**Patterns, trends and methodological associations in the measurement and valuation of childhood health utilities – Supplementary Materials**

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| **Table S1.** Search strategy | | |
| Database: PubMed, Embase, Web of Science, PsycINFO, EconLit, CINAHL, Cochrane Library | | |
| Date of search: (i) 26th January 2016 for articles from database inception to 31st December 2015; (ii) 1st July 2017 for articles from 1st January 2016 to 30th June 2017 | | |
| Limit search to title and abstract and English articles | | |
| **Search Category** |  | **Search Terms** |
| **Utility Terms** | 1 | Utilit\* or disutilit\* or HSUV |
| 2 | “quality adjusted life year\*” or QALY or “quality-adjusted life year\*” or “quality-adjusted life-year\*” |
| **3** | **OR (1 to 2)** |
| **Indirect Valuation Method Terms** | 4 | EQ-5D or “EQ 5D” or EQ5D or Euroqol or “Euro qol” or EQ-5D-Y or "EQ 5D Y" |
| 5 | Short-form survey-6D or short form 6D or SF-6D or “SF 6D” or SF6D |
| 6 | “health utilities index” |
| 7 | “quality of well being” or “quality of well-being” or QWB |
| 8 | 16D Health-Related Quality of Life or 16D HRQoL or 17D Health-Related Quality of Life or 17D HRQoL |
| 9 | AQoL-6D or Assessment of Quality of Life-6D |
| 10 | “Child Health Utility 9 Dimension” or CHU9D or CHU-9D or “CHU 9D” |
| 11 | Adolescent Health Utility Measure or AHUM |
| 12 | 15-dimensional instrument or 15 dimensional instrument |
| 13 | preference-based measure of HRQoL or preference based measure of HRQoL |
| 14 | multi-attribute utility instrument or multiattribute utility instrument |
| **15** | **OR (4 to 14)** |
| **Direct Valuation Method Terms** | 16 | Standard Gamble or standard-gamble |
| 17 | Time trade off or time trade-off |
| 19 | best worst scaling or best-worst scaling |
| 19 | Discrete choice experiment or discrete-choice experiment |
| 20 | person trade off or person trade-off |
| 21 | scoring algorithm or scoring-algorithm |
| 22 | utility elicitation or direct elicitation |
| **23** | **OR (16 to 22)** |
| **24** | **3 OR 15 OR 23** |
| **Childhood Terms** | 25 | Child\* or adolesc\* or kid or kids or youngster\* or teen\* or youth\* or infant\* or newborn\* or perinat\* or neonat\* or “parent proxy” |
| 26 | Pediatri\* or paediatri\* |
| **27** | **OR (25 to 26)** |
| **Main Search** | **28** | **24 AND 27** |
| **29** | **Remove non-English Title and/or Abstract** |
| **30** | **Remove Duplicates Across Databases** |

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| **Table S2.** Variables extracted from included studiesusing proforma | |
| **Variable** | **Note** |
| Bibliographic details | Author(s), title, year of publication |
| Country/geographical setting |  |
| Study setting | Hospital inpatient ward, hospital outpatient clinic, general practice, school, home or other |
| Health descriptor(s) | Health condition, disease, health state and/or intervention descriptor |
| Respondent type | Self-assessment by children or proxy-assessment by parents, caregivers, nurses, physicians or other proxies |
| Sample size | Including that of sub-samples (e.g., by age, gender or socioeconomic status) |
| Direct valuation method applied | If applicable |
| Indirect valuation method applied | If applicable |
| Tariff set | If indirect valuation method applied |
| Utility or VAS score | Including central statistics and measures of variability |
| Study design | Patient case series, cross-sectional study, longitudinal observational study (prospective or retrospective), randomised controlled trial (with or without economic evaluation), decision-analytic modelling or other |
| Administration mode | Self-administration in clinic or school setting, by postal survey or by online survey or interview administration by face-to-face or by telephone |
| Valuation of hypothetical health state |  |
| Response quality | Response rate, information on dropouts, reasons for loss to follow-up |
| Statistical methods for analysing utilities |  |
| Any reported methodological concerns | E.g., reliance of proxy respondents, low response rate, sample selection bias or other |

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| **Table S3.** Characteristics of studies included in the systematic review | | | | | | |
| **Reference** | **Health Condition** | **Intervention** | **Country of study population (of tariff population)** | **Valuation method** | **Respondent type and administration mode** | **Age of study population** |
| Aldebeyan et al (2017) [1] | Hypothetical adolescent idiopathic scoliosis |  | Canada | VAS, TTO, SG | Proxy-assessed by general public. Online survey | 12-18 |
| Anderson et al (2014) [2] | Risk of depression | Treatment: CBT in classroom  Control: usual school provision of health education | UK (UK) | EQ-5D-3L | Self-assessed by children. Self-administered paper questionnaire | 12-16 |
| Angelis et al (2016) [3] | Epidermolysis bullosa | Outpatient care | Bulgaria, France, Germany, Hungary, Italy, Spain, Sweden, UK | EQ-5D VAS | Self-assessed by children.  Postal survey | Mean: 7.2;  0-18 |
| Apajasalo et al (1996) [4] | Congenital skeletal dysplasia; End-stage heart, liver, kidney failure; Epilepsy; General health (control) | Patients with organ failure awaiting transplantation | Finland (Finland) | 16D | Self-assessed by children. Self-administered paper questionnaire | 12-15 |
| Apajasalo et al (1996b) [5] | Congenital skeletal dysplasia; End-stage heart, liver, kidney failure; Epilepsy; General health (control) | Patients with organ failure awaiting transplantation | Finland (Finland) | 17D | Self-assessed by children. Face-to-face interview | 8-11 |
| Apajasalo et al (1998) [6] | Congenital skeletal dysplasia |  | Finland (Finland) | 16D | Self-assessed by children. Self-administered paper questionnaire | 12-15 |
| Arkkila et al (2009) [7] | Receptive language disorder; General health (control) |  | Finland (Finland) | 16D | Self-assessed by children. Postal survey | Mean: 14.2; 12-17 |
| Arkkila et al (2011) [8] | Receptive language disorder; General health (control) |  | Finland (Finland) | 17D | Assessed together by children and parents. Postal survey | Mean: 10.1; 8-12 |
| Arnold et al (2014) [9] | Sickle cell disease; General health (control) | Stem cell transplantation | USA (Unspecified) | EQ-5D-3L VAS,  EQ-5D-3L | Self-assessed by children. Unspecified mode of administration | 12-14 |
| Autti-Ramo et al (2005) [10] | Hypothetical health states: Congenital adrenal hyperplasia; Glutaricaciduria type 1; LCHADD; MCADD; Phenylketonuria | Tandem mass spectrometry;  Screening for metabolic disease | Finland (Finland) | 16D | Proxy-assessed by physicians. Self-administered paper questionnaire | 0-2 |
| Baguelin et al (2010) [11] | Influenza A/H1N1 |  | UK (Unspecified) | EQ-5D-3L | Assessed together by children and parents. Postal survey | Unspecified |
| Balottin et al (2014) [12] | Migraine | Treatment: Psychotherapy  Control: CBT | Italy | EQ-5D-3L VAS | Self-assessed by children. Face-to-face interview | Mean: 10.2, 9.2; 6-18 |
| Banks et al (2008) [13] | Cancer patients: leukaemia, lymphoma, brain tumour | Intravenous chemotherapy | Canada (Unspecified) | HUI2, HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire | Mean: 9.5; 2-18 |
| Barr et al (1993) [14] | Cancer survivors: ALL | St. Jude VIII protocol; Memorial Sloan L2 protocol; DFCI 85-01; DFCI 87-01 | Canada (Canada) | HUI2 | Proxy-assessed by nurses after physician consultation. Self-administered paper questionnaire | Unspecified |
| Barr et al (1994) [15] | Cancer survivors: brain tumours (PNET, medulloblastoma, astrocytoma, glioma, glioblastoma) | Surgery; Chemotherapy | Canada (Canada) | HUI2 | Proxy-assessed by physicians, nurses or parents. Self-administered paper questionnaire | Unspecified |
| Barr et al (1997) [16] | Cancer patients: ALL in remission | DFCI 87-01; DFCI 91-01 | Canada (Canada) | HUI2 | Proxy-assessed by physicians, nurses or parents. Self-administered paper questionnaire | Median: 3.9; 0.9-14 |
| Barr et al (1999) [17] | Cancer survivors: brain tumour (PNET, medulloblastoma, astrocytoma, glioma, ependymoma) | Surgery; Chemotherapy; Radiotherapy | Canada (Canada) | HUI2, HUI3 | Proxy-assessed by nurses. Self-administered paper questionnaire | Mean: 9.5; 1.7-17.9 |
| Barr et al (2000) [18] | Cancer survivors: Wilm’s tumour; SNS tumour (neuroblastoma) | Surgery; Chemotherapy; Radiotherapy; Stem cell transplantation | Canada (Canada) | HUI2, HUI3 | Proxy-assessed by parents. Postal survey | Mean: 9.1, 7.8; 2.8-20 |
| Barr et al (2001) [19] | Cancer survivors: ALL; NHL; Hodgkin’s disease; Wilm’s tumour; neuroblastoma; STS; retinoblastoma; AML | Unspecified cancer therapy | Colombia, Honduras, Uruguay, Cuba (Canada) | HUI2, HUI3 | Proxy-assessed by parents or physicians. Self-administered paper questionnaire or face-to-face interview | Unspecified |
| Barton et al (2006) [20] | Hearing loss | Cochlear implantation | UK (Canada) | HUI3 | Proxy-assessed by parents. Postal survey | Unspecified |
| Baumann et al (2016) [21] | Very low birthweight/very preterm birth; General health (normal birthweight/term) |  | Germany (Canada) | HUI3 | Self-assessed by children; Proxy-assessed by parents.  Postal survey | Mean: 13 |
| Beckman et al (2016) [22] | Victims of bullying; General health (control) |  | Sweden (UK) | SF-6D | Self-assessed by children. Postal survey | Mean: 16.2; 15-18 |
| Beerthuizen et al (2016) [23] | Asthma | Treatment 1: Web-based asthma management  Treatment 2: 4-monthly FENO-based asthma management  Control: Standard asthma management | Netherlands (Netherlands) | EQ-5D-3L, EQ-5D VAS | Assessed together by children and parents.  Self-administered paper questionnaire | Mean: 10.6;  4-18 |
| Belfort et al (2011) [24] | Overweight or obese; General health (normal weight) |  | USA (Canada) | HUI2, HUI3 | Self-assessed by children or assessed together by children and parents. Face-to-face interview | Mean: 10.3, 11.5; 5-18 |
| Bennett et al (2000) [25] | Bacterial meningitis; Permanent sequelae (brain damage, deafness) | Emergency department; Hospitalisation | USA | Chained Gamble | Proxy-assessed by parents. Online survey | 0.25-3 |
| Bergfors et al (2015) [26] | Asthma | Inhaled steroids | Sweden | EQ-5D-Y VAS | Assessed together by children and caregivers. Self-administered paper questionnaire | Mean: 12.1; 8-16 |
| Bilcke et al (2012) [27] | Chickenpox |  | Belgium (Unspecified) | EQ-5D-3L | Proxy-assessed by parents. Face-to-face interview | 0-3 |
| Bilcke et al (2017) [28] | Experience of severe disease; General health |  | Belgium (Belgium) | EQ-5D-3L; EQ-5D VAS | Proxy-assessed by parents.  Postal survey | 0-12 |
| Billson et al (1994) [29] | Cancer survivors: ALL; brain tumours; Wilm’s tumour; retinoblastoma; Hodgkin’s disease; NHL; AML; STS; neuroblastoma; Ewing’s sarcoma; ovarian sarcoma; osteogenic sarcoma | Unspecified cancer therapy | UK (Canada) | HUI2 | Proxy-assessed by physicians or assessed together by children and parents. Self-administered paper questionnaire | 2-17 |
| Bodden et al (2008) [30] | Anxiety disorder: social phobia; separation anxiety disorder; panic disorder | Individual CBT;  Family CBT | Netherlands (UK) | EQ-5D-3L VAS,  EQ-5D-3L | Assessed together by children and parents. Self-administered paper questionnaire. | Mean: 12.3; 8-17 |
| Bolton et al (2014) [31] | Overweight or obese; General health (normal weight) |  | Australia (Australia) | AQoL-6D | Self-assessed by children. Self-administered paper questionnaire. | Mean: 14.5; 11-19.6 |
| Bolton et al (2016) [32] | General health: students from rural or urban areas | Diet and physical activity | Australia (Australia) | AQoL-6D | Self-assessed by children. Self-administered paper questionnaire | Mean: 14.6; 11-19 |
| Boran et al (2011) [33] | Cancer patient: ALL; Ewing’s sarcoma; Hodgkin’s disease; NHL; STS; PNET; Wilm’s tumour; medulloblastoma; neuroblastoma; osteosarcoma; AML | Chemotherapy: neutropenia stage; post-neutropenia stage | Turkey (Canada) | HUI2, HUI3 | Proxy-assessed by parents. Face-to-face interview. | Mean: 7.72; 0.9-14 |
| Boulton et al (2006) [34] | Vision disorder: nystagmus; visual pathway impairment |  | UK (Canada) | HUI3 | Proxy-assessed by parents. Face-to-face interview. | Mean: 6.17; 3-8 |
| Bouwmans et al (2014) [35] | ADHD; Comorbidities (learning disorder, autistic disorder, anxiety disorder, mood disorder, asthma, tic disorder, epilepsy, mental retardation) | ADHD medication | Netherlands (Netherlands) | EQ-5D-3L | Proxy-assessed by parents. Online survey. | Mean: 11.9; 8-18 |
| Boyer et al (2014) [36] | General health | School-based intervention for improving social and emotional wellbeing | UK (Unspecified) | CHU9D | Self-assessed by children. Unspecified mode of administration. | 8-10 |
| Boyer et al (2016) [37] | General health | “Roots of Empathy”: School-based intervention for improving social and emotional wellbeing | UK (Australia) | CHU9D | Self-assessed by children. Self-administered paper questionnaire | 8-9 |
| Boyle et al (2010) [38] | Overweight or obese; General health (normal weight) | Physical activity | UK (UK) | EQ-5D-Y VAS,  EQ-5D-Y | Self-assessed by children. Postal survey. | Mean: 13.2; 11-15 |
| Braam et al (2016) [39] | Cancer: haematological malignancy; brain and CNS tumour; other solid cancer | Treatment: “Quality of Life in Motion” – 12-week physical exercise and psychosocial training  Control: usual care without physical training | Netherlands (Netherlands) | EQ-5D-Y | Self-assessed by children. Self-administered paper questionnaire; Postal survey | Mean: 13.4; 8-18 |
| Bradlyn et al (1993) [40] | Cancer: ALL; lymphoma; osteosarcoma; neuroblastoma | Surgery; Chemotherapy; Radiotherapy | USA (USA) | QWB | Proxy-assessed by parents. Face-to-face interview. | Mean: 10; 4.8-17.7 |
| Brisson et al (2010) [41] | Acute rotavirus gastroenteritis | Primary care | Canada (Canada) | EQ-5D-3L VAS,  HUI2 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 1.42; 0-3 |
| Brown et al (2009) [42] | Heart failure | Heart transplant; Intensive care (ECMO bridging) | UK (Canada) | HUI2 | Proxy-assessed by parents. Face-to-face interview. | 1-16 |
| Brunner et al (2003) [43] | MSKD: juvenile rheumatoid arthritis; systemic lupus erythematosus; juvenile dermatomyositis; arthropathy secondary to haemophilia |  | Canada (Canada) | SG, VAS (Linear analogue scale, Categorical scale),  HUI3 | Proxy-assessed by parents or self-assessed by children. Face-to-face interview. | 1-18 |
| Brunner et al (2004) [44] | MSKD: juvenile rheumatoid arthritis; Castleman syndrome; systemic lupus erythematosus; juvenile dermatomyositis; arthritis associated with IBD; juvenile psoriatic arthritis; juvenile ankylosing spondylitis; sarcoidosis |  | USA | VAS, SG (Lifelong arthritis as pit) | Proxy-assessed by parents or self-assessed by children. Face-to-face interview. | 3-18 |
| Brussoni et al (2013) [45] | Injury: head; upper extremity; lower extremity; dislocation; internal organ; facial; open wounds; burn; nerve; dental; poisoning; asphyxia | Emergency department; Hospitalisation | Canada (UK) | EQ-5D-3L VAS,  EQ-5D-3L | Assessed together by children and parents. Postal survey or non-postal Self-administered paper questionnaire. | 0-16 |
| Bull et al (2014) [46] | Cancer survivors: medulloblastoma (WNT molecular group, SHH group, non-WNT/SHH group) | Protocol at SIOP-UKCCSG PNET3 clinical trial | UK (Unspecified) | HUI3 | Proxy-assessed by parents or self-assessed by children. Unspecified mode of administration. | Median: 15.7, 14.5, 14.7; 10.3-18.2 |
| Burstrom et al (2011) [47] | Asthma; Diabetes; JIA; Celiac disease; General health (no disease) |  | Sweden | EQ-5D-Y VAS | Self-assessed by children. Face-to-face interview. | Mean: 9.87; 8-12 |
| Burstrom et al (2014) [48] | JIA; Arthrogryposis; Myelomeningocele; Cerebral palsy; Lower limb deformities; Achondroplasia |  | Sweden | EQ-5D-Y VAS | Self-assessed by children. Postal survey or Face-to-face interview. | Mean: 12, 13.3; 7-17 |
| Buysse et al (2008) [49] | Meningococcal sepsis; Permanent sequelae (severe mental retardation, neurological impairment, mild renal failure) | Survivors of intensive care | Netherlands (Canada) | VAS, HUI2, HUI3 | Proxy-assessed by parents. Face-to-face interview. | Median: 14.5; 5.3-31.1 |
| Byford et al (2007) [50] | Depression; Comorbidity (behavioural disorder) | Treatment: CBT and selective serotonin reuptake inhibitor (SSRI)  Control: SSRI alone | UK (UK) | EQ-5D-3L VAS,  EQ-5D-3L | Self-assessed by children. Face-to-face interview. | Median: 14; 11-17 |
| Byford et al (2013) [51] | Depression; Comorbidity (behavioural disorder) | Treatment: CBT and selective serotonin reuptake inhibitor (SSRI)  Control: SSRI alone | UK (UK) | EQ-5D-3L | Self-assessed by children. Face-to-face interview. | Median: 14; 11-17 |
| Canaway and Frew (2013) [52] | General health |  | UK (UK, Netherlands) | CHU9D,  EQ-5D-Y | Self-assessed by children. Face-to-face interview. | Mean: 6.37; 6-7 |
| Canaway and Frew (2014) [53] | Overweight or obese; General health (normal weight) |  | UK (UK, Netherlands) | CHU9D,  EQ-5D-Y | Self-assessed by children. Face-to-face interview. | 6-7 |
| Cardarelli et al (2006) [54] | Cancer survivors: brain tumour; leukaemia; lymphoma; solid tumour | Radiotherapy | Italy (Canada) | HUI2 | Proxy-assessed by parents or self-assessed by children. Self-administered paper questionnaire. | Mean: 13.3; 8-28 |
| Carroll and Downs (2009) [55] | ADHD; Allergy; Asthma; Cerebral palsy; Gastroenteritis; Hearing loss; Mental retardation; Otitis media; Seizure disorder; Vision disorder | Intensive care; Hospitalisation | USA | Chained Gamble,  TTO | Proxy-assessed by parents from general public. Face-to-face interview. | Unspecified |
| Chadha et al (2010) [56] | Recurrent respiratory papillomatosis | Surgery | Canada (Canada) | VAS, HUI3 | Assessed together by children and caregivers. Face-to-face interview. | Median: 9; 1.42-17 |
| Chen et al (2008) [57] | Acne | Hypothetical acne treatment | USA | TTO | Self-assessed by children. Self-administered paper questionnaire. | Mean: 15.4; 14-18 |
| Chen et al (2014) [58] | Overweight or obese; General health (normal weight) | Physical activity | Australia (Australia) | CHU9D | Self-assessed by children. Self-administered paper questionnaire. | Mean: 10.6, 15.1; 9-16 |
| Chen et al (2015) [59] | General health |  | Australia (Australia) | CHU9D,  EQ-5D-Y | Self-assessed by children. Online survey. | Mean: 14; 11-17 |
| Cheng et al (2000) [60] | Hearing loss | Cochlear implantation | USA (Canada) | VAS, TTO, HUI3 | Proxy-assessed by parents. Postal survey. | Mean: 7.5, 7.4, 10 |
| Cheng et al (2011) [61] | Cancer patients: leukaemia; lymphoma; solid tumour; brain tumour | Chemotherapy with hypothetical modes of administration | Canada (Unspecified) | VAS, HUI2, HUI3 | Proxy-assessed by parents or self-assessed by children. Face-to-face interview. | 0-18 |
| Cheung et al (2016) [62] | Adolescent idiopathic scoliosis | Observation with regular follow-up; Bracing; Surgery | China (China) | EQ-5D-5L | Self-assessed by children. Face-to-face interview | Mean: 15.6; 10-20 |
| Chevreul et al (2015) [63] | Cystic fibrosis |  | France (Denmark, England, Italy, Netherlands, Scotland, Poland) | EQ-5D-5L VAS,  EQ-5D-5L | Assessed together by children and caregivers.  Online survey. | Mean: 8.5 |
| Chevreul et al (2015b) [64] | Fragile X syndrome |  | France (Denmark, England, Italy, Netherlands, Scotland, Poland) | EQ-5D-5L | Assessed together by children and caregivers.  Online survey. | Mean: 10.3 |
| Chiou et al (2005) [65] | Asthma |  | USA (USA) | PAHOM | Self-assessed by children. Self-administered paper questionnaire. | Mean: 9.31 |
| Chirivella et al (2009) [66] | Cancer patients: ALL; STS; Hodgkin’s disease; NHL; Ewing’s sarcoma; osteosarcoma; Wilm’s tumour; AML; ovarian tumour; germ cell tumour | Chemotherapy; Radiotherapy | India (Canada) | HUI2, HUI3 | Proxy-assessed by physicians. Self-administered paper questionnaire. | 5-15 |
| Clement et al (2015) [67] | Unilateral slipped capital femoral epiphysis | Surgery: prophylactic fixation or unilateral fixation | UK (UK) | SF-6D | Self-assessed by children.  Self-administered paper questionnaire | Mean: 12.3;  9-16 |
| Covaciu et al (2013) [68] | Allergy; Asthma; Rhinitis; Eczema; Food hypersensitivity | Inhaled steroids | Sweden | EQ-5D-3L VAS | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 8 |
| Cox et al (2005) [69] | Cancer patients: ALL | High-dose methotrexate therapy | USA (Unspecified) | HUI3 | Proxy-assessed by nurses. Self-administered paper questionnaire. | Median: 10; 6-18 |
| Creswell et al (2017) [70] | Anxiety disorder: Separation anxiety disorder; Social anxiety disorder; Generalised anxiety disorder; Specific phobia | Treatment: Brief guided parent-delivered cognitive behavioural therapy  Control: Solution-focused brief therapy | UK (UK, Unspecified) | CHU9D, EQ-5D-Y | Self-assessed by children; Proxy-assessed by caregivers. Self-administered paper questionnaire | Mean: 9.28; 5-12 |
| Cunha et al (2013) [71] | Admission to PICU: Elective postoperative; Respiratory; Sepsis; Trauma | Intensive care | Portugal (Canada) | HUI3 | Proxy-assessed by parents. Face-to-face or telephone interview. | 6-18 |
| Czyzewski et al (1994) [72] | Cystic fibrosis |  | USA (USA) | QWB | Proxy-assessed by parents or self-assessed by children. Face-to-face interview. | Mean: 8.74; 0.2-17.9 |
| Dakin et al (2010) [73] | Bilateral otitis media with effusion | Treatment: intranasal corticosteroids  Control: placebo | UK (Canada) | HUI2, HUI3 | Assessed together by children and parents. Self-administered paper questionnaire. | Mean: 6.39; 4-7 |
| de Bruin et al (2016) [74] | Insomnia | Treatment: Internet cognitive behavioural therapy (6 weeks)  Control: Face-to-face group cognitive behavioural therapy (6 weeks) | Netherlands (Netherlands) | EQ-5D-3L | Self-assessed by children. Online survey; Self-administered paper questionnaire | Mean: 15.4; 12-19 |
| de Jong et al (2012) [75] | Craniosynostosis:  Apert syndrome;  Crouzon syndrome;  Muenke syndrome;  Saethre-Chotzen syndrome |  | Netherlands (Canada) | VAS, HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 9.6; 4-18 |
| de Keizer et al (1997) [76] | Admission to PICU | Intensive care: cardiovascular and other surgery; non-surgical treatments | Netherlands (Canada) | HUI2 | Proxy-assessed by parents. Postal survey or non-postal Self-administered paper questionnaire | 1-16 |
| de Kinderen et al (2016) [77] | Epilepsy | Treatment: ketogenic diet  Control: usual care | Netherlands (Netherlands) | EQ-5D-Y | Self-assessed by children. Self-administered paper questionnaire. | Mean: 7.8, 8.1; 1.1-15.7 |
| de Lissovoy et al (2007) [78] | Cerebral palsy | Hypothetical intrathecal baclofen therapy | USA (Canada) | HUI2 | Proxy-assessed by physicians. Self-administered paper questionnaire. | Mean: 11 |
| de Sonneville-Koedoot et al (2015) [79] | Stuttering | Treatment: DCM therapy  Control: Lidcombe programme | Netherlands (Canada) | EQ-5D-3L VAS,  HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 4.51, 4.29; 3-6 |
| de Wolf et al (2011) [80] | Hearing loss: unilateral; bilateral | Bone-anchored hearing aid | Netherlands (Canada) | HUI3 | Assessed together by children and parents. Self-administered paper questionnaire. | Median: 4,7; 11-16 |
| Diarbakerli et al (2017) [81] | General health |  | Sweden (UK, Sweden) | EQ-5D-3L | Self-assessed by children. Postal survey | Mean: 14.5; 10-19 |
| Dillman et al (2016) [82] | Small bowel Crohn’s disease | MRI; Infliximab medical therapy | USA | VAS, TTO, SG | Assessed together by children and parents. Face-to-face interview | Mean: 15.2; 9-18 |
| Domellof et al (2014) [83] | ASD; Movement disorder; Learning disability; Hearing loss |  | Sweden | EQ-5D-Y VAS | Assessed together by children and parents. Postal survey. | Mean: 12, 11, 11.5, 12.3; 7-17 |
| Domino et al (2008) [84] | Depression | CBT alone; Fluoxetine alone; CBT and fluoxetine; Placebo | USA (USA) | Utility mapping from depression-free days | Self-assessed by children. Self-administered paper questionnaire. | Mean: 14.6; 12-18 |
| Domino et al (2009) [85] | Depression | CBT alone; Fluoxetine alone; CBT and fluoxetine; Placebo | USA (USA) | Utility mapping from depression-free days and from PQ-LES-Q | Self-assessed by children. Self-administered paper questionnaire. | Mean: 14.7; 12-17 |
| Duckworth et al (2015) [86] | Cancer survivors: brain tumours (PNET, medulloblastoma, ependymoma; germ cell tumour; astroglial tumour) | Surgery; Chemotherapy | Canada (Canada) | HUI2, HUI3 | Proxy-assessed by parents or self-assessed by children. Face-to-face interview. | Mean: 16.7 |
| Ebrahim and Parshuram (2015) [87] | Admission to PICU: Respiratory; Neurological; Circulatory; Oncological | Intensive care | Canada (Canada) | VAS, HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 10.3; 4-18 |
| Eidt-Koch et al (2009) [88] | Cystic fibrosis | Hospitalisation | Germany | EQ-5D-Y VAS | Self-assessed by children. Self-administered paper questionnaire. | Mean: 10.8, 15.9; 8-17 |
| Ekert et al (2001) [89] | Haemophilia | Hypothetical on-demand usual care; Hypothetical NovoSeven therapy | Australia (Unspecified) | EQ-5D-3L | Self-assessed by children. Face-to-face interview. | Mean: 14; 11-16 |
| Engelmann et al (2015) [90] | IBD: Crohn’s disease; Ulcerative colitis | IBD treatment and psychotherapy | Germany | EQ-5D-3L VAS | Assessed together by children and parents. Face-to-face interview. | Mean: 15.2; 10-18 |
| Epps et al (2005) [91] | JIA | Treatment: Hydrotherapy and land-based therapy  Control: Land-based therapy | UK (UK) | EQ-5D-3L | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 11,12; 4-19 |
| Ersberg and Gerdhem (2013) [92] | Congenital scoliosis; Idiopathic scoliosis; Neuromuscular scoliosis | Posterior/anterior surgery for spinal deformity | Sweden (UK) | EQ-5D-3L | Self-assessed by children. Postal survey. | Mean: 14.6, 14.7, 15.7; 9-20 |
| Fantaguzzi et al (2017) [93] | Victims of bullying | “Learning Together”: Intervention to reduce aggression and bullying | UK (UK, Australia) | CHU9D | Self-assessed by children. Self-administered paper questionnaire | Mean: 11.75; 11-12 |
| Feenstra et al (2012) [94] | Personality disorder; Substance use disorder; Somatoform disorder (conversion disorder, hypochondriasis); Eating disorder (anorexia nervosa, bulimia nervosa); Anxiety disorder (social phobia, panic disorder, agoraphobia, obsessive compulsive disorder, PTSD); Enuresis; Mood disorder (dysthymic disorder, major depressive disorder | Hospitalisation; Psychotherapy; Psychosocial nursing; Nonverbal therapies | Netherlands (Netherlands) | EQ-5D-3L | Self-assessed by children. Face-to-face interview. | Mean: 16.6; 14-19 |
| Feeny et al (2004) [95] | Extremely low birthweight; Extremely preterm birth; Comorbidities (neurosensory impairment, cerebral palsy, hydrocephalus, cognitive impairment, autism, unilateral/bilateral blindness, deafness); General health (control) |  | Canada (Canada) | SG (Pit: worst health), HUI2, HUI3 | Self-assessed by children. Face-to-face interview. | Mean: 14, 14.2, 14.4; 12-16 |
| Felder-Puig et al (2000) [96] | Cancer survivors: ALL; NHL; Hodgkin’s disease; AML; chronic myeloid leukaemia; osteosarcoma; Wilm’s tumour; Ewing’s sarcoma; immunodeficiency syndrome; STS; neuroblastoma | Unspecified cancer therapy | Austria (Canada) | HUI2 | Proxy-assessed by physicians or nurses or assessed together by children and parents. Self-administered paper questionnaire. | Median: 13; 6-30 |
| Fluchel et al (2008) [97] | Cancer survivors: ALL; brain tumour; Wilm’s tumour; retinoblastoma; Hodgkin’s disease; NHL; AML; STS; neuroblastoma; Ewing’s sarcoma; ovarian sarcoma; osteogenic sarcoma; General health (control) | Surgery; Chemotherapy; Radiotherapy | Uruguay (Canada) | HUI3 | Self-assessed by children. Face-to-face interview. | Mean: 13.6; 7-27 |
| Foreman et al (1999) [98] | Cancer survivors: medulloblastoma; ependymoma; astrocytoma; craniopharyngioma; ganglioglioma; germinoma; pituitary tumour | Surgery; Chemotherapy; Radiotherapy; Shunt | USA (Canada) | HUI2 | Proxy-assessed by parents. Telephone interview. | Mean: 16.4; 12.3-20.3 |
| Foster Page et al (2015) [99] | Dental caries | Resin infiltration; Fluoride varnish | New Zealand (UK) | CHU9D | Self-assessed by children. Face-to-face interview. | Mean: 8.3; 6.6-9.9 |
| Frew et al (2015) [100] | Overweight or obese; General health (normal weight) |  | UK (UK) | CHU9D | Self-assessed by children. Face-to-face interview. | Mean: 6.3; 6-7 |
| Friedman et al (2004) [101] | Atopic dermatitis | Visual aid | USA | VAS | Proxy-assessed by parents. Online survey. | 0.25-18 |
| Fu et al (2006) [102] | Cancer survivors: ALL; leukaemia; lymphoma; renal tumour; germ cell tumour; retinoblastoma; bone tumour; CNS tumour; STS; carcinoma | Surgery; Chemotherapy; Radiotherapy | El Salvador, Honduras, Nicaragua, Panama (Canada) | HUI2, HUI3 | Proxy-assessed by parents or physicians or self-assessed by children. Face-to-face interview or Self-administered paper questionnaire. | Median: 12.8; 3.4-25.8 |
| Furber and Segal (2015) [103] | Mental disorder | Child and adolescent mental health services (CAMHS) | Australia (UK, Australia) | CHU9D | Proxy-assessed by caregivers. Telephone interview. | Mean: 11.71; 5-17 |
| Furlong et al (2012) [104] | Cancer patients: ALL  Cancer survivors: ALL | DFCI 95-01; DFCI 95-05 | USA, Canada (Canada) | HUI2, HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 9.8; 5-20.8 |
| Gaitan-Lopez et al (2017) [105] | General health |  | Colombia | EQ-5D-Y VAS | Self-administered paper questionnaire | Mean: 12.7; 9-17 |
| Garcia-Gordillo et al (2016) [106] | General health |  | Spain (Spain) | EQ-5D-5L, EQ-5D VAS | Self-assessed by children. Self-administered paper questionnaire | 15-17 |
| Geneid et al (2011) [107] | Laryngotracheal stenosis; Comorbidities (asthma, language disorder, stuttering, ventricular septal defect, Down syndrome) | Early infancy laryngotracheal reconstruction | Finland (Finland) | 16D, 17D | Proxy-assessed by parents or self-assessed by children. Postal survey. | 0-15.9 |
| Gerald et al (2012) [108] | Asthma | Outpatient care | USA (USA) | PAHOM | Proxy-assessed by parents or self-assessed by children. Face-to-face interview. | 6-12 |
| Glaser et al (1999) [109] | Cancer survivors: brain tumour (PNET, astrocytoma, medulloblastoma, ependymoma) | Chemotherapy; Radiotherapy | UK (Canada) | HUI2, HUI3 | Proxy-assessed by physiotherapist, parents or physicians or self-assessed by children. Self-administered paper questionnaire. | Mean: 10.5; 6-16 |
| Glotzer et al (1995) [110] | Lead poisoning; Sequelae (reading disability) |  | USA | VAS | Proxy-assessed by physicians. Self-administered paper questionnaire. | 0-2 |
| Goorden et al (2016) [111] | Cannabis use disorder | Treatment: Multidimensional family therapy  Control: Individual cognitive behavioural therapy | Netherlands (Netherlands) | EQ-5D-3L | Self-assessed by children. Face-to-face interview | Mean: 16.7; 13-18 |
| Gospodarevskaya (2013) [112] | PTSD; Comorbidity (depression) |  | Australia (Unspecified) | AQoL-5D | Self-assessed by children. Self-administered paper questionnaire. | Mean: 18.3; 16-21 |
| Grano et al (2013) [113] | Risk of psychosis | Community- and family-orientated early mental health intervention | Finland (Finland) | 16D | Self-assessed by children. Telephone interview. | Mean: 15.3; 12-21 |
| Grano et al (2014) [114] | Risk of psychosis | Community- and family-orientated early mental health intervention | Finland (Finland) | 16D | Self-assessed by children. Telephone interview. | Mean: 15.1; 12-21 |
| Grant et al (2006) [115] | Cancer survivors: leukaemia; Hodgkin’s disease; Burkitt’s lymphoma; ependymoma; astrocytoma; medulloblastoma; neuroblastoma; Wilm’s tumour; bone tumour; STS; gonadal neoplasm | Surgery; Chemotherapy; Radiotherapy | Canada (Canada) | HUI2, HUI3 | Self-assessed by children. Postal survey. | 14.6-20.3 |
| Gray et al (2007) [116] | Extremely low birthweight; Extremely preterm birth; General health (normal term birth) |  | UK (Canada) | HUI3 | Self-assessed by children. Postal survey. | 15-16 |
| Greenough et al (2014) [117] | Extremely low birthweight; Extremely preterm birth; Admission to PICU | Intensive care; Treatment: HFO ventilation  Control: usual ventilation | UK, Ireland, Australia, Singapore (Unspecified) | HUI3 | Proxy-assessed by parents or self-assessed by children. Postal survey. | Mean: 12.5, 12.6; 11.2-14.4 |
| Gulati et al (2017) [118] | Lumbar disc herniation; Sciatica | Single-level lumbar microdiscectomy | Norway (Unspecified) | EQ-5D-3L | Self-assessed by children. Self-administered paper questionnaire | Mean: 17.5; 13-19 |
| Gundle et al (2017) [119] | Bone tumour: Osteosarcoma; Ewing’s sarcoma; Adamantinoma; Undifferentiated pleomorphic sarcoma | Limb salvage surgery | USA (Unspecified) | SF-6D | Self-assessed by children. Self-administered paper questionnaire | Mean: 16 |
| Haapamaki et al (2011) [120] | IBD: Crohn’s disease; Ulcerative colitis; Comorbidities (primary sclerosing cholangitis, asthma, allergy) | IBD treatment: aminosalicylic acid; azathioprine; corticosteroids | Finland (Finland) | 15D, 16D, 17D | Self-assessed by children or assessed together by children and parents. Postal survey. | Mean: 13.8; 7-19 |
| Haavisto et al (2013) [121] | Heart failure; Kidney failure; Liver failure | Kidney transplant; Liver transplant; Awaiting transplant | Finland (Finland) | 16D, 17D | Self-assessed by children. Self-administered paper questionnaire. | Mean: 11.3; 6.3-16.7 |
| Hailer et al (2014) [122] | Legg-Calve-Perthes disease |  | Sweden | EQ-5D-3L VAS | Self-assessed by children. Face-to-face interview. | 15-17 |
| Hakkaart-van Roijen et al (2011) [123] | Dyslexia; General health (no dyslexia) |  | Netherlands (Netherlands) | EQ-5D-3L | Proxy-assessed by physicians. Online survey. | Unspecified |
| Han et al (2011) [124] | Injury; Post-injury depression | Intensive care | USA (USA) | QWB | Self-assessed by children. Telephone interview. | Mean: 15; 12-19 |
| Hanberger et al (2009) [125] | Diabetes type I; Severe hypoglycaemia | Multiple insulin therapy | Sweden (Unspecified) | EQ-5D-3L | Proxy-assessed by parents or self-assessed by children. Postal survey. | 2.6-19.6 |
| Hartman et al (2016) [126] | Foetus affected by maternal use of tobacco |  | USA | Utility from Behaviour Problems Index | Proxy-assessed by parents. Postal survey | 4-14 |
| Hatam et al (2013) [127] | Phenylketonuria; Hypothyroidism; Galactosemia; Favism | Neonatal screening and treatment | Iran | TTO | Proxy-assessed by nurses. Face-to-face interview. | 0-2 |
| Hernandez et al (2016) [128] | Asthma |  | Unspecified (France) | EQ-5D-Y | Self-assessed by children. Online survey | 6-11 |
| Hinds et al (2007) [129] | Cancer patients: ALL | St. Jude Total 15 protocol | USA (Canada) | HUI3 | Proxy-assessed by nurses. Self-administered paper questionnaire. | Median: 8.6; 4.9-18.8 |
| Hodgkins et al (2013) [130] | ADHD | Treatment: stimulant lisdexamfetamine dimesylate  Control: osmotic-release oral system methylphenidate  Placebo | Unspecified (Unspecified) | HUI2 | Proxy-assessed by parents. Unspecified mode of administration. | 6-17 |
| Hoffmann et al (2011) [131] | Gastroenteritis; Rotavirus gastroenteritis | Hospitalisation; Primary care | Denmark (Denmark) | EQ-5D-3L VAS,  EQ-5D-3L | Proxy-assessed by parents. Self-administered paper questionnaire. | Median: 1.2; 0-4.7 |
| Hogan et al (2017) [132] | Chronic pain; Comorbidities (depression, anxiety, sleep problems, arthritis, back or neck problems, neuropathic pain, migraine, fibromyalgia, abdominal pain) |  | Canada (Canada) | HUI3 | Self-assessed by children. Postal survey | 12-17 |
| Holbrook et al (2005) [133] | Injury; Post-injury acute stress disorder | Intensive care; Hospitalisation | USA (USA) | QWB | Self-assessed by children. Telephone interview. | Mean: 15; 12-19 |
| Holbrook et al (2007) [134] | Injury; General health (control) | Intensive care; Hospitalisation | USA (USA) | QWB | Self-assessed by children. Face-to-face or telephone interview. | Mean: 15; 12-19 |
| Horsman et al (2008) [135] | Cancer survivors: germ cell tumour | Unspecified cancer therapy | Brazil (Unspecified) | HUI3 | Self-assessed by children. Self-administered paper questionnaire. | 13-18 |
| Huppertz et al (2008) [136] | Gastroenteritis (diarrhoea); Comorbidities (preterm birth, chronic lung disease, immunodeficiency, heart disease, atopic dermatitis) | Hospitalisation; Outpatient care | Germany | VAS | Proxy-assessed by parents. Self-administered paper questionnaire. | 0-2 |
| Iskrov et al (2015) [137] | Cystic fibrosis |  | Bulgaria (Unspecified) | EQ-5D-3L VAS,  EQ-5D-3L | Self-assessed by children. Online survey. | Mean: 16 |
| Janse et al (2005) [138] | ALL; Asthma; Cystic fibrosis; JIA |  | Netherlands (Canada) | HUI3 | Proxy-assessed by parents or physicians. Face-to-face or Self-administered paper questionnaire. | Mean: 8.5; 1.2-16.9 |
| Janssens et al (2009) [139] | Major external injury | Intensive care; Hospitalisation | Netherlands | EQ-5D-3L VAS | Assessed together by children and parents. Postal survey. | Mean: 15.1; 8-23 |
| Jelsma (2010) [140] | Allergy; Asthma; Eczema; MSKD; Headache; Diabetes; Depression; Heart disease; ADHD; General health (no disease) |  | South Africa | EQ-5D-3L VAS,  EQ-5D-Y VAS | Self-assessed by children. Self-administered paper questionnaire. | Mean: 15.5; 13-19.17 |
| Jelsma and Ramma (2010) [141] | Chronic illness; General health (no disease) |  | South Africa | EQ-5D-Y VAS | Proxy-assessed by parents or self-assessed by children. Self-administered paper questionnaire. | 7-12 |
| Jog et al (2016) [142] | Cerebral palsy | Onabotulinumtoxin A injection | Canada (Unspecified) | SF-6D | Self-assessed by children. Self-administered paper questionnaire | Mean: 16 |
| Joosten et al (2015) [143] | Chronic illness; Malnutrition | Steroids; Antibiotics; Diuretics | Netherlands | EQ-5D-3L VAS | Proxy-assessed by nurses. Self-administered paper questionnaire. | Median: 9.8; 4.2-13.4 |
| Juniper et al (1997) [144] | Asthma | Outpatient care | Canada (Canada) | VAS, SG,  10-dimensional HUI | Self-assessed by children. Face-to-face interview. | Mean: 12; 7-17 |
| Kang (2016) [145] | General health |  | South Korea (Unspecified) | CH-6D | Self-assessed by children. Online survey | 16-18 |
| Keating et al (2011) [146] | Overweight or obese; General health (normal weight) |  | Australia (Australia) | AQoL-6D | Self-assessed by children. Self-administered paper questionnaire. | Mean: 14.6; 11-18 |
| Kennedy and Leyland (1999) [147] | Cancer survivors: brain tumour (PNET, astrocytoma, glioma, medulloblastoma, ependymoma, germinoma, craniopharyngioma, ganglioneuroblastoma, ganglioglioma, choroid plexus papilloma) | Surgery; Chemotherapy; Radiotherapy; Shunt | UK (Canada) | HUI2 | Assessed together by children and parents. Face-to-face interview. | Mean: 8.6; 2.1-19.5 |
| Kennedy et al (2017) [148] | Bacterial meningitis (worst day of illness, after recovery); Long-term complications (hearing loss, fits/seizures, concentration and memory loss, amputations) | Inpatient tertiary care | UK (UK) | EQ-5D-Y, EQ-5D-Y VAS | Assessed together by children and parents.  Postal survey | 0-16 |
| Kesztyus et al (2014) [149] | Overweight or obese; General health (normal weight) | Physical activity | Germany | EQ-5D-Y VAS | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 7.1; 5.4-9.8 |
| Kim et al (2017) [150] | General health |  | South Korea | EQ-5D-Y VAS | Assessed together by children and parents. Postal survey | Mean: 9.5;  7-13 |
| Klaassen et al (2010) [151] | Cancer survivors: Hodgkin’s disease | Chemotherapy: POG 9425, POG 9426, AHOD 0031, GPOH-HD95;  Radiotherapy | Canada (Canada) | EQ-5D-3L VAS, HUI2, HUI3 | Self-assessed by children. Self-administered paper questionnaire. | Mean: 14.7; 8.9-18 |
| Knapp et al (2012) [152] | Life-threatening illness requiring palliative care | Palliative care | USA (Canada) | HUI2, HUI3 | Proxy-assessed by parents. Telephone interview. | Mean: 12.4; 5-21 |
| Kodra et al (2014) [153] | Haemophilia A/B |  | Italy (Spain) | EQ-5D-3L VAS,  EQ-5D-3L | Proxy-assessed by caregivers. Online survey. | Mean: 8; 2-17 |
| Koomen et al (2005) [154] | Non-haemophilus influenza type B bacterial meningitis; Permanent sequelae (learning or behavioural limitations) |  | Netherlands (Canada) | HUI2 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 9.7; 5.3-14.2 |
| Kotwicki et al (2001) [155] | Cystic fibrosis; Comorbidities (nasal polyposis, asthma, sinusitis) | Vitamin; Pancreatic enzymes; Oral antibiotics; Bronchodilator; Corticosteroids; Oral antiacids; Ibuprofen | USA (USA) | QWB | Proxy-assessed by parents. Face-to-face interview. | Mean: 7.7; 5-11 |
| Kramer et al (1994) [156] | Viral fever; Permanent sequelae (unilateral or bilateral hearing loss, hypertension, pneumonia, bacterial meningitis, viral meningitis, neurodevelopmental impairment, urinary tract infection) | Hypothetical screening methods for viral fever | Canada | VAS | Proxy-assessed by parents, physicians or parents from general public. Face-to-face interview. | 0.25-2 |
| Kulkarni et al (2008) [157] | Hydrocephalus | Surgery; Hospitalisation | Canada (Canada) | HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 14.1; 6-19 |
| Kulkarni et al (2008b) [158] | Hydrocephalus | Cerebrospinal fluid shunt | Canada (Canada) | HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 11.6; 5-18 |
| Kulkarni et al (2010) [159] | Hydrocephalus | Endoscopic third ventriculostomy; Cerebrospinal fluid shunt | Canada (Canada) | HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 10.4, 11.9; 5-18 |
| Kulkarni et al (2010b) [160] | Obstructive hydrocephalus | Endoscopic third ventriculostomy; Cerebrospinal fluid shunt | Canada (Canada) | HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 12.3, 12; 5-18 |
| Kulpeng et al (2013) [161] | Severe bacteraemia; Acute otitis media; Severe infection; Permanent sequelae to severe infection (epilepsy, hearing loss, pneumonia, lung disease, severe meningitis, mental retardation) | Hospitalisation | Thailand (Thailand, Canada) | EQ-5D-3L VAS, EQ-5D-3L, HUI2, HUI3 | Proxy-assessed by caregivers or assessed together by children and caregivers. Face-to-face interview. | Mean: 10; 5-14 |
| Ladner et al (2016)[162] | Chiari type I malformation |  | USA (Canada) | HUI3 | Assessed together by children and parents. Face-to-face interview. | Mean: 12; 5-17 |
| Laitakari et al (2015) [163] | Burns | Hospitalisation; Outpatient care | Finland (Finland) | 17D | Assessed together by children and parents. Postal survey. | Mean: 7 |
| Landfeldt et al (2015) [164] | Duchenne muscular dystrophy | Intensive care: ventilation support | Germany, Italy, UK, USA (Canada) | HUI3 | Proxy-assessed by caregivers. Online survey. | Mean: 14 |
| Lee et al (2005) [165] | Pertussis; Pneumonia | Vaccination | USA | Short-term TTO (8-week health state), Long-term TTO (lifetime health state), 0%/3% discount rate | Proxy-assessed by parents. Telephone interview. | 11-17 |
| Lee et al (2011) [166] | Diabetes type I; Complications (blindness, end-stage renal disease, angina, stroke, amputation) | Intensive insulin therapy | USA (Canada) | TTO, HUI3 | Proxy-assessed by parents or self-assessed by children. Face-to-face interview. | Mean: 13.7; 8-18 |
| Lee et al (2013) [167] | Epilepsy | Intensive care; Hospitalisation | UK (Unspecified) | EQ-5D-3L | Proxy-assessed by physicians. Delphi process. | 0.5-18 |
| Lenhard et al (2017) [168] | Obsessive compulsive disorder | Treatment: Internet-delivered CBT  Control: Usual care | Sweden (Sweden) | EQ-5D-Y, EQ-5D-Y VAS | Self-assessed by children. Online survey | Mean: 14.21; 12-17 |
| Lin et al (2016) [169] | Diabetes Type I |  | China (Japan) | EQ-5D-3L | Proxy-assessed by parents; Self-assessed by children. Face-to-face interview | 3-13; 13-20 |
| Liu et al (2016) [170] | Profound bilateral sensorineural hearing loss; Severe-profound deafness | Unilateral cochlear implant | China | HUI3 | Assessed together by children and parents. Postal survey | 4-11 |
| Lloyd et al (2010) [171] | Diabetes type I | Hypothetical treatments: insulin injection, infusion therapy | UK (UK) | SG, EQ-5D-3L VAS,  EQ-5D-3L | Proxy-assessed by parents or general public. Face-to-face interview. | Mean: 9.95, 15.13; 8-17 |
| Lloyd et al (2011) [172] | ADHD |  | UK | TTO, VAS | Proxy-assessed by general public. Face-to-face interview. | Mean: 11; 8-16 |
| Lloyd et al (2015) [173] | Hypophosphatasia | Intensive care: invasive ventilation | UK (UK) | EQ-5D-3L | Proxy-assessed by parents or physicians. Face-to-face interview | 0-18 |
| Lock et al (2010) [174] | Tonsillitis | Tonsillectomy | UK | Chained Gamble | Proxy-assessed by parents or self-assessed by children. Face-to-face interview. | 12-18 |
| Lovett et al (2010) [175] | Hearing loss | Cochlear implantation: unilateral/bilateral | UK (Canada) | VAS, HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 7.2; 1.5-16 |
| Lynch et al (2005) [176] | Depression | Treatment: CBT  Control: usual care | USA (USA) | Utility mapping from depression-free days | Proxy-assessed by physicians. Face-to-face interview. | Mean: 14.4; 13-18 |
| Lynch et al (2016) [177] | Moderate/severe depression; Subthreshold depression; No depression (general health) |  | USA (USA, Canada) | EQ-5D-3L, HUI2, HUI3, QWB,  SF-6D | Self-assessed by children. Telephone interview | Mean: 15.4; 13-17 |
| Maia et al (2016) [178] | ADHD; Comorbidities (oppositional defiant disorder, conduct disorder, anxiety disorder, mood disorder) | Immediate-release methylphenidate | Brazil (Canada) | HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 8.62, 13.67; 6-17 |
| Makkes et al (2013) [179] | Overweight or obese; Comorbidities (acanthosis nigricans, Blount’s disease, gallstones, hirsutism, pseudo-gynecomastia) |  | Netherlands (Netherlands) | EQ-5D-3L VAS,  EQ-5D-3L | Self-assessed by children. Self-administered paper questionnaire. | Mean: 14.8; 8-19 |
| Malik et al (2013) [180] | IBD: Ulcerative colitis | IBD treatment: usual therapy; proctocolectomy | Canada | EQ-5D-3L VAS | Proxy-assessed by parents. Postal survey. | Mean: 14.6, 13.4 |
| Marlow et al (2015) [181] | Acute rotavirus gastroenteritis | Emergency department; Hospitalisation | UK (UK) | VAS, HUI2 | Proxy-assessed by parents. Self-administered paper questionnaire. | Median: 1.16; 0-6 |
| Martin et al (2008) [182] | Acute rotavirus gastroenteritis | Hospitalisation; Primary care | UK (UK) | Adjusted EQ-5D-3L (Mobility and/or self-care domain set at 1), EQ-5D-3L | Proxy-assessed by physicians. Self-administered paper questionnaire. | 0-5 |
| Matza et al (2005) [183] | ADHD | Hospitalisation; Stimulant therapy; Non-stimulant therapy; Psychotherapy | UK, USA (UK) | VAS,  EQ-5D-3L | Proxy-assessed by parents. Face-to-face interview. | Mean: 10.2, 11.8; 7-18 |
| Matza et al (2005b) [184] | ADHD | Stimulant therapy; Non-stimulant therapy | USA | SG (Pit: death), SG (Pit: worst health), VAS | Proxy-assessed by parents. Face-to-face interview. | Mean: 10.2; 7-18 |
| McBain et al (2016) [185] | Post-traumatic stress disorder in war-affected youths | Treatment: “Youth Readiness Intervention” – group-based therapy  Control: Family and community support | Sierra Leon | Utility from WHO Disability Adjustment Scale II | Self-assessed by children. Face-to-face interview | Mean: 17.8; 15-24 |
| Midgley et al (2000) [186] | Liver disease: biliary atresia; biliary cirrhosis; alpha-antitrypsin deficiency; metabolic liver disease; fulminant hepatic failure; neonatal hepatitis | Liver transplant | USA (Canada) | HUI2 | Proxy-assessed by parents. Telephone interview. | Median: 4.94; 2-18 |
| Miller et al (2013) [187] | Risk of HIV infection | School-based prosocial care to reduce early marriage | Zimbabwe (Zimbabwe, Thailand) | EQ-5D-3L | Self-assessed by children. Face-to-face interview. | Unspecified |
| Miller et al (2014) [188] | Abusive head trauma | Intensive care: eye surgery; brain shunt | USA (Canada) | HUI2 | Proxy-assessed by physicians and caregivers.  Online survey. | Unspecified |
| Mittmann et al (1999) [189] | Acne; Allergy; Asthma; Back pain; Cardiovascular disease; Cancer survivors; Diabetes; Epilepsy; Gastric ulcer; Hypertension; JIA; Lung disease; Migraine; Sinusitis; Stroke; Urinary incontinence; Cataracts; General health (no disease) |  | Canada (Canada) | HUI3 | Self-assessed by children. Telephone interview. | 12-19 |
| Mort et al (2011) [190] | Cancer survivors: ALL; NHL; Hodgkin’s disease; neuroblastoma; Wilm’s tumour; gonadal tumour; osteosarcoma; STS; retinoblastoma | Surgery; Chemotherapy; Radiotherapy; Stem cell transplantation | Finland (Finland) | 16D, 17D | Self-assessed by children. Postal survey. | Mean: 14.4; 12-18 |
| Mpundu-Kaambwa et al (2017) [191] | General health |  | Australia (Australia) | CHU9D | Self-assessed by children. Online survey | Mean: 15.8; 15-17 |
| Mulhern (1999) [192] | Cancer survivors: medulloblastoma | Surgery; Radiotherapy | USA (Unspecified) | HUI2 | Proxy-assessed by physicians. Face-to-face interview. | 3-21 |
| Munzenberger et al (1999) [193] | Cystic fibrosis: pulmonary exacerbation | Hospitalisation; Intravenous tobramycin and ceftazidime | USA (USA) | QWB | Assessed together by children and parents. Face-to-face interview. | Mean: 14; 9-20 |
| Murillo et al (2017) [194] | Diabetes Type I | Insulin therapy: multiple daily injections or pump therapy | Spain | EQ-5D-Y VAS | Assessed together by children and parents. Online survey | 8-19 |
| Naraine et al (2002) [195] | Haemophilia | On-demand haemophilia treatment; Low-, medium-, high-dose prophylaxis | Canada | SG | Proxy-assessed by parents, adult patients or general public. Face-to-face interview. | Unspecified |
| Neufeld et al (2012) [196] | Haemophilia | Recombinant activated factor VII; Delivery type: on-demand, induction prophylaxis | USA (USA) | EQ-5D-3L VAS,  EQ-5D-3L | Proxy-assessed by caregivers. Self-administered paper questionnaire. | Unspecified |
| Nokso-Koivisto et al (2014) [197] | Tonsillitis | Tonsillectomy | Finland (Finland) | 16D, 17D | Self-assessed by children. Postal survey. | Mean: 9.4, 13.9; 7-15 |
| Nordyke et al (2011) [198] | Celiac disease; General health (control) | Intestine biopsy screening | Sweden | EQ-5D-Y VAS | Proxy-assessed by parents or Self-assessed by children. Postal survey or Self-administered paper questionnaire. | Mean: 12 |
| Nordyke et al (2013) [199] | Celiac disease; General health (control) | Intestine biopsy screening; Gluten diet | Sweden | EQ-5D-Y VAS | Self-assessed by children. Self-administered paper questionnaire. | Median: 13.2, 14.6 |
| Nwachukwu et al (2017) [200] | Patella dislocation (stable return or recurrent dislocation); General health |  | USA | VAS | Self-assessed by children. Telephone interview | Unspecified |
| Oh et al (1996) [201] | Acute otitis media; Adverse event (gastrointestinal, dermatological, serum sickness-like reaction) |  | Canada | VAS | Proxy-assessed by physicians. Postal survey. | 0.5-18 |
| Oostenbrink et al (2002) [202] | Bacterial meningitis; Permanent sequelae (hearing loss, epilepsy, mental retardation, severe retardation and tetraplegia, leg paresis, deafness) |  | Netherlands (UK, Canada) | EQ-5D-3L, HUI2, HUI3 (0: Worst health), HUI3 (0: Death) | Proxy-assessed by physicians. Self-administered paper questionnaire. | Mean: 6 |
| Orenstein et al (1990) [203] | Cystic fibrosis: pulmonary exacerbation | Antibiotic ciprofloxacin | USA (USA) | QWB | Self-assessed by children. Face-to-face interview. | 10-18 |
| Peasgood et al (2016) [204] | ADHD; General health (control, siblings of ADHD children) | Community mental health service; Specialist paediatric clinics | UK (UK) | CHU9D, EQ-5D-Y VAS | Self-assessed by children. Self-administered paper questionnaire | Mean: 11.8; 6-18, 10-15 |
| Peetsold et al (2009) [205] | Congenital diaphragmatic hernia; Comorbidities (cardiac abnormalities, neurological deficits) | Intensive care; Hospitalisation | Netherlands (Canada) | HUI3 | Self-assessed by children. Face-to-face interview. | Mean: 10.2 |
| Penn et al (2011) [206] | Cancer patients: brain tumour (ependymoma, germ cell tumour, astrocytoma, medulloblastoma, meningioma, pineoblastoma, craniopharyngioma); Comorbidity (hydrocephalus); General health (control) | Surgery; Chemotherapy; Radiotherapy | UK (Unspecified) | HUI3 | Proxy-assessed by parents or Self-assessed by children. Face-to-face interview. | Median: 11.1, 10.7; 3.6-18.9 |
| Pentek et al (2014) [207] | Duchenne muscular dystrophy; Mucopolysaccharidosis |  | Hungary (Unspecified) | EQ-5D-3L | Proxy-assessed by caregivers. Unspecified mode of administration. | Mean: 9.6 |
| Petersen et al (2017) [208] | General health; Chronic illness (long-term disability, illness or medical conditions; poor self-rated health status) |  | Australia (Australia) | CHU9D | Self-assessed by children. Online survey | 15-17 |
| Petracci and Cavrini (2013) [209] | Overweight or obese; General health (normal weight) | Physical activity | Italy | EQ-5D-Y VAS | Self-assessed by children. Self-administered paper questionnaire. | Unspecified |
| Petrou et al (2007) [210] | Bilateral permanent hearing impairment; Comorbidities (cerebral palsy, asthma, learning disabilities); General health (control) | Cochlear implantation | UK (Canada) | HUI3 | Proxy-assessed by caregivers. Face-to-face interview. | Mean: 7.9; 5.4-11.7 |
| Petrou et al (2009) [211] | Extremely low birthweight; Extremely preterm birth; Comorbidities (cognitive and/or functional disability); General health (control) |  | UK, Ireland (Canada) | HUI3 | Proxy-assessed by parents. Postal survey. | Median: 10.92 |
| Petrou et al (2010) [212] | Otitis media with effusion | Treatment: topical intranasal steroids  Control: placebo nasal spray | UK (UK, Canada) | EQ-5D-3L, HUI2, HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | 4-11 |
| Petrou et al (2010b) [213] | Extremely low birthweight; Extremely preterm birth; Comorbidities (ADHD, ASD, behavioural disorder, tic disorder, emotional disorder, cognitive impairment); General health (control) |  | UK, Ireland (UK, Canada) | HUI2, HUI3 | Proxy-assessed by parents. Postal survey. | Median: 10.92 |
| Petrou et al (2011) [214] | Extremely low birthweight; Extremely preterm birth; Comorbidity (neurodevelopmental impairment) |  | UK, Ireland (UK, Canada) | HUI2, HUI3 | Proxy-assessed by parents. Postal survey. | Unspecified |
| Petrou and Kupek (2009) [215] | ADHD; Asthma; ASD; Behavioural disorder; Blood diseases; Bone deformities; Osteogenesis imperfecta; Cardiovascular disease; Cerebral palsy; Chromosomal abnormalities; Down syndrome; Fragile X syndrome; Williams syndrome; CNS disorder; CNS infection (meningitis, encephalitis); Malignant tumour; Non-malignant tumour; Congenital conditions of the connective tissue; Congenital skeletal facial conditions; Cystic fibrosis; Diabetes; Digestive system disorder; Epilepsy; Head injury; Deafness; Hydrocephalus; JIA; Kidney disease; Language and speech disorder; Learning and physical disabilities; Global developmental delay; Metabolic disease; Motor disorder; Muscular dystrophy; Microcephaly; Respiratory disease; Skin disease; Spina bifida; Urogenital disorder; Vision disorder; General health (control) |  | UK (Canada) | HUI3 | Proxy-assessed by caregivers. Postal survey. | 5-16 |
| Philipsson et al (2013) [216] | Internalising disorder: recurrent psychosomatic problems | Treatment: dance classes  Control: primary care | Sweden (Canada) | HUI3 | Self-assessed by children. Face-to-face interview. | 13-18 |
| Pitt et al (2006) [217] | Atopic dermatitis |  | UK (UK) | VAS, Asthma-specific MAUI | Proxy-assessed by parents. Face-to-face interview. | Unspecified |
| Poenaru et al (2017) [218] | Hypothetical congenital conditions requiring surgery: Mild/severe hypospadias; Mild/severe imperforate anus; Hydrocephalus; Mild/severe spina bifida; Hirschsprung’s disease; Mild/severe abdominal wall defect; Intestinal atresia; Undescended testes; Cleft lip; Cleft palate | Surgery | Kenya | VAS, TTO | Proxy-assessed by physicians, nurses, allied health professionals, community members. Self-administered paper questionnaire | Unspecified |
| Pogany et al (2006) [219] | Cancer survivors: leukaemia; lymphoma; brain tumour; SNS tumour; retinoblastoma; renal tumour; hepatic tumour; bone tumour; STS; germ cell tumour; carcinoma; General health (control) | Surgery; Chemotherapy; Radiotherapy | Canada (Canada) | HUI3 | Proxy-assessed by parents or self-assessed by children or assessed together by parents and children. Postal survey. | 5-37 |
| Poley et al (2001) [220] | Imperforate anus | Neonatal surgery | Netherlands (UK) | EQ-5D-3L | Proxy-assessed by parents. Postal survey. | 5-15 |
| Poley et al (2002) [221] | Congenital diaphragmatic hernia | Neonatal surgery; ECMO bridging | Netherlands (UK) | EQ-5D-3L | Proxy-assessed by parents. Postal survey. | 5-15 |
| Polinder et al (2005) [222] | Injury: head; facial; extremity dislocation; internal organ; lower extremity; spinal cord; nerve; whiplash; open wounds; poisoning | Emergency department; Hospitalisation | Netherlands (UK) | EQ-5D-3L VAS,  EQ-5D-3L | Self-assessed by children or assessed together by children and parents. Postal survey. | Mean: 9.6; 5-14 |
| Portwine et al (2016) [223] | Survivors of high-risk neuroblastoma | Hematopoietic stem cell transplantation, High-dose chemotherapy, Immunotherapy; Protocols: CCG 3891, POG 9340/41/42, POG 9640, A3973, ANBL0532, MADDOC, SIOP-COJEC | Canada (Canada) | HUI2, HUI3 | Proxy-assessed by parents. Postal survey | 5-18 |
| Powell et al (2013) [224] | Acute severe asthma | Treatment: nebulised magnesium sulphate  Control: nebulised isotonic saline | UK (UK) | EQ-5D-3L | Proxy-assessed by parents. Postal survey. | Median: 4; 1-15 |
| Prince et al (2010) [225] | Refractory JIA | Etanercept | Netherlands (Canada) | HUI3 | Proxy-assessed by parents. Postal survey. | Median: 11.9 |
| Protudjer et al (2015) [226] | Food allergy | Outpatient care; Epinephrine autoinjector | Sweden (UK) | EQ-5D-3L | Proxy-assessed by parents. Postal survey. | Mean: 6; 0-12 |
| Quinn et al (2004) [227] | Very low birthweight; Very preterm birth; Retinopathy of prematurity | Cryotherapy in neonatal period | USA (Canada) | HUI3 | Proxy-assessed by parents. Face-to-face interview. | Mean: 10 |
| Qvist et al (2004) [228] | End-stage kidney failure: congenital nephrotic syndrome, polycystic kidney disease, prune-belly syndrome, neuroblastoma | Kidney transplant | Finland (Finland) | 17D | Self-assessed by children. Face-to-face interview. | Mean: 9.6; 8-11 |
| Raat et al (2002) [229] | Chronic illness; General health (no disease) |  | Netherlands (Canada) | HUI2 | Proxy-assessed by parents. Postal survey. | 5-13 |
| Raat et al (2004) [230] | General health |  | Netherlands (Canada) | VAS, HUI3 | Proxy-assessed by parents. Postal survey. | 4-13 |
| Rae et al (2008) [231] | Cancer patients: ALL | DFCI 95-001 | USA, Canada (Unspecified) | HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | 5-18 |
| Rae et al (2012) [232] | Cancer patients: ALL | DFCI 95-001; DFCI 00-001 | USA, Canada (Unspecified) | HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | 5-18 |
| Rae et al (2014) [233] | Cancer survivors: ALL  Cancer patients: ALL | DFCI 95-01; BFM protocol | USA, Canada (Canada) | HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | 5-12 |
| Rae et al (2016) [234] | Survivors of Hodgkin’s disease |  | Canada (Canada) | HUI2, HUI3 | Assessed together by children and caregivers. Postal survey | 5-15 |
| Raluy-Callado et al (2013) [235] | Mucopolysaccharidosis type II (Hunter syndrome) | Treatment for joint pain | USA, UK, Brazil, Germany (Canada) | HUI3 | Proxy-assessed by parents. Unspecified mode of administration. | Mean: 14.2; 5-30.9 |
| Raspa et al (2016) [236] | Fragile X syndrome |  | USA (Unspecified) | ABC-UI | Proxy-assessed by parents. Online survey |  |
| Ratcliffe et al (2012) [237] | General health |  | Australia (UK) | CHU9D, HUI2 | Self-assessed by children. Online survey. | Mean: 14; 11-17 |
| Ratcliffe et al (2012b) [238] | General health |  | Australia (UK, Australia) | CHU9D, AQoL-6D | Self-assessed by children. Online survey. | Mean: 15; 11-17 |
| Rautava et al (2009) [239] | Extremely low birthweight; Extremely preterm birth; Very low birthweight; Very preterm birth; General health (control) | Intensive care | Finland (Finland) | 17D | Proxy-assessed by parents. Postal survey. | Mean: 5 |
| Redouane et al (2016) [240] | Combined chronic diseases: Central nervous system disorders; Musculoskeletal disorders; Respiratory disorders; Genetic/metabolic disorders; Cardiac/renal disorders; Immunodeficiency | Invasive medical technologies: Enterostomy tube; Long-term ventilation | Canada (Canada) | HUI2, HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire | Mean: 10.6; 5-18 |
| Renier et al (2012) [241] | Injury in rural area; General health (no injury) |  | USA (Unspecified) | HUI3 | Self-assessed by children. Unspecified mode of administration. | 5-19 |
| Rhodes et al (2011) [242] | Overweight (insulin resistant, prediabetes); Diabetes type II; Diabetes complications (end-stage renal disease, blindness, amputation, heart disease) | Diabetes type II treatment: diet therapy, oral medication, insulin | USA | SG | Proxy-assessed by parents or self-assessed by children. Face-to-face interview. | Mean: 15.5; 12-18 |
| Rhodes et al (2012) [243] | Overweight (insulin resistant, prediabetes); Diabetes type II |  | USA (Canada) | HUI3 | Proxy-assessed by parents or self-assessed by children. Face-to-face interview. | Mean: 15.5; 12-18 |
| Roberts et al (2013) [244] | Extremely low birthweight; Extremely preterm birth; Comorbidities (intraventricular haemorrhage, cerebral palsy, hydrocephalus, cognitive impairment, unilateral/bilateral blindness, deafness); General health (control) | Intensive care: surgery, antenatal corticosteroids, postnatal corticosteroids, exogenous surfactant | Australia (Unspecified) | HUI3 | Self-assessed by children. Self-administered paper questionnaire. | Mean: 17.9, 18.1 |
| Robertson et al (2017) [245] | Obesity | Treatment: “Families for Health” – Information on parenting skills, social and emotional development and healthy eating  Control: Usual care | UK (Unspecified) | EQ-5D-Y, EQ-5D-Y VAS | Self-assessed by children; Proxy-assessed by parents. Self-administered paper questionnaire | Mean: 9.46; 6-11 |
| Robles et al (2015) [246] | General health |  | Spain | EQ-5D-Y VAS | Self-assessed by children. Online survey; Self-administered paper questionnaire | Mean: 11.7; 8-18 |
| Rochanathimoke et al (2014) [247] | Gastroenteritis | Hospitalisation | Thailand (Thailand) | EQ-5D-3L | Proxy-assessed by caregivers. Face-to-face interview. | Mean: 1.77; 0.17-5 |
| Rocque et al (2015) [248] | Spina bifida; Complications (myelomeningocele, closed spinal dysraphism, bowel incontinence) | CSF shunt; Chiari malformation II decompression; Tethered cord release | USA (Unspecified) | HUI3 | Assessed together by children and parents. Self-administered paper questionnaire. | Mean: 12.6; 5-20 |
| Rodriguez-Martinez et al (2013) [249] | Persistent asthma | Treatments: Fluticasone; Ciclesonide; Budesonide;  Control: Beclomethasone dipropionate | Colombia | SG | Proxy-assessed by parents. Face-to-face interview. | Unspecified |
| Roman (2010) [250] | Endometriosis | Laparoscopic excision | New Zealand (UK) | EQ-5D-3L VAS,  EQ-5D-3L | Self-assessed by children. Postal survey or Self-administered paper questionnaire. | Mean: 17.4 |
| Roposch et al (2011) [251] | Developmental hip dysplasia; Complication (secondary osteonecrosis) | Hospitalisation | UK (Canada) | HUI3 | Assessed together by children and caregivers. Face-to-face interview. | Mean: 14; 4-18 |
| Rosenbaum et al (2007) [252] | Cerebral palsy |  | Canada (Canada) | HUI3 | Proxy-assessed by caregivers. Self-administered paper questionnaire. | Mean: 16; 13-20 |
| Rowley et al (1998) [253] | Cystic fibrosis |  | USA | TTO | Assessed together and children and parents. Face-to-face interview. | 5-18 |
| Sach and Barton (2007) [254] | Sensorineural hearing loss: bilateral; unilateral; congenital; acquired | Unilateral cochlear implantation | UK (UK) | EQ-5D-3L VAS,  EQ-5D-3L | Proxy-assessed by parents. Face-to-face interview. | Mean: 9.29 |
| Saigal et al (1994) [255] | Extremely low birthweight; Extremely preterm birth; General health (control) |  | Canada (Canada) | HUI2 | Proxy-assessed by caregivers. Self-administered paper questionnaire. | Mean: 8 |
| Saigal et al (1996) [256] | Extremely low birthweight; Extremely preterm birth; Comorbidities (neurosensory impairment, cerebral palsy, hydrocephalus, cognitive impairment, autism, blindness, deafness); General health (control); Hypothetical health states associated with extremely low birthweight or extremely preterm birth children | Hypothetical neonatal care and use of health equipment | Canada | VAS, SG | Self-assessed by children. Face-to-face interview. | Mean: 14, 14.4; 12-16 |
| Saigal et al (1999) [257] | Hypothetical health states associated with extremely low birthweight or extremely preterm birth children | Hypothetical neonatal care and use of health equipment | Canada | SG | Proxy-assessed by physicians, nurses or parents or self-assessed by children. Face-to-face interview. | Mean: 8, 14.2 |
| Saigal et al (2000) [258] | Extremely low birthweight; Extremely preterm birth; Comorbidities (neurosensory impairment, cerebral palsy, hydrocephalus, cognitive impairment, autism, blindness, deafness); General health (control); Hypothetical health states associated with extremely low birthweight or extremely preterm birth children | Hypothetical neonatal care and use of health equipment | Canada | SG | Proxy-assessed by parents. Face-to-face interview. | Mean: 14, 14.4; 12-16 |
| Saigal et al (2003) [259] | Hypothetical health states associated with extremely low birthweight or extremely preterm birth children | Hypothetical neonatal care and use of health equipment | Canada | SG | Proxy-assessed by parents. Face-to-face interview. | Unspecified |
| Saigal et al (2016) [260] | Extremely low birthweight; Extremely preterm birth; Comorbidity (neurosensory impairment); General health |  | Canada (Canada) | HUI3 | Self-assessed by children. Face-to-face interview | Mean: 13.9; 12-16 |
| Saw et al (2003) [261] | Myopia | Corrective visual aid | Singapore | TTO, SG (Pit: Blindness) | Self-assessed by children. Face-to-face interview. | 15-18 |
| Scalone et al (2007) [262] | Cancer patients: ALL; General health (control) | Unspecified cancer therapy | Italy | EQ-5D-Y VAS | Self-assessed by children. Postal survey or Self-administered paper questionnaire. | 8-15 |
| Scalone et al (2012) [263] | Cancer patients: ALL; General health (control) | Chemotherapy maintenance phase | Italy | EQ-5D-Y VAS | Self-assessed by children. Postal survey or Self-administered paper questionnaire. | 8-15 |
| Scott et al (2017) [264] | General health; Combined congenital physical disabilities (spina bifida, muscle diseases, cerebral palsy); Combined acquired chronic conditions (diabetes, HIV, neurological, heart, renal and respiratory impairments); Combined acute illnesses (appendicitis, septic arthritis, leukaemia, bone fracture) | Intensive care; Nursing care; Wheelchairs and assistive devices | South Africa | EQ-5D-Y VAS | Self-assessed by children. Self-administered paper questionnaire; Face-to-face interview | Mean: 10.5; 8-12 |
| Secnik et al (2005) [265] | ADHD | Stimulant therapy; Psychotherapy; Hypothetical ADHD treatments (nonstimulant therapy, immediate-release stimulant therapy, extended-release stimulant therapy); Varying patient response to treatment | UK (UK) | EQ-5D-3L VAS,  SG (Pit: Death), SG (Pit: Worst health),  EQ-5D-3L | Proxy-assessed by parents. Face-to-face interview. | Mean: 12.6; 7-18 |
| Selvadurai et al (2002) [266] | Cystic fibrosis: pulmonary exacerbation | Treatment: Physical activity (aerobic training, resistance training)  Control: outpatient care (antibiotics, physiotherapy, nutrition supplement) | Australia (USA) | QWB | Proxy-assessed by physicians. Self-administered paper questionnaire. | Mean: 13.2; 8-16 |
| Semenov et al (2013) [267] | Sensorineural hearing loss: congenital; acquired | Cochlear implantation | USA (Canada) | HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Unspecified |
| Seyedifar et al (2016) [268] | Beta thalassemia major; Comorbidities (heart complication, diabetes, hepatitis) | Blood transfusions and iron chelation (injection or oral) | Iran (Iran, US) | EQ-5D-3L, VAS | Assessed together by children and parents. Self-administered paper questionnaire | 10-15; 15-20 |
| Sierwald et al (2016) [269] | Combined dental disorders: dental caries, malocclusion, cleft lip/palate; General health | Orthodontic treatment | Germany (Europe) | EQ-5D-Y, EQ-5D-Y VAS | Self-assessed by children. Self-administered by paper questionnaire | Mean: 11.9, 9.9 |
| Simonova et al (2013) [270] | Cystic fibrosis |  | Russia (Unspecified) | HUI2, HUI3 | Proxy-assessed by parents or self-assessed by children. Unspecified mode of administration. | Mean: 5, 6, 12, 15, 16 |
| Sims-Williams et al (2017) [271] | Spina bifida; Comorbidities (hydrocephalus, immobility) | Spina bifida surgical repair | Uganda (Unspecified) | HUI3, VAS | Self-assessed by children; Proxy-assessed by parents. Face-to-face interview; Self-administered paper questionnaire | 10-14 |
| Smith-Olinde et al (2008) [272] | Hearing loss | Cochlear implantation | USA (USA, Canada) | QWB, HUI3 | Proxy-assessed by caregivers. Self-administered paper questionnaire. | Mean: 7.3; 5-10 |
| Soucie et al (2017) [273] | Haemophilia A |  | USA (USA, UK) | EQ-5D-3L, SF-6D | Self-assessed by children. Self-administered paper questionnaire | 14-20 |
| Sparreboom et al (2012) [274] | Sensorineural hearing loss | Cochlear implantation: bilateral; unilateral | Netherlands (Canada) | VAS, HUI3 | Proxy-assessed by parents. Face-to-face interview. | Mean: 5.3; 2.4-8.5 |
| Sruamsiri et al (2013) [275] | Severe thalassemia | Reduced-intensity hematopoietic stem cell transplantation | Thailand (Thailand) | EQ-5D-3L | Self-assessed by children. Self-administered paper questionnaire. | Mean: 13.7; 9-18 |
| Stade et al (2006) [276] | Fetal alcohol effect; Fetal alcohol syndrome; Comorbidity (severe cognitive impairment); General health (control) | Neonatal care | Canada (Canada) | HUI3 | Proxy-assessed by parents, self-assessed by children or assessed together by children and parents. Face-to-face interview. | Mean: 14.5; 8-21 |
| Stevens and Freeman (2012) [277] | Admission to PICU | Intensive care: mechanical ventilation | UK (Canada) | HUI2, HUI3 | Proxy-assessed by parents or self-assessed by children. Postal survey. | Mean: 10.5; 5-18 |
| Stevens and Ratcliffe (2012) [278] | General health |  | Australia (UK) | CHU9D | Self-assessed by children. Online survey. | Mean: 14.5; 11-17 |
| Stolk et al (2000) [279] | Imperforate anus; General health (control) | Surgery in neonatal period | Netherlands (UK) | EQ-5D-3L VAS,  EQ-5D-3L | Proxy-assessed by parents or assessed together by children and parents. Postal survey. | Mean: 16.26; 1-51 |
| Stromqvist et al (2016) [280] | Lumbar disc herniation | Disc surgery | Sweden | EQ-5D-3L, EQ-5D VAS | Self-assessed by children. Self-administered paper questionnaire | Median: 19; 13-20 |
| Sung et al (2003) [281] | Cancer patients: ALL; Ewing’s sarcoma; Wilm’s tumour; brain tumour; lymphoma; STS; neuroblastoma; osteosarcoma | Chemotherapy | Canada (Canada) | VAS, HUI2, HUI3 | Proxy-assessed by parents. Face-to-face interview. | Mean: 7.2 |
| Sung et al (2003b) [282] | Cancer patients: ALL; Ewing’s sarcoma; Wilm’s tumour; brain tumour; lymphoma; STS; neuroblastoma; osteosarcoma; Arthritis; Haemophilia; Conditions requiring bone marrow transplant | Chemotherapy; Outpatient care | Canada (Canada) | VAS, SG (Pit: Death), SG (Pit: Worst health), TTO, HUI2, HUI3 | Proxy-assessed by parents. Face-to-face interview. | Mean: 8.9; 1-18 |
| Sung et al (2004) [283] | Cancer patients; Arthritis; Haemophilia; Conditions requiring bone marrow transplant; Hypothetical asthma as example of mild disability; Hypothetical stroke as example of moderate disability; Hypothetical injury as example of severe disability |  | Canada (Canada) | VAS, SG, TTO, HUI2, HUI3 | Proxy-assessed by parents or self-assessed by children. Face-to-face interview. | Mean: 13.7; 12-18 |
| Swales et al (2016) [284] | Borderline personality disorder; Recent occurrence of self-harm behaviour | Community mental health service: Dialectical behavioural therapy | UK (Unspecified) | EQ-5D-3L | Self-assessed by children. Online survey | 14-18 |
| Szecket et al (1999) [285] | Cancer survivors: retinoblastoma | Unspecified cancer therapy | Argentina (Canada) | HUI2, HUI3 | Proxy-assessed by physicians. Self-administered paper questionnaire. | Unspecified |
| Tejwani et al (2016) [286] | Hypothetical paediatric vesicoureteral reflux |  | USA | TTO | Proxy-assessed by general public. Online survey | 0-12 |
| Teuffel et al (2011) [287] | Hypothetical cancer patients with febrile neutropenia | Hypothetical cancer therapy: inpatient intravenous antibiotic therapy, outpatient intravenous antibiotic therapy, oral antibiotic therapy, inpatient IV therapy | Canada | SG mapping from VAS | Proxy-assessed by parents. Self-administered paper questionnaire. | Unspecified |
| Thomas et al (2011) [288] | Moderate to severe atopic dermatitis | Treatment: ion-exchange water softener  Control: usual primary care | UK (UK) | EQ-5D-3L | Assessed together by children and parents. Face-to-face interview. | Mean: 5.8, 5.1; 0.5-16 |
| Thorrington et al (2017) [289] | Influenza-like illness: fever, malaise, headache, myalgia, cough, sore throat, shortness of breath; General health (after recovery from influenza-like illness) |  | UK (Unspecified) | EQ-5D-3L | Proxy-assessed by parents. Postal survey | 6-11 |
| Tilford et al (2005) [290] | Spina bifida: sacral lesion, lower lumbar lesion, thoracic lesion; General health (control) |  | USA (Canada) | HUI2 | Proxy-assessed by caregivers. Telephone interview. | 5-17 |
| Tilford et al (2007) [291] | Traumatic brain injury | Intensive care: endotracheal intubation, mechanical ventilation, intracranial pressure monitoring, craniotomy | USA (USA) | QWB | Proxy-assessed by caregivers. Telephone interview. | Mean: 12.6; 5-18 |
| Tilford et al (2012) [292] | ASD: pervasive developmental disorder, Asperger’s disorder |  | USA (USA, Canada) | HUI3, QWB | Proxy-assessed by caregivers. Postal survey. | Mean: 8.6; 4-17 |
| Tilford et al (2015) [293] | ASD: pervasive developmental disorder, Asperger’s disorder |  | USA (USA, Canada) | HUI3, QWB | Proxy-assessed by caregivers. Postal survey. | Mean: 8.2; 4-17.9 |
| Tirado et al (2011) [294] | Laryngotracheal stenosis | Laryngotracheal reconstruction | Canada (Canada) | VAS, HUI3 | Proxy-assessed by parents, self-assessed by children or assessed together by children and parents. Face-to-face interview. | Mean: 9.6; 4-15 |
| Tong et al (2011) [295] | Kidney disease | Successful kidney transplant | Australia (Canada) | VAS, TTO, HUI2, HUI3 | Assessed together by children and parents. Face-to-face interview. | 12-19 |
| Tong et al (2013) [296] | Kidney disease | Failed kidney transplant; Hemodialysis; Peritoneal dialysis | Australia (Canada) | VAS, TTO, HUI2, HUI3, SF-6D | Assessed together by children and parents. Face-to-face or telephone interview. | Mean: 17.1; 12-25 |
| Trent et al (2011) [297] | Pelvic inflammatory disease; Permanent sequelae (ectopic pregnancy, infertility, chronic abdominal pain) | Hospitalisation | USA | VAS, TTO | Proxy-assessed by parents or self-assessed by children. Online survey. | Mean: 16.2; 12-19 |
| Trevino et al (2013) [298] | Overweight or obese |  | USA (Canada) | EQ-5D-3L VAS, HUI2, HUI3 | Self-assessed by children. Self-administered paper questionnaire. | Mean: 11; 10-12 |
| Trudel et al (1998) [299] | Cancer survivors: leukaemia, lymphoma, SNS tumour, renal tumour, hepatic tumour, bone tumour, STS  Cancer patients: leukaemia, lymphoma, solid tumour, brain tumour | Surgery; Chemotherapy; Radiotherapy | Canada (Canada) | HUI2 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 9.1; 4.1-17.3 |
| Ulfsdotter et al (2015) [300] | General health | All Children in Focus: universal parenting programme | Sweden | EQ-5D-Y VAS | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 6.09;  3-12 |
| van Baar et al (2011) [301] | Major injury; Burns | Hospitalisation | Netherlands (UK) | EQ-5D-3L | Assessed together by children and parents. Postal survey. | 5-15 |
| van der Kolk et al (2014) [302] | ADHD; General health (control) |  | Netherlands (Unspecified) | EQ-5D-3L | Proxy-assessed by parents. Online survey. | Mean: 11 |
| van Litsenburg et al (2013) [303] | Cancer survivors: ALL | Surgery; Chemotherapy | Netherlands (Canada) | HUI3 | Proxy-assessed by parents. Postal survey. | Mean: 9.3 |
| van Schaik et al (1999) [304] | Cancer survivors: Hodgkin’s disease | Chemotherapy; Radiotherapy | Canada (Canada) | HUI2, HUI3 | Self-assessed by children. Postal survey. | Median: 21.9; 9.4-31.5 |
| van Schooneveld et al (2015) [305] | Epilepsy | Hemispherectomy | Netherlands | EQ-5D-3L VAS | Proxy-assessed by parents. Face-to-face interview. | Median: 9.7, 13.8; 7.1-24.5 |
| Vermeulen et al (2017) [306] | Hypothetical behavioural disorders: Oppositional defiant disorder; Conduct disorder; Disruptive behavioural disorder; Comorbidities (ADHD, substance abuse); General health |  | Netherlands | EQ-5D VAS | Proxy-assessed by professionals working with children or adolescents; Self-assessed by children; Proxy-assessed by parents.  Postal survey; Self-administered paper questionnaire | Mean: 9, 15 |
| Vermeulen et al (2017b) [307] | Antisocial personality disorder: Chronically antisocial and seriously violent | Treatment: Multisystemic therapy  Control: Usual care – juvenile justice and child welfare services | Netherlands (UK) | EQ-5D-3L | Self-assessed by children; Proxy-assessed by parents. Self-administered paper questionnaire | Mean: 16;  12-18 |
| Verrips et al (2001) [308] | Very low birthweight; Very preterm birth |  | Netherlands (Canada) | HUI3 | Proxy-assessed by parents or self-assessed by children. Postal survey or face-to-face or telephone interview. | Mean: 14.3 |
| Verrips et al (2008) [309] | Extremely low birthweight; Extremely preterm birth | Prenatal steroid treatment; Ventilation | Canada, Germany, Netherlands (Canada) | HUI3 | Self-assessed by children. Postal survey or face-to-face interview. | Mean: 14; 12-16 |
| Verrips et al (2012) [310] | Very low birthweight; Very preterm birth |  | Netherlands (Canada) | HUI3 | Self-assessed by children. Postal survey. | Mean: 14 |
| Vitale et al (2001) [311] | JIA; Cerebral palsy; Scoliosis | Surgery | USA (Unspecified) | EQ-5D | Self-assessed by children. Self-administered paper questionnaire. | Mean: 14.6; 10-18 |
| Wake et al (2015) [312] | Speech disorder: receptive and/or expressive language delay at 4 years old | Speech therapy: Language for Learning (population-based intervention) | Australia | HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 6 |
| Wang et al (2002) [313] | Health states taken from Barr et al (1993), Kennedy and Leyland (1999), Barr et al (1999), Saigal et al (1994), Van Schaik et al (1999), Barr et al (2000); General health (control) |  | UK, Canada (Singapore) | HUI2 | Proxy-assessed by nurses, physicians or parents or assessed together by children and parents. Postal survey or Self-administered paper questionnaire. | 1.7-31.5 |
| Wasserman et al (2005) [314] | Haemophilia | Haemophilia treatment: on-demand; prophylaxis; inhibitor | USA | VAS, SG | Assessed together by children and parents. Face-to-face interview. | Mean: 10; 0.5-18 |
| Weigel et al (2016) [315] | Anorexia nervosa | Inpatient or outpatient mental health services | Germany | EQ-5D VAS | Self-assessed by children. Self-administered paper questionnaire | Mean: 15.6; 11-18 |
| Weiner et al (2016) [316] | Cancer survivors: Osteosarcoma, Ewing’s sarcoma, Myxoid liposarcoma, Fibromatosis | Unspecified cancer therapy | UK | EQ-5D VAS | Self-assessed by children. Self-administered paper questionnaire | 12-18 |
| Wijnen et al (2017) [317] | Epilepsy: Uncontrolled seizures, Not eligible for surgery | Treatment: Ketogenic diet  Control: Usual care | Netherlands (Netherlands) | EQ-5D-Y | Proxy-assessed by parents. Self-administered paper questionnaire | Mean: 7.8, 8.1;  2.1-16.5 |
| Wille et al (2010) [318] | General health |  | Germany, Spain | EQ-5D VAS;  EQ-5D-Y VAS | Self-assessed by children. Self-administered paper questionnaire | Mean: 13.9, 13;  10-18; 8-18 |
| Willems et al (2007) [319] | Low to moderately severe asthma | Treatment: Nurse-led telemonitoring for asthma symptoms  Control: usual care | Netherlands (UK) | EQ-5D-3L VAS,  EQ-5D-3L | Assessed together by children and parents. Self-administered paper questionnaire. | Mean: 10.6, 10.9; 7-18 |
| Willems et al (2009) [320] | Combined chronic illnesses: Asthma, Rheumatic disorders, Diabetes, Speech/language and/or hearing disorders |  | Netherlands | EQ-5D-Y VAS | Assessed together by children and parents. Postal survey | 7-18 |
| Wolke et al (2013) [321] | Very low birthweight; Very preterm birth; General health (control) |  | Germany (Canada) | HUI3 | Proxy-assessed by parents or self-assessed by children. Postal survey. | Mean: 13 |
| Wong et al (2017) [322] | Adolescent idiopathic scoliosis | Surgery, Braces | China (China) | EQ-5D-5L | Self-assessed by children. Self-administered paper questionnaire. | Mean: 15.5 |
| Wright et al (2003) [323] | Cancer survivors: ALL; Standard or high risk of relapse; General health (control) | DFCI 85-01; DFCI 87-01; DFCI 91-01; DFCI 95-01 | Canada (Unspecified) | HUI2, HUI3 | Assessed together by children and parents. Self-administered paper questionnaire. | Mean: 12.1, 11.9; 7-18.9 |
| Wright et al (2005) [324] | Cancer survivors: ALL; Standard or high risk of relapse; General health (control) | DFCI 85-01; DFCI 87-01; DFCI 91-01; DFCI 95-01 | Canada (Unspecified) | HUI3 | Proxy-assessed by parents. Self-administered paper questionnaire. | Mean: 12.2; 5.1-31.5 |
| Wright et al (2017) [325] | Depression | Treatment: Computerised cognitive behavioural therapy (Stressbusters)  Control: Accessing low-mood self-help website | UK (Unspecified) | EQ-5D-Y | Self-assessed by children. Self-administered paper questionnaire. | Mean: 15.5; 12-18 |
| Wu et al (2010) [326] | General health | REAL Kids Alberta programme to promote healthy body weight | Canada (USA) | EQ-5D-Y VAS,  EQ-5D-Y | Self-assessed by children. Self-administered paper questionnaire. | 10-11 |
| Wu et al (2012) [327] | Overweight or obese; General health (normal weight) | REAL Kids Alberta programme to promote healthy body weight; Physical activity | Canada | EQ-5D-Y VAS | Self-assessed by children. Self-administered paper questionnaire. | 10-11 |
| Wu et al (2014) [328] | General health | REAL Kids Alberta programme to promote healthy body weight | Canada (USA, Canada) | EQ-5D-Y VAS,  EQ-5D-Y | Self-assessed by children. Self-administered paper questionnaire. | 10-11 |
| Xu et al (2014) [329] | General health | Physical activity | China (UK, Australia) | CHU9D | Self-assessed by children. Self-administered paper questionnaire. | Mean: 14.1; 9-17 |
| Yaris et al (2001) [330] | Cancer patients: NHL; Hodgkin’s disease; brain tumour; neuroblastoma; germ cell tumour; STS; bone sarcoma | Surgery; Chemotherapy; Radiotherapy | Turkey (Canada) | HUI2 | Proxy-assessed by parents. Face-to-face interview. | Mean: 9.7; 2-16 |
| Yi et al (2003) [331] | Cystic fibrosis |  | USA (Canada) | VAS, TTO, SG, HUI2 | Self-assessed by children. Face-to-face interview. | Mean: 15.1; 12-18 |
| Yi et al (2009) [332] | IBD: Crohn’s disease; Ulcerative colitis; General health (control) |  | USA | VAS, TTO, SG | Self-assessed by children. Face-to-face interview. | Mean: 14.8, 15.5; 11-19 |
| Young et al (2010) [333] | Cerebral palsy |  | Canada (Canada) | HUI3,  AQoL-5D | Assessed together by children and caregivers. Postal survey. | Mean: 15.5; 13-17.9 |
| Young et al (2013) [334] | Spina bifida: thoracic lesion; high-lumbar lesion; low-lumbar lesion; sacral lesion |  | Canada (Canada) | HUI3,  AQoL-5D | Assessed together by children and caregivers. Postal survey. | Mean: 16; 13-17.9 |
| Rodriguez-Martinez et al (2016) [335] | Asthma: Suboptimal control, no exacerbation; Exacerbation; General health control |  | Colombia | SG | Proxy-assessed by parents. Face-to-face interview. | Unspecified |
| CBT: Cognitive-behavioural therapy; RCT: Randomised controlled trial; LCHADD: Long-chain acyl-CoA dehydrogenase deficiency; MCADD: Medium-chain acyl-CoA dehydrogenase deficiency; ALL: Acute lymphoblastic leukaemia; DFCI: Dana-Farber Cancer Institute; PNET: Primitive neuroectodermal tumour; NHL: Non-Hodgkin’s lymphoma; STS: Soft tissue sarcoma; AML: Acute myeloid leukaemia; ADHD: Attention-deficit hyperactivity disorder; MSKD: Musculoskeletal disorder; IBD: Inflammatory bowel disease; JIA: Juvenile idiopathic arthritis; PICU: Paediatric intensive care unit; DCM: Demands and capacities model; ASD: Autism spectrum disorder; PTSD: Post-traumatic stress disorder; HFO: High-frequency oscillation; BFM: Berlin-Frankfurt-Munster; CSF: Cerebral spinal fluid; REAL: Raising healthy eating and active living; CH-6D: Child Health 6 Dimensions; ABC-UI: Aberrant Behaviour Checklist Utility Index | | | | | | |

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| **Table S4.** Number of studies (% in interval) by study design and 5-year publication interval | | | | | | | |
|  | 1990-1994 | 1995-1999 | 2000-2004 | 2005-2009 | 2010-2014 | 2015-2017\* | Total |
| Patient case series | 5  (62.5) | 4  (19.0) | 8  (23.5) | 8  (12.7) | 16  (13.3) | 8  (9.0) | 49  (14.6) |
| Cross-sectional survey | 2  (25.0) | 12  (57.1) | 18  (52.9) | 35  (55.6) | 59  (49.2) | 45  (50.6) | 171  (51.0) |
| Longitudinal studies and RCTs without CUA | 1  (12.5) | 2  (9.5) | 4  (11.8) | 7  (11.1) | 20  (16.7) | 13  (14.6) | 47  (14.0) |
| Longitudinal studies and RCTs with CUA and decision models with primary utility assessment | 0  (0.0) | 3  (14.4) | 4  (11.8) | 13  (20.6) | 25  (20.8) | 23  (25.8) | 68  (20.4) |
|  | 8  (2.4) | 21  (6.3) | 34  (10.1) | 63  (18.8) | 120  (35.8) | 89  (26.6) | 335 |
| \* Covers up to 30th June 2017; RCT: Randomised controlled trial; CUA: Cost-utility analysis | | | | | | | |

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| **Table S5.** Number of samples (% in interval) by ICD-10 chapter and 5-year publication interval | | | | | | | |
|  | 1990-1994 | 1995-1999 | 2000-2004 | 2005-2009 | 2010-2014 | 2015-2017\* | Total |
| General health | 1  (1.0) | 9  (4.3) | 15  (3.4) | 23  (2.6) | 316  (20.1) | 137  (17.8) | 501  (12.6) |
| ICD-10 Chapter 1: Infectious and parasitic diseases | 36  (36.0) |  | 49  (11.2) | 64  (7.3) | 39  (2.5) | 7  (0.9) | 195  (4.9) |
| ICD-10 Chapter 2: Cancer | 33  (33.0) | 108  (50.9) | 105  (24.0) | 89  (10.1) | 93  (5.9) | 14  (1.8) | 442  (11.1) |
| ICD-10 Chapter 3: Diseases of the blood and immune system |  |  | 31  (7.1) | 20  (2.3) | 22  (1.4) | 12  (1.6) | 85  (2.1) |
| ICD-10 Chapter 4: Endocrine, nutritional and metabolic disorders | 3  (3.0) | 6  (2.8) | 39  (8.9) | 43  (4.9) | 258  (16.4) | 62  (8.0) | 411  (10.3) |
| ICD-10 Chapter 5: Mental and behavioural disorders | 3  (3.0) |  |  | 166  (18.9) | 305  (19.4) | 224  (29.0) | 698  (17.6) |
| ICD-10 Chapter 6: Nervous system disorders | 3  (3.0) | 3  (1.4) | 1  (0.2) | 33  (3.8) | 38  (2.4) | 36  (4.7) | 114  (2.9) |
| ICD-10 Chapter 7: Diseases of the eye |  | 1  (0.5) | 44  (10.1) | 16  (1.8) |  |  | 61  (1.5) |
| ICD-10 Chapter 8: Diseases of the ear | 6  (6.0) | 6  (2.8) | 6  (1.4) | 64  (7.3) | 74  (4.7) | 2  (0.3) | 158  (4.0) |
| ICD-10 Chapter 9: Circulatory system disorders | 3  (3.0) | 3  (1.4) | 4  (0.9) | 5  (0.6) | 1  (0.1) |  | 16  (0.4) |
| ICD-10 Chapter 10: Respiratory system disorders | 3  (3.0) | 6  (2.8) | 4  (0.9) | 36  (4.1) | 123  (7.8) | 20  (2.6) | 192  (4.8) |
| ICD-10 Chapter 11: Digestive system disorders |  | 1  (0.5) | 4  (0.9) | 6  (0.7) | 25  (1.6) | 24  (3.1) | 60  (1.5) |
| ICD-10 Chapter 12: Diseases of the skin |  | 1  (0.5) | 9  (2.1) | 11  (1.3) | 5  (0.3) |  | 26  (0.7) |
| ICD-10 Chapter 13: Musculoskeletal system disorders |  | 2  (0.9) | 34  (7.8) | 8  (0.9) | 17  (1.1) | 53  (6.9) | 114  (2.9) |
| ICD-10 Chapter 14: Genitourinary system disorders | 3  (3.0) | 1  (0.5) | 3  (0.7) | 4  (0.5) | 44  (2.8) | 1  (0.1) | 56  (1.4) |
| ICD-10 Chapter 16: Conditions originating in the perinatal period | 6  (6.0) | 47  (22.2) | 54  (12.3) | 30  (3.4) | 64  (4.1) | 9  (1.2) | 210  (5.3) |
| ICD-10 Chapter 17: Congenital malformations |  | 4  (1.9) | 8  (1.8) | 26  (3.0) | 29  (1.8) | 88  (11.4) | 155  (3.9) |
| ICD-10 Chapter 19: Injury, poisoning and other consequences of external causes |  | 3  (1.4) | 4  (0.9) | 211  (24.0) | 65  (4.1) | 14  (1.8) | 297  (7.5) |
| ICD-10 Chapter 21: Contact with health services |  | 10  (4.7) |  | 3  (0.3) | 35  (2.2) | 32  (4.2) | 80  (2.0) |
| Combined chronic diseases |  | 1  (0.5) | 24  (5.5) | 20  (2.3) | 21  (1.3) | 37  (4.8) | 103  (2.6) |
| Total | 100  (2.5) | 212  (5.3) | 438  (11.0) | 878  (22.1) | 1,574  (39.6) | 772  (19.4) | 3,974 |
| \* Covers up to 30th June 2017 | | | | | | | |

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| **Table S6.** Number of samples (% in interval) by valuation method and 5-year publication interval | | | | | | | |
|  | 1990-1994 | 1995-1999 | 2000-2004 | 2005-2009 | 2010-2014 | 2015-2017\* | Total |
| Visual analogue scales | 57  (57.0) | 22  (10.4) | 53  (12.1) | 104  (11.9) | 326  (20.7) | 270  (35.0) | 832  (20.9) |
| Trade-off-based direct valuation methods |  | 37  (17.5) | 184  (42.0) | 178  (20.3) | 102  (6.5) | 40  (5.2) | 541  (13.6) |
| Adult-specific MAUIs |  |  | 20  (4.6) | 116  (13.2) | 210  (13.3) | 130  (16.8) | 476  (12.0) |
| MAUIs compatible with childhood and adult populations | 43  (43.0) | 139  (65.6) | 178  (40.6) | 416  (47.4) | 613  (39.0) | 148  (19.2) | 1,537  (38.7) |
| Children- and/or adolescent-specific MAUIs |  | 14  (6.6) | 3  (0.7) | 57  (6.5) | 323  (20.5) | 176  (22.8) | 573  (14.4) |
| Utility from non-preference-based methods |  |  |  | 7  (0.8) |  | 8  (1.0) | 15  (0.4) |
| Total | 100  (2.5) | 212  (5.3) | 438  (11.0) | 878  (22.1) | 1,574  (39.6) | 772  (19.4) | 3,974 |
| \* Covers up to 30th June 2017 | | | | | | | |

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| **Table S7.** Number of samples (% in interval) by (i) age of sample, (ii) respondent type, (iii) administration mode and (iv) valuation of hypothetical state and 5-year publication category | | | | | | | |
|  | 1990-1994 | 1995-1999 | 2000-2004 | 2005-2009 | 2010-2014 | 2015-2017\* | Total |
| **(i) Age of sample\*\*** | | | | | | | |
| Sample contains pre-adolescent children | 55  (100) | 78  (44.6) | 161  (52.3) | 484  (64.2) | 931  (66.3) | 377  (53.6) | 2,086  (61.3) |
| Sample does not contain pre-adolescent children |  | 97  (55.4) | 147  (47.7) | 270  (35.8) | 474  (33.7) | 327  (46.4) | 1,315  (38.7) |
| Total | 55  (1.6) | 175  (5.1) | 308  (9.1) | 754  (22.2) | 1,405  (41.3) | 704  (20.7) | 3,401 |
| **(ii) Respondent type a** | | | | | | | |
| Self-assessment by children | 2  (2.0) | 73  (34.4) | 127  (29.0) | 135  (15.4) | 778  (49.4) | 383  (49.6) | 1,498  (37.7) |
| Proxy assessment | 98  (98.0) | 139  (65.6) | 311  (71.0) | 743  (84.6) | 796  (50.6) | 389  (50.4) | 2,476  (62.3) |
| Total | 100  (2.5) | 212  (5.3) | 438  (11.0) | 878  (22.1) | 1,574  (39.6) | 772  (19.4) | 3,974 |
| **(iii) Administration mode** | | | | | | | |
| Self-administered surveys | 39  (39.0) | 74  (34.9) | 155  (35.4) | 478  (54.4) | 1,079  (68.6) | 639  (82.8) | 2,464  (62.0) |
| Interview-administered surveys | 61  (61.0) | 138  (65.1) | 283  (64.6) | 400  (45.6) | 495  (31.4) | 133  (17.2) | 1,510  (38.0) |
| Total | 100  (2.5) | 212  (5.3) | 438  (11.0) | 878  (22.1) | 1,574  (39.6) | 772  (19.4) | 3,974 |
| **(iv) Valuation of hypothetical state** | | | | | | | |
| Actual health state | 43  (43.0) | 163  (76.9) | 304  (69.4) | 646  (73.6) | 1,467  (93.2) | 624  (80.8) | 3,247  (81.7) |
| Hypothetical health state | 57  (57.0) | 49  (23.1) | 134  (30.6) | 232  (26.4) | 107  (6.8) | 148  (19.2) | 727  (18.3) |
| Total | 100  (2.5) | 212  (5.3) | 438  (11.0) | 878  (22.1) | 1,574  (39.6) | 772  (19.4) | 3,974 |
| \* Covers up to 30th June 2017; \*\* Divided into two categories: samples with mean or median age below 12 or minimum age (if mean/median age not reported) below 12 and samples with mean or median age or minimum age 12 or above.  a Assessment together by children and parents or caregivers is treated as proxy assessment. | | | | | | | |