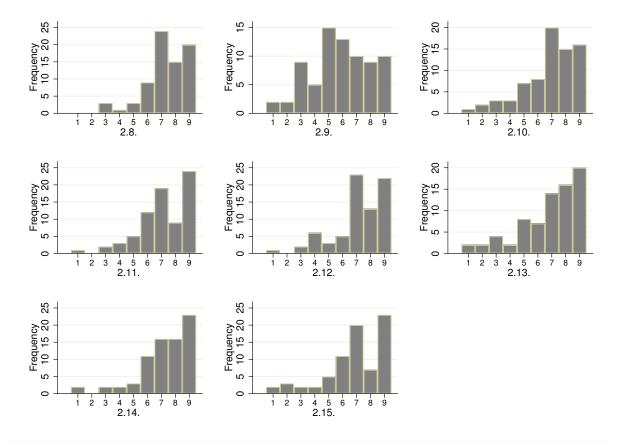


Figure 2.8: Table of histograms for emotional well-being life impact items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance

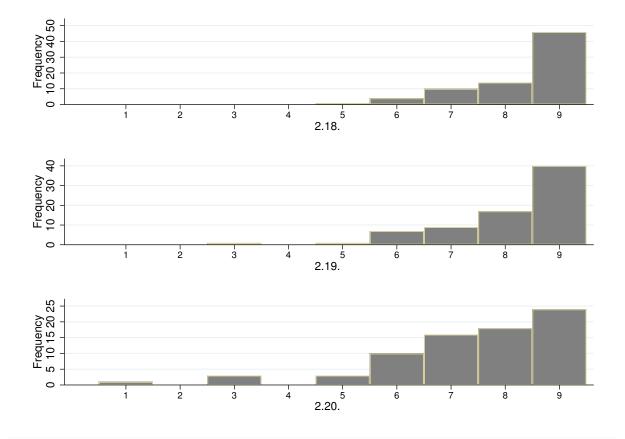


Figure 2.9: Table of histograms for work education life impact items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance

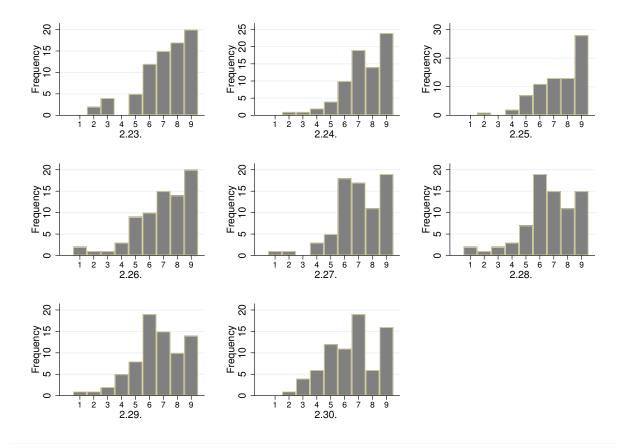


Figure 2.10: Table of histograms for social life impact items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance

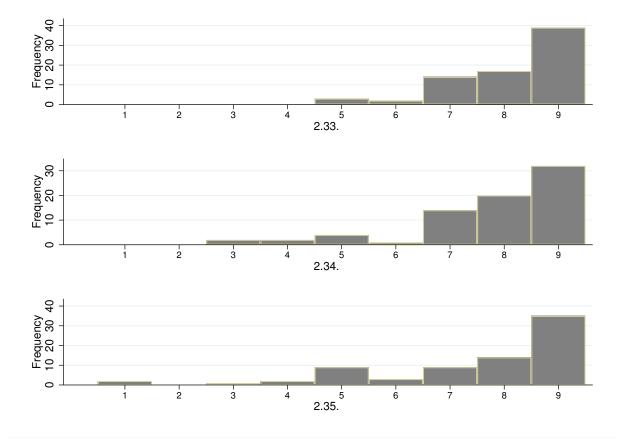


Figure 2.11: Table of histograms for overall health life impact items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance

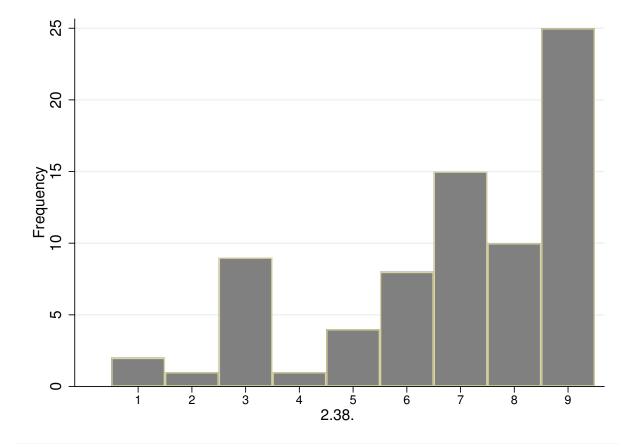


Figure 2.12: Table of histograms for environmental life impact items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance

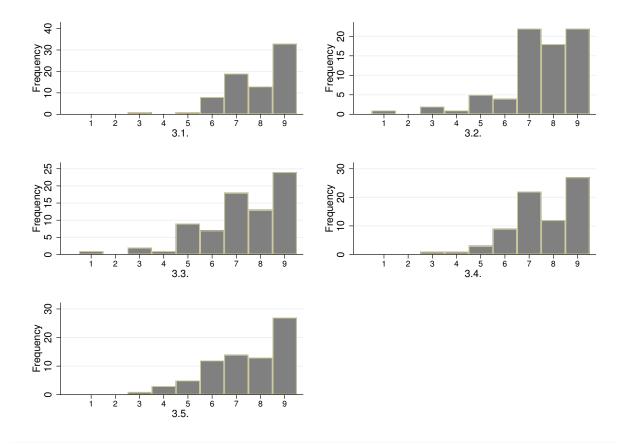


Figure 2.13: Table of histograms for aspects of treatment effectiveness items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance

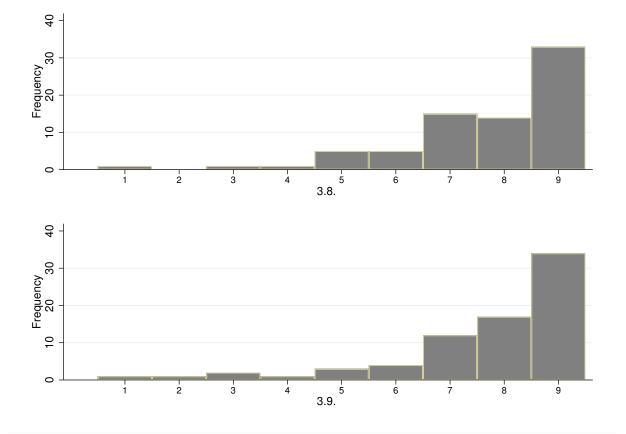


Figure 2.14: Table of histograms for medication use items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance

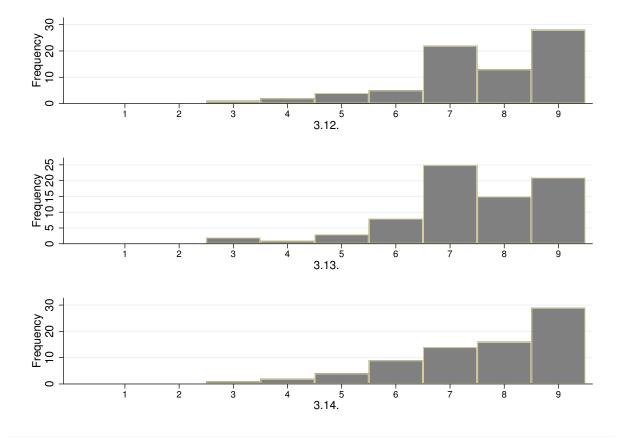


Figure 2.15: Table of histograms for financial impact items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance

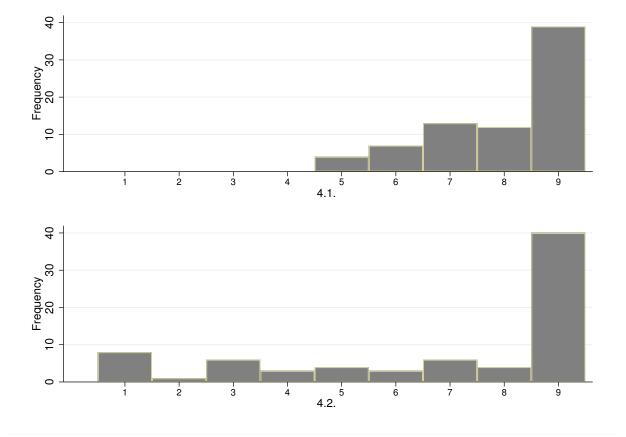
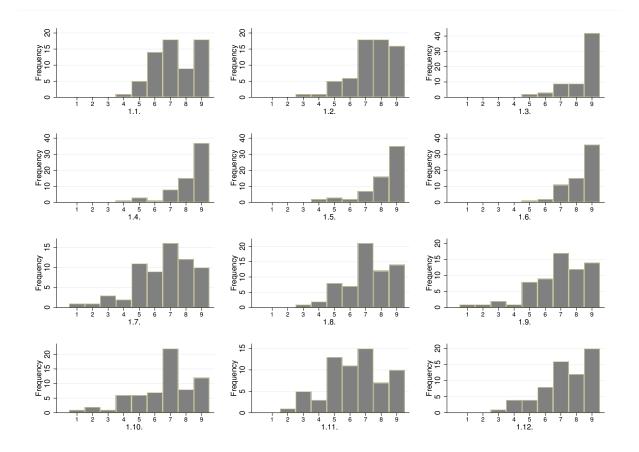


Figure 2.16: Table of histograms for adverse event items (chronic) - The figure shows a table of histograms for whole-panel ratings of importance



2.2.2 Episodic migraine and tension-type headache histograms

Figure 2.17: Table of histograms for physical symptom items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

2.3 Round one ratings by item and sub-panel groups

2.3.1 Chronic migraine and tension-type headache

Table 2.11 shows mean, median item ratings, inter-percentile range, inter-percentile range adjusted for asymmetry, appropriateness, and disagreement, for the whole panel and for each chronic migraine and tension-type headache item in Round 1 (See appendix for item look-up). Among the whole panel there was no evidence of disagreement on any items were rated important apart from two which were rated unsure. Table 2.12 shows the same results for the health care professionals/academics only. This sub-panel group disagreed on two items and were unsure about five items. The rest they rated as important. Table 2.13 shows the results for the public

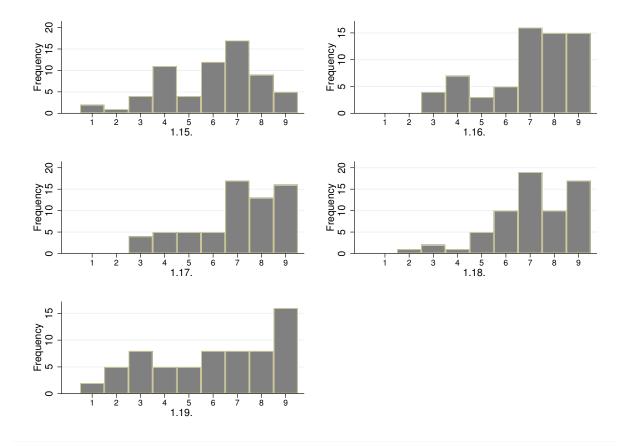


Figure 2.18: Table of histograms for emotional well-being symptom items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

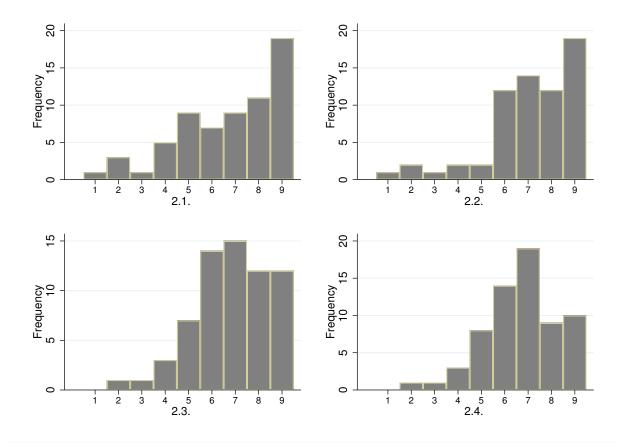


Figure 2.19: Table of histograms for activities of daily living life impact items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

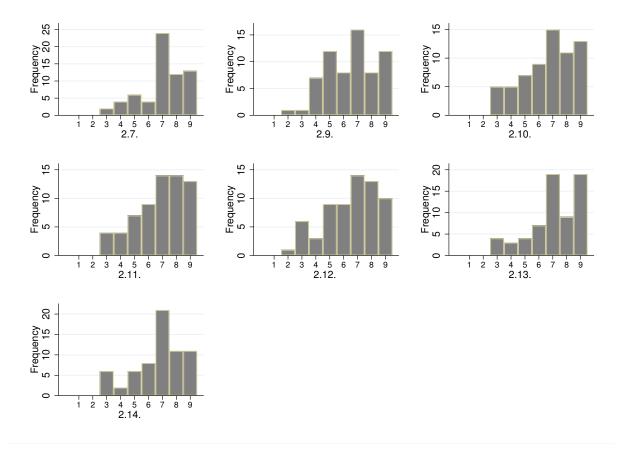


Figure 2.20: Table of histograms for emotional well-being life impact items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

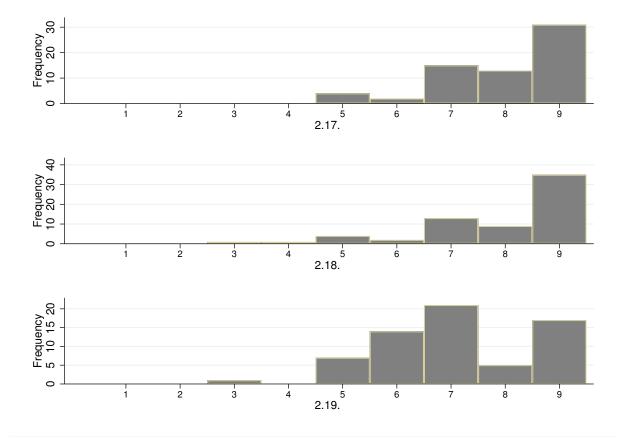


Figure 2.21: Table of histograms for work education life impact items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

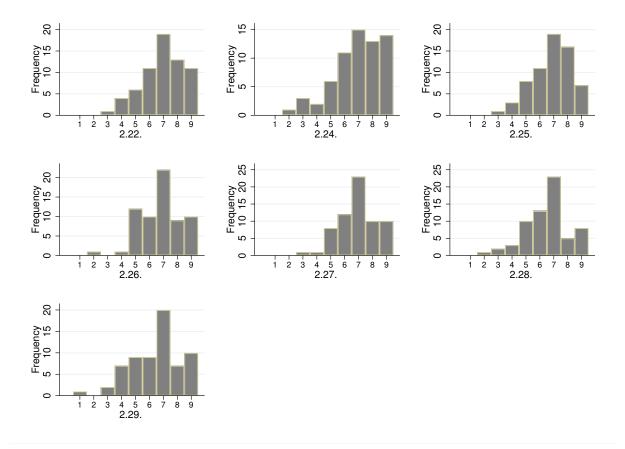


Figure 2.22: Table of histograms for social life impact items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

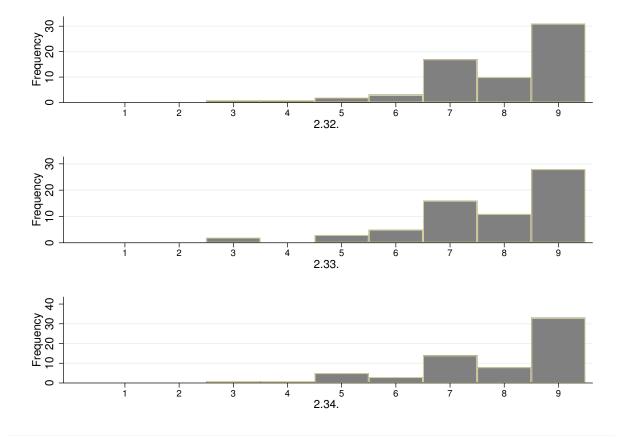


Figure 2.23: Table of histograms for overall health life impact items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

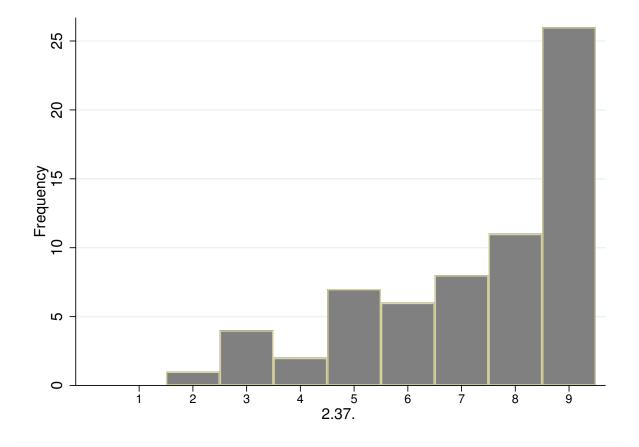


Figure 2.24: Table of histograms for environmental life impact items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

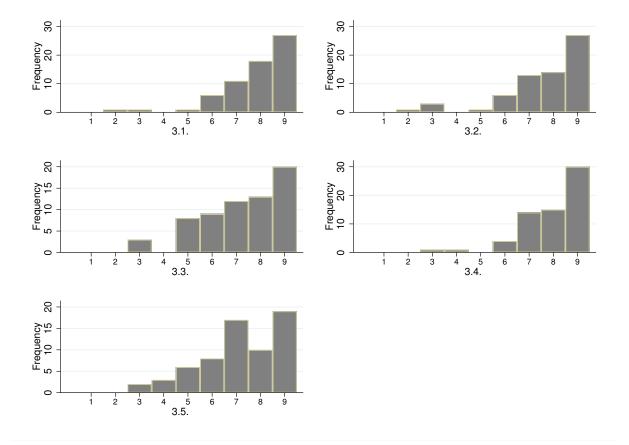


Figure 2.25: Table of histograms for aspects of treatment effectiveness items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

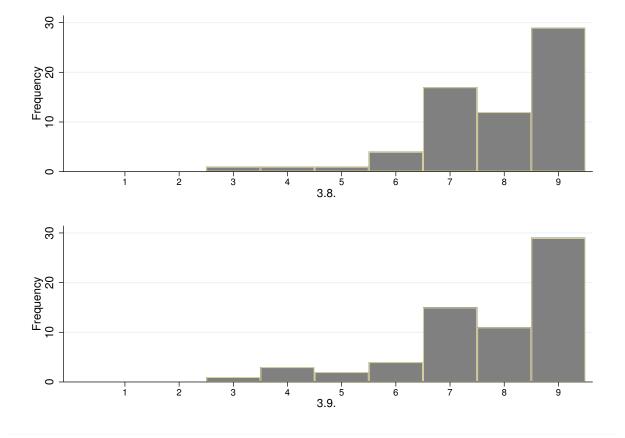


Figure 2.26: Table of histograms for medication use items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

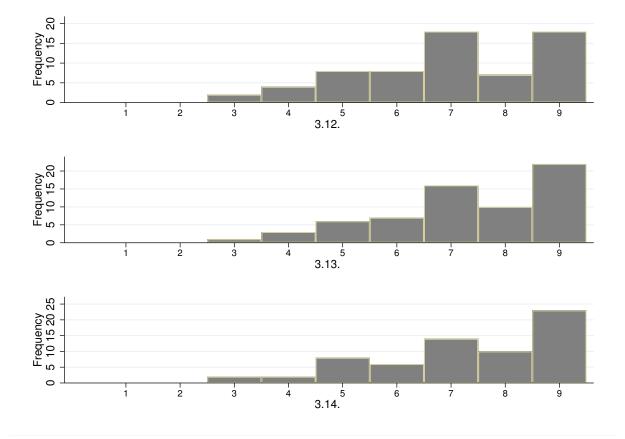


Figure 2.27: Table of histograms for financial impact items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

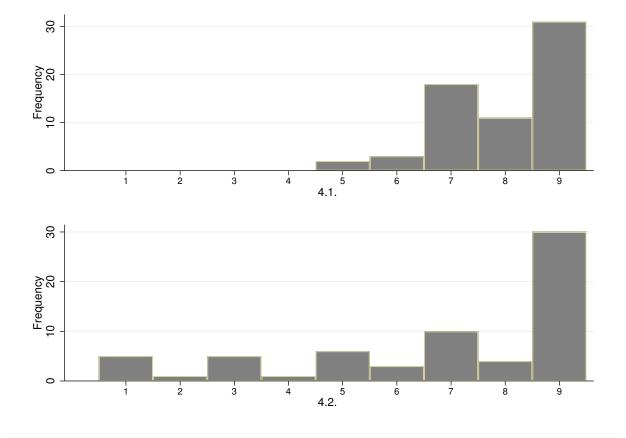


Figure 2.28: Table of histograms for adverse event items (episodic) - The figure shows a table of histograms for whole-panel ratings of importance

participants only. They thought that all the items were important apart from two, on which they were unsure, and did not disagree on any items. Table 2.14 shows that among the chronic items graded, using the bespoke grading method three items were rated A^{**}; 21 were rated A^{*}; 27 were rated A; 5 were rated B; and one was rated C.

2.3.2 Episodic migraine and tension-type headache

Table 2.15 shows mean, median item ratings, inter-percentile range, inter-percentile range adjusted for asymmetry, appropriateness, and disagreement, for the whole panel and for each episodic migraine and tension-type headache item in Round 1 (See appendix for item look-up). Among the whole panel there were four items that were rated unsure; the remainder were rated as important. There was disagreement on one item. Table 2.16 shows the same results for the health care professionals/academics only. This sub-panel group disagreed on one item and were unsure about 10 items; the rest they rated as important. Table 2.17 shows the results for the public participants only. They thought that all the items were important apart from two, on which they were unsure, and did not disagree on any items. Table 2.14 shows that among the chronic items graded, using the bespoke grading method four items were rated A^{**} ; 14 were rated A^* ; 27 were rated A; 10 were rated B; and one was rated C.

Important note

Please remember to review the qualitative data fields for each domain for details of the participants comments and suggestions for additional items. To distinguish between public and health care professionals/academics, please note that under the variable 'type' in the data set type 0 are the health care professionals/academics and type 1 are the public participants. Alternatively, public participants may be identified from their enrol codes, which begin with a 'p'.

Item	Importance	Disagreement	Mean	Median	P_{30}	P ₇₀	IPR	IPRAS
1.1.	Important	No	7.6	8	7	9	2	6.85
1.2.	Important	No	7.4	8	7	9	2	6.85
1.3.	Important	No	8.1	9	8	9	1	7.6
1.4.	Important	No	7.8	8	7	9	2	6.85
1.5.	Important	No	7.9	9	7	9	2	6.85
1.6.	Important	No	8.1	9	8	9	1	7.6
1.7.	Important	No	6.7	7	6	8	2	5.35
1.8.	Important	No	7.3	7	7	8	1	6.1
1.9.	Important	No	7.4	7	7	9	2	6.85
1.10.	Important	No	6.9	7	6	8	2	5.35
1.11.	Important	No	7	7	6	8	2	5.35
1.12.	Important	No	7.2	7	7	8	1	6.1
1.15.	Unsure	No	6	6	5	7	2	3.85
1.16.	Important	No	7	7	6	8	2	5.35
1.17.	Important	No	7.2	7	7	9	2	6.85
1.18.	Important	No	7.4	7	7	9	2	6.85
1.19.	Important	No	6.7	7	6	8	2	5.35
2.1.	Important	No	7.2	8	7	9	2	6.85
2.2.	Important	No	7.4	8	7	8	1	6.1
2.3.	Important	No	7.1	7	7	8	1	6.1
2.4.	Important	No	7	7	6	8	2	5.35
2.5.	Important	No	7.6	8	7	9	2	6.85
2.8.	Important	No	7.3	7	7	8	1	6.1
2.9.	Unsure	No	5.8	6	5	7	2	3.85
2.10.	Important	No	6.8	7	6	8	2	5.35
2.11.	Important	No	7.2	7	6	9	3	6.1

Table 2.11: Appropriateness, disagreement, median item ratings, inter-percentile range, and interpercentile range adjusted for asymmetry (whole panel; chronic migraine or tension-type headache)

Item	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
2.12.	Important	No	7.2	7	7	8	1	6.1
2.13.	Important	No	6.9	7	6	8	2	5.35
2.14.	Important	No	7.3	8	7	9	2	6.85
2.15.	Important	No	6.9	7	6	9	3	6.1
2.18.	Important	No	8.3	9	8	9	1	7.6
2.19.	Important	No	8.1	9	8	9	1	7.6
2.20.	Important	No	7.4	8	7	9	2	6.85
2.23.	Important	No	7.1	7	6	8	2	5.35
2.24.	Important	No	7.4	8	7	9	2	6.85
2.25.	Important	No	7.4	8	7	9	2	6.85
2.26.	Important	No	6.9	7	6	8	2	5.35
2.27.	Important	No	7	7	6	8	2	5.35
2.28.	Important	No	6.7	7	6	8	2	5.35
2.29.	Important	No	6.6	7	6	8	2	5.35
2.30.	Important	No	6.5	7	5	7	2	3.85
2.33.	Important	No	8.2	9	8	9	1	7.6
2.34.	Important	No	7.8	8	7	9	2	6.85
2.35.	Important	No	7.5	8	7	9	2	6.85
2.38.	Important	No	6.8	7	6	9	3	6.1
3.1.	Important	No	7.9	8	7	9	2	6.85
3.2.	Important	No	7.4	8	7	8	1	6.1
3.3.	Important	No	7.3	7	7	9	2	6.85
3.4.	Important	No	7.6	8	7	9	2	6.85
3.5.	Important	No	7.4	8	7	9	2	6.85
3.8.	Important	No	7.7	8	7	9	2	6.85
3.9.	Important	No	7.7	8	7	9	2	6.85
3.12.	Important	No	7.6	8	7	9	2	6.85

Table 2.11 – Continued

I	tem	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
3	.13.	Important	No	7.4	7	7	8	1	6.1
3	.14.	Important	No	7.6	8	7	9	2	6.85
4	.1.	Important	No	8	9	7	9	2	6.85
4	.2.	Important	No	6.8	9	6	9	3	6.1

Table 2.11 – Continued

Item	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
1.1.	Important	No	7.5	8	7	9	2	6.85
1.2.	Important	No	7.1	7	$\overline{7}$	9	2	6.85
1.3.	Important	No	7.8	8	7	9	2	6.85
1.4.	Important	No	7.6	8	7	9	2	6.85
1.5.	Important	No	7.8	8	7	9	2	6.85
1.6.	Important	No	8.1	8	8	9	1	7.6
1.7.	Important	No	5.8	7	5	7	2	3.85
1.8.	Important	No	7.1	7	7	8	1	6.1
1.9.	Important	No	7.3	7	7	8	1	6.1
1.10.	Important	No	6.5	7	5	8	3	4.6
1.11.	Unsure	No	6.4	6	5	$\overline{7}$	2	3.85
1.12.	Important	No	6.8	7	6	8	2	5.35
1.15.	Important	No	6.2	7	6	$\overline{7}$	1	4.6
1.16.	Important	No	7.2	7	7	8	1	6.1
1.17.	Important	No	7.7	8	7	9	2	6.85
1.18.	Important	No	7.2	7	6	8	2	5.35
1.19.	Important	No	6.7	7	6	8	2	5.35
2.1.	Important	No	6.9	7	6	8	2	5.35
2.2.	Important	No	7.3	8	7	9	2	6.85
2.3.	Important	No	7.3	7	7	8	1	6.1
2.4.	Important	No	6.9	7	6	8	2	5.35
2.5.	Important	No	7.2	7	7	8	1	6.1
2.8.	Important	No	6.9	7	6	8	2	5.35
2.9.	Unsure	No	5.5	5	4	$\overline{7}$	3	3.1
2.10.	Important	No	6.5	7	5	8	3	4.6
2.11.	Important	No	6.9	7	6	8	2	5.35
2.12.	Important	No	6.5	7	6	8	2	5.35
2.13.	Important	No	6.6	7	5	8	3	4.6
2.14.	Important	No	7.2	7	6	8	2	5.35
2.15.	Important	No	6.8	7	6	8	2	5.35
2.18.	Important	No	8.3	9	8	9	1	7.6
2.19.	Important	No	7.8	8	7	9	2	6.85
2.20.	Important	No	7.5	8	7	8	1	6.1
2.23.	Important	No	6.7	7	6	8	2	5.35
2.24.	Important	No	6.9	7	6	8	2	5.35
2.25.	Important	No	6.9	7	6	8	2	5.35
2.26.	Important	No	6.5	7	6	8	2	5.35
2.27.	Important	No	7.1	7	6	8	2	5.35
2.28.	Important	No	6.6	7	6	8	2	5.35
2.29.	Unsure	No	6.4	6	6	7	1	4.6
2.30.	Unsure	No	5.8	6	5	$\overline{7}$	2	3.85

Table 2.12: Appropriateness, disagreement, median item ratings, inter-percentile range, and interpercentile range adjusted for asymmetry (health professionals; chronic migraine or tension-type headache)

Item	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
2.33.	Important	No	7.9	8	7	9	2	6.85
2.34.	Important	No	7.2	8	7	8	1	6.1
2.35.	Important	No	6.5	7	5	9	4	5.35
2.38.	Unsure	Yes	5.9	6	3	8	5	3.1
3.1.	Important	No	7.7	8	7	9	2	6.85
3.2.	Important	No	7.2	8	7	8	1	6.1
3.3.	Important	No	6.9	7	6	8	2	5.35
3.4.	Important	No	7.4	7	7	8	1	6.1
3.5.	Important	No	7.1	7	6	8	2	5.35
3.8.	Important	No	7.7	8	7	9	2	6.85
3.9.	Important	No	7.5	8	7	9	2	6.85
3.12.	Important	No	7.7	8	7	9	2	6.85
3.13.	Important	No	7.5	7	7	9	2	6.85
3.14.	Important	No	7.2	7	6	9	3	6.1
4.1.	Important	No	8	9	7	9	2	6.85
4.2.	Important	Yes	6.5	9	3	9	6	3.85

Table 2.12 – Continued

Table 2.13: Appropriateness, disagreement, median item ratings, inter-percentile range, and interpercentile range adjusted for asymmetry (public participants; chronic migraine or tension-type headache)

Item	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
1.1.	Important	No	7.6	8	7	9	2	6.85
1.2.	Important	No	7.6	8	7	9	2	6.85
1.3.	Important	No	8.4	9	8	9	1	7.6
1.4.	Important	No	7.9	9	7	9	2	6.85
1.5.	Important	No	8	9	7	9	2	6.85
1.6.	Important	No	8.2	9	8	9	1	7.6
1.7.	Important	No	7.3	7	7	8	1	6.1
1.8.	Important	No	7.5	7.5	7	9	2	6.85
1.9.	Important	No	7.5	7.5	7	9	2	6.85
1.10.	Important	No	7.2	7	7	8	1	6.1
1.11.	Important	No	7.5	7	7	9	2	6.85
1.12.	Important	No	7.5	7	7	9	2	6.85
1.15.	Unsure	No	5.8	6	5	$\overline{7}$	2	3.85
1.16.	Important	No	6.8	7	6	8	2	5.35
1.17.	Important	No	6.8	7	6	9	3	6.1
1.18.	Important	No	7.5	7.5	7	9	2	6.85
1.19.	Important	No	6.6	7	6	8	2	5.35
2.1.	Important	No	7.4	8	7	9	2	6.85

Item	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
2.2.	Important	No	7.4	8	7	8	1	6.1
2.3.	Important	No	6.9	7	6	8	2	5.35
2.4.	Important	No	7	7	$\overline{7}$	8	1	6.1
2.5.	Important	No	7.9	9	8	9	1	7.6
2.8.	Important	No	7.7	8	7	9	2	6.85
2.9.	Unsure	No	6.1	6	5	8	3	4.6
2.10.	Important	No	7.1	7.5	7	8	1	6.1
2.11.	Important	No	7.4	7.5	7	9	2	6.85
2.12.	Important	No	7.7	8	7	9	2	6.85
2.13.	Important	No	7	8	7	9	2	6.85
2.14.	Important	No	7.3	8	7	9	2	6.85
2.15.	Important	No	7	7	7	9	2	6.85
2.18.	Important	No	8.3	9	8	9	1	7.6
2.19.	Important	No	8.4	9	8	9	1	7.6
2.20.	Important	No	7.3	8	7	9	2	6.85
2.23.	Important	No	7.5	8	7	9	2	6.85
2.24.	Important	No	7.8	8	7	9	2	6.85
2.25.	Important	No	7.8	8	7	9	2	6.85
2.26.	Important	No	7.3	8	7	9	2	6.85
2.27.	Important	No	7	7	6	9	3	6.1
2.28.	Important	No	6.7	7	6	8	2	5.35
2.29.	Important	No	6.8	7	6	8	2	5.35
2.30.	Important	No	7.1	7	6	9	3	6.1
2.33.	Important	No	8.4	9	8	9	1	7.6
2.34.	Important	No	8.3	9	8	9	1	7.6
2.35.	Important	No	8.4	9	8	9	1	7.6
2.38.	Important	No	7.6	8	7	9	2	6.85
3.1.	Important	No	8	8	7	9	2	6.85
3.2.	Important	No	7.6	8	7	9	2	6.85
3.3.	Important	No	7.5	8	7	9	2	6.85
3.4.	Important	No	7.7	8	7	9	2	6.85
3.5.	Important	No	7.7	8.5	7	9	2	6.85
3.8.	Important	No	7.7	8	7	9	2	6.85
3.9.	Important	No	7.8	8	8	9	1	7.6
3.12.	Important	No	7.6	8	7	9	2	6.85
3.13.	Important	No	7.4	7	7	8	1	6.1
3.14.	Important	No	7.9	8	8	9	1	7.6
4.1.	Important	No	8	9	7	9	2	6.85
4.2.	Important	No	7.1	9	6	9	3	6.1

Table 2.13 – Continued

Item	Grade
1.1.	A*
1.2.	A*
1.3.	A*
1.4.	A^*
1.5.	A^*
1.6.	A^*
1.7.	А
1.8.	A^*
1.9.	A^*
1.10.	А
1.11.	В
1.12.	А
1.15.	В
1.16.	А
1.17.	А
1.18.	А
1.19.	А
2.1.	А
2.2.	A^*
2.3.	А
2.4.	А
2.5.	A^*
2.8.	А
2.9.	С
2.10.	А
2.11.	А
2.12.	А
2.13.	А
2.14.	A
2.15.	A
2.18.	A**
2.19.	A*
2.20.	
2.23.	
2.24.	A
2.25.	
2.26.	
2.27.	
2.28.	A
2.29.	B
2.30.	
2.33. Contin	
Conti	nued on next page

 Table 2.14:
 Delphi chronic migraine and tension-type headache item grading

Tab	le 2.14 – Continued
Item	Grade
2.34.	A^*
2.35.	А
2.38.	В
3.1.	A^*
3.2.	A^*
3.3.	А
3.4.	A^*
3.5.	А
3.8.	A^*
3.9.	A^*
3.12.	A^*
3.13.	A^*
3.14.	А
4.1.	A**
4.2.	A**

Table 2.14 – Continued

 Table 2.15:
 Appropriateness, disagreement, median item ratings, inter-percentile range, and inter-percentile range adjusted for asymmetry (whole panel; episodic migraine or tension-type headache)

Item	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
1.1.	Important	No	7.3	7	6	8	2	5.35
1.2.	Important	No	7.4	8	7	8	1	6.1
1.3.	Important	No	8.3	9	8	9	1	7.6
1.4.	Important	No	8.2	9	8	9	1	7.6
1.5.	Important	No	8.1	9	8	9	1	7.6
1.6.	Important	No	8.3	9	8	9	1	7.6
1.7.	Important	No	6.6	7	6	8	2	5.35
1.8.	Important	No	7.1	7	$\overline{7}$	8	1	6.1
1.9.	Important	No	6.9	7	6	8	2	5.35
1.10.	Important	No	6.6	7	6	8	2	5.35
1.11.	Unsure	No	6.3	6	5	$\overline{7}$	2	3.85
1.12.	Important	No	7.3	7	$\overline{7}$	9	2	6.85
1.15.	Unsure	No	6	6	5	$\overline{7}$	2	3.85
1.16.	Important	No	7	7	$\overline{7}$	8	1	6.1
1.17.	Important	No	7	7	7	8	1	6.1
1.18.	Important	No	7.1	7	7	8	1	6.1
1.19.	Unsure	Yes	6	6	4	8	4	3.85
2.1.	Important	No	6.8	7	6	8	2	5.35
2.2.	Important	No	7.1	7	6	8	2	5.35
2.3.	Important	No	6.8	7	6	8	2	5.35

Item	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
2.4.	Important	No	6.7	7	6	7	1	4.6
2.5.	Important	No	7	7	7	8	1	6.1
2.8.	Unsure	No	5.8	6	5	7	2	3.85
2.9.	Important	No	6.5	7	5	8	3	4.6
2.10.	Important	No	6.7	7	6	8	2	5.35
2.11.	Important	No	6.8	7	6	8	2	5.35
2.12.	Important	No	6.5	7	6	8	2	5.35
2.13.	Important	No	7.1	7	7	8	1	6.1
2.14.	Important	No	6.7	7	6	8	2	5.35
2.15.	Important	No	8	8	7	9	2	6.85
2.18.	Important	No	8	9	7	9	2	6.85
2.19.	Important	No	7.1	7	6	8	2	5.35
2.20.	Important	No	6.9	7	6	8	2	5.35
2.23.	Important	No	7.1	7	7	8	1	6.1
2.24.	Important	No	6.9	7	6	8	2	5.35
2.25.	Important	No	6.8	7	6	8	2	5.35
2.26.	Important	No	6.8	7	6	7	1	4.6
2.27.	Important	No	6.9	7	6	8	2	5.35
2.28.	Important	No	6.5	7	6	7	1	4.6
2.29.	Important	No	6.5	7	6	7	1	4.6
2.32.	Important	No	7.9	8	7	9	2	6.85
2.33.	Important	No	7.7	8	7	9	2	6.85
2.34.	Important	No	7.8	9	$\overline{7}$	9	2	6.85
2.37.	Important	No	7.2	8	6	9	3	6.1
3.1.	Important	No	7.8	8	7	9	2	6.85
3.2.	Important	No	7.7	8	$\overline{7}$	9	2	6.85
3.3.	Important	No	7.2	8	6	9	3	6.1
3.4.	Important	No	8	8	7	9	2	6.85
3.5.	Important	No	7.2	7	7	8	1	6.1
3.8.	Important	No	7.9	8	7	9	2	6.85
3.9.	Important	No	7.7	8	7	9	2	6.85
3.12.	Important	No	7	7	6	8	2	5.35
3.13.	Important	No	7.3	7	7	9	2	6.85
3.14.	Important	No	7.3	8	7	9	2	6.85
4.1.	Important	No	8	8	7	9	2	6.85
4.2.	Important	No	6.9	8	6	9	3	6.1

Table 2.15 – Continued

Item	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
1.1.	Important	No	6.8	7	6	7	1	4.6
1.2.	Important	No	7.7	8	$\overline{7}$	8	1	6.1
1.3.	Important	No	8.3	9	8	9	1	7.6
1.4.	Important	No	8.2	9	8	9	1	7.6
1.5.	Important	No	8.1	9	8	9	1	7.6
1.6.	Important	No	8.3	9	8	9	1	7.6
1.7.	Unsure	No	5.9	6	5	8	3	4.6
1.8.	Important	No	6.7	7	6	7	1	4.6
1.9.	Important	No	6.6	7	6	7	1	4.6
1.10.	Important	No	6.8	7	6	7	1	4.6
1.11.	Important	No	6.4	7	5	7	2	3.85
1.12.	Important	No	7.5	8	$\overline{7}$	9	2	6.85
1.15.	Unsure	No	5.6	6	4	7	3	3.1
1.16.	Important	No	7	7	6	8	2	5.35
1.17.	Important	No	6.8	7	6	8	2	5.35
1.18.	Important	No	6.6	7	6	7	1	4.6
1.19.	Unsure	No	5.7	6	4	$\overline{7}$	3	3.1
2.1.	Important	No	6.4	7	5	8	3	4.6
2.2.	Important	No	6.8	7	6	8	2	5.35
2.3.	Important	No	6.8	7	6	8	2	5.35
2.4.	Important	No	6.5	7	6	$\overline{7}$	1	4.6
2.5.	Important	No	6.3	7	6	$\overline{7}$	1	4.6
2.8.	Unsure	No	5.6	5	5	$\overline{7}$	2	3.85
2.9.	Unsure	No	5.8	6	5	$\overline{7}$	2	3.85
2.10.	Unsure	No	6	6	5	$\overline{7}$	2	3.85
2.11.	Important	No	6.3	7	5	$\overline{7}$	2	3.85
2.12.	Unsure	No	6.1	6	5	$\overline{7}$	2	3.85
2.13.	Important	No	6.9	7	$\overline{7}$	8	1	6.1
2.14.	Important	No	6.4	7	6	7	1	4.6
2.15.	Important	No	7.7	8	7	9	2	6.85
2.18.	Important	No	7.7	8	7	9	2	6.85
2.19.	Important	No	6.8	7	6	$\overline{7}$	1	4.6
2.20.	Important	No	6.5	7	6	7	1	4.6
2.23.	Important	No	6.5	7	6	7	1	4.6
2.24.	Important	No	6.5	7	6	8	2	5.35
2.25.	Important	No	6.5	7	6	7	1	4.6
2.26.	Important	No	6.7	7	6	7	1	4.6
2.27.	Important	No	6.5	7	6	7	1	4.6
2.28.	Unsure	No	5.8	6	$\overline{5}$	$\frac{1}{7}$	2	3.85
2.29.	Unsure	No	$5.0 \\ 5.7$	6	5	$\frac{1}{7}$	$\frac{2}{2}$	3.85
2.32.	Important	No	7.3	7	7	8	1	6.1

Table 2.16: Appropriateness, disagreement, median item ratings, inter-percentile range, and inter-
percentile range adjusted for asymmetry (health professionals; episodic migraine or tension-type
 headache)

Item	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
2.33.	Important	No	6.9	7	7	8	1	6.1
2.34.	Important	No	7.2	7	$\overline{7}$	8	1	6.1
2.37.	Unsure	No	6.2	6	5	7	2	3.85
3.1.	Important	No	7.7	8	$\overline{7}$	9	2	6.85
3.2.	Important	No	7.5	8	$\overline{7}$	9	2	6.85
3.3.	Important	No	7	8	6	8	2	5.35
3.4.	Important	No	7.9	8	$\overline{7}$	9	2	6.85
3.5.	Important	No	6.6	7	6	8	2	5.35
3.8.	Important	No	7.4	7	$\overline{7}$	8	1	6.1
3.9.	Important	No	7.1	7	$\overline{7}$	8	1	6.1
3.12.	Important	No	6.7	7	6	8	2	5.35
3.13.	Important	No	7	7	6	8	2	5.35
3.14.	Important	No	7	7	6	8	2	5.35
4.1.	Important	No	7.8	8	$\overline{7}$	9	2	6.85
4.2.	Important	Yes	6	8	3	9	6	3.85

Table 2.16 – Continued

Table 2.17: Appropriateness, disagreement, median item ratings, inter-percentile range, and interpercentile range adjusted for asymmetry (public participants; episodic migraine or tension-type headache)

Item	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
1.1.	Important	No	7.7	8	7	9	2	6.85
1.2.	Important	No	7.1	7	7	8	1	6.1
1.3.	Important	No	8.4	9	9	9	0	8.35
1.4.	Important	No	8.2	9	8	9	1	7.6
1.5.	Important	No	8.1	9	8	9	1	7.6
1.6.	Important	No	8.3	9	8	9	1	7.6
1.7.	Important	No	7.2	7	7	8	1	6.1
1.8.	Important	No	7.4	8	7	8	1	6.1
1.9.	Important	No	7.1	8	7	8	1	6.1
1.10.	Important	No	6.4	7	5	8	3	4.6
1.11.	Unsure	No	6.2	6	5	7	2	3.85
1.12.	Important	No	7.1	7	7	8	1	6.1
1.15.	Important	No	6.3	7	6	7	1	4.6
1.16.	Important	No	6.9	7	7	8	1	6.1
1.17.	Important	No	7.1	8	7	8	1	6.1
1.18.	Important	No	7.6	8	7	9	2	6.85
1.19.	Important	No	6.4	7	5	8	3	4.6
2.1.	Important	No	7.1	7.5	6	9	3	6.1
2.2.	Important	No	7.4	7	7	9	2	6.85

Item	Importance	Disagreement	Mean	Median	P_{30}	P_{70}	IPR	IPRAS
2.3.	Important	No	6.9	7	6	8	2	5.35
2.4.	Important	No	6.9	7	6	7	1	4.6
2.5.	Important	No	7.7	8	7	9	2	6.85
2.8.	Unsure	No	6.1	6	5	7	2	3.85
2.9.	Important	No	7.2	7	7	8	1	6.1
2.10.	Important	No	7.3	8	7	9	2	6.85
2.11.	Important	No	7.4	8	7	8	1	6.1
2.12.	Important	No	6.9	7	6	8	2	5.35
2.13.	Important	No	7.3	7.5	7	9	2	6.85
2.14.	Important	No	7.1	7	7	8	1	6.1
2.15.	Important	No	8.2	9	8	9	1	7.6
2.18.	Important	No	8.2	9	8	9	1	7.6
2.19.	Important	No	7.4	7	7	9	2	6.85
2.20.	Important	No	7.4	7	7	8	1	6.1
2.23.	Important	No	7.7	8	7	8	1	6.1
2.24.	Important	No	7.3	7	7	9	2	6.85
2.25.	Important	No	7.2	7	7	8	1	6.1
2.26.	Important	No	6.9	7	6	8	2	5.35
2.27.	Important	No	7.3	7	7	8	1	6.1
2.28.	Important	No	7.1	7	7	7	0	5.35
2.29.	Important	No	7.2	7	7	8	1	6.1
2.32.	Important	No	8.4	9	8	9	1	7.6
2.33.	Important	No	8.5	9	8	9	1	7.6
2.34.	Important	No	8.4	9	9	9	0	8.35
2.37.	Important	No	8.2	9	8	9	1	7.6
3.1.	Important	No	8	8.5	8	9	1	7.6
3.2.	Important	No	7.8	8	8	9	1	7.6
3.3.	Important	No	7.4	7.5	7	9	2	6.85
3.4.	Important	No	8.1	8.5	8	9	1	7.6
3.5.	Important	No	7.7	8	7	9	2	6.85
3.8.	Important	No	8.4	9	8	9	1	7.6
3.9.	Important	No	8.3	9	8	9	1	7.6
3.12.	Important	No	7.3	7	7	9	2	6.85
3.13.	Important	No	7.6	8	$\overline{7}$	9	2	6.85
3.14.	Important	No	7.6	8	7	9	2	6.85
4.1.	Important	No	8.2	8.5	8	9	1	7.6
4.2.	Important	No	7.6	8	7	9	2	6.85

Table 2.17 – Continued

Item	Grade
1.1.	А
1.2.	A*
1.3.	A**
1.4.	A**
1.5.	A**
1.6.	A**
1.7.	В
1.8.	А
1.9.	А
1.10.	А
1.11.	В
1.12.	A^*
1.15.	В
1.16.	А
1.17.	А
1.18.	А
1.19.	В
2.1.	А
2.2.	А
2.3.	А
2.4.	А
2.5.	А
2.8.	С
2.9.	В
2.10.	В
2.11.	А
2.12.	В
2.13.	A*
2.14.	A
2.15.	A*
2.18.	A*
2.19.	A
2.20.	A
2.23.	A
2.24.	A
2.25.	A
2.26.	A
2.27.	A
2.28.	В
2.29.	B ^*
2.32.	A* A*
2.33. Contin	
Conti	nued on next page

 Table 2.18:
 Delphi episodic migraine and tension-type headache item grading

140	le 2.18 – Continued
Item	Grade
2.34.	A^*
2.37.	В
3.1.	A*
3.2.	A^*
3.3.	А
3.4.	A*
3.5.	А
3.8.	A^*
3.9.	A^*
3.12.	А
3.13.	А
3.14.	А
4.1.	A^*
4.2.	А

Table 2.18 – Continued

2.4 Round one qualitative analysis

Not required.

Transfer of files and data and the next round

All data and graphs have been/will be transferred to you in the same encrypted folder. Original Stata graphs are included should you wish to modify these for further use.

We have included a folder of editable results in various formats, in the case that it facilitates your final write up or any further analysis you may wish to do beyond those which Clinvivo has been contracted to provide. We look forward to receiving your Word documents detailing what content you would like to be displayed in Round 2.

Please contact us if you have any questions regarding the results presented in this report and we will of course be happy to help.

Methods

4.1 Round two sampling, recruitment, and material

The COSH Delphi study team provided Clinvivo with a list of public participants and health care professionals/academic participants of invitees and e-mail invitation wording (see Appendix). Clinvivo sent this along with a personalised link to the second round of delphi studies on chronic and episodic migraine, which ran from March 8, 2018 to March 22, 2018. We note that for the second round your focus has shifted to exclude tension type headache.

Reminders to complete the round(s) were sent by Clinvivo on March 15 and March 21, 2018. Details of Round 2 as it appeared to panellists, is provided in the appendix.

Data from the round were sent directly to a secure SQL database using our software. Once the round had closed we exported these data in CSV format and quantitative data were read into Stata (version 15.0) for analysis. Qualitative data were exported and formatted into an Excel file for examination by the COSH team.

4.2 Methods and analysis

Participants were asked to rate the priority of including each outcome in a core set, using an 11-point scale where 0=Not a priority and 10=An absolute priority. Participants were given 70 points to spend on rating 27 outcomes in the episodic part of the round and 31 outcomes in the chronic part of the round. All points were required to be spent. We summed the priority ratings for each outcome.

4.3 Qualitative analysis

Clinvivo was not contracted to undertake an analysis of qualitative data. The raw qualitative data have been transferred to you.

 $\mathbf{5}$

Round two results

Of the 42 public participants invited to the chronic round, and 34 invited to the episodic round, we received 33 responses (78.6% of the invited panel) for the chronic part of the round and 25 (73.5%) for the episodic part of the round.

Of the 37 health care professionals who were invited to complete both chronic and episodic parts of the round, we received 23 to the chronic part (62.2%) and 29 (78.4%) to the episodic part.

Thus, in Round 2, we received 56 completed responses (70.9%) for the chronic part and 54 (76.0%) for the episodic part.

Please note that, unlike in cross-sectional studies, the repose rate should be used as an indication of external generalisability since generalisability is not the aim of a delphi study (rather delphi is an expert panel decision about a subject matter).

5.1 Demographics

No additional demographics were collected on Round 2.

5.2 Sums of outcome priority ratings

Tables 5.1 to 5.6 show the sums of priorty ratings together, and seperately by sub-panel group, for episodic and chronic parts of the round. The outcomes in the tables are ordered by their ratings (highest rated to lowest rated).

Please note that the outcome number is not linked to those used in Round 1, as this is a subset with relatively fewer outcomes being considered. The outcome numbers are listed in the Appendix for Round 2. In addition, in the below tables the section and subdomain are listed for your convenience.

Outcome	Section	Subdomain	Sum of ratings
1.3	Physical symptoms	Pain with migraine	264
1.5	Physical symptoms	Frequency of migraine pain	258
1.6	Physical symptoms	Intensity of pain with migraine	253
Continued	on next page		

Table 5.1: Priority ratings for episodic outcomes (whole panel), ordered by highest rated

Outcome	Section	Subdomain	Sum of ratings
1.4	Physical symptoms	Duration of migraine pain	251
2.6	Work/education	Work activities	185
1.1	Physical symptoms	Cognitive function	162
4.1	Adverse events	Side effects	161
2.10	Overall health and well-being	Overall health	154
2.13	Environmental factors	Trigger factors	144
1.2	Physical symptoms	Increased sensitivities	143
2.8	Social	Family roles	136
2.11	Overall health and well-being	Self-management	136
2.7	Work/education	Need for time off	135
3.1	Aspects of treatment effectiveness	Satisfaction with treatment	131
1.8	Physical symptoms	Vomiting/nausia	122
3.4	Medication use	During migraine	120
2.12	Overall health and well-being	Unpredictability	117
1.7	Physical symptoms	Physical fatigue	110
2.1	Emotional well-being	Anxeity	108
2.2	Emotional well-being	Depressive mood	108
3.5	Medication use	Prophylactic	106
2.9	Social	Participation	103
3.3	Aspects of treatment effectiveness	Consistency of treatment effect	99
2.5	Emotional well-being	Stress	89
3.2	Aspects of treatment effectiveness	Confidence in treatment	73
2.4	Emotional well-being	Self-worth	59
2.3	Emotional well-being	Isolation	53

Table 5.1 – Continued

 Table 5.2: Priority ratings for episodic outcomes (professional sub-panel), ordered by highest rated

Outcome	Section	Subdomain	Sum of ratings
1.3	Physical symptoms	Pain with migraine	159
1.4	Physical symptoms	Duration of migraine pain	145
1.5	Physical symptoms	Frequency of migraine pain	140
1.6	Physical symptoms	Intensity of pain with migraine	136
2.6	Work/education	Work activities	115
4.1	Adverse events	Side effects	104
1.2	Physical symptoms	Increased sensitivities	94
1.8	Physical symptoms	Vomiting/nausia	89
3.1	Aspects of treatment effectiveness	Satisfaction with treatment	84
1.1	Physical symptoms	Cognitive function	73
2.7	Work/education	Need for time off	72
3.4	Medication use	During migraine	71
Continued	on next page		

Outcome	Section	Subdomain	Sum of ratings
2.8	Social	Family roles	70
3.5	Medication use	Prophylactic	69
2.13	Environmental factors	Trigger factors	63
2.1	Emotional well-being	Anxeity	61
2.10	Overall health and well-being	Overall health	55
2.11	Overall health and well-being	Self-management	54
2.9	Social	Participation	52
3.3	Aspects of treatment effectiveness	Consistency of treatment effect	52
2.12	Overall health and well-being	Unpredictability	50
2.5	Emotional well-being	Stress	48
1.7	Physical symptoms	Physical fatigue	45
2.2	Emotional well-being	Depressive mood	43
3.2	Aspects of treatment effectiveness	Confidence in treatment	41
2.4	Emotional well-being	Self-worth	25
2.3	Emotional well-being	Isolation	20

Table 5.2 – Continued

Table 5.3: Priority ratings for episodic outcomes (public sub-panel), ordered by highest rated

Outcome	Section	Subdomain	Sum of ratings
1.5	Physical symptoms	Frequency of migraine pain	118
1.6	Physical symptoms	Intensity of pain with migraine	117
1.4	Physical symptoms	Duration of migraine pain	106
1.3	Physical symptoms	Pain with migraine	105
2.10	Overall health and well-being	Overall health	99
1.1	Physical symptoms	Cognitive function	89
2.11	Overall health and well-being	Self-management	82
2.13	Environmental factors	Trigger factors	81
2.6	Work/education	Work activities	70
2.12	Overall health and well-being	Unpredictability	67
2.8	Social	Family roles	66
1.7	Physical symptoms	Physical fatigue	65
2.2	Emotional well-being	Depressive mood	65
2.7	Work/education	Need for time off	63
4.1	Adverse events	Side effects	57
2.9	Social	Participation	51
1.2	Physical symptoms	Increased sensitivities	49
3.4	Medication use	During migraine	49
2.1	Emotional well-being	Anxeity	47
3.1	Aspects of treatment effectiveness	Satisfaction with treatment	47
3.3	Aspects of treatment effectiveness	Consistency of treatment effect	47
Continued	on next page		

Outcome	Section	Subdomain	Sum of ratings
2.5	Emotional well-being	Stress	41
3.5	Medication use	Prophylactic	37
2.4	Emotional well-being	Self-worth	34
1.8	Physical symptoms	Vomiting/nausia	33
2.3	Emotional well-being	Isolation	33
3.2	Aspects of treatment effectiveness	Confidence in treatment	32

Table 5.3 – Continued

 Table 5.4:
 Priority ratings for chronic outcomes (whole panel), ordered by highest rated

Outcome	Section	Subdomain	Sum of ratings
1.6	Physical symptoms	Severity/ intensity of pain	285
1.3	Physical symptoms	Pain associated with Headache	270
1.5	Physical symptoms	Frequency of pain	242
1.4	Physical symptoms	Duration of pain	231
1.13	Emotional well-being	Daily tasks	199
1.15	Work/education	Work activities	197
1.1	Physical symptoms	Cognitive function	194
1.3	Adverse effects	reatment side effects	162
1.2	Physical symptoms	Increased sensitivities	137
1.7	Physical symptoms	Physical fatigue	136
1.16	Work/education	Needing to take time-off	131
1.23	Aspects of treatment effectiveness	Satisfaction with treatment	126
1.20	Overall health and well-being	Overall health	122
1.8	Physical symptoms	Sleep quality	114
1.14	Emotional well-being	Needing to rest	113
1.12	Emotional well-being	Stress	106
1.21	Overall health and well-being	Self-Management	105
1.22	Overall health and well-being	Unpredictability	99
1.18	Social	Family roles	94
1.9	Emotional well-being	Anxiety	93
1.27	Medication use	Prophylactic	82
1.19	Social	Participation	77
1.25	Aspects of treatment effectiveness	Consistency of treatment effect	77
1.26	Medication use	During headache	77
1.28	Financial impact	Financial impact	77
1.31	Adverse effects	Mortality (death)	77
1.24	Aspects of treatment effectiveness	Confidence in treatment	67
1.11	Emotional well-being	Self-worth	66
1.10	Emotional well-being	Feelings of isolation	58
1.29	Financial impact	Use of healthcare	56
Continued	on next page		

	Table off Commada		
Outcome	Section	Subdomain	Sum of ratings
1.17	Work/education	Social role	50

Table 5.4 – Continued

Outcome	Section	Subdomain	Sum of ratings
1.6	Physical symptoms	Severity/ intensity of pain	111
1.3	Physical symptoms	Pain associated with Headache	101
1.13	Emotional well-being	Daily tasks	101
1.5	Physical symptoms	Frequency of pain	96
1.15	Work/education	Work activities	89
1.4	Physical symptoms	Duration of pain	80
1.3	Adverse effects	Treatment side effects	69
1.23	Aspects of treatment effectiveness	Satisfaction with treatment	65
1.1	Physical symptoms	Cognitive function	59
1.12	Emotional well-being	Stress	55
1.8	Physical symptoms	Sleep quality	52
1.2	Physical symptoms	Increased sensitivities	51
1.7	Physical symptoms	Physical fatigue	49
1.16	Work/education	Needing to take time-off	49
1.31	Adverse effects	Mortality (death)	46
1.18	Social	Family roles	43
1.21	Overall health and well-being	Self-Management	43
1.27	Medication use	Prophylactic	42
1.26	Medication use	During headache	41
1.9	Emotional well-being	Anxiety	39
1.20	Overall health and well-being	Overall health	39
1.29	Financial impact	Use of healthcare	35
1.14	Emotional well-being	Needing to rest	34
1.17	Work/education	Social role	34
1.28	Financial impact	Financial impact	33
1.24	Aspects of treatment effectiveness	Confidence in treatment	32
1.19	Social	Participation	30
1.11	Emotional well-being	Self-worth	25
1.25	Aspects of treatment effectiveness	Consistency of treatment effect	25
1.10	Emotional well-being	Feelings of isolation	21
1.22	Overall health and well-being	Unpredictability	21

 Table 5.5: Priority ratings for chronic outcomes (professional sub-panel), ordered by highest rated

Outcome	Section	Subdomain	Sum of ratings
1.6	Physical symptoms	Severity/ intensity of pain	174
1.3	Physical symptoms	Pain associated with Headache	169
1.4	Physical symptoms	Duration of pain	151
1.5	Physical symptoms	Frequency of pain	146
1.1	Physical symptoms	Cognitive function	135
1.15	Work/education	Work activities	108
1.13	Emotional well-being	Daily tasks	98
1.3	Adverse effects	Treatment side effects	93
1.7	Physical symptoms	Physical fatigue	87
1.2	Physical symptoms	Increased sensitivities	86
1.20	Overall health and well-being	Overall health	83
1.16	Work/education	Needing to take time-off	82
1.14	Emotional well-being	Needing to rest	79
1.22	Overall health and well-being	Unpredictability	78
1.8	Physical symptoms	Sleep quality	62
1.21	Overall health and well-being	Self-Management	62
1.23	Aspects of treatment effectiveness	Satisfaction with treatment	61
1.9	Emotional well-being	Anxiety	54
1.25	Aspects of treatment effectiveness	Consistency of treatment effect	52
1.12	Emotional well-being	Stress	51
1.18	Social	Family roles	51
1.19	Social	Participation	47
1.28	Financial impact	Financial impact	44
1.11	Emotional well-being	Self-worth	41
1.27	Medication use	Prophylactic	40
1.10	Emotional well-being	Feelings of isolation	37
1.26	Medication use	During headache	36
1.24	Aspects of treatment effectiveness	Confidence in treatment	35
1.31	Adverse effects	Mortality (death)	31
1.29	Financial impact	Use of healthcare	21
1.17	Work/education	Social role	16

Table 5.6: Priority ratings for chronic outcomes (public sub-panel), ordered by highest rated

5.3 Note on pain /pain intensity items

We note for the researchers' consideration that in the episodic round the most valued items are all in the domain of pain. Item 1.3 (pain) and item 1.6 (intensity of pain) both scored highly. Is it possibly that there may be some overlap insofar as participants may have read and scored these as being similar? Conflation may be one option to consider here.

5.4 Ictal and inter-ictal periods

Table 5.7 and 5.8 show responses to the question of whether choice of outcomes would be influenced by the time of assessment (ictal or inter-ictal) in the episodic and chronic rounds respectively.

Panel	Yes $(\%)$	No (%)	Total (%)
Whole panel Professional Public	$\begin{array}{c} 28 \ (51.9) \\ 17 \ (58.6) \\ 11 \ (44.0) \end{array}$	$\begin{array}{c} 26 \ (48.2) \\ 12 \ (41.4) \\ 14 \ (56.0) \end{array}$	$54 (100) \\ 29 (100) \\ 25 (100)$

Table 5.8: View of whether ictal/inter-ictal periods would influence choice (chronic)

Panel	Yes $(\%)$	No (%)	Total (%)
Whole panel Professional Public	$\begin{array}{c} 25 \ (44.6) \\ 9 \ (39.1) \\ 16 \ (48.5) \end{array}$	$\begin{array}{c} 31 \ (55.4) \\ 14 \ (60.9) \\ 17 \ (51.5) \end{array}$	$56 (100) \\ 23 (100) \\ 33 (100)$

5.5 Self-certification of chronic migraine

Of the 33 public participants who responded to the chronic round, two (6%) reported that they did not have chronic migraine according to the provided definition. Of the 31 (93.9%) who reported that they did fit the definition, all (100%) reported that the diagnosis was made by a health professional.

5.6 Round two qualitative analysis

Not required.

Transfer of files and data and the next round

All data have been/will be transferred to you in the same encrypted folder.

We have included a folder of editable results in various formats, in the case that it facilitates your final write up or any further analysis you may wish to do beyond those which Clinvivo has been contracted to provide.

We look forward to receiving your Word documents detailing what content you would like to be displayed in Round 3.

Please contact us if you have any questions regarding the results presented in this report and we will of course be happy to help.

$\mathbf{7}$

Methods

7.1 Round three sampling, recruitment, and material

The COSH Delphi study team provided Clinvivo with a list of public participants and health care professionals/academic participants of invitees and e-mail invitation wording (see Appendix). Clinvivo sent this along with a personalised link to the final round of delphi studies on chronic and episodic migraine, which ran from April 26, 2018 to May 10, 2018.

Reminders to complete the round(s) were sent by Clinvivo on May 3, 2018 and May 9, 2018. Details of Round 3 as it appeared to panellists, is provided in the appendix.

Data from the round were sent directly to a secure SQL database using our software. Once the round had closed we exported these data in CSV format and quantitative data were read into Stata (version 15.0) for analysis. Qualitative data were exported and formatted into an Excel file for examination by the COSH team.

7.2 Methods and analysis

Participants were asked to indicate whether they were happy with a series of decisions. Frequency distributions of responces were tablutated by question ID number.

7.3 Qualitative analysis

Clinvivo was not contracted to undertake an analysis of qualitative data. The raw qualitative data have been transferred to you. Please remember to read through these.

Round three results

Of the 33 public participants invited to the chronic round, and 25 invited to the episodic round, we received 29 responses (88% of the invited panel) for the chronic part of the round and 23 (92%) for the episodic part of the round.

Of the 30 health care professionals who were invited to complete both chronic and episodic parts of the round, we received 23 to the chronic part (77%) and 21 (70%) to the episodic part. Thus, in Round 3, we received 52 completed responses (83%) for the chronic part and 44 (80%) for the episodic part.

8.1 Demographics

No additional demographics were collected on Round 3.

8.2 Tables of results

Tables 8.1 to 8.6 show the proportion of people responding 'Yes' to each of the questions. The question IDs match those listed on the PDF of Round 3 in the Appendix.

Question number	Number of positive responses (Yes)	Percentage of postitive responses (Yes)
2.1	30	68.2
2.2	29	65.9
2.3	20	45.5
2.4	32	72.7
2.5	27	61.4
2.6	25	56.8
3.1.i	44	100
3.1.ii	40	90.9
3.2.i	39	88.6
3.2.ii	38	86.4
3.3.i	43	97.7
Continued on next	page	

 Table 8.1: Frequency distributions for episodic questions (whole panel; n=44)

Question number	Number of positive responses (Yes)	Percentage of postitive responses (% Yes)
3.3.ii	40	90.9
3.4.i	44	100
3.4.ii	39	88.6
3.5.i	42	95.5
3.5.ii	37	84.1
3.6.i	40	90.9
3.6.ii	38	86.4
3.7.i	41	93.2
3.7.ii	39	88.6
4.1	27	61.36
4.2	38	86.4
4.3	39	88.6
4.4	37	84.1
4.5	32	72.7
4.6	37	84.1
4.7	35	79.6

Table 8.1 - Continued

 Table 8.2: Frequency distributions for episodic questions (professional sub-panel; n=21)

Question number	Number of positive responses (Yes)	Percentage of postitive responses (Yes)
2.1	15	71.4
2.2	15	71.4
2.3	11	52.4
2.4	13	61.9
2.5	11	52.4
2.6	9	42.9
3.1.i	21	100
3.1.ii	21	100
3.2.i	17	81.0
3.2.ii	16	76.2
3.3.i	21	100
3.3.ii	19	90.5
3.4.i	21	100
3.4.ii	19	90.5
3.5.i	19	90.5
3.5.ii	17	81.0
3.6.i	18	85.7
3.6.ii	17	81.0
3.7.i	21	100
3.7.ii	19	90.5
Continued on next	t page	

Question number	Number of positive responses (Yes)	Percentage of postitive responses (Yes)
4.1	13	61.9
4.2	19	90.5
4.3	20	95.2
4.4	16	76.2
4.5	11	52.4
4.6	17	81.0
4.7	17	81.0

Table 8.2 – Continued

 Table 8.3: Frequency distributions for episodic outcomes (public sub-panel; n=23)

Question number	Number of positive responses (Yes)	Percentage of postitive responses (Yes)
2.1	15	65.2
2.2	14	60.9
2.3	9	39.1
2.4	19	82.6
2.5	16	69.6
2.6	16	69.6
3.1.i	23	100
3.1.ii	19	82.6
3.2.i	22	95.7
3.2.ii	22	95.7
3.3.i	22	95.7
3.3.ii	21	91.3
3.4.i	23	100
3.4.ii	20	87.0
3.5.i	23	100
3.5.ii	20	87.0
3.6.i	22	95.7
3.6.ii	21	91.3
3.7.i	20	87.0
3.7.ii	20	87.0
4.1	14	60.9
4.2	19	82.6
4.3	19	82.6
4.4	21	91.3
4.5	21	91.3
4.6	20	87.0
4.7	18	78.3

Question number	Number of positive responses (Yes)	Percentage of postitive responses (Yes)
2.1	28	53.9
2.2	10	19.2
2.3	44	84.6
3.1.i	48	92.3
3.1.ii	48	92.3
3.2.i	51	98.1
3.2.ii	48	92.3
3.3.i	50	96.1
3.3.ii	49	94.2
3.4.i	48	92.3
3.4.ii	46	88.5
3.5.i	45	86.5
3.5.ii	44	84.6
3.6.i	39	75.0
3.6.ii	35	67.3
3.7.i	48	92.3
3.7.ii	44	84.6
4.1	42	80.8
4.2	31	59.6
4.3	37	71.2

Table 8.4: Frequency distributions for chronic outcomes (whole panel;n=52)

Table 8.5: Frequency distributions for chronic outcomes (professional sub-panel;n=23)

Question number	Number of positive responses (Yes)	Percentage of postitive responses (Yes)
2.1	11	47.8
2.2	4	17.4
2.3	16	69.6
3.1.i	20	86.9
3.1.ii	22	95.7
3.2.i	22	95.7
3.2.ii	22	95.7
3.3.i	22	95.7
3.3.ii	22	95.7
3.4.i	22	95.7
3.4.ii	19	82.6
3.5.i	17	73.9
3.5.ii	17	73.9
3.6.i	16	69.6
3.6.ii	14	60.9
Continued on next	t page	

Question number	Number of positive responses (Yes)	Percentage of postitive responses (Yes)
3.7.i	20	87.0
3.7.ii	18	78.3
4.1	16	69.6
4.2	14	60.9
4.3	15	65.2

Table 8.5 – Continued

Table 8.6: Frequency distributions for chronic outcomes (public sub-panel;n=29)

Question number	Number of positive responses (Yes)	Percentage of postitive responses (Yes)
2.1	17	58.6
2.2	6	20.7
2.3	28	96.6
3.1.i	28	96.6
3.1.ii	26	89.7
3.2.i	29	100
3.2.ii	26	89.7
3.3.i	28	96.6
3.3.ii	27	93.1
3.4.i	26	89.7
3.4.ii	27	93.1
3.5.i	28	96.6
3.5.ii	27	93.1
3.6.i	23	79.3
3.6.ii	21	72.4
3.7.i	28	96.6
3.7.ii	26	89.7
4.1	26	89.7
4.2	17	58.6
4.3	22	75.9

8.3 Round three qualitative analysis

Not required. We note that qualitative data were received and so please do remember to check these. Also lists of participants who would like a copy of a report summary may be found in the data set.

9

Transfer of files and data and the next round

All data have been/will be transferred to you in the same encrypted folder.

We have included a folder of editable results in various formats, in the case that it facilitates your final write up or any further analysis you may wish to do beyond those which Clinvivo has been contracted to provide.

Please contact us if you have any questions regarding the results presented in this report and we will of course be happy to help. 10

Appendix

10.1 Round One

10.1.1 Invitation wording provided to Clinvivo and used in invitations

Healthcare professionals

Dear [name]

Many thanks for agreeing to take part in the COSH Study which seeks to reach agreement between people who experience headaches, health professionals, and researchers on the key outcomes that should be included in all headache studies.

Please complete BOTH questionnaires: one for Episodic Migraine and one for Chronic Headache.

Please find below the links to each questionnaire for the first round of the survey (Round 1). Please click on the link to open the survey. Each questionnaire should take approximately 10 minutes to complete.

[episodiclink] [chroniclink] Please complete the round by 12 noon on Thursday 24th January, when it will close. We will be in touch again towards the end of February with the results from this round, and the second questionnaire for your completion.

With best wishes,

Kirstie Haywood and Kimberley White.

For public participants with a choice

Dear [name]

Many thanks for agreeing to take part in the COSH Study which seeks to reach agreement between people who experience headaches, health professionals, and researchers on the key outcomes that should be included in all headache studies. We would be grateful if you could please complete the ONE questionnaire that best reflects the type of headache you experience.

If you experience EPISODIC MIGRAINE: That is, a migraine that that occurs on 14 days or fewer per month. Please click on the following link to open the survey. The questionnaire should take approximately 10 minutes to complete.

[episodiclink] If you experience CHRONIC HEADACHES (chronic migraine or chronic tensiontype headache). That is, a headache occurring on 15 or more days per month for more than 3 months; this headache may or may not include the features of migraine headache, and may or may not be associated with medication overuse. Please click on the following link to open the survey. The questionnaire should take approximately 10 minutes to complete.

[chroniclink] Please complete the round by 12 noon on Thursday 24th January, when it will close. We will be in touch again towards the end of February with the results from this round, and the second questionnaire for your completion.

With best wishes,

Kirstie Haywood and Kimberley White.

For public participants doing chronic only

Dear [name]

Many thanks for agreeing to take part in the COSH Study which seeks to reach agreement between people who experience headaches, health professionals, and researchers on the key outcomes that should be included in all headache studies.

You have indicated that you experience CHRONIC HEADACHES (chronic migraine or chronic tension-type headache). That is, a headache occurring on 15 or more days per month for more than 3 months; this headache may or may not include the features of migraine headache, and may or may not be associated with medication overuse.

Please find below the link to the first round of the survey (Round 1). Please click on the link to open the survey. The questionnaire should take approximately 10 minutes to complete.

[chroniclink] Please complete the round by 12 noon on Thursday 24th January, when it will close. We will be in touch again towards the end of February with the results from this round, and the second questionnaire for your completion.

With best wishes,

Kirstie Haywood and Kimberley White.

For public participants doing episodic only

Dear [name]

Many thanks for agreeing to take part in the COSH Study which seeks to reach agreement between people who experience headaches, health professionals, and researchers on the key outcomes that should be included in all headache studies.

You have indicated that you experience EPISODIC MIGRAINES. That is, a migraine that that occurs on 14 days or fewer per month.

Please find below the link to the first round of the survey (Round 1). Please click on the link to open the survey. The questionnaire should take approximately 10 minutes to complete.

[episodiclink] Please complete the round by 12 noon on Thursday 24th January, when it will close. We will be in touch again towards the end of February with the results from this round, and the second questionnaire for your completion.

With best wishes,

Kirstie Haywood and Kimberley White.

10.1.2 Round one (chronic) as it appeared to participants

ne impact -	- Symptor	ns associat	ed with a Ch	ironic Hea	uache			
is section lists sy	mptoms that so	ome people may e	xperience with chro	onic headache (chronic migraine	or chronic tensio	n-type headacl	1e).
e 17 outcomes ar Physical sympton Symptoms assoc	ns (12 outcome		ing (5 outcomes).					
	portant you thir		owing outcomes are	assessed in res	earch studies of ch	ronic headache,	and select the r	umber that best
uestion ID: 622								
hysical sympto	oms							
			you think it is that is portant, 5=uncertair			ured. For each iten	n listed below, p	lease use the 9-
uestion ID: 623								
1. * Cognitive fur	nction - difficult	y concentrating, at	bility to think 'clearly	' or to remember	r things			
ot at all important								Very importa
1	2	3	4	5	6	7	8	9
uestion ID: 624								
2. * Increased se	nsitivities - to I	ight, sound, smell,	touch					
ot at all important		1						Very importa
1	2	3	4	5	6	7	8	9
3. * <i>Pain associa</i> ot at all important			of an unpleasant ph					
uestion ID: 625 3. * <i>Pain associa</i> t ot at all important 1	ted with Heada	ache - experience	of an unpleasant ph 4	nysical sensation	that aches or hurts	7	8	Very importa
3. * <i>Pain associa</i> ot at all important 1							8	
3. * Pain associa: ot at all important 1 uestion ID: 626	2	3					8	
3. * <i>Pain associa</i> ot at all important 1	2	3					8	
3. * Pain associa: ot at all important 1 uestion ID: 626 4. * Duration of pa	2	3					8	9
3. * Pain association ot at all important 1 uestion ID: 626 4. * Duration of pa ot at all important	2	3 vith a headache	4	5	6	7		9 Very importa
3. * Pain association of at all important 1 1 uestion ID: 626 4. * Duration of pa ot at all important 1	2	3 vith a headache	4	5	6	7		9 Very importa
3. * Pain association of a tail important 1 uestion ID: 626 4. * Duration of pain of a tail important 1 uestion ID: 627	2 in associated w 2	3 rith a headache	4	5	6	7		9 Very importa
3.* Pain associa: to at all important 1 uestion ID: 626 4.* Duration of pa to at all important 1 uestion ID: 627 5.* Frequency of	2 in associated w 2	3 rith a headache	4	5	6	7		9 Very importa
3. * Pain association of a tail important 1 uestion ID: 626 4. * Duration of pain of a tail important 1 uestion ID: 627	2 in associated w 2	3 rith a headache	4	5	6	7		9 Very importa
3. * Pain associa: to at all important 1 uestion ID: 626 4. * Duration of pain to at all important 1 uestion ID: 627 5. * Frequency of ot at all important	2 in associated w 2 <i>pain</i> associated	3 rith a headache 3 I with a headache	4	5	6	7	8	9 Very importa 9 Very importa
3. * Pain associa: t at all important 1 uestion ID: 626 4. * Duration of pa ot at all important 1 uestion ID: 627 5. * Frequency of , ot at all important 1	2 in associated w 2 <i>pain</i> associated	3 rith a headache 3 I with a headache	4	5	6	7	8	9 Very importa 9 Very importa
3. * Pain associa: t at all important 1 uestion ID: 626 4. * Duration of pa ot at all important 1 uestion ID: 627 5. * Frequency of , ot at all important 1 uestion ID: 628	2 in associated w 2 pain associated	3 rith a headache 3 with a headache 3	4	5	6	7	8	9 Very importe 9 Very importe
3. * Pain associa: t at all important 1 uestion ID: 626 4. * Duration of pa t at all important 1 uestion ID: 627 5. * Frequency of , t at all important 1 uestion ID: 628 6. * Sevrity/ inter.	2 in associated w 2 pain associated	3 rith a headache 3 I with a headache	4	5	6	7	8	9 Very importa 9 Very importa 9
3. * Pain associa: to at all important 1 uestion ID: 626 4. * Duration of pa ot at all important 1 uestion ID: 627 5. * Frequency of r ot at all important 1 uestion ID: 628 6. * Severity/ inter- ot at all important	2 in associated w 2 pain associated 2 sity of pain ass	3 rith a headache 3 with a headache 3 ociated with a hea	4 4 dache	5	6	7	8	9 Very importa 9 Very importa 9
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3. * Pain associa: t at all important 1 uestion ID: 626 4. * Duration of pain ot at all important 1 uestion ID: 627 5. * Frequency of ot at all important 1 uestion ID: 628 6. * Severity/ inter- ot at all important 1 uestion ID: 628	2 in associated w 2 pain associated 2 sity of pain ass 2	3 rith a headache 3 with a headache 3 ociated with a hea	4 4 dache 4	5	6	7	8	9 Very importa 9 Very importa 9
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1.8.* Physical fatigue - experiencing physical fatigue, tiredness, lacking in energy, feeling physically exhausted

1	2	3	4	5	6	7	8	
Overties ID: 004								
Question ID: 631 1.9. * Sleep quality -	baing able to	have a reatful also						
Not at all important	- being able to	nave a restiui siee	ιþ					Very
1	2	3	4	5	6	7	8	Very
Question ID: 632								
1.10. * Visual disturt	bances – distu	rbances to vision i	ncluding visual au	ra, blurred vision				
Not at all important	2	3	4	5	6	7	8	Very
	2	J	*	J	U	1	0	
Question ID: 633								
1.11. * Vertigo or dizz	ziness							
Not at all important								Very
1	2	3	4	5	6	7	8	
Question ID: 634								
1.12. * Vomiting and	/ or feelings of	nausea						
Not at all important								Very
1	2	3	4	5	6	7	8	
Question ID: 639 1.13. You may use th	is space to ela	aborate on any view	ws in relation to or	ne or more the abo	ve items. Please	note to which of th Maximum	he items your co length: 5000 chara	mments rel sters. Charact
1.13. You may use th Question ID: 640						Maximum	length: 5000 chara	mments rel cters. Charact
1.13. You may use th						Maximum ase add them her	length: 5000 chara	cters. Charact
1.13. You may use th Question ID: 640						Maximum ase add them her	e.	cters. Charact
1.13. You may use th Question ID: 640 1.14. If you would like						Maximum ase add them her	e.	cters. Characte
1.13. You may use th Question ID: 640 1.14. If you would like Question ID: 641	e to suggest a	dditional items for a	consideration unde			Maximum ase add them her	e.	cters. Charact
1.13. You may use th Question ID: 640 1.14. If you would like	e to suggest a	dditional items for a	consideration unde			Maximum ase add them her	e.	cters. Charact
1.13. You may use th Question ID: 640 1.14. If you would like Question ID: 641 Symptoms assoc	e to suggest a	dditional items for a	consideration unde			Maximum ase add them her	e.	cters. Charact
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1.13. You may use th Question ID: 640 1.14. If you would like Question ID: 641 Symptoms assoc Question ID: 642 1.15. * Anger - feeling Not at all important Question ID: 643	e to suggest a ciated with o gs of anger, ar 2	dditional items for o one's emotiona anoyance, irritation	consideration under I well-being	er this domain in th	e next round, ple	Maximum ase add them her Maximum	e. e. lengti: 5000 chara	cters. Charact
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1.13. You may use th Question ID: 640 1.14. If you would like Question ID: 641 Symptoms assoc Question ID: 642 1.15. * Anger - feeling Not at all important 1 Question ID: 643 1.16. * Anxiety - con Not at all important 1 Question ID: 644 1.16. * Anxiety - con Not at all important 1 Question ID: 644 1.17. * Depressive meta	e to suggest a iated with o gs of anger, ar 2 cerned, worrie 2	dditional items for o one's emotiona inoyance, irritation 3 d, fearful or anxiou 3	I well-being 4	er this domain in th	e next round, plea	Maximum ase add them her Maximum	length: 5000 charas	Very Very
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Question ID: 646 1.19. * Suicidal thoughts - extreme feelings of desperation, unhappiness, hopelessness Not at all important Very important 3 4 5 6 9 Question ID: 648 1.20. You may use this space to elaborate on any views in relation to one or more the above items. Please note to which of the items your comments relate. Maximum length: 500 characters. Characters left: 5000 Question ID: 649 1.21. If you would like to suggest additional items for consideration under this domain in the next round, please add them here. Naximum length: 5000 characters. Characters left: 5000 Question ID: 651 2 Section 2: Life impact - functioning, activities and general well-being This section lists the way in which chronic headache (chronic migraine or chronic tension-type headache) may impact an individual's life. The 28 outcomes are grouped across 6 areas: 1) Activities of daily living (5 outcomes) 2) Emotional well-being (6 outcomes) 3) Work / Education (3 outcomes) 4) Social impact (8 outcomes) 5) Overall health and well-being (3 outcomes) and 6) Environmental factors (1 outcome) Please rate how important you think it is that the following outcomes are assessed in research studies of chronic headache, and select the number that best represents your opinion. Question ID: 652 Activities of daily living Reminder: For each item please rate how important you think it is that is that the listed outcomes are measured. For each item listed below, please use the 9-point scale to rate importance; where 1=not at all important, 5=uncertain, 9=very important. Question ID: 653 2.1.* Being able to carry out usual tasks or basic activities relating to self-care – such as eating, washing, dressing, toileting, personal hygiene and continence, getting out of bed, bending down (basic activities of daily life) Not at all important Very important 1 2 3 4 5 6 7 8 9 Question ID: 654 2.2.* Being able to carry out usual tasks or daily activities inside or outside the home (not related to paid employment) that support an independent lifestyle – such as tidying one's home, walking short distances, managing finance, driving, using technology (instrumental activities of daily life) Not at all important Very important 5 1 3 4 6 7 8 9 2 Question ID: 656 2.3.* Being able to perform physical activities or hobbies / activities that require physical effort - including informal or organized sport, physical fitness, or active leisure pursuits Not at all important Very important 4 5 6 7 8 9 1 3 2 Question ID: 657 2.4. * Being able to carry out non-physical activities or hobbies - including reading for enjoyment, playing a musical instrument, going to the theatre or cinema, and watching the television Not at all important Very important 4 5 6 8 9

Question ID: 658

2.5. * Needing to rest or lie down *because of* a headache

uestion ID: 661 7. If you would lik								
If you would lik								
	e to suggest ad	ditional items for c	onsideration under	this domain in the	next round, pleas	e add them here. Maximum lei	ngth: 5000 charact	ers. Characters left: 8
uestion ID: 662								
motional well-	beina							
	J							
uestion ID: 663								
8. * <i>Coping</i> - Beir	ng able to cope v	vith the emotional	<i>impact</i> of headach	e on oneself (inclue	des managing stre	ss, embarrassmer	nt)	
ot at all important						ĺ		Very impor
1	2	3	4	5	6	7	8	9
uestion ID: 664								
9. * Embarrassm	ent - feeling em	barrassed or self-c	onscious					
ot at all important		_				_		Very impor
1	2	3	4	5	6	7	8	9
uestion ID: 665								
10. * Emotional s	<i>upport</i> – availa	bility of emotional	support from family	y members or friend	ds			
ot at all important								Very impor
1 nestion ID: 666	2 <i>isolation</i> – feeli 2	3 ng isolated; reduce 3	4 ed social interactio 4	5 ns 5	6	7 7	8 8	9 Very impor 9
1 uestion ID: 666 11. * <i>Feelings of</i> t at all important 1	<i>isolation</i> – feeli	ng isolated; reduce	ed social interactio	ns				Very impor
1 uestion ID: 666 11. * Feelings of ot at all important 1 uestion ID: 667	<i>isolation</i> – feeli	ng isolated; reduce	ed social interactio	ns 5	6			Very impor
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5

6

4

Not at all important

1

2 3

Very important

7 8 9

stion ID: 684						
* Family rol	es - being able to	<i>provide</i> usual car	e and support for f	amily and close fri	ends	
at all importan	t					
1	2	3	4	5	6	

Question ID: 685

2.25. * Family rol	es - being able to	<i>provide</i> usual car	e and support for f	family and close fr	iends			
Not at all importar	ıt							Very important
1	2	3	4	5	6	7	8	9

Quest

lot at all importan	ıt							Very import
1	2	3	4	5	6	7	8	9

N

Question ID: 683 2.24. * Family roles - relationships with family and close friendships (includes marriage; parenthood)

Not at all importar	ıt							Very impor
1	2	3	4	5	6	7	8	9

Question ID: 682 2.23. * Coping - being able to cope with the social impact of headache

Social

Question ID: 681

Question ID: 680
2.22. If you would like to suggest additional items for consideration under this domain in the next round, please add them here.
Maximum length: 5000 characters. Characters left: 5000

Question ID: 680

2.21. You may use this space to elaborate on any views in relation to one or more the above items. Please note to which of the items your comments relate. Maximum length: 5000 characters. Characters left: 5000

Question ID: 679

1 2 3 4 5 6

Question ID: 676 2.20. * Social role - relationships with work colleagues or peers Not at all important Very important 9

2 3 1 4 5

2.19. * Needing to take time-off work (paid or unpaid) / study Not at all important Very important 9

Question ID: 675

Very important 3 4 5 6 8 2 9

2.18. * Being able to carry out activities related to work (paid or unpaid)/ study to an acceptable or usual standard Not at all important

Question ID: 674

Work / Education

Question ID: 673

2.17. If you would like to suggest additional items for consideration under this domain in the next round, please add them here. Maximum length: 5000 characters. Characters left: 5000

Question ID: 672

2.16. You may use this space to elaborate on any views in relation to one or more the above items. Please note to which of the items your comments relate. Maximum length: 5000 characters. Characters left: 5000

Question ID: 671

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uestion ID: 686	n in cooid or loid		ability to participate	e in social or leisure	activition			
	II III SOCIAI OI IEIS	ure activities – a	ability to participate	e in social of leisure	acuviues			Vencimper
lot at all important 1	2	3	4	5	6	7	8	Very impor 9
1	2	3	4	5	0	1	0	9
uestion ID: 687								
.28. * Participatio	n in social activit	ies - ability to par	rticipate in social o	r leisure activities th	nat involve loud n	oises and/ or brigh	t lights	
ot at all important								Very impor
1	2	3	4	5	6	7	8	9
uestion ID: 688								
.29. * Social supp	oort – availability o	f family members	and friends to pro	vide help or suppor	t			
ot at all important								Very impor
1	2	3	4	5	6	7	8	9
uestion ID: 689								
30. * <i>Travel</i> – abil	lity to travel							
lot at all important								Very impor
1	2	3	4	5	6	7	8	9
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38. * Trigger factors - ability to avoi	d headache trigge	er factors					
ot at all important							Very import
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Medication Use (2 outcomes) Financial Impact (3 outcomes) ease rate how important you think i resents your opinion. estion ID: 706 epects of treatment effective eminder: For each item please rate bint scale to rate importance; where	ness how important you	u think it is that is	that the listed o	putcomes are mea			
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1.* Satisfaction with treatment							
ot at all important							Very import
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Jestion ID: 708							
2. * Confidence in treatment							Ventiment
at all important	3	4	5	6	7	8	Very import 9
estion ID: 709							
 * Credibility of treatment – belief 	in the trustworthin	ess, reliability or	integrity of treat	ment			
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Question ID: 591	
.3. * In which country are you resident?	
Please S	elect (
uestion ID: 592	
4. * Which of the following best describe your role? (please tick all that are relevent	ant)
uestion ID: 593	
ealth-care professional with a specific interest in Migraine / Headache	
Clinician	
Neurologist	
Neurologist Special Interest	
GP special interest	
Nurse Specialist	
Psychologist	
Pharmacist	
Chiro/Osteo/Physio	
Alternative Therapy	
Other	
luestion ID: 594	
luestion ID: 594	
Health Economist	
Clinical Academic	
Other health professional academic	
Clinical Trialist	
Systematic reviewer	
Measurement Expert	
Journal editor / member of editorial board	
Research - other	
luestion ID: 595	
lealth policy related activities	
Contribute to headache-related guideline development	
Health Service Manager/Provider/commissioner	
Member of national funding body	
hank you, please click Save to finish.	
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Prov 1 2 3 4 5 6 Next	
Save to complete later	Next Page >
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10.1.3 Round one (episodic) as it appeared to participants

Centor 1: Symptoms as sociated with an Episodic Migraine is section its symptoms that some people may experiment with splated migraine is action its symptoms as enclosed two testics: Physical symptom; With a Centomsets; and Symptoms associated with one we being (0 automes). is action that symptoms that been embodied well being (0 automes). is action that symptoms that been embodied well being (0 automes). is action that symptoms that been embodied well being (0 automes). is action that symptoms that been embodied well being (0 automes). is action that symptoms that been embodied well being (0 automes). is action that symptoms that been embodied and pool and (0 automes). is action that symptoms that been embodied and pool and (0 automes). is action that symptoms that been embodied and pool and (0 automes). is action that symptoms that been embodied and pool and (0 automes). is action that symptoms that been embodied and pool and (0 automes). is a important:	Section 1. Cumptomo							
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1.8. * Physical fatigue - experiencing physical fatigue, tiredness, lacking in energy, feeling physically exhausted

								Very importar
1	2	3	4	5	6	7	8	9
uestion ID: 510								
9. * Sleep quality	- being able to	have a restful slee	p					
lot at all important								Very importa
1	2	3	4	5	6	7	8	9
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uestion ID: 511								
.10. * Visual distur	bances - distu	irbances to vision i	ncluding visual au	ra, blurred vision				
lot at all important				_		_		Very importa
1	2	3	4	5	6	7	8	9
uestion ID: 512								
.11. * Vertigo or diz	ziness							
ot at all important								Very importa
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uestion ID: 513								
.12. * <i>Vomiting</i> and	/ or feelings of	fnausea						
lot at all important	17 OF IGGILINGS OF	i nausea						Very importa
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Question ID: 598								
Juestion ID: 596								
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Section 2: Li			-	-	al well-bell	ıg		
This section lists the			may impact an in	dividual's life.				
The 28 outcomes an 1) Activities of daily I	iving (5 outcom	es)						
 Emotional well-be Work / Education 	(3 outcomes)	s)						
 Social Impact (8 c Overall health and 	d well-being (3 d							
 Environmental fac Please rate how imp 			wing outcomos or	a accordin race	arch studios of a		and coloct the nur	nhor that host
epresents your opin			wing outcomes as	6 83363360 11 1636		naoure inigrame,	and select the har	nber that best
Question ID: 526								
Activities of dail	y living							
Activities of dail		to how important	ou think it is that i	o that the listed ou	teomos aro moso	urad. Far aaah ita	m listed below, pla	and use the Q
	n item please ra					ured. For each ite	m listed below, plea	ase use the 9-
Activities of dail Reminder: For each point scale to rate in	n item please ra					ured. For each ite	m listed below, plea	ase use the 9-
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Activities of dail Activities of dail Reminder: For each point scale to rate in Question ID: 527 2.1.* Being able to continence, getting co co continence, getting co co co continence, getting co c	n item please ra mportance; whe carry out <i>usual</i> ut of bed, bend 2 carry out <i>usual</i> is home, walking 2 2 berform <i>physic</i> is. 2 2 carry out <i>non-p</i>	tasks or basic ac ing down (basic a 3 tasks or daily ac short distances, r 3 al activities or ho 3	ortant, 5=uncertai ttivities relating te ttivities of daily life 4 tivities inside or or nanaging finance, 4 bblies / activities 4	n, 9=very importar p self-care – such p s utside the home (n driving, using tech 5 that require phys 5	nt. as eating, washin 6 ot related to paid nology (<i>instrumen</i> 6 <i>ical effort</i> – inclu 6	g, dressing, toileti 7 employment) that tail activities of da 7 ding informal or or 7	ng, personal hygie 8 support an independity life) 8 ganized sport, phy 8	very importat 9 ndent lifestyle – Very importat 9 sical fitness, or Very importat 9
Activities of dail Activities of dail Reminder: For each point scale to rate ii Question ID: 527 2.1.* Being able to c continence, getting c Question ID: 528 2.2.* Being able to c such as tidying one's Not at all important 1 Question ID: 529 2.3.* Being able to r active lessure pursuit Not at all important 1 Question ID: 529 2.3.* Question ID: 520	n item please ra mportance; whe carry out <i>usual</i> ut of bed, bend 2 carry out <i>usual</i> is home, walking 2 2 berform <i>physic</i> is. 2 2 carry out <i>non-p</i>	tasks or basic ac ing down (basic a 3 tasks or daily ac short distances, r 3 al activities or ho 3	ortant, 5=uncertai ttivities relating te ttivities of daily life 4 tivities inside or or nanaging finance, 4 bblies / activities 4	n, 9=very importar p self-care – such p s utside the home (n driving, using tech 5 that require phys 5	nt. as eating, washin 6 ot related to paid nology (<i>instrumen</i> 6 <i>ical effort</i> – inclu 6	g, dressing, toileti 7 employment) that tail activities of da 7 ding informal or or 7	ng, personal hygie 8 support an independity life) 8 ganized sport, phy 8	very importa 9 ndent lifestyle – Very importa 9 sical fitness, or Very importa 9

Question ID: 601

2.5. You may use this space to elaborate on any views in relation to one or more the above items. Please note to which of the items your comments relate. Maximum length: 5000 characters, Characters left: 5000

	ιυ suggest ad	ditional items for cons	aueration under t	nis domain in the	next round, pleas	e add them here. Maximum leni	gth: 5000 charact	ters. Characters left: 5
Question ID: 534								
Emotional well-b	eing							
Question ID: 535								
2.7. * <i>Coping</i> - Being Not at all important	g able to cope v	with the emotional imp	bact of migraine o	on oneself (include	es managing stres	s, embarrassment)		Very import
1	2	3	4	5	6	7	8	9
Question ID: 536								
2.8. * Embarrassme	nt - feeling em	barrassed or self-con	scious					
Not at all important								Very import
1	2	3	4	5	6	7	8	9
Question ID: 537								
				and an an film of				
	oport – avallad	ility of emotional supp	ort from family m	lembers or menas	5			
Not at all important	2	3	4	5	6	7	8	Very import 9
	2	3	4	5	0	1	0	9
								Very impor
2.10. * <i>Feelings of i</i> a Not at all important 1	2	3	4	5	6	7	8	Very import 9
Not at all important 1 Question ID: 539 2.11. * <i>Frustration</i> – Not at all important	being annoyed	d or upset about not b	eing able to achi	eve what one wisi	hes			9 Very impor
Not at all important 1 Question ID: 539 2.11. * Frustration –						7	8 8	9
Not at all important 1 Question ID: 539 2.11.* Frustration – Not at all important 1 Question ID: 540 2.12.* Self-worth –	being annoyed	d or upset about not b	eing able to achi	eve what one wisi	hes 6	7	8	9 Very import 9
Not at all important 1 Question ID: 539 2.11. * <i>Frustration</i> – Not at all important 1 Question ID: 540	being annoyed	d or upset about not b	eing able to achi	eve what one wisi	hes 6	7	8	9 Very import 9
Not at all important 1 Question ID: 539 2.11. * <i>Frustration</i> – Not at all important 1 Question ID: 540 2.12. * <i>Self-worth</i> – Not at all important	being annoyed 2 feeling like a br	d or upset about not b	eing able to achi 4 nclude feeling val	5 ued or helpless; a	6 accepted or reject	7 ad; feelings of self-e	8 Psteem	9 Very import 9 Very import
Not at all important 1 Question ID: 539 2.11. * Frustration Not at all important 1 Question ID: 540 2.12. * Self-worth 1	being annoyed 2 feeling like a br	d or upset about not b	eing able to achi 4 nclude feeling val	5 ued or helpless; a	6 accepted or reject	7 ad; feelings of self-e	8 Psteem	9 Very import 9 Very import
Not at all important 1 Question ID: 539 2.11. * <i>Frustration</i> – Not at all important 1 Question ID: 540 2.12. * <i>Self-worth</i> – Not at all important	being annoyed 2 feeling like a br	d or upset about not b	eing able to achi 4 nclude feeling val	5 ued or helpless; a	6 accepted or reject	7 ad; feelings of self-e	8 Psteem	9 Very import 9 Very import
Not at all important 1 2 Cuestion ID: 539 2 Constant all important 1 2 Cuestion ID: 540 2 Cuestion ID: 541 2 Cuestion ID: 541	2 feeling like a bu 2	d or upset about not b	eing able to achir 4 nclude feeling val	5 ued or helpless; a	6 accepted or reject	7 ad; feelings of self-e	8 Psteem	9 Very import 9 Very import
Not at all important 1 2 Cuestion ID: 539 2 Constant all important 1 2 Cuestion ID: 540 2 Cuestion ID: 541 2 Cuestion ID: 541	2 feeling like a bu 2	d or upset about not b 3 urden to others; can in 3	eing able to achir 4 nclude feeling val	5 ued or helpless; a	6 accepted or reject	7 ad; feelings of self-e	8 Psteem	9 Very import 9 Very import 9
Not at all important 1 2Question ID: 539 22.11. * Frustration – Not at all important 1 2Question ID: 540 22.12. * Self-worth – Not at all important 1 2Question ID: 540 2.1. * Self-worth – Not at all important 1 2Question ID: 541 2.13. * Stress - feelin	2 feeling like a bu 2	d or upset about not b 3 urden to others; can in 3	eing able to achir 4 nclude feeling val	5 ued or helpless; a	6 accepted or reject	7 ad; feelings of self-e	8 Psteem	9 Very import 9 Very import 9
Not at all important 1 2 Cuestion ID: 539 2 2 1 1 <i>Frustration</i> Not at all important 1 2 Cuestion ID: 540 2 1 2 Cuestion ID: 541 2 Cuestion ID: 541 2 Cuestion ID: 541 CUEstion	2 2 feeling like a bu 2	d or upset about not b 3 urden to others; can in 3	eing able to achir 4 nclude feeling val 4	sve what one wisl 5 ued or helpless; a 5	6 accepted or rejectr 6	7 ad; feelings of self-e	8 Insteem	9 Very import 9 Very import 9 Very import
Not at all important 1 2 Cuestion ID: 539 2.11.* Frustration – Not at all important 1 2 Cuestion ID: 540 2.12.* Self-worth – Not at all important 1 2 Cuestion ID: 541 2.13.* Stress - feelin Not at all important 1	2 2 feeling like a bu 2	d or upset about not b 3 urden to others; can in 3	eing able to achir 4 nclude feeling val 4	sve what one wisl 5 ued or helpless; a 5	6 accepted or rejectr 6	7 ad; feelings of self-e	8 Insteem	9 Very import 9 Very import 9 Very import
Not at all important 1 2 Cuestion ID: 539 2 C.11.* Frustration – Not at all important 1 2 Cuestion ID: 540 2 C.12.* Self-worth – Not at all important 1 2 Cuestion ID: 541 2 Cuestion ID: 542 2 Cuestion ID: 542	being annoyed 2 feeling like a bu 2 ngs of distress, 2	d or upset about not b 3 urden to others; can ir 3 frustration or irritation 3	eing able to achin 4 nclude feeling val 4	sve what one wisl 5 ued or helpless; a 5	6 accepted or rejectr 6	7 ad; feelings of self-e	8 Insteem	9 Very import 9 Very import 9 Very import
Not at all important 1 2 Cuestion ID: 539 2 C.11.* Frustration – Not at all important 1 2 Cuestion ID: 540 2 C.12.* Self-worth – Not at all important 1 2 Cuestion ID: 541 2 Cuestion ID: 542 2 Cuestion ID: 542	being annoyed 2 feeling like a bu 2 ngs of distress, 2	d or upset about not b 3 urden to others; can in 3	eing able to achin 4 nclude feeling val 4	sve what one wisl 5 ued or helpless; a 5	6 accepted or rejectr 6	7 ad; feelings of self-e	8 Insteem	9 Very import 9 Very import 9 Very import
Not at all important 1 2 Cuestion ID: 539 2 2 1 1 <i>Frustration</i> Vot at all important 1 2 Cuestion ID: 540 2 1 2 1 2 1 2 1 2 2 1 1 2 2 2 1 1 <i>Stress</i> - feelin Not at all important 1 2 2 2 1 1 <i>Stress</i> - feelin Not at all important 1 2 2 2 1 1 <i>Stress</i> - feelin Not at all important 1 2 2 2 1 1 <i>Stress</i> - feelin Not at all important 1 2 2 2 1 1 <i>Stress</i> - feelin 2 2 2 1 1 <i>Stress</i> - feelin 2 2 2 2 1 1 <i>Stress</i> - feelin 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	being annoyed 2 feeling like a bu 2 ngs of distress, 2 ngs of worry, co	d or upset about not b 3 urden to others; can ir 3 frustration or irritation 3	eing able to achin 4 nclude feeling val 4 n 4	sve what one wisi 5 ued or helpless; a 5	hes 6 accepted or rejecte 6	7 ad; feelings of self-e 7 7	8 8 8	Very import 9 Very import 9 Very import 9 Very import
Not at all important 1 2 Cuestion ID: 539 2 Cuestion ID: 540 2 Cuestion ID: 540 2 Cuestion ID: 541 2 Cuestion ID: 541 2 Cuestion ID: 542	being annoyed 2 feeling like a bu 2 ngs of distress, 2	d or upset about not b 3 urden to others; can ir 3 frustration or irritation 3	eing able to achin 4 nclude feeling val 4	sve what one wisl 5 ued or helpless; a 5	6 accepted or rejectr 6	7 ad; feelings of self-e	8 Insteem	Very import 9 Very import 9 Very import 9

Question ID: 543 Work / Education Question ID: 544								
Work / Education								
Question ID: 544								
2.17. * Being able to o	carry out <i>activitie</i>	s related to work	k (paid or unpaid,)/ <i>study</i> to an acc	eptable or usual st	andard		
lot at all important								Very importa
1	2	3	4	5	6	7	8	9
uestion ID: 545								
18. * Needing to tal	ke time-off work (paid or unpaid) / s	study					
ot at all important				_		_		Very import
1	2	3	4	5	6	7	8	9
uestion ID: 546								
.19. * Social role - r	elationships with v	work colleagues o	or peers					
lot at all important								Very importa
1	2	3	4	5	6	7	8	9
uestion ID: 606 21. If you would like uestion ID: 555 ocial uestion ID: 556					e next round, plea	se add them here. Maximum len	gth: 5000 characte	rs. Characters left: 56
.22. * <i>Coping</i> – bein	ig able to cope wit	th the social imp	act of migraine o	on oneself				
lot at all important								Very import
1	2	3	4	5	6	7	8	9
Question ID: 557								
23. * Family roles -	- relationshins wit	h family and close	e friendshine (inc	ludes marriage: p	arenthood)			
lot at all important	. siadonaripa Wit							Very importa
1	2	3	4	5	6	7	8	9
	2	3	4	5	0	1	0	9
uestion ID: 558 24. * <i>Family roles</i> -			and support for f	amily and close fr	iends 6	7	8	Very importa
lot at all important 1	2	3						
1	2	3						
1 uestion ID: 559								
1			tion with intimate	and personal rela	ationships; ability to	o show affection to o	others	Very import

Question ID: 604

Very important

Not at all important	2	3						Very importa
			4	5	6	7	8	9
		J.		, in the second s	Ŭ		Ĭ	, i i i i i i i i i i i i i i i i i i i
Question ID: 562								
2.28. * Social suppo	rt – availability	of family members a	and friends to pro	vide help or suppo	ort			
Not at all important								Very importa
1	2	3	4	5	6	7	8	9
Question ID: 563								
2.29. * <i>Travel</i> – ability	v to travel							
Not at all important	, 10 11 11 10							Very importa
1	2	3	4	5	6	7	8	9
	is space to slok	porate on any views	in relation to one	or more the abov	e items. Please n	ote to which of the it Maximum leng	ems your com th: 5000 characte	ments relate. rs. Characters left: 50
2.30. You may use th	iis space to eiat	•						io. onarabició ion. or
2.30. You may use th	is space to elar							
	iis space to elar							
Question ID: 608			nsideration under	this domain in the	e next round, pleas	se add them here.	ih: 5000 characte	
Question ID: 608			nsideration under	this domain in the	e next round, pleas	se add them here.	ih: 5000 characte	
Question ID: 608 2.31. If you would lik Question ID: 565	e to suggest ad		nsideration under	this domain in the	e next round, pleas	se add them here.	h: 5000 characte	
Question ID: 608 2.31. If you would lik Question ID: 565 Overall health an Question ID: 566	e to suggest add	ditional items for co				se add them here.	h: 5000 characte	
Question ID: 608 2.31. If you would lik Question ID: 565 Dverall health an Question ID: 566 2.32.* Overall health	e to suggest add	ditional items for co				se add them here.	h: 5000 characte	rs. Characters left: 50
2.30. You may use th Question ID: 608 2.31. If you would lik Question ID: 565 Overall health an Question ID: 566 2.32. * Overall health Not at all important	e to suggest add	ditional items for co				se add them here.	h: 5000 characte	rs. Characters left: 50 Very importa
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Question ID: 608 2.31. If you would lik Question ID: 565 Overall health an Question ID: 566 2.32.* Overall healt Not at all important	e to suggest ad d well-being h – an individua	ditional items for co	atus; the ability to) live a 'normal' life	,	se add them here. Maximum leng		rs. Characters left: 50 Very importe
Question ID: 608 2.31. If you would lik Question ID: 565 Dverall health an Question ID: 566 2.32. * Overall health Not at all important	e to suggest ad d well-being h – an individua	ditional items for co	atus; the ability to) live a 'normal' life	,	se add them here. Maximum leng		rs. Characters left: 50 Very importa
Question ID: 608 2.31. If you would lik Question ID: 565 Overall health an Question ID: 566 2.32. * Overall health Not at all important 1 Question ID: 567 2.33. * Self-Manager	e to suggest add d well-being h – an individua	ditional items for co I's general health st	atus; the ability to	b live a 'normal' life	6	se add them here. Maximum leng	8	very importa
Question ID: 608 2.31. If you would lik Question ID: 565 Overall health an Question ID: 566 2.32. * Overall health Not at all important 1 Question ID: 567 2.33. * Self-Manager self-efficacy	e to suggest add d well-being h – an individua	ditional items for co I's general health st	atus; the ability to	b live a 'normal' life	6	se add them here. Maximum leng	8	very importe 9
Question ID: 608 2.31. If you would lik Question ID: 565 Overall health an Question ID: 566 2.32. * Overall health Not at all important Question ID: 567 2.33. * Self-Manager self-efficacy Not at all important	e to suggest ad d well-being <i>h</i> – an individua 2 <i>nent</i> - ability to	ditional items for co ''s general health st 3 effectively decrease	atus; the ability to 4 a / minimize / cont	b live a 'normal' life 5 trol the impact of r	6 nigraine on onese	se add them here. Maximum long 7	8 lical, diet, lifes	very importa 9 Very importa 9
Question ID: 608 2.2.31. If you would lik Question ID: 565 Dverall health an Question ID: 566 2.32.* Overall health Not at all important 1 Question ID: 567 2.33.* Self-Manager	e to suggest add d well-being h – an individua	ditional items for co I's general health st	atus; the ability to	b live a 'normal' life	6	se add them here. Maximum leng	8	very importe 9
Question ID: 608 2.31. If you would lik Question ID: 565 Overall health an Question ID: 566 2.32. * Overall health Not at all important Question ID: 567 2.33. * Self-Manager self-efficacy Not at all important	e to suggest ad d well-being <i>h</i> – an individua 2 <i>nent</i> - ability to	ditional items for co ''s general health st 3 effectively decrease	atus; the ability to 4 a / minimize / cont	b live a 'normal' life 5 trol the impact of r	6 nigraine on onese	se add them here. Maximum long 7	8 lical, diet, lifes	very importa 9 tyle choices etc); Very importa
Question ID: 608 2.31. If you would lik Question ID: 565 Overall health an Question ID: 566 2.32.* Overall health Question ID: 567 2.33.* Self-Manager self-efficacy Not at all important 1	e to suggest ad d well-being <i>h</i> – an individua 2 <i>nent</i> - ability to	ditional items for co ''s general health st 3 effectively decrease	atus; the ability to 4 a / minimize / cont	b live a 'normal' life 5 trol the impact of r	6 nigraine on onese	se add them here. Maximum long 7	8 lical, diet, lifes	very importa 9 tyle choices etc); Very importa
Question ID: 608 Question ID: 565 Question ID: 566 Question ID: 566 Question ID: 567 Question ID: 568	e to suggest add d well-being h – an individua 2 nent - ability to 2	ditional items for co I's general health st 3 effectively decrease	atus; the ability to 4 9 / minimize / cont 4	b live a 'normal' life 5 trol the impact of r 5	6 nigraine on onese 6	se add them here. Maximum long 7	8 lical, diet, lifes	very importa 9 tyle choices etc); Very importa
Question ID: 608 2.31. If you would lik Question ID: 565 Overall health an Question ID: 566 2.32.* Overall health Not at all important 1 Question ID: 567 2.33.* Self-Manager self-efficacy Not at all important 1 Question ID: 568 2.34.* Unpredictabl	e to suggest add d well-being h – an individua 2 nent - ability to 2	ditional items for co I's general health st 3 effectively decrease	atus; the ability to 4 9 / minimize / cont 4	b live a 'normal' life 5 trol the impact of r 5	6 nigraine on onese 6	se add them here. Maximum long 7	8 lical, diet, lifes	Very importa 9 tyle choices etc); Very importa 9
Question ID: 608 2.31. If you would lik Question ID: 565 Overall health an Question ID: 566 2.32. * Overall health Not at all important Question ID: 567 2.33. * Self-Manager self-efficacy Not at all important	e to suggest add d well-being h – an individua 2 nent - ability to 2	ditional items for co I's general health st 3 effectively decrease	atus; the ability to 4 9 / minimize / cont 4	b live a 'normal' life 5 trol the impact of r 5	6 nigraine on onese 6	se add them here. Maximum long 7	8 lical, diet, lifes	very importa 9 tyle choices etc); Very importa

Question ID: 560

Not at all important

2.26. * Participation in social or leisure activities - ability to participate in social or leisure activities

.38. You may use this s	2	migraine trigge 3	r factors 4					
.37. * Trigger factors - lot at all important 1 Question ID: 611 .38. You may use this s	2							
Lot at all important 1 Question ID: 611 .38. You may use this s	2							
1 Question ID: 611 .38. You may use this s		3	4					Very importar
Question ID: 611 2.38. You may use this s Question ID: 612				5	6	7	8	9
.38. You may use this s	space to elabora							
.38. You may use this s	space to elabora							
	space to elabora							
Question ID: 612		ate on any view	s in relation to one	e or more the ab	ove items. Please n			iments relate. ars. Characters left: 500
luestion ID: 612						Waxinginie	ngth. 5000 characte	sis. Characters left. Soc
uestion ID: 612								
00				allela de secto la d	he and a set of a last			
.39. If you would like to	suggest addition	onal items for c	onsideration under	r this domain in 1	ne next round, piea:	Se add them here. Maximum le	ngth: 5000 characte	ers. Characters left: 500
uestion ID: 573								
ection 3: Treat	tment effe	ectiveness	s and Finan	cial Impac	t			
his section lists aspects	of treatment ef	ffectiveness an	d financial impact	associated with	episodic migraine.			
he 10 outcomes are gro								
) Aspects of treatment e) Medication Use (2 out		outcomes)						
) Financial Impact (3 ou								
lease rate how importa	ant you think it i	is that the follow	ving outcomes are	assessed in res	earch studies of epi	sodic migraine,	and select the n	umber that best
epresents your opinion.								
Question ID: 574								
spects of treatment	nt effectiven	ess						
Reminder: For each iten								
point scale to rate impor	rtance; where 1	=not at all impo				red. For each item	n listed below, pl	ease use the 9-
			ortant, 5=uncertain			red. For each item	n listed below, pl	ease use the 9-
Question ID: 575			ortant, 5=uncertain			red. For each item	n listed below, pl	ease use the 9-
	reatment		ortant, 5=uncertain			red. For each item	n listed below, pl	ease use the 9-
.1.* Satisfaction with tr	reatment		ortant, 5=uncertain			red. For each item	n listed below, pl	
.1.* Satisfaction with t	reatment	3	ortant, 5=uncertain			red. For each item	n listed below, pl	
8.1. * <i>Satisfaction</i> with tr Not at all important		3		, 9=very importa	nt.	red. For each item		Very importa
.1.* <i>Satisfaction</i> with the lot at all important		3		, 9=very importa	nt.	red. For each item		Very importa
.1.* <i>Satisfaction</i> with the lot at all important		3		, 9=very importa	nt.	red. For each item		Very importa
.1.* Satisfaction with tr lot at all important 1 tuestion ID: 576	2	3		, 9=very importa	nt.	red. For each item		Very importa
1.* Satisfaction with the lot at all important 1 1 Question ID: 576 .2.* Confidence in treat	2	3		, 9=very importa	nt.	red. For each item		Very importa
A.1.* Satisfaction with the volume of the second se	2	3		, 9=very importa	nt.	red. For each item 7 7		Very importa
Question ID: 576 3.2. * Confidence in trea Vot at all important	2 atment		4	, 9=very importa	nt. 6	red. For each item 7 7	8	Very importar 9 Very importar
A.1.* Satisfaction with the locat at all important 1 Question ID: 576 A.2.* Confidence in treated to the locat at all important 1	2 atment		4	, 9=very importa	nt. 6	red. For each item 7 7	8	Very importa
A.1.* Satisfaction with the locat all important 1 Question ID: 576 A.2.* Confidence in treated to the locat all important 1 Question ID: 577	2 atment 2	3	4	5 5	6 6	red. For each item 7 7	8	Very importa
A.1.* Satisfaction with the locat at all important 1 Question ID: 576 A.2.* Confidence in treat Not at all important 1 Question ID: 577 A.3.* Credibility of treated	2 atment 2	3	4	5 5	6 6	red. For each item 7 7	8	Very importai 9 Very importai 9
1. * Satisfaction with the tot at all important 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	2 tment 2	3 In the trustworthi	4 4 ness, reliability or	5 5 integrity of treat	nt. 6	7	8	Very importat 9 Very importat 9
Satisfaction with the lot at all important Satisfaction ID: 576 Soft at all important Soft at all importa	2 atment 2	3	4	5 5	6 6	red. For each item 7 7	8	Very importai 9 Very importai 9
1. * Satisfaction with the foot at all important 1 2 Question ID: 576 4.2.* Confidence in treated at all important 1 2 Question ID: 577 4.3.* Credibility of treated tot at all important 1	2 tment 2	3 In the trustworthi	4 4 ness, reliability or	5 5 integrity of treat	nt. 6	7	8	Very importat 9 Very importat 9
1. * Satisfaction with the lot at all important 2. 2. 2. 2. 2. 2. 2. 2. 2. 2	2 tment 2	3 In the trustworthi	4 4 ness, reliability or	5 5 integrity of treat	nt. 6	7	8	Very importat 9 Very importat 9
1.1.* Satisfaction with the view of the second seco	2 ttment 2 mment - belief in 2	3 In the trustworthi	4 4 ness, reliability or	5 5 integrity of treat	nt. 6	7	8	Very importat 9 Very importat 9
1. * Satisfaction with the lot at all important Usestion ID: 576	2 ttment 2 mment - belief in 2	3 In the trustworthi	4 4 ness, reliability or	9=very importa	nt. 6	7	8	Very importat 9 Very importat 9 Very importat 9
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Not at all important

Very important

	2	3	4	5	6	7	8	9
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	his space to elab	orate on any views	in relation to on	e or more the abo	ve items. Please no	te to which of the	items your com	ments relate.
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edication use								
uestion ID: 580								
3. * The type (pote	ency) and dose (how much) of med	ication <i>taken wh</i>	en experiencing	a migraine or head	ache		
t at all important							1	Very importa
1	2	3	4	5	6	7	8	9
uestion ID: 581								
. * The type (pote	ency) and dose (how much) of med	ication taken to	<i>prevent</i> a migrain	e or headache			
ot at all important		_		_		_	_	Very importa
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Question ID: 618

3.16. If you would like to suggest additional items for consideration under this domain in the next round, please add them here. Maximum length: 5000 characters. Characters left: 5000

Question ID: 586

4.

Section 4: Complications (Adverse Events)

This section lists events that *may occur* following (or during) treatment for **episodic migraine**. Please note that these are only possibilities and do not occur in everyone. There are just two outcomes.

Please rate how important you think it is that the following outcomes are assessed in research studies of episodic migraine, and select the number that best represents your opinion.

Reminder: For each item please rate how important you think it is that is that the listed outcomes are measured. For each item listed below, please use the 9point scale to rate importance; where 1=not at all important, 5=uncertain, 9=very important.

Question ID: 587

4.1.* Treatment side effects - experiencing undesired secondary effects from taking medications for migraine

Not at all importar	Not at all important Very impo								
1	2	3	4	5	6	7	8	9	

Question ID: 588 4.2. * Mortality (death) Not at all important Very important 1 2 3 4 5 6 9 8 Question ID: 619 4.3. You may use this space to elaborate on any views in relation to one or more the above items. Please note to which of the items your comments relate. Maximum length: 5000 characters. Characters left: 5000 Question ID: 620 4.4. If you would like to suggest additional items for consideration under this domain in the next round, please add them here. Maximum length: 5000 characters. Characters left: 5000 Question ID: 590 5. Section 5: A few questions about you: Finally, we would like to ask a few questions about you: Question ID: 731 5.1. * What is your gender? Male Female

Question ID: 732 5.2. * What is your age?

18-25		
26-35		
36-45		
46-55		
56-65		
>66 years		
Question ID: 591		

5.3. * In which country are you resident?

Please Select	٢

Question ID: 592

5.4. * Which of the following best describe your role? (please tick all that are relevant)

Question ID: 593
Health-care professional with a specific interest in Migraine / Headache
Clinician
Neurologist
Neurologist Special Interest
GP special interest
Nurse Specialist
Psychologist
Pharmacist
Chiro/Osteo/Physio
Alternative Therapy
Other
Question ID: 594
Health-related research
Health Economist
Clinical Academic
Other health professional academic
Clinical Trialist
Systematic reviewer
Measurement Expert
Journal editor / member of editorial board
Research - other
Question ID: 595
Health policy related activities
Contribute to headache-related guideline development
Health Service Manager/Provider/commissioner
Member of national funding body
Thank you, please click Save to finish.
Save
Prev 1 2 3 4 5 6 Next

Save to complete later

Next Page >

10.2 Round Two

10.2.1 Invitation wording provided to Clinvivo and used in invitations

Healthcare professionals

Dear [name]

Many thanks for agreeing to take part in the COSH Study. Please find below the links to Round 2 of the Delphi survey where you can review the results from Round 1 and complete the Round 2 questionnaires.

Once again we would like you to complete TWO questionnaires: one for Episodic Migraine and one for Chronic Migraine. The two questionnaires have been retained due to the differences in outcomes considered most important, and hence to be considered in round 2. However, each questionnaire is significantly shorter than those completed in Round 1, requiring approximately 15 minutes to complete.

episodiclink

chroniclink

Please complete the round by 23:59 UTC on Thursday 22nd March, when it will close.

With best wishes,

Kirstie Haywood and Kimberley White.

Public participants

Dear [name]

Many thanks for agreeing to take part in the COSH Study. Please find below the link to Round 2 of the Delphi survey where you can review the results from Round 1 and complete the Round 2 questionnaire.

chronic/episodic link

Please complete the round by 23:59 UTC on Thursday 22nd March, when it will close.

With best wishes,

Kirstie Haywood and Kimberley White.

10.2.2 Round two (episodic) as it appeared to participants

	0								P	pints spent so
Episodic I	Migraine	•								
There was cons										n Round 1.
	ore created a	shortlist of outo	omes based or	n those rated m	nost highly by p	patients and he	alth professiona	als. Outcomes	achieving a	a median score of C MIGRAINE list
includes 27 outo				,		,,	2.2.000			
The <i>focus of R</i> Whereas previo are now asking	usly you rate	d absolute impo	ortance on a 9-p	point scale (for	your considera	ation both the p	banel median, ar	nd your rating,	are shown	come set. for each item), we
	cimum of 70 one outcom are happy wi	 points to spen e. For outcomes th your choice. 	d - please spen s that you feel a You will find the	d more points are not a priorit number of ava	on those outco y, please rate t ailable spendin	omes that you t these as 0. You ng points restric	think should be p must spend all trive, but this is it	prioritised. You your 70 points intentional in o	can alloca s. You can r rder to help	restrict the
Question ID: 50	1									
1.	-									
Section 1:	Sympto	oms assoc	ciated wit	h an epis	odic migr	raine				
Physical syn	nptoms									
Question ID: 50	2									
1.1.* Cognitive		difficulty concent	trating, ability to	think 'clearly'	or to remembe	er things				
							l ratina: 7 on a s	scale of 1 to 9	, where 9 i	s most important.
Your previous ra									,	
										An absolute priority
Not a priority 0	1	2	3	Α	5	6	7	8	9	An absolute priority 10
U	1	2	3	4	5	0	1	0	9	10
Median (the poi		-	nd, smell, touch panel's respor		ve and half wer	re below) pane	l rating: 8 on a s	scale of 1 to 9	, where 9 i	s most important.
Your previous ra	nt where 50%	6 (or half) of the	panel's respor		ve and half wer	re below) pane	l rating: 8 on a s	scale of 1 to 9		
<i>Your previous ra</i> Not a priority	nt where 50%	% (or half) of the ortance: # on a s	panel's respor	ases were abov			l rating: 8 on a s			An absolute priority
Your previous ra	nt where 50%	6 (or half) of the	panel's respor		ve and half wer	re below) pane. 6	l rating: 8 on a s 7	scale of 1 to 9		
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Your previous ra	nt where 509 ating for impo 1	% (or half) of the ortance: # on a s	panel's respor	ases were abov			l rating: 8 on a s 7			An absolute priority
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Your previous ra Not a priority 0 Question ID: 50 1.3. * Pain asso	nt where 509 ating for impo 1 4 ociated with	K (or half) of the brtance: # on a s 2 Migraine – exp	panel's respor scale of 1 to 9 3 erience of an u	ases were abov 4	5 sical sensation	6 that aches or	7 hurts	8	9	An absolute priority
Your previous ra Not a priority 0 Question ID: 50 1.3. * Pain asso Median (the poi	nt where 509 ating for impo 1 4 bociated with nt where 509	K (or half) of the brtance: # on a s 2 Migraine – exp K (or half) of the	panel's respor scale of 1 to 9 3 erience of an u panel's respor	ases were abov 4	5 sical sensation	6 that aches or	7 hurts	8	9	An absolute priority 10
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Your previous ra Not a priority 0 Question ID: 50 1.3. * Pain assu Median (the poi Your previous ra	nt where 509 ating for impo 1 4 bociated with nt where 509	K (or half) of the brtance: # on a s 2 Migraine – exp K (or half) of the	panel's respor scale of 1 to 9 3 erience of an u panel's respor	ases were abov 4	5 sical sensation	6 that aches or	7 hurts	8	9 9 where 9 is	An absolute priority 10 s most important.
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Your previous ra Not a priority 0 Question ID: 50 1.3.* Pain asso Median (the poir Your previous ra Not a priority 0 Question ID: 50 1.4.* Duration of Median (the poir Your previous ra Not a priority 0	nt where 509 1 1 4 4 5 5 67 pain associated with 1 5 5 67 pain associating for impositing for impositing 1 1	6 (or half) of the trtance: # on a t 2 Migraine – exp 6 (or half) of the rtance: # on a t 2 iated with a mig 6 (or half) of the rtance: # on a t	panel's respor scale of 1 to 9 3 erience of an u panel's respor scale of 1 to 9 3 raine panel's respor scale of 1 to 9	A npleasant physes were about A a sees were about A a a sees were about A a set of the about A a set of	5 sical sensation re and half wer 5	6 that aches or i re below) pane 6	7 hurts I rating: 9 on a s I rating: 9 on a s	8 scale of 1 to 9 8 scale of 1 to 9	9 , where 9 ii 9	An absolute priority 10 s most important. An absolute priority 10 s most important. An absolute priority
Your previous ra Not a priority 0 Question ID: 50 1.3.* Pain asso Median (the poir Your previous ra Not a priority 0 Question ID: 50 Question ID: 50	nt where 509 1 1 4 4 5 5 6 6	6 (or half) of the trance: # on a tr 2 Migraine – exp 6 (or half) of the c and iated with a mig 6 (or half) of the trance: # on a tr 2 2 2	panel's response scale of 1 to 9 3 erfence of an up panel's response scale of 1 to 9 3 raine panel's response scale of 1 to 9 3	A npleasant physes were about A a sees were about A a a sees were about A a set of the about A a set of	5 sical sensation re and half wer 5	6 that aches or i re below) pane 6	7 hurts I rating: 9 on a s I rating: 9 on a s	8 scale of 1 to 9 8 scale of 1 to 9	9 , where 9 ii 9	An absolute priority 10 s most important. An absolute priority 10 s most important. An absolute priority
Your previous ra Not a priority 0 Question ID: 50 1.3. * Pain asso Median (the poi Your previous ra Not a priority 0 Question ID: 50 1.4. * Duration of Median (the poi Your previous ra Not a priority 0 Question ID: 50 1.5. * Frequence	nt where 509 atting for imposi- atting for i	6 (or half) of the trance: # on a to 2 Migraine – exp 6 (or half) of the trance: # on a to 2 iated with a mig 6 (or half) of the trance: # on a to 2 booliged with a mig 2 booliged with	panel's response scale of 1 to 9 3 erience of an u panel's response scale of 1 to 9 3 raine panel's response scale of 1 to 9 3 3	A npleasant physical season of the season of	5 sical sensation re and half wer re and half wer 5	6 that aches or I re below) pane 6 6 6	7 hurts I rating: 9 on a st 1 rating: 9 on a st 7	8 scale of 1 to 9 8 scale of 1 to 9 8	9 , where 9 ii , 9 9 , where 9 ii	An absolute priority 10 s most important. An absolute priority 10 s most important. An absolute priority 10
Your previous ra Not a priority Question ID: 50 1.3. * Pain asso Median (the poi Your previous ra Not a priority 0 Question ID: 50 1.4. * Duration of Median (the poi Question ID: 50 1.5. * Frequenc, Median (the poi	nt where 509 ating for impo 1 4 5 5 6 6 7 9 of pain assoc 1 1 6 6 9 of pain assoc 1	6 (or half) of the trance: # on a t 2 Migraine – exp 6 (or half) of the retrance: # on a t 2 iated with a mig 2 ciated with a m ciated with a m 6 (or half) of the	panel's response scale of 1 to 9 3 erience of an u panel's response scale of 1 to 9 3 raine panel's response scale of 1 to 9 3 3 igraine panel's response scale of 1 to 9	A npleasant physical season of the season of	5 sical sensation re and half wer re and half wer 5	6 that aches or I re below) pane 6 6 6	7 hurts I rating: 9 on a st 1 rating: 9 on a st 7	8 scale of 1 to 9 8 scale of 1 to 9 8	9 , where 9 ii , 9 9 , where 9 ii	An absolute priority 10 s most important. An absolute priority 10 s most important. An absolute priority
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Question ID:	507									
1.6. * Severit	y/ intensity of pa	in associated v	vith a migraine							
			-	nses were abov	e and half wer	e below) panel r	atina: 9 on a s	cale of 1 to 9.	where 9 is m	ost important.
Your previous	s rating for impo	rtance: # on a	scale of 1 to 9							
, Not a priority									An	absolute priority
0	1	2	3	4	5	6	7	8	9	10
	<i>al fatigue</i> – exp					ng physically ex e <i>below) panel r</i>		scale of 1 to 9,	where 9 is m	ost important.
our previous	s rating for impo	rtance: # on a :	scale of 1 to 9							
Not a priority									An a	absolute priority
0	1	2	3	4	5	6	7	8	9	10
Median (the p	ng and / or feelin point where 50% a rating for impo	6 (or half) of the			e and half were	e below) panel r	ating: 7 on a s	scale of 1 to 9,		ost important.
0	1	2	3	4	5	6	7	8	9	10
motional	well-being		cuoning,	activities	and gene	eral well-b	eing			
Question ID: 1	y-concerned, v	vorried, fearful	or anxious		-	e ral well-b o	-	scale of 1 to 9,	where 9 is m	ost important.
Question ID: 2.1. * Anxiety Median (the p	520 y – concerned, v	worried, fearful 5 (or half) of the	or anxious e panel's respor		-		-	cale of 1 to 9,	where 9 is m	ost important.
Question ID: : 2.1. * Anxiety Median (the p Your previous Not a priority	520 y – concerned, v point where 50% s rating for impo	worried, fearful 5 (or half) of the rtance: # on a :	or anxious e panel's respor scale of 1 to 9	nses were abov	e and half were	e below) panel ri	ating: 7 on a s		An a	absolute priority
Question ID: : 2.1. * Anxiety Median (the p Your previous	520 y – concerned, v	worried, fearful 5 (or half) of the	or anxious e panel's respor		-		-	acale of 1 to 9, 8		
Question ID: 1 Aedian (the p Aedian (the p Your previous Not a priority 0 Question ID: 1 Question ID: 1 Questio	520 y – concerned, v point where 50% s rating for impo 1 521 521 sive mood – fee	worried, fearful ; (or half) of the trance: # on a : 2 elling sad, feelil (or half) of the	or anxious a panel's response scale of 1 to 9 3 ng down, feelin panel's respon	nses were above	e and half were 5	a below) panel ri 6	ating: 7 on a s	8	An a 9 where 9 is m	absolute priority 10
Duestion ID: 1 2.1.* Anxiety Median (the p Your previous Not a priority 0 Duestion ID: 1 2.2.* Depres Median (the p Your previous Not a priority	520 y – concerned, v point where 50% rating for impo 521 521 521 521 521 521	worried, fearlul ; (or half) of the trance: # on a : 2 eling sad, feelin ; (or half) of the trance: # on a :	or anxious scale of 1 to 9 3 ng down, feelin panel's respon scale of 1 to 9	4 g sorry for ones nses were abow	e and half were 5	6 6 lepressed e below) panel r	ating: 7 on a s 7 ating: 7 on a s	8 scale of 1 to 9,	An a 9 where 9 is m	absolute priority 10 ost important. absolute priority
Auestion ID: 1 1.1.* Anxiety Aedian (the p four previous lot a priority 0 Auestion ID: 1 2.2.* Depres Aedian (the p four previous lot a priority 0 Auestion ID: 1 3.* Feeling Median (the p	520 y - concerned, v(so ionint where 50% a rating for impo 521 solve mood – 1e solvint where 50% a rating for impo a rating for impo 538 538 538 538	worried, fearful is (or half) of the trance: # on a : 2 eling sad, feelin is (or half) of the 2 eeling isolated; (or half) of the	or anxious panel's respon- scale of 1 to 9 3 ng down, feelin ng down, feelin ng apanel's respon- scale of 1 to 9 3 reduced socia panel's respon-	4 g sorry for ones nses were abow 4 l interactions nses were abow	e and half were 5 well, or feeling o e and half were 5	6 6 lepressed e below) panel r	ating: 7 on a s 7 ating: 7 on a s 7	8 scale of 1 to 9,	An i 9 where 9 is m An i 9	absolute priority 10 oost important. absolute priority 10
Auestion ID: 1 1.1.* Anxiety Action ID: 1 Auestion ID: 1 Auestion ID: 1 Auestion ID: 1 Auestion ID: 1 Action ID: 1 Action ID: 1 Action ID: 1 Auestion ID: 1 Auestio	520 y - concerned, v point where 50% rating for impo 521 521 521 521 521 538 538 538 538 538 538 538 538	worried, fearful ; (or half) of the rtance: # on a : 2 eling sad, feeli is (or half) of the rtance: # on a : 2 eeling isolated; ; (or half) of the rtance: # on a :	or anxious panel's responsed scale of 1 to 9 3 ng down, teelin panel's responsed scale of 1 to 9 3 creduced social panel's responsed to 9	4 g sorry for ones rses were abow 4 l interactions rses were abow	e and hall were 5 well, or feeling o e and hall were 5	e below) panel ri 6 iepressed below) panel ri 6 below) panel ri	ating: 7 on a s 7 ating: 7 on a s 7 ating: 7 on a s	8 scale of 1 to 9, 8	An i 9 where 9 is m 9 where 9 is m An i	absolute priority 10 ost important. absolute priority 10 ost important. absolute priority
Inestion ID: 1. Anxiety leadian (the p leadian (the p))))))))))))))))))))))))))))))))))))	520 y - concerned, v point where 50% rating for impo 521 521 521 521 538 s of isolation 1 538 s of isolation 1 538 s rating for impo 1	worried, fearful ; (or half) of the rtance: # on a : 2 eling sad, feeli is (or half) of the rtance: # on a : 2 eeling isolated; ; (or half) of the rtance: # on a :	or anxious panel's responsed scale of 1 to 9 3 ng down, teelin panel's responsed scale of 1 to 9 3 creduced social panel's responsed to 9	4 g sorry for ones rses were abow 4 l interactions rses were abow	e and hall were 5 well, or feeling o e and hall were 5	e below) panel ri 6 iepressed below) panel ri 6 below) panel ri	ating: 7 on a s 7 ating: 7 on a s 7 ating: 7 on a s	8 scale of 1 to 9, 8	An i 9 where 9 is m 9 where 9 is m An i	absolute priority 10 ost important. absolute priority 10 ost important. absolute priority
uestion ID: 1. * Anxiety ledian (the p our previous ot a priority 0 uestion ID: 1 2. * Depress eledian (the p our previous ot a priority 0 uestion ID: 1 3. * Feeling ledian (the p our previous ot a priority 0 uestion ID: 2 0	520 y - concerned, v point where 50% rating for impo 521 521 521 521 521 538 s of isolation (1 538 s of isolation (1 1 538 540	worried, fearlul is (or half) of the rtance: # on a : 2 eling sad, feelin is (or half) of the rtance: # on a : 2 eeling isolated; is (or half) of the rtance: # on a : 2	or anxious e panel's response scale of 1 to 9 3 ng down, feelin e panel's response scale of 1 to 9 3 creduced social e panel's response scale of 1 to 9 3	4 g sorry for ones asses were abow 4 l interactions asses were abow 4 l at	e and half were 5 welt, or feeling of e and half were 5 e and half were 5	e below) panel ri 6 iepressed below) panel ri 6 below) panel ri	ating: 7 on a s 7 ating: 7 on a s ating: 7 on a s 7 7	8 ecale of 1 to 9, 8 ecale of 1 to 9, 8	An i 9 where 9 is m An i 9 9	absolute priority 10 ost important. absolute priority 10 ost important. absolute priority
tuestion ID: 1 1.1.* Anxiety ledian (the p iour previous ot a priority 0 uestion ID: 1 2.* Depres tedian (the p iour previous ot a priority 0 uestion ID: 1 0 uestion ID: 2 0 uestion ID: 2 0 uestion ID: 2 0 1 4 4 4 .* Self-wood	520 y - concerned, v(solini where 50% s rating for impo 521 521 521 538 1 538 538 538 538 538 538 538 538	worried, fearful is (or half) of the rtance: # on a : 2 eling sad, feelin is (or half) of the rtance: # on a : 2 eeling isolated; is (or half) of the rtance: # on a : 2 e a burden to o	or anxious scale of 1 to 9 3 ng down, feelin panel's respon scale of 1 to 9 3 reduced social panel's respon scale of 1 to 9 3 3 there; can inclu	4 g sorry for ones sees were abow 4 l interactions sees were abow 4 ude feeling value	e and half were 5 e and half were 5 e and half were 5 e and half were 5 e and half were 5	e below) panel n 6 1epressed a below) panel n 6 a below) panel n 6 6	ating: 7 on a s 7 ating: 7 on a s ating: 7 on a s 7 7	8 accale of 1 to 9, accale of	An i 9 where 9 is m An i 9 9	10 10 10 10 10 10 10 10 10 10

Not a priority									An a	bsolute priority
0	1	2	3	4	5	6	7	8	9	10

rour providue	rating for impo	1000. # Off d (
Not a priority									An a	bsolute priority	1
0	1	2	3	4	5	6	7	8	9	10	

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

2.10. * Overall health - an individual's general health status; the ability to live a 'normal' life

Question ID: 566

Overall health and well-being

Question ID: 565

 Not a priority
 An absolute priority

 0
 1
 2
 3
 4
 5
 6
 7
 8
 9
 10

Your previous rating for importance: # on a scale of 1 to 9

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 7 on a scale of 1 to 9, where 9 is most important.

2.9. * Participation in social or leisure activities – ability to participate in, or commit to, social or leisure activities Following qualitative feedback in round 1, this outcome was modified slightly (added words are shown in italics). Thus, please note the rating below relates to the original outcome question. We would like you to evaluate the priority for inclusion of the revised outcome.

Question ID: 560

Not a priority An absolute										
0	1	2	3	4	5	6	7	8	9	10

Your previous rating for importance: # on a scale of 1 to 9

original outcome question. We would like you to evaluate the priority for inclusion of the revised outcome Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 7 on a scale of 1 to 9, where 9 is most important.

2.8. * Family roles - being able to provide usual care and support for family and close friends; including ability to commit to activities Following qualitative feedback in round 1, this outcome was modified slightly (added words are shown in italics). Thus, please note the rating below relates to the original outcome question. We would like you to evaluate the priority for inclusion of the revised outcome

Question ID: 558

Social

Question ID: 555

Not a priority An absolute priority											
0	1	2	3	4	5	6	7	8	9	10	

Your previous rating for importance: # on a scale of 1 to 9

2.7.* Needing to take time-off work (paid or unpaid) / study
Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 9 on a scale of 1 to 9, where 9 is most important.

Question ID: 545

Not a priority An absolute priority										
0	1	2	3	4	5	6	7	8	9	10

Your previous rating for importance: # on a scale of 1 to 9

2.6. "Being able to carry out activities related to work (paid or unpaid)/ study to an acceptable or usual standard Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important.

2.6.* Being able to carry out activities related to work (paid or unpaid)/ study to an acceptable or usual standard

Question ID: 544

Question ID: 543

Not a priority An ab									
0 1 2 3 4 5 6 7 8	9 10								

Your previous rating for importance: **# on a scale of 1 to 9**Not a priority

2.5.* Stress - feelings of distress, frustration or irritation
Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 7 on a scale of 1 to 9, where 9 is most important.

Question ID: 541

An absolute priority

9 10

8

Question ID: 567

2.11.* Self-Management - ability to effectively decrease / minimize / control the impact of migraine on oneself (e.g., pharmacological, diet, lifestyle choices etc); self-efficacy

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important.

Not a priority An absolute prior										
0	1	2	3	4	5	6	7	8	9	10

Question ID: 568

2.12.* Unpredictability of a migraine - uncertainty of being symptom free or able to engage in activities

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 9 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority An absolute pri										
0	1	2	3	4	5	6	7	8	9	10

2.13.* Trigger factors - ability to avoid / manage migraine trigger factors Following qualitative feedback in round 1, this outcome was modified slightly (added words are shown in italics). Thus, please note the rating below relates to the original outcome question. We would like you to evaluate the priority for inclusion of the revised outcome. Median (the point where 50% (or hall) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important.

5

6

7

Your previous rating for importance: # on a scale of 1 to 9

Your previous rating for importance: # on a scale of 1 to 9

Not a priority									An a	bsolu
0	1	2	3	4	5	6	7	8	9	

ot a priority									
0	1	2	3	4	5	6	7	8	ç

t a priority								
0	1	2	3	4	5	6	7	8

4

Question ID: 570

Question ID: 571

Not a priority

0

Question ID: 574 3

Environmental factors

Section 3: Treatment effectiveness and Financial Impact Aspects of treatment effectiveness

1 2 3

Question ID: 575

3.1.* Satisfaction with treatment

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority									An at	solute priority
0	1	2	3	4	5	6	7	8	9	10
Question ID: 57	6									

3.2.* Confidence in treatment

Median (the point where 50% (or hall) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority

Not a priority									An a	bsolute priority
0	1	2	3	4	5	6	7	8	9	10

Question ID: 578

3.3.* Consistency of treatment effect

Median (the point where 50% (or hall) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority									An a	absolute priority
0	1	2	3	4	5	6	7	8	9	10

Question ID: 579

Medication Use

Your previous rating for importance: # on a scale of 1 to 9 Not a priority An absolute priority 1 2 3 4 5 6 7 8 9 0 10 Question ID: 581 3.5. * The type (potency) and dose (how much) of medication *taken to prevent* a migraine Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9 Not a priority An absolute priority 8 0 4 5 6 7 1 2 3 9 10 Question ID: 586 4. **Complications (Adverse Events)** Question ID: 587 4.1. * Treatment side effects - experiencing undesired secondary effects from taking medications for migraine Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9 Not a priority An absolute priority 1 2 3 4 5 6 7 8 0 9 10 Question ID: 744 5. * DURING A MIGRAINE (ICTAL) and BETWEEN MIGRAINES (INTER-ICTAL PERIOD): Would your choice of outcomes be influenced by the time at which they are assessed? That is, during a migraine (ICTAL) or between migraines (INTER-ICTAL Would your c period). Yes No Question ID: 745 5.1. * If YES, please explain how this would vary: Maximum length: 5000 characters. Characters left: 5000 Question ID: 746 5.2. Any other comments? Maximum length: 5000 characters. Characters left: 5000 Thank you, please click Save to finish. Save Prev 1 2 3 Next Save to complete later Next Page >

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important.

Question ID: 580

3.4. * The type (potency) and dose (how much) of medication taken when experiencing a migraine

10.2.3 Round two (chronic) as it appeared to public participants

	17								Points spe
	e CHRONIC I	MIGRAINE - tha le every day, an					more than 3-m	ionths; this hea	dache may not include
Yes									
No									
Question ID: 74	18								
		ic Migraine beer	n diagnosed by	:					
Health P	rofessional								
Self-diag	nosis								
Other									
Question ID: 74	10								
0.1.i. * (please									
ų									
Question ID: 75	50								
		adache do you	have?						
Question ID: 62	21								
CHRONIC	MIGRAI	NE							
		ement between the number of c							included in Round 1.
it least 7 ('imp		ve and/or indica							achieving a median score e CHRONIC MIGRAINE
Vhereas previo	ously you rated		rtance on a 9-p	oint scale (for	your considera	ation both the pa	anel median, a	nd your rating,	a core outcome set. are shown for each item),
0-points to an oints until you	y one outcome are happy wit omes. The nu	e. For outcomes	that you feel a fou will find the	re not a priorit number of av	y, please rate t ailable spendin	hese as 0. You g points restrict	must spend al ive, but this is	l your 70 points intentional in o	can allocate a maximum b. You can re-arrange you rder to help restrict the le your points.
Physical syr	nptoms								
Question ID: 62	23								
		ifficulty concent							
				ses were abou	e and half wer	e below) panel	rating: 8 on a :	scale of 1 to 9	, where 9 is most import
our previous i	aung ior impo	rtance: # on a s	cale of 1 to 9						
lot a priority									An absolute pri

		0	1	2	3	4	5	6	
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Your previous rating for importance: # on a scale of 1 to 9 Not a priority

1.10. * Feelings of isolation - feeling isolated; reduced social interactions

0	1	2	3	4	5	6	7	8	9	10

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 7 on a scale of 1 to 9, where 9 is most important.

Median (the po	oint where 50%	(or half) of the	panel's respon	ises were abov	re and half wer	e below) panel	rating: 7 on a s	scale of 1 to 9	where 9 is m	ost important.
Your previous r	rating for impor	tance: # on a s	cale of 1 to 9							
Not a priority									An a	bsolute priority
0	1	2	3	4	5	6	7	8	9	10

Not a priority An absolute priority 1 2 3 4 5 6 7 8 9 10 0

Your previous rating for importance: # on a scale of 1 to 9

1.9. * Anxiety - concerned, worried, fearful or anxious

1.8.* Sleep quality - being able to have a restful sleep

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 7 on a scale of 1 to 9, where 9 is most important.

Question ID: 631

2 3 4 5 6 7 0 1

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 7 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

1.7. * Physical fatigue - experiencing physical fatigue, tiredness, lacking in energy, feeling physically exhausted

Question ID: 630

Your previous	rating for impor	tance: # on a s	scale of 1 to 9							
Not a priority									An a	bsolute priority
0	1	2	3	4	5	6	7	8	9	10

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 9 on a scale of 1 to 9, where 9 is most important.

Question ID: 628 1.6.* Severity/ intensity of pain associated with a headache

Not a priority

Question ID: 662 Emotional well-being

Question ID: 643

Question ID: 666

Not a priority									An a	absolute priority
0	1	2	3	4	5	6	7	8	9	10

Your previous rating for importance: # on a scale of 1 to 9

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating; 9 on a scale of 1 to 9, where 9 is most important.

1.5. * Frequency of pain associated with a headache

An absolute priority
 0
 1
 2
 3
 4
 5
 6
 7
 8
 9
 10
 Question ID: 627

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9 Not a priority

1.4. * Duration of pain associated with a headache

Question ID: 626

An absolute priority

An absolute priority

8 9 10

1.11.* Self-worth - feeling like a burden to others; can include feeling valued or helpless; accepted or rejected; feelings of self-esteem

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 7 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority									An a	bsolute priority
0	1	2	3	4	5	6	7	8	9	10

Question ID: 669

1.12. * Stress - feelings of distress, frustration or irritation

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority									An a	bsolute priority	
0	1	2	3	4	5	6	7	8	9	10	

Question ID: 652

Activities of daily living

Question ID: 654

1.13. * Being able to carry out usual tasks or daily activities inside or outside the home (not related to paid employment) that support an independent lifestyle - such as tidying one's home, walking short distances, managing finance, driving, using technology (instrumental activities of daily life)

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9 Not a priority

NOT a priority									All d	ibsolute phonty
0	1	2	3	4	5	6	7	8	9	10

Question ID: 658

1.14. * Needing to rest or lie down because of a headache

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority									An a	absolute priority
0	1	2	3	4	5	6	7	8	9	10

Question ID: 673

Work / Education

Question ID: 674

1.15. * Being able to carry out activities related to work (paid or unpaid)/ study to an acceptable or usual standard

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 9 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority									An a	bsolute priority
0	1	2	3	4	5	6	7	8	9	10

Question ID: 675

1.16. * Needing to take time-off work (paid or unpaid) / study

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 9 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority									An a	absolute priority
0	1	2	3	4	5	6	7	8	9	10

Question ID: 676

1.17. * Social role - relationships with work colleagues or peers

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

An absolute priority

Not a priority

uestion ID: 681 ocial uestion ID: 684 18. * Family roles olowing qualitative iginal outcome qu uestion ID: 686 19. * Participation olowing qualitative iginal outcome qu uestion ID: 686 19. * Participation olowing qualitative iginal outcome qu uestion ID: 686 19. * Participation olowing qualitative iginal outcome qu uestion ID: 686	a feedback k estion. We there 50% (r g for importa 1 n in social a feedback k estion. We there 50% (r	in round 1, this would like you for half) of the p ance: # on a se 2 or leisure act in round 1, this would like you for half) of the p	s outcome was to evaluate the panel's respon cale of 1 to 9 3 tivities – ability s outcome was to evaluate the panel's respon	modified sligh e priority for in ses were abov 4 v to participate modified sligh e priority for in	tity (added wor clusion of the r ve and half wer 5 in, or commit tity (added wor clusion of the r	ds are shown ir revised outcome e below) panel 6 to, social or leisi ds are shown ir	rating: 8 on a s	please note the	where 9 is mo An a 9	
Action ID: 684 IS.* Family roles Illowing qualitative ginal outcome qu actian (the point w ur previous rating t a priority 0 Interstion ID: 686 IS.* Participation ID: 686 IS.* Participation ID: 686 IS.* Participation ginal outcome qu actian (the point w ur previous rating t a priority	a feedback k estion. We there 50% (r g for importa 1 n in social a feedback k estion. We there 50% (r	in round 1, this would like you for half) of the p ance: # on a se 2 or leisure act in round 1, this would like you for half) of the p	s outcome was to evaluate the panel's respon cale of 1 to 9 3 tivities – ability s outcome was to evaluate the panel's respon	modified sligh e priority for in ses were abov 4 v to participate modified sligh e priority for in	tity (added wor clusion of the r ve and half wer 5 in, or commit tity (added wor clusion of the r	ds are shown ir revised outcome e below) panel 6 to, social or leisi ds are shown ir	rating: 8 on a s	please note the	where 9 is mo An a 9	ost importa
8. • Family roles llowing qualitative ginal outcome qu <i>ur previous rating</i> t a priority 0 9.• Participation llowing qualitative ginal outcome qu <i>isdian (the point w</i> <i>ur previous rating</i> t a priority	a feedback k estion. We there 50% (r g for importa 1 n in social a feedback k estion. We there 50% (r	in round 1, this would like you for half) of the p ance: # on a se 2 or leisure act in round 1, this would like you for half) of the p	s outcome was to evaluate the panel's respon cale of 1 to 9 3 tivities – ability s outcome was to evaluate the panel's respon	modified sligh e priority for in ses were abov 4 v to participate modified sligh e priority for in	tity (added wor clusion of the r ve and half wer 5 in, or commit tity (added wor clusion of the r	ds are shown ir revised outcome e below) panel 6 to, social or leisi ds are shown ir	rating: 8 on a s	please note the	where 9 is mo An a 9	ost importa
8. • Family roles llowing qualitative ginal outcome qu sodian (the point w ur previous rating t a priority 0 19.• Participation llowing qualitative ginal outcome qu sodian (the point w ur previous rating t a priority	a feedback k estion. We there 50% (r g for importa 1 n in social a feedback k estion. We there 50% (r	in round 1, this would like you for half) of the p ance: # on a se 2 or leisure act in round 1, this would like you for half) of the p	s outcome was to evaluate the panel's respon cale of 1 to 9 3 tivities – ability s outcome was to evaluate the panel's respon	modified sligh e priority for in ses were abov 4 v to participate modified sligh e priority for in	tity (added wor clusion of the r ve and half wer 5 in, or commit tity (added wor clusion of the r	ds are shown ir revised outcome e below) panel 6 to, social or leisi ds are shown ir	rating: 8 on a s	please note the	where 9 is mo An a 9	ost importa
Illowing qualitative ginal outcome qu adaan (the point w uur previous rating 0 0 uestion ID: 686 19.° Participation Illowing qualitative ginal outcome qu sedian (the point w uur previous rating ot a priority	a feedback k estion. We there 50% (r g for importa 1 n in social a feedback k estion. We there 50% (r	in round 1, this would like you for half) of the p ance: # on a se 2 or leisure act in round 1, this would like you for half) of the p	s outcome was to evaluate the panel's respon cale of 1 to 9 3 tivities – ability s outcome was to evaluate the panel's respon	modified sligh e priority for in ses were abov 4 v to participate modified sligh e priority for in	tity (added wor clusion of the r ve and half wer 5 in, or commit tity (added wor clusion of the r	ds are shown ir revised outcome e below) panel 6 to, social or leisi ds are shown ir	rating: 8 on a s	please note the	where 9 is mo An a 9	ost importa
dinal outcome qu didan (the point w ur previous rating t a priority 0 estion ID: 686 9, • Participation lowing qualitative ginal outcome qu welan (the point w ur previous rating t a priority	n in social estion. We not imported feedback i estion. We there 50% (vould like you for half) of the p ance: # on a se 2 or leisure act in round 1, this would like you for half) of the p	to evaluate the panel's respon cale of 1 to 9 3 tivities – ability s outcome was to evaluate the panel's respon	e priority for in ses were abov 4 v to participate modified sligh e priority for in	in, or commit ty (added wor clusion of the r	e below) panel 6 to, social or leisi ds are shown ir	e. rating: 8 on a s 7 yure activities italics). Thus,	scale of 1 to 9,	where 9 is mo An a 9	ost importa
ur previous rating t a priority 0 0 0 0 0 0 0 0 0 0 0 0 0	1 n in social feedback i stion. We there 50% (i	or leisure act n round 1, this would like you or half) of the p	3 itivities – ability s outcome was to evaluate the panel's respon	4 v to participate modified sligh e priority for in	in, or commit i tty (added wor clusion of the r	6 to, social or leisi ds are shown in	7 ure activities italics). Thus,	8	An a 9	bsolute pri
t a priority 0 0 10 10 10 10 10 10 10 10	1 n in social e feedback i estion. We there 50% (i	or leisure act in round 1, this would like you for half) of the p	3 iivities – ability s outcome was to evaluate the panel's respon	modified sligh e priority for in	in, or commit a ttly (added wor clusion of the r	to, social or leise ds are shown ir	ure activities hitalics). Thus,		9	
0 uestion ID: 686 19. * Participation llowing qualitative ginal outcome qu adian (the point w ur previous rating t a priority	n in social e feedback i estion. We there 50% (or leisure act in round 1, this would like you 'or half) of the p	tivities – ability s outcome was to evaluate the panel's respon	modified sligh e priority for in	in, or commit a ttly (added wor clusion of the r	to, social or leise ds are shown ir	ure activities hitalics). Thus,		9	
uestion ID: 686 19. * Participation Idowing qualitative iginal outcome qu edian (the point w pour previous rating ot a priority	n in social e feedback i estion. We there 50% (or leisure act in round 1, this would like you 'or half) of the p	tivities – ability s outcome was to evaluate the panel's respon	modified sligh e priority for in	in, or commit a ttly (added wor clusion of the r	to, social or leise ds are shown ir	ure activities hitalics). Thus,			
19. * Participation Illowing qualitative ginal outcome qu edian (the point w pur previous rating ot a priority	e feedback i estion. We there 50% (i	in round 1, this would like you for half) of the p	s outcome was to evaluate the panel's respon	modified sligh e priority for in	tly (added wor clusion of the r	ds are shown ir	italics). Thus,	nlease note the		
19. * Participation llowing qualitative ginal outcome qu edian (the point w our previous rating ot a priority	e feedback i estion. We there 50% (i	in round 1, this would like you for half) of the p	s outcome was to evaluate the panel's respon	modified sligh e priority for in	tly (added wor clusion of the r	ds are shown ir	italics). Thus,	nlease note the		
llowing qualitative ginal outcome qu edian (the point w ur previous rating it a priority	e feedback i estion. We there 50% (i	in round 1, this would like you for half) of the p	s outcome was to evaluate the panel's respon	modified sligh e priority for in	tly (added wor clusion of the r	ds are shown ir	italics). Thus,	nlease note the		
ginal outcome qu edian (the point w ur previous rating it a priority	estion. We here 50% (would like you for half) of the p	to evaluate the panel's respon	e priority for in	clusion of the r					alates to the sta
<i>ur previous rating</i> t a priority				ses were abov	e and half we		9.		e rating below r	elates to tr
t a priority	n for importa	ance: # on a s i	cale of 1 to 9			e below) panel	rating: 7 on a s	cale of 1 to 9,	where 9 is mo	ost import
0									An a	bsolute pri
	1	2	3	4	5	6	7	8	9	10
ur previous rating	n for importa	ance: # on a s i	cale of 1 to 9							
ot a priority 0	1	2	3	4	5	6	7	8	An a 9	bsolute pri 10
0		2	5	-	3	ů,		0	3	10
estion ID: 695										
		lity to offortivo	ly decrease / n	ninimize / cont	rol the impact	of headache on	oneself (e.g., p	harmacologics	diat lifestula	
	ement - abi	iity to enective					(5/1	mannacologica	ii, ulei, illesiyle	choices et
lf-efficacy				ses were abov	ve and half wer	e below) panel				
lf-efficacy edian (the point w	here 50% (or half) of the p	panel's respon	ses were abov	ve and half wer	e below) panel				
21. * Self-Manage If-efficacy edian (the point w our previous rating ot a priority	here 50% (or half) of the p	panel's respon	ses were abov	ve and half wer	e below) panel			where 9 is mo	

1.23. * Satisfaction with treatment

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority

An absolute priority

0	1	2	3	4	5	6	7	8	9	10
Question ID: 7	08									
	ence in treatm	ont								
			nanal'a raanar	and word abo	in and half way	a balaw) papal	rating: 9 on a	coolo of 1 to 9	, where 9 is mo	ot importa
		rtance: # on a s		Ses were abou	re anu nan wei	e below) parier	raung. o on a :	scale of 1 to 5	, where 5 is inc	simpona
Not a priority	aung ior impor	nance. # on a c							An ol	osolute prior
0	1	2	3	4	5	6	7	8	9	10
	-	_								
Question ID: 7	10									
1.25. * <i>Consis</i>	tency of treatr	nent effect								
Median (the po	oint where 50%	(or half) of the	panel's respon	ses were abou	ve and half wer	e below) panel	rating: 8 on a	scale of 1 to 9	, where 9 is mo	st importa
Your previous	rating for impo	rtance: # on a s	scale of 1 to 9							
Not a priority									An al	osolute prior
0	1	2	3	4	5	6	7	8	9	10
		6 (or half) of the rtance: # on a s		ises were abou	ve and half wer	e below) panel	rating: 8 on a	scale of 1 to 9	, where 9 is mo	st importai
Not a priority									An al	osolute prio
0	1	2	3	4	5	6	7	8	9	10
Question ID: 7	15									
1.27. * The typ	e (potency) an	d dose (how m	uch) of medicat	ion <i>taken to p</i>	prevent a head	ache				
Median (the po	oint where 50%	o (or half) of the	panel's respon	ises were abou	ve and half wer	e below) panel	rating: 8 on a	scale of 1 to 9	, where 9 is mo	st importa
Your previous	rating for impo	rtance: # on a s	scale of 1 to 9							
Not a priority									An al	osolute prior
0	1	2	3	4	5	6	7	8	9	10
Question ID: 7	18									
Financial Im	pact									
Question ID: 7	19									
1.28. * <i>Financ</i>	<i>ial impact</i> - ec	onomic cost as	sociated with tr	eatment for he	eadache (to the	individual (out	-of-pocket expe	enses) and hea	althcare system)	
Median (the po	oint where 50%	or half) of the	panel's respon	ses were abou	ve and half wer	e below) panel	rating: 8 on a	scale of 1 to 9	, where 9 is mo	st importa
Your previous	rating for impo	rtance: # on a s	scale of 1 to 9							
Not a priority									An al	osolute prior
0	1	2	3	4	5	6	7	8	9	10
Question ID: 7	35									
1.29. * Use of	healthcare re	sources in resp	onse to heada	che						
					ve and half wer	e below) panel	rating: 7 on a	scale of 1 to 9	, where 9 is mo	st importa
		rtance: # on a s				,,				
.our previous	aang ior impor									

,											
Not a priority									An a	bsolute priority	1
0	1	2	3	4	5	6	7	8	9	10	

Complications (Adverse Effects)

Median (the poir										
					e and half wer	e below) panel	rating: 9 on a s	scale of 1 to 9), where 9 is mo	ost import
Your previous ra	ating for impor	rtance: # on a :	scale of 1 to 9							
Not a priority										bsolute pri
0	1	2	3	4	5	6	7	8	9	10
Question ID: 726	6									
1.31. * Mortality	(death)									
Median (the poir	nt where 50%	(or half) of the	panel's respor	nses were abov	e and half wer	e below) panel	rating: 9 on a s	scale of 1 to 9	, where 9 is ma	ost import
Your previous ra	ating for impor	rtance: # on a s	scale of 1 to 9							
Not a priority									An a	ibsolute pr
0	1	2	3	4	5	6	7	8	9	10
		your this would	1000							
Question ID: 74		now this would	vary:				M	laximum length: 5	000 characters. Ch	aracters left
Question ID: 745 2.1. * If YES, ple	ease explain h	now this would	vary:				M	laximum length: 5	000 characters. Ch	aracters left:
Question ID: 748 2.1. * If YES, ple Question ID: 748	ease explain h	now this would	vary:				M	laximum length: 5	000 characters. Ch	laracters left
Question ID: 74	ease explain h	now this would	vary:						000 characters. Ch	
Question ID: 748 2.1. * If YES, ple Question ID: 748	ease explain h	now this would	vary:							
Question ID: 745 2.1. * If YES, ple Question ID: 746 2.2. Any other o	6 comments?		vary:							
Question ID: 745 2.1. * If YES, ple Question ID: 746 2.2. Any other o	6 comments?		vary:							
Question ID: 745 2.1. * If YES, ple Question ID: 746 2.2. Any other o	6 comments?		vary:		Save					
Question ID: 745 2.1. * If YES, ple Question ID: 746 2.2. Any other o	6 comments?		vary:		Save					
Question ID: 748 2.1. * If YES, ple Question ID: 748	se click Save		vary:		Save					
Question ID: 744 2.1. * If YES, pie Question ID: 744 Question ID: 744 Thank you, piea	se click Save	to finish.	vary:		Save					

10.2.4 Round two (chronic) as it appeared to professional participants

I. CHRONIC MIGR										
There was considerable a	AINE									
However, we need to redu									Round 1.	
We have therefore create at least 7 ('important') or a now includes 31 outcome	bove and/or indic									
The focus of Round 2 is Whereas previously you r are now asking you to rat	ated absolute imp	ortance on a 9-p	oint scale (for	your consideration	ation both the p	anel median, a	and your rating	, are shown		
We would like you to 'sg You have a maximum of 10-points to any one outc points until you are happy number of outcomes. The	70-points to spen ome. For outcome with your choice.	d - please spend s that you feel at You will find the	d more points re not a priorit number of ava	on those outco y, please rate f ailable spendir	omes that you these as 0. You ng points restric	nink should be must spend al tive, but this is	prioritised. You Il your 70 point intentional in d	u can allocat s. You can r order to help	e a maximum of e-arrange your restrict the	
Question ID: 622										
Physical symptoms										
Question ID: 623										
1.1.* Cognitive function	- difficulty concer	trating, ability to	think 'clearly'	or to remembe	er things					
Median (the point where S					-	rating: 8 on a	scale of 1 to s	9, where 9 is	s most important.	
Your previous rating for in	portance: # on a	scale of 1 to 9								
lot a priority								,	An absolute priority	
Not a priority								9	10	
0 1 Question ID: 624 I.2.* Increased sensitiv Median (the point where & Your previous rating for in Not a priority	0% (or half) of the	e panel's respons scale of 1 to 9	ses were abov					9, where 9 is	An absolute priority	
0 1 Question ID: 624 1.2.* Increased sensitiv Median (the point where s Your previous rating for in	ties - to light, sou	nd, smell, touch						9, where 9 is		
Question ID: 624 1.2.* Increased sensitiv Median (the point where 5 Your previous rating for in Not a priority 0 1	ties - to light, sou 0% (or half) of the uportance: # on a	nd, smell, touch e panel's respons scale of 1 to 9	ses were abov	re and half wei	re below) panel	rating: 8 on a a	scale of 1 to s	9, where 9 is	An absolute priority	
0 1 Question ID: 624 1.2. * Increased sensitiv Median (the point where 5 Your previous rating for in Not a priority 1 Question ID: 625	ties - to light, sou 0% (or half) of the portance: # on a 2	nd, smell, touch a panel's respons scale of 1 to 9	ses were abov	re and half wer	re below) panel	rating: 8 on a :	scale of 1 to s	9, where 9 is	An absolute priority	
0 1 Question ID: 624	ties - to light, sou 0% (or half) of the portance: # on a 2 th Headache - ex	nd, smell, touch a panel's respons scale of 1 to 9 3	ses were abov 4 unpleasant phy	re and half were so that the second s	re below) panel 6	rating: 8 on a : 7	scale of 1 to 9	9, where 9 is	An absolute priority 10	
0 1 Question ID: 624 4.2.* Increased sensitive Median (the point where 5 Your previous rating for in Not a priority 0 0 1 Question ID: 625 1.3.* Pain associated with Median (the point where 5 the point where 5	ties - to light, sou 0% (or half) of the portance: # on a 2 th Headache - ex 0% (or half) of the	nd, smell, touch a panel's respons scale of 1 to 9 3 perience of an u	ses were abov 4 unpleasant phy	re and half were so that the second s	re below) panel 6	rating: 8 on a : 7	scale of 1 to 9	9, where 9 is	An absolute priority 10	
0 1 Question ID: 624	ties - to light, sou 0% (or half) of the portance: # on a 2 th Headache - ex 0% (or half) of the	nd, smell, touch a panel's respons scale of 1 to 9 3 perience of an u	ses were abov 4 unpleasant phy	re and half were so that the second s	re below) panel 6	rating: 8 on a : 7	scale of 1 to 9	9, where 9 is 9	An absolute priority 10 s most important.	
0 1 Question ID: 624	ties - to light, sou 0% (or half) of the portance: # on a 2 th Headache - ex 0% (or half) of the	nd, smell, touch a panel's respons scale of 1 to 9 3 perience of an u	ses were abov 4 unpleasant phy	re and half were so that the second s	re below) panel 6	rating: 8 on a : 7	scale of 1 to 9	9, where 9 is 9	An absolute priority 10	
0 1 Question ID: 624	ties - to light, sou 0% (or half) of the portance: # on a 2 th Headache - ex 0% (or half) of the portance: # on a	nd, smell, touch a panel's respons scale of 1 to 9 3 perience of an u a panel's respons scale of 1 to 9	ses were abov 4 unpleasant phy	re and half wei 5 vsical sensatio	e below) panel 6 n that aches or re below) panel	rating: 8 on a : 7 hurts rating: 9 on a :	scale of 1 to 9	9, where 9 is 9 9	An absolute priority 10 s most important. An absolute priority	
0 1 Question ID: 62+	ties - to light, sou 0% (or half) of the portance: # on a 2 th Headache - ex 0% (or half) of the portance: # on a	nd, smell, touch a panel's respons scale of 1 to 9 3 perience of an u a panel's respons scale of 1 to 9	ses were abov 4 unpleasant phy	re and half wei 5 vsical sensatio	e below) panel 6 n that aches or re below) panel	rating: 8 on a : 7 hurts rating: 9 on a :	scale of 1 to 9	9, where 9 is 9 9	An absolute priority 10 s most important. An absolute priority	
0 1 Question ID: 62+ Increased sensitive Hedian (the point where & Sensitive Your previous rating for in 1 Question ID: 625 Increased sensitive Question ID: 625 Sensitive Your previous rating for in Sensitive Question ID: 625 Sensitive Question ID: 625 Sensitive Question ID: 626 Sensitive	ties - to light, sou 0% (or half) of the portance: # on a 2 th Headache - ex 0% (or half) of the portance: # on a 2	nd, smell, touch a panel's respons scale of 1 to 9 3 scale of 1 to 9 scale of 1 to 9 3	ses were abov 4 unpleasant phy	re and half wei 5 vsical sensatio	e below) panel 6 n that aches or re below) panel	rating: 8 on a : 7 hurts rating: 9 on a :	scale of 1 to 9	9, where 9 is 9 9	An absolute priority 10 s most important. An absolute priority	
0 1 Question ID: 62⊀	ties - to light, sou 0% (or half) of the portance: # on a 2 th Headache - ex 0% (or half) of the portance: # on a 2 ociated with a head	nd, smell, touch a panel's respons scale of 1 to 9 3 scale of 1 to 9 scale of 1 to 9 3 adache	ses were abov 4 unpleasant phy ses were abov 4	re and half wee 5 viscal sensatio re and half wee 5	re below) panel 6 n that aches or re below) panel 6	rating: 8 on a . 7 hurts rating: 9 on a .	scale of 1 to 1 8 scale of 1 to 1 8	9, where 9 is 9 9, where 9 is 9, where 9 is 9	An absolute priority 10 8 most important. An absolute priority 10	
0 1 Question ID: 62+	ties - to light, sou 0% (or half) of the portance: # on a 2 th Headache - ex 0% (or half) of the portance: # on a 2 ociated with a hee 0% (or half) of the	nd, smell, touch a panel's respons scale of 1 to 9 3 scale of 1 to 9 scale of 1 to 9 3 adache a panel's respons	ses were abov 4 unpleasant phy ses were abov 4	re and half wee 5 viscal sensatio re and half wee 5	re below) panel 6 n that aches or re below) panel 6	rating: 8 on a . 7 hurts rating: 9 on a .	scale of 1 to 1 8 scale of 1 to 1 8	9, where 9 is 9 9, where 9 is 9, where 9 is 9	An absolute priority 10 8 most important. An absolute priority 10	
0 1 Question ID: 624 Increased sensitive Median (the point where & Your previous rating for in Not a priority 1 Question ID: 625 Increased where & 1.3. * Pain associated with Median (the point where & Your previous rating for in Not a priority 1 Question ID: 626 1 Question ID: 626 1.4. * Duration of pain ass Median (the point where & Your previous rating for in	ties - to light, sou 0% (or half) of the portance: # on a 2 th Headache - ex 0% (or half) of the portance: # on a 2 ociated with a hee 0% (or half) of the	nd, smell, touch a panel's respons scale of 1 to 9 3 scale of 1 to 9 scale of 1 to 9 3 adache a panel's respons	ses were abov 4 unpleasant phy ses were abov 4	re and half wee 5 viscal sensatio re and half wee 5	re below) panel 6 n that aches or re below) panel 6	rating: 8 on a . 7 hurts rating: 9 on a .	scale of 1 to 1 8 scale of 1 to 1 8	9, where 9 is 9 9, where 9 is 9, where 9 is 9, where 9 is	An absolute priority 10 s most important. An absolute priority 10 s most important.	
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t a priority 0	1	2	3	4	5	6	7	8	9	10
estion ID: 630	D									
. * Physical f	fatigue – exp	eriencing physi	cal fatigue, tire	dness, lacking	in energy, feeli	ing physically ex	chausted			
edian (the poir	nt where 50%	(or half) of the	panel's respon	ises were abov	e and half wer	e below) panel i	rating: 7 on a	scale of 1 to 9), where 9 is i	nost important.
ur previous ra	ating for impor	tance: # on a s	scale of 1 to 9							
t a priority									An	absolute priority
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estion ID: 631	1									
		ble to have a r	estful sleep							
				ises were abov	e and half wer	e below) panel i	rating: 7 on a	scale of 1 to 9), where 9 is I	nost important.
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t a priority									An	absolute priority
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dian (the poir r previous ra	nt where 50%	(or half) of the	panel's respon	ases were abov 4	e and half wen	e below) panel i 6	rating: 7 on a : 7	scale of 1 to 9		nost important. absolute priority 10
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edian (the point ur previous ra t a priority 0 eestion ID: 666 (0. * Feelings edian (the point ur previous ra estion ID: 666 (1. * Self-worn ddian (the point ur previous ra	nt where 50% of isolation in where 50% of isolation in where 50% of isolation in where 50% of it isolation in the set of it is it	(or half) of the tance: # on a s 2 - feeling isolat (or half) of the tance: # on a s 2 2	panel's respon add; reduced so panel's respon scale of 1 to 9 add; reduced so panel's respon acale of 1 to 9 3 athers; can incl panel's respon	4 cial interaction sees were about 4 ude feeling val	5 e and half were 5 ued or helpless	6 e below) panel n 6 s; accepted or re	7 rating: 7 on a a 7	8 scale of 1 to 5 8 so f self-ested	An 9 0, where 9 is r An 9	absolute priority 10 most important. absolute priority 10
adian (the point ur previous ra t a priority 0 4 4 a priority 0 4 a priority 10 a for 10 a fo	nt where 50% of isolation in where 50% of isolation in where 50% of isolation in where 50% of it isolation in the set of it is it	(or half) of the tance: # on a s 2 - feeling isolat (or half) of the tance: # on a s 2 2 se a burden to ((or half) of the	panel's respon add; reduced so panel's respon scale of 1 to 9 add; reduced so panel's respon acale of 1 to 9 3 athers; can incl panel's respon	4 cial interaction sees were about 4 ude feeling val	5 e and half were 5 ued or helpless e and half were	6 e below) panel n 6 s; accepted or re	7 rating: 7 on a a 7	8 scale of 1 to 5 8 ss of self-estee scale of 1 to 5	An 9 0, where 9 is in An 9 0, where 9 is in 0, where 9 is in	absolute priority 10 most important. absolute priority 10 most important. absolute priority
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Activities of daily living

1.6.* Severity/ intensity of pain associated with a headache

1.13. * Being al – such as tidyin										ts spent (so far: 0/70
Median (the po	int where 50%	(or half) of the	panel's respon	ises were abov	e and half were	e below) panel	rating: 8 on a s	cale of 1 to 9,		o opone	50 101. 07.0
Your previous r	ating for impor	tance: # on a s	cale of 1 to 9								
Not a priority									An a	absolute priority	
0	1	2	3	4	5	6	7	8	9	10	
Out of the ID of	-										
Question ID: 65	8										

1.14. * Needing to rest or lie down because of a headache

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority An absolute prior											bsolute priority
	0	1	2	3	4	5	6	7	8	9	10

Question ID: 673

Work / Education

Question ID: 674

1.15. * Being able to carry out activities related to work (paid or unpaid)/ study to an acceptable or usual standard

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 9 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority			

Not a priority An absolute priority										
0	1	2	3	4	5	6	7	8	9	10

Question ID: 675

1.16. * Needing to take time-off work (paid or unpaid) / study

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 9 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority									An a	bsolute priority
0	1	2	3	4	5	6	7	8	9	10

Question ID: 676

1.17. * Social role - relationships with work colleagues or peers

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority An absolute priority											
0	1	2	3	4	5	6	7	8	9	10	

Question ID: 681

Social

Question ID: 684

1.18.* Family roles - being able to provide usual care and support for family and close friends; including ability to commit to activities Following qualitative feedback in round 1, this outcome was modified slightly (added words are shown in italics). Thus, please note the rating below relates to the original outcome question. We would like you to evaluate the priority for inclusion of the revised outcome.

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 8 on a scale of 1 to 9, where 9 is most important. Your previous rating for importance: # on a scale of 1 to 9

Not a priority									An a	absolute priority
0	1	2	3	4	5	6	7	8	9	10

Question ID: 686

1.19. * Participation in social or leisure activities – ability to participate in, or commit to, social or leisure activities Following qualitative feedback in round 1, this outcome was modified slightly (added words are shown in italics). Thus, please note the rating below relates to the original outcome question. We would like you to evaluate the priority for inclusion of the revised outcome.

Median (the point where 50% (or half) of the panel's responses were above and half were below) panel rating: 7 on a scale of 1 to 9, where 9 is most important.

	1	2	3	4	5	6	7	8	Point	ts spent so far:
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Question ID: 693										
		h al a a								
Overall health	h and well-	-being								
Question ID: 694										
.20. * Overall h		-								
our previous ra				ises were abov	e and nail wei	re below) parle	raung: 9 on a	scale of 1 to 9,	where 9 is mo	si important.
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0	1	2	3	4	5	6	7	8	9	10
Question ID: 695	;									
.21. * Self-Man elf-efficacy	agement - a	bility to effectiv	ely decrease / r	minimize / contr	ol the impact	of headache or	n oneself (e.g.,	pharmacologica	al, diet, lifestyle	choices etc);
Aedian (the poin	t where 50%	(or half) of the	nanel's respon	ises were abov	e and half we	re below) pane	ratina: 8 on a	scale of 1 to 9.	where 9 is mo	st important.
our previous ra						, p		,		
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Question ID: 706	6	_		4	5	6	7	8	9	10
Question ID: 706	6	_		4	5	6	7	8	9	10
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Question ID: 706 Aspects of tre Question ID: 707 .23. * Satisfact Aedian (the poin Your previous rai	eatment ef	ffectiveness tment	panel's respon						where 9 is ma	st important.
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	14								Poin	its spent so fa
1.26. * The type	e (potency) ar	d dose (how m	uch) of medicat	ion taken whe	n experiencii	ng a headache				
Median (the po	int where 50%	6 (or half) of the	panel's respon	ses were abov	e and half wei	e below) panel	rating: 8 on a s	scale of 1 to 9), where 9 is m	ost important.
Your previous r	ating for impo	rtance: # on a s	scale of 1 to 9							
Not a priority									An a	absolute priority
0	1	2	3	4	5	6	7	8	9	10
Question ID: 71										
	u pr	id dose (how mi	,							
		6 (or half) of the		ises were abov	e and half wei	e below) panel	rating: 8 on a s	scale of 1 to 9), where 9 is m	ost important.
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Not a priority		2	2		-	0	7	0		absolute priority
0	1	2	3	4	5	6	1	8	9	10
	al impact - eo	conomic cost as 6 (or half) of the								
Your previous r	ating for impo	rtance: # on a s	scale of 1 to 9							
Not a priority										absolute priority
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Question ID: 73 1.29. * Use of I Median (the po. Your previous r. Not a priority 0 Question ID: 74 Complicatio Question ID: 77 Question ID: 78 Question ID: 78 Question ID: 79 Question ID: 79 Median (the po. Your previous r.	healthcare re int where 50% ating for impo 1 13 ns (Advers 25 nnt side effects int where 50%	sources in resp 5 (or half) of the rtance: # on a s 2 e Effects) 5 - experiencing 6 (or half) of the	undesired secco panel's respon	4 ondary effects f	e and half wee 5	e below) panel	rating: 7 on a s	scale of 1 to 5	, where 9 is m An a 9	ost important. absolute priority 10 ost important.
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2. * DURING A MIGRAINE (ICTAL) and BETWEEN MIGRAINES (INTER-ICTAL PERIOD): Would your choice of outcomes be influenced by the time at which they are assessed? That is, during a migraine (ICTAL) or between migraines (INTER-ICTAL period).

Yes

No	
Question ID: 745 2.1. * If YES, please explain how this would vary:	Points spent so far: 0/70 Maximum length: 5000 characters. Characters left: 5000
Question ID: 746 2.2. Any other comments?	Maximum length: 5000 characters. Characters left: 5000
Thank you, please click Save to finish.	ive
Prev 1 2 a Next	
Save to complete later	Next Page >

10.3 Round Three

10.3.1 Invitation wording provided to Clinvivo and used in invitations

Healthcare professionals

Dear [name],

Many thanks for agreeing to take part in the COSH study. Please find below links to the third and final round of the Delphi survey where you can review the results from Round 2 and complete the Round 3 questionnaire.

Once again we would like you to complete TWO questionnaires: one for Episodic Migraine and one for Chronic Migraine. The two questionnaires have been retained due to the differences in outcomes considered most important, and hence considered in Round 3. However, each questionnaire is significantly shorter than those completed on Round 2, requiring approximately 10 minutes to complete.

episodiclink

 $\operatorname{chroniclink}$

Please complete Round 3 by 23.59 UTC Thursday 10th May 2018.

With best wishes,

Kirstie Haywood and Kimberley White.

Public participants

Dear [name],

Many thanks for agreeing to take part in the COSH study. Please find below the link to the third and final round of the Delphi survey where you can review the results from Round 2 and complete the Round 3 questionnaire.

link

Please complete Round 3 by 23.59 UTC Thursday 10th May 2018.

With best wishes,

Kirstie Haywood and Kimberley White.

10.3.2 Round three (episodic) as it appeared to participants

Question ID: 1019

EPISODIC MIGRAINE:

There are four sections to this questionnaire.

Question ID: 1020

1. Results from outcome prioritisation in Round 2:

In Round 2 participants were asked to spend points (total 70) based on how strongly they felt that particular outcomes should be included in the core outcome set for EPISODIC MIGRAINE. Participants were advised to spend more points on outcomes that should be prioritised, with a maximum of 10-points per outcome. Participants were asked to consider 27 potential outcomes shortlisted from Round 1.

There was considerable agreement between all participants (both patients and health professionals) with regards to those outcomes that should be prioritised for inclusion in future EPISODIC MIGRAINE studies. We have listed the outcomes given the highest priority (top 50% of items, ranked 1 to 13 inclusive) for inclusion in future EPISODIC MIGRAINE studies. The results reflect the combined results from both groups – patients and health professionals (Table 1).

TABLE 1. Outcomes prioritised for inclusion in EPISODIC MIGRAINE studies by both patient and health professional groups (combined results)(ranked 1 to 13 inclusive).

RANK (max Sum of combined ratings 27) (max 540)

Outcomes

1	264	Pain associated with Migraine - experience of an unpleasant sensation that aches or hurts
2	258	Frequency of pain associated with a migraine
3	253	Severity or intensity of pain associated with a migraine
4	251	Duration of pain associated with a migraine
5	185	Being able to carry out activities related to work (paid or unpaid) or study to an acceptable or usual standard
6	162	Cognitive function - difficulty concentrating, ability to think 'clearly' or to remember things
7	161	Treatment side-effects - experiencing undesired secondary effects from taking medications for migraine
8	154	Overall health - an individual's general health status; the ability to 'live a normal life'
9	144	Trigger factors – the ability to avoid / manage migraine trigger factors
10	143	Increased sensitivities - to light, sound, smell or touch
11	136	Family roles - able to provide usual care or support for family or close friends, including ability to commit activities
11	136	Self-management – ability to effectively decrease / minimise/ control the impact of migraine on oneself (e.g. pharmaceutical, diet, lifestyle choices etc)
13	135	Needing to take time-off work (paid or unpaid) or study

Question ID: 1021

2. Group differences in Round 2:

To ensure that group differences were observed, the results from the two groups were considered both separately and combined. Whilst there was little disagreement between groups, several outcomes were prioritised in the top 50% of outcomes for just one of the groups, but did not make the top 50% of combined results.

In the knowledge that there was a difference between sub-groups, we would like you to please reconsider these items for inclusion in the final list of prioritised outcomes. If 70% or more of respondents vote 'YES', the outcome will be added to the prioritised list.

Should the following outcomes be included in a core outcome set for studies of EPISODIC MIGRAINE? Please indicate 'Yes' or 'No'?

Prioritised in top 50% of outcomes by health professionals:

BANK	Sum of	Items
(Combined Results)	combined ratings (max 540)	itoina
Question ID: 1022		
2.1.*		
14	131	Satisfaction with treatment (Health professionals ranked this item 9/27, whereas patients ranked it 20/27)
Yes		
No		
Question ID: 1023		
2.2.*		
15	122	Vorniting and/ or feelings of nausea (Health professionals ranked this item 8/27, whereas patients ranked it 25/27)
Yes		
No		
Question ID: 1024		
2.3. *		
16	120	The type (potency) and dose (how much) of a medication <i>taken when experiencing</i> a migraine (Health professionals ranked this item 12/27, whereas patients ranked it 18/27)
Yes		
No		

Prioritised in top 50% of outcomes by patients: Question ID: 1025 2.4. * Unpredictability of a migraine – uncertainty of being symptom free or able to engage in activities (Patients ranked this item 10/27, whereas health professionals ranked it 21/27) 17 117 Yes No Question ID: 1026 2.5. * Physical fatigue – experiencing physical fatigue, tiredness, lacking in energy, feeling physically exhausted (Patients ranked this item 11/27, where health professionals ranked it 23/27) 18 110 Yes No Question ID: 1027 2.6. * 19 108 Depressive mood – feeling sad, feeling down, feeling sorry for oneself, or feeling depressed (Patients ranked this item 13/27, whereas health professionals ranked it 24/27) Yes No Question ID: 1029 3. Core categories (domains) for EPISODIC MIGRAINE: We have grouped the prioritised outcomes into categories (also referred to as domains) which describe broader aspects of health. The categories (domains) describe the aspects of EPISODIC MIGRAINE that need to be measured, as a minimum, to appropriately assess the impact of episodic migraine or effects of healthcare. The categories (domains) describe WHAT should be measured in a core outcome set for studies of episodic migraine. Ideally, a core outcome set should include 7 categories (domains) or fewer. Seven categories (domains) are proposed for the EPISODIC MIGRAINE core outcome set (Table 2). Please consider the following questions per proposed category (domain): Question ID: 1030 Table 2. EPISODIC MIGRAINE - proposed domains and associated outcomes Rank Prioritised outcomes (rank 1 to 13/27 inclusive) Category (domain) and definition Question ID: 1031 3.1. 1 Pain associated with Migraine – experience of an unpleasant sensation that aches or hurts (1/27) PAIN Experience of an unpleasant sensation in the head that aches or hurts; the frequency, intensity and duration of the pain is important · Frequency of pain associated with a migraine (2/27) Severity or intensity of pain associated with a migraine (3/27) • Duration of pain associated with a migraine (4/27) Question ID: 1032 3.1.i. * Are you happy with the grouping of prioritised outcomes for the PAIN category (domain)? Yes No Question ID: 1033 3.1.ii. * Are you happy with the proposed PAIN category (domain) and definition? Yes No Question ID: 1034 3.1.iii. Do you have any additional comments re the PAIN category (domain)? Maximum length: 5000 characters. Characters left: 5000 Question ID: 1036 Question ID: 1035 3.2.

Question ID: 1028

2

· Being able to carry out activities related to work (paid or

USUAL ACTIVITIES

	 unpaid) or study to an acceptable or usual standard (5/27) Family roles – able to provide usual care or support for family 	 Being able to carry out usual activities (including paid or unpaid work, study, domestic chores, care or support for family or close friends) to an acceptable or usual
	or close friends, including ability to commit activities (11/27) Needing to take time-off work (paid or unpaid) or study (13/27) 	standard Being able to participate in, or commit to, usual activities
Question ID: 10	37	
3.2.i. * Are you	happy with grouping of prioritised outcomes for the USUAL ACTIVITIES category	(domain)?
Yes		
No		
Question ID: 10	338	
3.2.ii. * Are you	happy with the proposed USUAL ACTIVITIES category (domain) and definition?	
Yes		
No		
Question ID: 10	139	
3.2.iii. Do you h	have any additional comments re the USUAL ACTIVITIES category (domain)?	Maximum length: 5000 characters. Characters left: 5000
		maximum lengui. Soco characteris. Characteris ten. Soco
Question ID: 10	40	
3.3. 3	Cognitive function – difficulty concentrating, ability to think	COGNITION
	'clearly' or to remember things (6/27)	Difficulty concentrating, ability to 'think clearly', or to
		remember things
Question ID: 10		
Question ID: 10	¹⁴¹ happy with grouping of prioritised outcomes for the COGNITION category (domain the construction of the construction o	2
Yes	happy wan grouping of phonased bacomes for the occurrence category (domain	
No		
Question ID: 10		
	happy with the proposed COGNITION category (domain) and definition?	
Yes		
No		
Question ID: 10		
3.3.iii. Do you h	have any additional comments re the COGNITION category (domain)?	Maximum length: 5000 characters. Characters left: 5000
Question ID: 10)44	
3.4.		
4	 Treatment side-effects – experiencing undesired secondary effects from taking medications for migraine (7/27) 	ADVERSE EVENTS
		 Experiencing undesired secondary effects from taking medications for migraine
Question ID: 10	145	
3.4.i. * Are you	happy with grouping of prioritised outcomes for the ADVERSE EVENTS category	(domain)?
Yes		
No		
Question ID: 10	146	
	happy with the proposed ADVERSE EVENTS category (domain) and definition?	
Yes		
No		
Question ID: 10)47	
	have any additional comments re the ADVERSE EVENTS category (domain)?	
	,	Maximum length: 5000 characters. Characters left: 5000
Question ID: 10	148	

3.5. 5 • An individual's general health status; the ability to 'live a normal OVERALL HEALTH

	life' (8/27)	 An individual's general health status; the ability to 'live normal life'
Question ID: 1	049	
3.5.i. * Are you	happy with grouping of prioritised outcomes for the OVERALL HEALTH category	(domain)?
Yes		
No		
Question ID: 1	usou u happy with the proposed OVEALL HEALTH category (domain) and definition?	
Yes		
No		
Question ID: 1		
3.5.iii. Do you	have any additional comments re the OVERALL HEALTH category (domain)?	Maximum length: 5000 characters. Characters left:
Question ID: 1	052	
3.6.		
6	 Trigger factors – the ability to avoid / manage migraine trigger factors (9/27) 	SELF-MANAGEMENT
	 Self-management – ability to effectively decrease / minimise/ 	 Ability to effectively decrease / minimise/ control the impact of migraine on oneself (e.g. pharmaceutical, di
	control the impact of migraine on oneself (e.g. pharmaceutical, diet, lifestyle choices etc) (11/27)	lifestyle choices etc) Ability to avoid / manage migraine trigger factors
		, , , , , , , , , , , , , , , , , , , ,
Question ID: 1	053	
	happy with grouping of prioritised outcomes for the SELF-MANAGEMENT categor	ry (domain)?
Yes		
No		
Question ID: 1	054	
3.6.ii. * Are you	a happy with the proposed SELF-MANAGEMENT category (domain) and definition	?
3.6.ii. * Are you		?
		?
Yes No	I happy with the proposed SELF-MANAGEMENT category (domain) and definition	?
Ves No Question ID: 1	u happy with the proposed SELF-MANAGEMENT category (domain) and definition	
Ves No Question ID: 1	I happy with the proposed SELF-MANAGEMENT category (domain) and definition	
Ves No Question ID: 11 3.6.iii. Do you	u happy with the proposed SELF-MANAGEMENT category (domain) and definition 055 have any additional comments re the SELF-MANAGEMENT category (domain)?	
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Ves No Question ID: 11 3.6.iii. Do you Question ID: 11 3.7. 7 Question ID: 11 3.7. 7 Question ID: 11 3.7. 7 Question ID: 11 9.7. 7 Question ID: 11 9.7. 7.7. 7.7. 7.7. 7.7. 7.7. 7.7. 7.7. 7.7. 7.7. 7.7. 7.7. 7.7. 7.7. 7.7. 7.7.7. 7.7. 7.7. 7.7. 7.7.7. 7.	happy with the proposed SELF-MANAGEMENT category (domain) and definition biology and definition biology and additional comments re the SELF-MANAGEMENT category (domain)? biology and the second sensitivities – to light, sound, smell or touch (10/27) biology and the second sensitivities – to light, sound, smell or touch (10/27) biology and the second sensitivities – to light, sound, smell or touch (10/27) biology and the second sensitivities – to light, sound, smell or touch (10/27) biology and the second sensitivities – to light, sound, smell or touch (10/27) biology and the second sensitivities – to light, sound, smell or touch (10/27) biology and touch and the second	Maximum length: 5000 characters. Characters left: ASSOCIATED SYMPTOMS • Increased sensitivities – to light, sound, smell or touch
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Question ID: 1061		
3.9. Do you have any additional comments about the proposed categories		length: 5000 characters. Characters left: 5000
Question ID: 1062		
Additional Outcomes:		
inally, in the case that 70% or more of participants vote to include one of the be included within a category (domain). If 70% or more of respondents vote the second se	additional outcomes listed in SECTION 2 in the "YES", the outcome will be included in the propo	prioritised list, the outcome will need sed category (domain).
or each of the outcomes under consideration for inclusion (in SECTION 2)	lease indicate if you happy with the overarching	domain we have assigned:
Prioritised in top 50% of items by health professionals: Dutcome	Domain	
Question ID: 1063		
: 1.* Satisfaction with treatment Health professionals ranked this item 9/27, whereas patients anked it 20/27)	MEDICATION USE	
Ves		
No		
Question ID: 1064		
1.2.* Satisfaction with treatment Health professionals ranked this item 9/27, whereas patients anked it 20/27)	TREATMENT SATISFACTION	N
Ves		
No		
Ruestion ID: 1065		
.3.* omiting and/ or feelings of nausea Health professionals ranked this item 8/27, whereas patients anked it 25/27)	ASSOCIATED SYMPTOMS	
Yes		
No		
Question ID: 1066		
.4.* he type (potency) and dose (how much) of a medication taken then experiencing a migraine Health professionals ranked this item 12/27, whereas patients anked it 18/27.	MEDICATION USE	
Ves		
No		
Question ID: 1067		
rioritised in top 50% of items by patients:		
Question ID: 1068		
5.5.* Inpredictability of a migraine – uncertainty of being symptom eo rable to engage in activities Patients ranked this item 10/27, whereas health professionals anked it 21/27.	SELF-MANAGEMENT	
Ves		
No		
Question ID: 1069		
.6.* hysical fatigue – experiencing physical fatigue, tiredness, acking in energy, feeling physically exhausted Patients ranked this item 11/27, where health professionals anked it 23/27	ASSOCIATED SYMPTOMS	
Yes		
No		
Question ID: 1070		
.7.* Jepressive mood – feeling sad, feeling down, feeling sorry for neself, or feeling depressed	EMOTIONAL WELL-BEING	

Save	
Thank you, please click Save to finish.	
No	
Yes	
Would you like to receive a summary of the results?	
Question ID: 1073	
Question ID: 1072 Many thanks for participating in the COSH study and for completing the three rounds of questionnaire completion	
4.8. Do you have any additional comments about the core categories (domains)?	Maximum length: 5000 characters. Characters left: 50
Question ID: 1071	
No	
Yes	
(Patients ranked this item 13/27, whereas health professionals anked it 24/27)	

10.3.3 Round three (chronic) as it appeared to participants

Question ID: 1074

CHRONIC MIGRAINE:

There are four sections to this questionnaire.

Question ID: 1075

1. Results from outcome prioritisation in Round 2:

In Round 2 participants were asked to spend points (total 70) based on how strongly they felt that particular outcomes should be included in the core outcome set for CHRONIC MIGRAINE. Participants were advised to spend more points on outcomes that should be prioritised, with a maximum of 10-points per outcome. Participants were asked to consider 31 potential outcomes shortlisted from Round 1.

There was considerable agreement between all participants (both patients and health professionals) with regards to those outcomes that should be prioritised for inclusion in future CHRONIC MIGRAINE studies. We have listed the outcomes given the highest priority (top 50% of items, ranked 1 to 15 inclusive) for inclusion in future CHRONIC MIGRAINE studies. The results reflect the combined results from both groups – patients and health professionals (Table 1).

TABLE 1. Outcomes prioritised for inclusion in CHRONIC MIGRAINE studies by both patient and health professional groups (combined results)(ranked 1 to 15 inclusive).

RANK (max 31)	Sum of combined ratings (max 560)	Outcomes
1	285	Severity or intensity of pain associated with a migraine
2	270	Pain associated with Migraine – experience of an unpleasant sensation that aches or hurts
3	242	Frequency of pain associated with a migraine
4	231	Duration of pain associated with a migraine
5	199	Being able to carry out usual tasks or daily activities inside or outside the home (not related to paid employment) that support an independent lifestyle – such as tidying one's home, walking short distances, managing finance, driving, usual technology (instrumental activities of daily life)
6	197	Being able to carry out activities related to work (paid or unpaid) or study to an acceptable or usual standard
7	194	Cognitive function - difficulty concentrating, ability to think 'clearly' or to remember things
8	162	Treatment side-effects - experiencing undesired secondary effects from taking medications for migraine
9	137	Increased sensitivities – to light, sound, smell or touch
10	136	Physical fatigue – experiencing physical fatigue, tiredness, lacking in energy, feeling physically exhausted
11	131	Needing to take time-off work (paid or unpaid) or study
12	126	Satisfaction with treatment
13	122	Overall health - an individual's general health status; the ability to 'live a normal life'
14	114	Sleep quality – being able to have a restful sleep
15	113	Needing to rest or lie down because of a migraine

Question ID: 1076

2. Group differences in Round 2:

To ensure that group differences were observed, the results from the two groups were considered both separately and combined. Whilst there was little disagreement between groups, several outcomes were prioritised in the top 50% of outcomes for just one of the groups, but did not make the top 50% of combined results.

In the knowledge that there was a difference between sub-groups, we would like you to please reconsider these items for inclusion in the final list of prioritised outcomes. If 70% or more of respondents vote 'YES', the outcome will be added to the prioritised list.

Should the following outcomes be included in a core outcome set for studies of CHRONIC MIGRAINE? Please indicate 'Yes' or 'No'?

		Prioritised in top 50% of outcomes by health professionals:
RANK (Combined Results: max 31)	Sum of combined ratings (max 560)	Items
Question ID: 1077		
2.1.*		
16	103	Stress – feelings of distress, frustration or irritation (Health professionals ranked this item 10/31, whereas patients ranked it 20/31)
Yes		
No		
Question ID: 1078		
2.2.*		
26	77	Mortality (death) (Health professionals ranked this item 15/31, whereas patients ranked it 29/31)
• Yes		
No		
Question ID: 1079		

Prioritised in top 50% of outcomes by patients:

Question ID: 1080 2.3. * 18 99 Unpredictability of a migraine – uncertainty of being symptom free or able to engage in activities (Patients ranked this item 14/31, whereas health professionals ranked it 31/31) Yes No Question ID: 1081 3. Core categories (domains) for CHRONIC MIGRAINE: We have grouped the prioritised outcomes into categories (also known as domains) which describe broader aspects of health. The categories (domains) describe the aspects of CHRONIC MIGRAINE that need to be measured, as a minimum, to appropriately assess the impact of chronic migraine or effects of healthcare. The categories (domains) describe WHAT should be measured in a core outcome set for studies of chronic migraine. Ideally, a core outcome set should include 7 categories (domains) or fewer. Seven categories (domains) are proposed for the CHRONIC MIGRAINE core outcome set (Table 2). Please consider the following questions per proposed category (domain) Question ID: 1082 Table 2. CHRONIC MIGRAINE - proposed categories (domains) and associated outcomes Rank Prioritised outcomes (rank 1 to 13/31 inclusive) Category (domain) and definition Question ID: 1083 3.1. 1 Severity or intensity of pain associated with a migraine (1/31) ΡΔΙΝ Pain associated with Migraine – experience of an unpleasant sensation that aches or hurts (2/31) Experience of an unpleasant sensation in the head that aches or hurts; the frequency, intensity and duration of the pain is important' Frequency of pain associated with a migraine (3/31) Duration of pain associated with a migraine (4/31) Question ID: 1084 3.1.i. * Are you happy with grouping of prioritised outcomes for the PAIN category (domain)? Yes No Question ID: 1085 3.1.ii. * Are you happy with the proposed PAIN category (domain) and definition? Yes No Question ID: 1086 3.1.iii. Do you have any additional comments re the PAIN category (domain)? Maximum length: 5000 characters. Characters left: 5000 Question ID: 1087 3.2. Being able to carry out usual tasks or daily activities inside or outside the home (not related to paid employment) that support an independenti filestyle – such as tidying one's home, walking short distances, managing finance, driving, usual technology (instrumental activities of daily life) (5/31) 2 USUAL ACTIVITIES Being able to carry out usual activities (including paid or unpaid work, study, domestic chores, care or support for family or close friends) to an acceptable or usual standard Being able to carry out activities related to work (paid or unpaid) or study to an acceptable or usual standard (6/31) · Being able to participate in, or commit to, usual activities Needing to take time-off work (paid or unpaid) or study (11/31) Question ID: 1088 3.2.i. * Are you happy with grouping of prioritised outcomes for the USUAL ACTIVITIES category (domain)? Yes No Question ID: 1089

3.2.ii. * Are you happy with the proposed USUAL ACTIVITIES category (domain) and definition?

Yes

No

Question ID: 1090

3.2.iii. Do you have any additional comments re the USUAL ACTIVITIES category (domain)?

Maximum length: 5000 characters. Characters left: 5000

to all the second	
Question ID: 1091	
3.	
 Cognitive function – difficulty concentrating, ability to think 'clearly' or to remember things (7/27) 	COGNITION Difficulty concentrating, ability to 'think clearly', or to remember things
uestion ID: 1092	
3.i. * Are you happy with grouping of prioritised outcomes for the COGNITION category	ry (domain)?
Yes	
No	
uestion ID: 1093	
.3.ii. * Are you happy with the proposed COGNITION category (domain) and definition	?
Yes	
No	
Question ID: 1094	
.3.iii. Do you have any additional comments re the COGNITION category (domain)?	Maximum length: 5000 characters. Characters left: 50
	waxinum rengin. 5000 characters. Characters ien. 50
Question ID: 1095	
.4. 4 • Treatment side-effects – experiencing undesired secondary effects from taking medications for migraine (8/31)	ADVERSE EVENTS Experiencing undesired secondary effects from taking medications for migraine
Question ID: 1096	
4.i. * Are you happy with grouping of prioritised outcomes for the ADVERSE EVENTS	category (domain)?
Yes	
No	
Question ID: 1097	
.4.ii. * Are you happy with the proposed ADVERSE EVENTS category (domain) and do	efinition?
Yes	
Yes	
Ves No	
Ves No Ruestion ID: 1098	nain'?
Ves No	nain)? Maximum length: 5000 characters. Characters left: 50
Ves No Ruestion ID: 1098	nain)? Maximum length: 5000 characters. Characters left: 50
Ves No Ruestion ID: 1098	nain)? Maximum length: 5000 characters. Characters left: 50
Yes No No Additional comments re the ADVERSE EVENTS category (don additional comments	Maximum length: 5000 characters. Characters left: 50
Yes No	Maximum length: 5000 characters. Characters left: 51 ASSOCIATED SYMPTOMS Increased sensitivities – to light, sound, smell or touch Physical fatigue – experiencing physical fatigue, tiredness, lacking in energy, beling physical fatigue, the deling physical fatigue schusters
Yes No Ves No Ves Increased sensitivities – to light, sound, smell or touch (9/31) Physical fatigue – experiencing physical fatigue, tiredness, lacking in energy, feeling physically exhausted (10/31)	Maximum length: 5000 characters. Characters left: 51 ASSOCIATED SYMPTOMS Increased sensitivities – to light, sound, smell or touch Physical fatigue – experiencing physical fatigue, tirednass, lacking in energy, feeling physically exhauster Sileep quality – being able to have a restrilu sleep Needing to rest or lie down because of a headache
Ves No Ves No Ves No Ves Ves No Vestor ID: 1098 4.iii. Do you have any additional comments re the ADVERSE EVENTS category (don Vestor ID: 1099 5. · Increased sensitivities – to light, sound, smell or touch (9/31) · Physical fatigue – experiencing physical fatigue, tiredness, tacking in energy, feeling physical fatigue, tiredness, tacking in energy, teeling to have a restful sleep (14/31) · Steep quality – being able to have a restful sleep (14/31) · Needing to rest or lie down because of a headache (15/31)	Maximum length: 5000 characters. Characters left: 51 ASSOCIATED SYMPTOMS • Increased sensitivities – to light, sound, smell or touch • Physical falgue – experiencing physical falgue, tiredness, lacking in energy, feeling physical falgue, etiledness, lacking in Aneva en astful sleep • Silee quality – being able to have a restful sleep
Yes No Ves Increased sensitivities – to light, sound, smell or touch (9/31) Physical fatigue – experiencing physical fatigue, tiredness, lacking in energy, feeling physical fatigue (10/31) Siee quality – being able to have a restful sleep (14/31) Needing to rest or lie down because of a headache (15/31) uestion ID: 1100	Associated symptoms Associated symptoms Increased sensitivities – to light, sound, smell or touch Physical faligue – experiencing physical faligue, tiredness, lacing in energy, healing physical lighted schause Sleep quality – being able to have a restful sleep Needing to rest or lie down because of a headache
Yes No Ves No Ves No Ves Ves Ves No Ves	Associated symptoms Associated symptoms Increased sensitivities – to light, sound, smell or touch Physical faligue – experiencing physical faligue, tiredness, lacing in energy, healing physical lighted schause Sleep quality – being able to have a restful sleep Needing to rest or lie down because of a headache
	Associated symptoms Associated symptoms Increased sensitivities – to light, sound, smell or touch Physical faligue – experiencing physical faligue, tiredness, lacing in energy, healing physical lighted schause Sleep quality – being able to have a restful sleep Needing to rest or lie down because of a headache
	Associated symptoms Associated symptoms Increased sensitivities – to light, sound, smell or touch Physical faligue – experiencing physical faligue, tiredness, lacing in energy, healing physical lighted schause Sleep quality – being able to have a restful sleep Needing to rest or lie down because of a headache
Ves No Ves No Ves S S S Increased sensitivities - to light, sound, smell or touch (9/31) Physical fatigue - experiencing physical fatigue, tredness, lacking in energy, feeling physical fatigue, kitedhess, lacking in energy. Teeling physical fatigue could (10/31) Sleep quality - being able to have a restful sleep (14/31) Needing to rest or lie down because of a headache (15/31) Ves No Ne	Associated symptoms Associated symptoms Increased sensitivities – to light, sound, smell or touch Physical faligue – experiencing physical faligue, tiredness, lacing in energy, healing physical lighted schause Sleep quality – being able to have a restful sleep Needing to rest or lie down because of a headache
Ves No Ves No Ves Ves Ves Ves Ves No Ves Ves No Ves Ves No Ves Ves No Ves No Ves Ves No Ves No	Assimum length: 5000 characters. Characters left: 5 ASSOCIATED SYMPTOMS - Increased sensitivities – to light, sound, smell or touch - Physical fatigue – experiencing physical fatigue, tredness, lacking in energy, feeling physical fatigue, - Sleep quality – being able to have a restful sleep - Needing to rest or lie down because of a headache PTOMS category (domain)?
Ves No Ves No Ves No Ves Ves S S S Increased sensitivities – to light, sound, smell or touch (9/31) Physical fatigue – experiencing physical fatigue, tiredness, lacking in energy, feeling physical fatigue, tiredness, lacking in crest or lie down because of a headache (15/31) Ves No	Assimum length: 5000 characters. Characters left: 50 ASSOCIATED SYMPTOMS • Increased sensitivities – to light, sound, smell or touch • Physical fatigue – oxperiencing physical fatigue, • Sieep quality – being able to have a restful sleep • Needing to rest or lie down because of a headache PTOMS category (domain)?
Yes No No No Increased sensitivities – to light, sound, smell or touch (9/31) Physical fatigue – experiencing physical fatigue, tiredness, lacking in energy, feeling physical/atigue, tiredness, lacking in energy, feeling physical/atigue energy, feeling physical/atigue, tiredness, lacking in energy, feeling physical/atigue, tirednesy, lacking in energy, feeling physical	Assimum length: 5000 characters. Characters left: 5 ASSOCIATED SYMPTOMS - Increased sensitivities – to light, sound, smell or touch - Physical fatigue – experiencing physical fatigue, tredness, lacking in energy, feeling physical fatigue, - Sleep quality – being able to have a restful sleep - Needing to rest or lie down because of a headache PTOMS category (domain)?

Question ID: 1103	//	
3.6.		
6 • Satisfaction with treatment (12/31)	MEDICATION USE	
Question ID: 1104		
3.6.i. * Are you happy with grouping of prioritised outcomes for the MEDICATION USE categor	y (domain)?	
Ves		
No		
Question ID: 1105		
3.6.ii. * Are you happy with the proposed MEDICATION USE category (domain) and definition?	?	
Yes		
No		
Question ID: 1106		
3.6.iii. Do you have any additional comments re the MEDICATION USE category (domain)?		
	Maximum length: 5000 characters. Characters left: 5000	
Question ID: 1107		
3.7.		
 An individual's general health status; the ability to 'live a normal 	OVERALL HEALTH	
life' (8/27)	 An individual's general health status; the ability to 'live a normal life' 	
	nomaine	
Question ID: 1108		
3.7.i. * Are you happy with grouping of prioritised outcomes for the OVERALL HEALTH category	ry (domain)?	
Yes		
No		
Question ID: 1109		
3.7.ii. * Are you happy with the proposed OVERALL HEALTH category (domain) and definition	?	
Yes		
No		
Question ID: 1110		
3.7.iii. Do you have any additional comments re the OVERALL HEALTH category (domain)?		
Maximum length: 5000 characters. Characters left: 5000		
Question ID: 1111		
3.8. If you've ticked NO to any of the above questions, please indicate why and how the proposed category (domain) needs to change. Maximum length: 5000 characters. Characters left: 5000		
Question ID: 1112	A	
3.9. Do you have any additional comments about the proposed domains?		
	Maximum length: 5000 characters. Characters left: 5000	
Question ID: 1113		
4. Additional Outcomes:		
Finally, in the case that 70% or more of participants vote to include one of the additional outcomes listed in SECTION 2 in the prioritised list, the outcome will need to be included within a domain. If 70% or more of respondents vote 'YES', the outcome will be included in the proposed domain.		
For each of the outcomes under consideration for inclusion (in SECTION 2) please indicate if you happy with the overarching domain we have assigned:		
Prioritised in top 50% of items by health professionals:		
Outcome	Domain	
Question ID: 1114		
4.1.* Stress – feelings of distress, frustration or irritation	EMOTIONAL WELL-BEING	
(Health protessionals ranked this item 10/31, whereas patients ranked it 20/31)		
Yes		

No		
Question ID: 1115		
4.2.* Mortality (death) (Health professionals ranked this item 15/31, whereas patients ranked it 29/31))		ADVERSE EVENTS
Yes		
No		
Question ID: 1116		
Prioritised in top 50% of items by patients:		
Question ID: 1117 4.3.* Unpredictability of a migraine – uncertainty of being symptom free or able to engage in activities (Patients ranked this item 14/31, whereas health professionals ranked it 31/31)		SELF-MANAGEMENT
Ves		
No		
Question ID: 1118		
4.4. Do you have any additional comments about the core categories (doma	uins)?	Maximum length: 5000 characters. Characters left: 500
Question ID: 1119		
Many thanks for participating in the COSH study and for completing the three	e rounds of o	questionnaire completion.
Question ID: 1120		
* Would you like to receive a summary of the results?		
Yes		
No		
Thank you, please click Save to finish.		
Save		
Save to complete later		Next Page >

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