Headache Review - Cephalalgia

Appendix 1.1 : Search strategies: Construct searches

Database: Embase Classic+Embase <1947 to 2017 Week 16>

Search Strategy:

- 1 exp chronic daily headache/ or exp episodic tension headache/ or exp headache/ or exp primary headache/ or exp chronic tension headache/ or exp new daily persistent headache/ or exp secondary headache/ or exp tension headache/ (201706)
- 2 (headache* or migraine*).ti,ab. (136921)
- 3 (headache* adj3 (mixed or combination or tension or tension type or muscle contraction or psychomyogenic or stress or ordinary or essential or psychogenic)).tw. (6527)
- 4 ((chronic adj2 daily adj2 headache*) or (daily adj2 persistent adj2 headache*)).ti,ab. (1530)
- 5 long term headache*.tw. (43)
- 6 1 or 2 or 3 or 4 or 5 (244190)
- 7 (daily or persistent or chronic).mp. (2456082)
- 8 6 and 7 (56510)
- 9 exp migraine aura/ or exp ophthalmoplegic migraine/ or exp migraine/ or exp migraine with aura/ or exp migraine without aura/ (57058)
- 10 ((withdrawal or overuse or "over use" or "over-use" or misuse or "mis-use" or abuse or induced) adj5 (medication* or medicine* or analges* or drug* or opiate* or opioid* or nsaids or non-opiate or ergot* or painkiller* or pain killer* or pain-killer*) adj5 (headache* or migraine*)).mp. (20637)
- 11 ((rebound or transformed) adj5 (headache* or migraine*)).ti,ab. (450)
- 12 8 or 9 or 10 or 11 (119498)
- 13 (HR-PRO or HRPRO or HRPRO or HRQL or HRQoL or QL or QoL).mp. (73860)
- 14 (quality of life or life quality).tw. (310350)
- 15 (health index or health indices or health profile).mp. (5057)
- 16 (patient or self or child or parent or carer or proxy).mp. (8459912)
- 17 (report or reported or reporting or rated or rating or based or assessed or assessment assessments or disability or function or functional or functions or subjective or utility or utilities or wellbeing or well being).mp. (12222752)

- 18 (index or indices or instrument or instruments or measure or measures or questionnaire or questionnaires or profile or profiles or scale or scales or score or scores or status or survey or surveys).ti,ab. (5157109)
- 19 health related quality of life.ti,ab. (44869)
- 20 quality adjusted life year.ti,ab. (5178)
- 21 QALY.tw. (11466)
- 22 value of life.tw. (309)
- 23 ((health adj2 utility*) or disutili*).mp. (2799)
- 24 willingness to pay.tw. (5728)
- 25 contingent valuation.tw. (697)
- 26 standard gamble.tw. (945)
- 27 SG.tw. (11070)
- 28 time tradeoff.tw. (250)
- 29 time trade off.tw. (1369)
- 30 TTO.tw. (1299)
- 31 mapping.tw. (161946)
- 32 cross walking.tw. (17)
- 33 transfer to utility.tw. (12)
- 34 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 (17788699)
- exp 'intermethod comparison', or exp 'data collection method', or exp 'validation study', or exp 'feasibility study', or exp 'pilot study', or exp 'psychometry', or exp 'reproducibility', or reproducib*.ab,ti. or 'audit'.ab,ti. or psychometr*.ab,ti. or clinimetr*.ab,ti. or exp 'observer variation', or 'observer variation'.ab,ti. or exp 'discriminant analysis', or exp 'validity', or reliab*.ab,ti. or valid*.ab,ti. or 'coefficient'.ab,ti. or 'internal consistency'.ab,ti. or (cronbach* and ('alpha' or 'alphas')).ab,ti. or 'item correlation'.ab,ti. or 'item correlations'.ab,ti. or 'item selections'.ab,ti. or 'item selections'.ab,ti. or 'item reduction'.ab,ti. or 'agreement'.ab,ti. or 'precision'.ab,ti. or 'imprecision'.ab,ti. or 'precise values'.ab,ti. or 'test-retest'.ab,ti. or ('test' and 'retest').ab,ti. or ('retest').ab,ti. or 'inter-tester'.ab,ti. or 'inter-

'dimensionality'.ab,ti. or 'subscale*.ab,ti. or 'multitrait scaling analysis'.ab,ti. or 'multitrait scaling analyses'.ab,ti. or 'item discriminant'.ab,ti. or 'interscale correlation'.ab,ti. or 'interscale correlations'.ab,ti. or (('error' or 'errors') and (measure* or correlat* or evaluat* or 'accuracy' or 'accurate' or 'precision' or 'mean')).ab,ti. or 'individual variability'.ab,ti. or 'interval variability'.ab,ti. or 'rate variability'.ab,ti. or 'variability analysis'.ab,ti. or ('uncertainty' and ('measurement' or 'measuring')).ab,ti. or 'standard error of measurement'.ab,ti. or sensitiv*.ab,ti. or responsive*.ab,ti. or ('limit' and 'detection').ab,ti. or 'minimal detectable concentration'.ab,ti. or interpretab*.ab,ti. or (small* and ('real' or 'detectable') and ('change' or 'difference')).ab,ti. or 'meaningful change'.ab,ti. or 'minimal important change'.ab,ti. or 'minimally important difference'.ab,ti. or 'minimal detectable change'.ab,ti. or 'minimal detectable difference'.ab,ti. or 'minimal real difference'.ab,ti. or 'minimally real difference'.ab,ti. or 'minimally detectable difference'.ab,ti. or 'minimally real difference'.ab,ti. or 'ceiling effect'.ab,ti. or 'floor effect'.ab,ti. or 'item response model'.ab,ti. or 'irt'.ab,ti. or 'rasch'.ab,ti. or 'differential item functioning'.ab,ti. or 'diff.ab,ti. or 'computer adaptive testing'.ab,ti. or 'item bank'.ab,ti. or 'cross-cultural equivalence'.ab,ti. (5156030)

- 36 (addresses or biography or case reports or comment or directory or editorial or festschrift or interview or lectures or legal cases or legislation or letter or news or newspaper article or patient education handout or popular works or congresses or consensus development conference or consensus development conference, nih or practice guideline).pt. not (*animals/ not *humans/) (1526497)
- 37 (12 and 34 and 35) not 36 (20124)
- 38 limit 37 to (human and english language and (adult <18 to 64 years> or aged <65+ years>)) (10502)
- 39 limit 38 to yr="1980 2016" (10296)

Database: Ovid MEDLINE(R) <1946 to April Week 2 2017>

Search Strategy:

- 1 Headache/ (26018)
- 2 exp headache disorders/ or exp headache disorders, primary/ (32133)
- 3 exp Tension-Type Headache/ (1860)
- 4 (headache* adj3 (mixed or combination or tension or tension type or muscle contraction* or psychomyogenic or stress or ordinary or essential or psychogenic)).tw. (4133)
- 5 ((chronic adj2 daily adj2 headache*) or (daily adj2 persistent adj2 headache*)).ti,ab. (950)
- 6 (headache* or hemicrania simplex).mp. (74687)
- 7 long term headache*.mp. (19)
- 8 chronic headache*.mp. (1518)
- 9 exp Headache Disorders/ (32133)
- 10 tension headache*.mp. (1004)
- 11 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 (88376)
- 12 (daily or persistent or chronic).mp. (1583660)
- 13 11 and 12 (17326)
- 14 migraine*.mp. or exp Migraine with Aura/ or exp Migraine Disorders/ or exp Ophthalmoplegic Migraine/ or exp Migraine without Aura/ (32683)
- 15 (withdrawal or overuse or "over use" or "over-use" or misses or "mis-use" or abuse or induced).mp. adj5 (medication* or medicine* or analges* or drug* or opiate* or opioid* or NSAIDS or non-opiate* or non opiate* or ergot* or painkiller* or painkiller* or painkiller* or painkiller* or painkiller* or painkiller*. (deadache* or migraine*).ti, ab. (3474)
- 16 ((rebound or transformed) adj5 (headache* or migraine*)).ti,ab. (327)
- 17 13 or 14 or 15 or 16 (45932)
- 18 (HR-PRO or HRPRO or HRPRO or HRQL or HRQoL or QL or QoL or PRO or PROS or PROM or PROMs).mp. (189311)
- 19 (quality of life or life quality).mp. (228883)
- 20 (health index* or health indices or health profile* or health status).mp. (128028)
- 21 ((patient or self or proxy) adj (appraisal* or appraised or report or reported or reporting or rated or rating or ratings or based or assessed or assessment*)).mp. (155466)

- 22 ((disability or function or functional or functions or subjective or utility or utilities or wellbeing or well being or health) adj2 (index or indices or instrument or instruments or measure or measures or questionnaire* or profile or profile or scale or scales or score or status or survey or surveys)).ti,ab. (182045)
- 23 health related quality of life.ti,ab. (27920)
- 24 quality adjusted life year.ti,ab. (3358)
- 25 QALY.tw. (5322)
- 26 value of life.tw. (249)
- 27 ((health adj2 utility*) or disutili*).mp. (1384)
- 28 willingness to pay.tw. (3086)
- 29 contingent valuation.tw. (498)
- 30 standard gamble.tw. (749)
- 31 SG.tw. (6571)
- 32 time tradeoff.tw. (252)
- 33 time trade off.tw. (884)
- 34 TTO.tw. (746)
- 35 mapping.tw. (122495)
- 36 cross walking.tw. (6)
- 37 transfer to utility.tw. (8)
- 38 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 (834011)
- 39 (instrumentation or methods).sh. or Validation Stud- ies.pt. or Comparative Study.pt. or exp Psychometrics/ or psychometr*.ti,ab. or clinimetr*.tw. or clino- metr*.tw. or exp "Outcome Assessment (Health Care)"/ or outcome assessment.ti,ab. or outcome measure*.tw. or exp observer variation/ or observer variation.ti,ab. or exp Health Status Indicators/ or exp reproducibility of results/ or reproducib*.ti,ab. or exp discriminant analysis/ or reliab*.ti,ab. or unreliab*.ti,ab. or valid*.ti,ab. or coefficient.ti,ab. or homogeneity.ti,ab. or homogeneous.ti,ab. or internal consistency.ti,ab. or (cronbach* and (alpha or alphas)).ti,ab. or (item and (correlation* or selection* or reduction*)).ti,ab. or agreement.ti,ab. or precision.ti,ab. or imprecision.ti,ab. or "precise values".ti,ab. or (test and retest).ti,ab. or (reliab* and (test or retest)).ti,ab. or stability.ti,ab. or inter-reter.ti,ab. or inter-reter.ti,ab. or intra-tester.ti,ab. or intra-tester.t

error.ti,ab. or errors.ti,ab. or "individual variabil- ity".ti,ab. or (variability and (analysis or val- ues)).ti,ab. or (uncertainty and (measurement or measuring)).ti,ab. or "standard error of measurement".ti,ab. or sensitiv*.ti,ab. or responsive*.ti,ab. or ((minimal or minimally or clinical or clinically) and (important or significant or detectable) and (change or difference)).ti,ab. or (small* and (real or detectable) and (change or difference)).ti,ab. or meaningful change.ti,ab. or "ceiling effect".ti,ab. or "floor effect".ti,ab. or "Item response model".ti,ab. or IRT.ti,ab. or Rasch.ti,ab. or "Differential item functioning".ti,ab. or "computer adaptive testing".ti,ab. or "cross-cultural equivalence".ti,ab. (5772794)

- 40 (addresses or biography or case reports or comment or directory or editorial or festschrift or interview or lectures or legal cases or legislation or letter or news or newspaper article or patient education handout or popular works or congresses or consensus development conference or consensus development conference, nih or practice guideline).pt. not (*animals/ not *humans/) (3636046)
- 41 (17 and 38 and 39) not 40 (2028)
- 42 limit 41 to (english language and humans and "all adult (19 plus years)") (1412)
- 43 limit 42 to yr="1980 2016" (1405)

Appendix 1.2 Named measure searches

Datahace.	Fmhase	Classic+Embase	<19/17 to	2017 '	Mook 165
Database.	LIIIDase	ClassicTLIIIDase	\134/ LU	201/	AAGEV TO~

Search Strategy:

- 1 exp chronic daily headache/ or exp episodic tension headache/ or exp headache/ or exp primary headache/ or exp chronic tension headache/ or exp new daily persistent headache/ or exp secondary headache/ or exp tension headache/ (201706)
- 2 (headache* or migraine*).ti,ab. (136921)
- 3 (headache* adj3 (mixed or combination or tension or tension type or muscle contraction or psychomyogenic or stress or ordinary or essential or psychogenic)).tw. (6527)
- 4 ((chronic adj2 daily adj2 headache*) or (daily adj2 persistent adj2 headache*)).ti,ab. (1530)
- 5 long term headache*.tw. (43)
- 6 1 or 2 or 3 or 4 or 5 (244190)
- 7 (daily or persistent or chronic).mp. (2456082)
- 8 6 and 7 (56510)
- 9 exp migraine aura/ or exp ophthalmoplegic migraine/ or exp migraine/ or exp migraine with aura/ or exp migraine without aura/ (57058)
- 10 ((withdrawal or overuse or "over use" or "over-use" or misuse or "misuse or induced) adj5 (medication* or medicine* or analges* or drug* or opiate* or opioid* or nsaids or non-opiate* or non opiate or ergot* or painkiller* or pain killer* or pain-killer*) adj5 (headache* or migraine*)).mp. (20637)
- 11 ((rebound or transformed) adj5 (headache* or migraine*)).ti,ab. (450)
- 12 8 or 9 or 10 or 11 (119498)
- acy 'intermethod comparison'/ or exp 'data collection method'/ or exp 'validation study'/ or exp 'feasibility study'/ or exp 'pilot study'/ or exp 'psychometry', or exp 'reproducibility'/ or reproducib*.ab,ti. or 'audit'.ab,ti. or psychometr*.ab,ti. or clinimetr*.ab,ti. or clinometr*.ab,ti. or exp 'observer variation', or 'observer variation'.ab,ti. or exp 'discriminant analysis'/ or exp 'validity'/ or reliab*.ab,ti. or valid*.ab,ti. or 'coefficient'.ab,ti. or 'internal consistency'.ab,ti. or (cronbach* and ('alpha' or 'alphas')).ab,ti. or 'item correlation'.ab,ti. or 'item correlations'.ab,ti. or 'item selection'.ab,ti. or 'item selections'.ab,ti. or 'item selections'.ab,ti. or 'internal reductions'.ab,ti. or 'agreement'.ab,ti. or 'precision'.ab,ti. or 'precision'.ab,ti. or 'precision'.ab,ti. or 'precision'.ab,ti. or 'interater'.ab,ti. or 'inter

correlations'.ab,ti. or (('error' or 'errors') and (measure* or correlat* or evaluat* or 'accuracy' or 'accurate' or 'precision' or 'mean')).ab,ti. or 'individual variability'.ab,ti. or 'interval variability'.ab,ti. or 'rate variability'.ab,ti. or 'variability'.ab,ti. or 'computer adaptive testing'.ab,ti. or 'computer adaptive testing'.ab,ti. or 'computer adaptive testing'.ab,ti. or 'corresponsive* or 'accuracy' or 'accuracy' or 'accuracy' or 'accuracy' or 'precision' or 'mean')).ab,ti. or 'individual variability'.ab,ti. or 'interval variability'.ab,ti. or 'raccuracy' or 'accuracy' or 'accuracy' or 'precision' or 'mean')).ab,ti. or 'individual variability'.ab,ti. or 'enterval variability'.ab,ti. or 'standard error of measurement'.ab,ti. or sensitiv*.ab,ti. or responsive*.ab,ti. or 'meaning')).ab,ti. or 'detectable') and ('change' or 'difference')).ab,ti. or 'meaningful change'.ab,ti. or 'minimal detectable') and ('change' or 'difference')).ab,ti. or 'minimal detectable') and ('change' or 'difference').ab,ti. or 'minimal important difference'.ab,ti. or 'minimal important difference'.ab,ti. or 'minimal important difference'.ab,ti. or 'minimal detectable change'.ab,ti. or 'minimal detectable change'.ab,ti. or 'minimal real change'.ab,ti. or 'minimal real difference'.ab,ti. or 'minimally real difference'.ab,ti. or 'ceiling effect'.ab,ti. or 'floor effect'.ab,ti. or 'item response model'.ab,ti. or 'rasch'.ab,ti. or 'differential item functioning'.ab,ti. or 'diff.ab,ti. or 'computer adaptive testing'.ab,ti. or 'cross-cultural equivalence'.ab,ti. (5156030)

- 14 (burden of migraine questionnaire or BURMIG or (beck depression inventory or BDI) or (comprehensive headache related quality of life questionnaire or CHQQ) or (completeness of response survey or CORS) or (cognitive impairment scale for migraine attacks or MIG-SCOG) or (chronic pain coping inventory or CPCI) or (depression anxiety stress scale or DASS) or (functional assessment in migraine or FAIM or FAIMQ) or (female sexual function index or FSFI) or (health utilities index or HUI) or (headache impact test or HIT 6 or HIT-6) or (headache impact score or HIS) or (headache management self-efficacy scale or HSES) or (headache-specific locus of control or headache specific locus of control) or (headache disability inventory or HDI) or (headache disability scale or HDS) or ((hospital anxiety and depression scale) or HADS) or ((headache-attributed restriction, disability, social handicap and impaired participation questionnaire) or HARDSHIP or HARDSHIPQ) or (headache activities of daily living index or HADLI) or (headache under response to treatment questionnaire or HURT or HURTQ) or (headache impact questionnaire or HIQ or HIMQ) or (headache needs assessment survey or HANA) or (headache intensity or headache duration or headache severity) or (henry ford hospital headache disability inventory or HDI) or (impact of migraine-tension type headache-neck pain or Impact M-TTH-NP) or (italian perceived disability scale or IPDS) or (migraine treatment optimisation questionnaire or M-TOQ-15) or (migraine treatment satisfaction measure or MTSM) or (migraine-specific quality of life scale or MSQoL) or ((migraine work and productivity loss questionnaire) or MWPLQ) or (migraine disability assessment score or MIDAS) or (migraine disability assessment questionnaire or MDAS) or (migraine screen questionnaire or MS-Q) or (migraine impact questionnaire or MIQ) or (migraine specific quality of life questionnaire or MSQL or MSQ or MSQV 2 1) or (24-h MSQoLQ or 24-hour migraine specific quality of life questionnaire) or (patient perception of migraine questionnaire or PPMQ) or (patient health questionnaire or PHQ-9) or (pain disability index or PDI) or (pittsburg sleep quality index or PSQI) or (subjects global impression of change or SGIC) or (pain catastrophizing scale or PCS) or (visual aura rating scale or VARS) or (waters headache questionnaire or WHQ) or (numerical rating scale or NRS or numerical pain intensity scale or numerical pain rating scale or numeric scale for pain or NRS pain or NRS-pain) or (visual analogue scale or visual analogue scale for pain or VAS) or (rating scale or analogue scale) or (SF36 or SF 36 or SF-36 or short form 36 or shortform 36 or short-form 36) or (SF12 or SF 12 or SF-12 or short form 12 or short-form 12) or (SF6D or SF 6D or SF-6D or short form 6D or shortform 6D or short-form 12) form 6D) or (eurogol or euro gol or euro-gol or EQ5D or EQ5D or EQ-5D)).tw. (552600)
- 15 (addresses or biography or case reports or comment or directory or editorial or festschrift or interview or lectures or legal cases or legislation or letter or news or newspaper article or patient education handout or popular works or congresses or consensus development conference or consensus development conference, nih or practice guideline).pt. not (*animals/ not *humans/) (1526497)
- 16 (12 and 13 and 14) not 15 (3250)
- 17 limit 16 to (human and english language and (adult <18 to 64 years> or aged <65+ years>)) (1794)
- 18 limit 17 to yr="1980 2016" (1760)

Database: Ovid MEDLINE(R) <1946 to April Week 2 2017>

Search Strategy:

- 1 Headache/ (26018)
- 2 exp headache disorders/ or exp headache disorders, primary/ (32133)
- 3 exp Tension-Type Headache/ (1860)
- 4 (headache* adj3 (mixed or combination or tension or tension type or muscle contraction* or psychomyogenic or stress or ordinary or essential or psychogenic)).tw. (4133)
- 5 ((chronic adj2 daily adj2 headache*) or (daily adj2 persistent adj2 headache*)).ti,ab. (950)
- 6 (headache* or hemicrania simplex).mp. (74687)
- 7 long term headache*.mp. (19)
- 8 chronic headache*.mp. (1518)
- 9 exp Headache Disorders/ (32133)
- 10 tension headache*.mp. (1004)
- 11 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 (88376)
- 12 (daily or persistent or chronic).mp. (1583660)
- 13 11 and 12 (17326)
- 14 migraine*.mp. or exp Migraine with Aura/ or exp Migraine Disorders/ or exp Ophthalmoplegic Migraine/ or exp Migraine without Aura/ (32683)
- 15 (withdrawal or overuse or "over use" or "over-use" or misuse or "mis-use" or abuse or induced).mp. adj5 (medication* or medicine* or analges* or drug* or opiate* or opioid* or NSAIDS or non-opiate* or non opiate* or ergot* or painkiller* or pain killer* or pain-killer*).ti,ab. adj5 (headache* or migraine*).ti,ab. (3474)
- 16 ((rebound or transformed) adj5 (headache* or migraine*)).ti,ab. (327)
- 17 13 or 14 or 15 or 16 (45932)
- 18 (instrumentation or methods).sh. or Validation Stud- ies.pt. or Comparative Study.pt. or exp Psychometrics/ or psychometr*.ti,ab. or clinimetr*.tw. or clino- metr*.tw. or exp "Outcome Assessment (Health Care)"/ or outcome assessment.ti,ab. or outcome measure*.tw. or exp observer variation/ or observer variation.ti,ab. or exp Health Status Indicators/ or exp reproducibility of results/ or reproducib*.ti,ab. or exp discriminant analysis/ or reliab*.ti,ab. or valid*.ti,ab. or coefficient.ti,ab. or homogeneity.ti,ab. or homogeneous.ti,ab. or internal consistency.ti,ab. or (cronbach* and (alpha or alphas)).ti,ab. or (item and (correlation* or selection* or reduction*)).ti,ab. or agreement.ti,ab. or interrater.ti,ab. or interrester.ti,ab. or interr

inter-technic intratechnician.ti,ab. or intratechnician.ti,ab. or interactonician.ti,ab. or inte

- 19 (burden of migraine questionnaire or BURMIG or (beck depression inventory or BDI) or (comprehensive headache related quality of life questionnaire or CHQQ) or (completeness of response survey or CORS) or (cognitive impairment scale for migraine attacks or MIG-SCOG) or (chronic pain coping inventory or CPCI) or (depression anxiety stress scale or DASS) or (functional assessment in migraine or FAIM or FAIMQ) or (female sexual function index or FSFI) or (health utilities index or HUI) or (headache impact test or HIT 6 or HIT-6) or (headache impact score or HIS) or (headache management self-efficacy scale or HSES) or (headache-specific locus of control or headache specific locus of control) or (headache disability inventory or HDI) or (headache disability scale or HDS) or ((hospital anxiety and depression scale) or HADS) or ((headache-attributed restriction, disability, social handicap and impaired participation guestionnaire) or HARDSHIP or HARDSHIPQ) or (headache activities of daily living index or HADLI) or (headache under response to treatment questionnaire or HURT or HURTQ) or (headache impact questionnaire or HIQ or HIMQ) or (headache needs assessment survey or HANA) or (headache intensity or headache duration or headache severity) or (henry ford hospital headache disability inventory or HDI) or (impact of migraine-tension type headache-neck pain or Impact M-TTH-NP) or (italian perceived disability scale or IPDS) or (migraine treatment optimisation questionnaire or M-TOQ-15) or (migraine treatment satisfaction measure or MTSM) or (migraine-specific quality of life scale or MSQoL) or ((migraine work and productivity loss questionnaire) or MWPLQ) or (migraine disability assessment score or MIDAS) or (migraine disability assessment questionnaire or MDAS) or (migraine screen questionnaire or MS-Q) or (migraine impact questionnaire or MIQ) or (migraine specific quality of life questionnaire or MSQL or MSQ or MSQV 2 1) or (24-h MSQoLQ or 24-hour migraine specific quality of life questionnaire) or (patient perception of migraine questionnaire or PPMQ) or (patient health questionnaire or PHQ-9) or (pain disability index or PDI) or (pittsburg sleep quality index or PSQI) or (subjects global impression of change or SGIC) or (pain catastrophizing scale or PCS) or (visual aura rating scale or VARS) or (waters headache questionnaire or WHQ) or (numerical rating scale or NRS or numerical pain intensity scale or numerical pain rating scale or numeric scale for pain or NRS pain or NRS-pain) or (visual analogue scale or visual analogue scale for pain or VAS) or (rating scale or analogue scale) or (SF36 or SF 36 or SF-36 or short form 36 or shortform 36 or short-form 36) or (SF12 or SF 12 or SF-12 or short form 12 or shortform 12 or short-form 12) or (SF6D or SF 6D or SF-6D or short form 6D or shortform 6D or short-form 12) or short-form 12) or (SF6D or SF 6D or SF-6D or SFform 6D) or (eurogol or euro gol or euro-gol or EQ5D or EQ5D or EQ-5D)).tw. (315280)
- 20 (addresses or biography or case reports or comment or directory or editorial or festschrift or interview or lectures or legal cases or legislation or letter or news or newspaper article or patient education handout or popular works or congresses or consensus development conference or consensus development conference, nih or practice guideline).pt. not (*animals/ not *humans/) (3636046)
- 21 (17 and 18 and 19) not 20 (1566)
- 22 limit 21 to (english language and humans and "all adult (19 plus years)") (1255)
- 23 limit 22 to yr="1980 2016" (1243)

Appendix 1.3 List of measures included in 'named PROM' searches (EMBASE and MEDLINE) (Total n = 51)

(burden of migraine questionnaire or BURMIG or

(beck depression inventory or BDI) or

(comprehensive headache related quality of life questionnaire or CHQQ) or

(completeness of response survey or CORS) or

(cognitive impairment scale for migraine attacks or MIG-SCOG) or

(chronic pain coping inventory or CPCI) or

(depression anxiety stress scale or DASS) or

(functional assessment in migraine or FAIM or FAIMQ) or

(female sexual function index or FSFI) or

(health utilities index or HUI) or

(headache impact test or HIT 6 or HIT-6) or

(headache impact score or HIS) or

(headache management self-efficacy scale or HSES) or

(headache-specific locus of control or headache specific locus of control) or

(headache disability inventory or HDI) or

(headache disability scale or HDS) or

((hospital anxiety and depression scale) or HADS) or

((headache-attributed restriction, disability, social handicap and impaired participation questionnaire) or

HARDSHIP or HARDSHIPQ) or

(headache activities of daily living index or HADLI) or

(headache under response to treatment questionnaire or HURT or HURTQ) or

(headache impact questionnaire or HIQ or HImQ) or

(headache needs assessment survey or HANA) or

(headache intensity or headache duration or headache severity) or

(henry ford hospital headache disability inventory or HDI) or

(impact of migraine-tension type headache-neck pain or Impact M-TTH-NP) or

(italian perceived disability scale or IPDS) or

(migraine treatment optimisation questionnaire or M-TOQ-15) or

(migraine treatment satisfaction measure or MTSM) or

(migraine-specific quality of life scale or MSQoL) or

((migraine work and productivity loss questionnaire) or MWPLQ) or

(migraine disability assessment score or MIDAS) or

(migraine disability assessment questionnaire or MDAS) or

(migraine screen questionnaire or MS-Q) or

(migraine impact questionnaire or MIQ) or

(migraine specific quality of life questionnaire or MSQL or MSQ or MSQV 2 1) or

(24-h MSQoLQ or 24-hour migraine specific quality of life questionnaire) or

(patient perception of migraine questionnaire or PPMQ) or

(patient health questionnaire or PHQ-9) or

(pain disability index or PDI) or

(pittsburg sleep quality index or PSQI) or

(subjects global impression of change or SGIC) or

(pain catastrophizing scale or PCS) or

(visual aura rating scale or VARS) or

(waters headache questionnaire or WHQ) or

(numerical rating scale or NRS or numerical pain intensity scale or numerical pain rating scale or numeric rating scale for pain or NRS pain or NRS-pain) or

(visual analogue scale or visual analogue scale for pain or VAS pain or VAS-pain or VAS) or

(rating scale or analogue scale) or

(SF36 or SF 36 or SF-36 or short form 36 or shortform 36 or short-form 36) or

(SF12 or SF 12 or SF-12 or short form 12 or shortform 12 or short-form 12) or

(SF6D or SF 6D or SF-6D or short form 6D or shortform 6D or short-form 6D) or

(euroqol or euro qol or euro-qol or EQ5D or EQ5D)).tw. (552600)

Appendix 2. Table 1: Multi-item PROMs identified (n=39) from full-text articles assessed for eligibility (searched 1980-2016); n=23 PROMs included in final review ('inuse' 2000-2016).

PROM	Developer / article in which identified	Include / exclude from full review	Justification	Evaluations included in review (n)	
Migraine-specific (10)		5/10		1988- 1999	Post- 2000
BURMIG questionnaire	Andree, C., M. Vaillant, C. Rott, Z. Katsarava and P. S. Sandor (2008). "Development of a self-reporting questionnaire, BURMIG, to evaluate the burden of migraine." <u>Journal of Headache & Pain</u> 9(5): 309-315.	No	Developed in Swiss population – evidence of translation into English not clear in article. Initial evaluation in Swiss population. Exclude.	-	(1)
Functional Assessment in Migraine Questionnaire (FAIM)	Pathak, D. S., D. J. Chisolm and K. A. Weis (2005). "Functional Assessment in Migraine (FAIM) questionnaire: development of an instrument based upon the WHO's International Classification of Functioning, Disability, and Health." Value in Health 8(5): 591-600.	Yes	Fulfils inclusion criteria	-	1
Headache Needs Assessment (HANA) survey	Cramer, J. A., S. D. Silberstein and P. Winner (2001). "Development and validation of the headache needs assessment (HANA) survey." <u>Headache</u> 41 (4): 402-409.	Yes	Fulfils inclusion criteria	-	1
Migraine Disability Assessment Scale (MIDAS)	Stewart, W. F., R. Lipton, K. Kolodner, J. Liberman and J. Sawyer (1999A). "Reliability of the migraine disability assessment score in a population- based sample of headache sufferers." Cephalalgia 19(2): 107-114.	Yes	Fulfils inclusion criteria	2	10
Migraine Quality of life Questionnaire (MQoLQ)	Hartmaier, S. L., N. C. Santanello, R. S. Epstein and S. D. Silberstein (1995). "Development of a brief 24-hour migraine-specific quality of life questionnaire." <u>Headache</u> 35(6): 320-329.	No	No evaluations identified post-2000. Used as a comparator in establishing evidence in support of a new measure – the MTSM – but this is limited [32].	(1)	0

Migraine-specific Quality of Life Questionnaire (MSQ) v1.	Jhingran, P., J. T. Osterhaus, D. W. Miller, J. T. Lee and L. Kirchdoerfer (1998). "Development and validation of the migraine-specific quality of life questionnaire." <u>Headache</u> 38 (4): 295-302.	No	Succeeded by MSQ v2.1	(1)	-
Migraine-specific Quality of Life Questionnaire (MSQ) v2.	Jhingran, P., S. M. Davis, L. M. LaVange, D. W. Miller and R. W. Helms (1998). "MSQ: Migraine-specific quality-of-life questionnaire: Further investigation of the factor structure." PharmacoEconomics 13(6): 707-717.	No	Succeeded by MSQ v2.1	(1)	-
Migraine-specific Quality of Life Questionnaire (MSQ) v2.1.	Martin, B. C., D. S. Pathak, M. I. Sharfman, J. U. Adelman, F. Taylor, W. J. Kwong and P. Jhingran (2000). "Validity and reliability of the migraine-specific quality of life questionnaire (MSQ Version 2.1)." Headache 40(3): 204-215.	Yes	Fulfils inclusion criteria	-	9
Migraine-specific Quality of Life Questionnaire (MSQoL)	Wagner, T. H., D. I. Patrick, B. S. Galer and R. A. Berzon (1996). "- A new instrument to assess the long-term quality of life effects from migraine: development and psychometric testing of the MSQOL." <u>Headache</u> 36 (8): 484-492.	Yes	Fulfils inclusion criteria	2	1
Migraine Symptom Frequency Bother questionnaire	Patrick, D. L., M. L. Martin, D. M. Bushnell and J. Pesa (2003). "Measuring satisfaction with migraine treatment: expectations, importance, outcomes, and global ratings." <u>Clinical Therapeutics</u> 25 (11): 2920-2935.	No	Ad hoc measure developed specifically for single study. Not evaluated or applied again.	-	1
Headache-specific (8)		6/8			
Comprehensive Headache Related Quality of Life Questionnaire (CHQQ)	Manhalter, N., G. Bozsik, A. Palasti, E. Csepany and C. Ertsey (2012). "The validation of a new comprehensive headache-specific quality of life questionnaire." <u>Cephalalgia</u> 32 (9): 668-682.	No	Non-Anglicised evaluations (n=2)	-	(2)

EUROLIGHT questionnaire	Andree, C., Vallaint M., Barre, J., Katsarava R. et al. (2009). "Development and Validation of the EUROLOGHT questionnaire to evaluate the burden of primary headache disorders in Europe." Cephalalgia 3 (9):1082-1100.	Yes	Fulfils inclusion criteria	-	1
Headache Activities of Daily Living Index (HADLI)	Vernon, H. and G. Lawson (2015). "Development of the headache activities of daily living index: Initial validity study." <u>Journal of Manipulative and Physiological Therapeutics</u> 38 (2): 102-111.	Yes	Fulfils inclusion criteria	-	1
Headache Attributed Restriction, Disability, Social Handicap and Impaired Participation (HARDSHIP) questionnaire	Steiner, T. J., G. Gururaj, C. Andree, Z. Katsarava, I. Ayzenberg, S. Y. Yu, M. Al Jumah, R. Tekle-Haimanot, G. L. Birbeck, A. Herekar, M. Linde, E. Mbewe, K. Manandhar, A. Risal, R. Jensen, L. P. Queiroz, A. I. Scher, S. J. Wang and L. J. Stovner (2014). "Diagnosis, prevalence estimation and burden measurement in population surveys of headache: presenting the HARDSHIP questionnaire." Journal of Headache and Pain 15(1).	No	Interview-administration only – modular instrument: demographic, diagnostic, headache-attributed burden – symptoms, health-care utilisation, disability, productive time loss, impact on education, career and earnings, control, relationships and family, qol, well-being, co-morbidities.	-	-
Headache Disability Impact Questionnaire (HDI)	Niere K, Quin A. Development of a headache-specific disability questionnaire for patients attending physiotherapy. <i>Man Ther.</i> 2009 Feb;14(1):45-51	Yes	Fulfils inclusion criteria	-	1
Headache Impact Test (HIT)	Bjorner, J. B., M. Kosinski and J. E. Ware Jr (2003A). "Calibration of an item pool for assessing the burden of headaches: An application of item response theory to the Headache Impact Test (HITTM)." Quality of Life Research 12(8): 913-933.	Yes	Fulfils inclusion criteria	-	3
Headache Impact Test- 6 (HIT-6)	Bjorner, J. B., M. Kosinski and J. E. Ware Jr (2003C). "Using item response theory to calibrate the Headache Impact Test (HITTM) to the metric of traditional headache scales." Quality of Life Research 12(8): 981-1002.	Yes	Fulfils inclusion criteria	-	12
Henry Ford hospital headache disability inventory (HDI).	Jacobson, G. P., N. M. Ramadan, S. K. Aggarwal and C. W. Newman (1994). "The Henry Ford hospital headache disability inventory (HDI)." Neurology 44(5): 837-842.	No	No evaluations identified post-2000		-

SF-36 'Headache- specific' Modification	Magnusson JE, Riess CM, Becker WJ. Modification of the SF-36 for a headache population changes patient-reported health status. <i>Headache</i> . 2012; 52(6): 993-1004.	Yes	Fulfils inclusion criteria	-	1
Response to treatment	(7)	6/7			
Completeness of Response Survey (CORS)	Coon, C. D., S. E. Fehnel, K. H. Davis, M. C. Runken, M. E. Beach and R. K. Cady (2012). "The development of a survey to measure completeness of response to migraine therapy." <u>Headache</u> 52 (4): 550-572.	Yes	Fulfils inclusion criteria	-	1
Migraine Assessment of Current Therapy (Migraine-ACT) Questionnaire	Dowson, A. J., S. J. Tepper, V. Baos, F. Baudet, D. D'Amico and S. Kilminster (2004). "Identifying patients who require a change in their current acute migraine treatment: The Migraine Assessment of Current Therapy (Migraine-ACT) questionnaire." <u>Current Medical Research and Opinion</u> 20 (7): 1125-1135.	Yes	Fulfils inclusion criteria	-	2
Migraine Therapy Assessment Questionnaire (M-TAQ)	Chatterton ML ¹ , Lofland JH, Shechter A, Curtice WS, Hu XH, Lenow J, Smullens SN, Nash DB, Silberstein SD. Reliability and validity of the migraine therapy assessment questionnaire. Headache. 2002 Nov-Dec;42(10):1006-15.	Yes	Fulfils inclusion criteria	-	1
Migraine Therapy Optimisation Questionnaire (M-TOQ)	Lipton, R. B., K. Kolodner, M. E. Bigal, D. Valade, M. J. A. Lainez, J. Pascual, A. Gendolla, G. Bussone, N. Islam, K. Albert and B. Parsons (2009). "Validity and reliability of the migraine-treatment optimization questionnaire." <u>Cephalalgia</u> 29 (7): 751-759.	Yes	Fulfils inclusion criteria	-	1
Migraine Treatment Satisfaction Measure (MTSM)	Patrick, D. L., M. L. Martin, D. M. Bushnell and J. Pesa (2003). "Measuring satisfaction with migraine treatment: expectations, importance, outcomes, and global ratings." <u>Clinical Therapeutics</u> 25 (11): 2920-2935.	Yes	Fulfils inclusion criteria	-	2

Patient Perception of Migraine Questionnaire (PPMQ)	Davis, K. H., L. Black and B. Sleath (2002). "Validation of the Patient Perception of Migraine Questionnaire." <u>Value in Health</u> 5 (5): 422-430.	(Yes)	Fulfils inclusion criteria – but succeeded by PPMQ-R	-	1
Patient Perception of Migraine Questionnaire – Revised (PPMQ-R)	Revicki, D. A., M. Kimel, K. Beusterien, J. W. Kwong, J. A. Varner, (2006).	Yes	Fulfils inclusion criteria	-	2
Generic (8) Generic quality of life / I	health status	6/8			
Profile measures (4)	T	3/4			
		-			
Short Form Health Survey 8 (SF-8)	Turner-Bowker, D. M., M. S. Bayliss, J. E. Ware Jr and M. Kosinski (2003). "Usefulness of the SF-8TM Health Survey for comparing the impact of migraine and other conditions." Quality of Life Research 12(8): 1003-1012.	Yes	Fulfils inclusion criteria	-	4
Short Form Health Survey 12 (SF-12)	Lipton, R. B., S. W. Hamelsky, K. B. Kolodner, T. J. Steiner and W. F. Stewart (2000). "Migraine, quality of life, and depression: a population-based case-control study." Neurology 55 (5): 629-635.	Yes	Fulfils inclusion criteria	-	1
Short Form Health Survey 36 (SF-36)	Solomon, G. D., F. G. Skobieranda and L. A. Gragg (1993). "Quality of life and well-being of headache patients: measurement by the medical outcomes study instrument." <u>Headache</u> 33 (7): 351-358.	Yes	Fulfils inclusion criteria	-	5
World Health Organisation Disability Assessment II (WHO- DAS II)	Raggi, A., M. Leonardi, G. Bussone and D. D'Amico (2011). "Value and utility of disease-specific and generic instruments for assessing disability in patients with migraine, and their relationships with health-related quality of life." Neurological Sciences 32(3): 387-392.	No	Non-Anglicised evaluations (n=3)	-	3

Utility measures (4)		3/4			
EuroQol EQ-5D-3L	Essink-Bot, M. L., P. F. Krabbe, G. J. Bonsel and N. K. Aaronson (1997). "An empirical comparison of four generic health status measures. The Nottingham Health Profile, the Medical Outcomes Study 36-item Short-Form Health Survey, the COOP/WONCA charts, and the EuroQol instrument." Medical care 35(5): 522-537. Non-Anglicised evaluation Anglicised evaluations included in review (n=3)	Yes	Fulfils inclusion criteria	-	3
Health Utilities Index (HUI)	Mo, F., B. C. Choi, F. C. Li and J. Merrick (2004). "Using Health Utility Index (HUI) for measuring the impact on health-related quality of Life (HRQL) among individuals with chronic diseases." The Scientific World Journal 4: 746-757.	No	Succeeded by HUI-3	-	1
Health Utilities Index-3 (HUI-3)	Brown, J. S., P. J. Neumann, G. Papadopoulos, G. Ruoff, M. Diamond and J. Menzin (2008). "Migraine frequency and health utilities: findings from a multisite survey." Value in Health 11(2): 315-321.	Yes	Fulfils inclusion criteria	-	(1)
Quality of Well Being Scale (QWB-8)	Sieber, W. J., K. M. David, J. E. Adams, R. M. Kaplan and T. G. Ganiats (2000). "Assessing the impact of migraine on health-related quality of life: An additional use of the quality of well-being scale-self-administered." Headache 40(8): 662-671.	Yes	Fulfils inclusion criteria	-	1

Appendix 3: Table 2: Assessment criteria for the quality of reported measurement properties [17,19,20].

Measurement property	Rating	Assessment of quality
Reliability		
Internal consistency	+	Cronbach's alpha(s) > 0.70
- the extent to which items within a measure are	?	Cronbach's alpha not evaluated or dimensionality unknown
internally consistent	-	Cronbach's alpha(s) < 0.70
Reliability	+	Intra-class Correlation Coefficient (ICC)/weighted Kappa >0.70 OR Pearson's r >0.80
(test-retest / inter-rater / inter-rater)	?	Neither ICC/weighted Kappa, not Pearson's r evaluated
 the extent to which a measure provides the same results on repeated completions, assuming no change in the underlying health state 	-	ICC/weighted Kappa <0.70 OR Pearson's r <0.80
Validity		
Content validity - the extent to which the item content of a measure is an adequate reflection of the construct being measured	?	Authors provide a clear description of the measurement aim, target population, concept(s) measured and process of item selection. Members of the target population and experts in the field were clearly identified as being involved in development. For measures applied for the first time in a new population, evidence that the views of members of the target population (and experts in the field) have been sought to determine relevance, comprehension and comprehensiveness. Insufficient evidence available No detail re measurement aim, target population, concept(s) measured, process of item selection; members of the target population or experts were not specifically involved in development. For measures applied for the first time in a new population, evidence whereby the relevance and acceptability of the measure with members of the target audience or experts was not provided.
Construct validity - Structural validity - the extent to which PROM scores adequately reflect the dimensionality of the construct being measured.	+ ? -	Factors should explain 50% of the variance Explained variance not reported Factors explain < 50% of the variance
Construct validity - Hypothesis testing - convergent (the extent to which measures of related constructs are related to each other)	+	Correlations with measures of the same construct should be >0.50 OR at least 75% of the results in accordance with hypothesized associations AND correlations with related constructs should be higher than with those reported with unrelated constructs Only report correlations with unrelated constructs

- discriminant (the extent to which a measure can	-	Correlations with measures of the same construct are <0.50 OR < 75% of the results in accordance with hypothesized associations OR
demonstrate differences between groups known to		correlations with related constructs are lower than those reported with unrelated constructs
differ on important variables)		
Responsiveness	+	Change-score correlations with measures of the same construct are >0.50 OR at least 75% of the results are in accordance with
- the ability to detect important change over time in the		hypothesized associations OR the Area Under the Curve (AUC) is >0.70 AND change-score correlations with measures of related constructs
construct being measured (criterion / construct-based		are higher than those reported with unrelated constructs
assessment)	?	Solely correlations with unrelated constructs
	-	Change-score correlations with measure of the same construct < 0.50 OR < 75% of the results are in accordance with hypothesized
		associations OR AUC is <0.70 AND change-score correlations with related constructs are lower than those reported with unrelated
		constructs

Appendix 4: Table 3 Characteristics of reviewed PROMs evaluated in the headache population (total = 23)

PROM (Author; web-link ^b ; completion format) ^c	Items n ^a	Construct	Response options (range)	Recall Period	Score range	Administration
production from production formally		Domains (items)	(80)			
Condition-specific (17)	•					Time
Migraine-impact (5/17)						
Functional Assessment in Migraine (FAIM) (Pathak et al, 2005)[33] Self-completion Items listed in development paper	9+5	Underpinned by the WHO ICF. Focus on the functional impact of migraine. 3 domains: Two mental function: Attention/Thought (5): concentration, control of life, focus on issues, spontaneity, think quickly. Perception (4): find a peaceful place, light/sound/interaction avoidance. One overall domain: 'Activity and Participation'(5): select up to 5 items from list of 28.	Item stem: How much does each item impact on their lives? 7-point scale: 1= 'not at all' to 7 – 'all of the time'	Within 24-hours of their typical migraine onset	Item summation within the three domains. A/T: range 5-35 P: range 4-28 A/P: range 5-35 Lower scores indicate less functional impact.	5-10 minutes Not reported in headache population
Headache Needs Assessment (HANA) (Cramer et al,2001)[34] Self-completion Copy of PROM in appendix to paper	7	Migraine quality of life – frequency and bothersomeness (7): Anxiety/worry; depression/discouragement; self-control; energy; function/work; family/social activities; overall impact of migraines.	For each item: Frequency: How often has this problem occurred?: never / rarely / sometimes / often / all the time) Bothersomeness: How much has this problem bothered you?: not at all / a little / some / a lot / a great deal.	Not stated	Item summation. Total range 7-175, where lower scores indicate less impact.	5-10 minutes Not reported in headache population
Migraine Disability Assessment Score (MIDAS) (Stewart et al. 1999)[35] http://www.achenet.org/midas/	12	Migraine disability (but attribution is 'headache') 3 domains (5 scored items) Missed days/ reduced productivity at paid work (2)	Item stem: About ALL of the headaches you have had Frequency - number of days/ half days of disability	3 months	Total score derived as sum of lost days, where greater number of days indicates greater migraine-related disability.	5-10 minutes Not reported in headache population

Self-completion		Missed days/ reduced productivity at household work (2) Missed non-work activities (1) Plus: 2 unscored items Frequency of headaches (how many days?) (1) Headache pain severity (1)	Not scored: Number of days Scale 0-10 (0= no pain at all, and 10= pain as bad as can be)			
Migraine-Specific Quality of Life Questionnaire version 2.1 (MSQ v2.1) (Martin et al, 2000 [36] http://www.outcomes- trust.org/instruments.htm#msql2.1 Contact for further details and copy of questionnaire: michael.c.runken@gsk.com Self-completion	9	Health-related quality of life - impairments attributed to migraine 3 domains (14 items) Role function – Restrictive (RR)(7): social – family/friends; leisure (2); work/ADL(3); cognition (1); symptoms: fatigue (1) Role function – Preventive (RP)(4): symptoms: fatigue (1); work /ADL (2); social (1) Emotional function (EF)(3): frustration (1); feeling a burden (1); letting others down (1)	Item stem: How often have migraines interfered with / limit/ed your ability to / keep you from getting as much done / had difficulty in / How often have you had to cancel / need help / have to stop / not able to go because of your migraine 6-point categorical scale: None of the time (1), A little bit of the time (2), Some of the time (3), A good bit of the time (4), Most of the time (5), All of the time (6).	4 weeks	Items summed within the three domains and transformed to 0-100 scale. Higher scores indicate a worse quality of life	5-10 minutes Not reported in headache population
Migraine-Specific Quality of life (MSQOL) measure	1	Needs-based migraine-specific quality of life	Item stems: Various – include: 'I try to avoid	Responders advised to	All items summed (score range 20-80) and	5-10 minutes
(McKenna et al, 1998) [37]		3 domains (20 items):	' / 'It's important for	'choose the answer that	transformed to 0-100 scale.	

http://www.galen-research.com/content/measures/ MSQoL%20UK%20-%20First%20page%20sample.pdf Payment required to access full version of the questionnaire Self-completion		Avoidance behaviours (10) Social relations (6) Feelings (4)	me' / 'I feel helpless' / 'I worry about' 4-point categorical response scale: range: Yes, very much / I try very hard / very important (1) Yes, quite a lot / I try quite hard / quite important (2) A little / I do not try very hard / not very important (3) Not at all / I do not try at all / it's not important at all (4)	applies to you: between migraine attacks OR with any treatment you use now.	Higher scores indicate better quality of life	Not reported in headache population
Headache-impact (6/17)		<u> </u>				
EUROLIGHT (Andree et al, 2010)[28] http://www.l-t-b.org/index.cfm/spKey/publications.html Self-completion	1	Burden of primary headache disorders. Includes assessment of headache characteristics, co morbidities, disease management and quality of life 6 sections (103 items): 1) Biographical (age, gender, language and employment) 2) Screening questions for headache (life-time and 1-year prevalence) 3) Diagnostic questions - based on the criteria of the International Classification of Headache Disorders (ICHD-II) 4) Questions about any headache experienced 'yesterday' (point prevalence) 5) Use of healthcare resources (medicines, investigations, consultations, etc.)	All domains categorical response categories – various number of options	Headache frequency in past month/yesterday Healthcare past 30 days Headache impact on 'own life' Headache-related lost time in past 3 months	Various As per WHOQoL, HALT-index and HADS.	Not reported. Will require considerable completion time

		6) Impact of headache on work, family life and social activities: includes items taken from the WHOQOL (8-items), the HALT-index and HADS.				
Headache Activities of Daily Living Index (HADLI) (Vernon & Lawson, 2015) [29] Self-completion	1	Headache-related 'activity disability' - ability of an individual to engage with usual activities of daily life during headache episode 1 domain (9 items): Personal care Lifting Reading (including computers) Sleeping (over last week) Exercising (over last week) Social activities Work Driving or travelling Recreation	6-point categorical response options, where 0 is best ability and 5 is worst ability.	During headache episode 'when you have a headache'	Item summation: score range 0 to 45, where 45 is maximum activity disability. Total score converted to percentage	3 minutes
Headache Disability Questionnaire (HDQ) (Niere & Quin, 2009) [30] Self-completion	1	Headache specific disability in patients presenting for physiotherapy treatment 3 domains (9 items): Pain (2): usual pain intensity; when pain is severe. Activity Limitation (4): Decreased efficiency in nonwork activities Decreased ability to work/study Decreased efficiency in housework or chores Proportion of times when work is missed Activity Prevention (3): Number of days where chores prevented	11 point Numerical Rating Scales Anchors (0-10): Adjectival anchors: No pain (0) - Worst pain (10) Never (0) - Always (10) None (0) - Everyday (10) Not reduced (0) - Unable to work (10) Not reduced (0) - Unable to perform (10)	Past 1-month	Item summation. Index range 0-90, where higher scores indicate greater headachespecific disability.	??

		Number of days non-work activities prevented Number of days in last month when had to lie down for >1 hour;				
Headache Impact Test (HIT) CAT-HIT (IRT-HIT) (Bjorner JB et al. 2003a [3]; Ware JE et al, 2003 [57]) Self-completion- requires internet interface for CAT completion	3	Headache impact Items, derived from four established measures: MIDAS MSQ (v1.0) Headache Disability Index (HDI) Headache Impact Questionnaire (HIMQ) Plus experimental items generated from clinical trial data, and consultation with clinicians. One domain 'Headache Impact': 54-item 'item bank' Items cover a wide spectrum of headache impact, including minor headache. Items cover of pain, role and social functioning, energy/fatigue, cognitive function, and mental health	Up to five categorical responses Internet completion only using Computerized Adaptive Testing (CAT): CAT-HIT	1-month	Scored using Item Response Methods (IRT) (also referred to as IRT-HIT). Number of completed items determined by 'stopping rule': mean number 6/54 items. Norm-based scoring with mean 50 (SD 10), where higher scores indicate very severe headache impact.	Approximate response times of 1.5 minutes for those with least headache impact (HIT scores < 50) Range from 2.4 items/ minute for a 9-item survey to 3.3 items/minute for a 6-item survey
Headache Impact Test (HIT-6) (Kosinski et al, 2003a) [31] https://www.optum.com/optum-outcomes/what-we-do/disease-specific-health-surveys/hit-6.html Self-completion	8	Headache impact Static, short-form HIT: 6 domains (6-items) Pain (headache - how often is the pain severe?) (1) Social functioning (limit your ability to do usual daily activities – work / adl / social?) (1)	Equally weighted 5- option categorical scale with specific item score (generated to closely match the IRT score) Item stem: 'how often?' Attribution: 'when you have a headache /	3 items (Vitality; Psychological distress; Cognition): past 4weeks 2 items (Pain. Role limitation): 'when you have a headache'	Item summation to create index score: range 36-78 Score interpretation (norm-based mean 50 (SD 10)): >60: very severe impact 56-59: substantial impact	

		Role functioning (how often do you wish you could lie down?) (1) Vitality (too tired to do work or adl?) (1) Cognitive functioning (limit ability to concentrate on work or adl?) (1) Psychological distress (felt fed up or irritated) (1)	because of your headache' Range (weighted item responses): Never (6 points), Rarely (8 points), Sometimes (10 points), Very Often (11 points), Always (13 points)	1 item (Social function): how often do headaches limit 	50-55: some impact 49 or <: little or no impact	
'Headache' SF-36 (Magnusson J.E. et al. 2012)[32] Self-completion	1	Headache-related health status Modification of original SF-36 to 'improve applicability' to the headache population by inserting 'including your headaches' to 6/36 items: physical functioning (item 3); role limitation - physical (item 4); social functioning (items 6 and 10); bodily pain (items 7 and 8)	Equally weighted 3 or 5 point Likert Scale	4 weeks or 1 week	Scale scores transformed to 0-100 calibrated at 50 as the norm 8 domains 2 summary scales	5-10 minutes
Response to migraine-specific treatment (6/17) Completeness of Response to Migraine Therapy Survey (CORS) (Coon CD. et al. 2012) [38] Both versions of CORS illustrated in full in appendix to article	1	Optimal treatment: considers factors important to patients when considering the initiation/continuation of migraine treatment Two modules: 1. 'Static CORS' – to evaluate	Item stem and response options: 1.'Static CORS':	'overall experience with your current migraine treatment'	1.'Static CORS': three domains scores based on item summation FCR (6): 1a,2b,3b,4b,5b,6b SCR (6): 1b,2c,3c,4c,5c,6c SRF (4): 7,8,9,10	10-15 minutes Not reported in headache population
Self-completion		treatment at a single time- point 5 domains (24 items): Frequency of Complete Relief (FCR) (6 – how often complete	categorical response options range 3, 4 or 5-options: FCR: how often does your current M Rx		- where higher scores indicate better medication response 2.'Comparative CORS': item summation to	

relief of symptoms* plus	completely relieve	produce index score
irritability /moodiness**)	your X?: 5-point (0-4):	(range 8 to 40), where
asincy / moduliess /	range 0= none of the	higher scores suggest a
	time, to 4 = all or	better response to
Speed of Complete Relief (SCR)	almost all of the time.	current medication
(6 - how quickly complete relief	annost an or the time.	than previous
of symptoms* plus irritability/	SCR: how quickly does	than previous
moodiness**)	your current M Rx	
modumess ,	completely relieve	
	your X?: 4-point (1-4):	
Speed of Return to	range 4 = < 30 mins,	
Functionality (SRF)(4 – able to	to 1 = > 2hrs	
concentrate/ think; normal	101 7 21113	
activities; functioning normally	SRF: how quickly are	
(100%); feeling completely	you able to after	
normal (100%))	taking your current M	
	RX?: 5-point (1-5):	
Frequency of Migraine	range 5 = < 30 mins,	
Recurrence (FMR)(1)	to 1 = > 4hrs	
Confidence in Treatment		
(CIT)(2)	FMR: 5-point (0-4):	
	range 0= none of the	
5 additional items describe	time, to 4 = all or	
presence of symptoms*:	almost all of the time.	
	CIT: 3-point (0-2):	
24-items address:	range 0 = not at all	
Symptoms* - Headache-	confidence, 1 =	
specific pain; neck/shoulder	somewhat confident;	
pain; nausea; sensitivity to	to 2 = very confident.	
light; sensitivity to sound (5		
items). Emotional well-being –		
**irritability or moodiness		
Cognition – ability to		
'concentrate or think'		
ADL – resumption of normal		
activities		
Function – resumption of		
normal functioning (100%)		
Feeling 'completely normal'		
(100%)		
Confidence in current medical:		
frequency of return of M		

		within 24hrs; confidence that Rx will completely relieve M; confidence that M will not come back. 2. 'Comparative CORS (8 items) – for the comparative evaluation of two treatments at a single time-point. 8 domains (8 items): Completeness of Relief (1) Speed of Relief (1) Persistence of Relief (1) (e.g. prevented symptoms from coming back within 24-hrs) Return to Normal Function (1) Fatigue (1) Confidence in Treatment (2): that one does would completely relieve M within 2-hrs; that M would not come back within 24-hrs Overall Satisfaction (1) – most satisfied	2. 'Comparative CORS': Which medication provided the complete / quicker / longer-lasting / allowed more normal function / experience less fatigue / feel more confidence that one does would completely relieve your M within 2 hours?: 5-point categorical scale (1-5); where a score of '1' favours the previous medication; a score of 3 suggests no preference between medications; a score of 5 favours the study medication.			
Migraine – Assessment of Current Therapy (M-ACT) Copy included in publication (Dowson et al, 2004)[39] Self-completion	2	4 domains (27 long-form/ 4 short): Headache impact (11/1) Global assessment of relief (9/1) Consistency of response (3/1) Emotional response (4/1)	Item stem: 'When you take your treatment: Dichotomous answers: Yes/No, where Yes = 1 and No = 0	Varies: between 2hours and 48- hours	Item summation	5-10 minutes Not reported in headache population
Migraine Therapy Assessment Questionnaire (M-TAQ) CUESS PROM review FTC: Appendices Edited 2705	1	To identify barriers to optimal migraine management and improve patient outcomes	Dichotomous answers: Yes/No,	Varies – mostly 2 hours.	Item summation Range 0 to 8 (items 3 and 4 scored together),	5-10 minutes

(Chatterton et al. 2002)[40]		A disease- management/screening tool to	where Yes = 1 and No = 0		where higher scores	Not reported in headache
(Chatterton et al, 2002)[40]		identify individuals whose	= 0		indicates greater number of migraine	population
Self-completion		migraine management is sub- optimal (9)			issues	роринилоп
Copy of PROM included in appendix to paper		Migraine control, frequency of			Also 3 domains:	
		attacks, knowledge and			Migraine control;	
		behavioural barriers, economic			Knowledge/behaviour	
		burden, treatment satisfaction			/treatment satisfaction;	
					Economic burden,	
Migraine-Treatment Optimization Questionnaire	1	Aims to support treatment	Dichotomous	Last 4 weeks	M-TOQ 15	5-10 minutes
		optimization – defined as the	answers: Yes/No,		Item summation	
(M-TOQ)		achievement of realistic	where Yes = 1 and No		producing five domain	Not reported in
		treatment goals.	= 0		scores or an index	headache
(Lipton RB. et al. 2009) [41]					score. High scores	population
		The M-TOQ was developed to			suggest good response	
Self-completion		provide a rapid assessment of			to treatment,	
		migraine therapy for use in			suggesting that	
		primary care settings			treatment change is	
		M TOO 15, 5 domains /15			<i>unlikely</i> to be required.	
		M-TOQ 15: 5 domains (15 items):				
		Functioning (3)			M-TOQ 5	
		Rapid relief of headache (3)			Item summation	
		Consistency of response (3)			producing an index	
		Prevention of recurrence (3)			score. If answer 'Yes' to	
		Side effects (3)			all five items -	
		Side effects (5)			treatment is considered	
		M-TOQ 5: 5 domains (5 items)			satisfactory.	
		Functioning (1)			If answer 'no' to any	
		Rapid relief of headache (1)			single question, a	
		Consistency of response (1)			change in treatment	
		Prevention of recurrence (1)			should be considered.	
		Side effects (1)				
					A 'treatment	
					optimization' table is	
					provided to support	
					score interpretation	
					and clinical decision-	
					making (Table 5)[24]	
Migraine Treatment Satisfaction Measure	2	Migraine treatment	TE-M: 5-point	At onset and 24	Overall 'MTSM'	15-20 minutes
		satisfaction	response scale (1-5)	hours after	treatment satisfaction	
(MTSM)			where 1 is the worst	migraine episode	score is generated as	

(Patrick et al, 2003) [42] Self-completion		4-part assessment: 1) Expectations of Treatment for Migraine (TE-M); 9 items) – worded to express the 9 attributes as an 'expectation'. 2) Importance Ranking for Migraine Treatment (IR-M); 9 items) – respondents rank items to express their 'desired expectations; for each attribute. 3) Outcomes of Treatment for Migraine (TO-M); 9-items – correspond to the TE-M items) – produces a self-report of treatment outcome for each attribute. 4) Satisfaction with Migraine Treatment (PST-M; 9-items) – reflect satisfaction with treatment outcome across the 9 attributes. 9 attributes ('items') associated with migraine relief: Pain relief Speed of relief Freedom from pain Additional symptoms Confidence in treatment Disruption in life Dosing Freedom from relapse	case scenario (eg, no relief) and 5 is the best (eg total relief). IR-M: ranking items on a 10cm line (where 0 = not important and 10 = most important). Intersection with the line = score (range 0-10). TO-M: 5-point response scale (1-5) reflecting actual outcome, where 1 = worst case scenario (eg no relief) to 5 = best case (eg total relief). PST=M: 10cm VAS where 0 = most dissatisfied and 10 = most satisfied.		the sum of the nine derived attribute scores (a detailed scoring procedure is detailed by the developers [27]): score represents patients expectations about Rx, modified by Rx experience, weighted by their adjusted importance values, and used to modify the raw satisfaction values [27]. Scores also calculable for three domains: Expectations (TE-M) Outcomes (TO-M) Satisfaction (PST-M)	Not reported in headache population
Patient Perception of Migraine Questionnaire -Revised	2	Ease of use Patient satisfaction with acute	Core domains 1 to 4	4 weeks	Item summation to	
(PPMQ-R) (Revicki DA et al. 2006)[43]	2	migraine therapy Core: 4 domains (19 items) Efficacy: satisfaction with treatment efficacy (11) Function: ability to perform	and 3 global items: 7- point 'Likert' scale: range 1 = very satisfied to 7 = very dissatisfied.	4 weeks	create domain scores: Domain 1: range 11 to 77 Domain 2: range 4 to 28 Domain 3: range 2 to 8	
		usual activities (4) Ease of Use (2)	Domain 5 – 'Bothersomeness': 5-		Domain 4: range 2 to 8: where lower scores	

		Cost (2) (may be removed where 'cost' is not a consideration). Additional fifth domain (10 items): 'Bothersomeness' or 'Tolerability' - related to side effects (10) 3 global items: Overall satisfaction with medication effectiveness Side effects General treatment	point 'Likert' scale: range 1 = not at all, to 5 = extremely.		suggest greater satisfaction with treatment. Item summation of three core domains (Efficacy, Function and Ease) to produce 'Total Satisfaction Score': score transformed to 0-100, where higher scores represent greater satisfaction.	
Generic measures (6)						
Profile measures (3/6)						
Short Form 36-item Health Survey (SF-36) (version 1 (v1)) [Ware et al, 1994] [44] https://campaign.optum.com/content/optum/en/optum-outcomes/what-we-do/health-surveys.html Self-completion or interview administered		General health status 8 domains (36 items) Bodily pain (BP)(2) General health (GH)(5) Mental health (MH) (5) Physical functioning (PF)(10) Role limitation-emotional (RE)(3) Role limitation-physical (RP)(4) Social functioning (SF)(2) Vitality (V)(4)	Categorical: 2-6 options	Recall: Standard 4- weeks Acute 1-week	Requires algorithm to score domains Norm-based scoring: score transformed to 0-100 (mean 50 (SD 10)) Individual domain scores ('profile') or 2 summary scales: Physical Component Summary Mental Component Summary	15 to 30 mins Not reported in headache population
Short Form 12-item Health Survey (SF-12)(v1) [Ware et al, 1995][45] https://campaign.optum.com/content/optum/en/optum-outcomes/what-we-do/health-surveys.html	1	Health Status 8 domains (12 items) Physical functioning ((n items per domains???) Social functioning Role physical Bodily pain	Categorical: 2-6 options	Recall: Standard 4- weeks Acute 1-week	Requires algorithm to score domains Norm-based scoring: score transformed to 0-100 (mean 50 (SD 10)) 2 summary scales:	5-15 minutes Not reported in headache population

Self-completion or interview administered		Mental health Role emotional Vitality General health			Physical Component Summary Mental Component Summary	
Short Form 8-item Health Survey (SF-8)(v1) [Ware et al, 2001][46] https://campaign.optum.com/optum-outcomes/what-we-do/health-surveys.html?gclid=CPj1nb6YoM8CFXQo0wodZXEDLQ	1	Health Status 8 domains (8 items) Physical functioning (1) Social functioning (1) Role physical (1) Bodily pain (1) Mental health (1) Role emotional (1) Vitality (1) General health (1)	Categorical: 2-6 options	Recall: Standard 4- weeks Acute 1-week	Requires algorithm to score domains Norm-based scoring: score transformed to 0-100 (mean 50 (SD 10)) 2 summary scales: Physical Component Summary Mental Component Summary	5-10 minutes Not reported in headache population
Utility measures (3/6)						
EuroQoL EQ-5D (3L) (EuroQoL Group, 1990)[47] http://www.euroqol.org/ Self-completion or interview administered	3	Quality of Life 5 domains (5 items) Mobility Self-care Usual activities Pain/discomfort Anxiety/depression	3-point descriptive response options: no problems, some problems, severe problems.	Today	Utility index value (society assigned value system algorithm): - 0.59 to 1.00 where 1.00 is perfect quality of life, 0 is death, and <0 is a health state worse than death	2 to 5 mins Not reported in headache population
Health Utility Index – 3 (HUI-3) (Feeney et al, 2002)[48] http://www.healthutilities.com/hui3.htm Self-completion or interview administered	1	Multi-attribute health status classification system Describes the comprehensive health state of an individual as 8 domains (attributes) (8 items): Vision Hearing Speech Ambulation Dexterity Emotion Cognition	1 to 5 or 1 to 6 descriptive response options per attribute / domain, where 1 is best health, 5 or 6 is worst health.	Current	Standard algorithms. 0 to 1.00 where 1.00 is perfect QoL	5 mins Not reported in headache population

		Pain			
Quality of Well-being Scale	1	Generic measure of HRQoL;		Overall score based on	
		used to calculate QALYs		a preference-weighted	
(QWB)			6-days	average functioning in	
		QWB – interview administered	3-days	previous 6-days.	QWB-SA:
(QWB - Kaplan et al, 1993 [49]; QWB-SA - Andresen et al,		(fewer than QWB-SA)			average 11
1998 [50])		QWB-SA – self-administered		Utility index score: 0.0	minutes
		(77 items)		(death) to 1.0 (perfect	
Interview and self-administered (SA)				health)	
		Symptom scale			
		3 scales of function: mobility,			
		physical activity, social activity			

Appendix 5: Table 4: Characteristics of included studies (n= 46)

Study	Country ^g	Population and	Study: design, setting, sample size ^g	Mean gage	Gender	Treatment descriptions ^g	% missing	PROM focus;
(Author;yr)	Language ^g	Headache definition		(SD; range)	distribution (F Female) ^g		responses: acceptable?g*	Additional info ^g
[ref]								
Andree et al 2010 [28]	Five countries: UK, Italy, Spain, Germany/Austria, France	Patients from mixed settings with diagnosis of headache: International Classification of Headache Disorders (ICHD-II) 2004	International cross-sectional survey: Population recruitment: UK and Italy: Headache/migraine associations; France/ Austria/ Italy: Neuroscience clinics; Germany/ Luxembourg: population based cohort; Spain: GP population Total n=426 UK n=131 Italy n= 60 Spain n=107	Total: 44.0 (+/- 11.38)	Total: F 75.0%	NA	Total: quoted as 66-100% (data NR) not quoted at item level	EUROLITE - development
			Germany/Austria n= 83					
			France n=45					
Bagley et al	Data from 9	Chronic (CM) and	International Burden of Migraine Study (IBMS)	Total:	Total:	N/A	Not reported at	MSQ 2.1
2012 [54]	countries: US, Canada, France,	Episodic Migraine (EM)		40.3 (11.4)	F 83.5%		item level	
	Germany, Spain, UK, Australia, Italy, Taiwan.		Web-based, cross-sectional population survey					Includes a 'review' of the
	i aiwaii.	Detailed definitions (p410)	Participants recruited from established database of headache / migraine patients (n	EM 40.2 (11.4)	EM F 83.4%			development / earlier evaluation

			63,001): all received e-invitation to 'opt in' via		CM F 85.6%			papers for MSQ
			web-link.					and HIT-6.
	Suggests that	EM: <15 HDPM		CM 41.7				
	questionnaires		30.7% responded to email invitation; 55%	(12.1)				
	completed in	CM: >/= 15 HDPM	eligible to participate.	(==:=/				
			eligible to participate.					
	'official language							
	of the country' –							
	but results then		Company and the design of the Control of the Contro					
	combined		Surveys completed by 81.9%					
			Total n 8726					
			10(4) (1 8726					
			514 0007					
			EM n 8227					
			CM n 499					
Bigal et al	US	Patients registered	Retrospective assessment of patient clinic notes	CM 38.3	CM F 72.5%	N/A	Not reported at	MIDAS
2003 [69]		with a specialist	(for those who had previously completed the	(95% CI			group or item	
		headache clinic	MIDAS)	36.5 to			level	
			,	40.1)				
	US English			,	EM F 68.6%			
		CM: daily or near-	CM 182					
		daily headaches		EM 36.1				
		lasting >4hrs if	EM 86	(95% CI				
				•				
		untreated, >15 days		34.1 to				
		per month, fulfilling		38.0)				
		CDH.						
		EM: HIS for migraine						
		+/- aura						
Bjorner et	US	General population	National Survey of Headache Impact (NSHI) –	NR	NR	N/A		HIT development
al 2003a [3]			longitudinal survey (baseline and 3/12)			·		paper
20050 [5]			Solding and Street (Sustaine and S/12)				N/A	Pape.
	US English	At least 1 headache in		Reported				
	J	4/52 prior to	Sampling frame: randomly generated list of	elsewhere				Focus: item pool
		interview (not	telephone numbers from 48 US states.	in NSHI				development.
		hangover, cold, flu)		papers				Informed by items
								from the: MSQ
								(v2), HDI, HIMQ,
								MIDAS
								.=
L	l .	l: = 1: 10	l .	I .	ı	1	l	l .

			Interviews with convenience sample of eligible					
			respondents (mean duration 21.5mins (rge 17-					
			27 mins) – schedule not detailed					
			,					
			Telephone interviews n= 1016					
			Headache prevalence in 4/52 period= 45.7%					
			Headactie prevalence in 4/52 period= 45.7%					
Blumenfeld	Data from 9	Chronic (CM) and	International Burden of Migraine Study (IBMS)	Total:	Total:	N/A	Not reported at	MIDAS
et al 2010	countries: US,	Episodic Migraine					item level	
[71]	Canada, France,	(EM)		40.3 (11.4)	F 83.5%			
[]	Germany, Spain,	()						
	UK, Australia, Italy,		Web-based, cross-sectional population survey					* Sub-division of
	Taiwan.							Grade IV into IV-A
	raiwan.	Detailed definitions		EM 40.2	EM F 83.4%			severe disability
		(p410)	Participants recruited from established	(11.4)				(score 21-40) and
								IV-B very severe
			database of headache / migraine patients (n		CM F 85.6%			disability (41-270):
		514 45 115 514	63,001): all received e-invitation to 'opt in' via	CM 41.7	CIVI 1 03.070			reflects number of
	Suggests that	EM: <15 HDPM	web-link.	(12.1)				people with CM
	questionnaires	CM: >/= 15 HDPM	30.7% responded to email invitation; 55%	(12.1)				who fall into the
	completed in	CIVI. 7/- 13 HDFIVI	eligible to participate.					grade IV category.
	ʻofficial language		eligible to participate.					(ceiling effect –
	of the country' –							worst scores)
	but results then							
	combined		Surveys completed by 81.9%					
			Total n 8726					Includes a 'review'
								of the
								development /
			FM = 9227					earlier evaluation
			EM n 8227					papers for MSQ
			CM n 499					and HIT-6.
			S					
Droug et el	US	Coro cocking actions	Cross costional survey superting and a server	440(116)	F 87%	NI/A	Not reported	HUI-3
Brown et al	US	Care-seeking patients	Cross-sectional survey questionnaire – primary	44.0 (11.6)	F 8/70	N/A	Not reported.	HUI-3
2005 [79]		for migraine	focus evaluation of the HUI-3 in this population					(MIDAS)
		headache - registered						(171107-0)
		at three sites						
		representing varied						

	T.			1	I .			T 1
	US English	models of healthcare: primary care speciality clinic, non- profit HMO.	Consecutive patients recruited (each site total n50). N 150		(Causasian 87%)			Mean HUI-3 scpre 0.62 (SD0.26)
		EM: physician diagnosed at least 1- year before study enrolment (medical chart review)	N 130					
Chatterton et al 2002 [40]	US US English	Migraine diagnosis At least 1 migraine per month and	Cross-sectional survey questionnaire - primary focus evaluation of the M-TAQ; two-week test-retest (of individual items) on sub-set (n 100)	40.0 Range 18- 63	F n 219 (91%)	N/A	Not reported.	M-TAQ – development paper
			N 243		(Caucasian 63%)			(SF-36, MIDAS, Beck Depression Inventory)
								Test-retest at 2- weeks (n 100)
Coeytaux et al 2006 [58]	US English	Specialist headache clinic Chronic Daily Headache (CDH): presence of headache on >/= 15 days in the month prior to enrolling in clinical trial	Randomized clinical trial: Usual medical care (UMC) (n37) v UMC plus acupuncture (n34) Questionnaires administered at baseline and 6/52. Include patient self-report of meaningful improvement/no change/ deterioration at 6/52.	Mean 46.0; range 19-83 yrs.	F 80% (n 57) (93% white (n 66))	Usual medical care (UMC) (n37) v UMC plus acupuncture (n34) (consisting of 10 treatments over 6-wks)	Complete follow- up data for 71/74 enrolled patients (96%)	Patient-reported change in status at 6/52: 42% improved; 44% no change; 14% worse
		Total recruited with CDH n 71						

		Mean duration of CDH 24.2 (SD 5.8) days						
Cole et al 2009 [60]	US and Canada US English	1.Participants in clinical trial; and 2. Members of the general population EM or Self-report Headache: EM: minimum 6-mth history of Migraine (HIS criteria) with 3-12 Migraines per mth but not >15 HDPM during the 28-day prospective baseline period. Self-report headache at least once in past 4-weeks (prior to phone interview)	1. Pooled data from 2 randomized clinical trials (RCTs) (n 916) (Topiramite for Migraine prevention) 2. Population-based database (n 1016)	1. rge 12-65 yrs 2. rge 18-65 yrs Additional data NR	NR	Double-blind placebo-controlled RCT No intervention	Missing data: handling detailed p1181 (Bayesian multivariate imputation method)	Focus on MID calculation for MSQ v2.1 (anchor and distribution based analysis) (p1182)
Cole et al 2007 [51]	US and Canada US English	Participants in a clinical trial	Retrospective data analysis: pooled data from 2 randomized clinical trials (RCTs) (n 916) (Topiramite for Migraine prevention)	40.7 (10.7)	NR	Double-blind placebo- controlled RCT - Prophylactic migraine treatment	Missing data detailed. MSQ v2.1: Baseline:	MSQ v2.1

		6-mth history of Migraine (IHS criteria) with 3-12 Migraines per mth but not >15 HDPM during the 28- day prospective baseline period.	MSQ v2.1 completed baseline, 2/4/6mths				range 0% (several items) to 0.44% (items 3 and 4)	Reports results for both 14-item (v2.1) and a revised 13-item measure (informed by results of initial testing)
Coon et al 2012 [38]	US English	Patients registered with specialist headache clinics (8 sites) IHS diagnosis of migraine +/- aura for at least 1 year based on medical, medication and migraine history. During 3-mths prior to study enrolment – required to have x 3 to 8 migraine attacks per month and to have used triptans at least x2 per month.	Clinical study (before / after) (sumatriptan and naproxen versus usual therapy) n 916 Baseline (BL) static CORS completed to reflect experience of 'usual therapy'. After 2-mths treatment with Suma/Nap they completed the EOS static CORS (re-phrased to focus on Suma/Nap); comparative CORS also completed.	44.3 (11.0); range 19- 65yrs	F 87.1% (91.2% white)	Visit 1 (for 2-mths): participants treated any migraine with single-tablet formulation of Suma/Nap.	Not reported (at survey level)	Focus: treatment- specific measure - CORS Mean 22.4yrs (13.2; range 1-53) since Migraine onset) Average HIT-6 at baseline 61.7 (range 42-76) suggesting severe impact of headache
Cramer et al 2001 [34]	US US English	Patients with history of migraine. Migraine not defined.	Development and initial evaluation of the HANA: data from three studies:	1.Mean NR. Range 19- >65	1. F 804/994 (81%) 2. F 17/28 (61%)	N/A Migraine prophylaxis clinical trial Usual care	'No floor or ceiling effects' reported (but data not illustrated)	HANA - development paper (HDI)

			1.Participants in the Life Impact Survey – a web-	2. 40.7	3. F 21/25			
			based survey (supported and widely publicised	(11.1);	(84%)			
			by various Headache and Migraine groups)	range 16-69				
			, , , , , , , , , , , , , , , , , , ,					
			N 994					
				3. 44.0;				
				range 16-62				
			2.Participants in a migraine prophylaxis clinical trial.					
			N 28					
			N 25					
			3. 1-month test-retest cohort: 'no change in status' (anchor not reported)					
			N 25					
Davida et el	Data francis	Clinical trial	Multipational annual label 1991 (1991 1991 1991	Tatal	F 050/			DDMAO / autotro-l
Davis et al	Data from 6	Clinical trial	Multinational, open-label trial (oral naratriptan)	Total	F 85%			PPMQ (original
2002 [76]	countries: Spain,	participants	vs 'usual therapy for M'. Duration 3-months	population				version)
	NZ, NL, Hungary,			38.4				
	Finland, Canada				(98% white)			
		Diagnosad according	Descline and 2 mths completion (and of trial)		(96% Wille)			Limited detail re
		Diagnosed according	Baseline and 3-mths completion (end of trial)	6				
		to IHS criteria		Country				PPMQ
				mean age				development (
				range:				
		N 793		Spain 36.2				
		N 793		(9.1) to				
				Canada				
				40.2 (8.7)				
				10.2 (0.7)				
Dodick et al	US	Patients aged >18	RCT – patients randomized 1 : 1 ratio to	38.2	F 85.3%	N/A	NR	MIDAS
2007 [61]		years with chronic	topiramate 100 mg/day or placebo (double-					
		migraine	blind period 16weeks)					MSQ v2.1
	US English					Report responsiveness		Subjective Global
	OS LIIBIISII					(correlation of change		impression of
		Migraino dafinad	n220					
		Migraine defined	n328			scores)		change (SGIC)
		according ICHD-II,				Calculate MID (within-		
		with duration of 30				person (MIC)) for MSQv2.1		
1		minutes or longer.				person (who) for wisQv2.1		
]]			

		CM identified based on Silberstein–Lipton criteria, which required the presence of at least 15 headache days during the 28-day prospective baseline period				SGIC completed at the end of the study – 7-point scale (1= very much improved to 7= very much worse) Physician GIC also completed.		
Dowson et al 2004 [39]	International study: 5 counties: UK, US, Spain, Germany, Italy. All questionnaires translated into local language.	Patients registered at secondary care headache centres and attending for migraine treatment. Migraine diagnosed according to IHS criteria (1998; 2004): participants aged 18-65yrs; minimum 1 yr history of migraine; average 1-4 attacks per month and minimum 24-hrs between attacks, and able to distinguish migraine from other headache.	Development and initial evaluation of the M-ACT: Open, prospective, multi-national, observational, two-visit study. Baseline (n 185) 1-week test-retest (n 143) (no change in treatment during this time; but no health transition question reported). Questionnaire completed in clinic or by telephone.	44.0; range 14-87 (93% aged 18-65)	F 68% (Caucasian 99.4%)	N/A	NR	M-ACT – development paper (SF-36, MIDAS, M- TAQ)
Gillard et al 2012 [73]	Data from 9 countries: US, Canada, France, Germany, Spain, UK, Australia, Italy, Taiwan.	Episodic and chronic M Migraine defined according to International Classification of Headache Disorders (2 nd Edition): plus	International Burden of Migraine Study (IBMS) Cross-sectional, web-based observation study: paired observations of participants Individuals randomly assigned to training or 'validation' samples	NR in this paper for total pop. Presented by MSQ and HIT-6 completion (Table 1 p486)	Range 83- 86% female	N/A	NR – assumed how dealt with??	EQ-5D with HIT-6 and MSQv2.1 Conclusion: relationship between the EQ- 5D and both measures is adequate to use

	Suggests that questionnaires completed in 'official language of the country' – but results then combined	Chronic >/= 15 days per month; Episodic (< 15 HD per mth) Total > 8500 CM >450 EM >8000	Aim: to develop empirical algorithms to estimate health state utility values from disease-specific QOL scores in individuals with migraine	Range (Median) 39-42 yrs (range 18- 85)				regressions equations to estimate EQ-5D utility values. The preferred HIT-6 and MSQ algorithms can be used to estimate HSU in trials where a preference based measure is not used.
Kawata et al 2005 [55]	US English	New adult patients at university headache- speciality practice Diagnosis not specified	Cross-sectional survey All new patients who presented at clinic from Jan-Sept 2001 N 309	41.0 (SD 13) Range 18- 91 yrs.	F 77%	NR	Questionnaire response rate 309/369 (84%). HIT completion not reported at item level	HIT
Kilinster et al 2006 [74]	International study: 5 counties: UK, US, Spain, Germany, Italy. All questionnaires translated into local language.	Patients registered at secondary care headache centres and attending for migraine treatment. Migraine diagnosed according to IHS criteria (1998; 2004): participants aged 18-65yrs; minimum 1 yr history of migraine; average 1-4 attacks per month and minimum 24-hrs between attacks, and able to distinguish migraine from other headache.	Secondary analysis of data from the M-ACT study database (Dowson et al, 2000): evaluation of M-ACT reliability and validity. Open, prospective, multi-national, observational, two-visit study. Data analysed for total population and per country Baseline (n 185) 1-week test-retest (n 143) Questionnaire completed in clinic or by telephone.	44.0; range 14-87 (93% aged 18-65)	F 68% (Caucasian 99.4%)	N/A	NR	M-ACT (SF-36, MIDAS, M- TAQ)

Kimel et al 2008 [75]	US US English	Minimum 6/12 history that met HIS criteria for Migraine with aura; experienced 2-6 Migraines per mth in the 3mths prior to screening (screening assessment to confirm diagnosis)	Data from two identical phase 3 trials: fixed dose sumatriptan + naproxen sodium Vs placebo N 1304	40.1 (11.09)	F 87.8%	Fixed dose sumatriptan + naproxen sodium Vs placebo	Detailed p514- 515	PPMQ-R Evaluate psychometric properties in clinical trial setting
Kosinski et al 2003 [31]	US US English	Members of the general population with experience of recent headache (self-diagnosed?) A headache in the last 4-weeks that was not due to cold, flu, head injury, hangover	Two on-line community-based surveys (platform AOL's Opinion Place). Time 1: n 1103 Time 2: n 540	Time 1. 37.0 Time 2. 37.5	Time 1: F 73% Time 2: F 72%	N/A		(HIT and) HIT-6 development paper
Lipton et al 2003 [77]	US and UK US / UK English	Migraine (n 399) and non-migraine (n 379) controls (data pooled for both populations p631) HIS defined migraine (computer-assisted telephone interview (CATI)): HIS migraine +/- aura: 6 or more M in last year, but 15 or < headaches (any type) in previous month.	Two population-based studies (UK and US) – cross-sectional survey. Evaluation of migraine, quality of life (SF-12) and depression: patients with migraine versus non-migraine counterparts.	NR in this article – web-link provided.	NR	Nil.	NR	SF-12

Lipton et al 2009 [41]	6 countries: Canada, France, Germany, Italy, Spain, USA	Community-based population	Focus to establish the reliability and validity of a new measure – the M-TOQ: evaluation in five languages.	43.1 (12.4)	F 90.1%	N/A	NR	M-TOQ
	Spalli, USA	IHS for Migraine +/- aura; at least x1 M per mth in the past 3mths; and no change in Rx for M in past 3mths.	25 Primary care centres: N 253 (n50 per language) Questionnaire completion during clinic-based interview: package of measures including M-TOQ, MIDAS, HIT-6, MSQoL. (Unclear if all pen and paper or some touch-screen completion). Test-retest completion at 7-10 days (pen and paper completion).			Evaluation of: data quality (missing values not reported), structural validity, internal consistency reliability, itemtotal correlation, convergent validity.		(HIT-6, MSQoL)
Lipton et al 2016 [59]	US English	Eligible adults (aged 18–65 years) - International Classification of Headache Disorders (ICHD-2) diagnostic criteria for CM .	Patients with CM from PREEMPT (Phase 3 REsearch Evaluating Migraine Prophylaxis Therapy) were randomized (1:1) to receive onabotulinumtoxinA or placebo for two 12- week cycles in the double-blind (DB) phase, followed by three 12-week cycles of open-label (OL) onabotulinumtoxinA (onabotulinumtoxinA/onabotulinumtoxinA	Baseline 41 (SD 10) yrs White 90%	F 85%	PREEMPT clinical trial Focus of report – the pooled HRQOL outcomes for 56-week treatment period.	Missing HIT-6 data were imputed using a prespecified, modified last observation carried forward technique (6,7).	HIT-6 36-49 no impact 55-55 substantial impact 60-78 severe impact
		To be eligible for inclusion, patients must have had >15 headache days during the 28-day screening period (baseline), during which >4 hours of each headache day were continuous headache and >50%	(O/O) and placebo/onabotulinumtoxinA (P/O) groups, respectively). n1236 participants (O/O, n607; P/O, n629) participated in both phases HRQoL endpoints were assessed over 56 weeks using the HIT-6 and MSQv2.1			Baseline Mean HIT-6 65.4 (4.2) Mean MSQ: RR 38.6 RP 56.0 EF 42.2	All observed MSQ data were analyzed without imputation for missing values.	MSQv2.1 Range 0 (poor) to 100 (goodHRQoL) Paper describes where the measures have

		probable migraine days. Mean duration since CM onset 19yrs				At baseline most patients were severely debilitated by their migraines: 93% reporting a total HIT-6 score >60 (severe impact) and another 5% reporting a score of 56–59 (substantial impact)		proposed MIC or MID
Magnusson et al 2012 [32]	Canada US English	Pre-IHS definition for chronic migraine; patients fulfilled criteria for transformed migraine +/- medication overuse All patients were diagnosed with Migraine and had headache on >15 days per mth (fulfilling IHS criteria)	Patient registered with specialist headache centre studies: 1) Canadian Headache Outpatient Registry and Database (CHORD) (n 83); 2) Calgary Specialist headache clinic study (n 76) Groups had similar demographics, number of H days and amount of H-related disability	1)41.0	1) F n64; M n19 2) F n64; M n12	N/A	N/R	SF-36 Headache Modification (SF- 36, HIT-6) Group 1 completed the SF- 36 Headache Modification; Group 2 the original SF-36 (v1)
Martin et al 2000 [36]	US US English	Patients attending 4 outpatient headache speciality clinics Diagnosed according to IHS criteria	Multicenter, nondrug, prospective, parallel group, quasi-experimental design. N= 267 (157 new and 110 stable)	New patients: 39.0 Stable patients: 44.6	F 90.6%	Stable patients: TAU New patients: acute or prophylactic medications recommended by headache specialist	Item level: no missing observations or out of range values for either group	MSQ v2.1

	I		T	1			I	
Martin et al 2008 [65]	US US English	Sub-set of participants with CH in a large multi-site RCT.	Secondary analysis of RCT data: Headache Management Progammes (HMP): aimed at reducing H-related disability, improving process of care, reducing management costs.	45.4 (11.6)	F 75% (59.7% Caucasian)	N/A	NR	MTSM (SF-36, MIDAS)
		RCT inclusion: >21 yrs old; MIDAS score >5; intending to continue with general medical care; CH diagnosis defined below:	Primary focus: MTSM evaluation in a sub-set of RCT population; Baseline (parts 1 and 2) and 6-mths (parts 3 and 4): self-completion (mail)					
		CH: tension-type, migraine or mixed aetiology. Diagnosed by primary care physician (frequent and/or difficult to manage headaches)						
McKenna et al 1998 [37]	UK and US English Part of international study conducted in 8 countries.	Patients with history of migraine. UK: Migraine diagnosed by clinician US: Migraine diagnosed by clinical specialist	Development and initial evaluation of UK version. 1. Qualitative: interviews (UK n 30; US n25) and focus groups (US). Recruitment: UK from general practice, British Migraine Association, pharma company employees. US: from specialist clinics.	1. NR 2. 47.6; range 22-92	1.NR 2. F n72 (83%)	NA	NR	MSQoL – development paper
		No further definition provided.	2. Postal survey (UK): Baseline n 87/90 completed questionnaire; 2-week test-retest questionnaire n87/87.					

Niere & Quin 2009 [30]	Australia Australian English	Patients attending private practice out- patient physiotherapy clinics (n45) for headache management	Cross-sectional evaluation of the HDQ Clinicians' selected consecutive patients meeting inclusion criteria	38.3 (12.2) Range 18.0- 74.0	F n93 (83.8%)	NA	Item response rates: 95%-100% (14 of 16 items at least 98%)	HDQ – development paper
		IHS diagnostic criteria (1988) for Migraine +/- aura, Migraine with aura and tension type headache. Diagnostic criteria for cervicogenic headache.	N 111					
Patrick et al 2000 [52]	8 countries: US, UK, France, Denmark, Germany, Italy, Spain, Sweden.	Previous participants in placebo-controlled trial: recruited into long-term observational study. Registered with specialist headache clinics. IHS – diagnosed with Migraine	Non-comparative long-term observational study of zolmitriptan (Zomig) for acute treatment of migraine attack of any intensity (over 12-mths) N 1383	41.2 (10.01); range 12-66	1190 F; 193 M (86:14) Caucasian: 96.5%			Focus: MSQoL (20-item) (Also SF-36 (US only; n= 1115). Questionnaires completed: after treating 1, 5 and 17 M attacks or at 3-mthly intervals
Patrick et al 2003 [42]	US and UK English	Development and initial evaluation of new measure (MTSM) Participants identified by their referring clinician as "a migraine patient starting a new treatment."	1.Participants in initial interviews / focus groups – item generation (US (30); UK (24)) and confirmation (23); Headache experts (US 3; UK 1). No additional detail. 2.Participants in clinic-based study (n=29) – to test the feasibility of using the MTSM in a clinical setting and to generate a preliminary data set from small group of patients.			New migraine treatment. 22 (75.9%) started on a triptan (ie, sumatriptan, naratriptan, rizatriptan, zolmitriptan, or almotriptan); 12/22 (54.5%) were already receiving a triptan, and the other 10	NR	Development and initial evaluation of the MTSM Questionnaire completed baseline and follow-up.

Pathak et al US and Germany Migraine (IHS): at least 3 migraines in previous 12/mths. Potation Potat	Initial evidence for validity assessed against 24-hr MQoLQ and SF-36.
Pathak et al 2005 [33] Pathak et al 2005 [33] Pick et al 300 [185]: at least 3 migraines in previous 12mths. Pick et al 2005 [33] Pick et al 2005 [33] Pick et al 300 [30] Pic	against 24-hr
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2) Pre-testing – item evaluation and	
reduction: n153 US and n148 G 71.5%	
Germany 3) Pilot test and final item reduction: Study 3: US	
3) Pilot test and final item reduction: Study 3: US n75 US and n83 Germany 38.8 (11.2) Study 3:	
6 41 0	
(13.5) US 76.8 %	
G 69.9%	
Rendas- US, Canada, UK, International trial Secondary analysis of data from two multicentre Study 1: Trial 1: Not reported	Comparative
Baum et al Croatia, Germany participants with double blind placebo controlled RCTs of chronic	1 1 11 611
2013 [12] and Switzerland. diagnosis of migraine: migraine patients receiving BOTOX as 41.6 (10.5) F 87.5%	evaluation of the
prophylaxis	evaluation of the MSQ v2.1 and HIT-

		ICHD-II for migraine, with the exception of "complicated migraine" ≥15 headache days during 4-week baseline phase; each headache day of ≥4 hours of continuous headache; ≥50% of baseline headache days migraine/probable migraine days.	Total N 1376 Trial 1: n 672 Trial 2: n 704	Study 2: 41.0 (10.6)	Trial 2: F 85.4%		
Rendas- Baum et al 2014 [53]	US, Canada, UK, Croatia, Germany and Switzerland.	International trial participants with diagnosis of migraine: ICHD-II for migraine, with the exception of "complicated migraine" ≥15 headache days during 4-week baseline phase; each headache day of ≥4 hours of continuous headache; ≥50% of baseline headache days migraine/probable migraine days.	Secondary analysis of data from two multicentre double blind placebo controlled RCTs of chronic migraine patients receiving BOTOX as prophylaxis Total N 1376 Trial 1: n 672 Trial 2: n 704	Study 1: 41.6 (10.5) Study 2: 41.0 (10.6)	Trial 1: F 87.5% Trial 2: F 85.4%	Not reported	Comparative evaluation of the HIT-6 and MSQ v2.1
Revicki et al 2006 [43]	US US English	Primary Care and neurology speciality clinics (n=50)	Longitudinal observational study: patients receive usual medical care; study investigators had discretion to change or prescribe medications	39.0 (11.0)	F n 181 (91%)	Detailed Table 3 (p 246)	PPMQ-R Development / revision paper

		Documented diagnosis of migraine +/- aura (1988 IHS criteria 1.1 and 1.2): 2 to 8 Migraine attacks per month for at least 3-mths prior to study enrolment. Able to distinguish Migraine from other Headache	N 200 Convenience sampling from participating clinics (not detailed)		(Caucasian n 63 (82%))		Ceiling effects for all 10 Bothersome items (>50%) and two ease of use items.	Participants kept a Migriane diary and completed the draft PPMQ-R at 24-hrs post-Rx for each M attack (MSQv2.1)
Sauro et al 2010 [70]	Canada Canadian English	Patients registered with Neurology Outpatient practices - patients referred by family physician or other specialist Patients diagnosed according to IHS criteria - except patients with chronic daily headache (headache on 15 days a month or more).	Cross-sectional evaluation Patients identified from the Canadian Headache Outpatient Registry and Database (CHORD) — patients registered with five neurology outpatient practices (Sept 2001-Jan 2004) N 798	40.3 (SD 13.7)	F 77%	NR	Response rate 92% Item level: only those with 'valid scores' included in the analysis.	HIT-6
Sieber et al 2000 [64]	Canada Canadian English	n89 adults 'known to suffer with migraine'	Cross-sectional, comparative evaluation of QWB and QWB-SA for patients with migraine. Postal self-completion of QWB-SA Telephone-administered completion of QWB	42.2 (9.8) Range 36 to 64yrs	F 87%	Questionnaires completed at 3-points: first, on a day when migraine had not been experienced within previous 7-days; 2 nd and 3 rd within 48hrs of onset of migraine.	Not reported. Greater number of completions of QWB than QWB-SA	QWB (interview) QWB-SA (self- administered)

Stafford et al 2012 [72]	UK English	Members of the general population who had recently experienced a Migraine: IHS definition: Migraine +/- aura. At least 1 Migraine in the last 7 days and history of physician diagnosed Migraine for at least 6mths.	Cross-sectional observational study. Recruited via Migraine support groups and support group databases – eligibility confirmed via telephone interview. Aged >18yrs. N 105 Mean number of monthly Migraines 5.22 (4.1); range 1 to 20. MIDAS grade: iv 51/106 lii 32/106 li 14/106 l 9/106	47.45 (11.71)	F n 81 (76.4%) (Caucasian n 89 (83.2%))		Missing items dealt with as recommended by EQ-5D developers 1 patient did not complete EQ-5D for current health status – therefore numbers reduced from 106 to 105	Focus: generating utilities to reflect Migraine severity for participants most recent attack (past 4-weeks) and their current health state outside of an attack. Tension-related aspects of M not evaluated. EQ-5D self-completed retrospectively to reflect most recent M: completed for each level of M severity experienced (mild, mod and/or severe) during this attack. Also completed EQ-5D to reflect current non-M health state.
Stewart et al 1999 [35]	US and UK US and UK English	Computer-Assisted Telephone Interview (CATI) based diagnosis of migraine (IHS criteria)	Postal self-completion of MIDAS – population based samples of patients with migraine-headache confirmed with CATI: UK n100 and US n97 Baseline and test-retest completion at 18-days	Range 18- 55yrs	F US 83.5% UK 60%	N/A Evaluation of MIDAS reliability.	NR	Initial development / refinement of MIDAS and testing of reliability

Stewart et al 1999 [66]	US US English	Computer-Assisted Telephone Interview (CATI) based diagnosis of migraine (IHS criteria)	Postal self-completion of MIDAS – population based samples of patients with migraine-headache confirmed with CATI: US n97 and n80 non-migraine subjects	Range 18- 55yrs	F US 83.5%	N/A Evaluation of MIDAS reliability	NR	Initial reliability resting of MIDAS
			Baseline and test-retest completion at 21-days					
Stewart et al 2000 [67]	US	Patients with a confirmed diagnosis of migraine	Population based interview survey	37.6 (9.3)	F 75.7%	NA (Treatment As Usual)	Interview participation rate 67%	MIDAS
	US English		n=144					
		Initial migraine status determined from IHS based CATI algorithm	(a total of 12967 diary days)				Inadequate diary entry 16.5%	
		Migraine status confirmed by clinical examination at initial clinic visit						
Stewart et al 2003 [68]	US and UK English	Total n= 397	Secondary data analysis from three population based studies	Mean NR	F 78%	N/A	NR	Focus: relationshi between headach features (freq,
		59% MIDAS grade III or IV		62% aged 25 – 44yrs				pain intensity, quality, assoc symptoms) and the MIDAS
		Initial migraine status determined from IHS based CATI algorithm		(range <25 to 55+)				Telephone interview-based completion??

Turner- Bowker et al 2003 [7]	US English	Patient self-report or patient-reported doctors' diagnosis of migraine	Cross-sectional Internet (AOL) and mail population survey Convenience population sample Total N=7557 Migraine n=1478	Range 35– 44 years	F 53%	Not assessed	Total questionnaire response rate 27.8% Internet response rate unreported	SF-8
Vernon & Lawson 2015 [29]	Canada/UK Canadian English	Patients attending a chiropractic clinic and self-diagnosed with primary migraine, tension-type or cervicogenic headache	Cross-sectional completion of HADLI Participants recruited by advertisement/ personal solicitation N 53	37.3 (12) yrs.	F 41 (77.4%)	NA	NR	HADLI development paper
Ware et al 2003 [57]	US US English	General population At least 1 headache in 4/52 prior to interview (not hangover, cold, flu)	Two studies: 1.National Survey of Headache Impact (NSHI) – longitudinal survey (baseline and 3/12) Sampling frame: randomly generated list of telephone numbers from 48 US states. Telephone interviews with convenience sample of eligible respondents n= 1016 Headache prevalence in 4/52 period= 45.7% 2.On-line community-based survey (platform AOL's Opinion Place): respondents randomly			Detail: Ware 2000 *Med Care) and Bjorner 2003a [9]		HIT (total) CAT-HIT HIT-6-D ('static') and improved version (HIT-6) in study 2 SF-8 Focus: evaluation of CAT-based estimates vs 'static' scores: reliability and validity (plus

			selected and screened for eligibility: n 1103 included. Test-retest at 2-weeks for sub-group (n 540).					respondent burden)
Xu et al 2011 [78]**	US English	Participants in a multi-centre clinical trial. M defined by IHS (+/-aura); Between 1 – 6 moderate to severe Migraine attacks per month	Secondary analysis of data from a multi-centre (20 sites) double-blind RCT of treatment for acute Migraine (Talcagepant). Rx duration was for a single Migraine attack of moderate to severe intensity. N 330 All data pooled for EQ-5D analysis. Disutilities calculated for selected patients with mod/severe Migraine pain at baseline who reported pain freedom at 24-hrs (difference in EQ-5D scores between time-points calculated)	Mean NR Range 20- 65 yrs.	F n 292 (88.5%) (Caucasian n 259 (78.5%))		NR	EQ-5D (3D) Completed at baseline (whilst experiencing a mod/severe M and prior to dosing) and 24-hr post Rx within an acute M attack. Patients also completed Pain levels during this time (4-grade: no/mild/mod/severe).
Yang et al 2010 [56]	US US English	Population based survey – self-completed questionnaires CM and EM: Categorised into 3-groups: 1) CM (=/>15 HDPM) = 6.4%;2) EM (<15 HDPM) = 42.1%; 3)	Participants in National Survey of Headache impact (NSHI) (n= 1096) and the HIT-6 Validation study (n= 54) N= 2049 Focus of analysis: reliability and validity of HIT-6 in patients with varying headache frequency days.	Mean NR Range 18- 69yrs 56.3% aged 18-39	F 75%	NA NA	NR	HIT-6 (SF-8) HIT-6 scores calculated across the 3 groups: 1) CM = 62.5 (7.8); 2) EM = 60.2 (6.8); 3) Non-M headache = 49.1 (8.7)

Study (Author;yr) [ref]	Country ^g Language ^g	Survey included a Migraine screener ID Migraine criteria – p359) and number of headache days per month (HDPM) Population and Headache definition	Study: design, setting, sample size ⁸	Mean ^g age (SD; range)	Gender distribution (F Female) [§]	Treatment descriptions ⁸	% missing responses: acceptable?8*	PROM focus;
		Non-M headache = 51.5%						

Footnote:

• Missing values: a. At survey level; b. At item level (data quality – frequency with which items were missing (ie. Non-completed) and how did the authors deal with missing values? Bagley 2012: HDPM Headache days per month (p410 for detail); IBMS – International Burden of Migraine Study (2009).

Appendix 6: Table 5 Content comparison at item level (number of items) of condition-specific measures (n= 17)

				Do	mains o	of Health-rela	ited Qual	ity of Life (Fe	errans et a	al, 2005 [25]))*				Response to Tr	Treatment		
			Symptom	Status				Fur	nctional St	atus			General Health Perception		nesponse to 11	cument		
			Sympto	oms		Physical		Social	/ Role		Psy	chological						
PROMª	Items (n) ^b						Social /	/ Role	ADL / V	Vork	EWB	Cognition		Return to normal	Confidence / Satisfaction with Rx	Side effects	Other	
		General	Headache Frequency	Headache Intensity	Pain	Physical	Limit	Prevent	Limit	Prevent								
Condition-spe	cific (17)																	
Migraine impo	act (5/17)																	
FAIM [33]	9+5						5				5		4					
HANA [34]	7	1					1		1		3		1					
MIDAS [35]	5 + 2		1*	1*				1	4									
MSQv2.1[36]	14	2					2	1	3	2	3	1						
MSQoL [37]	20						6		10		4							
Headache imp	oact (6/17,																	
EUROLIGHT ^d [28]	103	Х	Х	Х	Х	Х	Х		Х		Х	Х						
HADLI [29]	9	1				1		2	4			1						
HDQ [30]	9				2		1		3	3								
CAT-HIT e	54	Х			Х		Х		Х		Х	Х						
[3,57]																		
HIT-6 [31]	6	1			1		1		1		1	1						
SF-36 Headache	6/36				2	1	2		1									
[32]																		
Response to n	 niaraine-si	pecific treat	ment (6/17)															
Static CORS	24	9	, , , ,		5				2		3	1		1	3			
Comp CORS																		
[38]	8	4												1	3			
M-ACT [39]	27													20	7			
	4													2	2			
M-TAQ [40]	9	1	1							1				1	1		4	
M-TOQ15	15	1		1	2				2		1			1	4	3		
M-TOQ-5 [41]	5				1				1						2	1		
MTSM [42]	45	1			3				1						3			
PPMQ-R [43]	19	3			6		2		2		1		2 (cost)		3			
	10	8									1	1						

Footnote:

*Ferrans et al (2005) revision to the Wilson and Cleary Model of Health Related Quality of Life (HRQOL)[25]: The model describes five levels of patient outcomes from biological and psychological variables through to overall quality of life (subjective well-being assessed by an individuals perceived level of happiness or satisfaction with life), and includes symptoms (for example, physical, emotional, cognitive symptoms perceived by the patient), functional status (for example, physical, social, role and psychological function) and general health perceptions (a subjective rating incorporating all of the preceding health concepts). Additionally, characteristics of the individual (such as values and preferences) and those of the environment (such as social, economic and psychological support) are considered.

^a PROM content; ^b Number of items per PROM

Migraine-impact:

^a FAIM – Functional Assessment in Migraine: 9 items across three domains. 1) Attention/Thought (5 items); 2) Perception (4 items); 3) Activity and Participation (5 items)

HANA - Headache Needs Assessment: 7 items to reflect migraine frequency and bothersomeness. 1 item in each of following area: Anxiety/worry; depression/discouragement; self-control; energy; function/work; family/social activities; overall impact of migraines.

MIDAS - Migraine Disability Assessment Score: 3 domains (5 scored items): Missed days/ reduced productivity at paid work (2 items); Missed days/ reduced productivity at household work (2 items); Missed non-work activities (1 items)

MSQv2.1 - Migraine-Specific Quality of Life Questionnaire version 2.1: 3 domains (14 items): 1) Role function – Restrictive (RR)(7 items): social – family/friends; leisure (2); work/ADL (3); cognition (1); symptoms: fatigue (1); 2) Role function – Preventive (RP)(4 items): symptoms: fatigue (1); work /ADL (2); social (1); 3) Emotional function (EF)(3 items): frustration (1); feeling a burden (1); letting others down (1).

MSQOL - Migraine-Specific Quality of life: 3 domains (20 items): 1) Avoidance behaviours (10); 2) Social relations (6); 3) Feelings (4).

Headache impact:

EUROQLIGHT: 6 sections (103 items): 1) Biographical (age, gender, language and employment); 2) Screening questions for headache; 3) Diagnostic questions; 4) Questions about any headache experienced 'yesterday' (point prevalence); 5) Use of healthcare resources (medicines, investigations, consultations, etc.); 6) Impact of headache on work, family life and social activities: includes items taken from the WHOQOL (8-items), the HALT-index and HADS. ^d EUROLIGHT – number of items per domain not clear (denoted by X).

HADLI - Headache Activities of Daily Living Index: 1 domain (9 items): Personal care, Lifting, Reading (including computers), Sleeping (over last week), Exercising (over last week), Social activities, Work, Driving or travelling, Recreation.

HDQ – Headache Disability Questionnaire: 3 domains (9 items): 1) Pain (2 items): usual pain intensity; when pain is severe; 2) Activity Limitation (4 items): Decreased efficiency in non-work activities; Decreased ability to work/study; Decreased efficiency in housework or chores; Proportion of times when work is missed; 3) Activity Prevention (3 items): Number of days where chores prevented; Number of days non-work activities prevented; Number of days in last month when had to lie down for >1 hour.

HIT (CAT-HIT) - Headache Impact Test: One domain 'Headache Impact': 54-item 'item bank'. Items cover a wide spectrum of headache impact, including minor headache. Items cover of pain, role and social functioning, energy/fatigue, cognitive function, and mental health.

e CAT-HIT: Number of completed items is individualised and determined by 'stopping rule': mean number 6/54 items (denoted by X)

HIT-6 — Headache Impact Test -item (static): 6 domains (6 items): 1) Headache pain severity(1); 2) Social functioning - usual daily activities(1); 3) Role functioning (how often do you wish you could lie down?) (1); 4) Vitality(1); 5) Cognitive functioning(1); 6) Psychological distress(1).

SF-36 Headache - Inserts 'including your headaches' to 6/36 items: physical functioning (item 3); role limitation - physical (item 4); social functioning (items 6 and 10); bodily pain (items 7 and 8)

Response to migraine-specific treatment:

CORS - Completeness of Response to Migraine Therapy Survey: Two modules: 1. Static CORS - 5 domains (24 items): 24-items address: Symptoms, Emotional well-being, Cognition, ADL, Function, Confidence in current medical. 2. Comparative CORS (8 domains (8 items)): Completeness of Relief (1), Persistence of Relief (1), Return to Normal Function (1), Fatigue (1)

Confidence in Treatment (2), Overall Satisfaction (1) – most satisfied.

M-ACT - Migraine - Assessment of Current Therapy: 4 domains (27 long-form/ 4 short): Headache impact (11/1); Global assessment of relief (9/1); Consistency of response (3/1); Emotional response (4/1).

M-TAQ - Migraine Therapy Assessment Questionnaire: 9 items - Migraine control, frequency of attacks, knowledge and behavioural barriers, economic burden, treatment satisfaction.

M-TOQ - Migraine-Treatment Optimization Questionnaire M-TOQ: 15- and 5-item versions: 5 domains (15/5 items): Functioning (3/1), Rapid relief of headache (3/1), Consistency of response (3/1), Prevention of recurrence (3/1), Side effects (3/1).

MTSM - Migraine Treatment Satisfaction Measure: 4-part assessment: 1) Expectations of Treatment for Migraine (TE-M; 9 items); 2) Importance Ranking for Migraine Treatment (IR-M; 9 items); 3) Outcomes of Treatment for Migraine (TO-M; 9-items); 4) Satisfaction with Migraine Treatment (PST-M; 9-items). Considered across 9 attributes ('items') associated with migraine relief: Pain relief; Speed of relief; Freedom from pain; Additional symptoms; Confidence in treatment; Disruption in life; Dosing; Freedom from relapse; Ease of use

PPMQ-R - Patient Perception of Migraine Questionnaire -Revised: Core: 4 domains (19 items): Efficacy: satisfaction with treatment efficacy (11); Function: ability to perform usual activities (4); Ease of Use (2); Cost (2) (may be removed where 'cost' is not a consideration). Additional fifth domain (10 items): 'Bothersomeness' or 'Tolerability' - related to side effects (10). 3 global items: Overall satisfaction with medication effectiveness; Side effects; General treatment.

Appendix 7: Table 6: Methodological quality (COSMIN^a) of each study (n=46) per PROM (n=23) and investigated measurement property.

PROM ^b	Country	Headache	(n)	Reliability			Validity				Responsiveness		Interpretability
Study (n)	(language)	definition	,	Internal consistency	Reliability	Measurement error	Content validity	Structural validity	Hypothesis testing	Known- groups validity	Responsiveness (COSMIN)	Responsiveness - other	
Condition-spec	cific (17)												
Migraine-impo	act (5/17)												
FAIM (1)													
Pathak et al 2005 [33]	US English German	M	69 83	Good			Fair	Good	Good				
HANA (1) Cramer et al 2000 [34]	US English	M		Poor	Poor		Poor	Poor	Poor	Poor			
MIDAS (12)										1			
Stewart et al 1999a [35]	US and UK English	M (IHS)	US 97 UK 100	Poor	Poor								
Stewart 1999b [66]	US English	M (IHS)	97	Poor	Poor								
Stewart et al 2000 [67]	US English	M (IHS)	144						Fair				
Stewart et al 2003 [68]	US and UK English	M (IHS)	397						Poor				
Bigal et al 2003 [69]	US English	СМ	182							Fair			
Dodick et al 2007 [61]	US English	CM (ICHD-II)	328								Fair		
Martin et al 2008 [65]	US English	CH – TT/M/mixed	124						Fair				
Lipton et al 2009 [41]	Multiple	M (IHS)	253	Poor					Fair				
Sauro et al 2010 [70]	Canadian English	CH (IHS)	798						Fair	Fair			
Blumenfeld et al 2010 [71]	Multiple	CM; EM	8726							Fair			
Yang et al 2010 [56]	US English	CM; EM	>600						Good	Good			
Bagley et al 2012 [54]	Multiple	CM; EM	8726 total						Fair				
Stafford et al 2012 [72]	UK English	M (IHS)	105						Fair				
MSQ v2.1 (9)													
Martin et al 2000 [36]	US English	M (IHS) / EM	267	Good	Good		Fair		Excellent	Excellent			

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Revicki et al	US English	EM (IHS 1.1,	200					Good				
2006 [43]		1.2)										
Dodick et al 2007 [61]	US English	CM (ICHD-II)	328							Fair		Poor
Cole et al 2007 [51]	US English	EM (IHS)	916	Excellent			Excellent	Fair				
Cole et al	US English	EM										Fair
2009 [60]												
Blumenfeld	US English	CM and EM							Fair			
et al 2010												
[71]												
Bagley et al 2012 [54]	US English	CM; EM	8726 total	Fair				Fair	Fair			
Gillard et al 2012 [73]	Multiple	CM; EM	8726						Fair			
Rendas-	US English	CM (ICHD-II)	1376	Good	Good		Good	Good	Good		SRM	1
Baum et al		(,										
2013 [12]	UC Faralish	CM (ICHD-II)	1376					Card				
Rendas- Baum et al	US English	CIVI (ICHD-II)	13/6					Good				
2014 [53]												
Lipton et al	US English	CM (ICHD-II)	1236								% exceeding	
2016 [59]		,									MIC or MID	
MSQoL (3)												
McKenna et	UK English	M (IHS)		Poor	Fair	Excellent		Poor	Fair			
al 1998 [37]												
Patrick et al 2000 [52]	US English	М	1376	Fair		Fair	Good		Fair		ES; SRM	Poor
Lipton et al	Multiple	M (IHS)	253	Poor				Fair				
2009 [41]		(EM?)										
Headache-imp	act (6/17)											
EUROLIGHT (1												
Andree et al	Multiple	Headache –	426	Poor	Poor	Fair		Poor	Poor			
2010 [28]	UK English	all types	131									
HADLI (1)								+	+			
Vernon et al	Canadian	Self-	53	Fair		Poor	Fair		+			
2015 [29]	English	diagnosed headache: M, TT, CG	33	Tall		7001	Tall					
UDO (1)												
HDQ (1)	Australian	M (IHCD):	111	Eair		Door	Enir		1			
Niere & Quin 2009 [30]	Australian	M (IHSD); Mixed: TT, CG, 'other'	111	Fair		Poor	Fair					

	1			I	1		1	1		4		
LUT (2)												
HIT (3)		11.10 5)	1016				- " .					
Bjorner et al 2003a [3]	US English	H (C or E)	1016			Fair	Excellent					
Ware et al 2003 [57]	US English	Н	1.1016 2.1103		Fair	Fair		Good	Good	Poor		
Kosinski et al 2003a [31]	US English	Н	1103		Fair	Fair		Fair	Fair			
HIT-6 (12)												
Kosinski et al 2003a [31]	US English	Н	1103	Fair	Fair	Fair		Fair	Fair	Fair		
Ware et al 2003 [57]	US English	Н	1.1016 2.1103		Fair	Fair		Good	Good	Poor		
Kawata et al 2005 [55]	US English	Н	309	Fair			Fair	Fair				
Coeytaux et al 2006 [58]	US English	CDH	71	_								Fair
Lipton et al 2009 [41]	Multiple	M (IHS) (EM?)	253	Poor				Fair				
Sauro et al 2010 [70]	Canadian English	CH (IHS)	798					Fair	Fair			
Yang et al 2010 [56]	US English	CM; EM	>600	Good	Fair			Good+	Good			
Gillard et al 2012 [73]	Multiple	M (ICHD): CM and EM	9048						Fair			
Bagley et al 2012 [54]	US English	CM; EM	8726 total					Fair				
Magnusson et al 2012 [32]	US English	CM (+/- MOU)	159					Poor				
Rendas- Baum et al 2013 [12]	US English	CM (ICHD-II)	1376					Good				
Rendas- Baum et al 2014 [53]	US English	CM (ICHD-II)	1376	Good	Good		Good	Good	Good		SRM	
Lipton et al 2016 [59]	US English	CM (ICHD-II)	1236								% exceeding MIC or MID	
SF-36 'Headac	he-specific' (1)											
Magnusson et al 2012 [32]	US English	CM	159			Poor / nil		Fair				
Response to m	igraine-specifi	c treatment (6/	(17)									

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CORS (1)													
Coon et al	US English	M (IHS)	916	Fair			Good	Fair	Fair		Fair		
2012 [38]													
M-ACT (2)													
Dowson et al	Multiple	M (IHS)	185		Fair		Poor		Poor				
2004 [39]													
Kilinster et al	Multiple	M (IHS)	185		Fair				Poor				
2006 [74]													
M-TAQ (1)													
Chatterton	US English	M (IHS)	243		Fair		Fair		Fair				
et al 2002	00 2.18.10.1	()											
[40]													
[.0]													
M-TOQ 19/15/	/5 (1)												
Lipton et al	Multiple	M (IHS)	253	Fair	Fair		Fair	Fair	Fair				
2009 [41]	Widitiple	(EM?)	233	I all	I all		I all	Tan	I all				
2005 [41]		(LIVI:)											
MTSM (2)													
Patrick et al	US English	М	29	Poor			Good		Fair	Fair			
2003 [42]	U3 Eligiisii	IVI	29	P001			Good		Fall	Full			
Martin et al	US English	CH –	124	Fair			Poor	Fair	Good	Good			
2008 [65]	US Eligiisii	TT/M/mixed	124	Fall			POOI	Fall	Good	Good			
2008 [65]		TT/W/THIXEU											
DDMO D (2)													
PPMQ-R (2)	LIC Explish	ENA /ILIC 4 4	200	F	F		E II I	E II t	E II I	Cood		50	F-11
Revicki et al	US English	EM (IHS 1.1,	200	Excellent	Fair		Excellent	Excellent	Excellent	Good		ES	Fair
2006 [43]		1.2)											
Kimel et al	US English	M (IHS)	1304	Excellent				Good	Good	Good			
2008 [75]													
Generic measu	ures (6)												
Profile measur	res (3/6)												
SF-36 (5)													
Patrick et al	US English	М	1376									ES, SRM	
2000 [52]													
Martin et al	US English	M (IHS) /	267						Good				
2000 [36]		EM											
Davis et al	Multiple	M (IHS)	793						Poor				
2002 [76]													
Kawata et al	US English	Н	309						Fair				
2005 [55]	<u> </u>												
Martin et al	US English	CH -	124						Fair				
2008 [65]		TT/M/mixed											
SF-12 (1)													
Lipton et al	US and UK	M (IHS)	M 399							Fair			
2003 [75]	English	(
2003 [73]		l	i	i	<u> 1</u>	L	I		I	l		1	1

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			Control								
			379	1							
SF-8 (4)											
Kosinski et al 2003a [31]	US English	M (self- report)	1103					Fair			
Ware et al 2003 [57]	US English	Н	1.1016 2.1103					Good			
Turner- Bowker et al 2003 [7]	US English	M (self- report)	465					Good	Good		
Yang et al 2010 [56]	US English	CM; EM	>600					Good	Good		
Utility measures (3/6)											
EuroQoL EQ-5I	D-3L (3)										
Xu et al 2011 [78]**	US and UK English	M (HIS)	330						Poor		
Gillard et al 2012 [73]	Multiple	M (ICHD): CM and EM	9715 CM 555 EM 9160						Fair		
Stafford et al 2012 [72] *	Uk English	M (IHS)	105					Fair	Fair		
HUI-3 (1)											
Brown et al 2008 [79]	US English	EM	150						Poor		
OWB and OWI	QWB and QWB-SA (1)										
Sieber et al 2000 [64]	US English	М	89	Poor					Fair		

Footnote:

^a COSMIN – Consensus on Standards for Measurement Instruments. Four-grade rating for study methodological quality: Excellent, Good, Fair Poor. [20,21]

^b PROM acronyms (detailed in text and Tables 1 and 2)

^c Headache definition: H – Headache (general); CH – Chronic Headache; TT – Tension Type; CG – Cervico Genic; CDH – Chronic Daily Headache; M – Migraine; EM – Episodic M; CM – Chronic M; IHS – International Headache Society – headache classification system (https://www.ichd-3.org/); ICHD – International Classification of Headache Disability (https://www.ichd-3.org/).

^{*}Focus of paper: generating utilities to reflect Migraine severity; **Focus of paper: calculating disutilities.