

Towards standardization of economic evaluations:

an overview of instruments to measure quality of life
and resources in youth with psychosocial problems.

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List of abbreviations

16D- Sixteen Dimensional measure of HRQoL	KINDL-R- Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescent - Revised Version
17D- Seventeen Dimensional measure of HRQoL	KMIN- Kenniscentrum meetinstrumenten VUMC
AHUM- Adolescent Health Utility Measure	MSLSS- Multidimensional Student's Life Satisfaction Scale
AQoL 6D- Assessment of Quality of Life 6D for adolescents	NJi- Nederlands Jeugdinstituut (Netherlands Youth Institute)
AQOL-MHS - Adolescent Quality of Life Mental Health Scale	O- Other
CA-SUS- Child and Adolescent Service Use Schedule	OoP- Out of pocket
CASA - Child and Adolescent Services Assessment interview	P- Personal social services
CHIP- Child Health and Illness Profile	PedsQL- Pediatric Quality of Life Inventory
CHIP-AE:SRF- Child Health and Illness Profile - Adolescent Edition: Self Report Form	PROMIS- Patient-Reported Outcomes Measurement Information System
CHIP-CE:PRF- Child Health and Illness Profile - Child Edition: Parent Report Form	PROMs- Patient-Reported Outcome Measures
CHIP-CE:SRF- Child Health and Illness Profile - Child Edition: Self Report Form	Proqolid- Patient-Reported Outcome and Quality of Life Instruments Database
CHQ-CF87- Child Health Questionnaire - Child Form 87	QALYs- Quality Adjusted Life Years
CHQ-PF28- Child Health Questionnaire - Parent Form 28	QoL- Quality of life
CHQ-PF50- Child Health Questionnaire - Parent Form 50	QOLPAV- Quality of Live Profile: Adolescent Version
CHSCS - PS- Comprehensive Health Status Classification System - Preschool	QWB- Quality of Well-Being Scale
CHU9D- Child Health Utility Index 9D	SACA- Services Assessment for Children and Adolescents
COSMIN- Consensus-based Standards for the selection of health Measurement Instruments	SCAPI- Services for Children and Adolescents, Parent Interview
CQOL- Child Quality of Life Questionnaire	SF-HLQ- Short Form-Health & Labour Questionnaire
CSRI- Client Service Receipt Inventory	SHIFT- Self-Harm Intervention, Family Therapy
CSRI-C Client Service Receipt Inventory Children version	SSC- Social security benefits/contributions
DIRUM- Database of Instruments for Resource Use Measurement	SURF- Services Use and Risk Factors measure Youths' Reports of Services.
DUX-25- Dutch-Child-AZL-TNO-Quality-of-Life	TACQOL- TNO-AZL-Child-Quality-of-Life
ED- Education sector	TAPQOL- TNO-AZL-Preschool-Children-Quality-of-Life
EM- Employers	TiC-P Adults- Trimbos and iMTA questionnaire on Costs associated with Psychiatric illness- Adults
EQ-5D-Y- EuroQol Five Dimensions Health Questionnaire, Youth	TiC-P Children- Trimbos and iMTA questionnaire on Costs associated with Psychiatric illness children
EU- European Union	V- Voluntary costs
EuHEA- European conference on health economics	VHO- Dutch Services and Support Questionnaire, Vragenlijst Hulp en Ondersteuning
GCQ- Generic children's quality of life questionnaire	WPAI + CIQ:SHP, V2.0- Work Productivity and Activity Impairment Questionnaire plus Classroom Impairment Questions: Specific Health Problem Version 2.0
H: Health service	YQOL-R- Youth Quality of Life Instrument - Research Version
HLQ- Health and Labour Questionnaire	
HUI2/3- Health Utilities Index Mark 2/3	
iPCQ iMTA Productivity Cost Questionnaire	
ITQOL- Infant and Toddler Quality of Life Questionnaire	

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Introduction

In the past decade, there has been increasing interest in the societal impact of interventions in the youth sector, which has resulted in a growing attention for economic evaluations. Stakeholders increasingly base their decision-making on outcomes of economic evaluations. Therefore, a standardized method for performing economic evaluations in the youth sector is important. However, methods and instruments which are used in economic evaluations have traditionally been developed for the somatic (health) care and moreover adult populations, making standardization, reliability, and execution of methods for economic evaluations challenging.

In 2016, a broad consultation into the standardization of economic evaluations in the youth sector took place. Five main methodological issues and challenges were identified, namely 1) outcome measurement, 2) outcome identification, 3) cost valuation, 4) outcome valuation, and 5) time horizon/ analytical approach. According to stakeholders, standardization of the measurement for costs and quality of life is a central issue that has to be resolved to come to a standardization of economic evaluations in the youth sector [1]. This led to a call from ZonMw to make an overview of available instruments to measure quality of life and resources.

The aim of the current report is to provide an overview of available instruments to measure cost and quality of life in the youth sector for economic evaluations as described in the ZonMw approved project (729300201).

To reach this aim mixed methods are used. First, a meta-review was performed to identify relevant instruments. A second systematic review was aimed at identifying the psychometric properties (i.e. internal consistency, reliability, measurement error, content validity, structural validity, hypothesis testing, reproducibility, criterion validity and feasibility) of the identified instruments. Third, an online consultation took place to assess familiarity and suitability of the identified instruments. Later an expert meeting was organized to come to a selection of instruments and to set a (research) agenda for the standardization of economic evaluations in youth.

For each identified instrument we assessed: a. the evidence base of the instrument, b. the validity and reliability of the instrument, c. the goal and target audience of the instrument, d. the setting for which the instrument is suitable, e. who should administer or complete the questionnaire, f. where the instrument or questionnaire can be used in practice, g. the availability of a Dutch (validated) version, h. for which type of economic evaluation the instrument is suitable, and i. for which perspective of an economic evaluation the instrument is most suitable, e.g. societal, health care perspective, insurance perspective, perspective of the municipality.

2. Methods

Several steps were taken in this project (also see Figure 1). The rationale behind and procedure for each step is described in this paragraph.

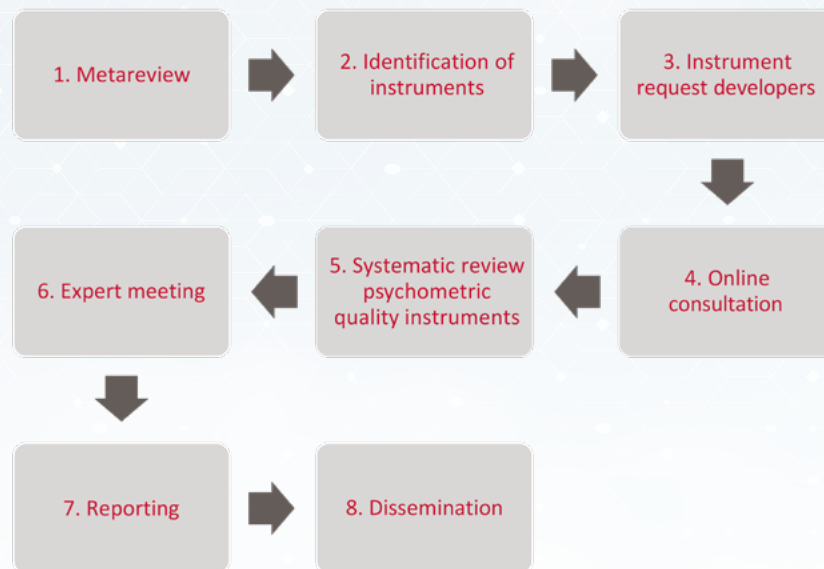


Figure 1. Steps of identifying and scoring instruments

2.1 Meta-review

First, a meta-review was performed to identify suitable published systematic review on the 1) economic evaluation of psychosocial interventions, 2) on the reliability and validity of quality of life (QoL) and 3) on the reliability and validity of resource use measurement instruments.

A two-step approach was taken.

Regarding the scientific literature, we searched Pubmed (medline), PsycInfo, Embase, Econlit, NHS EED, DARE, CRD and Web of Science, these databases cover medical, social, economic and psychological research. For grey literature we searched Google Scholar, Google, COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN) [2], Picarta, and several relevant online repositories for questionnaires. For QoL instruments these were: Kenniscentrum meetinstrumenten VUMC (KMIN), Patient-Reported Outcome and Quality of Life Instruments Database (Proqolid), Patient-Reported Outcome Measures (PROMs, University of Oxford), Patient-Reported Outcomes Measurement Information System (PROMIS). For costing instruments, we searched the Database of Instruments for Resource Use Measurement (DIRUM)[3]. Next, reference lists of relevant literature were checked for missing information, also earlier performed reviews by the authors were checked for relevant instruments [4-6]. Recent literature was searched to assess whether there were newly developed instruments missed in the meta-review.

The search terms per database can be found in Appendix 1a for QoL and Appendix 1b for the costing instruments.

Reviews were included when they aimed at studies for youth below the age of 18 in high income countries, aimed at QoL or costing instruments that could be used in social, cognitive or psychiatric development of children, and were written in English or Dutch.

Reviews were excluded when they aimed at curative or palliative treatment, or somatic illnesses and conditions, screening or diagnostic interventions, or vaccinations. Selection and screening of the QoL reviews was performed by two authors

(LS and APG), disagreement was resolved by consensus between the two authors.

For costing instruments titles and abstracts were screened for inclusion by one author (DKW), and full texts were screened once the articles were judged eligible for inclusion or when eligibility was uncertain. In case of uncertainty whether or not to include a review, consensus was reached through discussion among the project team of costing instruments (DKW, SE, CD, GvdB).

2.2 Identification of instruments

The identified reviews were searched for relevant instruments.

For QoL the inclusion criteria were that the instrument should be a measure of generic health related quality of life suitable for use in social, cognitive or psychiatric development of youth. Furthermore, the instrument should not be aimed at a specific disorder or problem.

For costing instruments, the inclusion criteria were that the instrument has to request volumes of resource use, also, the instrument should not aim at the use of solely administrative data. Based on these inclusion criteria the relevant instruments were identified in the literature.

2.3 Instrument request

Not all instruments were publicly available, in that case the developers were approached with a request for the instrument. We were able to receive nearly all instruments, except for the AHUM (which was no longer available), AQOL-MHS, CQOL, DUX-25, ITQOL, QOLPAV, Self-Harm Intervention Family Therapy (SHIFT) Young person Questionnaire Booklet, the EU-CAHMSRI, and both of the Services Use and Risk Factors measure (SURF) reports (Parents as well as Youth).

2.4 Online consultation

An online consultation survey was developed and sent by email to 51 experts and stakeholders in January 2018. This consultation served as a low-threshold assessment of usability and employability of the identified instruments for economic evaluations of psychosocial care for youth.

The 51 stakeholders had been consulted in the previous broad consultation [7] or were part of the consortia “Effective working in youth care”. Stakeholders were considered experts in the field of economic evaluations, and/or impact research within the youth field, and consisted of researchers employed by universities, researchers employed by knowledge institutes, youth care professionals and policy advisors for the municipality.

The survey was divided in two parts, the first part aimed at QoL instruments, the second at costing instruments. On the basis of the answer to the question whether the respondent was familiar with QoL instruments and/or costing instruments respectively, the respondent received subsequent questions on that particular instrument. Respondents were asked about their familiarity with the retrieved instruments, and whether they used the respective instrument. For QoL-instruments it was asked whether the respondent thought the instrument was suitable for specific age ranges and, if the instrument was not deemed suitable, why the instrument was unsuitable. Regarding costing instruments respondents were asked whether the expert thought all relevant cost items for research in the youth sector were included in the instrument. According to the guidelines of the National Health Care Institute (Dutch: “Zorginstituut Nederland”) the societal perspective is commonly prescribed [8].

Furthermore, the experts were asked to rank the instruments (both QoL and costing instruments) they were familiar with, in order of preference. Moreover, respondents were inquired whether they were aware of any instruments that were not previously identified in the search. The online survey (in Dutch) is available in Appendix 2.

2.5 Systematic review psychometric properties

For each identified instrument, a systematic review was performed to assess its psychometric properties. Databases (Pubmed (medline), Psycinfo, NHS EED, DARE, CRD, Embase, Econlit and Web of Science) were searched for relevant studies. Furthermore, literature lists of relevant papers and reviews were checked for missing studies. A full overview of the search terms can be found for QoL in Appendix 4a and for costing instruments in Appendix 4b.

Studies were included if the paper described the instrument and the psychometric research performed concerned healthy youngsters or youth with psychosocial problems below the age of 18 years old. Papers were excluded when they were not written in English or Dutch, or solely focused on youth with somatic difficulties and did not include a healthy or social, cognitive or psychiatric problems group. Selection and screening of the studies was performed by either by APG or LS for QoL or DKW for costing instruments.

Psychometric properties (i.e. internal consistency, reliability, measurement error, content validity, structural validity, hypothesis testing, cross cultural validity, criterion validity, responsiveness and feasibility) were scored (yes, investigated this psychometric property/ no, did not investigate this psychometric property) using the definitions provided by the COSMIN ([9, 10]). A summary of the definitions used can be found in the Appendix 5.

2.6 Expert meeting

An expert meeting (Dutch: “klankbordgroep”) was organized on February 22nd, 2018. A subgroup of seven experts that participated in the online consultation also joined this expert meeting. The aim of this meeting was to come to a selection of instruments and to set a (research) agenda for the standardization of economic evaluations in youth. The meeting was structured so that at least the translation of foreign language instruments into Dutch, the adaptation or merging of existing instruments, modular set-up of cost questionnaires, validation research, and implementation activities were discussed.

The meeting was divided in two parts. First an update on the project was given. Second, an interactive worksession was prepared in which the following questions were discussed:

1. Is there missing information in the presented instruments (for instance domains for QoL, cost items for resource instrument)?
2. How can the hiatus be solved? In what way have the experts dealt with this until now? Is there a solution possible, needed or already practice-based developed?
3. What is important in choosing a suitable instrument? Is there one preferred instrument for either topic (QoL and cost)?
4. What is needed in the (near) future in terms of content, psychometric research, implementation, or other topics to ensure standardization of economic evaluations in the youth sector?

2.7 Reporting

The current report is the first reflection of the extensive research done in approved ZonMw project (72930020). In addition, two English-language articles are being prepared which will be submitted to international scientific journals. Furthermore, a Dutch overview is available, which includes both QoL instruments and costing instruments, as well as psychometric properties of these instruments. This overview serves as decision aid to choose for a suitable and available instrument in the given research population.

2.8 Dissemination

The results of this project are important for several stakeholders (including knowledge institutes, clinicians, and researchers). During the dissemination stage we will try to reach these groups.

3. Results

This chapter describes the results following the first six steps of the research method.

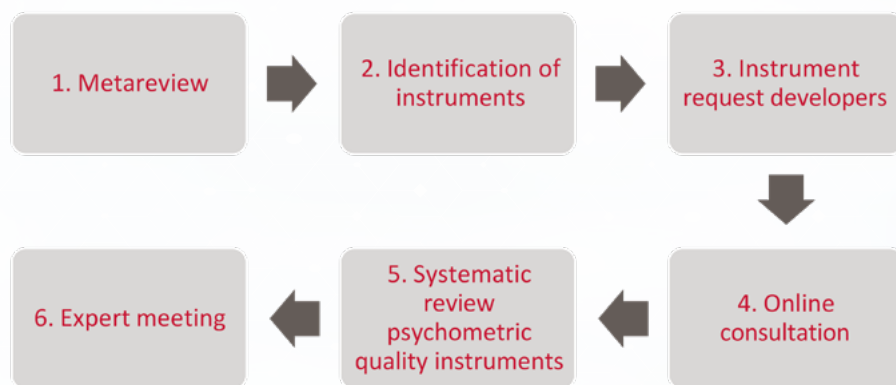


Figure 2. Steps of identifying and scoring instruments

3.1 Meta-review

For QoL a total of 1,636 papers were identified through meta-review. After the first selection based on title and abstract 43 papers remained for inclusion. No additional reviews were identified through our grey literature search. From these 43, 14 were not suitable for this review, which led to 29 reviews included in this meta-review.

For the costing instruments a total of 880 papers were identified through reviews. Another 62 papers were identified through grey literature search. After removal of duplicates and the first selection based on title and abstract, 68 papers remained. From these 64 were not suitable for this review, which led to 4 reviews included in this meta-review. Flowchart for both QoL and costs meta-reviews can be found in appendix 3a and appendix 3b.

3.2 Identification of instruments

With respect to QoL, a total of 23 unique questionnaires were identified. An overview of the domains within the identified QoL questionnaires can be found in Figure 3. The subdivision in domains in this figure is based on the World Health Organization's definition of QoL.

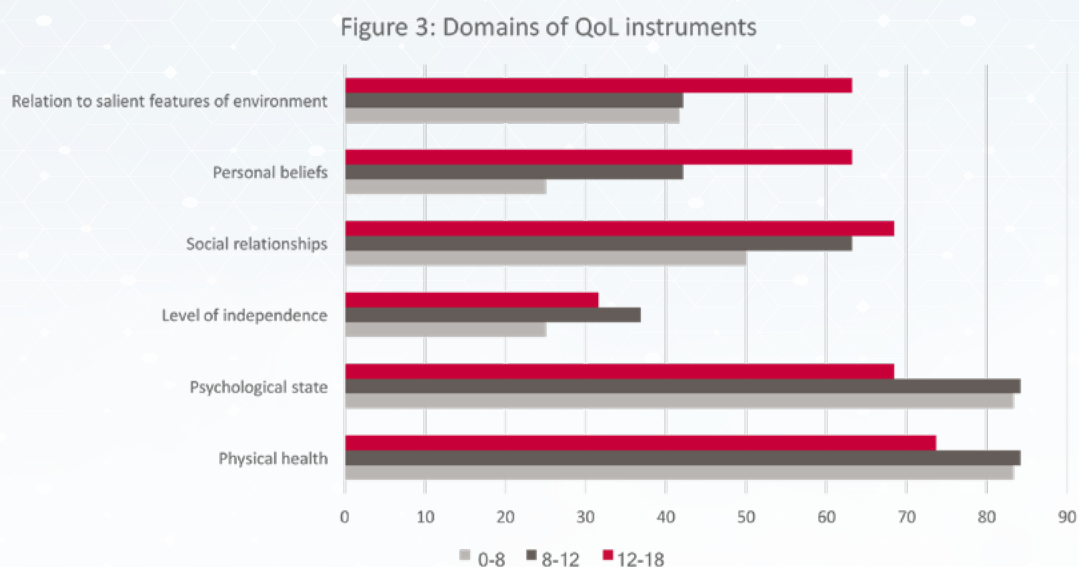


Figure 3. Domains measured in the identified Quality of Life instruments per age group (0-8 years old, 8-12 years old, and 12-18 years old)

Of these 23 questionnaires, 7 had both a proxy and a self-report version (DUX-25, CQOL, 16D, TACQOL, CHSCS, CHIP, CHU9D, EQ5D-y, KINDL-R CHQ, KIDscreen, PEDsQL), and 6 with only a self-report (MSLSS, 17D, AHUM, HUI2/3, GCQ, QWB, YQOL, AQOL, QOLPAV). Fourteen questionnaires were available in Dutch (Chip, CHQ, DUX-25, PEDSQL, TACQOL, TAPQOL, YQOL, HUI2/3, EQ-5D-Y, ITQOL, KIDSCREEN, CHUD9, QWB, KINDL-R). Eight questionnaires were preference-based and had a value set available (AHUM, AQOL, CHUD9, EQ-5D-Y, HUI2/3, QWB, 16D, 17D), which allows the calculation of utility scores (and with this Quality Adjusted Life Years; QALYs).

Table 1 provides an overview and summary of the domains of the identified instruments. A written summary per instrument can be found in the catalogue in appendix 7.

Table 1. Summary and scoring of instruments to measure QoL in youth.

Measure	Full name	Abbreviation	Described in	Developer	Domains	Age	Mode of administration	Preference based	Proxy?	Items	Time to complete	Country of origin	Language availability
CHIP	Child Health and Illness Profile - Child Edition: Parent Report Form	CHIP-CE:PRF	[11-21]	Starfield et al. (1993)	Satisfaction, comfort, risk avoidance, resilience, achievement, if necessary as a supplement to the parent-report form: disorders	6-11	Parent-report form	no	yes, parents	76 or 45	15-20 min	VS	Available in 38 languages
	Child Health and Illness Profile - Child Edition: Self Report Form	CHIP-CE:SRF	[11, 14-16, 18-21, 23-28]	Starfield et al. (1993)	Satisfaction, comfort, risk avoidance, resilience, achievement	6-11	Self-report form	no	no	45	15 min	VS	Available in 38 languages
	Child Health and Illness Profile - Adolescent Edition: Self Report Form	CHIP-AE:SRF	[11, 14-16, 19-21, 23, 27-30]	Starfield et al. (1993)	Satisfaction, discomfort, disorders, risks, resilience, achievement	12-17	Self-report form	no	no	153	30 min	VS	Available in 38 languages
CHQ	Child Health Questionnaire - Parent Form 50	CHQ-PF50	[11-13, 15, 16, 18-21, 24, 26, 28, 29, 31-38]	Landgraf et al. (1998) [39]	physical functioning, role limitations-emotional/behavioral, role limitations-physical, bodily pain, behavior, mental health, self-esteem, general health perceptions, parental impact-emotional, parental impact-time, family activities, family cohesion	5-18	parent-report form	no	Yes, parents	50	10-15 min	VS	Available in 50 languages
	Child Health Questionnaire - Parent Form 28	CHQ-PF28	[14, 15, 19-21, 26, 28, 29, 31-33, 37, 38]	Landgraf et al. (1998) [39]	physical functioning, role limitations-emotional/behavioral, role limitations-physical, bodily pain, behavior, mental health, self-esteem, general health perceptions, parental impact-emotional, parental impact-time, family activities, family cohesion	5-18	parent-report form	no	yes, parents	28	5-10 min	VS	Available in 50 languages
	Child Health Questionnaire - Child Form 87	CHQ-CF87	[12-16, 18, 20, 21, 23, 26-29, 31-33, 35, 37, 38, 40]	Landgraf et al. (1998) [39]	physical functioning, role limitations-emotional/behavioral, role limitations-physical, bodily pain, behavior, mental health, self-esteem, general health perceptions, parental impact-emotional, parental impact-time, family activities, family cohesion	10-18	self-report form	no	no	87	14 min	VS	Available in 21 languages
DUX-25	Dutch-Child-AZL-TNO-Quality-of-Life	DUX-25	[12, 13, 16, 20, 21, 37, 41]	TNO institute, Koopmans et al. (2001)	home, physical, emotional, social	5-16	parent-and self-report form	no	yes, parents	25		NL	Available in 1 language

Measure	Full name	Abbreviation	Described in	Developer	Domains	Age	Mode of administration	Preference based	Proxy?	Items	Time to complete	Country of origin	Language availability
	Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescent - Revised Version	KINDL-R	[13, 16, 19-21, 23-25, 27, 29, 32, 38, 41-45]	Ravens-Sieberer & Bullinger (1998)	physical, general, self-esteem, family, social contacts, school	3-17	parent- and self-report form	no	yes, parents	child 4-6: 12, 7-13 and 14-17: 24, parents 3-6 and 7-17: 24	unknown	GER	Available in 28 languages
PedsQL	Pediatric Quality of Life Inventory	PedsQL	[12, 14-18, 20, 21, 23-25, 27, 28, 33, 35-38, 40-43, 45, 47-51]	Varni et al. (1998)	school functioning, emotional functioning, social functioning, physical functioning	2-18	parent- and self-report form	no	yes, parents	23	4 min	VS	Available in >70 languages
TACQOL	TNO-AZL-Child-Quality-of-Life	TACQOL	[12, 13, 16, 20, 21, 23, 24, 27, 29, 36, 37, 40, 41, 43, 51]	TNO institute, Vogel s et al. (1998) [53]	physical complaints (body), motor functioning (motor), autonomous functioning (self), social functioning (social), cognitive functioning (cognition), positive psychological functioning (emopos), negative psychological functioning (emoneg)	6-15	parent- and self-report form	no	yes, parents	child 8-11: 63, child 12-15: 54, parent 6-11: 63	10 min	NL	Available in 9 languages
TAPQOL	TNO-AZL-Pre-school-Children-Quality-of-Life	TAPQOL	[21, 24, 33, 42, 54]	TNO institute, Fekkes et al. (2000) [55]	physical functioning: sleeping, appetite, problems with lungs/stomach/skin, motor functioning; social functioning: play with peers, self-esteem, social comfort, problem behavior; cognitive functioning: understanding what others say, speech, elaborating in expressive language; emotional functioning: mood, anxiety and liveliness	1-5	parent-report form	no	yes, parents	43		NL	Available in 14 languages
YQOL	Youth Quality of Life Instrument - Research Version	YQOL-R	[12, 13, 18, 19, 21, 23, 27, 31, 36, 40, 44]	Patrick et al. (2002) [56]	sense of self, social relationships, culture and community, general quality of life	11-18	self-report form	no	no	42 or 16		VS	Available in 7 languages
HUI	Health Utilities Index Mark 2	HUI2	[14, 17-19, 21, 23, 27, 36, 44, 49, 57]	McMaster University	sensation, mobility, emotion, cognition, self-care, pain, fertility	5 and older	5-8: proxy-administration, 8 and above: self-report form	yes	yes, parents	7	self: 8-10, interview: 3-5 min	Canada	Available in 32 languages

Measure	Full name	Abbreviation	Described in	Developer	Domains	Age	Mode of administration	Preference based	Proxy?	Items	Time to complete	Country of origin	Language availability
	Health Utilities Index Mark 3	HUI3	[14, 17, 18, 21, 44, 49, 51, 57, 58]	McMaster University	vision, hearing, speech, ambulation, dexterity, emotion, cognition, pain	5 and older	5-8: proxy-administration, 8 and above: self-report form	yes	yes, parents	8	self: 8-10, interview: 3-5 min	Canada	Available in 32 languages
AQOL-MS	Adolescent Quality of Life Mental Health Scale	AQOL-MHS	[44]	Chavez et al. (2012) [59]	self, peers, family, school, environment	12-18	self-report	no	no	20		USA (using Latin-American youth)	Available in 1 language (Spanish)
AQOL 6D	Assessment of Quality of Life 6D for adolescents	AQoL 6D	[14, 60]	Richardson et al. (2012) [61]	physical ability, social and family relationships, mental health, coping, pain, senses (vision, hearing and communication)	adolescents	self-report form	yes	no	20	2-3 min	Australia	Available in 5 languages
EQ-5d-Y	EuroQoL Five Dimensions Health Questionnaire, Youth	EQ-5D-Y	[13, 14, 18, 27, 43, 44, 57, 58, 62]	Wille et al. (2010) [63]	mobility, looking after myself, doing usual activities, having pain or discomfort, feeling worried, sad or unhappy	8-15	parent- and self-report form	yes	yes, parents	5	5 min	international consortium	Available in >40 languages
MSLSS	Multidimensional Student's Life Satisfaction Scale	MSLSS	[18, 44]	Huebner (1994) [64]	family, friends, school, living environment, self	8-18	self-report form, interview-administration	no	no	6 or 40		USA	Available in 2 languages
QOLPAV	Quality of Live Profile: Adolescent Version	QOLPAV	[21, 47]	Raphael [65] et al. (1996)	being (physical, psychological, spiritual), belonging (physical, social, community), becoming (practical, leisure, growth)	14-20	self-report form	no	no	54		Canada	Available in 1 language
ITQOL	Infant and Toddler Quality of Life Questionnaire	ITQOL	[33] 37	Klassen et al. (2003) [66]	8 infant concepts: physical abilities, growth and development, bodily pain/discomfort, temperament and moods, general behavior perceptions, getting along with others, general health perceptions, changes in health; 5 parent concepts: impact-emotional, impact-time, mental health, general health, family cohesion	2 months - 5 years	parent-report form	no	yes, parents	47 or 97		Canada	Available in 18 languages
KIDSCREEN	KIDSCREEN	KIDSCREEN	[14, 18, 37, 48] [21, 23, 27, 38, 54]	EU consort (2001-2004)	52 item: physical well-being, psychological well-being, moods and emotions, self-perception, autonomy, parent relations and home life, social support and peers, school environment, social acceptance (bullying), financial resources; 10 and 27 item: physical well-being, psychological well-being, parent relations and autonomy, social support and peers, school environment	8-18	parent- and self-report form	no	yes, parents	52, 27 or 10	52 item: 10-20 min, 27 item: 10-15 min, 10 item: 5 min	Austria, GER, VK, NL, SW, FR, GR	Available in >35 languages

Measure	Full name	Abbreviation	Described in	Developer	Domains	Age	Mode of administration	Preference based	Proxy?	Items	Time to complete	Country of origin	Language availability
CHU9D	Child Health Utility Index 9D	CHU9D	[14, 57, 60]	Stevens (2009) [67]	worried, sad, pain, tired, annoyed, school work/homework, sleep, daily routine, ability to join activities	7-17	parent- and self-report form	yes	yes	9		UK	Available in 9 languages
16D	Sixteen Dimensional measure of HRQoL	16D	[42] 20 21, 37	Apajasalo et al. (1996) [68]	mobility, vision, hearing, breathing, sleeping, eating, speech, excretion, school and hobbies, mental function, discomfort and symptoms, depression, distress, vitality, appearance, friends	12-15	self-report form, proxy-report form and interview-administration	yes	yes, parents	16	5-10 min	Finland	Available in 5 languages
17D	Seventeen Dimensional measure of HRQoL	17D	[42] 20 21, 37	Apajasalo et al. (1996) [69]	mobility, vision, hearing, breathing, sleeping, eating, speech, excretion, school and hobbies, learning and memory, discomfort and symptoms, depression, distress, vitality, appearance, friends, concentration	8-11	self-report form, structured interview	yes	no	17	20-30 min	Finland	Available in 4 languages
CQOL	Child Quality of Life Questionnaire	CQOL	[18, 21, 23, 25, 29, 51]	Graham et al. (1997) [70]	getting about and using hands, doing things for self, soiling or wetting, school, out of school activities, friends, family relationships, discomfort due to bodily symptoms, worries, depression, seeing, communication, eating, sleep, appearance	9-15	parent- and self-report form	no	yes, parents	15		UK	Available in 1 language
AHUM	Adolescent Health Utility Measure	AHUM	[60]	Beusterien et al. (2012) [71]	self-care, pain, mobility, strenuous activities, self-image, health perceptions	12-18	self-report form	yes	no	6		UK	Available in 1 language
CHSCS	Comprehensive Health Status Classification System - Pre-school	CHSCS - PS	[18, 21]	Saigal et al. (2005) [72]	vision, hearing, speech, mobility, dexterity, self-care, emotion, learn/remember, think/problem-solve, pain, general health, behavior	2,5-5	parent- and nurse-report form	yes but no valuation set available	yes, parents and nurse	12	10 min	Canada/Australia	Available in 1 language?
GCQ	Generic children's quality of life questionnaire	GCQ	[20, 21, 25, 26]	Collier et al. (1997) [73]		6-14	self-report form, interview-administration	no	no	25		UK	Available in 1 language
QWB	Quality of Well-Being Scale	QWB	[14, 17, 32, 49] [27, 30, 43, 51, 54, 57, 60]	Kaplan et al. (1976) [74]	chronic symptoms or problems, acute physical symptoms, mobility, physical activity, social activity including the role of expectations	all ages	self-report form, interview-administration	yes	no	76 (QWB complete) or 10 (mental health sub-scale)	10-30 min	USA	Available in 8 languages

Regarding the costing instruments, a total of 20 unique questionnaires were identified, see Table 2 for a summary. Of these 20 questionnaires, 6 had both a proxy and a self-report-version, CASA, CA-SUS, DATCAP, SACA, SHIFT, and the SURF. Another 8 instruments only had a proxy version; the CSRI-C, EU-CAHMSRI, Costdiary, SCOPE, TiC-P Children, SCAP, VHO, and the 'Vragenlijst Intensieve Jeugdzorg: Zorggebruik en productieverlies'. Finally, there were 6 instruments with only an adult version, the CSRI, HLQ, iPCQ, SF-HLQ, TiC-P Adults, and the WPAI + CIQ:SHP, V2.0. These adult instruments were used to assess health care use or loss of productivity of the parents, due to their child's condition. There were no instruments with only a children's self-report version. Nine questionnaires were available in Dutch; the iPCQ, Costdiary (Bodden et al.), (SF-)HLQ, TiC-P Adults, TiC-P Children, VHO, HLQ and the 'Vragenlijst Intensieve Jeugdzorg: Zorggebruik en productieverlies'.

Table 2. Summary and scoring of costing instruments.

Measure	Full name	Abbreviation	Reference and instrument identification	Developer	Age (child)	Person(s) Completing Instrument	Administration method	Instrument Type	Recall period	Country of Origin	Costing perspective	Adaptation / merging existing instrument	Adaptations
CA-SUS	Child and Adolescent Service Use Schedule	CA-SUS	[75-78], SLE, RC, H	Byford et al. (1999)	11 - 17	Patient/ Parent/carer	In person	Recall questionnaire	maximum 3 to 9 months	United Kingdom	H, P, ED	★2	
TiC-P Children	TiC-P for children	TiC-P: C	[1, 79], GL	iMTA 1[80]	0-18	Parent/carer	In person Via post	Recall questionnaire	3 months	Netherlands	H, P, O, OoP, ED	★2	
Vragenlijst Intensieve Jeugdzorg: Zorggebruik en productieverlies	Vragenlijst Intensieve Jeugdzorg: Zorggebruik en productieverlies		[1, 79], GL	iMTA 1[80]	4 - 17	Parent/carer	Measure	Recall questionnaire	maximum 1 to 3 months	Netherlands	H, P, ED, O, EM	★2	
HLQ	Health and Labour Questionnaire	HLQ	[4, 81], GL	iMTA 1[82]	NA	Patient (Employee)	In person	Recall questionnaire	2 weeks	Netherlands	EM		
TiC-P Adults	Trimbos and iMTA questionnaire on Costs associated with Psychiatric illness	TiC-P Adults	[4, 83, 84], GL	iMTA 1[78]	NA	Parent/carer	In person Via post	Recall questionnaire	maximum 1 to 3 months	Netherlands	H, P, EM, O		TiC-P Mini TiC-P Midi [85]
VHO	Dutch Services and Support Questionnaire, Vragenlijst Hulp en Ondersteuning	VHO	[4, 86], GL, D	Wansink et al. (2016) [87]	3 - 10	Parent/carer/ Researcher	In person Via post	Recall questionnaire	maximum 3-6 months	Netherlands	H, P, O, V, ED	★2	
CASA	Child and Adolescent Services Assessment interview	CASA Child interview	[88, 89], SLE	Barbara J. Burns, Ph.D [90]	8 - 18	Patient/ Parent/carer	In person Via telephone (follow up)	Recall questionnaire	3 months	USA	H, ED, P, O, V	no	
CASA	Child and Adolescent Services Assessment interview	CASA Parent interview	[88, 89], SLE	Barbara J. Burns, Ph.D [86]	8 - 18	Parent/carer	In person Via telephone (follow up)	Recall questionnaire	3 months	USA	H, ED, P, O, V	no	
CSRI-C	Client Service Receipt Inventory Childrens version	CSRI-C	[89], SLE, D	Jennifer Beecham [91]	4 - 10	Parent/carer/ Researcher	In person	Recall questionnaire	maximum 4 to 6 months	United Kingdom	H, P, ED, EM		Costs due to special schools, foster caring and residential placements have been included. Medications and criminal justice content have been excluded. Another adaptation possibility is the variation in period of recall – between 6 and 12 months

Measure	Full name	Abbreviation	Reference and instrument identification	Developer	Age (child)	Person(s) Completing Instrument	Administration method	Instrument Type	Recall period	Country of Origin	Costing perspective	Adaptation / merging existing instruments	Adaptations
	Cost diary Bodden et al 2008		[4, 92-94], SLE, GL, RC	Bodden [92]	8 - 18	Parent/carer	In person Via post	Diary	2 weeks (prospective)	Netherlands	H, P, ED, EM, V, O, OoP		
SHIFT	Self-Harm Intervention, Family Therapy Parent or Carers Questionnaire Booklet	SHIFT	[89] SLE, D, H	Sandy Tubeuf, Yemi Oluboyede, Chris McCabe [95]	11 - 17	Parent/carers booklet	Via post	Recall questionnaire	maximum 1 to 3 months	United Kingdom	H, P, O, ED, OoP, EM		NA
	Self-Harm Intervention, Family Therapy (SHIFT) Young person Questionnaire Booklet	SHIFT	[63] SLE, D	Sandy Tubeuf, Yemi Oluboyede, Chris McCabe [90]	11 - 17	Young person booklet	Via post	Recall questionnaire	maximum 1 to 3 months	United Kingdom	H, OoP, P, O, EM, ED		NA
SCOPE	Studying the Scope of Parental Expenditures	SCOPE	[96] in [63] SLE, D	Department of Medical Genetics, University of British Columbia, Canada	1 - 18	Parent/carer	Via computer	Recall questionnaire	maximum 4 to 6 months	Canada	H, P, EM, O	★3	
WPAI + CIQ:SHP, V2.0	Work Productivity and Activity Impairment Questionnaire plus Classroom Impairment Questions: Specific Health Problem Version 2.0	WPAI + CIQ:SHP, V2.0	[63] SLE, D, RC	Margaret Reilly, M.A., M.P.H.	12 - 17	Patient	In person Via computer Via post	Recall questionnaire	7 days	USA	EM		
iPCQ	iMTA Productivity Cost Questionnaire	iPCQ	[97, 98], GL, P	iMTA 1	NA	Patient (Employee)	Via post	Recall questionnaire	4 weeks	Netherlands	EM	★8,9	

Measure	Full name	Abbreviation	Reference and instrument identification	Developer	Age (child)	Person(s) Completing Instrument	Administration method	Instrument Type	Recall period	Country of Origin	Costing perspective	Adaptation / merging existing instruments	Adaptations
DATCAP	DATCAP	DATCAP	[99], GL	French, M.T. (2003) [100].	12 - 18	Parent/carer	In person	Recall questionnaire	maximum 1 year	USA	OoQ, EM		Brief DATCAP Adult outpatient Adult residential Adolescent outpatient Adolescent residential Detoxification Intensive outpatient Methadone maintenance
	DATCAP	DATCAP	[91], GL	French, M.T. (2005) [101].	12 - 18	Parent/carer	In person	Recall questionnaire	maximum 1 year	USA	H, P, OoP, SSC		
	DATCAP Care-taker	DATCAP	[91], GL	French, M.T. (2005) [93]	12 - 18	Patient/ Parent/carer	In person	Recall questionnaire	maximum 1 year	USA	OoP, EM, H, P		
CSRI	Client Service Receipt Inventory	CSRI	[77], [102], [103] and [104], GL, D	Jennifer Beecham / Martin Knapp	NA	Parent/carer Researcher	In person Via telephone Via computer Other can be adapted to a wide context	Recall questionnaire	Not specified	United Kingdom	H, P, EM, V, O		Numerous adaptations, a.o.: *a version for family carers of children with autism spectrum disorder [105], *CSRI-Pain: *CSRI-EU
SCAPI	Services for Children and Adolescents, Parent Interview	SCAPI	[75], [106,107], RC, GL	NIMH 10 [108]	7 - 9.9	Parent/carer	In person	Recall questionnaire	maximum recall period 1 to 3 months	USA	H, P, O, ED		
SF-HLQ	Short Form-Health & Labour Questionnaire	SF-HLQ	[109], [110,111], RC	iMTA 1	NA	Patient (Employee)	Via post	Recall questionnaire	4 weeks	Netherlands	EM		
SACA	Services Assessment for Children and Adolescents Parent version	SACA	[112, 113], RC	Stiffman et al. (2000), [114]	11 - 17	Parent/carer	In person	Recall questionnaire	12 months	USA	H, P, O, ED	★4,5,6,7	SACA (Mental Health Services Utilization) SACA Brief (Mental Health Services Utilization) SACA Not So Brief (Mental Health Services Utilization) SACA Not So Brief-Revised (Mental Health Services Utilization) SACA for Kids SACA for Sibs SACA for Young Adults SACA for Young Adults II Services Assessment for Children and Adolescents (SACA-C): Computerized version of the SACA SACA Siblings

Measure	Full name	Abbreviation	Reference and instrument identification	Developer	Age (child)	Person(s) Completing Instrument	Administration method	Instrument Type	Recall period	Country of Origin	Costing perspective	Adaptation / merging existing instrument	Adaptations
	SACA (Services Assessment for Children and Adolescents) Adolescent report version	SACA	[112, 113], RC	Stiffman et al. (2000), [103]	11 - 17	Parent/Carer Researcher	In person	Recall questionnaire	12 months	USA	H, P, O, ED	★4,5,6,7	
EU-CAHMSRI	EU-CAHMSRI	EU-CAHMSRI	[115], RC	Kilian, R.C.L., McDaid, D. et al (2009)	6 - 21	Parent/Carer	In person		maximum 1 to 6 months	Austria	H, P, O, ED, OoP	★3	
SURF	Services Use and Risk Factors measure Parents' Reports of Services	SURF	[113, 116], RC	National Institute of Mental Health (NIMH)	9 - 17	Patient/Parent/carer/	In person	Recall questionnaire	12 months	USA	H, P, O, ED		
	Services Use and Risk Factors measure 'Youths' Reports of Services.	SURF	[102, 105], RC	National Institute of Mental Health (NIMH)	9 - 17	Patient/Parent/carer/	In person	Recall questionnaire	12 months	USA	H, P, O, ED		

Reference & instrument identification: D identified via search in DIRUM, SLR Q identified via systematic literature review, GL Grey Literature, P identified via PROQUOLID, RC identified via referencecheck, identified via HTA database

Costing perspective (one or more) : H health to specify; H health service; P personal social services; OoP patient [and carer] out-of-pocket costs; ED education sector; EM employers; SOC societal; V voluntary;

SSC social security benefits/contributions; O other with option to specify

Developer: 1 Institute for Medical Technology Assessment, 10 National Institute of Mental Health

Adaptation / merging existing instrument: 2 TiC-P, 3 CSRI, 4 CASA, 5 SCAP, 6 Referral Sequence and Problem Interview, 7 SURF, 8 PRO- DISQ, 9 SF-HLQ

In the next step we analyzed the possible perspective of each instrument by clustering the costing units according to an earlier performed study by Ridyard and colleagues [117]. Therefore, each instrument was labeled with one or more possible costing perspectives: health service (H), personal social services (P), patient [and carer] out-of-pocket costs (OoP), education sector (ED), employers (EM), voluntary (V), social security benefits/contributions (SSC), other (O). Figure 4 shows the amount of different costing perspectives each instrument includes.

Figure 4: amount and different costingperspectives per instrument

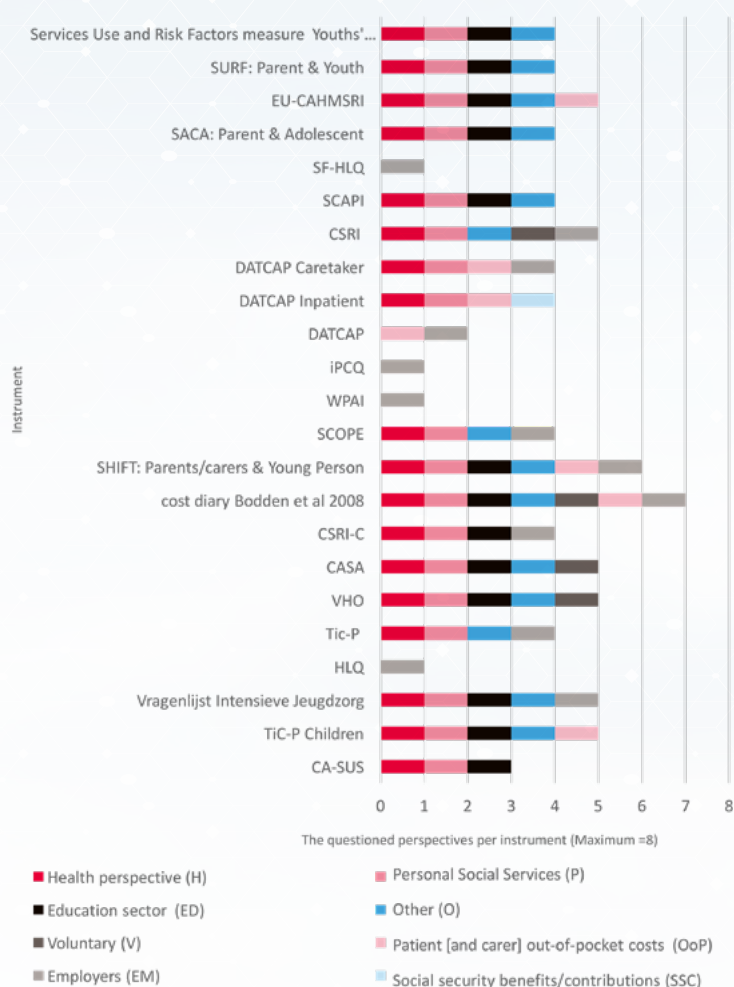


Figure 4. Amount and different perspectives per instrument. (H: Health service, P: Personal social services, ED: Education sector, O: Other, V: Voluntary costs, OoP: Out of pocket, EM: Employers, SSC: Social security benefits/contributions)

For an overview see table 2 summary and scoring costing instruments.

Figure 4 makes visible that the cost diary developed by Bodden [86] and the SHIFT instrument include most perspectives. Also it shows, that out-of-pocket costs, voluntary costs and social security benefits/contributions are not included in most instruments.

The National Healthcare Institute prescribes three categories of costing perspectives to include in economic evaluations. A specification of the cost categories is described in table 3. The third column explicates the clustering of each costing perspective by the author (DKW). An overview of all the requested cost items can be found in Appendix 9

Category	Specification of the type of costs within the category	Costing perspective
Healthcare costs	The costs within the healthcare system are all costs that are directly related to the prevention, diagnosis, treatment, rehabilitation and care. In the case of psychosocial treatment for youth and their parents, this includes youth care, treatments on alcohol and drug abuse and so on.	health service (H), personal social services (P).
Patient & family costs	The costs for patient and family include travel expenses (both time and travel costs), personal payments (out-of-pockets costs) such as travel costs and diet costs.	patient [and carer] out-of-pocket costs (OoP).
Other sector costs	Costs incurred in other sectors depend on the intervention to be evaluated. This could for example concern productivity costs (not being able to go to work because of the child's problem) or the costs of school days lost, special education or criminal justice costs.	education sector (ED), employers (EM), voluntary (V), social security benefits/ contributions (SSC), other (O).

Table 3: Specification of the costing categories prescribed by the National Healthcare Institute ('Zorginstituut Nederland').

Although several instruments (cost diary Bodden TiC-P Children and the VHO) touch upon all categories of costs, i.e. health care sector, patient and family and costs in other sector, these instruments are overall not complete in that they incorporate each relevant item of that category. In Appendix 8 the classification scheme of Drost [118] is presented which reflects all relevant items in mental health care. None of the instruments touch upon all items, making it unlikely that there is one generic instrument for the psychosocial care in youth which we can recommend.

3.3 Online consultation

An online consultation survey was developed and sent by email to 51 experts and stakeholders in January of 2018. This served as a low-threshold assessment of usability and employability for economic evaluations of psychosocial care for young people. In total 21 stakeholders completed the questionnaire.

3.3.1 Quality of life

Regarding QoL, Figure 5 shows the percentage of respondents familiar with each questionnaire. The EQ-5D-Y was the most well-known (n = 17), followed by the HUI (n = 14) and the PedsQL (n = 13). None of the participants were familiar with the MSLSS, QOLPAV, CQOL, AHUM and GCQ. Figure 6 shows the percentage of respondents that had worked with the questionnaire, as a percentage of respondents familiar with the questionnaire. The EQ-5D-Y had been used most (n = 9), followed by the HUI (n = 6) and the PedsQL and TACQOL (n = 5). Although the questionnaires were known by the respondents, no one had used the CHIP, DUX-25, AQOL, MSLSS, 16D, 17D, or CHSCS. Figure 7 shows the percentage of respondents familiar with the questionnaire who deemed it suitable for the age group 0 – 8. The PedsQL was deemed most suitable (61.5%), followed by the KINDL-R (50%) and the TAPQOL and ITQOL (33.3%). Overall, suitability of QoL questionnaires for this age group compared to other age groups received low scores for most questionnaires. Reasons that were given were that the respective questionnaire and its domains were not considered suitable for use in young aged children, or that a proxy would not be able to make a correct assessment for the child in question. Suitability of the questionnaires for the age group 9 – 12 received higher scores, as can be seen in Figure 8. It seems that the YQOL was found most suitable for this age group, but only 1 person knew this instrument. Suitable questionnaires are the KIDSCREEN (77.8%) and the KINDL-R (75%). Reasons for questionnaires being unsuitable according to the participants were that the respective questionnaire and its domains were not considered suitable for the age group, or that a proxy

would not be able to make a correct assessment for the child in question. Additionally, some questionnaires focused too much on somatic or physical items instead of on psychosocial items. Suitability for the age group 13 – 18 can be seen in Figure 9. Suitable questionnaires are the KINDL-R and CHIP (75%). Reasons for questionnaires being unsuitable according to the participants were that the respective questionnaire focused too much on somatic or physical items instead of on psychosocial items. Lastly, the participants were asked to rank the questionnaires they were familiar with (Figure 10) based on their preference for the instrument. The questionnaire that was ranked first place most often was the KIDSCREEN; every participant who was familiar with the KIDSCREEN ranked it on the first position (n=9). Other questionnaires which were ranked on first position often were the DUX-25 (50%) and the HUI (37.5%). Questionnaires that appeared in the top 3 most often were the YQOL, the KIDSCREEN and the 17D, although the YQOL and the 17D appeared in just 1 ranking each. The questionnaires that appeared in most rankings, the EQ-5D-Y (n = 14) and the PedsQL (n = 10), were ranked first 21.4 and 20 percent of the times respectively, and appeared in the top 3, 64.3 and 70 percent of the times, respectively.

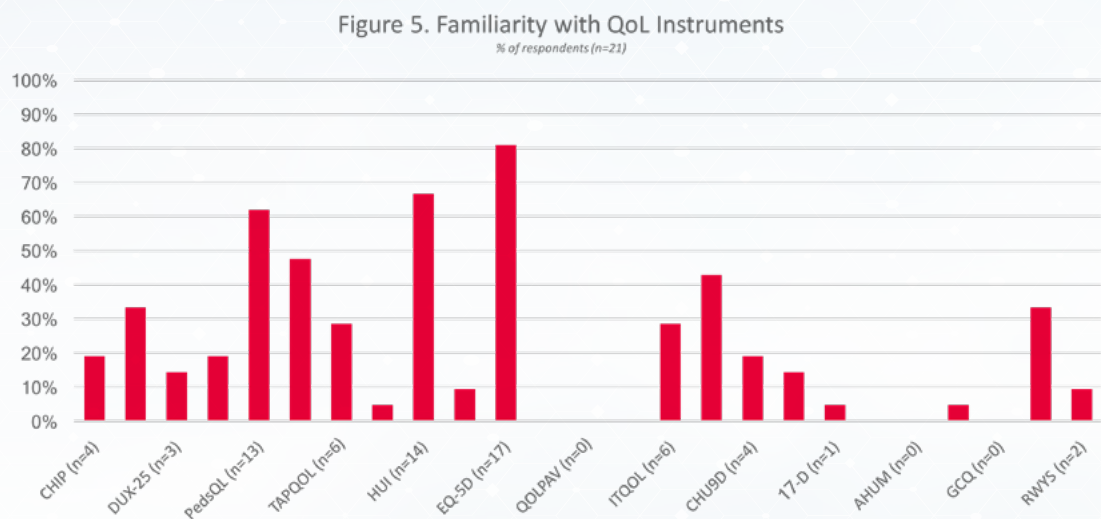


Figure 5. Familiarity with QoL instruments

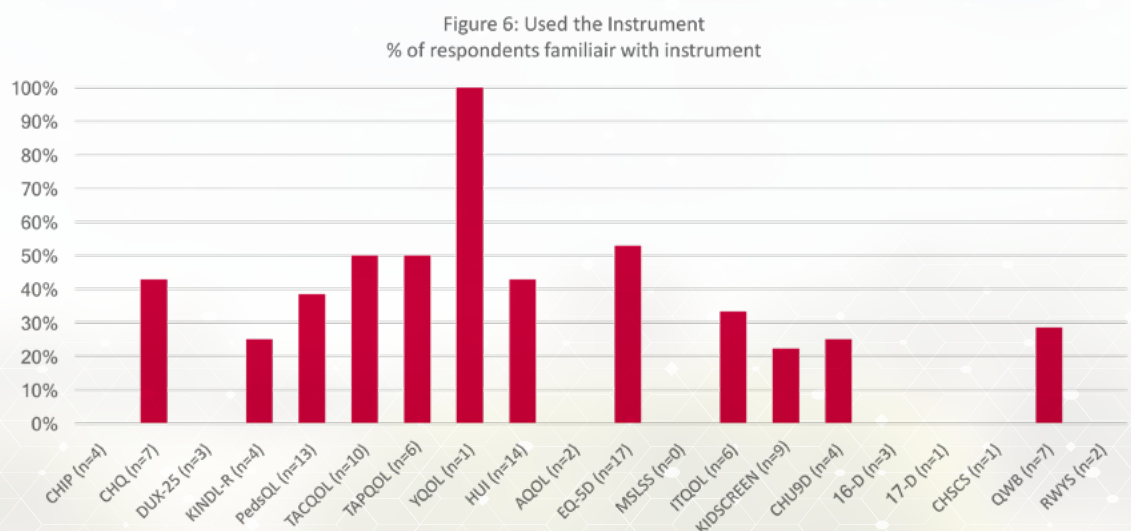


Figure 6. Used the questionnaire

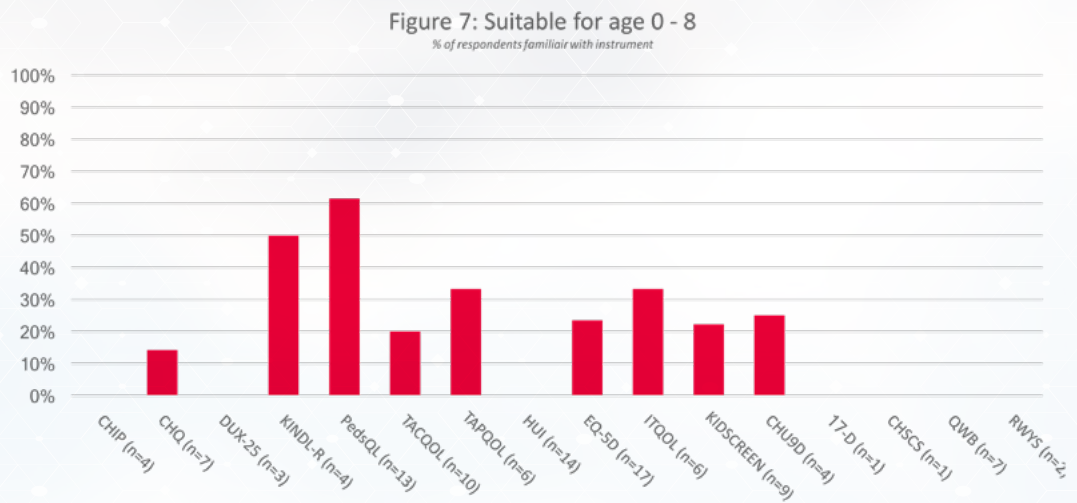


Figure 7. Quality of life instruments suitable for age 0-8

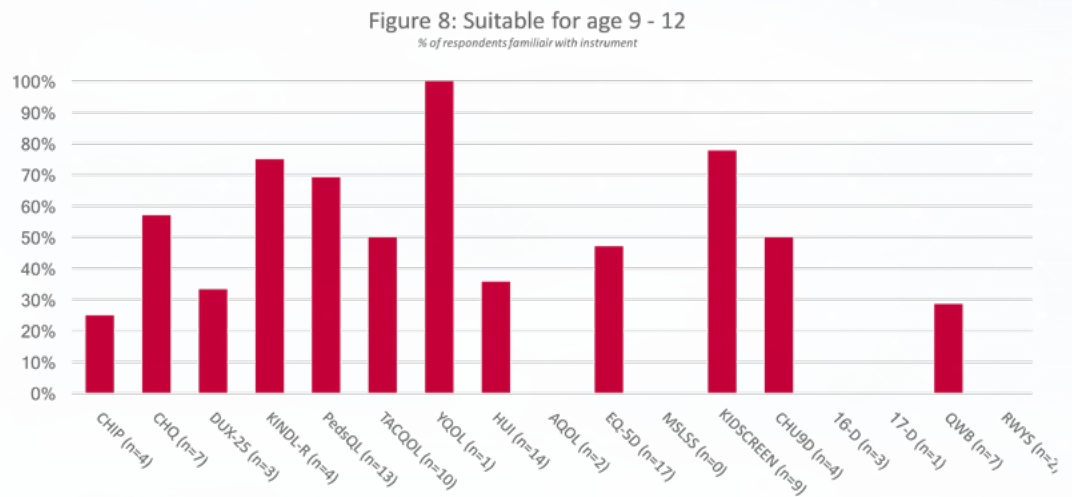


Figure 8. Quality of life instruments suitable for age 9-12

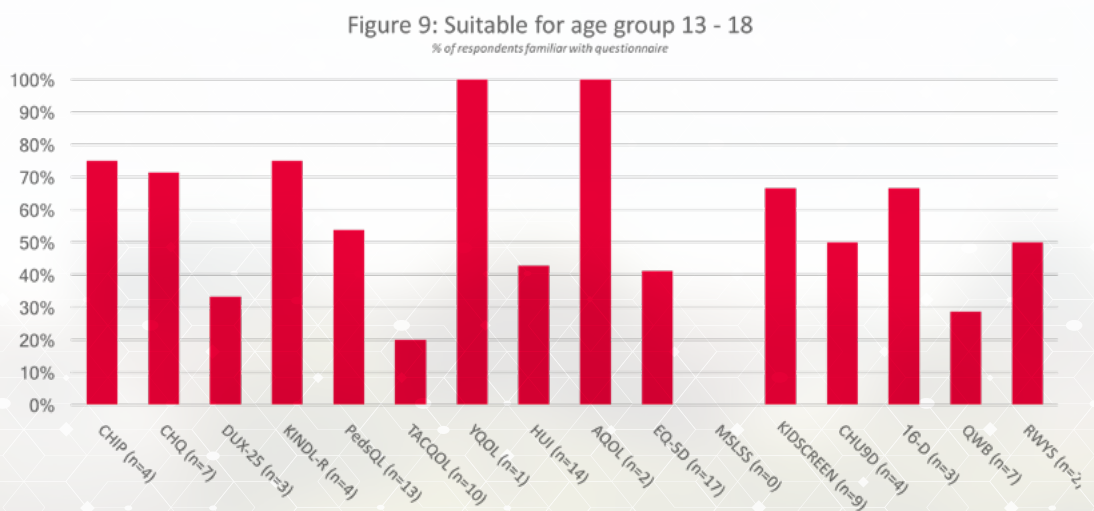
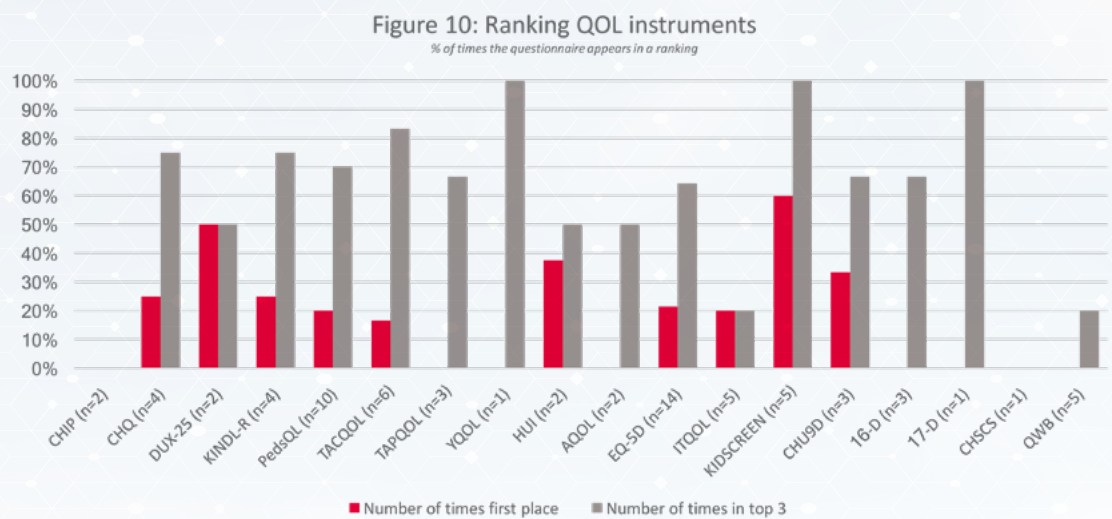


Figure 9. Quality of life instruments suitable for age 13-18



3.3.2 Costing instruments

Almost two third (n=13; 62%) of the responders to the survey were familiar with costing instruments and had ever used one or more instruments.

Figure 11 the figure shows per instrument the percentage of respondents who indicated that they were familiar with it.

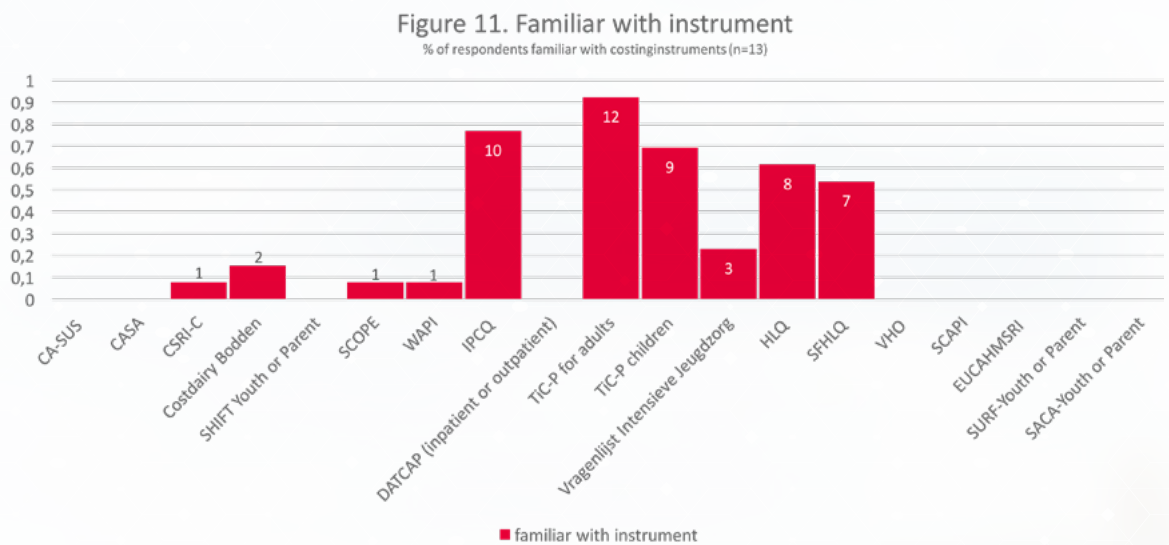


Figure 11. Familiarity with Costing instruments.

The TiC-P for adults was the most well-known ($n = 12$), followed by the IPCQ ($n = 10$) and the TiC-P Children ($n = 9$). None of the participants were familiar with the CASUS, CASA, SHIFT, DATCAP, VHO, SCAP, EU-CAHMSRI, SURF and SACA.

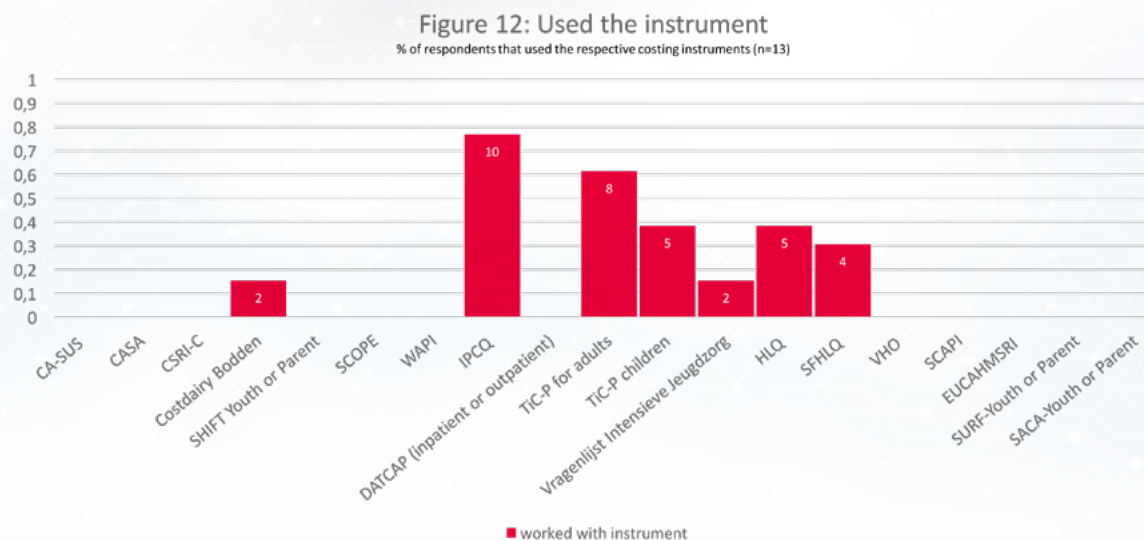


Figure 12. Used the instrument

The IPCQ had been used the most ($n = 10$) indicating that persons that were familiar with it, have also worked with the IPCQ. Two thirds of the respondents that were familiar with the TiC-P Adults, also worked with it. Almost all experts that know the TiC-P Children also have worked with this instrument. Although the questionnaires were known, no one had used the CSRI-C, SCOPE, or WAPI (also see Figure 12).

Participants were asked whether cost categories were missed in the instruments they worked with. In general, respondents adjust the instrument themselves depending on the relevant research question, intervention or study population. As for specific instruments, for the HLQ and the cost diary of Bodden, no cost categories were missed. Considering the TiC-P Adults respondents noticed that sometimes this instrument contains too many questions on therapies like speech therapy. On the other hand, items like patient and family costs, and absence from school or work were missed within the TiC-P Adults.

Lastly, the participants were asked to rank the instruments they were familiar with on preferability (Figure 13).

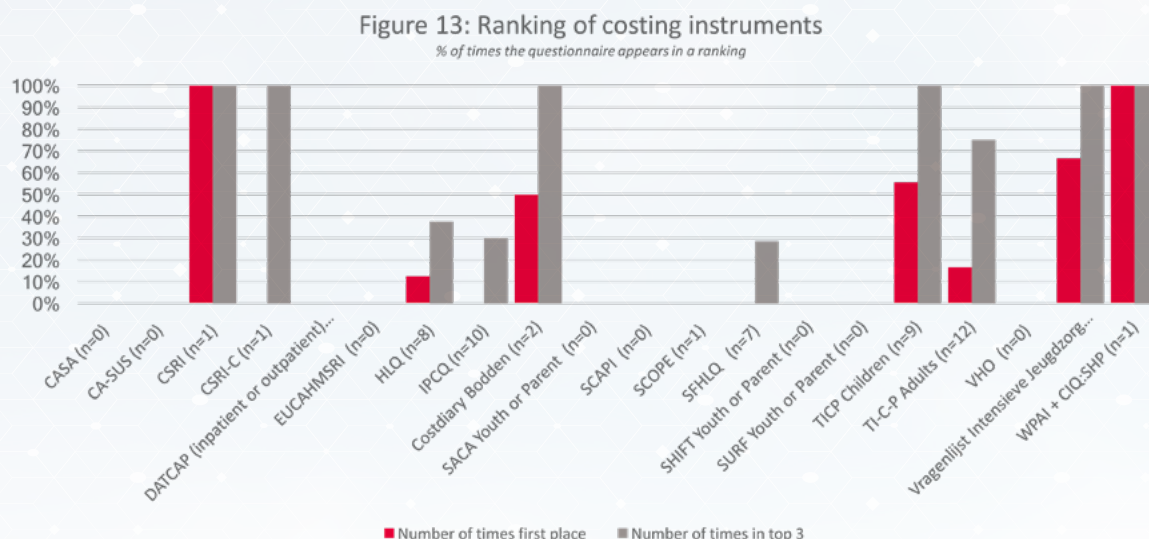


Figure 13. Ranking of costing instruments based on preference of the experts

The questionnaire that was ranked on the first position most often were the CSRI and the WPAI, but only one person used these instruments.

When taking this into account the TiC-P Children was ranked most often on the first position. Instruments which were ranked on the first position most often after the TiC-P Children were the TiC-P Adults (15,4%) and the “Vragenlijst Intensieve jeugdzorg” (15,4%). Questionnaires that appeared in the top 3 most often were also these three instruments, as well as the IPCQ and the HLQ (both with 23,1%). Interestingly, in case of the TiC-P Adults, of the six respondents who worked with it, only one respondent put this questionnaire on number 1. Four of them put it on the third place. Furthermore, except for the CSRI (or CSRI-C) no international instruments were used or preferred.

3.4 Systematic review psychometric quality instruments

195 studies into the psychometric properties of QoL instruments for youth were identified through systematic searching. Research into the psychometric properties of QoL instruments for youth mostly looked at internal consistency, reliability, structural validity, and hypothesis testing. A high number of studies investigated the feasibility and content validity, of the instruments. Much less attention was given to measurement error, cross cultural validity, responsiveness, and criterion validity, also see Figure 16.

The instrument with most studies into its psychometric properties was the PedsQL with 50 studies. PRISMA flow charts for all searches are available in Appendix 6. A summary of psychometric qualities in youth with psychosocial problems is available in Appendix 7. Although a full evaluation of the psychometric quality of all identified questionnaires is beyond the scope of the current project, we can overall state that the quality was highly variable.

Figure 14: Psychometric properties

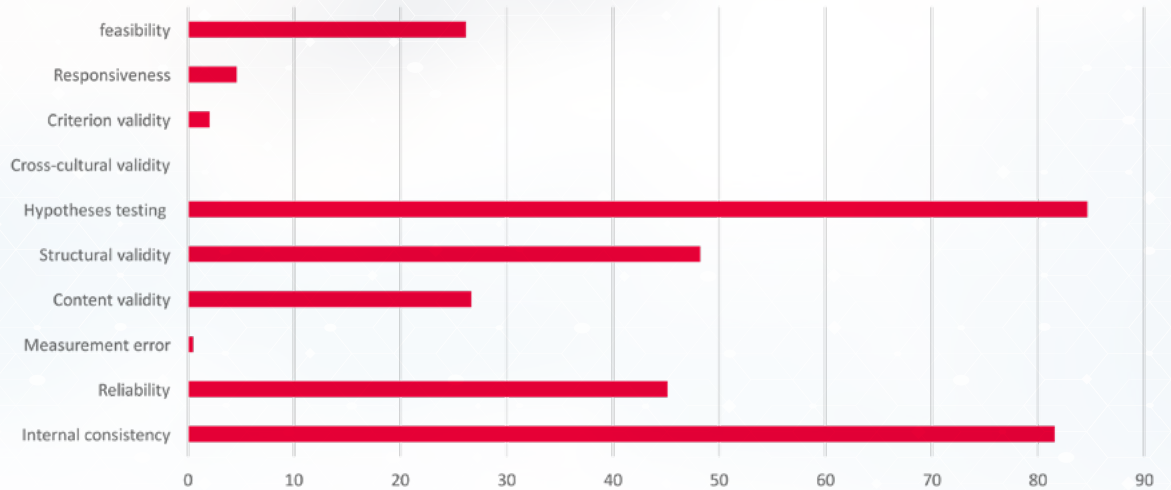


Figure 14. Psychometric characteristic measured in quality of life instruments. Percentages reflect percentage of 195 identified studies.

As for costing instruments, in general, research into the psychometric properties of costing instruments for youth looked at feasibility and hypothesis testing. About one-in-four instruments (25%) were investigated for the reliability. No attention was given to measurement error, cross cultural validity, responsiveness, and structural validity, also see Figure 14. The instrument with most studies into its psychometric properties was the SACA (Services Assessment for Children and Adolescents), with 4 studies. PRISMA flow charts for all searches are available in Appendix 5b. A full paper by paper summary is presented in Appendix 7.

Figure 15: Psychometric properties costing instruments

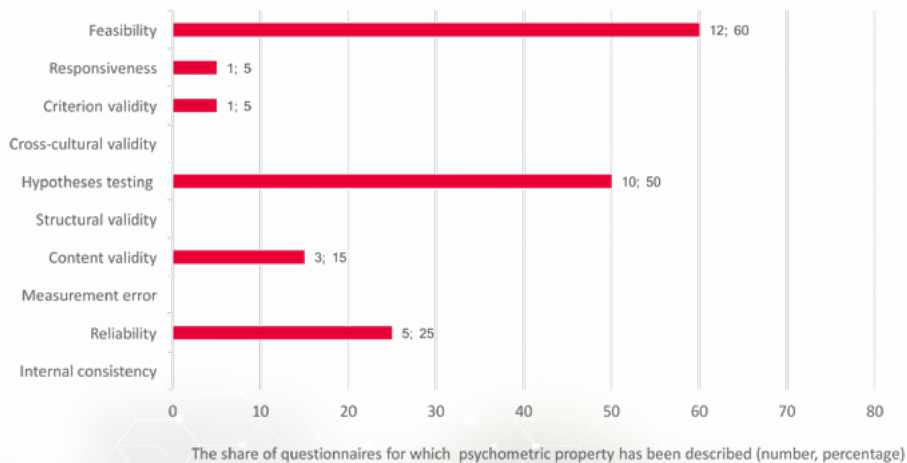


Figure 15. Psychometric properties of the costing instruments

3.5 Expert panel results

An expert panel meeting was organized on February 22th, 2018. A subgroup of the experts that participated in the online consultation (n=7) also participated in this expert panel. Experts worked for university (n=6), knowledge institutes (n=1), and the municipality of Rotterdam (n=1).

The aim of this meeting was to come to a selection of instruments and to set a (research) agenda for the standardization of economic evaluations in youth. However, this aim proved difficult to accomplish, and no consensus was reached during this meeting.

Regarding QoL instruments the experts voiced that in the current instruments to measure quality of life, not enough items address factors that are influenced by psychosocial problems, such as social factors and emotional factors. At this moment many of the instruments mainly focus on physical domains.

Furthermore, experts highlighted that there is a need for age specific Dutch value sets. It is important that value sets are age specific since valuations change over time, especially in childhood and young adolescence.

What is important in choosing a suitable instrument?

First of all, experts from a research background stressed that when performing an economic evaluation, it was important to choose a preference based instrument. However, the expert from the municipality stressed that in her line of work, she was far more interested in predictors of long term outcome. Furthermore, it was important that the items in the questionnaire should be easy to understand for the age category of interest. Also, it was deemed important that both a proxy version and a self-version of the questionnaire is available, and that the instrument is was short. In choosing an instrument the experts also took the price of the instrument into account, and suggested that an instrument should be available that had good quality for a reasonable price or free of charge.

When currently missing information psychometric research, content or other topics was discussed, it was voiced that an instrument should be available that is reasonably priced or free of charge, that does not have too many items, has a parent and a proxy version available, is easy to understand for all age categories, and has a Dutch value set available with takes different valuations over age categories into account. It is important that an instrument is electronically available.

Lastly, experts stressed that particularly in this group of children with psychosocial problems, taking cognitive age, and not calendar age into account when developing or choosing an instrument is of great importance.

In the case of costing instruments, first of all no known costing instruments were missed in the presented instruments. As for missed cost items, in the existing questionnaires a number of cost items are missing, e.g. the new subdivision in youth care since the decentralization. However, no reference prices are available either for these 'new' forms of help.

One of the experts raised the question how we could secure the psychometric quality of each costing instruments that is used in a study, as each study needs an adapted version of the original instrument, making research in the reliability and validity less feasible.

The experts denoted that the most important aspect in the use of costing instruments is that the cost items must be relevant for the intended study population and intervention. Thus including the right concepts, addressing these with the right and relevant questions, in such a way that it is understandable for the respondents. In other words, costing instruments should at the least be tested on content validity, face validity and feasibility. Furthermore, the experts considered international comparison desirable, mainly to avoid duplication of work. Besides that, also cross-cultural validation of the items of cost questionnaires was also deemed important. COSMIN describes cross-cultural validity as: The degree to which the performance of the items on a translated or culturally adapted HR-PRO instrument are an adequate reflection of the performance of the items of the original version of the HR-PRO instrument. Since we performed this research for the Dutch situation, we checked whether existing instruments were translated into Turkish or Moroccan. Because these are the largest language groups besides Dutch in the Netherlands, and therefore relevant for economic evaluations. Finally, it would be useful if the instrument and its outcome could be placed next to administrative data.

In sum, the experts denoted that a sound costing instrument should be researched on content validity, face validity, feasibility, construct validity, convergent validity and cross-cultural validity as important (psychometric) aspects of costing instruments.

There was no instrument that was mentioned as the most favored instrument. However, most experts had worked before with the TiC-P Children or the cost diary of Bodden [86], adjusting it to their own research. This own modification of existing instruments is common practice in economic evaluation research, but the experts stated it would be expedient both for the amount of work as well as the comparability and standardization of economic evaluations in youth domain, if there would be some kind of standardized repository.

Ideally:

- 1.) In this database are questions formulated in a standardized manner,
- 2.) In this database questions can be selected on the basis of the target group and / or the relationship between factors is indicated
- 3.) This database is accessible (no copyright versions) and understandable (language level B1).

3.6 Dissemination

For the purpose of dissemination, the overview or decision aid of instruments will be included in the instruments database of the Netherlands Youth Institute. The costing instruments will be submitted for the DIRUM database.

The NJi database contains descriptions of instruments to support professionals and researchers in the youth sector in their judgment and decision-making. Therefore, the database is currently adapted to be able to include all relevant information retrieved by this project. This report and the reference and linking to the database will also be recorded in the online file 'Cost-effectiveness' on the website of the NJi. Besides this, one or more factsheets will be written and will be distributed via the website of the NJi, social media and relevant conferences.

For the inclusion of the costing instruments in the DIRUM database all cost categories have to be classified according to the DIRUM costing categories. For this purpose, contact has been made with the developers of the database. We have been in contact with Dr. Joanna Thorn and Professor William Hollingworth of University of Bristol who are heading DIRUM and in July a face to face meeting to make further steps on this.

This report will be sent to all stakeholders who were approach for the expert meeting. Furthermore, two review articles will be written about this project.

A symposium is organized at the EuHEA conference in Maastricht in July 2018. This conferences is aimed at national and international economic associations as well as those who foster health economics at European universities. The focus of this conference is on new perspectives in health economics methods and in the role of health economics in policy making. Considering the target audience and the focus of EuHEA, this conference is a perfect fit for the dissimination of the results of the current project, ensuring that all relevant stakeholders are reached. Possibilities for organizing a symposium afternoon at the NJi will be explored.

4. Summary and main findings

The aim of the current study was to provide an overview of available instruments to measure cost and quality of life in the youth sector as described in the ZonMw approved project (729300201).

From the meta-reviews a total of 23 QoL instruments and 20 costing instruments were identified. In a next step the psychometric properties of these questionnaires were mapped. Concerning QoL instruments, a reasonable amount of studies investigated psychometric properties (195 studies), but much less research was available into the psychometric properties of costing instruments (32 studies). The types of psychometric properties that were assessed were also different; for both types of instruments research on psychometric properties mainly concerned feasibility, hypothesis testing and reliability. Instruments measuring QoL were more often judged on internal consistency, structural validity and content validity, compared to costing instruments. For both types of instruments, very little or no research was performed into measurement error, criterion validity, cross-cultural validity or responsiveness. Cross-cultural validity and measurement error were even completely absent in the psychometric research of costing instruments.

Next to the psychometric properties the completeness of the instruments turned out to be an issue, there is for instance no single QoL or costing instrument that includes all domains/ (cost) items which are relevant of psychosocial care in youth. Furthermore, not one instrument is applicable for children/adolescents of all ages. Together, this leads to the conclusion that it is difficult to recommend one single QoL or costing instrument. Awaiting further instrument development, in order to support the choice of a QoL or a costing instrument, a decision aid has been developed in this study.

5. Discussion and recommendations

Concerning QoL, we found that none of the identified instruments was perfect for broad use in economic evaluation of youth care. The meta-reviews combined with the results from the expert panel show that all instruments have disadvantages ranging from lack of psychometric research, no proxy version available, not suitable for young children (under the age of 8), no Dutch value set for youth under 18, not enough focus on relevant domains / items (e.g. social and emotional domains) for use in youth with psychosocial problems. We therefore recommend the development of an instrument that fulfills all these demands, either by adjusting an existing instrument or by development of a new instrument. When one intends to perform a cost-utility analysis currently the best available instrument is the EQ-5D-Y. The advantage of this instrument is that the questionnaire is available in Dutch, with a proxy and a self-report version available. An additional advantage is that a youth-specific value set for the Dutch population is currently being developed by the EuroQol group. However, a disadvantage to using the EQ-5D-Y for cost-utility analysis of youth care is the lack of questions that portrait psychosocial problems, and the instrument seems to be very similar to the adult version making it questionable whether the items are understandable and important for QoL in (very young) children and adolescents. Although it is recommended by the Dutch guidelines for health economic evaluations, it needs to be mentioned that stakeholders from the municipalities currently may prefer other type of economic evaluations (e.g. cost-effectiveness) over cost-utility analysis. Doing so broadens the range of potentially useful QoL questionnaires. However, other experts in

the panel, stressed that when performing economic evaluations, it is of great importance to perform cost-utility analysis, for the sake of comparability between studies and allocation decisions at the macro level. We recommend, when choosing a questionnaire for use in cost-utility or cost effectiveness analysis, to use our decision aid for QoL questionnaires. Experts also stressed that in choosing a QoL instrument it was important that the instrument is freely available, or inexpensive to use, short, has understandable items, and includes all relevant domains. Another issue is that children of e.g. 4 years old differ from adolescents of e.g. 16 years old. It is likely that one single QoL instrument for use in cost-utility analysis may therefore not suffice. To this can be added, that in youth with psychosocial problems, biological age may not reflect cognitive age. In conclusion, we recommend the development of a linked set of age-specific preference-based instruments for QoL in youth that fulfills all demands, along with a conceptual analysis of what constitutes QoL/wellbeing in youth (of different ages).

Concerning cost instruments, none of the identified instruments include all relevant items in psychosocial care for youth, making it unlikely that there is one generic instrument for the psychosocial care in youth which we can recommend. The review combined with the results from the expert panel show that all instruments have some disadvantages, ranging from lack of psychometric research, no proxy version available, to missing costing categories, such as out of pocket costs or costing categories that have arisen since the decentralization of the youth help since 2015. We recommend the development of a broad instrument or repository that overcomes these limitations. For example, a master costing instrument containing several modules, or alternatively, a (web-based) 'cost item bank' can be developed, from which researchers can select the relevant items for use in their economic evaluation. For the time being, we recommend to use (or adapt) an existing instrument such as the TiC-P Children [80] or the cost diary developed by Bodden et al. [92]. Both instruments were ranked in the top 3 of preferred instruments by the experts. Both instruments differ in that the TiC-P relies on recall, whereas the cost diary of Bodden et al. is prospective. The choice to use either one method should be standardized, again for the sake of comparability. Further methodological research and consensus among experts should guide important choices such as 'what', 'who', 'how' and 'when' to ask.

With the current study, we have followed up on some of the recommendations as stated in the report 'Broad Consultation as Part of the Standardization of Economic Evaluation Research in the Youth Sector' [1]. The results of this project may serve as a start towards the actual development of preference-based QoL- and costing instruments for broad use in economic evaluations of psychosocial care in youth in The Netherlands.

6. References

1. Evers, S.M.A.A., Dirksen, C.D., Broad consultation as part of the standardization of economic evaluation research in the field of youth. 2016, Maastricht University Medical Center; Department of Clinical Epidemiology and Medical Maastricht University; Department of Health Services Research Trimbos Institute, Netherlands Institute of Mental Health and Addiction.
2. COSMIN database. Available from: <http://database.cosmin.nl/>.
3. DIRUM database. Available from: <http://www.dirum.org/instruments/search>
4. Kremer, I.E.H., et al., Kosteneffectiviteit van jeugdinterventies in Nederland: een systematische literatuurreview. Kind en adolescent, 2017. 38(1): p. 1-30.
5. Vinken, T., Economic Evaluations of Interventions addressing Behavioural Problems in Youth . A Systematic Review., in Faculty of Health, Medicine, and Life Sciences 2017, Maastricht University: Maastricht.
6. Weill, L., The Cost-effectiveness of Psychosocial Interventions Addressing Overweight and Obesity among Youngsters. A systematic literature review, in Faculty of Health, Medicine, and Life Sciences. 2017, Maastricht University: Maastricht.
7. Dirksen, C. and S. Evers, Broad Consultation as Part of the Standardization of Economic Evaluation Research in the Youth Sector. 2016.
8. Richtlijn voor het uitvoeren van economische evaluaties in de gezondheidszorg. 2016, Zorginstituut Nederland Diemen. p. 38.
9. Mokkink, L.B., et al., COSMIN checklist manual. Amsterdam: COSMIN, 2012.
10. Terwee, C.B., et al., Rating the methodological quality in systematic reviews of studies on measurement properties: a scoring system for the COSMIN checklist. Quality of Life Research, 2012. 21(4): p. 651-657.
11. Garnock-Jones, K.P. and G.M. Keating, Atomoxetine: a review of its use in attention-deficit hyperactivity disorder in children and adolescents. Paediatr Drugs, 2009. 11(3): p. 203-26.
12. Coghill, D., The impact of medications on quality of life in attention-deficit hyperactivity disorder: CNS drugs, 2010. 24(10): p. 843-866.
13. Danckaerts, M., et al., The quality of life of children with attention deficit/hyperactivity disorder: a systematic review. European child & adolescent psychiatry, 2010. 19(2): p. 83-105.
14. Payakachat, N., et al., Autism spectrum disorders: a review of measures for clinical, health services and cost-effectiveness applications. Expert review of pharmacoeconomics & outcomes research, 2012. 12(4): p. 485-503.
15. Epstein, J.N. and M.D. Weiss, Assessing treatment outcomes in attention-deficit/hyperactivity disorder: a narrative review. The primary care companion for CNS disorders, 2012. 14(6).
16. Dey, M., M.A. Landolt, and M. Mohler-Kuo, Health-related quality of life among children with mental disorders: a systematic review. Qual Life Res, 2012. 21(10): p. 1797-1814.
17. Ikeda, E., E. Hinckson, and C. Krägeloh, Assessment of quality of life in children and youth with autism spectrum disorder: A critical review. Quality of Life Research, 2014. 23(4): p. 1069-1085.
18. Janssens, A., et al., Measurement properties of multidimensional patient-reported outcome measures in neurodisability: a systematic review of evaluation studies. Developmental Medicine & Child Neurology, 2016. 58(5): p. 437-451.
19. Coghill, D.R., et al., Systematic review of quality of life and functional outcomes in randomized placebo-controlled studies of medications for attention-deficit/hyperactivity disorder. European child & adolescent psychiatry, 2017. 26(11): p. 1283-1307.
20. Rajmil, L., et al., Generic health-related quality of life instruments in children and adolescents: a qualitative analysis of content. Journal of adolescent Health, 2004. 34(1): p. 37-45.
21. Solans, M., et al., Health-Related Quality of Life Measurement in Children and Adolescents: A Systematic Review of Generic and Disease-Specific Instruments. Value in health, 2008. 11(4): p. 742-764.

22. Starfield, B., et al., Adolescent health status measurement: development of the Child Health and Illness Profile. Vol. 91. 1993. 430-5.
23. De Kroon, M. and P. Hodiament, Kwaliteit van leven, gemeten in de kinderspsychiatrie. 2008.
24. Paltzer, J., E. Barker, and W.P. Witt, Measuring the health-related quality of life (HRQoL) of young children in resource-limited settings: a review of existing measures. *Quality of Life Research*, 2013. 22(6): p. 1177-1187.
25. Cremeens, J., C. Eiser, and M. Blades, Characteristics of health-related self-report measures for children aged three to eight years: a review of the literature. *Quality of Life Research*, 2006. 15(4): p. 739-754.
26. Schmidt, L., A. Garratt, and R. Fitzpatrick, Child/parent-assessed population health outcome measures: a structured review. *Child: Care, Health and Development*, 2002. 28(3): p. 227-237.
27. Ravens-Sieberer, U., et al., Generic health-related quality-of-life assessment in children and adolescents. *Pharmacoeconomics*, 2006. 24(12): p. 1199-1220.
28. Coghill, D., et al., Practitioner review: quality of life in child mental health—conceptual challenges and practical choices. *Journal of Child Psychology and Psychiatry*, 2009. 50(5): p. 544-561.
29. Harding, L., Children's quality of life assessments: a review of generic and health related quality of life measures completed by children and adolescents. *Clinical Psychology & Psychotherapy*, 2001. 8(2): p. 79-96.
30. Spieth, L.E. and C.V. Harris, Assessment of health-related quality of life in children and adolescents: an integrative review. *Journal of pediatric psychology*, 1996. 21(2): p. 175-193.
31. Klassen, A.F., Quality of life of children with attention deficit hyperactivity disorder. Expert review of pharmacoeconomics & outcomes research, 2005. 5(1): p. 95-103.
32. DeCivita, M., et al., Evaluating health-related quality-of-life studies in paediatric populations. *Pharmacoeconomics*, 2005. 23(7): p. 659-685.
33. Msall, M.E., Measuring functional skills in preschool children at risk for neurodevelopmental disabilities. *Developmental Disabilities Research Reviews*, 2005. 11(3): p. 263-273.
34. Matza, L.S., et al., Impact of atomoxetine on health-related quality of life and functional status in patients with ADHD. Expert review of pharmacoeconomics & outcomes research, 2006. 6(4): p. 379-390.
35. Upton, P., J. Lawford, and C. Eiser, Parent-child agreement across child health-related quality of life instruments: a review of the literature. *Quality of life research*, 2008. 17(6): p. 895.
36. Evans, J., S. Seri, and A.E. Cavanna, The effects of Gilles de la Tourette syndrome and other chronic tic disorders on quality of life across the lifespan: a systematic review. *European child & adolescent psychiatry*, 2016. 25(9): p. 939-948.
37. Galloway, H. and E. Newman, Is there a difference between child self-ratings and parent proxy-ratings of the quality of life of children with a diagnosis of attention-deficit hyperactivity disorder (ADHD)? A systematic review of the literature. *ADHD Attention Deficit and Hyperactivity Disorders*, 2017. 9(1): p. 11-29.
38. groSse Schlarmann, J., S. Metzger-Blau, and W. Schnepf, The use of health-related quality of life (HRQOL) in children and adolescents as an outcome criterion to evaluate family oriented support for young carers in Germany: an integrative review of the literature. *BMC Public Health*, 2008. 8(1): p. 414.
39. Landgraf, J.M., et al., Canadian-French, German and UK versions of the Child Health Questionnaire: methodology and preliminary item scaling results. Vol. 7. 1998. 433-45.
40. Cavanna, A.E., et al., Health-related quality of life in Gilles de la Tourette syndrome: a decade of research. *Behavioural neurology*, 2013. 27(1): p. 83-93.
41. Lee, Y.-c., et al., Meta-analysis of quality of life in children and adolescents with ADHD: By both parent proxy-report and child self-report using PedsQL™. *Research in developmental disabilities*, 2016. 51: p. 160-172.
42. Feeney, R., et al., Health-related quality-of-life of children with speech and language difficulties: a review of the literature. *Int J Speech Lang Pathol*, 2012. 14(1): p. 59-72.

43. Gomersall, T., et al., Measuring quality of life in children with speech and language difficulties: a systematic review of existing approaches. *International journal of language & communication disorders*, 2015. 50(4): p. 416-435.
44. Jonsson, U., et al., Annual Research Review: Quality of life and childhood mental and behavioural disorders—a critical review of the research. *Journal of child psychology and psychiatry*, 2017. 58(4): p. 439-469.
45. Vieira, J. and F.R. e Silva, Quality of life in children with obsessive-compulsive disorder. *Acta medica portuguesa*, 2016. 29(9): p. 549-555.
46. Ravens-Sieberer, U. and M. Bullinger, Assessing health-related quality of life in chronically ill children with the German KINDL: first psychometric and content analytical results. *Quality of life research*, 1998. 7(5): p. 399-407.
47. Zekovic, B. and R. Renwick, Quality of life for children and adolescents with developmental disabilities: Review of conceptual and methodological issues relevant to public policy. *Disability & Society*, 2003. 18(1): p. 19-34.
48. Tavernor, L., et al., Finding out what matters: validity of quality of life measurement in young people with ASD. *Child: care, health and development*, 2013. 39(4): p. 592-601.
49. Chiang, H.-M. and I. Wineman, Factors associated with quality of life in individuals with autism spectrum disorders: A review of literature. *Research in Autism Spectrum Disorders*, 2014. 8(8): p. 974-986.
50. Coluccia, A., et al., Quality of life in children and adolescents with obsessive-compulsive disorder: a systematic review and meta-analysis. *Neuropsychiatric disease and treatment*, 2017. 13: p. 597.
51. Eiser, C. and R. Morse, Can parents rate their child's health-related quality of life? Results of a systematic review. *Quality of life research*, 2001. 10(4): p. 347-357.
52. Varni, J.W., M. Seid, and C.A. Rode, The PedsQL: measurement model for the pediatric quality of life inventory. Vol. 37. 1999. 126-39.
53. Vogels, T., et al., Measuring health-related quality of life in children: The development of the TACQOL parent form. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 1998. 7(5): p. 457-465.
54. Weber, S., A. Jud, and M. Landolt, Quality of life in maltreated children and adult survivors of child maltreatment: a systematic review. *Quality of life research*, 2016. 25(2): p. 237-255.
55. Fekkes, M., et al., Development and psychometric evaluation of the TAPQOL: A health-related quality of life instrument for 1-5-year-old children. *Qual. Life Res.*, 2000. 9(8): p. 961-972.
56. Patrick, D.L., T.C. Edwards, and T.D. Topolski, Adolescent quality of life, part II: initial validation of a new instrument. *Journal of adolescence*, 2002. 25(3): p. 287-300.
57. Adlard, N., P. Kinghorn, and E. Frew, Is the UK NICE "reference case" influencing the practice of pediatric quality-adjusted life-year measurement within economic evaluations? *Value in Health*, 2014. 17(4): p. 454-461.
58. Griebisch, I., J. Coast, and J. Brown, Quality-adjusted life-years lack quality in pediatric care: a critical review of published cost-utility studies in child health. *Pediatrics*, 2005. 115(5): p. e600-e614.
59. Chavez, L., K. Mir, and G. Canino, Starting from scratch: the development of the adolescent quality of life-mental health scale (AQOL-MHS). *Culture, Medicine, and Psychiatry*, 2012. 36(3): p. 465-479.
60. Chen, G. and J. Ratcliffe, A review of the development and application of generic multi-attribute utility instruments for paediatric populations. *Pharmacoeconomics*, 2015. 33(10): p. 1013-1028.
61. Richardson, J.R.J., et al., Construction of the descriptive system for the Assessment of Quality of Life AQoL-6D utility instrument. Vol. 10. 2012. 38.
62. Wu, E.Q., et al., Cost Effectiveness of Pharmacotherapies for Attention-Deficit Hyperactivity Disorder. *CNS drugs*, 2012. 26(7): p. 581-600.
63. Wille, N., et al., Development of the EQ-5D-Y: A child-friendly version of the EQ-5D. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 2010. 19(6): p. 875-886.

64. E.S., H., Preliminary development and validation of a multidimensional life satisfaction scale for children. *PSYCHOL. ASSESS.*, 1994. 6(2): p. 149-158.
65. Raphael, D., et al., The quality of life profile—adolescent version: Background, description, and initial validation. *Journal of Adolescent Health*, 1996. 19(5): p. 366-375.
66. Klassen, A.F., et al., Health related quality of life in 3 and 4 year old children and their parents: preliminary findings about a new questionnaire. *Health and quality of life outcomes*, 2003. 1(1): p. 81.
67. Stevens, K., Developing a descriptive system for a new preference-based measure of health-related quality of life for children. *Quality of Life Research*, 2009. 18(8): p. 1105-1113.
68. Apajasalo, M., et al., Quality of life in early adolescence: A sixteen-dimensional health-related measure (16D). *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, 1996. 5(2): p. 205-211.
69. Apajasalo, M., et al., Quality of life in pre-adolescence: A 17-dimensional health-related measure (17D). *QUAL. LIFE RES.*, 1996. 5(6): p. 532-538.
70. Graham, P., J. Stevenson, and D. Flynn, A new measure of health-related quality of life for children: Preliminary findings. *Psychology & Health*, 1997. 12(5): p. 655-665.
71. Beusterien, K.M., et al., Development of the multi-attribute Adolescent Health Utility Measure (AHUM). *Health Qual. Life Outcomes*, 2012. 10.
72. Saigal, S., et al., Development, reliability and validity of a new measure of overall health for pre-school children. *Vol. 14*. 2005. 243-57.
73. Collier, J., D. MacKinlay, and D. Phillips, Norm values for the Generic Children's Quality of Life Measure (GCQ) from a large school-based sample. *Qual. Life Res.*, 2000. 9(6): p. 617-623.
74. Kaplan, R.M., J.W. Bush, and C.C. Berry, Health status: types of validity and the index of well-being. *Health Serv Res*, 1976. 11(4): p. 478-507.
75. Goodyer, I.M., et al., A randomised controlled trial of cognitive behaviour therapy in adolescents with major depression treated by selective serotonin reuptake inhibitors. The ADAPT trial. *Health Technol Assess*, 2008. 12(14): p. 80.
76. Goodyer, I.M., et al., Cognitive behavioural therapy and short-term psychoanalytical psychotherapy versus a brief psychosocial intervention in adolescents with unipolar major depressive disorder (IMPACT): a multicentre, pragmatic, observer-blind, randomised controlled superiority trial. 2017. 4: p. 109-119.
77. Kilian, R., et al., Cost-effectiveness analysis in child and adolescent mental health problems: an updated review of literature. *International Journal of Mental Health Promotion*, 2010. 12(4): p. 45-57.
78. Ridyard, C.H. and D.A. Hughes, Methods for the Collection of Resource Use Data within Clinical Trials: A Systematic Review of Studies Funded by the UK Health Technology Assessment Program. *Value in Health*, 2010. 13(8): p. 867-872.
79. Bouwmans, C.A.M., et al., Handleiding Vragenlijst Intensieve Jeugdzorg. *Zorggebruik en productieverlies*. 2012, IMTA: Rotterdam. p. 45.
80. Bouwmans, C.A.M., Schawo, S.J., Jansen, D.E.M.C., Vermeulen, K.M., Reijneveld, S.A., & Hakkaart- van Roijen. L., Handleiding Vragenlijst Intensieve Jeugdzorg: *Zorggebruik en productieverlies*. 2012, Erasmus Universiteit Rotterdam Instituut Beleid & Management Gezondheidszorg: Rotterdam.
81. Posthumus, J.A., Preventive effects and cost-effectiveness of the Incredible Years program for parents of preschoolers with aggressive behavior, in Department of Child an Adolescent Psychiatry 2009, University Medical Center.
82. Hakkaart-van Roijen, L.E.-B., M.L., Health and Labour Questionnaire (HLQ). 2010, 1) Institute for Medical Technology Assessment, Erasmus University Rotterdam. 2) Department of Public Health and Social Medicine, Erasmus University Rotterdam.: Rotterdam.

83. Snoeren, F., et al., Design of a quasi-experiment on the effectiveness and cost-effectiveness of using the child-interview intervention during the investigation following a report of child abuse and/or neglect. *BMC Public Health*, 2013. 13: p. 1164.
84. Vermeulen, K.M., et al., Cost-effectiveness of multisystemic therapy versus usual treatment for young people with antisocial problems. *Criminal Behaviour and Mental Health*, 2017. 27(1): p. 89-102.
85. Timman, R., et al., Development of the Treatment Inventory of Costs in Psychiatric Patients: TIC-P Mini and Midi. *Value Health*, 2015. 18(8): p. 994-9.
86. Wansink, H.J., et al., Cost-effectiveness of preventive case management for parents with a mental illness: a randomized controlled trial from three economic perspectives. *BMC Health Services Research*, 2016. 16(1): p. 228.
87. Wansink, H.J., Preventive basic care management for families with parental mental illness: Theory, effects, cost-effectiveness and effect moderators. 2016: [Sl: sn].
88. Burns, B.J., A. Angold, and E.J. Costello, Measuring child, adolescent, and family service use. *New Directions for Evaluation*, 1992. 1992(54): p. 17-29.
89. Mayer, S., et al., Health-Related Resource-Use Measurement Instruments for Intersectoral Costs and Benefits in the Education and Criminal Justice Sectors. *Pharmacoeconomics*, 2017. 35(9): p. 895-908.
90. Burns, B.J., *CASA Glossary*. 1996.
91. Beecham, J.H.J., & Chisholm D., *CSRI - Childrens Version*. 2010, Centre for the Economics of Mental Health (CEMH): London.
92. Bodden, D.H., et al., Costs and cost-effectiveness of family CBT versus individual CBT in clinically anxious children. *Clin Child Psychol Psychiatry*, 2008. 13(4): p. 543-64.
93. Simon, E., et al., Cost-effectiveness of child-focused and parent-focused interventions in a child anxiety prevention program. *Journal of Anxiety Disorders*, 2012. 26(2): p. 287-296.
94. Simon, E., C.D. Dirksen, and S.M. Bögels, An explorative cost-effectiveness analysis of school-based screening for child anxiety using a decision analytic model. *European child & adolescent psychiatry*, 2013. 22(10): p. 619-630.
95. Cottrell D., B., P., Eisler I., Fortune S., Green J., House A., Owens, D., Simic M., Collinson M., Farrin A., Graham L., Nixon J., McCabe C., Oluboyede Y., & Tubeuf, S., Self-Harm Intervention, Family Therapy: a randomised controlled trial of family therapy vs. treatment as usual for young people seen after second or subsequent episodes of self-harm, in *SHIFT Protocol V8.0_2012.06.18*. 2012, NHS National Institute for Health Research.
96. Genereaux, D., C.D. van Karnebeek, and P.H. Birch, Costs of caring for children with an intellectual developmental disorder. *Disability and health journal*, 2015. 8(4): p. 646-651.
97. Bouwmans, C., et al., IMTA productivity cost questionnaire (iPCQ). *Value in Health*, 2014. 17(7): p. A550.
98. Bouwmans, C., et al., The iMTA Productivity Cost Questionnaire: A Standardized Instrument for Measuring and Valuing Health-Related Productivity Losses. *Value Health*, 2015. 18(6): p. 753-8.
99. Schawo, S., et al., The search for relevant outcome measures for cost-utility analysis of systemic family interventions in adolescents with substance use disorder and delinquent behavior: a systematic literature review. *Health and quality of life outcomes*, 2017. 15(1): p. 179.
100. French, M.T., *Drug Abuse Treatment Cost Analysis Program (DATCAP) USER'S MANUAL Eighth Edition*. 2003, University of Miami: Florida.
101. French, M.T., *Drug Abuse Treatment Cost Analysis Program (DATCAP): Client (Outpatient) Version. Third Edition*. 2005, University of Miami: Florida.
102. Green, J., et al., Inpatient treatment in child and adolescent psychiatry—a prospective study of health gain and costs. *Journal of Child Psychology and Psychiatry*, 2007. 48(12): p. 1259-1267.

103. Schmidt, U., et al., A randomized controlled trial of family therapy and cognitive behavior therapy guided self-care for adolescents with bulimia nervosa and related disorders. *American Journal of Psychiatry*, 2007. 164(4): p. 591-598.
104. Beecham, J. and M. Knapp, Costing psychiatric interventions. *Measuring mental health needs*, 2001. 2: p. 200-224.
105. Järbrink, K., E. Fombonne, and M. Knapp, Measuring the parental, service and cost impacts of children with autistic spectrum disorder: a pilot study. *Journal of autism and developmental disorders*, 2003. 33(4): p. 395-402.
106. Foster, E.M., et al., Treatment for ADHD: Is More Complex Treatment Cost-Effective for More Complex Cases? *Health services research*, 2007. 42(1p1): p. 165-182.
107. Jensen, P.S., et al., Cost-effectiveness of ADHD treatments: findings from the multimodal treatment study of children with ADHD. *American Journal of Psychiatry*, 2005. 162(9): p. 1628-1636.
108. Roper, M.T., *Services for Children and Adolescents, Parent Interview (SCAPI)*. 2002. p. 1-29.
109. Bouwmans, C., et al., Feasibility, reliability and validity of a questionnaire on healthcare consumption and productivity loss in patients with a psychiatric disorder (TiC-P). *BMC Health Serv Res*, 2013. 13: p. 217.
110. Hakkaart-van Roijen, L. and M.-L. Essink-Bot, *Handleiding Vragenlijst Over Ziekte en Werk: De Integrale Kosten Per Nieuwe Hoofd-halstumorpatient, Van Diagnose Van de Primaire Tumor Tot 10 Jaar Follow-up, Inclusief de Kosten Voor Een Eventuele Recidiefbehandeling*. 1999: Institute for Medical Technology Assessment, Erasmus Universiteit.
111. Van Roijen, L., et al., Labor and health status in economic evaluation of health care: The Health and Labor Questionnaire. *International journal of technology assessment in health care*, 1996. 12(3): p. 405-415.
112. Horwitz, S.M., et al., Reliability of the Services Assessment for Children and Adolescents. *Psychiatric Services*, 2001. 52(8): p. 1088-1094.
113. Jensen, P.S., et al., The services for children and adolescents-parent interview: Development and performance characteristics. *Journal of the American Academy of Child & Adolescent Psychiatry*, 2004. 43(11): p. 1334-1344.
114. Stiffman, A.R., et al., The Service Assessment for Children and Adolescents (SACA): Adult and Child Reports. *Journal of the American Academy of Child & Adolescent Psychiatry*, 2000. 39(8): p. 1032-1039.
115. Zechmeister-Koss, I., et al., Services Use of Children and Adolescents before Admission to Psychiatric Inpatient Care. *J Ment Health Policy Econ*, 2016. 19(2): p. 103-113.
116. Leaf, P.J., et al., Mental Health Service Use in the Community and Schools: Results from the Four-Community MECA Study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 1996. 35(7): p. 889-897.
117. Ridyard, C.H. and D.A. Hughes, Development of a Database of Instruments for Resource-Use Measurement: Purpose, Feasibility, and Design. *Value in Health*, 2012. 15(5): p. 650-655.
118. Drost R.M., P.A.T., Ruwaard D., Evers S.M., Inter-Sectoral Costs and Benefits of Mental Health Prevention: Towards a New Classification Scheme *J Ment Health Policy Econ*, 2013. 16(4): p. 179-86.

