

**Table S2.1 - Characteristics of included papers**

Study no.	Author (year) & (Reference no.)	Type of study/study design	Sample characteristics	Outcome domains	Outcome measures
1	Baca, C. B., et al. (2011).  (1)	<b>Observational</b>  Prospective, community-based cohort study of newly diagnosed childhood epilepsy, with ongoing prospective follow up.	<ul style="list-style-type: none"> <li>• 277 children 129 females, 148 males.</li> <li>• Mean age: 13 range: 8-17</li> <li>• New diagnosed epilepsy, unprovoked seizure between 28 days and 15 years.</li> </ul>	Health related quality of life  Cognitive function	Child health questionnaire (CHQ)  Neurologic medical records, parent interviews, school records, and standardized neuro-psychological testing using the Wechsler Intelligence Scale for Children.
2	Baca, C. B. et al., (2012)  (2)	<b>Observational</b>  Prospective community-based study of long-term outcomes of childhood-onset epilepsy. (The Connecticut Study of Epilepsy).	<ul style="list-style-type: none"> <li>• 277 parent-child dyads</li> <li>• Mean age of child: 5.1, SD: 2.5.</li> <li>• Newly diagnosed childhood epilepsy.</li> </ul>	Health related quality of life	Child health questionnaire (CHQ)
3	Bast et al., (2003)  (3)	<b>Systematic Review (SR)</b>  SR of the influence of sulthiame on EEG in BECTS	<ul style="list-style-type: none"> <li>• 66 children</li> <li>• Diagnosis of BECTS</li> <li>• Mean age: 8.3, range 3-10 years</li> </ul>	The rate of treatment failure events  EEG	Any first seizure  EEG
4	Benson, A., et al. (2016)  (4)	<b>Qualitative</b>  Mixed qualitative & quantitative in 2 stages. Phase one: qualitative exploratory design using semi-structured interviews.  Phase 2: Questionnaires/cross-sectional survey	Phase one: <ul style="list-style-type: none"> <li>• 33 Children aged 6-16 years, mean age: 7.33 and 40 parents.</li> <li>• Prescription of anti-epileptic medication</li> </ul> Phase two: <ul style="list-style-type: none"> <li>• 47 children aged 8-18 years; mean age 13.19, and 72 parents.</li> </ul>	Themes: Social exclusion in epilepsy, Activity restrictions, Teasing/bullying, concealment, stigma coaching  Stigma	Interview  Child Stigma Scale (CSS)
5	Borggraefe et al., (2013)	<b>Randomised Controlled Trial (RCT)</b>	<ul style="list-style-type: none"> <li>• 44 children between 6-12 years of age</li> <li>• Diagnosis of BECTS</li> </ul>	Primary endpoint: occurrence of a treatment failure event	Occurrence of a seizure during the observation period – 24 weeks after reaching target dose.

Supplementary 2. Characteristics of included papers and provisional list of papers

Study no.	Author (year) & (Reference no.)	Type of study/study design	Sample characteristics	Outcome domains	Outcome measures
	(5)	Randomised, double-blinded controlled trial (over 26 months). Non inferiority trial of LEV (Levetiracetam) compared to STM (Sulthiame). Randomly allocated to the LEV or STM treatment arm.	<ul style="list-style-type: none"> <li>• LEV group (n=21): mean age: 8.7, 6 females</li> <li>• STM group (n=22): mean age: 9.0, 10 females</li> </ul>	Dropouts related to adverse events/occurrence of a drug related adverse reaction	Adverse events e.g. general symptoms, pain etc. Urine analysis
6	Chong et al. (2016)  (6)	<b>SR of Qualitative Studies</b>  Systematic review of qualitative studies on the experiences of children and adolescence.	<ul style="list-style-type: none"> <li>• 951 participants overall.</li> <li>• Participants aged 3-21 years</li> <li>• Diagnosed with epilepsy.</li> </ul>	Themes: Loss of Bodily Control: Being overtaken, Susceptibility to physical harm, Fragility of the brain, Alertness to mortality, Bodily powerlessness, Loss of Privacy: Declarative Disease, Humiliating Involuntary Action, Unwanted special attention, Social embarrassment of medicine taking, Inescapable inferiority and discrimination: Vulnerability to Prejudice, Consciousness of abnormality, Limiting social freedom, Therapeutic Burden and Futility: Awaiting a Fabled Remission, Overwhelming Life Disruption, Social and spiritual connectedness	Interview
7	Connock et al., (2006).  (7)	<b>SR</b>  SR to examine the clinical effectiveness and cost-effectiveness of newer anti-epileptic drugs (AEDs) for epilepsy in children. Drugs included: gabapentin,	<ul style="list-style-type: none"> <li>• Young people with epilepsy under 18 years old and mixed age groups with epilepsy if including persons less than 18 years old.</li> </ul>	Premature discontinuation due to adverse events  Seizure frequency	Adverse events e.g. vomiting, infection, headache, fever.  The number of seizures during maintenance

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Study no.	Author (year) & (Reference no.)	Type of study/study design	Sample characteristics	Outcome domains	Outcome measures
		lamotrigine, levetiracetam, oxcarbazepine, tiagabine, topiramate and vigabatrin.			
8	Coppola et al., (2007)  (8)	<b>RCT</b>  Randomised to levetiracetam (LEV) group, and an Oxcarbazepine (OXC) group.  LEV & OXC – 5mg/kg – up to a daily maximum dose of 20 mg/kg.	<ul style="list-style-type: none"> <li>39 children aged between 3.3 to 14 years (m: 8.4) were randomised to receive monotherapy with LEV levetiracetam or OXC.</li> <li>New diagnosis of BECTS according to ILAEO, absence of neurological and mental deficits.</li> </ul>	Complete seizure freedom  Awake & sleep EEG	Seizure freedom (recorded in an epilepsy diary)  EEG
9	Smith et al., (2015)  (9)	<b>Meta-Analysis</b>  Evaluation of 22 studies of literacy and/or language skills in children with rolandic epilepsy, published after 2000.	<ul style="list-style-type: none"> <li>Children and adolescents with rolandic epilepsy, aged 5-18 years.</li> </ul>	Language & Literacy	Reading measured with: GORT accuracy (Gray, Oral, Reading Tests), WIAT (Weschler Individual Achievement Test), WRAT (Wide Range Achievement Test)  Phonological processing measured with: TOWRE (test of word reading efficacy)  Expressive language measured with: CELF (Clinical Evaluation of Language Fundamentals)  Receptive language measured with: CELF, Peabody Picture Vocabulary Test (PPVT)
10	Gutter et al., (2013)  (10)	<b>Observational</b>  Purpose of study were to explore the prevalence of	<ul style="list-style-type: none"> <li>131 children – partial epilepsy aged 4 to 10 years and 161 age and sex matched controls.</li> </ul>	Sleep	Sleep Disturbance Scale for children (SDSC), Medical Outcomes Study-Sleep Scale (MOSS –S) and Groningen

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Study no.	Author (year) & (Reference no.)	Type of study/study design	Sample characteristics	Outcome domains	Outcome measures
		sleep disturbances in a large cohort of school-age children with partial epilepsy.		Restrictions in childhood epilepsy  School environment/Peers & social support/autonomy & parent relations/psychological wellbeing/physical wellbeing	Sleep Quality Scale (GSQS) Hague Seizure Severity Scale (HSSS), the Hague Side Effects Scale (HaSES) and  Hague Restrictions in Childhood Epilepsy Scale (HaRCES)  Kidscreen-27
11	Kim et al., (2015) (11)	<b>Observational</b>  Investigate cortical thickness and gray matter volume abnormalities in BECTS.	<ul style="list-style-type: none"> <li>20 children (14 males, mean age: 7.5),</li> <li>Newly diagnosed BECTS</li> </ul>	EEG  Cortical thickness/grey matter	EEG  MRI
12	Lewis et al., (2008) (12)	<b>Observational</b>  E-survey and interviews	<ul style="list-style-type: none"> <li>44 children and young people with epilepsy aged 3-23 (parent responses on behalf of child).</li> <li>Interviews with a separate group of 22 children and young people with epilepsy.</li> </ul>	Impact of epilepsy on school	E-survey
13	Liu et al., (2016) (13)	<b>RCT</b>  Children were randomised into two groups Group 1: topiramate once every night  Group 2: topiramate twice a day.	<ul style="list-style-type: none"> <li>85 children</li> <li>54 males and 31 females aged from 3.3 years to 13 years. Diagnosed with benign childhood epilepsy</li> </ul>	EEG  Seizure frequency  Adverse events	EEG  Parent recorded  Parent recorded/physiological measures of blood, urine.
14	Loiselle et al., (2016)	<b>Observational</b>  Trajectories	<ul style="list-style-type: none"> <li>120 children with epilepsy and their care giver</li> </ul>	Paediatric epilepsy side-effects	Paediatric Epilepsy Side Effects Questionnaire (PESQ) (Mortia et al., 2012).

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Study no.	Author (year) & (Reference no.)	Type of study/study design	Sample characteristics	Outcome domains	Outcome measures
	(14)	of health-related quality of life (HRQOL) among children with newly diagnosed epilepsy, and evaluate key predictors of HRQOL trajectories.	<ul style="list-style-type: none"> <li>2-12 years old, received an epilepsy diagnosis on day of study recruitment</li> </ul>	<p>Health-related quality of life</p> <p>Parental fears about the impact of a child's seizures on functioning</p>	<p>Care-giver proxy report version of the PedsQL 4.0 (Varni, Seid &amp; Kurtin, 2001).</p> <p>The Parent Report of Psychosocial Care (Austin, Dunn, Huster &amp; Rose, 1998) – Includes the five-item Concerns and Fears subscale (assesses parental fears about the impact of the child's seizures on functioning and outcomes)</p>
15	Melchionda et al., (1999) (15)	<b>Observational</b>  Evaluate long term evolution of headaches associated with rolandic centrotemporal spikes	<ul style="list-style-type: none"> <li>32 children with rolandic centro temporal spikes</li> </ul>	Headache	Occurrence of symptom
16	Mitsudome et al., (1997) (16)	<b>Observational</b>  Effectiveness of clonazepam on rolandic discharges.	<ul style="list-style-type: none"> <li>32 children with centro temporal spikes (CTS) that has episodes of headache (16 females) with centro-temporal spikes (CTS) at EEG</li> <li>52 matched controls</li> </ul>	EEG	EEG
17	Moffat et al., (2009) (17)	<b>Observational</b>  Impact of childhood epilepsy on quality of life	<ul style="list-style-type: none"> <li>22 children (11 male, 11 female)</li> <li>Mean age; 9, Range: 7-12</li> <li>Experiences partial seizures and some generalised seizures.</li> </ul>	Themes: Impact on social life, developmental/role related issues, psychological epilepsy related issues, peer acceptance, school-related issues, academic impact, family reactions, adjustment, compliance, seizure experience, fear, coping, the future,	Interview

Supplementary 2. Characteristics of included papers and provisional list of papers

Study no.	Author (year) & (Reference no.)	Type of study/study design	Sample characteristics	Outcome domains	Outcome measures
				translational periods, medical experiences, emotional impact	
18	Nevitt et al., (2016)  (18)	<b>SR</b>  RCT's with a comparison of carbamazepine monotherapy with phenobarbitone monotherapy in individuals with epilepsy	<ul style="list-style-type: none"> <li>Children or adults with partial onset seizures</li> <li>Individuals with a new diagnosis of epilepsy</li> </ul>	Seizures  Adverse events  IQ  Memory	Incidence of seizures  Side effects, withdrawals, incidence of allergic reactions  WISC-R Scale, Bender-Gestalt test
19	Rating et al., (2000)  (19)	<b>RCT</b>  Children were randomized to receive either STM or a placebo	<ul style="list-style-type: none"> <li>66 children</li> <li>Aged between 3-10 years</li> <li>Diagnosis of BECTS (or has 2 ore</li> </ul>	Adverse events	Adverse event
20	Reilly et al., (2015)  (20)	<b>Observational</b>  Factors associated with quality of life in childhood epilepsy.	<ul style="list-style-type: none"> <li>Children recruited from the CHES study (identification of children with 'active' epilepsy born between 1995 and 2007'.</li> <li>Children aged 5-15 years</li> </ul>	Quality of life	QOLCE US
21	Ronen et al., (1999)  (21)	<b>Observational/qualitative</b>  Identifying the attributes of Health related quality of life (HRQOL) in childhood epilepsy.	<ul style="list-style-type: none"> <li>29 children and their parents</li> <li>Mean age: 9.2</li> <li>Simple/complex partial seizures</li> </ul>	Themes: Experience of epilepsy, life fulfilment/time use, home activities, school issues, and activities, social experiences, impact of epilepsy	Interview
22	Sajobi et al., (2017)  (22)	<b>Observational</b>  Trajectories across health related quality of life domains in children with new onset epilepsy	<ul style="list-style-type: none"> <li>373 children with new-onset epilepsy</li> </ul>	Family life event changes  Family functioning/resources	The Family Inventory of Life Event Changes (FILE)  Family inventory of resources and management (FIRM)

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Study no.	Author (year) & (Reference no.)	Type of study/study design	Sample characteristics	Outcome domains	Outcome measures
				Health-related quality of life  Epilepsy severity	QOLCE-55  Global Assessment of Severity of Epilepsy (GASE)  The Family adaptability, partnership, growth, affection and resolve (APGAR)
23	Schmitt et al., (2009)  (23)	<b>Observational</b>  Effects of valproic acid on sleep in children with epilepsy	<ul style="list-style-type: none"> <li>• 46 children</li> <li>• Aged 1.7-17.4 years, mean 8.4</li> <li>• History of generalised epilepsies</li> </ul>	Sleep	Sleep habits survey
24	Schraegle et al., (2016)  (24)	<b>Observational</b>  Executive functioning and HRQOL in childhood epilepsy	<ul style="list-style-type: none"> <li>• 130 children</li> <li>• Mean age: 11.6 years, SD: 3.6 years</li> <li>• Epilepsy diagnosis</li> </ul>	Executive functioning  Behaviour  Memory  Intelligence  HRQOL	Behaviour rating inventory of executive functioning (BRIEF)  BRIEF  BRIEF  Wechsler Intelligence Scales (WSI-II) (WISC-IV)  Quality Of Life in Childhood Epilepsy scale (QOLCE)
25	Seidel et al., (1999)  (25)	<b>Observational</b>  Cognitive and behavioural effects of carbamazepine in rolandic children.	<ul style="list-style-type: none"> <li>• 27 Children</li> <li>• 12 diagnosed with benign rolandic epilepsy or migraine headache, 15 with migraine</li> <li>• Mean age BECTS: 9.7, aged between 6-12 years</li> </ul>	Intelligence  Language  Memory  Motor skills	Wechsler Intelligence Scale for Children 3 <sup>rd</sup> edition  Boston Naming Test  Wide Range Assessment of Memory and Learning  Finger tapping test, Grooved pegboard test

Supplementary 2. Characteristics of included papers and provisional list of papers





Study no.	Author (year) & (Reference no.)	Type of study/study design	Sample characteristics	Outcome domains	Outcome measures
30	Turky et al., (2008) (30)	<b>Observational</b>  Epidemiological study aimed at determining the prevalence of behavioural and emotional problems in a UK community-based population of children and adolescents with epilepsy	<ul style="list-style-type: none"> <li>• 56 children and adolescents with epilepsy aged 4-17.</li> <li>• 25 males, 31 females.</li> <li>• Diagnosis of epilepsy, age at epilepsy onset: 6 years old.</li> </ul>	<p>Strengths &amp; difficulties</p> <p>Seizure severity</p> <p>Moods, feelings &amp; emotions</p> <p>Impact of paediatric epilepsy</p> <p>Quality of life in epilepsy</p>	<p>Strengths &amp; difficulties questionnaire (SDQ)</p> <p>Revised Liverpool Seizure Severity Scale</p> <p>The Moods and Feelings Questionnaire (MFQ)</p> <p>The Impact of Paediatric epilepsy scale (IPES)</p> <p>Quality of Life in Epilepsy Inventory for Adolescents (QOLIE-AD-48)</p>
31	Turner et al., (2004) (31)	<b>Observational</b>  Prospective, randomized, single-blinded, crossover, placebo-controlled, pilot clinical trial investigating exposure to music on EEG of children with BECTS.	<ul style="list-style-type: none"> <li>• 4 children aged 5-9 years, were selected from EEGs diagnostic of BECTS</li> </ul>	Interictal epileptiform discharges (IED)	EEG
32	Verhey et al., (2009) (32)	<b>Observational</b>  QOL in children with epilepsy and agreement between child and parent	<ul style="list-style-type: none"> <li>• Children aged 8-17 years were included with a diagnosis of active epilepsy</li> <li>• 375 children and 378 parents</li> </ul>	Health related quality of life	CHEQOL-25

Supplementary 2. Characteristics of included papers and provisional list of papers

Study no.	Author (year) & (Reference no.)	Type of study/study design	Sample characteristics	Outcome domains	Outcome measures
33	Wille et al., (2010)  (33)	<b>Preference based/HRQOL measure</b>  Development of the EQ-5D-Y	<ul style="list-style-type: none"> <li>Epilepsy measure designed for young people</li> </ul>	Mobility  Looking after myself  Usual activities  Pain/discomfort and feeling worried  Sad or unhappy	EQ-5DY
34	Stevens et al., (2011)  (34)	<b>Preference based/HRQOL measure</b>  Development of the Child Health Utility (CHU9D)	<ul style="list-style-type: none"> <li>247 children recruited from general and clinical paediatric populations tested</li> </ul>	Sad  Pain  Tired  Annoyed  School Work  Sleep  Daily routines and activities	CHU9D
35	Feeny et al., (2002)  (35)	<b>Preference based/HRQOL measure</b>  Development of the Health Utilities Index Mark 3 (HUI3)	<ul style="list-style-type: none"> <li>A random sample of the general population (<math>\geq 16</math> years of age) in Hamilton, Ontario, Canada completed preference surveys</li> </ul>	Vision  Hearing  Speech  Ambulation  Dexterity  Emotion	HUI3

Supplementary 2. Characteristics of included papers and provisional list of papers

Study no.	Author (year) & (Reference no.)	Type of study/study design	Sample characteristics	Outcome domains	Outcome measures
				Cognition Pain	
36	Mulhern et al., (2012)  (36)	<b>Preference based/HRQOL measure</b>  NEWQoL-6D	Epilepsy measure designed for adults <ul style="list-style-type: none"> <li>Used sample of 1611 respondents with newly diagnosed epilepsy from SANAD study to generate classification system</li> </ul>	Worry about attacks  Depression  Memory  Concentration  Stigma  Control	NewQoL-6d
37	Sadeghi et al., 2014  (37)	<b>SR of outcome measures</b>	Conceptual analysis – no participants  Conceptual/theoretical analysis – no participants		DISABKIDS (Epilepsy Module)  ECQ (Epilepsy and children questionnaire)  ELQOL (epilepsy and learning disabilities quality of life)  EFA (Epilepsy Foundations of American Concerns Index)  Glasgow Epilepsy Outcome Scale (GEOS-C)  ICI (Impact of Childhood Illness)  ICNDS (Impact of Childhood Neurologic Disability)  IPES (Impact of Paediatric epilepsy scale)  QOLCE

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Study no.	Author (year) & (Reference no.)	Type of study/study design	Sample characteristics	Outcome domains	Outcome measures
					QOLIE-AD QOLPES (Quality of life in paediatric epilepsy) PedsQL Neuro-QOL

Supplementary 2. Characteristics of included papers and provisional list of papers

**Table S2.2** - Provisional list of outcomes identified from systematic review and provided to the team

COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)
<b>Physiological: Nervous System Outcomes</b>	Seizures	Seizure remission	Proportion seizure free	8, 18, 28
			Proportion of patients who are seizure free at 3 months, 12 months	28
			Complete seizure freedom	8
		Seizure frequency	Seizure frequency	7, 13, 18
			Seizure frequency and severity	11
			Mean seizure frequency per month	18, 20
		Seizure duration	Mean seizure duration	20, 18
		Seizure severity	Seizure severity	10, 22, 30, 37
			Severity of epilepsy	24, 22
		Seizure control	Seizure control	18

COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)
<b>Physical Functioning</b>	Sleep	Sleep duration	Overall sleep	10
			Sleep start time & end	23
			Assumed sleep per night	23
			Actual sleep per night	23
			Assumed sleep per nap	23
			Actual sleep time per nap	23
			No. of hours of sleep	10
			Nap per day	23
			Sleep	34
			Sleep quality	
		Disorders of initiating and maintaining sleep	10	
		Sleep breathing disorders	10	
		Sleep quality	10	
		Sleep hyperhidrosis	10	
		Sleep disturbance/insomnia	10	
		Disorders of arousal	10	
		Sleep-wake transition disorders	10, 23	
		Breathing problems/headache in sleep	10	

Supplementary 2. Characteristics of included papers and provisional list of papers

COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)
		Sleep efficiency	Sleep adequacy	10
			Morningness/eveningness	23
		Daytime sleepiness	Sleepiness	23
			Disorders of excessive somnolence	10
			Daytime somnolence	10
			Energy/fatigue	20, 37
			Tired	34
	Physical health	Pain	Bodily pain/discomfort	1, 2
			Pain/discomfort – feeling worried	33
			Pain	34, 35, 37,
		Physical functioning	Physical functioning	1, 14, 22, 30, 37
			Physical restrictions	10, 20, 37
			Physical wellbeing	10
			Physical impact of epilepsy	21
			Role/social limitations physical	1, 2
			Change in health	1, 2, 37
				37

Supplementary 2. Characteristics of included papers and provisional list of papers

COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)
			Physical health	
	Manual ability	Manual ability	Mobility	33
			Ambulation	35
			Dexterity	35
			Motor skills	25
<b>Social Functioning</b>	Usual activities	Usual activities	Usual activities	33
		Recreation & Leisure	Activity restrictions	4
			Social activities	20, 37
		Self-care	Looking after self	33
			Independence	37
	Behaviour	Behaviour	Behaviour	1, 2, 30, 24
			Behavioural regulation	24
			Internalizing behaviour	25
			Externalizing behaviour	25
			Self-concept: behavioural adjustment	26
			Conduct problems	30

Supplementary 2. Characteristics of included papers and provisional list of papers



COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)
			Prosocial behaviour	30
			Peer problems	30
			Parental ratings of behaviour	25
			Social behaviour	30, 37
			Social health: sociability	37
			Social health: social role performance	37
			Role/social limitations: behavioural	1, 2
		Family functioning & cohesion	Family cohesion	1, 2
			Family activities	1, 2
			Family resources	22
			Parent impact – time/emotion	1, 2, 37
		Educational participation	School environment	10, 14
	Social	Social life/Engagement with friends & peers	Social exclusion in epilepsy	4
			Teasing/bullying	4, 21

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COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)
			Social embarrassment of medicine taking	6
			Limiting social freedom	6
			Social life	17
			Social interactions	20, 37
			Peers & Social support	10
			Social functioning	14, 22, 30, 37
			Social interactions	20, 37
			Peer problems	30
			Social support	30, 37
			Interpersonal/social	32, 37
			Teasing/bullying	4, 21
			Communication	26, 30, 37
			Social impact of epilepsy/Impact on social activities	37
		Stigma	Social embarrassment of medicine taking	6
			Inescapable inferiority and discrimination: vulnerability to prejudice	6
			Unwanted special attention	6

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COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)		
			Stigma	4, 36, 37, 20, 30		
<b>Role functioning</b>	Family relationships	Autonomy & relationships with parents	Family relationships & functioning	22, 37		
			Autonomy & parent relations	10		
			Family life event changes	22		
			Autonomy	NF		
			Family	NF		
			Impact of epilepsy on relationships with family, peers and siblings	37		
<b>Emotional functioning/wellbeing</b>	Mental Health	Behavioural difficulties	Behavioural difficulties	30		
			Depression	20, 23, 36, 22, 34, 33		
			Sad	34		
			Sad or unhappy	33		
		Anxiety	Anxiety	20, 37		
			Self-esteem	1, 2, 20, 37		
					Over-all self-concept	26
					Self-concept: physical appearance and attributes	26

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COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)
		Mental wellbeing	Mental health	1, 2
			Psychological wellbeing	10
			Emotional control	24
			Self-concept: happiness & satisfaction	26
			Moods, feelings and emotions (over 2 weeks)	30, 37
			Mood/Mood state	37
			Intrapersonal/emotional	32
			Annoyed	34, 37
			Emotion	35
			Optimism	37
			Emotional functioning	37
			Attitude towards epilepsy	26, 30, 37
			Fear of seizures	NF
			Psychological functioning	14
			Control/helplessness	20, 37
			Impact of epilepsy (psychosocial)	30, 26
			Emotional disorders	30

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COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)
			Role/social limitations emotional	1, 2
			Epilepsy impact: effects of epilepsy and antiepileptic medications	30
			Disclosure & normality	6, 32, 37
		Secrecy	Secrecy	32, 4
			Concealment	4
		Fears about epilepsy	Parental fears about the impact of a child's seizure	14
			Worries/concerns	32, 34, 36, 37
			Concerns about epilepsy	37
			Future worries	37
			Fear of seizures	37
			Parental concern	37
			Impact of seizures	37
			Prospects for the future	37
<b>Cognitive Functioning</b>	Cognition	Language & Literacy	Reading	9
			Phonological processing	9

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COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)
			Expressive language	9, 20, 25, 37
			Receptive language	9, 20, 25, 37
			Speech	35
		Memory	Memory	18, 22, 30, 25, 27, 30, 36, 37
			Working memory	24
		Intelligence	IQ scores	18, 24, 25, 29
		Concentration	Attention/concentration	20, 30, 36, 25, 37
			Hyperactivity/inattention	30
		Executive functioning	Metacognitive index	24
			Planning/organisation	24
			Executive functioning (Global executive composite)	24
		Cognition	Speeded visual search and mental flexibility	25
			Cognition	35
			Cognitive function	1, 37, 22
			Control	36

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COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)
			Cognitive effects of epilepsy	37
			Applied cognition: general concerns	37
			Speeded visual search and mental flexibility	25
			Other cognitive	37
		School performance	Self-concept: Intellectual and school status	26
			School/scholastic functioning	37
			Education	37
			Impact of epilepsy on academic achievement	37
			Impact of epilepsy on school	10
			Academic self-concept:	26
<b>Global quality of life</b>	Global quality of life	Global quality of life	Global general health	1, 2, 14, 20, 22, 30, 32, 37
			General health perceptions	1, 2, 30, 37
			Impact of epilepsy on health	37
			General/overall health	37
			Overall impact of epilepsy	37

Supplementary 2. Characteristics of included papers and provisional list of papers

COMET Taxonomy	Outcome Domain	Aspects of health	Outcome identified verbatim in individual study	Study number of papers retrieved from systematic review (See Table 1)
			Total impact of childhood neurologic disability	37
			Health related quality of life	14, 20, 30, 32, 37
<b>Adverse events/effects</b>	Adverse events	Unintended adverse events	Routine urine test	13, 5
			Liver and renal function	13
			Weight	13
			Routine blood test	13
			Paediatric epilepsy side effects	14, 18, 10
			Adverse events	18, 19, 28, NF, 5, 7, 13, 15, 30, 35, 37, 11
			Anti-epileptic drug side effects	37, 10
			Seizure effects	37
			Headache	15
			Hearing	35
			Vision	35
			Safety/injury	37

Supplementary 2. Characteristics of included papers and provisional list of papers



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