Glossary

Disability	In the context of health experience, the World Health Organization (WHO) defines disability as 'any restriction or lack (resulting from an impairment) of ability to perform an action in the manner or within the range considered normal for a human being'.
Dimension	Areas of perception or experience that comprise an aspect of HRQoL. Usually these are components within the domains of health, though in some models these exist as adjacent concepts that overlap several core domains of health.
Domains of health	The global health domain refers to health as one of the domains of human existence. Within health there are the physical, psychological and social domains (core domains of health) (see also sub-domains).
Functioning	The International Classification of Disability, Functioning and Health (ICF) states that functioning encompasses 'all body functions (physical and psychological), activities and participation'.
Global measure of HRQoL	Appraisal of HRQoL perception in all core domains in a single item
HRQoL elements	Concepts that make up each dimension
HRQoL items	Individual questions or other appraisal tools in a measurement instrument used to measure the elements
HRQoL measurement instrument	A questionnaire comprising items that measure elements to understand an aspect or aspects of HRQoL status
Impairment	The ICF defines impairment as 'problems in body function and structure such as significant deviation or loss'.
Profile measure	Multiple questions to measure one or more dimensions of HRQoL
Recall time	The time period over which respondents are asked to recall events in the measurement instrument
Reliability	The extent to which the instrument is internally consistent and produces similar scores with multiple replications under the same circumstances (test–retest stability)
Respondent burden (RB)	Time effort and other demands placed on those completing the measurement instrument
Responsiveness/ sensitivity	Ability of an instrument to detect changes over time and differences between populations / subgroups / repeated surveys
Setting	The situation in which the study using the measurement instrument was conducted
Standard gamble (SG)	A method of preference elicitation for utility estimation that involves asking respondents to choose between alternative outcomes, one of which involves uncertainty. Respondents are asked how much in terms of risk of death, or some other outcome worse than the one being valued, they are prepared to accept in order to avoid the certainty of the health state being valued.

Sub-domains	Components within the domains of health that can be defined and measured as separate concepts
Time trade-off (TTO)	A method of preference elicitation for utility estimation developed as an alternative to standard gamble (SG), designed to overcome the problems of explaining probabilities to respondents. The choice is between two alternatives, both with certain prospects– (i.e. years in full health (x) and years (t) in the health states being valued). The respondent is asked to consider trading a reduction in their length of life for a health improvement. The health state value is the fraction of healthy years equivalent to a year in a given health state (i.e. x/t).
Validity	The degree to which an instrument measures what it is supposed to measure. Three types of evidence can support this:

Content validity	Extent to which a measure appropriately covers its topic
Criterion validity	How closely the measure correlates to a 'gold standard'
Construct validity	Extent to which a measure behaves consistently with the hypothesis underpinning the measure.

Visual analogue scale (VAS)	A type of response scale in self-complete questionnaires. It is a line, usually with well-defined end-points. When used as a method of preference elicitation for utility estimation, this type of scale commonly looks like a thermometer, and allows respondents to indicate the desirability of a health state. The VAS does not allow individuals to express their preferences explicitly for one health state compared with another, nor their preferences and trade-offs.
Wellbeing	Absence of impairment (physical and psychological)

Appendix A: Evaluation of HRQoL measurement instruments

Table A1: Key to abbreviations and star rating system of usefulness for population monitoring

Attribute	★	☆	No star
Respondent burden (RB)	<3 minutes to complete or 1–5 items	3–9 minutes to complete or 6–20 items	10+ minutes to complete or >20 items
HRQoL domains (D)	Samples from physical, psychological and social domains	Global domain sampled	Samples one or two of physical, psychological and social domains
Construct validity (CV)	Extensive evidence (consistent with several other measures)	Some evidence	No evidence
Test–retest repeatability (T–R)	ICC>0.7	ICC 0.4–0.7 inclusive	ICC<0.4
Internal consistency (IC)	Cronbach's α >0.7	Cronbach's α 0.4–0.7	Cronbach's α <0.4
Sensitivity (S)	Extensive evidence (several studies)	Some evidence	No evidence

Table A2: Generic adult HRQoL measures

Review criteria	EuroQol 5D (EQ-5D)					
Type of instrument	Profile/Utility					
HRQoL domains	Global ☑		Psychological ☑			
	Physical ☑		Social ☑			
Content areas	Mobility, self-care, usual activities, pain/discomfort, anxiety/depression					
Mode of administration	Self-administered					
Respondent burden						
Number of items	5 + 1 Visual Analogue Scale (VAS)					
Time required	One minute					
Time recall	Today					
Settings used	Population health surveys. Clinical studies. Used in conjunction with disease-specific instruments.					
Reliability						
Test–retest (ICC)	No published data identified					
Internal consistency (Cronbach's α)	No published data identified					
Validity						
Content validity						
Source of items	Developed after review of existing measures					
Selection of items	EuroQol Group consensus after pilot testing in general population.					
Construct validity	General pop.: Broad agreement with SF-36 (Brazier et al. 1993). Visual analogue scores were positively correlated with SF-12 Physical Component Summary (PCS) (r=0.55) and Mental Component Summary (MCS) (r=0.41) (Johnson & Coons 1998). Asthma pop.: Moderate correlation with SGRQ (–0.68) and levels of asthma control (0.70), poor correlation with FEV_1 (0.21) (Szende et al. 2004). Moderate correlation with PCS of SF-12 (0.49, p<0.01) and total AQLQ-McMaster (0.56, p<0.01) (Garratt et al. 2000).					
Criterion validity	Asthma pop.: Moderate correlation with the SF-36 dimensions (0.48–0.60) (Szende et al. 2004) and the SF-12 (PCS 0.49 and MCS 0.37) (Garratt et al. 2000)					
Responsiveness	Asthma pop.: Low to moderate responsiveness (effect size and standardised mean) (0.32, 0.29) of EQ-5D utility measure over six months with treatment and worsening asthma symptoms (Oga et al. 2002). Linear relationship between change in score of EuroQoL 5D and self-reported asthma transition (Garratt et al. 2000).					
Sensitivity	Significant difference between mobility, usual activities and pain/discomfort domains of people with and without asthma in US population sample (Johnson & Coons 1998) General pop.: Unable to differentiate between people with and without a chronic physical problem (Brazier et al. 1993) General pop.: Greater ceiling effect than SF-36 (Brazier et al. 1993) Ceiling effects in asthma population (Szende et al. 2004)					
Australian data	NSW Health Survey					
Other comments	Higher score represents better health.					
Usefulness for population monitoring	RB ★	D ★	CV ☆	T–R	IC	S ☆

(continued)

Table A2 (continued): Generic adult HRQoL measures

Review criteria	Healthy Days (CDC-HRQoL 4)
Type of instrument	Profile
HRQoL domains	Global ☑ Psychological ☑ Physical ☑ Social ☑
Content areas	Self-perceived health, recent physical health, recent mental health, recent activity limitation
Mode of administration	Interview (computer assisted telephone or face-to-face)
Respondent burden	
Number of items	4
Time required	One minute
Time recall	Past 30 days
Settings used	Population studies, surveillance systems, prevention research
Reliability	
Test–retest (ICC)	General population sample: ICC = 0.75 for self-reported health and healthy days measures and ICC 0.58–0.71 for other measures (Andresen et al. 2003) Healthy days summary measure had slightly higher reliability than each of its component measures (i.e. physical and mental health) (Andresen et al. 2003). Reliability decreased as time between tests increased (Andresen et al. 2003). Older adults produced lower reliability (Andresen et al. 2003).
Internal consistency (Cronbach's α)	No published data identified
Validity	
Content validity	
Source of items	Workshops with experts in quality of life and functional status measurement, surveillance methods and public health policy
Selection of items	Expert opinion based on selection criteria (public health policy focus, public and expert perspectives, objectivity versus subjectivity, sensitivity to population variability, generic versus condition-specific measures, cultural specificity, personal versus societal, time orientation, reliability and validity, and practicality).
Construct validity	General pop.: A strong positive relationship observed between activity limitation and the healthy days index (Spearman's Rank Correlation coefficient 0.48). Subjects reporting higher levels of self-perceived health had fewer days of impaired activity limitation, physical health and mental health (Ounpuu et al. 2000). Healthy days measures able to predict hospitalisation and mortality in a population of low - income older adults (CDC 2000)
Criterion validity	No published data identified
Responsiveness	All four questions sensitive to physical activity levels, employment status, income levels (Ford et al. 2004)
Sensitivity	People with current asthma reported significantly more mean mentally unhealthy days, mean physically unhealthy days and more mean days with activity limitation than people without asthma (Ford et al. 2003).
Australian data	No published data identified
Other comments	14-item version also available (takes 2–3 minutes to complete). Content areas are activity limitation, pain days, depression days, anxiety days, sleepless days, vitality days. No information for people with asthma. In the general population, there was a correlation observed with related SF-36 subscales: 0.55 with depression, 0.56 with pain, 0.50 with vitality (CDC 2000). Healthy days measures explain 59% of the variation in the PCS summary score of the SF-36 and 64% of the variation in the MCS summary score of the SF-36. Unhealthy days directly related to global life satisfaction question (CDC 2000). A 10-fold difference in the number of unhealthy days reported by adults with excellent versus poor self-assessed general health (CDC 2000).
Usefulness for pop. monitoring	RB ★ D ★ CV ☆ T–R ★ IC S ☆

(continued)

Table A2 (continued): Generic adult HRQoL measures

Review criteria	Health Utilities Index Mark III (HUI)					
Type of instrument	Utility					
HRQoL domains	Global ☒		Psychological ☑			
	Physical ☑		Social ☒			
Content areas	Vision, hearing, speech, ambulation, dexterity, emotion, cognition, pain					
Mode of administration	Self-administered, face-to-face interview					
Respondent burden	*Self*	*Interviewer*				
Number of items	15	40 (skip pattern)				
Time required	5–10 minutes	3–5 minutes				
Time recall	Past one or two or four weeks or usual					
Settings used	Population studies, clinical studies. Also used to evaluate economic outcomes.					
Reliability						
Test–retest (ICC)	General pop.: 0.77 (Boyle et al. 1995)					
Internal consistency (Cronbach's α)	No published data identified					
Validity						
Content validity						
Source of items	Derived from previous questionnaire (Health Utilities Index Mark II)					
Selection of items	No published information identified					
Construct validity	HUI III score significantly associated with frequency of cough, wheeze, dyspnoea and night time awakening (Moy et al. 2004). No correlation observed with levels of airway obstruction (predicted FEV1) (Spearman Rank Correlation coefficient = 0.15) (Moy et al. 2004). Significant correlation with AQLQ-McMaster overall score (0.57) ($p<0.001$) (Leidy & Coughlin 1998)					
Criterion validity	No published data identified					
Responsiveness	No published data identified					
Sensitivity	Scores were significantly correlated with asthma severity as measured by symptom frequency (cough, wheeze, dyspnoea and night time wakening) (Moy et al. 2004). Mean scores in people with asthma (0.86) were lower than for people without a National Population Health Survey condition (0.93) (Mittmann et al. 1999). General pop.: Ceiling effects, unable to differentiate between several levels of positive health that is experienced by the majority of the general population (Richardson & Zumbo 2000)					
Australian data	No published data identified in populations with asthma					
Other comments	The HUI III primarily measures the impact of physical impairment on everyday life. It measures the impact of social problems on everyday life to a much lesser extent (Richardson & Zumbo 2000).					
Usefulness for population monitoring	RB	D	CV ☆	T–R ★	IC	S ☆

(continued)

Table A2 (continued): Generic adult HRQoL measures

Review criteria	Medical Outcomes Study short-form 36 (SF-36)
Type of instrument	Profile
HRQoL domains	Global ☑ Psychological ☑ Physical ☑ Social ☑
Content areas	General health, physical functioning, role limitations (physical problems), bodily pain, general health perceptions, vitality, social functioning, role limitations (emotional problems), mental health
Mode of administration	Self-administered, interview (face-to-face or telephone). Computerised version also available.
Respondent burden	
Number of items	36
Time required	5–10 minutes
Time recall	Past four weeks (standard) and past week (acute)
Settings used	Population studies. Clinical studies. Outpatients. International Quality of Life Assessment Project.
Reliability	
Test–retest (ICC)	Asthma population: 0.68 (MCS), 0.65 (PCS) (Juniper et al. 2001)
Internal consistency (Cronbach's α)	Asthma population: 0.64–0.86 (Ware & Gandek 1998); 0.77–0.92 (Ried et al. 1999); 0.91 (Bousquet et al. 1994), PCS 0.88, MCS 0.81 (van der Molen et al. 1997). General population: 0.81–0.92 (Australian version) (Sanson-Fisher & Perkins 1998)
Validity	
Content validity	
Source of items	Derived from previous questionnaire (Medical Outcome Study (MOS) General Health Survey Instrument). Eight health concepts selected from 40 in the MOS. Most frequently measured health concepts from widely used health surveys (six) and concepts most affected by disease and treatment (two) (Ware & Sherbourne 1992).
Selection of items	Factor analysis to reproduce results from Medical Outcome Study General Health Survey.
Construct validity	Asthma pop.: SF-36 scores decreased with increasing severity of asthma measured by health care utilisation (Ried et al. 1999), clinical score and pulmonary function (Bousquet et al. 1994). Significantly lower scores across each individual scale of the SF-36 and MCS and PCS in people with severe asthma (dyspnoea, wakening at night and morning symptoms) (SA Omnibus 1998) (Goldney & Ruffin 2003). Physical Component Summary (PCS) and Mental Component Summary (MCS) were significantly worse in people who had wheeze in the last 12 months (ECRHS) (Matheson et al. 2002), high total symptom scores (van der Molen et al. 1997), nocturnal symptoms and those with asthma who had lost 1–5 days from work or school (Adams et al. 2001) and those with a greater number of asthma control problems in the last four weeks (Vollmer et al. 1999). PCS showed significant correlation with changes in FEV_1 (Ware & Gandek 1998), morning peak expiratory flow (van der Molen et al. 1997), bronchial hyperresponsiveness (van der Molen et al. 1997) and GINA asthma control level (Szende et al. 2004). Changes in FEV_1 and FVC moderately (yet significantly) influenced the Physical functioning, Role physical, Bodily pain, Vitality and Role emotional scales of the SF-36 (Sato et al. 2004). Weak to moderate correlation with AQLQ-McMaster (Oga et al. 2003) and high correlation with SGRQ (–0.74) (Szende et al. 2004)
Criterion validity	No published data identified
Responsiveness	Asthma population: Varied from low to high responsiveness (0.28–0.95) for changes in health status over time (six months) (Oga et al. 2003)
Sensitivity	Scores significantly lower in people with asthma than people in the general population across all subscales (SA Omnibus 1995) (Adams et al. 2001)
Australian data	SA Omnibus 1990 onwards—face-to-face population survey conducted annually ECRHS follow-up study data from Melbourne 1998–99 (Matheson et al. 2002) North West Adelaide Health Survey, 1995 National Health Survey
Other comments	Higher score represents better health. Subscales of the SF-36 most affected by asthma were general health perceptions, vitality and physical role functioning (Ried et al. 1999). General pop.: Bodily pain, Social functioning, Role emotional and Mental health subscales were significantly lower when administered by mail compared with phone (Perkins & Sanson-Fisher 1998).
Usefulness for pop. monitoring	RB D ★ CV ★ T–R ☆ IC ★ S ☆

(continued)

Table A2 (continued): Generic adult HRQoL measures

Review criteria	Medical Outcomes Study short-form 12 (SF-12)					
Type of instrument	Profile					
HRQoL domains	Global ☑		Psychological ☑			
	Physical ☑		Social ☑			
Content areas	General health, physical functioning, role limitations due to emotional problems, vitality, bodily pain, mental health, social functioning					
Mode of administration	Self-administered, interview (face-to-face or telephone).					
Respondent burden						
Number of items	12					
Time required	2–3 minutes					
Time recall	Past four weeks (standard), Past week (acute)					
Settings used	Population studies, clinical trials					
Reliability						
Test–retest (ICC)	PCS= 0.89 (US) 0.864 (UK), MCS=0.76 (US), 0.774 (UK) (adult patients with chronic conditions) (Ware et al. 1996)					
Internal consistency (Cronbach's α)	Correlation with SF-36 PCS=0.951. Correlation with SF-36 MCS=0.969 (Ware et al. 1996)					
Validity						
Content validity						
Source of items	Derived from previous questionnaire (SF-36)					
Selection of items	Forward step regression analysis (multiple R^2 0.911 for prediction of PCS-36 and 0.918 for prediction of MCS-36 (Ware et al. 1996)					
Construct validity	As symptoms increased, there were differences in the physical component but not the mental component of the SF-12 (Osman et al. 2000). As frequency of symptoms in the previous month increased, SF-12 PCS scores decreased (Osman et al. 2000). The physical subscale was able to distinguish all levels of symptom frequency (none, occasional not every week, weekly). Moderate correlation between PCS of SF-12 and EuroQol (0.49) (Garratt et al. 2000) General pop.: Moderate correlation between PCS of SF-12 and EuroQol visual analogue score r=0.55 (Johnson & Coons 1998). Weaker correlation between MCS of SF-12 and EuroQol visual analogue score (r=0.41) in general population (Johnson & Coons 1998).					
Criterion validity	General population data from Australia showed that the SF-36 summary scale scores are reproduced with a high degree of accuracy with the SF-12 (Sanderson & Andrews 2002). Very high product-moment correlations between SF-36 and SF-12 PCS (0.94–0.96) and MCS (0.94–0.97) (Gandek et al. 1998a). In US, the SF-12 reproduced the SF-36 summary measures with the same interpretations (Gandek et al. 1998b).					
Responsiveness	Not as reliable as the SF-36 for measuring changes in health status over time and between age groups in a sample of women from the Australian general population (Schofield & Mishra 1998) Significant linear relationship between change in score of PCS and self-reported asthma transition (Garratt et al. 2000) MCS shows little or no responsiveness (self-reported asthma transition after six months) (Garratt et al. 2000)					
Sensitivity	MCS and PCS summary scores lower in people with asthma (NW Adelaide Health Survey) (Adams et al. 2003) Significant difference between PCS of people with and without asthma in US population sample (Johnson & Coons 1998)					
Australian data	North West Adelaide Health Survey, National Survey of Mental Health and Wellbeing, South Australia Health Monitor Surveys 1997, 1998, 2000, 2003					
Other comments	Higher score on the SF-12 represents better health.					
Usefulness for population monitoring	RB ☆	D ★	CV ★	T–R ★	IC ★	S ☆

(continued)

Table A2 (continued): Generic adult HRQoL measures

Review criteria	Nottingham Health Profile (NHP)					
Type of instrument	Profile					
HRQoL domains	Global ☒		Psychological ☑			
	Physical ☑		Social ☑			
Content areas	Energy level, emotional reactions, physical mobility, pain, social isolation, sleep					
Mode of administration	Self-administered					
Respondent burden						
Number of items	38 (Part I)					
Time required	5–10 minutes					
Time recall	The present time					
Settings used	Population studies and community settings in the UK, intervention studies					
Reliability						
Test–retest (ICC)	No published data identified					
Internal consistency (Cronbach's α)	0.59–0.79 (Jans et al. 1999)					
Validity						
Content validity						
Source of items	Interviewed 768 lay individuals asking about how they felt when experiencing different states of health and produced 2,200 statements describing effects of ill health					
Selection of items	Grouped the 2,200 statements according to the function described and scrutinised for redundancy. Tested against medical information and independent assessments of individuals' wellbeing to reduce number of items. Re-tested on patients and reduced to 38 items.					
Construct validity	Statistically significant correlation between degree of dyspnoea and all dimensions of the NHP. Also between physical mobility dimension and frequency of sleep disturbances, frequency of problems in performing household activities and total consultation rate (Jans et al. 1999). Statistically significant change in energy score related to lung function (FEV_1) in people with asthma (van Schayck et al. 1995)					
Criterion validity	Correlation with sleep disturbance, performance of household activities, dyspnoea was moderate to low ($r<0.43$) (Jans et al. 1999).					
Responsiveness	Responsiveness to asthma treatment over six months ranged from low to moderate (0.21–0.61) for all six dimensions (Oga et al. 2003).					
Sensitivity	Quality of life scores for people with asthma were 2–3 times higher than for people in the general population for all domains of the NHP except emotional reaction score and sleep score (van Schayck et al. 1995). Small range of NHP scores in people with asthma; therefore, NHP is less sensitive for the purpose of detecting differences in quality of life in people whose health is only slightly compromised (Jans et al. 1999). Ceiling effects: High percentage of people with asthma scored best score (88% for pain and social isolation subscales) (Jans et al. 1999).					
Australian data	No published data identified for populations with asthma					
Other comments	Higher score in the NHP represents worse health					
Usefulness for population monitoring	RB	D ★	CV ☆	T–R	IC ☆	S ☆

(continued)

Table A2 (continued): Generic adult HRQoL measures

Review criteria	Sickness Impact Profile (SIP)					
Type of instrument	Profile					
HRQoL domains	Global ☒		Psychological ☑			
	Physical ☑		Social ☑			
Content areas	Ambulation, mobility, body care and movement, communication, alertness behaviour, emotional behaviour, sleep and rest, eating, work, recreation and pastimes, home management, social interaction					
Mode of administration	Self-administered, face-to-face interview					
Respondent burden						
Number of items	136					
Time required	20–30 minutes					
Time recall	Today					
Settings used	Population and clinical settings. Used in patients with COPD and asthma. Outpatients.					
Reliability						
Test–retest (ICC)	0.87–0.97 (Bergner et al. 1981)					
Internal consistency (Cronbach's α)	0.81–0.94 (Bergner et al. 1981)					
Validity						
Content validity						
Source of items	Survey of patients, carers, health professionals and healthy people as well as literature					
Selection of items	Items selected on basis of discriminative ability and reliability					
Construct validity	Moderate correlate with self-assessment for dysfunction (0.54–0.63) and a disability index (0.55–0.61) (Bergner et al. 1981, quoted in Coons 2000)					
Criterion validity	Weak correlation between total SIP score and total AQLQ-Sydney total score (Marks et al. 1993) Good correlation with the LWAQ (r=0.66) (Hyland 1991), r=0.56 (Rutten-van Molken et al. 1995) Good correlation between physical domain score and AQLQ-McMaster symptoms (r=0.58, p<0.0001) and AQLQ-McMaster activity limitations (r=0.50, p<0.0001) subscales (Rowe & Oxman 1993) Correlation between psychosocial subscale of SIP and emotions subscale of AQLQ-McMaster (Juniper et al. 1993)					
Responsiveness	No published data identified					
Sensitivity	SIP not able to distinguish between stable and improved subjects (Marks et al. 1993).					
Australian data	Marks et al. 1993 (44 adults with asthma who were attending allergy or hospital asthma clinics assessed at baseline plus 3–4 months later)					
Other comments	None					
Usefulness for population monitoring	RB	D ★	CV ☆	T–R ★	IC ★	S

Table A3: Asthma-specific adult HRQoL measures

Review criteria	Asthma Quality of Life Questionnaire (McMaster) (AQLQ-McMaster)					
Disease scope	Asthma					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Symptoms, activity limitations (chosen by respondent), emotional function, exposure to environmental stimuli					
Mode of administration	Self-administered, interview (face-to-face or telephone)					
Respondent burden						
Number of items	32					
Time required	10–15 minutes					
Time recall	Last two weeks					
Settings used	Patients with asthma, primary care					
Reliability						
Test–retest (ICC)	0.95 (Juniper et al. 2001; Juniper et al. 1999c), 0.90 (Sanjuas et al. 2002), 0.91 (Leidy & Coughlin 1998), 0.81–0.93 (Revicki et al. 1998), 0.97 (Tan et al. 2004).					
Internal consistency (Cronbach's α)	0.82 (Juniper et al. 1999c), 0.96 (Sanjuas et al. 2002), 0.95 (Leidy & Coughlin 1998), 0.81–0.96 (Garratt et al. 2000), 0.80–0.93 (Revicki et al. 1998), 0.97 (Tan et al. 2004), 0.88 (van der Molen et al. 1997)					
Validity						
Content validity						
Source of items	Review of general HRQoL measures, patients' experiences, consultation with chest physicians. Guided by characteristics considered essential for final questionnaire and list of seven criteria (Juniper et al. 1992).					
Selection of items	Impact method for item selection (items removed that are least important to the majority of asthma patients) (Juniper et al. 1992)					
Construct validity	Changes in AQLQ-McMaster showed strong relationship with changes in medication use and asthma control and weaker relationship with airway hyperresponsiveness and peak expiratory flow (Juniper et al. 1993). Overall scores responded consistently with the number of asthma control problems in past four weeks (Vollmer et al. 1999). High correlation with symptom scores and β agonist use ($p<0.0001$) (van der Molen et al. 1997).					
Criterion validity	Significant correlation with Health Utilities Index for all subscales (Leidy & Coughlin 1998). Moderate correlation between AQLQ-McMaster symptoms and physical domain scores of the SIP ($r=0.58$) and moderate correlation between AQLQ-McMaster activity limitations and physical domain scores of the SIP ($r=0.50$) (Rowe & Oxman 1993). Good correlation between AQLQ-McMaster overall scale and SF-36 PCS ($r=0.69$) (Mancuso et al. 2001), 0.58 (Garratt et al. 2000).					
Responsiveness	Responsiveness ratio of overall score=1.29 for spirometric and clinical measures of asthma severity and asthma control score (Tan et al. 2004). Three domains highly responsive to asthma treatment over six months (standardised response mean >0.8) environment domain less responsive (standardised response mean=0.57); low to moderate responsiveness to worsening asthma symptoms (Oga et al. 2003). More responsive than LWAQ (Oga et al. 2002). One standard error of measurement identified the minimal important difference in responsive dimensions of the AQLQ-McMaster (Wyrwich et al. 2002). Highly responsive to minor changes in ED patient severity status (Rowe & Oxman 1993). Significant relationship between change in AQLQ-McMaster total score and self-reported asthma transition (Garratt et al. 2000).					
Sensitivity	Significant correlation with an asthma disease severity scale (ED visit or hospitalisation due to asthma in last year, chronic cough, wheeze, phlegm, breathlessness or night-time symptoms, FEV_1 % predicted $\leq$70%) (Leidy & Coughlin 1998) and predicted FEV_1 (Rowe & Oxman 1993). Little evidence of floor or ceiling effect (Garratt et al. 2000).					
Australian data	Clinical trial: Rutherford et al. 2003					
Other comments	Of 234 people surveyed in the north-east of England, the average person failed to complete 0.98 items of the activity limitations domain, largely due to the questions on individualised activity limitations (Garratt et al. 2000). Individualised items less suitable for repeated cross-sectional surveys and not included in the standardised version of the questionnaire (AQLQ(S)-McMaster). Acute version available with recall time of half an hour (Juniper et al. 2004).					
Usefulness for pop. monitoring	RB	D ★	CV ★	T–R ★	IC ★	S ★

(continued)

Table A3 (continued): Asthma-specific adult HRQoL measures

Review criteria	Mini Asthma Quality of Life Questionnaire (McMaster) (Mini AQLQ-McMaster)					
Disease scope	Asthma					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Symptoms, activity limitations, emotional function, exposure to environmental stimuli					
Mode of administration	Self-administered, interview (face-to-face or telephone)					
Respondent burden						
Number of items	15					
Time required	Not reported					
Time recall	Last two weeks					
Settings used	Developed for use in clinical trials					
Reliability						
Test–retest (ICC)	0.83 (Juniper et al. 1999b)					
Internal consistency (Cronbach's α)	0.80 (Juniper et al. 1999b)					
Validity						
Content validity						
Source of items	Derived from previous questionnaire (AQLQ-McMaster)					
Selection of items	Impact method for item selection (items removed that are least important to the majority of asthma patients)					
Construct validity	Measurement properties not as strong as for the AQLQ-McMaster but Mini AQLQ-McMaster measures the same construct (Juniper et al. 1999b) Correlated less well with SF-36 PCS and beta agonist use than the AQLQ-McMaster (Juniper et al. 1999b)					
Criterion validity	Strong correlation with the AQLQ-McMaster overall score, symptoms domain, emotional function and environmental domains (r>0.80) and moderate for activity domain (r=0.63) (Juniper et al. 1999b) No statistically significant difference in scores for the overall quality of life and symptoms and emotional function domains of the AQLQ-McMaster and the Mini AQLQ-McMaster (Juniper et al. 1999b)					
Responsiveness	Responsiveness index was lower than for the AQLQ-McMaster (0.97 vs 1.35) but this was not a statistically significant difference (Juniper et al. 1999b).					
Sensitivity	No published data identified					
Australian data	No published data identified					
Other comments	Higher score represents better quality of life Sample size needs to be twice that required for the AQLQ-McMaster (Juniper et al. 1999b). Includes five individualised items and therefore less suitable for repeated cross-sectional surveys.					
Usefulness for population monitoring	RB ☆	D ★	CV ☆	T–R ★	IC ★	S

(continued)

Table A3 (continued): Asthma-specific adult HRQoL measures

Review criteria	Standardised Asthma Quality of Life Questionnaire (McMaster) (AQLQ(S)-McMaster)					
Disease scope	Asthma					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Symptoms, activity limitations (strenuous exercise, moderate exercise, work-related activities, social activities and sleep), emotional function, exposure to environmental stimuli					
Mode of administration	Self-administered, interview (face-to-face or telephone or computerised version)					
Respondent burden						
Number of items	32					
Time required	10–15 minutes					
Time recall	Last two weeks					
Settings used	Clinical studies					
Reliability						
Test–retest (ICC)	Overall score: 0.96 (Juniper et al. 1999a), 0.97 (Tan et al. 2004) Activities domain: 0.87 (Juniper et al. 1999a), 0.94 (Tan et al. 2004)					
Internal consistency (Cronbach's α)	Overall score: 0.97 (Tan et al. 2004)					
Validity						
Content validity						
Source of items	Derived from previous questionnaire (AQLQ-McMaster)					
Selection of items	Individualised items in the AQLQ-McMaster were replaced with five generic activities that were most frequently identified by asthma patients as being the most troublesome in day-to-day living.					
Construct validity	Correlation between overall score and lung function (FEV_1 % predicted and PEFR % predicted) ($p<0.01$), number of asthma admissions in last 12 months ($p<0.01$), number of asthma medications ($p<0.01$) (Tan et al. 2004)					
Criterion validity	Moderate correlation between activity domains of AQLQ(S)-McMaster and AQLQ-McMaster (0.77) (Juniper et al. 1999a) Overall correlation between AQLQ(S)-McMaster and AQLQ-McMaster was 0.99 (Juniper et al. 1999a).					
Responsiveness	Responsiveness index was 1.34 and not significantly different to that obtained for the AQLQ-McMaster (1.35) ($p=0.35$) (Juniper et al. 1999a). Overall score and each sub-scale able to detect differences in lung function over time ($p<0.01$) (Tan et al. 2004).					
Sensitivity	Able to detect difference between group of patients who remained stable and those who had changed between visitis ($p<0.0001$) (Juniper et al. 1999a)					
Australian data	No published data identified					
Other comments	Higher score represents better quality of life. For this version of the McMaster questionnaire, standardised, generic activities replace the individualised activities selected by the respondents for the AQLQ-McMaster, making it more appropriate for purposes of population monitoring.					
Usefulness for population monitoring	RB	D ★	CV ☆	T-R ★	IC ★	S ☆

(continued)

Table A3 (continued): Asthma-specific adult HRQoL measures

Review criteria	Asthma Quality of Life Questionnaire (Sydney) (AQLQ-Sydney)
Disease scope	Asthma
HRQoL domains	Global ☑ Social ☑ Physical ☑ Psychological ☑
Content areas	Breathlessness, mood disturbance, social disruption, concerns for health, overall
Mode of administration	Self-administered
Respondent burden	
Number of items	20
Time required	Five minutes
Time recall	Past four weeks
Settings used	Patients with asthma. Clinical trials.
Reliability	
Test–retest (ICC)	Asthma pop.: 0.80 (Marks et al. 1992)
Internal consistency (Cronbach's α)	Asthma pop.: 0.92 (outpatients) (Marks et al. 1992), 0.94 (community sample with asthma) (Marks et al. 1992), 0.91 (Ware et al. 1998), 0.94 (Gupchup et al. 1997), 0.94 and 0.95 (Katz et al. 1999)
Validity	
Content validity	
Source of items	Focus group and interviews with asthma educators
Selection of items	Principal components analysis
Construct validity	Significant correlation between AQLQ-Sydney total score and degree of bronchial hyperresponsiveness (Marks et al. 1993) AQLQ-Sydney total score was significantly correlated with baseline asthma severity scores (Katz et al. 1999). Better pulmonary function (FEV_1 predicted) was associated with less asthma impact (Katz et al. 1999). RV coefficients showed a significant relationship between breathlessness scale and pulmonary function (% predicted FEV_1), treatment impact, cough, chest tightness, wheezing, shortness of breath, overall condition, night-time symptoms and overall symptoms (Ware et al. 1998). Breathlessness subscale and total score were strong predictors of global patient-rated asthma severity, National Asthma Education and Prevention Program asthma-severity classification based on symptom frequency and number of work days missed in the past four weeks (Bayliss et al. 2000).
Criterion validity	Scores showed significant correlation with PCS and MCS scores of SF-36 (Katz et al. 1999). Better SF-36 scores were associated with lower AQLQ-Sydney scores (Katz et al. 1999). Emotional impact subscale of AQLQ-Sydney was significantly correlated with SF-36 MCS (r=–0.60) (Katz et al. 1999).
Responsiveness	Breathlessness scale was sensitive to change in lung function, National Asthma Education and Prevention Program asthma severity and patient-rated asthma severity (Bayliss et al. 2000). Changes in AQLQ-Sydney were significantly associated with changes in asthma severity and physical and mental status (Katz et al. 1999).
Sensitivity	Total score and each subscale able to distinguish between stable and improved patients (Marks et al. 1993). Scores showed significant correlation with asthma severity scores based on symptom frequency, hospitalisations for asthma, and past and current use of asthma medication (Katz et al. 1999). Total score and all domains correlated with markers of severe asthma (number of asthma medications taken in previous three months) (Gupchup et al. 1997), and GINA classification of asthma severity (Spanish version of questionnaire) (Belloch et al. 2003).
Australian data	Marks et al. 1993
Other comments	Lower AQLQ-Sydney scores represent better health. Good acceptability of items by group of 106 patients in the United States since none of them chose 'I don't know' option for any of the 20 items of the AQLQ-Sydney (Gupchup et al. 1997).
Usefulness for pop. monitoring	RB ☆ D ★ CV ★ T–R ★ IC ★ S ★

(continued)

Table A3 (continued): Asthma-specific adult HRQoL measures

Review criteria	Asthma Symptom Utility Index (ASUI)					
Disease scope	Asthma					
HRQoL domains	Global ☒		Social ☒			
	Physical ☑		Psychological ☒			
Content areas	Frequency and severity of cough, wheeze, shortness of breath and wakening at night and side-effects of asthma medication					
Mode of administration	Face-to-face interview					
Respondent burden						
Number of items	11					
Time required	Not reported					
Time recall	Past two weeks					
Settings used	Ambulatory care, recruits from pharmacy database					
Reliability						
Test–retest (ICC)	0.74 (2-week reproducibility) (Revicki et al. 1998)					
Internal consistency (Cronbach's α)	No published data identified					
Validity						
Content validity						
Source of items	Clinical practice, review of literature, patient interviews, discussion with clinicians in regard to symptoms of primary concern in practice, evaluation of treatment effectiveness					
Selection of items	Continued to conduct interviews with patients ranking importance of symptoms and problems that were troublesome and distressing until no new information was generated. Content analysis.					
Construct validity	Significant correlation with percent predicted FEV_1 (r=0.27, p< 0.01), FEV_1/FVC (r=0.27, p<0.001) as well as the AQLQ-McMaster (r=0.77) and HUI II (r=0.36) (Revicki et al. 1998). ASUI scores significantly correlated with percent predicted FEV_1 (Spearman correlation 0.27, p=0.009) (Moy et al. 2004).					
Criterion validity	No published data identified					
Responsiveness	Able to distinguish between levels of asthma severity (by percentage predicted FEV_1 or symptom frequency) (Moy et al. 2004)					
Sensitivity	No published data identified					
Australian data	No published data identified					
Other comments	Scores in a sample of 161 adult asthma patients ranged from 0.04 to 1.0 (Revicki et al. 1998).					
Usefulness for population monitoring	RB ☆	D	CV ☆	T–R ☆	IC	S

(continued)

Table A3 (continued): Asthma-specific adult HRQoL measures

Review criteria	Integrated Therapeutics Group Asthma Short Form (ITG-ASF)					
Disease scope	Asthma					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Symptom-free index, functioning with asthma, psychosocial impact of asthma, asthma energy and asthma confidence in health					
Mode of administration	Self-administered					
Respondent burden						
Number of items	15					
Time required	Not reported					
Time recall	Past four weeks					
Settings used	Clinical setting					
Reliability						
Test–retest (ICC)	No published data identified					
Internal consistency (Cronbach's α)	0.78–0.93 (Bayliss et al. 2000)					
Validity						
Content validity						
Source of items	Initial pool of items: 20 from AQLQ-Sydney, 3 items from the ITG physical symptom/side effect battery, 3 items from the ITG Psychosocial symptom/side effect battery					
Selection of items	Principal components method of factor analysis					
Construct validity	Each scale of the ITG-ASF was significantly predictive of global patient-rated asthma severity on a 5-point scale, asthma severity classification based on patient-reported symptom frequency and number of missed workdays in the last 4 weeks (Bayliss et al. 2000).					
Criterion validity	No published data identified					
Responsiveness	ITG-ASF total was comparable to AQLQ-Sydney for coefficients of responsiveness to change in pulmonary function, workdays missed and disease severity (Bayliss et al. 2000).					
Sensitivity	No published data identified					
Australian data	No published data identified					
Other comments	None					
Usefulness for population monitoring	RB ☆	D ★	CV ☆	T–R	IC ★	S

(continued)

Table A3 (continued): Asthma-specific adult HRQoL measures

Review criteria	Living with Asthma Questionnaire (Hyland) (LWAQ)					
Disease scope	Asthma					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Social/leisure, sport, sleep, holidays, work and other activities, colds, mobility, effects on others, medication use, sex, dysphoric states and attitudes					
Mode of administration	Self-administered, face-to-face interview					
Respondent burden						
Number of items	68					
Time required	15–20 minutes					
Time recall	None specified					
Settings used	Patients with asthma, clinical trials					
Reliability						
Test–retest (ICC)	Asthma pop.: r= 0.948 (Hyland 1991)					
Internal consistency (Cronbach's α)	Asthma pop.: 0.94 (van der Molen et al. 1997), 0.85 (Hommel et al. 2002)					
Validity						
Content validity						
Source of items	Focus groups of patients with asthma					
Selection of items	Principal component analysis					
Construct validity	Significant correlation with symptom scores (r=0.41, p<0.001) and morning PEF (p<0.001), beta agonist use, PC20 and FEV_1 (p<0.05) (van der Molen et al. 1997), subjective illness severity (r=0.48) (Hommel et al. 2002), the Medical Research Council Dyspnoea scale (p<0.05) (Nishimura et al. 2004) Physical health construct score correlated with total symptom scores (r=0.41) and beta agonist use (r=0.27, p<0.001) (van der Molen et al. 1997).					
Criterion validity	Good correlation with the SIP (r=0.66) (Hyland 1991), (r=0.56) (Rutten-van Molken et al. 1995)					
Responsiveness	Responsiveness in people with asthma undergoing treatment was lower than for the AQLQ-McMaster (Oga et al. 2002).					
Sensitivity	No published data identified					
Australian data	No published data identified					
Other comments	Physical health construct and mental health construct scores can be calculated from LWAQ. SF-36 and AQLA-McMaster performed better than LWAQ in group of mild asthmatics (van der Molen et al. 1997).					
Usefulness for population monitoring	RB	D ★	CV ★	T–R ★	IC ★	S

(continued)

Table A3 (continued): Asthma-specific adult HRQoL measures

Review criteria	Quality of Life for Respiratory Illness Questionnaire (QoLRIQ)					
Disease scope	Asthma and Chronic Obstructive Pulmonary Disease (COPD)					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Breathing problems, physical problems, emotions, general activities, triggering situations: weather and allergic, daily/domestic activities, social activities: activities, sexuality, QoLRIQ total					
Mode of administration	Self-administered					
Respondent burden						
Number of items	55					
Time required	Not reported					
Time recall	Past year					
Settings used	Clinical setting					
Reliability						
Test–retest (ICC)	Asthma pop.: 0.90 (van Stel et al. 2003)					
Internal consistency (Cronbach's α)	Asthma pop.: 0.94 (van Stel et al. 2003)					
Validity						
Content validity						
Source of items	Published reports, health professionals and experts					
Selection of items	Principal components analysis					
Construct validity	Self-assessed health status and self-rated change in disease symptoms in people with moderate to severe asthma (van Stel et al. 2003) Poorer pulmonary function was a strong predictor of poor HRQoL ($p<0.01$) (Hesselink et al. 2004).					
Criterion validity	Significant correlations with general activities and daily/domestic activities and several domains of the SF-36 (van Stel et al. 2003)					
Responsiveness	No published data identified					
Sensitivity	No published data identified					
Australian data	No published data identified in populations with asthma					
Other comments	None					
Usefulness for population monitoring	RB	D ★	CV ☆	T-R ★	IC ★	S

(continued)

Table A3 (continued): Asthma-specific adult HRQoL measures

Review criteria	St George's Respiratory Questionnaire (SGRQ)					
Disease scope	Airways disease					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Symptoms (frequency and severity), activities that cause or are limited by breathlessness, social functioning, psychological disturbances resulting from airways disease					
Mode of administration	Self-administered, interview (face-to-face or telephone)					
Respondent burden						
Number of items	76					
Time required	10 minutes					
Time recall	Over the last year, over the last three months, these days					
Settings used	Patients with asthma and COPD. Clinical trials.					
Reliability						
Test–retest (ICC)	Asthma pop.: 0.9 (Jones et al. 1992), 0.94 (Spanish language version) (Sanjuas et al. 2002) Good repeatability over one year (Jones 1991)					
Internal consistency (Cronbach's α)	Asthma pop.: 0.86 (Spanish language version) (Sanjuas et al. 2002)					
Validity						
Content validity						
Source of items	Unknown					
Selection of items	Factor analysis. Each item has an empirically derived weight from a sample of 140 patients with a wide range of severity of asthma and a wide age range.					
Construct validity	Symptom score significantly higher in those with frequent or daily wheeze, and cough and sputum production. Activity score showed moderate correlation with anxiety score, depression score, and general health. Higher in people with frequent wheeze. Impact score higher in those with wheeze. Total score was significantly higher in those with frequent wheeze, cough and sputum (Jones et al. 1992). Changes in all subscales correlated with frequency of asthma symptoms (day cough or wheeze and night disturbance caused by cough, wheeze or other asthma symptoms) in people with mild asthma (Osman et al. 2000). Strong correlation with dypsnoea. Global, impacts and activity scores showed significant correlations with $\%FEV_1$ (Sanjuas et al. 2002). SGRQ scores agreed with the direction of change in airway hyperresponsiveness in 69% of cases and with the direction of change of FEV_1 in 54.6% of cases (134 people with asthma) (Ritva et al. 2000). People with significantly lower scores across all subscales were more likely to contact a family practice in the 12 months after interview (Osman et al. 2000). Linear relationship with self-rated five-point general health scale (SF-1) (Jones et al. 1994)					
Criterion validity	Comparison made with psychosocial and physical scores of the SIP. Correlation with SGRQ impacts score were the highest; correlations with SGRQ activity score were considerably higher than correlations with AGRQ symptoms score (Jones 1991).					
Responsiveness	Significant correlation between overall score and number of asthma control problems in the last four weeks (Vollmer et al. 1999) Significant differences in all of the SGRQ scores according to asthma severity, classified according to GINA guidelines (Hungarian version of questionnaire) (Meszaros et al. 2003)					
Sensitivity	Discriminating capacity among levels of airflow limitation (Sanjuas et al. 2002). Not able to discriminate among patient severity categories based on the frequency of nocturnal and daily symptoms. More than twice as sensitive as the SIP in detecting differences in disease activity in patients with asthma (Jones 1991).					
Australian data	General practice in Adelaide (Pilotto et al. 2003)					
Other comments	None					
Usefulness for population monitoring	RB	D ★	CV ★	T–R ★	IC ★	S ☆

Table A4: Generic childhood HRQoL measures

Review criteria	Child Health and Illness Profile–Adolescent Edition (CHIP-AE)					
Type of instrument	Profile					
Age range	11–17 years					
HRQoL domains	Global ☑		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Satisfaction (health and esteem), discomfort (physical, emotional and activity), resilience (physical activities, social, home safety, family), risks (achievement and peer), disorders, achievement					
Mode of administration	Self-administered by parent or child					
Respondent burden						
Number of items	153					
Time required	30 minutes					
Time recall	Previous four weeks and 12 months					
Settings used	Cross-sectional survey of schools. Clinical setting.					
Reliability						
Test–retest (ICC)	Sample of schoolchildren: r=0.49–0.87 (Starfield et al. 1995)					
Internal consistency (Cronbach's α)	General pop.: 0.79–0.92 (Starfield et al. 1993)					
Validity						
Content validity						
Source of items	Literature, focus groups, health professionals and expert panels					
Selection of items	Factor analysis and second-order factor analysis					
Construct validity	No published data identified					
Criterion validity	No published data identified					
Responsiveness	No published data identified					
Sensitivity	Teenagers with doctor-diagnosed asthma and recent wheezing scored significantly higher in the discomfort, risks and disorders domains and significantly lower on the satisfaction domain than teenagers without asthma (Forrest et al. 1997). Teenagers with diagnosed asthma but no recent wheezing had similar scores to those without asthma (Forrest et al. 1997).					
Australian data	No published data identified in populations with asthma					
Other comments	None					
Usefulness for population monitoring	RB	D ★	CV	T–R ☆	IC ★	S ☆

(continued)

Table A4 (continued): Generic childhood HRQoL measures

Review criteria	Child Health Questionnaire Parent Form 50 (CHQ-PF50)					
Type of instrument	Profile					
Age range	5–12 years					
HRQoL domains	Global ☑		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Physical functioning, role/social (emotional, behavioural and physical), bodily pain, general behaviour, mental health, self-esteem, general health perceptions, change in health, parental impact (emotional and time), family activities, family cohesion					
Mode of administration	Parent-administered					
Respondent burden						
Number of items	50					
Time required	Unspecified					
Time recall	Last four weeks					
Settings used	Clinical trials					
Reliability						
Test–retest (ICC)	Asthma pop.: 0.37–0.84 (Asmussen et al. 2000) General pop.: 0.31–0.84 (Raat et al. 2002)					
Internal consistency (Cronbach's α)	Asthma pop.: 0.65–0.96 (Asmussen et al. 2000), 0.67–0.90 (Raat et al. 2002) General pop.: 0.39–0.96 (mean 0.72) (Raat et al. 2002), 0.60–0.93 (Waters et al. 2000)					
Validity						
Content validity						
Source of items	Multiple sources (literature review, interviews, focus groups with parents and children)					
Selection of items	Factor analysis					
Construct validity	No published data identified					
Criterion validity	No published data identified					
Responsiveness	No published data identified					
Sensitivity	Sensitive to differences in disease severity as measured by recent symptom activity, but not sensitive to differences in disease severity as measured by medication use (Asmussen et al. 2000).					
Australian data	Waters & Landgraf 1997, Waters et al. 2000					
Other comments	None					
Usefulness for population monitoring	RB	D ☆	CV	T–R ☆	IC ☆	S ☆

(continued)

Table A4 (continued): Generic childhood HRQoL measures

Review criteria	Child Health Questionnaire Parent Form 28 (CHQ-PF28)					
Type of instrument	Profile					
Age range	5–12 years					
HRQoL domains	Global ☑		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Physical functioning, role/social (emotional, behavioural and physical), bodily pain, general behaviour, mental health, self-esteem, general health perceptions, change in health, parental impact (emotional and time), family activities, family cohesion					
Mode of administration	Parent-administered					
Respondent burden						
Number of items	28					
Time required	Unspecified					
Time recall	Last four weeks					
Settings used	Prospective cohort study (children with asthma admitted to ED)					
Reliability						
Test–retest (ICC)	No published data identified					
Internal consistency (Cronbach's α)	No published data identified					
Validity						
Content validity						
Source of items	No published data identified					
Selection of items	No published data identified					
Construct validity	Psychosocial and physical subscales significantly associated with an improvement of the child's overall status (parental perception) (Gorelick et al. 2003). Moderate correlation with physical health score and number of days of school/day care missed by child (Spearman correlation coefficient=–0.35), number of days of work/school missed by parent (Spearman correlation coefficient=–0.35) and number of days of symptoms after ED visit (Spearman correlation coefficient=–0.39) (Gorelick et al. 2003). Weaker correlations for all of these outcomes and the psychosocial health score (Gorelick et al. 2003).					
Criterion validity	No published data identified					
Responsiveness	Scores are moderately responsive to changes in functional status. Moderate correlation observed for those with poor outcome and physical health score (Pearson=–0.43) and psychosocial health score (–0.31) (Gorelick et al. 2003)					
Sensitivity	Mean scores on the physical health score were significantly higher in children with a good outcome compared with those with a poor outcome (five or more days of school or day care missed by the child or caretaker, persistent asthma symptoms above baseline at 14 days or unscheduled return for care) (Gorelick et al. 2003).					
Australian data	No published data identified in populations with asthma					
Other comments	Gorelick et al. (2003) used a two- week recall period instead of four weeks.					
Usefulness for population monitoring	RB	D ★	CV ☆	T–R	IC	S ☆

(continued)

Table A4 (continued): Generic childhood HRQoL measures

Review criteria	Pediatric Quality of Life Inventory (PedsQL)					
Type of instrument	Profile					
Age range	2–18 years					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Physical functioning, emotional functioning, social functioning and school functioning					
Mode of administration	Self-administered or parent-administered, or telephone					
Respondent burden						
Number of items	23					
Time required	Less than five minutes					
Time recall	Past one month					
Settings used	Hospital setting, paediatrician's offices, community clinics, healthy children, population studies					
Reliability						
Test–retest (ICC)	No published data identified					
Internal consistency (Cronbach's α)	General pop.: Self-report (5–18 years) 0.68–0.88 (Varni et al. 2001), 0.71–0.87 (Varni et al. 2003) General pop.: Parent-report (2–18 years) 0.75–0.90 (Varni et al. 2001), 0.74–0.88 (Varni et al. 2003) Asthma pop.: Self-report (5–18 years) 0.74–0.90 (Varni et al. 2004) Asthma pop.: Parent-report (2–18 years) 0.77–0.91 (Varni et al. 2004)					
Validity						
Content validity						
Source of items	Focus groups and cognitive interviews					
Selection of items	No published data identified					
Construct validity	No published data identified					
Criterion validity	Significant correlation ($p<0.001$) with all subscales of PedsQL and all subscales of PAQLQ (child self-report) (Varni et al. 2004)					
Responsiveness	No published data identified					
Sensitivity	Significantly lower (worse) scores for all subscales for children with asthma compared with healthy children (both child and parent-report) (Varni et al. 2004)					
Australian data	No published data identified in populations with asthma					
Other comments	Missing items: 0.6% (self-report) and 2.1% (parent proxy-report). Higher percentage of missing items for proxy report of school functioning scale (3.5% (5–18 years) and 40.0% (2–4 years)) (Varni et al. 2004). Teen version also available for ages 13–18					
Usefulness for population monitoring	RB ☆	D ★	CV ☆	T–R	IC ★	S ☆

Table A5: Asthma-specific childhood HRQoL measures

Review criteria	About My Asthma (AMA)					
Disease scope	Asthma					
Age range	6–12 years					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Thoughts about asthma, family impacts, worries, behaviour, missing school, fear, embarrassment, missing PE classes, sleep disruption, pets					
Mode of administration	Self-administered or interview with child aged less than 9 or 10 years old					
Respondent burden						
Number of items	44					
Time required	15–20 minutes					
Time recall	None specified					
Settings used	Children from an asthma day camp					
Reliability						
Test–retest (ICC)	0.572 (Mishoe et al. 1998)					
Internal consistency (Cronbach's α)	0.93 (Mishoe et al. 1998)					
Validity						
Content validity						
Source of items	Adapted from the 'About my Illness' instrument after feedback from children with asthma					
Selection of items	Factor analysis					
Construct validity	No published data identified					
Criterion validity	A moderate, negative correlation observed between AMA and the overall QoL and emotional function domains of the PAQLQ (Mishoe et al. 1998). Decreased QoL and emotional function in children measured using the PAQLQ correlated with increased levels of stress in the AMA questionnaire.					
Responsiveness	No published data identified					
Sensitivity	No published data identified					
Australian data	No published data identified					
Other comments	None					
Usefulness for population monitoring	RB	D ★	CV	T–R ☆	IC ★	S

(continued)

Table A5 (continued): Asthma-specific childhood HRQoL measures

Review criteria	Adolescent Asthma Quality of Life Questionnaire (AAQLQ)					
Disease scope	Asthma					
Age range	12–17 years					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Symptoms, medication, physical activities, emotion, social interaction, positive effects					
Mode of administration	Self-administered					
Respondent burden						
Number of items	32					
Time required	5–7 minutes					
Time recall	Not stated					
Settings used	Hospital setting					
Reliability						
Test–retest (ICC)	0.90 (total score), 0.76–0.85 (six domains) (Rutishauser et al. 2001)					
Internal consistency (Cronbach's α)	0.93 (total score), 0.70–0.90 (six domains) (Rutishauser et al. 2001) 0.87 (total score, 0.76–0.87 (six domains) (Sommerville et al. 2004).					
Validity						
Content validity						
Source of items	Critical review of literature, existing measures, expert opinion, focus groups. Determined by expert panel (Rutishauser et al. 2001).					
Selection of items	Item reduction using clinical impact method					
Construct validity	Weak to moderate correlation with severity of coughing and wheezing, number of hospitalisations in the last 12 months, patient-rated symptom severity (Rutishauser et al. 2001) German version: High correlation with patient-rated symptom severity (Spearman rank=0.73, p<0.0001). Negative correlation (p<0.0001) with coughing in last 14 days (r=–0.59), wheezing in last 14 days (–0.51), shortness of breath in last 14 days (–0.71) and sleeping difficulties in last 14 days (–0.52) (Sommerville et al. 2004).					
Criterion validity	High correlation with the PAQLQ (Spearman rank correlation=0.81 (Rutishauser et al. 2001) =0.85 (Sommerville et al. 2004)					
Responsiveness	No published data identified					
Sensitivity	No published data identified					
Australian data	Questionnaire developed in Australia by Rutishauser et al. (2001)					
Other comments	None					
Usefulness for population monitoring	RB	D ★	CV ★	T–R ★	IC ★	S

(continued)

Table A5 (continued): Asthma-specific childhood HRQoL measures

Review criteria	Childhood Asthma Questionnaire A (CAQ-A)					
Disease scope	Asthma					
Age range	4–7 years					
HRQoL domains	Global ☑		Social ☑			
	Physical ☒		Psychological ☑			
Content areas	Quality of living (enjoyment of all daily activities), distress (feelings about asthma)					
Mode of administration	Self-administered (with assistance)					
Respondent burden						
Number of items	15 (Australian version)					
Time required	15–20 minutes					
Time recall	None used					
Settings used	School children					
Reliability						
Test–retest (ICC)	Australian version: Distress: r=0.63, Quality of living: r=0.68 (French 1996) (One week) UK: Distress: Pearson correlation (r)=0.63, ICC=0.63, Quality of living: r=0.59, ICC=0.59 (French et al. 1994) (One week)					
Internal consistency (Cronbach's α)	Australian version: Distress: 0.72, Active quality of living: 0.66 (French et al. 1998). UK: Distress: 0.60, Active quality of living 0.63 (French et al. 1994)					
Validity						
Content validity						
Source of items	Focus groups with children with asthma (Australian version)					
Selection of items	Psychometric item analysis					
Construct validity	Distress scale (but not quality of living scale) correlated with parent-rating of child's asthma severity (r=0.42, p<0.01) (French & Christie 1995). Distress scale significantly correlated with frequency of night waking (r=0.26, p<0.05) and effect on the family (r=0.38, p<0.01). Quality of living scale negatively correlated with frequency of night waking (r=–0.24, p<0.05) and effect on the family (r=–0.25, p<0.05) (French & Christie 1995).					
Criterion validity	No published data identified					
Responsiveness	Active quality of living scale was higher in children without asthma compared with children with asthma (p=0.005) (French et al. 1998).					
Sensitivity	Australian children with asthma showed lower quality of living scores than Australian children without asthma. In contrast, children in the UK showed no difference in quality of living scores in children with and without asthma. This is because Australian children without asthma rate their quality of living much higher than those in the UK (French 1996).					
Australian data	French (1996)					
Other comments	Smiley faces used instead of conventional Likert scale categories.					
Usefulness for population monitoring	RB	D	CV ★	T–R ☆	IC ☆	S ☆

(continued)

Table A5 (continued): Asthma-specific childhood HRQoL measures

Review criteria	Childhood Asthma Questionnaire B (CAQ-B)					
Disease scope	Asthma					
Age range	8–11 years					
HRQoL domains	Global ☑		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Active quality of living, passive quality of living, distress (feelings about asthma symptoms), severity					
Mode of administration	Self-administered (with assistance)					
Respondent burden						
Number of items	25 (Australian version)					
Time required	10–15 minutes					
Time recall	None used					
Settings used	School children					
Reliability						
Test–retest (ICC)	Australian version: Pearson correlation=0.73–0.75 (French 1996) (Three weeks) UK: Pearson correlation=0.73–0.75, ICC=0.72–0.75 (French et al. 1994) (Three weeks)					
Internal consistency (Cronbach's α)	Australian version: 0.62–0.90 (French et al. 1998) UK: 0.44–0.82 (French et al. 1994)					
Validity						
Content validity						
Source of items	Focus groups with children with asthma (Australian version)					
Selection of items	Psychometric item analysis					
Construct validity	Positive correlation between effect on family and distress subscale (r=0.45, p<0.001) and severity subscale (r=0.41, p=0.001) and negative correlation between effect on family and active quality of living scale (r=–0.26, p<0.025) (French & Christie 1995). Positive correlation between parent-rated effect on the family and severity subscale (r=0.47, p=0.001) and weak negative correlation between parent-rated effect on the family and active quality of living subscale (r=–0.35, p<0.005) (French 1996).					
Criterion validity	No published data identified					
Responsiveness	No published data identified					
Sensitivity	Severity subscale was significantly associated with severity of asthma (p<0.001) (French et al. 1998). Active quality of living scale was higher in children without asthma compared with children with asthma (p<0.001) (French et al. 1998). Australian children with asthma showed lower active quality of living scores than Australian children without asthma. In contrast, children in the UK showed no difference in active quality of living scores in those with and without asthma. This is because Australian children without asthma rate their quality of life much higher than those in the UK (French 1996).					
Australian data	French 1996					
Other comments	None					
Usefulness for population monitoring	RB	D ★	CV ★	T–R ★	IC ☆	S ★

(continued)

Table A5 (continued): Asthma-specific childhood HRQoL measures

Review criteria	Childhood Asthma Questionnaire C (CAQ-C)					
Disease scope	Asthma					
Age range	12–16 years					
HRQoL domains	Global ☑		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Active quality of living, teenage quality of living (teenage social activities), distress (feelings about asthma symptoms and social impact), severity, reactivity (awareness of environmental triggers)					
Mode of administration	Self-administered					
Respondent burden						
Number of items	40 (Australian version)					
Time required	10–20 minutes					
Time recall	None used					
Settings used	School children					
Reliability						
Test–retest (ICC)	Australian version: Pearson correlation=0.73–0.84 (French 1996) (Three weeks) UK: Pearson correlation=0.73–0.84, ICC=0.73–0.84 (French et al. 1994)					
Internal consistency (Cronbach's α)	Australian version: 0.52–0.83 (French et al. 1998) UK: 0.50–0.80 (French et al. 1994)					
Validity						
Content validity						
Source of items	Focus groups with children with asthma (Australian version)					
Selection of items	Psychometric item analysis					
Construct validity	Active quality of living score decreased with increasing severity of asthma ($p<0.05$) (French 1996).					
Criterion validity	No published data identified					
Responsiveness	No published data identified					
Sensitivity	Severity subscale was significantly associated with severity of asthma ($p<0.001$) (French et al. 1998). Active quality of living scale was higher in children without asthma compared with children with asthma ($p<0.05$) (French et al. 1998).					
Australian data	No published data identified					
Other comments	None					
Usefulness for population monitoring	RB	D ★	CV ☆	T–R ★	IC ☆	S ★

(continued)

Table A5 (continued): Asthma-specific childhood HRQoL measures

Review criteria	Children's Health Survey for Asthma (CHSA)					
Disease scope	Asthma					
Age range	5–12 years					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Physical health, activity (child and family), emotional health (child and family), health care utilisation, asthma triggers, family demographics					
Mode of administration	Parent-administered, interview in person or by telephone to parent					
Respondent burden						
Number of items	48					
Time required	20 minutes					
Time recall	Two weeks or two months (two versions)					
Settings used	Cross-sectional studies					
Reliability						
Test–retest (ICC)	0.60–0.85 (Asmussen et al. 1999), r=0.62–0.86 (Asmussen et al. 1999)					
Internal consistency (Cronbach's α)	0.81–0.92 (Asmussen et al. 1999)					
Validity						
Content validity						
Source of items	American Academy of Pediatrics expert work group, parent focus groups, parent cognitive interviews					
Selection of items	Item reduction after each item was reviewed on a list of criteria including high ceiling effect, low expert review rating, low item-total scale correlation, improved scale α coefficient if item deleted, low item covariance with majority of other scale items.					
Construct validity	Physical health and emotional health (child) scales showed correlations with disease severity (measured by recent symptom activity and medication use) (Asmussen et al. 1999).					
Criterion validity	No published data identified					
Responsiveness	No published data identified					
Sensitivity	No published data identified					
Australian data	No published data identified					
Other comments	None					
Usefulness for population monitoring	RB	D ★	CV ☆	T–R ☆	IC ★	S

(continued)

Table A5 (continued): Asthma-specific childhood HRQoL measures

Review criteria	How Are You? (HAY)					
Disease scope	Generic and asthma-specific components					
Age range	8–12 years					
HRQoL domains	Global ☑		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Generic, physical activities, cognitive activities, social activities, asthma symptoms, self-management, emotions related to asthma, self-concept, physical complaints					
Mode of administration	Self-administered by child or parent					
Respondent burden						
Number of items	72 (40 items for asthma)					
Time required	20 minutes					
Time recall	None specified					
Settings used	Children with asthma (whole questionnaire) and children without asthma (generic component only)					
Reliability						
Test–retest (ICC)	0.11–0.83 (le Coq et al. 2000) (One week) (0.11 for social activities)					
Internal consistency (Cronbach's α)	0.61–0.81 (le Coq et al. 2000) 0.71–0.83 (le Coq et al. 2000) (includes 256 children with asthma and 273 children without asthma)					
Validity **Content validity** Source of items	List of items from existing instruments and literature was sent to a panel of experts in childhood asthma (paediatricians, general practitioners, asthma nurses and child psychologists) to review and suggest additional items.					
Selection of items	Factor analysis					
Construct validity	Children with symptoms of asthma scored lower in all dimensions than children without symptoms of asthma (le Coq et al. 2000). Mean differences reported by children did not differ significantly from mean differences reported by parents (le Coq et al. 2000).					
Criterion validity	No published information identified					
Responsiveness	HAY scores changed when clinical status improved or deteriorated for all dimensions except for frequency of cognitive activities and self-management (le Coq et al. 2000).					
Sensitivity	Children with asthma had lower scores than children without asthma in the physical activities and social activities domains (le Coq et al. 2000).					
Australian data	No published data identified					
Other comments	None					
Usefulness for population monitoring	RB	D ★	CV ☆	T–R ☆	IC ★	S ☆

(continued)

Table A5 (continued): Asthma-specific childhood HRQoL measures

Review criteria	Integrated Therapeutics Group Child Asthma Short Form (ITG-CASF)					
Disease scope	Asthma					
Age range	5–12 years					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☒			
Content areas	Day time symptoms, night-time symptoms and functional limitations					
Mode of administration	Self-administered by parent					
Respondent burden						
Number of items	Eight					
Time required	Unspecified					
Time recall	Past four weeks					
Settings used	Prospective cohort studies, longitudinal studies					
Reliability						
Test–retest (ICC)	No published data identified					
Internal consistency (Cronbach's α)	0.84–0.92 (Bukstein et al. 2000)					
Validity						
Content validity						
Source of items	Previous questionnaire					
Selection of items	Stepwise, item reduction analysis					
Construct validity	Significant correlation between score at follow up (two weeks after being treated in Emergency Department) and number of missed days of school or days of limited activities (Gorelick et al. 2004) Mean scores at follow up were significantly higher in those who were classed by parents as being 'improved' and also those whose symptoms had returned to baseline (Gorelick et al. 2004).					
Criterion validity	No published data identified					
Responsiveness	Correlation between change in ITG-CASF score (from time being treated in ED and two weeks later) and number of limited activity days (r=–0.51) (Gorelick et al. 2004)					
Sensitivity	Significant association between ITG-CASF and asthma severity, with scores lowest amongst those with severe, persistent asthma and highest amongst those with mild intermittent asthma (Gorelick et al. 2004) Mean scores for mild cases of asthma (physician-rated) were significantly better (higher) than mean scores for moderate/severe cases of asthma (physician-rated) (Bukstein et al. 2000).					
Australian data	No published data identified					
Other comments	None					
Usefulness for population monitoring	RB ☆	D	CV ☆	T–R	IC ★	S ★

(continued)

Table A5 (continued): Asthma-specific childhood HRQoL measures

Review criteria	Paediatric Asthma Quality of Life Questionnaire (PAQLQ)					
Disease scope	Asthma					
Age range	7–17 years					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Symptoms (shortness of breath, wheeze, cough, tightness of chest, tiredness), activity limitations (physical, social, school, sleeping), emotional function (frustration, fear, anxiety, anger, feeling different and left out)					
Mode of administration	Interview or self-administered by child					
Respondent burden						
Number of items	23					
Time required	7–15 minutes					
Time recall	Previous one week					
Settings used	Patients with asthma					
Reliability						
Test–retest (ICC)	0.95 (Juniper et al. 1996), 0.84 0.71 (overall score) (children from Singapore) (Clarke et al. 1999)					
Internal consistency (Cronbach's α)	0.90 (Mishoe et al. 1998)					
Validity						
Content validity						
Source of items	Adapted from previous questionnaire					
Selection of items	Impact method for item selection (items removed that are least important to the majority of asthma patients)					
Construct validity	Significant correlation with patient-rated symptom severity, number of hospitalisations in the past 12 months, coughing in last seven days, wheezing in last seven days, sleeping in last seven days (Rutishauser et al. 2001) Significant correlation between changes in PAQLQ score and changes in clinical asthma control ($p<0.001$) in children from Singapore (Clarke et al. 1999) Scores on the PAQLQ were significantly correlated with parents HRQoL scores using the Paediatric Caregiver's Quality of Life Questionnaire (Vila et al. 2003) and scores also correlated with peak flow rate (Reichenberg & Broberg 2003).					
Criterion validity	No published data identified					
Responsiveness	No published data identified					
Sensitivity	Significant differences in PAQLQ total scores of children in Singapore whose asthma remained stable and those whose asthma status changed (e.g. differences in inhaled medication or natural fluctuations in asthma) (Clarke et al. 1999).					
Australian data	No published data identified					
Other comments	The one version of the questionnaire available covers a wide age range and there is no social domain, which may be an important domain of quality of life for adolescents.					
Usefulness for population monitoring	RB	D ★	CV ★	T–R ☆	IC ★	S ☆

(continued)

Table A5 (continued): Asthma-specific childhood HRQoL measures

Review criteria	Pediatric Quality of Life Asthma Module (PedsQL-Asthma Module)					
Disease scope	Asthma					
Age range	2–18					
HRQoL domains	Global ☒		Social ☑			
	Physical ☑		Psychological ☑			
Content areas	Asthma symptoms, treatment problems, worry and communication					
Mode of administration	Self-administered or parent-administered, or telephone					
Respondent burden						
Number of items	28					
Time required	Unspecified					
Time recall	Past 1 month					
Settings used	Children enrolled in clinical studies, children attending an asthma summer camp					
Reliability						
Test–retest (ICC)	No published data identified					
Internal consistency (Cronbach's α)	Child-report: 0.58–0.85 Parent-report: 0.82–0.91 (Varni et al. 2004)					
Validity						
Content validity						
Source of items	Previous disease-specific modules of the PedsQL, literature, focus groups and cognitive interviews					
Selection of items	No published data identified					
Construct validity	Significant correlation between asthma symptoms subscale, treatment problems subscale and worry subscale with all scales of the PAQLQ (Varni et al. 2004)					
Criterion validity	Significant correlation between emotions scale of PAQLQ and communication subscale of PedsQL ($p<0.05$) (Varni et al. 2004)					
Responsiveness	No published data identified					
Sensitivity	No published data identified					
Australian data	No published data identified					
Other comments	Missing items: 0.8% (self-report) and 1.5% (parent proxy-report) (Varni et al. 2004)					
Usefulness for population monitoring	RB	D ★	CV ☆	T–R	IC ★	S

Appendix B: Excluded measures

Table B1: Summary of measures excluded from evaluation: generic measures

Measure	Reason for exclusion
Assessment of Quality of Life (AQoL)	Not used in populations with asthma
15D	Insufficient evaluation data available
CDC-Health-Related Quality of Life Measure (CDC-HRQoL) (Healthy days 14)	Insufficient evaluation data available
Centre for Epidemiologic Studies Depression Scale	Not used in populations with asthma
Dartmouth Primary Care Co-op info project coop charts	Not used in populations with asthma
Duke Anxiety-Depression Scale	Not used in populations with asthma
Duke Health Profile	Not used in populations with asthma
Global Quality of Life Scale	Not used in populations with asthma
Health Utilities Index	Not used in populations with asthma
Illness Behaviour Questionnaire	Not used in populations with asthma
Index for Measuring Health (Grogono Health Index)	Not used in populations with asthma
Multidimensional Index of Life Quality	Not used in populations with asthma
McMaster Health Index Questionnaire	Not used in populations with asthma
Patient Generated Index	Not used in populations with asthma
Psychological General Well-Being Index	Not used in populations with asthma
Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD)	Not used in populations with asthma
Perceived Quality of Life Scale	Not used in populations with asthma
Quality of Life Questionnaire	Not used in populations with asthma
Quality of Life Inventory (QOLI)	Not used in populations with asthma
Quality of Wellbeing Scale	Not used in populations with asthma since 1991
SF-6D	Not used in populations with asthma
SF-8	Not used in populations with asthma
SF-36 version 2	Not used in populations with asthma (however, very similar to SF-36)
Single item life satisfaction scale	Insufficient evaluation data available
Single item self-rated health (SF-1)	Insufficient evaluation data available
WHO Quality of Life Assessment	Not used in populations with asthma

Table B2: Summary of measures excluded from evaluation: asthma-specific measures

Measure	Reason for exclusion
Airways Questionnaire 20	Insufficient evaluation data available
Asthma Impact Survey	Insufficient evaluation data available
Child Health Related Quality of Life	Insufficient evaluation data available
Life Activities Questionnaire for Asthma	Insufficient evaluation data available
Asthma Bother Profile	Insufficient evaluation data available

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