Measuring the impact of asthma on quality of life in the Australian population

Australian Centre for Asthma Monitoring

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Woolcock Institute of Medical Research

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Foreword

Asthma contributes a substantial burden of ill-health in Australia. For several years now, governments, consumer organisations and health care professionals have accepted the challenge of developing new policies and strategies to try to reduce this burden. Selection, targeting and evaluation of health care policy alternatives depend on the provision of timely, reliable and authoritative information to those making decisions. The Australian Centre for Asthma Monitoring (ACAM) was established in 2002 as a collaborating unit of the Australian Institute of Health and Welfare to coordinate the provision of information for these and other stakeholders in asthma. This report forms part of the work of the Centre.

The burden of asthma on individuals and on society includes a substantial impact on quality of life. There is a widely held view that monitoring the impact of asthma should include measures of its impact on quality of life. However, there is no generally agreed approach to population-based monitoring of quality of life in relation to specific chronic diseases, such as asthma.

This report provides a comprehensive review of approaches to measuring the impact of asthma on quality of life that can be used in population-based monitoring. It is concluded that no single measure can be used in all circumstances. Rather, selection from the range of alternative measures should be based on the specific monitoring task and the attributes that are most relevant to that task.

This report is intended for use by policy makers, data agencies and researchers involved in measuring population health. While the main focus is on population monitoring in relation to asthma, the findings will be of interest to those whose focus is on other chronic diseases.

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Abbreviations

AAQLQ	Adolescent Asthma Quality of Life Questionnaire
ABS	Australian Bureau of Statistics
ACAM	Australian Centre for Asthma Monitoring
AIHW	Australian Institute of Health and Welfare
AMA	About My Asthma
AQLQ-McMaster	Asthma Quality of Life Questionnaire (McMaster)
AQLQ(S)-McMaster	Standardised Asthma Quality of Life Questionnaire (McMaster)
AQLQ-Sydney	Asthma Quality of Life Questionnaire (Sydney)
AQoL	Assessment of Quality of Life instrument
ASUI	Asthma Symptom Utility Index
CAQ-A	Childhood Asthma Questionnaire A
CAQ-B	Childhood Asthma Questionnaire B
CAQ-C	Childhood Asthma Questionnaire C
CATI	Computer assisted telephone interview
CDC-HRQoL 4	Centers for Disease Control and Prevention health-related quality of life measures 4: Healthy Days Measures
CEA	Cost-effectiveness analysis
CHIP-AE	Child Health and Illness Profile — Adolescent Edition
CHQ-PF 28/50	Child Health Questionnaire Parent Form 28/50
CHSA	Children's Health Survey for Asthma
COPD	Chronic Obstructive Pulmonary Disease
CUA	Cost–utility analysis
CV	Construct validity
CVD	Cardiovascular disease
D	HRQoL domains
ECRHS	European Community Respiratory Health Survey
EQ-5D	EuroQol-5D
FEV_1	Forced expiratory volume in one second
HAY	How Are You?
HRQoL	Health-related quality of life
HUI	Health Utilities Index Mark III
IC	Internal consistency
ICC	Intraclass correlation coefficient
ICF	International Classification of Disability, Functioning and Health

ITG-ASF	Integrated Therapeutics Group Asthma Short Form
ITG-CASF	Integrated Therapeutics Group Child Asthma Short Form
LWAQ	Living with Asthma Questionnaire (Hyland)
MAUI	Multi-attribute Utility Index
MCS	Mental components summary
Mini AQLQ-McMaster	Mini Asthma Quality of Life Questionnaire (McMaster)
NHP	Nottingham Health Profile
NHS	National Health Survey
PAQLQ	Paediatric Asthma Quality of Life Questionnaire
PCS	Physical components summary
PedsQL	Pediatric Quality of Life Inventory
PedsQL-Asthma Module	Pediatric Quality of Life Asthma Module
Pop.	Population
QALYs	Quality adjusted life years
QoL	Quality of life
QoLRIQ	Quality of Life for Respiratory Illness Questionnaire
RB	Respondent burden
S	Sensitivity
SA	South Australia
SF-36/12	Medical Outcomes Study Short-form 36/12
SIP	Sickness Impact Profile
SG	Standard gamble
SGRQ	St George's Respiratory Questionnaire
TTO	Time trade-off
T–R	Test–retest
VAS	Visual analogue scale

Executive summary

Asthma is a common chronic disease that affects persons of all ages. People with asthma report impacts on the physical, psychological and social domains of quality of life.

Health-related quality of life (HRQoL) measures have been developed to complement traditional health measures such as prevalence, mortality and hospitalisation as indicators of the impact of disease. The inclusion of health and patient-focused measures of impact in population monitoring for asthma is important for guiding clinical management, predicting health outcomes, formulating clinical policy and assisting in the allocation of resources.

A range of HRQoL measurement instruments is available and choosing the most appropriate requires consideration of the context in which it will be implemented and the purposes of the data collection. The principal objective of this report is to develop a framework for assessing HRQoL measures and to make recommendations for measuring the impact of asthma on HRQoL in the Australian population.

A number of measures have been included in Australian population surveys as indicators of HRQoL. Commonly, these have been single item measures to assess perceptions of life and health or to address specific issues such as reduced activity days. In this document, the attributes of these and other measurement instruments for HRQoL have been reviewed to assess their ability to accomplish the purposes of population monitoring, including comparing HRQoL in different diseases, monitoring HRQoL over time and allocating resources.

Single item measures are useful as low cost measures of overall health and have been widely used in population health surveys. However, they are restricted in content validity and sensitivity as measures of the impact of asthma on HRQoL and are vulnerable to measurement error. These limitations are not always overcome by large sample sizes or frequently repeated surveys, and sole reliance on such measures is not recommended for future monitoring.

The use of more valid and sensitive multi-item, multi-dimensional measurement instruments is limited by the practical and cost considerations of large surveys. Furthermore, many of these instruments were designed for individual patient management, and measure HRQoL with excessive precision for the purposes of large population monitoring studies. However, there are a number of shorter HRQoL profile measures that have been developed in recent years. These instruments measure HRQoL with adequate precision, validity and sensitivity and have lower respondent burden than the longer HRQoL profiles. The increased efficiency of these measures is an advantage for population health monitoring. In the future, other solutions to the problem may include the use of dynamic health assessments based on item response theory questionnaire batteries.

Recommendations

1 HRQoL measures

No single measure will be appropriate for all the purposes of population monitoring. It is acknowledged that population studies are expensive to administer, and measures need to conform to the time and cost constraints of these activities. However, there is value in the use of multi-item measures that sample from all HRQoL domains and this should be balanced with the practical considerations. This report identifies three key tasks in population monitoring and makes recommendations for the type of HRQoL measures that should be used in each of these.

1.1 For tasks that involve comparing people with asthma with people without asthma and/or people with other diseases, it is recommended that generic (i.e. non-disease-specific) HRQoL measures be used. For most tasks it will be appropriate to use a global measure, which encompasses all the domains of HRQoL. This is most reliably and validly achieved with a multi-item, multi-dimensional scale (profile measure). An example of a well validated, generic HRQoL profile measure that would reasonably conform to the practical constraints of population surveys is the SF-12 (Ware & Gandek 1998).

Where this is not feasible, a brief or single item global measure may be acceptable for measuring overall population means. However, lack of precision and measurement error may limit its usefulness for more detailed comparisons of subgroups or for examination of risk factors.

Under some circumstances, where the focus of investigation does not extend to all aspects of HRQoL, it is appropriate to limit the scope of the outcome measured to one or more domains or dimensions of quality of life (e.g. reduced activity days, physical health, symptoms etc.). Instruments that are limited to these domains are available and would be appropriate in that context.

1.2 For tasks that involve monitoring changes over time in the impact of asthma and measuring differences between subgroups of people with asthma, it is recommended that asthma-specific quality of life questionnaires be used. These instruments have greater content validity and may have greater sensitivity and responsiveness for this purpose. They are suitable for use when it is intended that they will be completed only by people with asthma. One instrument that would be suitable is the AQLQ-Sydney (Marks et al. 1993).

1.3 Economic evaluationsthat assist in the prioritisation of resource allocation use data from multi-attribute utility indices (MAUIs). While several generic instruments, such as the EQ-5D, are available and have been used for this purpose, there is limited information on their suitability for monitoring in relation to asthma.

2 Approaches to population monitoring of HRQoL

As noted above, the use of instruments that are comprehensive enough to provide adequate validity and reliability poses a problem for population health monitoring due to the cost and respondent burden involved. We have made recommendations for alternative sampling strategies that could overcome this dilemma.

2.1 The use of multi-item, multi-dimensional HRQoL profile questionnaires in relatively small population samples may be more efficient than using single item measures in very large populations. This can be achieved by selecting sub-samples nested within larger population surveys.

2.2 When the task is monitoring change over time, it may be more efficient to use comprehensive multi-item, multi-dimensional questionnaires at less frequent intervals, rather than single item instruments at frequent intervals. For example, the implementation of comprehensive measures identified in recommendations 1.1 and 1.2 every five years would be satisfactory for monitoring HRQoL impacts in the adult population, and would yield valuable time series data. For most purposes, the time interval over which change can be expected is relatively long.

Implementation of these recommendations in the National Health Survey could be achieved by incorporating the SF-12 every second survey, and the AQLQ-Sydney on alternate surveys, to respondents with asthma. A link between these surveys could be achieved by including a single item general health status measure ('In general, how would you rate your health?') in each survey. This is particularly straightforward because this question is one item within the SF-12.

3 HRQoL measures in children

A substantial proportion of the burden of asthma in Australia occurs in children and this report highlights specific issues to address in monitoring the HRQoL impacts of asthma in children.

3.1 It is recommended that an asthma-specific HRQoL measure designed for children is used to assess the impact of asthma among children in population surveys. An example of a suitable instrument is the Paediatric Asthma Quality of Life Questionnaire (PAQLQ) (Juniper 1996 et al.). The presently available generic HRQoL measures for use in children are not generally feasible for implementation in large scale population health monitoring.

4 Further research

The current recommendations relate to monitoring the impact of asthma on HRQoL using existing measures. The main problems inherent in using these existing instruments for population health monitoring relate to the trade-off between breadth and depth; that is, the range of aspects of health covered, and the precision with which each aspect is measured within an instrument of acceptable length. Recent research in dynamic health assessment methodology offers the promise of brief yet valid, precise and sensitive measures.

4.1 It is recommended that further research be implemented to develop the application of dynamic health assessment for asthma-specific outcomes.

1 Introduction

Chronic diseases are responsible for a substantial portion of the burden of ill health in Australia and similar countries. The physical, psychological and social consequences of chronic disease have detrimental and long-term impacts on the quality of life of affected individuals. The extent of this impact depends on the severity and prognosis of the disease as well as an individual's personal values, attitudes and beliefs. Asthma is a chronic disease that is prevalent in Australia and many other developed countries. There is evidence that its prevalence increased in many countries during the latter part of the twentieth century, particularly among children (ACAM 2003; Downs et al. 2001; Peat et al. 1994). In Australia, asthma affects around 12% of the population, leading to over 40,000 hospitalisations and 397 deaths in 2002 (ACAM 2003). While this report is focused on the quality of life impacts of asthma, it is expected that much of the information here will be relevant to other National Health Priority Areas, particularly those dealing with chronic illness.

This report reviews the methods for assessing the impact of asthma on quality of life from a population health perspective. In this chapter, background information is presented that, along with the approaches for measuring health-related quality of life described in Chapter 2, underpins the framework to assessing health-related quality of life that has been adopted for this report. Specific methods for quantifying the impact of asthma on quality of life are assessed in Chapter 3 in order to suggest useful approaches to population-based monitoring in Chapter 4.

1.1 Objectives

The key objectives of this report are:

- to describe a conceptual framework for selecting measures to monitor the impact of asthma on health-related quality of life in a population context;
- to systematically evaluate the value of measures that have been used within a population setting to assess quality of life in people with asthma; and
- to make recommendations for methods for population-based surveillance of the impact of asthma on health-related quality of life in Australia.

1.2 Health-related quality of life

Quality of life is a subjective concept based on an individual's perception of the impact that events and experiences have on his or her life. It encompasses the 'individual's satisfaction or happiness with [their] life' in key areas or domains that are important to the individual (ATS 2004). It has been acknowledged that quality of life is a difficult concept to define or measure (Fayers & Machin 2000) and its specific domains and dimensions vary in relative importance among individuals, in part depending on their social and cultural background. However, five domains:—physical, psychological, social, economic and spiritual—are commonly regarded as relevant to quality of life (Spilker 1990; Testa & Simonson 1996). Health-related quality of life (HRQoL) refers to the component of overall quality of life that is determined primarily by health status (Juniper 2001) and focuses on the physical, psychological and social core domains.

1.2.1 Why measure HRQoL?

Measuring HRQoL has a role in describing health outcomes, guiding and assessing clinical management, predicting health outcomes, formulating clinical policy and allocating health resources. Traditional measures of disease impact such as prevalence, mortality and hospitalisation rates are of limited use in understanding the extent of the impact of the disease on the individual. Prevalence measures describe the number of people who have the disease but provide no information on impacts of the disease on individuals. Fortunately, death is a very rare outcome of asthma, particularly among children and young adults, and deaths due to asthma reported in the elderly can be associated with other diseases as a contributing cause (AIHW 2002). Mortality data, therefore, reflect the 'tip of the iceberg' of the impact of asthma. Hospitalisation rates and other health care utilisation measures may be more useful as an indicator of some impacts of asthma in the population because a substantial proportion of people with asthma experience acute episodes, take medication, visit their doctor or attend the hospital Emergency Department. However, these data provide an incomplete indication of the impact of asthma and tend to reflect those people with more severe or poorly controlled disease. Furthermore, they are influenced by non-disease factors, in particular accessibility of the health care service whose utilisation is being measured.

A range of objective clinical measures of asthma, such as symptoms, lung function and medication requirement, are also regarded as indicators of asthma status. However, these clinical measures also provide only a limited range of information about asthma outcomes and impact and there is only a weak to moderate correlation between these clinical indices and HRQoL scores (Juniper et al. 2004; Marks et al. 1993; Williams et al. 2000). HRQoL measures complement traditional health and clinical measures and capture the broader impacts that asthma has in the physical, psychological and social aspects of life.

1.2.2 Components of HRQoL

Measures of HRQoL have been used as outcome measures to assess the impact of conditions and/or their treatments on the perception of wellbeing and everyday functioning of the individual. HRQoL can be measured at three levels (Spilker 1990). Most broadly, HRQoL can be measured as the global or overall assessment of an individual's wellbeing. However, greater precision can be achieved in measures that focus on assessing the individual's wellbeing and functioning in each of the three core HRQoL domains: physical, psychological and social (Spilker 1990). These more detailed HRQoL measures usually assess dimensions of perception or experience within these core domains (Guyatt et al. 1993; Testa & Nackley 1994). Dimensions often measured include symptoms, physical functioning and disability in the physical domain; positive and negative affect and behaviour in the psychological domain; and the individual's relationships and roles (work and leisure) in the social domain. A simple model of the interrelationships between quality of life, the domains of quality of life and HRQoL is illustrated in Figure 1.1. Note that HRQoL can be both a determinant of health and the outcome of disease impacts. In other words, the relationship between health and quality of life is reciprocal, with each influencing the other.

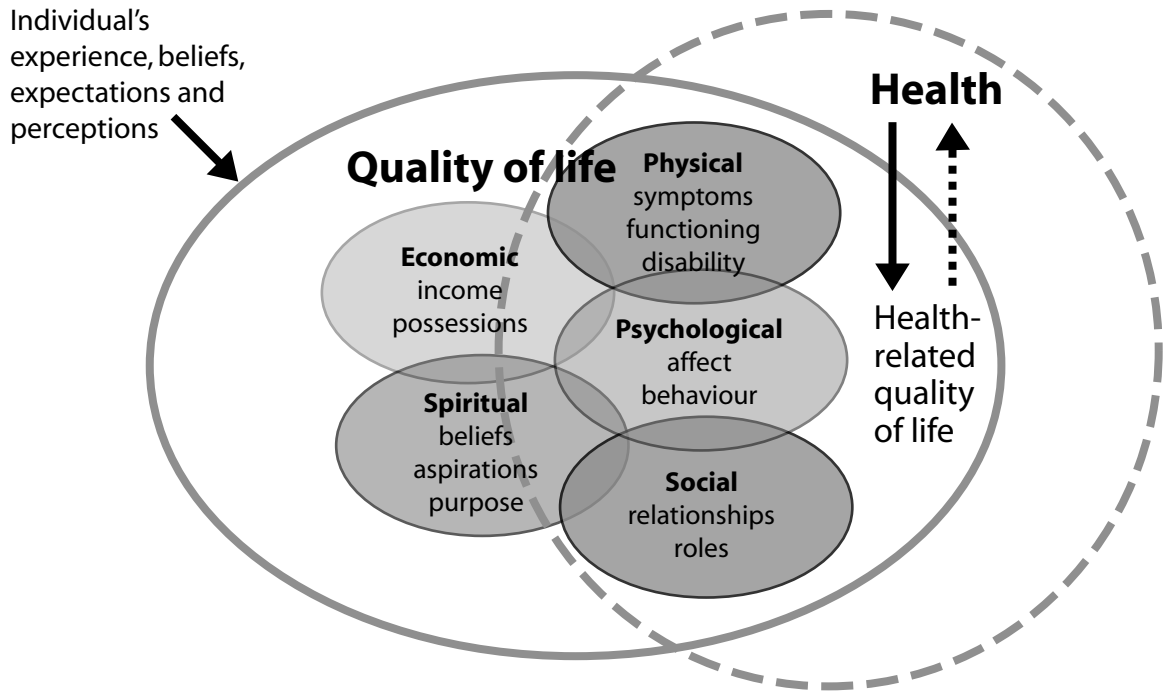


Figure 1.1: Model of interrelationship between health, quality of life and health-related quality of life

It has been suggested that some measures of HRQoL are really measuring how people assess the 'quality of their health' or 'health status' and are not measuring how health impacts on their wellbeing (Bradley 2001). For example, a woman who is aware that she has a chronic illness may assess her health status as poor, even if that illness does not cause any substantial impact on her life or wellbeing**.**

Questionnaires assessing health status will yield different results to those assessing wellbeing. This debate, which affects the nomenclature for these measures, is unresolved. For the purposes of this report, we have accepted a broad definition of HRQoL measures and have evaluated some instruments that could be described as health status measures.

1.2.3 Relation to disability

Disability is an umbrella term that encompasses impairment of structure and/or function, limitation of activities and restriction on participation (AIHW 2003). Disability arises from the interaction of specific disease effects with environmental factors and personal factors. Disability can be considered one of the outcomes of asthma, which is influenced by disease severity and control. The level of disability is also influenced by environmental factors, such as exposure to triggers, availability of effective treatment, and requirement for physical activity. Personal factors, such as comorbidity, coping style and adherence to treatment, also affect the level of disability arising from asthma.

The relationship between disability and HRQoL is not well defined. We have chosen to focus on HRQoL because there is a relatively large body of published information on its measurement in people with asthma. Disability can also be measured and classified (AIHW 2003) but there has been little work in this field in relation to asthma.

1.3 Population health monitoring

The goal of a population-based approach to health is to understand and improve health at the population level. This extends beyond responding to diseases and treating those who are sick to focusing on the health of the population as a whole and subgroups within the population. This is consistent with the World Health Organization definition of health: 'Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (WHO 1948). Approaching health in this way directs activity towards the prevention of disease and promotion of good health, as well as the allocation of health care resources to areas of greatest potential gain. It necessitates that inequities in subgroups of the population are identified and addressed where poorer health is a result of exposure to risk factors and disadvantage in access to services and healthy choices.

Population health monitoring is necessary for collecting information that will identify the impact of a range of factors that relate to health. In contrast to a clinical situation, population health monitoring is usually carried out in a setting where most (70–80%) of the general population do not have chronic diseases or mental health problems that substantially impact on HRQoL. Therefore, an important consideration in measuring HRQoL in the population is that the measures used are able to capture variation in positive health states rather than only those with poor health status (Ware et al. 1981).

1.3.1 Current monitoring activities in Australia

There are several population health monitoring activities currently in place in Australia that can potentially facilitate monitoring HRQoL. In general, these are cross-sectional surveys of representative samples of the population that are periodically repeated. These include the National Health Survey, state and territory computer assisted telephone interview (CATI) surveys and other surveys.

The National Health Survey has been conducted in 1989–1990, 1995 and 2001 by the Australian Bureau of Statistics (ABS). Prior to this, surveys in 1977–1978 and 1983 collected information that has continued in the current National Health Survey, and future surveys will occur every three years. Trained interviewers conduct face-to-face structured interviews with participants from randomly selected households. Information is obtained about one adult and all children in each selected private dwelling sampled throughout rural and metropolitan Australia. The survey questions concern health status (particularly in relation to the National Health Priority Areas), health service usage and lifestyle factors that impact on health. Questions have been included to measure HRQoL such as life satisfaction, self-perceived health status and reduced activity days. The interviews are completed in approximately 45 minutes per household. In 2001, 26,863 participants responded to the general survey.

The Disability, Ageing and Carers Survey has been conducted by the ABS in 1988, 1993, 1998 and 2003. It focuses on people with a disability or specific restriction, older people, and carers. It collects information on long-term health conditions, problems with activities and need for assistance with activities, and employment and schooling restrictions among other things. For the purposes of this survey, people with a disability includes people with a range of impairments causing restriction in activity and people with long-term health conditions requiring ongoing treatment (ABS 2000).

Since approximately 1990, most Australian State Health Authorities have conducted computer assisted telephone interview (CATI) surveys for surveillance of health status, health behaviours and outcomes in these jurisdictions. Participants are sampled using either

random digit dialling or electronic white pages to obtain a representative sample of the general population. Interviews take 15–20 minutes. The models for these surveys have evolved independently and vary between jurisdictions. Work is currently being undertaken to develop a national consensus over the approach and priorities (CATI Technical Reference Group 2003). These surveys have sometimes incorporated HRQoL instruments, such as the EQ-5D in the 1997–1998 New South Wales Health Surveys (NSW Health Public Health Division 2000).

The South Australian Health Omnibus Survey (Wilson et al. 1992) has been implemented annually since 1990 and collects disease, service use and risk factor information from a random sample of the South Australian population.

Finally, a number of surveys have been conducted by researchers, professional bodies, consumer groups, local agencies or others with commercial interests to provide information that may be relevant to population health monitoring (e.g. Bauman et al. 1992; Matheson et al. 2002). These surveys have incorporated various health outcome measures that are relevant to HRQoL.

The quality of information of HRQoL in the community would be improved by the development of a consistent approach that could be applied across various survey platforms. This would provide valuable time series information for monitoring the impact of asthma and other conditions. Furthermore, the development of standard approaches would mean that data from these surveys could be combined across the surveys in meta-analyses.

1.3.2 Challenges in monitoring asthma

Asthma is an episodic, chronic respiratory disease characterised by episodes of widespread airway narrowing accompanied by symptoms such as wheezing, coughing and shortness of breath. The episodes may be triggered by identifiable stimuli or may occur without obvious cause. Severe episodes can be life-threatening. There is substantial public interest in widespread reports that the prevalence of this disease is increasing, particularly in the developed world (Burney 2002; Peat et al. 1994; Robertson et al. 1991).

Defining asthma

International comparisons of asthma in adults (Burney et al. 1996) and in children (Asher et al. 1995) indicate that Australia has one of the highest asthma prevalence rates in the world. In order for comparisons to be valid, a consistent definition of asthma needs to be applied. The following descriptive 'definition' of asthma has been widely adopted since 1997:

> 'Asthma is a chronic inflammatory disorder of the airways in which many cells and cellular elements play a role, in particular, mast cells, eosinophils, T lymphocytes, macrophages, neutrophils and epithelial cells. In susceptible individuals this inflammation causes recurrent episodes of wheezing, breathlessness, chest tightness and coughing, particularly at night or in the early morning. These episodes are usually associated with widespread but variable airflow obstruction that is often reversible either spontaneously or with treatment. The inflammation also causes an increase in existing bronchial hyperresponsiveness to a variety of stimuli.'(NAEPP 1997).

This definition, however, presents several difficulties for population monitoring of asthma. In particular, there are multiple independent symptoms of asthma that overlap with other respiratory diseases, can vary over time and occur on a continuum where the definition of what is and what is not asthma is arbitrary. There are also practical constraints in being able

to measure the pathological features of asthma on a large scale, particularly in children. These factors mean that accurately monitoring asthma in the population requires consideration of the alternatives to address these constraints.

For population surveillance purposes, an operational definition for current asthma has been recommended in the *Review of proposed National Health Priority Area asthma indicators and data sources* (Baker et al. 2004). The label 'current asthma' is applied to people who report ever being told they have asthma by a doctor or nurse and who additionally report that they have had symptoms of asthma or taken treatment for asthma in the last 12 months. This definition can be used in large population surveys to identify people who have been diagnosed with, and still experience, asthma. Using a similar, but not identical, definition ('ever asthma' and states 'still has asthma'), the 2001 National Health Survey found that 11.6% of Australians had asthma as a current condition including 13.9% of children aged 0 to 17 years (ACAM 2003).

Relation of HRQoL to severity and control of asthma

There is no generally agreed definition of 'control' or 'severity' in relation to asthma. However, severity is often regarded as an inherent abnormality, which when modified by variable environmental exposures and by treatments, results in a given level of 'control' (Figure 1.2). In other words, control is inherently modifiable but 'severity' is not. According to this framework, it is virtually impossible to measure the 'severity' of asthma in the real world since the expression of the disease will almost always be modified by environmental and/or treatment factors.

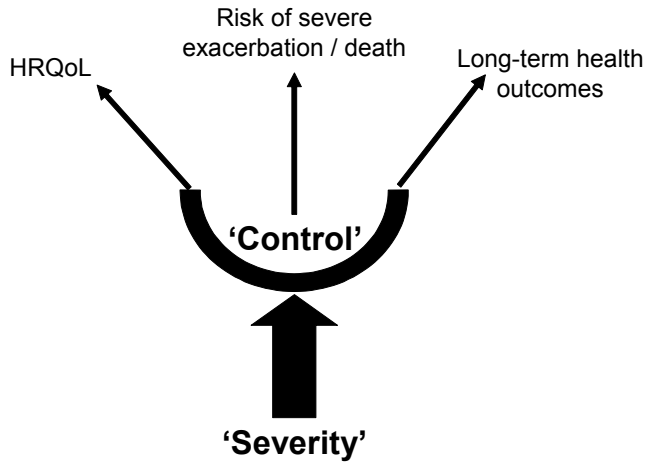


Figure 1.2: Relationship between 'severity' and 'control' on outcomes

The concept of asthma 'control' is used by clinicians to describe a range of clinical features that are used to assess the effectiveness of current therapy in an individual patient and the need for modification of therapy. Monitoring of changes in markers of control is used in management and self-management plans to guide changes in medication.

Ideally, the best measures of 'control' are those that are predictive for the important outcomes for asthma: distressing symptoms, impaired functional capacity, and risk of severe exacerbations resulting in hospitalisation or even premature death. Evidence about the

measures of control that are most useful for this purpose is quite limited but the National Asthma Council Consensus Guidelines recommend daytime symptom frequency, nocturnal symptom frequency, need for bronchodilator, level of lung function and (in some cases) variability in lung function as appropriate indicators (NAC 2002). Recent evidence has suggested that some physiological indices, such as airway hyperresponsiveness (Sont et al. 1999) and sputum eosinophil count (Green et al. 2002), may be more useful measures for guiding appropriate treatment modifications.

HRQoL is an outcome of asthma. People with inherently severe asthma can be expected, on average, to have worse outcomes and, hence, worse HRQoL than people with less severe disease. Similarly, since 'control' is intended as a predictor of asthma outcomes, it would be expected that during periods of poor asthma control, HRQoL would be poorer (Vollmer et al. 1999). However, as noted above (Figure 1.2), HRQoL is not the same as asthma severity or asthma control (Juniper et al. 2004). HRQoL can be regarded as a broad-ranging, but not all encompassing, outcome of asthma.

In this chapter we have attempted to describe what we mean by HRQoL, its relevance to population health monitoring for asthma and its relation to other outcome measures. The next chapter of this report presents a framework for measuring HRQoL.

2 Conceptual framework for measuring HRQoL in asthma

The development of valid and standardised methods for measuring HRQoL is challenging because of the uniqueness inherent in an individual's perception of their quality of life. Nonetheless, it is widely appreciated that measuring HRQoL as an outcome of diseases such as asthma is essential to understanding their impact (Guyatt et al. 1993; Schipper 1983). It is for this reason that standardised methods of assessment of HRQoL have been developed and validated so that comparisons can be made between populations and various groups (Jones et al. 1994).

In this chapter, we describe a conceptual framework for measuring HRQoL for the purpose of population monitoring in relation to asthma. This encompasses what is being measured, why it is being measured and how it is measured. Included is a review of how asthma impacts on HRQoL, what types of measures are available to assess HRQoL, and what characteristics indicate a good measure (attributes, breadth and depth). The implementation of HRQoL measures in Australian health surveys to date is reviewed in light of the conceptual issues raised. At the end of this chapter, the conceptual framework is used to provide principles that can be used to guide the selection of HRQoL measures for different purposes in population monitoring. The strengths and weaknesses of specific HRQoL measurement instruments are reviewed in Chapter 3.

2.1 How does asthma affect HRQoL?

Most people who identify asthma as their main disabling condition report some restriction in their core activities and also report poorer health status than people without asthma. Table 2.1 summarises the impacts of asthma on the domains of HRQoL. In the 1995 National Health Survey, 12% of people with asthma reported taking days off from work or school in the preceding two weeks due to asthma (ABS 1995). There is also evidence that asthma is associated with a predisposition to anxiety and depression in adults, although the subject remains controversial (Harrison 1989; Osman 2002; Rand & Butz 2000). People with asthma experience sleep disturbances and often feel tired and frustrated because of their asthma (Sawyer & Fardy 2003). In the United States, people with asthma report more physically unhealthy days (6.5 days vs 2.9 days), mentally unhealthy days (5.2 days vs 3.0 days) and days with activity limitation (3.7 days vs 1.6 days) in the previous month than respondents who did not have asthma (Ford et al. 2003).

Children with asthma may also identify specific issues that impact on their HRQoL, such as feeling angry, frustrated and socially isolated (Juniper 2001). In the Living With Asthma study, one in five children with asthma did not ride a bike, play at school or play with animals and one in three did not participate in organised sports (Sawyer & Fardy 2003). Parents of children with asthma were more anxious than parents of children who did not have asthma. In another Australian study conducted among school children (Sawyer et al. 2001), the physical health, mental health and role and social functioning dimensions of HRQoL were significantly worse among children with asthma than among those without asthma. Children with more severe asthma had the poorest HRQoL outcomes.

Table 2.1: Impact of asthma on HRQoL for the individual and family

Core domains of HRQoL	Impact on individual	Impact on family
GLOBAL		
Overall assessment of wellbeing	Influenced by disease severity and level of disability as well as underlying emotional and social factors that can impact on the outcomes of the disease as well as on the ability to manage and control symptoms and risk factors	Members of the family may take on a carer role and provide support and assistance in daily/core activities. In adults, there may be the presence of comorbidities impacting on overall health, or asthma may have been present over a longer duration with adaptation of the family to limitations on lifestyle.
PHYSICAL		
Symptoms	Coughing, wheezing, loss of sleep	Sleep disrupted
Physical functioning	Walking up stairs, playing sport, exercise and other physical activity Sleep disrupted	Dependence on family members for assistance with activities such as shopping and housework
Disability	Restriction in ability to perform normal actions Limited in ability to complete activities of daily living	
PSYCHOLOGICAL		
Mental and emotional health	Fear of lack of control and anxiety about an asthma attack Embarrassment in taking medication Stress in remembering to take medication Increased risk of depression (especially if other chronic diseases are present) Children and adolescents often have lower self-esteem and see themselves as different.	Anger, frustration, depression by burden asthma places on family Parents anxious, worried about child's asthma, fear of an attack, lack of control, risk of their child's death Stress on family members due to difficulties in negotiating medication compliance and communication between family, carers and clinicians
Behaviour	Asthma can be a contributing factor in causing behavioural problems in children.	
SOCIAL		
Daily role	Restricted in usual activities Restricted in study activities Increased sick days and missed school days Restriction in participation in community social activities	Family life disrupted (e.g. night disturbances, visits to health services) Family restricted in social activities, holidays and keeping pets
Work	Restricted in work activities Increased sick days Long-term limitations in employment, and possibly lower educational attainment	Can contribute to restriction in employment for family members either in choice of occupation or in hours able to work Carer burden for parents if child sick, with lower productivity
Personal relationships	Impaired contact with friends, relatives and reduced participation in social events and increased isolation In children and adolescents, asthma can inhibit relationships with peers and modify social circles.	Contact with relatives and friends can be restricted.

Other studies have also found that children and adolescents with asthma have more behavioural problems (Bussing et al. 1995), lower self-perceived health status (Forrest et al. 1997), and lower self-esteem, self-pity and sometimes embarrassment in taking medication (Donnelly 1994). In a United Kingdom study of 773 children aged between 5–17 years who had current asthma, children reported that asthma restricted their participation in everyday activities and caused frequent school absences and night disturbances (Lenney et al. 1994). Substantial proportions stated that there were times when they could not complete a sports lesson (up to 50%), when school work productivity was reduced due to being sleepy in

lessons and having attention deficit problems (>50%) or when they were sometimes not able to go to school following a disturbed night (41%).

Asthma also has impacts on HRQoL for the family. Having a child with asthma has an impact on the parent or caregiver's time, other siblings and family-related activities (Halfon & Newacheck 2000). Families may be confronted with decisions about holidays, keeping pets, installation of special furnishings, and extra cleaning to control the environment (Warner & Warner 1991). There may be an added burden from the costs of medications and health care (Toelle et al. 1995). A parent or caregiver of a child with asthma may have to take time off from work or from daily activities to care for their child (Halfon & Newacheck 2000). The extra demand on time and responsibility adds to the family's emotional and financial burden and can increase stress and put pressure on relationships (Rand & Butz 2000). These findings highlight the impact of asthma on the emotional and social dimensions, as well as on the physical dimension, of HRQoL.

2.2 Purposes of measuring HRQoL

HRQoL can be used to describe health outcomes, guide clinical management, predict health outcomes, formulate clinical policy and direct the allocation of resources. The main functions for which HRQoL measures are used may be classified as discrimination, evaluation and prediction (Kirshner & Guyatt 1985).

2.2.1 Discrimination

One of the purposes of population monitoring in asthma is to discern subgroups of the population who have greater or lesser impacts attributable to asthma (Feeny et al. 1999). This requires an instrument that can discriminate between groups with a higher burden of disease. High burden subgroups identified in this way may then be targeted for specific interventions or further investigation into the causes (e.g. environmental, economic or cultural) of the observed disparities.

2.2.2 Evaluation

Perhaps the most common context for health research is evaluating the effect of an intervention. In clinical trials the intervention may be a drug or some other form of treatment, which is usually evaluated in a randomised controlled trial. In the population setting, it is common to evaluate the impact of new programs or management guidelines, either using a cluster randomised design or, more simply, by tracking change in outcomes over time. Evaluative measures of HRQoL are required for this purpose. Many HRQoL measurement instruments have been designed for these settings, particularly asthma-specific HRQoL measures. The key attributes of these measurement instruments is that they are valid measures of change in HRQoL and that they are responsive to within-subject change in the HRQoL attributes (Kirshner & Guyatt 1985).

2.2.3 Prediction

Predictive instruments are used in HRQoL measurement either to predict the result in another measure or to forecast an outcome at a future time (Feeny et al. 1999). These can be useful for assisting in decision making processes, classifying individuals entering a study or

identifying those who are likely to develop a particular outcome (Kirshner & Guyatt 1985). Predictive HRQoL measures might be used to predict future health needs and economic impacts. For example, Eisner et al. (2002) conducted a prospective cohort study aiming to determine the effectiveness of HRQoL measures for identifying those at risk of adverse health outcomes. This study measured HRQoL using the Short-Form 12 questions (SF-12) and the Integrated Therapeutics Group Asthma Short Form (ITG-ASF) battery measurement instruments to test HRQoL as a predictor of future health care utilisation based upon the subjects' current asthma status and known risk factors for health care utilisation. It found that people with better baseline asthma-specific HRQoL scores had a significantly lower risk of all cause hospitalisation.

2.3 Types of HRQoL measures

2.3.1 Generic and specific HRQoL measures

The focus of the content within an HRQoL instrument may be on impacts that are relevant to a specific disease or, alternatively, on impacts that are relevant to a broad range of health conditions. Both generic and disease-specific instruments have a role in the assessment of HRQoL. Generic questionnaires aim to assess the impact of any and all adverse health states on HRQoL, without reference to the impacts of any specific disease. Disease-specific HRQoL instruments measure the specific impacts of the target disease.

Generic HRQoL measurement instruments can be used to assess overall HRQoL in all individuals in the study population. The strength of these instruments is that all members of the population, including those with no illness and those with a range of different illnesses, are measured on the same scale. It therefore allows comparison of HRQoL outcomes between population groups with different diseases.

Reference values, based on the scores in healthy individuals, have been derived for some generic HRQoL questionnaires (Mishra & Schofield 1998). This facilitates the assessment of the HRQoL of subgroups, such as those with asthma, relative to other members of the population or relative to reference values (Ware & Gandek 1998). The limitation of these questionnaires is that they may not adequately focus on those aspects of HRQoL that are particularly relevant to the people with a particular disease and, hence, may lack sensitivity in relation to the impacts of a specific disease.

Specific measurement instruments are designed for specific diagnostic or population groups, such as people diagnosed with asthma. The rationale for these questionnaires is that they will be more relevant and more sensitive to differences between population subgroups and responsive to changes over time (Patrick & Deyo 1989). Disease-specific profiles or health indexes are widely recognised as useful tools for assessing the impact of asthma, and particularly for evaluating the impact of interventions to ameliorate the condition.

In population-based monitoring the important limitation of disease-specific instruments is that they are only applicable to people with that condition in the population and, unlike generic instruments, cannot be used to compare HRQoL with the general population or with other diseases or population groups. However, in order to achieve a time series that can be used to monitor changes in disease outcomes over time and allow comparison between subgroups or populations with a particular condition, there is value in using disease-specific measures. These are more sensitive to the specific HRQoL issues of concern in the subpopulation with the disease of interest.

Another possible limitation of some disease-specific measures is that they may not be accurate in attributing impacts to the specific disease in question. This is not an issue when the impact is unique to a specific disease (e.g. wheeze, or embarrassment about inhaler use, for people with asthma) but may be a problem when the adverse outcome could have many possible causes (such as tiredness or time away from work or school). Respondents may inadvertently underestimate or overestimate the importance of a specific cause for these non-specific adverse outcomes.

2.3.2 Utility scales

Utility-based measures of HRQoL differ from all other types of HRQoL measures in one fundamental way; they value health as well as describing it. The HRQoL instruments described in other sections of this chapter are designed to quantify a respondent's perception of his or her own current health state, in terms of a set of standardised questions and responses. These instruments are often explicitly multi-dimensional, with a separate summary score for each dimension, and although various dimensions of health are described, their relative value is not captured. Health states in utility instruments are also described in terms of a number of dimensions, but the value of each health state is summarised as a single index. This utility index incorporates the relative value of the component dimensions and levels of health, and reflects respondents' preferences for different health states. However, the value that is linked with a particular health state is not necessarily the value of a particular individual, nor do respondents necessarily value their own health state.

The theories and methodologies underlying utility-based measures are rooted in economic theories of decision making, and the measurement methods are conceptually and operationally complex. Consistent with the conceptual framework used in this report, utility-based measures are summarised here in terms of what is being measured, why it is being measured and how it is measured.

Utility measures include a defined set of health states, covering a wide range from worst to best possible health. The values associated with a particular health state are called health state preference scores or utility weights. Under a set of strong assumptions, utility is a cardinal scale, with an absolute zero (death). Full health is given a value of one, and states worse than death are possible. However, interval scale properties have not been proven empirically (Cook et al. 2001).

Measurement in the utility-based approach has two parts: one describes the relevant health states and the other ascribes utility values to those health states. Multi-attribute utility indices (MAUI) describe health states systematically in terms of a series of domains (or 'attributes') and levels, similar to a HRQoL profile. The number of health states defined by a MAUI is a function of the number of items and response options. For example, the generic utility instrument EQ-5D (formerly known as EuroQoL), describes health states in terms of five domains (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression), each of which has three levels (e.g. no pain, moderate pain, extreme pain) (Rabin & de Charro 2001). Thus, the EQ-5D describes a total of 243 health states, representing all possible 3^5 combinations of those domains and levels. MAUIs can be used like HRQoL profiles to allow individual patients to describe their own current health state in terms of the domains and levels in the MAUI. The health states described by MAUIs may not be suitable for a particular research study. In this case, health states may be described in a series of vignettes specific to the particular research context.

The second component in the utility-based approach ascribes utility weights to health states. Three methods commonly used for valuing health states are the standard gamble (SG), time trade off (TTO), and the visual analogue (VAS) (see Glossary). SG and TTO are cognitively complex and must be administered by a trained interviewer. Determining utility weights is, therefore, labour-intensive and expensive, which may explain why Australian weights are available for only one MAUI, the Assessment Quality of Life Instrument (AQoL). Some MAUIs define an enormous number of health states, and it is not always feasible to value all of them. Instead, their value is interpolated from the values of a subsample of health states, using an algorithm that combines the utility associated with each dimension into an overall utility index, either algebraically or by statistically modelling. Thus, the utility weight associated with a particular health state in a MAUI represents a very complex synthesis of a sample of respondents' valuations.

A key question in the valuation exercise is: 'Whose preferences and values matter?' Decisions about the allocation of health budgets require a societal perspective and may warrant values from a general population, while decisions about best treatment may be better informed by people who have experienced the health condition, whether personally or vicariously via a friend or relative. People who have experienced a poor health state tend to value it more than do people without such experience. Arguably, only people who have experienced a health state can value it truly, but on the other hand they may over-value it. This conundrum cannot be resolved, and is perhaps a conceptual limitation of the utility approach. A pragmatic solution may be to recognise that values from different perspectives may differ, and to choose the appropriate perspective and sample from which to determine utility weights for a particular decision context.

Most of the widely used MAUIs have published general population-based utility weights. However, the validity of the MAUI within a specific population depends, in part, on the extent to which the weights are applicable to that population. Most sets of weights have been derived in British or North American populations. The AQoL is the only MAUI with utility weights from an Australian sample.

2.4 Attributes of HRQoL measures

Attributes of HRQoL measurement instruments that are important for population health monitoring include validity, reliability, responsiveness, sensitivity and interpretability. In addition, practical issues such as cost and the suitability for use in special populations need to be considered when evaluating available HRQoL measures. Table 2.2 summarises the attributes of HRQoL measures as they relate to the purposes of measuring HRQoL.

2.4.1 Validity

Since HRQoL cannot be directly observed, it cannot be directly quantified. Validation is a process of establishing the extent to which an instrument measures what it is intended to measure (in this case, HRQoL) (Fayers & Machin 2000; Streiner & Norman 2001). The ability of HRQoL instruments to measure HRQoL accurately can be addressed through assessment of content validity, criterion validity and construct validity.

Content validity refers to whether an instrument adequately covers the topic being measured (Streiner & Norman 2001). The method used to derive the content of the questionnaire is relevant to its content validity. For instance, the use of psychometric techniques to sample content adequately from the HRQoL domains of interest contributes evidence of content

validity (Kaplan et al. 1976). Face validity is related to content validity and assesses the extent to which the items within the instrument appear, to the person interpreting the data, to both encompass, and be limited to, the range of topics relevant to impacts on HRQoL.

Criterion validity refers to the degree of agreement of the measure with a gold standard (or 'criterion'). This is not possible in relation to HRQoL measurement instruments, as there is no gold standard. In quality of life research, comparisons of test instruments with longer in-depth interviews exploring the domain the instrument purports to measure are sometimes used as assessments of criterion validity (Fayers & Machin 2000).

Construct validity refers to whether the measurement instrument produces findings that are consistent with expectations based on the hypothetical model (or construct) that underpins the instrument (Kaplan et al. 1976; Kirshner & Guyatt 1985). Determining construct validity is an ongoing process whereby the larger the body of supporting evidence confirming expectations for a construct, the stronger the construct validity. In HRQoL measurement for asthma, correlations between HRQoL measurement instruments and markers of severity have been used to support the construct validity of some measurement instruments (Marks et al. 1992, 1993).

2.4.2 Reliability

The assessment of reliability examines the extent to which a measurement instrument has reproducible and consistent results, and encompasses internal consistency and repeatability (Fayers & Machin 2000). Internal consistency refers to the degree to which items within a measurement instrument are interrelated and measure the same thing. The correlation between items within the instrument can be statistically assessed, with the most widely used statistic for assessing internal consistency being Cronbach's α (Cronbach 1951). Internal consistency is an important attribute of all scales that are scored, as it is a prerequisite for valid interpretation of the overall score.

Repeatability refers to the level of agreement between repeated administrations under the same conditions (test–retest reliability), usually over a short time interval. It is quantified for each item and for the overall questionnaire using the kappa statistic, for binary and categorical outcomes, and the intraclass correlation coefficient, for continuous measures (Fleiss & Cohen 1973). Repeatability is a major consideration in the population monitoring context as surveys are almost always periodically repeated.

2.4.3 Responsiveness and sensitivity

Responsiveness is the ability of an instrument to detect change within individuals over time, and sensitivity is the ability of the instrument to detect differences between groups (Fayers & Machin 2000). Instruments in which a large proportion of respondents select the highest or the lowest response categories ('ceiling' and 'floor' effects) and those in which there is a large gap between the available levels, so that most respondents are clustered on either side of this gap, lack responsiveness and sensitivity. The importance of responsiveness and sensitivity depends on the purpose of the HRQoL measurement. Responsiveness is particularly important in evaluative instruments, which are commonly used in the clinical setting but not in population health surveys. Sensitivity is important in discriminative instruments.

In a population health survey, sensitivity is a key issue for detecting differences between groups in the population such as people with and without asthma. Sensitivity is also an important attribute of questionnaires used in repeated cross-sectional surveys to measure

change, over time, in a population because the individuals responding each time will differ. Therefore, sensitivity is generally more important than responsiveness in population health.

Table 2.2: Summary of attributes needed for the purposes of HRQoL measurements

Purpose of measurement	Validity	Reliability	Responsiveness / sensitivity	Example in people with asthma
Discriminative	Cross-sectional construct validity – relationship between the measure and external measures at a point in time	Internal consistency and test–retest repeatability	Ability to detect differences between subjects (sensitivity)	Health surveys to compare HRQoL in people with and without asthma or with severe and mild asthma
Evaluative	Longitudinal construct validity – relationship between changes in measure and external measures over time	Internal consistency is relevant to interpretation. Should be repeatable in subjects known to be stable but responsive in those who have changed.	Ability to detect within-subject changes over time (responsiveness)	Evaluation of an asthma self-management intervention Assessment of an asthma control program for school children Clinical trial for new asthma medication or treatment regimen
Predictive	Predictive validity – predictions based on the measures are proven correct	As for discriminative instruments	Not applicable	Classification of subjects into categories according to a criterion/gold standard measure Prediction of demand for health care services for asthma

Sources: Feeny et al. 1999; Guyatt et al. 1992; Kirshner & Guyatt 1985.

2.4.4 Interpretability

Interpretability has been defined as 'the degree to which one can assign qualitative meaning—that is, clinical or commonly understood connotations—to a quantitative score' (Lohr & Aaronson 1996). It is an essential attribute of any HRQoL instrument. Much as for validity, determining interpretability is an evolving process through accumulation of a body of evidence with repeated experience in a variety of contexts (Ware & Keller 1996).

The interpretation of HRQoL scores poses a number of difficulties. HRQoL means different things to different people at different times and in different contexts. A person's perception of his/her health state may change over time. Furthermore, the numeric values of HRQoL measurement scales are arbitrary and there are many different HRQoL instruments with their own scales, meaning it is difficult to standardise across measures (Gonin et al. 1996).

It is important to point out that statistical significance testing does not necessarily assist in interpreting the findings. A statistically significant result (for example, $p < 0.05$) indicates that the observed difference is unlikely to have occurred by chance. However, it does not convey any information about the size or meaning of the observed difference.

One approach to the interpretation of population data on HRQoL is to compare the observed levels to population normative values (see Figure 2.4), or alternatively, to the values seen in other diseases or other population groups. This gives a reference point or points, which the reader can use in interpreting the data for the disease and population under study (Osoba & King 2004).

2.4.5 Feasibility and practical issues

Population surveys are commonly administered by telephone, face-to-face interview or self-completion. Inclusion of HRQoL instruments within a survey necessitates that the instrument be compatible with the survey design. For example, the use of telephone interviews precludes the administration of visual analogue scales. Furthermore, the mode of administration may influence the outcome of the HRQoL measurements. Participants may respond differently in the anonymous setting of a self-completed questionnaire compared with a face-to-face interview.

A critical issue relating to survey design is respondent burden, that is the demand placed on respondents to participate in the survey. The number and complexity of survey questions largely determine the time required to complete the survey and, hence, the respondent burden. In telephone or interviewer-administered surveys, the time required to complete the survey also affects the cost of conducting the survey. In large health surveys, it is likely that HRQoL measures will be competing for survey space with a range of other measures, such as questions about service utilisation and disease management. For this reason there are limitations on the amount of time available for HRQoL questions in population health surveys. These limitations and costs need to be considered when selecting HRQoL measures for this purpose.

The time period over which participants are asked to recall events is also a major consideration in population surveys, particularly when comparing results between surveys. In relation to asthma, it is important that the time period be long enough to encompass some of the short-term variability that is inherent in the disease. However, as for all disease states, it is important that it not be so long that recall error is likely to occur.

2.4.6 Applicability to special populations

In addition to the general performance criteria described above, population monitoring measures used in Australia must be suitable for use in a culturally and linguistically diverse society. Methods for iterative forwards and backwards translation of questionnaires to obtain valid data in languages other than the original language have been described (Chwalow et al. 1992) and many of the widely used questionnaires have been translated into other European languages. However, translations into languages common within the Australian community are less widely available. Furthermore, simple linguistic translation may not be adequate. It seems likely that cultural differences in attitudes, values and beliefs would influence the content of domains of HRQoL that are appropriate to measure. Under some circumstances it may be advantageous to develop questionnaires that are specifically appropriate to cultural groups.

Adult Indigenous Australians report diagnoses of asthma more commonly and have higher rates of hospitalisation for asthma than non-Indigenous adults (ACAM 2003). It is likely that assessing the quality of life impact of asthma and other diseases among Indigenous Australians poses some specific challenges in developing measures that are linguistically and culturally sensitive and appropriate. In a study of urban Indigenous Australians, family and spiritual beliefs were important determinants of perceptions of health (King et al. 1999). Other issues are similar to those seen in non-Indigenous communities in Australia (Freidoon Khavarpour confirmed this by email on 11 November 2003). Therefore, the inclusion of the spiritual domain in a measurement instrument may be a consideration when measuring HRQoL in this population.

A similar issue arises in relation to differing age groups: the content of quality of life domains differs through the phases of life. This has been recognised, to a limited extent, with the development of child-specific HRQoL questionnaires and some adolescent questionnaires. However, in general, issues of the elderly have not been specifically addressed in asthma-related quality of life questionnaires.

2.5 Breadth and depth of HRQoL measures

Within the broad types of HRQoL measurement instruments exist instruments of differing levels of breadth (coverage) and depth (precision), ranging from single item (single question) and very brief questionnaires to comprehensive, multi-item, multi-dimensional HRQoL profiles. These are described in the following sections and summarised in Figure 2.1

Coverage of an instrument can be evaluated in terms of its content validity (Section 2.4.1), while precision (or reliability) is related to responsiveness and sensitivity as well as internal consistency (Sections 2.4.2 and 2.4.3). In population monitoring, sufficient precision is needed to discriminate subgroups.

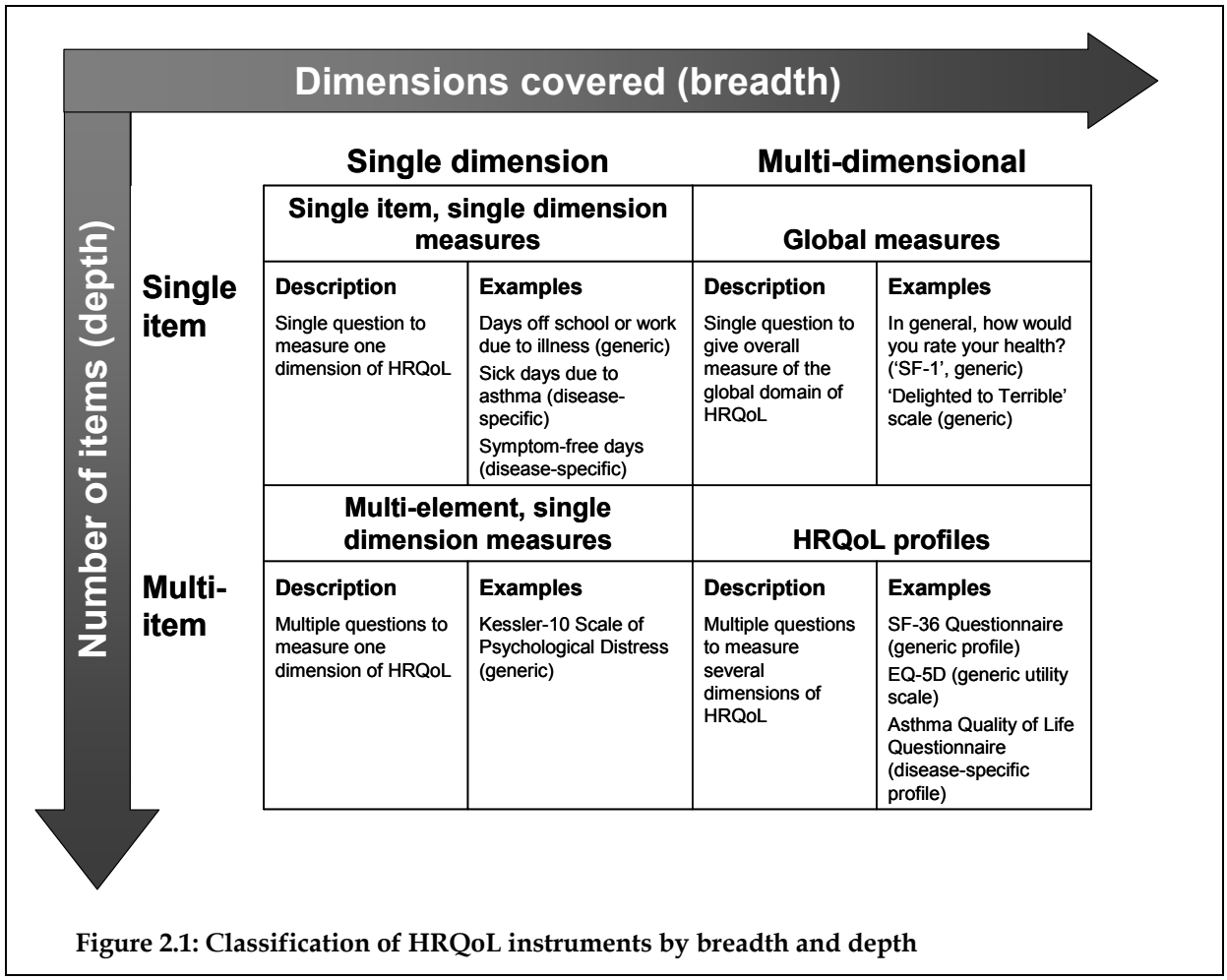


Figure 2.1: Classification of HRQoL instruments by breadth and depth

2.5.1 Single item and brief measures

The broadest and simplest class of HRQoL measures are those that endeavour to summarise the domains and dimensions of HRQoL simultaneously in a single question (sometimes referred to as global domain measures). A widely used example is the question 'In general, would you say your health is excellent, very good, good, fair or poor?' sometimes referred to as the 'SF-1'.

Brief global measures have the advantage of being simple to use with low respondent burden (the effort and time required for a respondent to answer) and this can be particularly attractive in large-scale population surveys where there are many questions competing for space in the survey and each question adds substantially to the costs. Furthermore, global measures of self-perceived health status have been shown to be predictive of mortality (Heidrich et al. 2002; Idler & Benyamini 1997; Miilunpalo et al. 1997). This supports the construct validity of these measures.

The main disadvantage of single item or very brief instruments is that the content, although it may be broad ranging or global in intent, does not adequately sample from a comprehensive range of HRQoL dimensions and may not adequately reflect all the relevant domains for all individuals. Using one question is vulnerable to influence by the respondents' individual interpretations of the question, and is also unable to provide detail about the dimensions of HRQoL that may have influenced the response. These measures do not provide information about the relative impact on the individual physical, psychological and social domains of health (Sloan et al. 2002), and this limits their usefulness in terms of planning an appropriate response. These limitations relate to content validity (Section 2.4.1). A further disadvantage is that since they usually have only a small number of possible response options, the measurement range is coarse in relation to the underlying latent continuum of real health states in the population. The limited response options in single item measures reduces the instrument's precision and, hence, its sensitivity or ability to discriminate differences in HRQoL between population groups. Hence, due to problems with content validity, sensitivity and reliability, studies using these single item or very brief global instruments as the sole tool for assessing HRQoL should be interpreted with some caution (Bradley 2001; Jones et al. 1994).

Some single item measurement instruments only focus on a single HRQoL domain rather than HRQoL globally. Sick days due to asthma—that is, the number of days away from work or school or the number of reduced activity days due to asthma—and symptom-free days—that is, the number of days in which the subject does not experience asthma symptoms—are both examples of this form of disease-specific, single domain, single item measures for the impact of asthma (CDC 2000). These single item, single dimension measures may be more valid and sensitive for their intended purpose than the single item global measures, as long as their interpretation does not extend beyond the single domain or dimension that has been measured. As asthma is an episodic disease, it can be difficult to capture adequately the time-variable impacts in a single measure. Some of the single item, single dimension measures referred to above, such as sick days, unhealthy days or healthy days, represent a useful way to address this issue of time variability. However, they should *not* be interpreted as global measures of HRQoL impacts.

2.5.2 Multi-item and multi-dimensional HRQoL profiles

In contrast to single item or very brief HRQoL measures, HRQoL profiles that contain multiple items to measure multiple dimensions are able to assess the physical, psychological

and social domains of HRQoL more comprehensively (Testa & Simonson 1996). By measuring several dimensions (issues, or areas of interest) within each domain, such questionnaires may more relevant to the disease or intervention that is being investigated (Table 2.3). By including multiple items relevant to a domain, these questionnaires achieve greater precision in measuring that domain. In other words, multi-item, multi-dimension instruments generally measure HRQoL with greater content validity and precision than the single item or very brief questionnaires referred to above.

There are some circumstances when the purpose of monitoring may relate particularly to one domain of HRQoL. For example, in evaluating the impact of an intervention designed to reduce school absences due to asthma, it would be most appropriate to choose a measure with maximal validity, reliability and sensitivity in this dimension. Indeed, this may not be an asthma-specific questionnaire but rather a measure of overall absence from school. Similarly, an intervention addressing the psychological consequences of asthma might best be evaluated by using a psychological questionnaire. In other circumstances, the physical domain may be the focus of attention and one of the questionnaires which focuses on physical function would be most appropriate. The important issue is that investigators should be aware of the domains that are encompassed by the measures they use and, where possible, should select measures that target the domains that are relevant to their monitoring purpose.

Table 2.3: Summary of key HRQoL elements for assessing the impact of asthma

Core domains	Dimensions	Elements of HRQoL in people with asthma		
Physical	Symptoms, impairment in physical functioning, disability	• Tiredness • Restricted physical activity	• Impairment of physical functioning • Exercise limitations	• Symptom free days • Days limited in core activities
Psychological	Positive and negative affect, behaviour	• Distress • Anxiety • Depression • Fear	• Frustration • Coping with an attack • Dependence on sprays/medication	• Expression of being bothered by asthma • Embarrassment at taking medication
Social	Role performance, personal relationships	• Restriction in work and usual activities	• Sick days • Missed school days	• Contact with friends, relatives • Participation in social events

There are several approaches to scoring or summarising the information contained within multi-item (or multi-element) instruments. The psychometric approach is to extract meaning about dimensions and domains from a number of items or elements using a variety of statistical tools. A number of specific strategies are employed to select relevant items, group them in a meaningful way and combine information from responses to individual items to generate summary information (Juniper et al. 1997). This may yield an overall summary score or a profile of scores for specific dimensions, or both. These scores can be used to summarise the impact of having asthma on the core domains of HRQoL and make comparisons between different population groups. Psychometric measures provide quantitative information but can be used only to compare with data collected using the same scale.

There is no absolute reference or anchor point for psychometric scales and, hence, the meaning of any given scale score is unique to that scale. An alternative scoring approach is to quantify information about health status on a scale between perfect health and death. This approach is based on utility theory and is discussed in Section 2.3.2.

The main disadvantage of HRQoL profiles is that they are longer and, therefore, more expensive to implement. They also involve a greater respondent burden. Generally, longer measurement instruments are more precise. However, for population monitoring purposes, in which surveys are administered to large populations, the precision of multi-item profiles may be greater than that needed to distinguish population subgroups adequately or to detect clinically relevant change over time. Under these circumstances, shorter instruments may be adequate, as long as they have sufficient content validity; that is, they sample from all HRQoL domains. Consideration should be given to the balance between level of precision required and efficiency when selecting instruments for population monitoring.

2.5.3 Dynamic health assessment

Most of the multi-item instruments developed to date have been developed with classical psychometric theory. In this approach, a large pool of relevant items is developed, then various procedures and criteria are used to select a subset of the best items for inclusion in the instrument. The same items are then administered to every person every time the instrument is used. In this sense, these instruments are fixed or 'static'. As noted above, practical considerations dictate that relatively few items are used in many health applications.

Brief, static instruments have three important limitations. First, if the items represent a broad range of health, they are spread sparsely along the underlying latent continuum of real health states, producing a coarse, imprecise scale prone to measurement error. Poor precision in the measurement of each individual's health is not relevant when the purpose is to estimate the mean health status of a population; precise estimates of the mean are achieved by surveying very large samples. However, population surveys may also be used to investigate relationships among various factors, such as determinations of health. In this case, greater precision in the health measurement scale increases the power of subgroup analyses and regression.

Second, if the items are targeted at a limited range of health, representing only a portion of the underlying continuum, the resulting scale will suffer from ceiling or floor effects when used in subgroups whose true health lies outside the measured range. As noted above, ceiling and floor effects compromise the sensitivity of a scale to differences among patients and its responsiveness to change.

The third consideration is the integration of evidence across levels of health care, from population health monitoring through clinical research to individual patient management. These levels require different precision: instruments used to screen and monitor individual patients must be very precise to minimise classification errors and to detect individual changes reliably, while imprecise instruments are suitable for population health monitoring when errors at the individual level do not matter. The precision required for clinical trials and health services research falls somewhere between these two extremes. Instruments developed for one level are often not appropriate for another; they are either too long or too imprecise or they target the wrong part of the health range. For example, the SF-36 (with 36 items and eight domains) is suitable for clinical research, but it is not precise enough for use in individual patient management (McHorney & Tarlov 1995). Different instruments are often used at different levels, making it difficult to translate knowledge derived at one level to another level, and to link populations and policy to patients and practice.

Ideally, we would measure health on a common metric with a range of instruments that could be cross-calibrated and whose precision and content could be suited to the context and

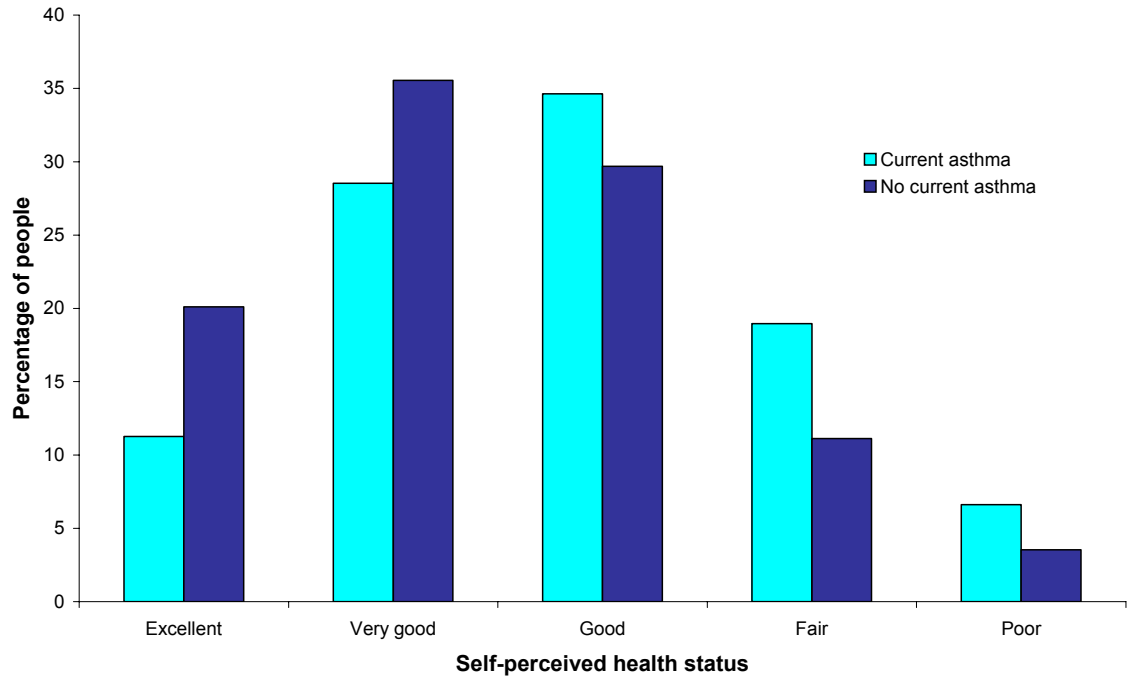
needs of the application. New research suggests this ideal may be achievable (Hays et al. 2000). There is growing appreciation of another psychometric approach, 'modern psychometrics', because of its potential to address the limitations of static instruments. This approach has the same starting point as does the classical psychometrics approach: it begins with a large pool of relevant items. This pool of items is then administered to a heterogeneous sample, representing the full spectrum of possible health states. Item response theory is then used to characterise each item in terms of where it sits along the latent health continuum and how sharply it discriminates among people in different states of health. The corresponding item response statistics calibrate items relative to the latent variable. A response to a single item, or any combination of items, can then be given a score which locates the respondent on a common metric. The more items that are asked, the more precisely the respondent is located on the latent continuum.

In this measurement approach, the only question common to every respondent at every assessment time is the first question. The second question is determined by the answer to the first, the third question is determined by the answer to the second, and so on. Thus, each respondent is asked questions that are relevant to their current state of health; people in good health are not asked questions about poor health and vice versa. This is in contrast to static instruments, where everyone is asked the same questions, including some that may not be at all relevant to some people. The number of questions asked depends on the precision required. Since the number and content of questions varies each time a subject's health is assessed, this approach is called 'dynamic health assessment'. The iterative, logical process that determines which and how many items are used is suited to computer administration. Initially developed for educational applications, this was called computer adaptive testing; now it is being applied to health assessment it is called dynamic health assessment (Bayliss et al. 2000).

This new dynamic approach overcomes a number of the limitations of traditional, static health assessment. First, it matches precision to the assessment context, allowing the same (albeit dynamic) instrument to be used for monitoring patients and populations, resolving the problem of interpretation across the three levels of health care described above. Second, it optimises the number of questions asked with respect to the information needs and purpose of the assessment, resolving past tension between respondent burden and precision. Third, it ensures the content is relevant to the respondent, facilitating compliance with questionnaire completion. Fourth, it allows existing static instruments to be calibrated to a common metric, resolving the problem of interpretation across different instruments.

The implications for population health are that dynamic assessment will allow the most efficient allocation of a quota of questions to the competing topics of interest in a survey, and will maximise interpretability and, hence, usefulness of the ensuing data.

One aspect of dynamic health assessment is currently identified as a potential concern and limitation: the assumption of unidimensionality in the underlying item response theory. This means the pool of items that the dynamic instrument draws from must pertain to a single aspect of health or HRQoL, the notional latent variable or underlying continuum. HRQoL is multi-dimensional; the challenge is to identify a complete set of distinct dimensions and to operationalise them in a way that is meaningful for people in different states of health and with different disease conditions or disabilities. While the potential and limitations of dynamic health assessment are not yet fully realised or understood, it is definitely worthy of further investigation (Cella & Chang 2000; Hambleton 2000).



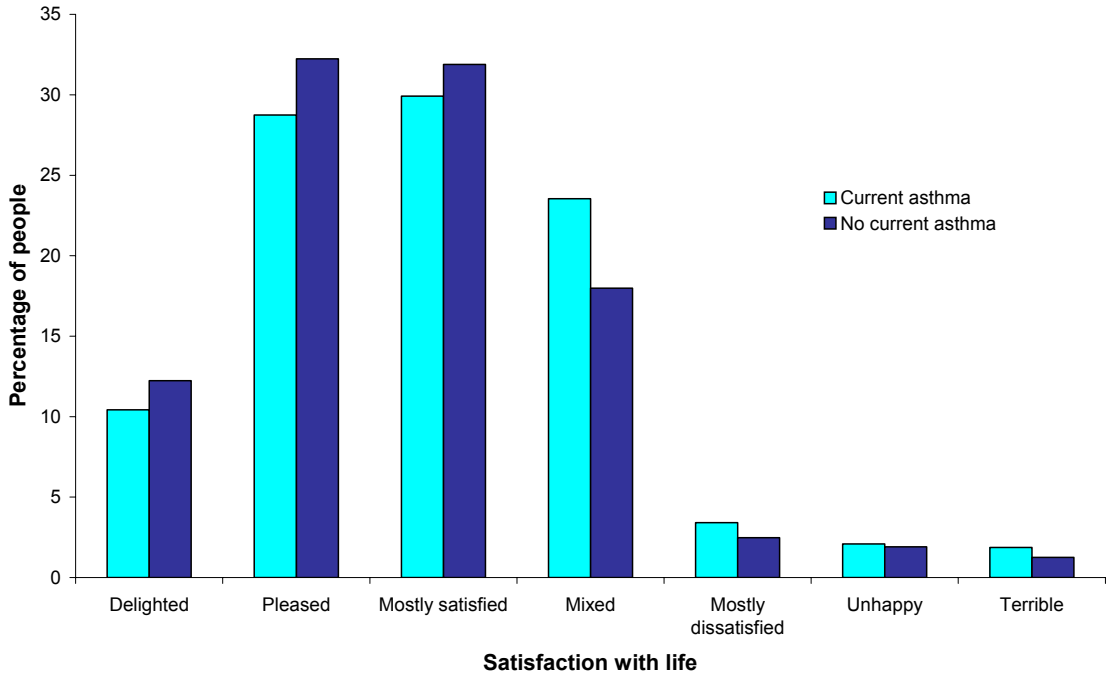
Source: ABS National Health Survey, 2001.

Figure 2.2: Self-reported health status by asthma status, age 18 years and over, Australia 2001

2.6 Examples of population monitoring of HRQoL: two Australian health surveys

Population health monitoring is usually accomplished through repeated cross-sectional surveys on selected health issues in a representative sample of the population or a subset of the population. These surveys afford the opportunity to compare HRQoL and other outcomes for different diseases with the general population norms for a broad range of population health data. The selection of items for inclusion can be based on identified health concerns, such as the National Health Priority Areas (AIHW & DHFS 1997), and behavioural factors, such as physical activity and diet, that are known to influence health. This section presents data collected in two population health surveys in Australia to demonstrate the use of a range of HRQoL measures. The findings are discussed in light of the strengths and weaknesses of the measures used.

In the 2001 National Health Survey (NHS), measures that related to HRQoL were the SF1 self-rated health status measure (five response options), and a question to rate life satisfaction (seven response options). These are examples of single item global measures, which are often used in large population surveys because of the minimal cost and time to implement such measures. Compared with people without current asthma, people with asthma were less likely to select the most positive response options and more likely to select negative response options for both of these questions (Figures 2.2 and 2.3).



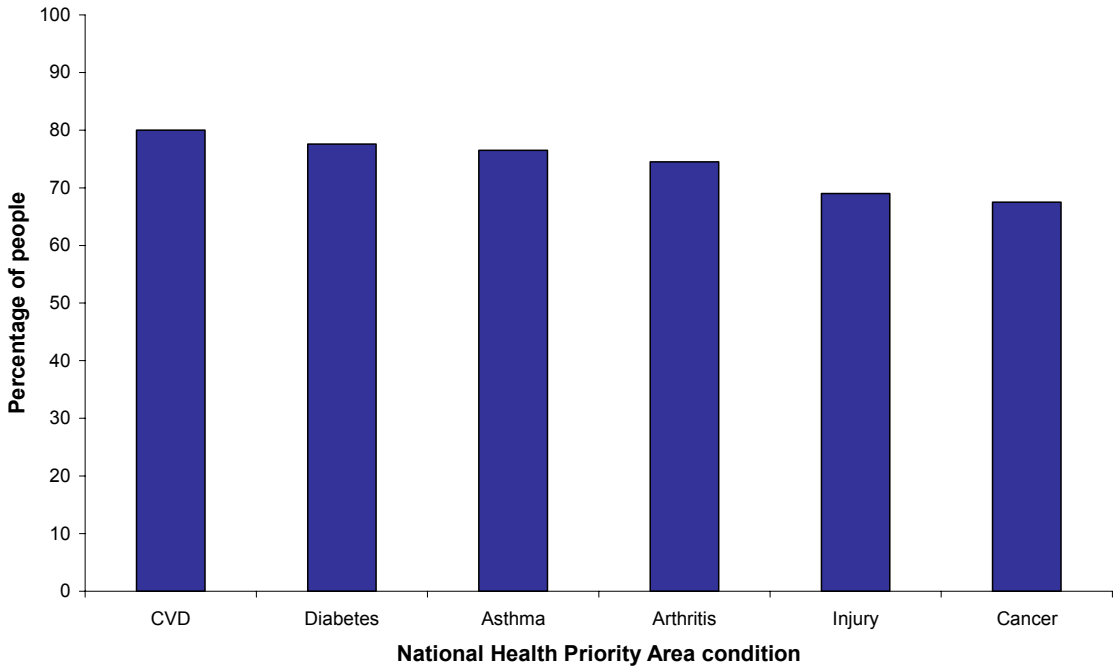
Source: ABS National Health Survey, 2001.

Figure 2.3: Satisfaction with life by asthma status, age 18 years and over, Australia 2001

The 2001 NHS also included single item, single dimension HRQoL questions:

- 'In the last 2 weeks, have you stayed away from your (work/school/place of study) for more than half the day because of any illness or injury you had?'
- 'In the last two weeks, have you had any other days of reduced activity?'

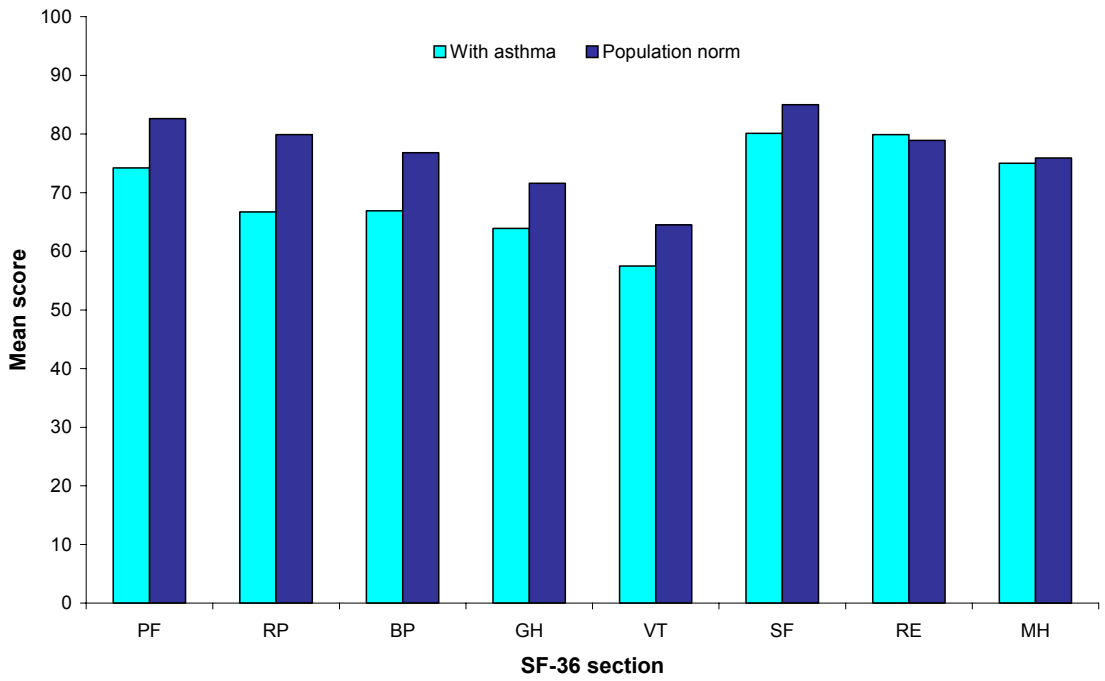
In Figure 2.4, these two questions were combined to create 'Any reduced activity days' and used to make comparisons among diseases that were the subject of National Health Priority Areas at that time. More than two-thirds of people who currently had the selected conditions reported reduced activity days in the last two weeks. The highest prevalence was in those with cardiovascular disease (CVD) and diabetes. People with asthma were more likely to report reduced activity days than those with arthritis, injuries or cancer. Unlike the global measures, this has a narrower focus on elements within HRQoL domains (Table 2.3).



Source: ABS National Health Survey, 2001.

Figure 2.4: Percentage of people with each National Health Priority Area condition reporting any reduced activity days, age 18 years and over, Australia 2001

The South Australian Health Omnibus Survey, conducted in 1998 among 3,010 adults sampled from the general population, incorporated the SF-36 questionnaire (Ware & Sherbourne 1992) to assess HRQoL (Wilson et al. 2002). This is an example of a multi-item, multi-dimensional HRQoL profile in a population survey. This instrument provides a profile of scores on eight HRQoL or health status dimensions (Ware & Sherbourne 1992). The information provided from this measure is able to indicate the relative impacts of asthma on the different HRQoL dimensions. Figure 2.5 shows that having current asthma reduces scores in most dimensions of the SF-36 compared with the population norm. However, the greatest impact was on physical dimensions, with little impact on emotional and mental health.



Note: PF—physical functioning, RP—role: physical, BP—bodily pain, GH—general health, VT—vitality, SF—social functioning, RE—role: emotional, MH—mental health. There was a significant difference between the mean scores of people in metropolitan areas with and without asthma for all domains ($p<0.001$ except for RE, where $p=0.003$).

Source: Wilson et al. 2002.

Figure 2.5: SF-36 scores in people with asthma and the population norm, age 15 years and over, South Australia, 1998

2.7 Selecting HRQoL measures for population monitoring

The conceptual framework developed in this chapter will be used in this section to derive principles that can guide the selection of HRQoL measures. In selecting instruments for measuring HRQoL in populations, it is important to identify those that are suitable for the intended monitoring purpose and context. The three commonly described purposes for measuring HRQoL are discrimination, evaluation and prediction (Section 2.2). These correspond to three key purposes of population monitoring which are discussed here: (1) Comparison of the impact of different diseases, (2) monitoring of changes over time and (3) economic evaluation. In this section, we provide guidelines to assist in the selection of measures for each of these purposes, focusing on monitoring the impact of asthma.

2.7.1 Comparisons of the impact of different diseases or health states

An advantage of population surveys is that they can collect information about many diseases and health states across a representative sample of the general population. Therefore, measuring HRQoL in these surveys can be used to make comparisons between different diseases and health states. This has value for understanding the relative burden that different

conditions have in the population and enables policy makers to determine how priorities should be set in the health care system. It also supports the development of interventions that will target those conditions that have the greatest impact in the population.

The measure used for this purpose should be discriminative, so that it is optimised for comparisons between groups in the population with different disease and health states. As it is also necessary to measure HRQoL without reference to specific diseases or specific disease manifestations, a generic HRQoL measure is likely to be most appropriate. The content of the generic questionnaire should not only be interpretable to people with all states of ill-health but also encompass a comprehensive range of impacts, so that the specific effects of various diseases can be measured.

2.7.2 Monitoring changes over time

Another important reason for population health monitoring is to monitor changes in health outcomes over time in repeated cross-sectional surveys. This is used to examine the impact of changes in the physical, social and economic environment, and in disease management practices, and health and other policy.

The specific choice of an evaluative instrument (with high responsiveness) or a discriminative instrument (with high reliability and sensitivity) depends on the study design. In a cohort study, where the same subjects are being monitored over time, an evaluative instrument is required. However, in a repeated cross-sectional study design, in which different subjects are surveyed at each time point, a sensitive, discriminative instrument is required.

There is value in using disease-specific measures in order to achieve a time series that can be used to monitor changes in a disease outcome over time and allow comparison between subgroups or populations with a particular condition. It is also important that the scope of content of the selected instrument is well matched to the expected effects of the interventions or exposures it is required to evaluate or monitor. For example, where the purpose is to monitor the impact of an asthma policy intervention, a disease-specific questionnaire that focuses on asthma will be more responsive than a generic questionnaire, in which scores will be heavily influenced by impacts that are not relevant to the asthma policy intervention (Marks et al. 1993; Rutten-van Molken et al. 1995).

2.7.3 Resource allocation

A third purpose of monitoring HRQoL in population surveys is to generate information that can be used to guide decision making processes by forecasting an outcome at a future time, such as future health needs and economic impacts (Feeny et al. 1999), or by identifying those who are likely to develop a particular outcome (Kirshner & Guyatt 1985). For this purpose, the measure should be suitable for predictive functions and should be measured on a scale that can be incorporated into economic analysis.

In economic evaluation, the consequences of health care programs or treatments are compared with their costs (Drummond et al. 1997). Health outcomes are key components of such analyses, where the aim is to determine which programs or treatments are worth funding, given the alternative uses of resources. Utility-based approaches were developed for use in economic evaluations, and are generally used in this way, but are sometimes also used as outcome measures in their own right. Cost–utility analysis (CUA) requires that health outcomes are adjusted by utility weights, yielding units such as quality adjusted life years (QALYs). In CUA, utilities provide a common metric, allowing comparison across

diverse health conditions such as asthma, cancer and heart disease. Cost-effectiveness analysis (CEA) requires only that the outcomes are measured in the same units in the programs or treatments being compared. When HRQoL is the health outcome of interest, utilities may be an appropriate unit and are suitable for CEA because they integrate domains of HRQoL into a single index.

3 Evaluation of HRQoL measures used in asthma

Over the last 20 to 30 years there has been rapid development of HRQoL measurement instruments and this field continues to evolve. As described in the preceding Chapter, there are many options for HRQoL measurement, with strengths and weaknesses applying for different purposes. The challenge is to identify the instruments with attributes that are suited to the specific population health monitoring task.

There is an increasing appreciation of the benefits of using formally evaluated and well validated measures to assess HRQoL. Although a few surveys have used multi-item, multi-dimensional instruments such as the SF-36 (e.g. Wilson et al. 2002), most general health surveys have used single item measures, both global and single dimensional, for measuring HRQoL or health status. Some brief disease-specific measures (e.g. sick days due to asthma) have also been used. In most cases there has been little or no formal evaluation of the attributes of these brief or single item instruments. They have the benefit of low cost when used in large monitoring activities. However, in Chapter 2, the limitations of these instruments, including problems with sensitivity and content validity, were identified.

In this chapter, we present the findings of a systematic review of the attributes of instruments that have been used in population studies to assess the HRQoL impact of asthma.

3.1 Review inclusion criteria

The aim was to systematically review the attributes of HRQoL measurement instruments to assess their suitability for population health monitoring tasks. Studies evaluating the reliability and validity of generic and asthma-specific HRQoL measurement instruments were identified using Medline, World Wide Web and expert input. The HRQoL measurement instruments included in the review were:

- those used to investigate populations with asthma between 1991 and June 2004;
- those used in population studies (applied to generic measures only); and
- those with formal evaluation of attributes, including validity and reliability.

In addition, we included only asthma-specific measures that had been used by multiple research groups.

It is acknowledged that there are a number of important measures that did not meet these inclusion criteria. This is because this evaluation focused on measures that had been used in population-based studies in which asthma had been one of the focuses of investigation. This was necessary for identifying evidence relevant to asthma monitoring. However, these selection criteria resulted in the inclusion of a wide range of multi-dimensional measures. A list of measures that were considered but not included in the evaluation has been compiled in Appendix B with reasons for exclusion.

3.2 Framework for assessment of HRQoL measures

A systematic approach was developed to evaluate the HRQoL measurement instruments included in this review. The purpose was to identify measures that would be sensitive to differences between populations, subgroups and changes over time; include content that was relevant to HRQoL concerns of people with asthma and, hence, be valid as measures of HRQoL impact of asthma; and also be meaningful and useful in populations with and without asthma. The framework for describing, assessing and making recommendations relating to the suitability of these instruments for population monitoring is described in Table 3.1. This framework included a rating out of six stars (see Table 3.2.).

Table 3.1: Framework for assessing HRQoL measurement instruments

Type of instrument The type of HRQoL measurement instrument: global, profile or utility measure
HRQoL domains The domains included in instrument: global, physical, psychological and social
Content areas A description of the dimensions included in each instrument
Mode of administration How the instrument was administered (e.g. self-administered, interview, computer assisted telephone survey)
Respondent burden Time effort and other demands placed on those completing the instrument
Time recall The time period over which respondents were asked to recall events
Settings used The setting(s) in which the study using the instrument was conducted
Reliability ▪ Internal consistency: the extent to which elements of the questionnaire are measuring the same domain (quantified with Cronbach's α) ▪ Test–retest repeatability: the extent to which the repeated administration of the instrument under the same conditions results in similar scores (quantified with the interclass correlation coefficient—ICC)
Validity The degree to which an instrument measures what it is supposed to measure **Content validity** The extent to which the material covered by the instruments encompasses, and is limited to, the intended purpose of the questionnaire. Provides an evaluation of the processes used to derive the content of the instrument. This includes: ▪ Source of items: source from which items for the instrument were identified, such as from focus groups (qualitative methods) or previous questionnaires; and ▪ Method of selection of items: process used to select items for inclusion in the final instrument (e.g. psychometric methods such as factor analysis). **Construct validity** The extent to which the correlation with or difference from other measures, such as markers of disease severity, accords with theoretical expectations. **Criterion validity** Describes comparisons with a gold standard. This method of assessment is not applicable to the evaluation of HRQoL measures.
Responsiveness Describes evidence of the ability of an instrument to detect changes in individuals over time

(continued)

Table 3.1 (continued): Framework for assessing HRQoL measurement instruments

Sensitivity Describes evidence of the ability of an instrument to detect differences between populations / subgroups / repeated surveys
Australian data Identifies studies implementing the instrument in Australia
Other comments Any further information that informs the overall evaluation of the instrument
Usefulness for population monitoring A star rating system used to rate the usefulness of a measure for population monitoring based on six key questionnaire attributes (see Table 3.2)

A star rating system was adopted to summarise six attributes that were selected for their relevance for population health monitoring (Table 3.2). For respondent burden, HRQoL domains, construct validity and sensitivity, the ratings categories were based on the conceptual framework described in Chapter 2. For the reliability measures (test–retest and internal consistency) cut-offs for statistical values were used that were applicable to a population monitoring context (Streiner & Norman 2001). Good ratings were assigned a black star; moderate ratings, a white star; and poor ratings (or no data), no star. An overall rating was derived by adding all the stars, whereby two white stars were equated to one black star (see Tables 3.3, 3.4, 3.6 and 3.7).

In interpreting this information, it is important to consider the relevance of specific attributes to the population monitoring tasks (as discussed in Chapter 2). The rating used in this evaluation gave all attributes equal weighting; however, some users might choose to apply weights that reflect their own resources and priorities. For example, it is acknowledged in this report that respondent burden is a particularly important issue in a population monitoring context. However, we have chosen not to give this greater weight in our evaluation because, as suggested in Chapter 2, it needs to be balanced with other attributes. These and many of the issues that need to be considered in evaluating measures are discussed in the following sections.

Table 3.2: Evaluation rating system for HRQoL instruments

Attribute	★	☆	No star
Respondent burden (RB)	<3 minutes to complete, or approximately 1–5 items	3–9 minutes to complete, or approximately 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	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

Note: Where there was a range of values for an attribute for a questionnaire, the least favourable value was used as the basis for the rating.

3.3 Evaluation of measures in relation to monitoring tasks

The details of the review of the 30 evaluated HRQoL measures are contained in Appendix A. The star rating summary is reported in Table 3.3 (adult generic measures), Table 3.4 (adult disease-specific measures), Table 3.6 (childhood generic measures) and Table 3.7 (childhood asthma-specific measures). A more detailed interpretation of the evaluation is contained in subsequent sections.

3.3.1 Generic measures

The selection among generic measures of HRQoL represents a compromise between feasibility, on the one hand, and validity, reliability and sensitivity or discriminative capacity on the other. Single item measures are by far the most widely used generic measures of HRQoL in Australian population surveys. However, any single item measure is limited in content validity, reliability and sensitivity.

The SF-36 is a multi-item, multi-dimensional measure that has 36 questions, measures eight HRQoL dimensions and takes five to ten minutes to complete (Bousquet et al. 1994; McHorney 1993). The Sickness Impact Profile (SIP) has 136 questions, measures 12 dimensions and can take up to 30 minutes to complete (Bergner et al. 1981; Rutten-van Molken et al. 1995). Long, detailed HRQoL measurement instruments can be unattractive for use in large population health surveys because of respondent burden. This is a major limitation of the Sickness Impact Profile and is reflected in its infrequent use compared with the SF-36 in population-based studies.

More recently, shortened versions of the SF-36 have been developed such as the SF-12, which has 12 items (Ware et al. 1996). The SF-12 has been used in population studies and in people with asthma (Garratt et al. 2000) and rated relatively well in our evaluation (Table 3.3). These instruments reduce respondent burden and cost. However, the compromise is that they measure HRQoL with less precision than the longer version (Ware et al. 1996). This is more a limitation for individual monitoring, while for population monitoring they have the advantage of increased efficiency.

Healthy Days is another relatively short multi-dimensional HRQoL measure that has been used for several years in the United States Behavioural Risk Factor Surveillance System. It has four questions taking only one minute to complete. It also has a 14-question version (not included in evaluation, see Appendix B) (Hennessy et al. 1994). This measure has low respondent burden. However, its scope is restricted to the physical and psychological domains of HRQoL: 'focusing on the quality and functional impact of perceived physical and mental health during the immediate past.' (Hennessy et al. 1994:569).

Measures used to assess the impact of asthma should have a period of recall that is sufficiently long to capture intermittent symptom or exacerbation episodes but not so long that recall is unreliable. Although there is no clear evidence about appropriate recall period, clinical observation would suggest that two to four weeks may be optimal. The SF-36 and SF-12 have been evaluated for recall over the last four weeks and last week (acute). Similarly, Healthy Days measures health impacts over the last 30 days. The SIP focuses on 'today', making it less suitable for asthma monitoring based on this criterion.

Table 3.3: Ratings of usefulness for population monitoring: generic adult measures

Instrument	Respondent burden	HRQoL domains	Construct validity	Test–retest	Internal consistency	Sensitivity	Total (2☆=★)
EuroQol-5D (EQ-5D)	★	★	☆			☆	★★★
Healthy Days (CDC-HRQoL 4)	★	★	☆	★		☆	★★★★
Health Utilities Index Mark III (HUI)			☆			☆	★
Medical Outcomes Study, short form 36 (SF-36)		★	★	☆	★	☆	★★★★
Medical Outcomes Study, short form 12 (SF-12)	☆	★	★	★	★	☆	★★★★★
Nottingham Heath Profile (NHP)		★	☆		☆	☆	★★☆
Sickness Impact Profile (SIP)		★	☆	★	★		★★★☆

In summary, HRQoL profiles are not commonly used in population surveys due to respondent burden and cost. However, shorter profiles such as the SF-12 are more efficient for measuring all domains of HRQoL with acceptable validity, reliability and sensitivity and these may be used more widely in population health monitoring. An added advantage of the SF-12 is that it includes the single item health status measure often referred to as the SF-1 (Section 2.5.1), which has been used in many population surveys. Therefore, adoption of the SF-12 for population monitoring will not compromise time series based on the SF-1.

3.3.2 Disease-specific measures

In order to monitor changes in disease outcomes over time, there is value in using disease-specific measures, as these are more sensitive to the specific HRQoL issues of concern in the subpopulation with the disease of interest. The disease-specific measures for asthma that have been used in population surveys are mainly single item, single dimension measures such as 'sick days due to asthma' and 'nights woken due to asthma'. However, as noted in Chapter 2, these cannot be considered holistic measures of asthma-related quality of life. This can best be accomplished by including multi-item, multi-dimensional measures in asthma monitoring surveys. The questionnaires in Table 3.4 are potentially suitable for this task. Three of these have been extensively evaluated for use in adults with asthma: the St George's Respiratory Questionnaire (SGRQ) (Jones 1991), the McMaster Asthma Quality of Life Questionnaire (AQLQ-McMaster) (Juniper et al. 1992), and the Sydney Asthma Quality of Life Questionnaire (AQLQ-Sydney) (Marks et al. 1992). These measures were given relatively high ratings in our evaluation (Table 3.4). The original AQLQ-McMaster includes five items that are individually tailored to respondents. This design feature increases the instrument's responsiveness in longitudinal study designs, such as clinical trials. However, it makes it unsuitable for use in cross-sectional studies because the actual content of the questionnaire is not the same for all respondents. The Standardised AQLQ-McMaster (AQLQ(S)-McMaster) was developed to overcome this problem. It replaces the five variable items with five standardised items and this questionnaire is suitable for use in cross-sectional studies. However, this questionnaire has only recently been developed and has not been evaluated or used extensively at this point in time. Hence, Table 3.4 shows that the AQLQ(S)-McMaster did not rate as highly as the questionnaires referred to above.

In relation to respondent burden, the SGRQ contains more items (76) than theAQLQ-McMaster and the AQLQ-Sydney, and takes approximately 10 minutes to complete. The AQLQ-McMaster contains 32 items and takes 10–15 minutes to complete while the AQLQ-Sydney contains 20 items and takes around five minutes to complete. Therefore, the AQLQ-Sydney has the lowest respondent burden, which is an advantage when including the instrument as a component in a broader population health survey, and is reflected in its higher rating than the other measures. Briefer versions of both the AQLQ-McMaster (the Mini AQLQ-McMaster) (Juniper et al. 1999b) and the SGRQ (Paul Jones, personal communication) may make them more acceptable for use in large surveys. However, the Mini AQLQ-McMaster retains five non-standardised items, which makes it unsuitable for use in cross-sectional surveys.

The SGRQ was designed for use in people with both asthma and chronic obstructive pulmonary disease (COPD) whereas the other questionnaires are designed for use only in adults with asthma. This broader range of the SGRQ comes at the cost of less disease specificity and, hence, potentially less sensitivity and responsiveness (Sanjuas et al. 2002). The SGRQ, AQLQ-McMaster and AQLQ-Sydney have been mainly used in clinical populations of patients with asthma. However, some have been used in population-based samples of patients with asthma (Marks et al. 1997; Premaratne et al. 1999).

All three questionnaires have been shown to have good test–retest reliability: AQLQ-McMaster (intraclass correlation coefficient, ICC>0.9), SGRQ (ICC>0.9), and AQLQ-Sydney (ICC=0.8) (Appendix A: 49, 52, 57).

Of the disease-specific multi-item, multi-dimensional HRQoL questionnaires, the AQLQ-Sydney, which is the only one of these developed and tested in Australia, may be the most suitable for population monitoring purposes.

Table 3.4: Ratings of usefulness for population monitoring: disease-specific adult measures

Instrument	Respondent burden	HRQoL domains	Construct validity	Test–retest	Internal consistency	Sensitivity	Overall (2☆=★)
Asthma Quality of Life Questionnaire (McMaster) (AQLQ-McMaster)		★	★	★	★	★	★★★★★
Mini Asthma Quality of Life Questionnaire (McMaster) (Mini AQLQ-McMaster)	☆	★	☆	★	★		★★★★
Standardised Asthma Quality of Life Questionnaire (McMaster) (AQLQ(S)-McMaster)		★	☆	★	★	☆	★★★★
Sydney Asthma Quality of Life Questionnaire (AQLQ-Sydney)	☆	★	★	★	★	★	★★★★★☆
Asthma Symptom Utility Index (ASUI)	☆		☆	☆			★☆
Integrated Therapeutics Group Asthma Short Form (ITG-ASF)	☆	★	☆		★		★★★
Living with Asthma Questionnaire (Hyland) (LWAQ)		★	★	★	★		★★★★
Quality of Life for Respiratory Illness questionnaire (QoLRIQ)		★	☆	★	★		★★★☆
St George's Respiratory Questionnaire (SGRQ)		★	★	★	★	☆	★★★★☆

3.3.3 Utility scales

Utility measures were developed for use in economic evaluations. There are a number of generic multi-attribute utility indices (MAUIs), including the EQ-5D, the Health Utilities Index (HUI) (Furlong et al. 2001), the Assessment of Quality of Life (AQoL) (Hawthorne et al. 2001), and the SF-6D (Brazier et al. 1998) (see Table 3.5).

Of these, the EQ-5D is by far the most widely used with over 200 published papers relating to this instrument (reviewed in Brazier et al. 1998; Garratt et al. 2002; Hawthorne & Richardson 2001). The EQ-5D has been widely evaluated in the population context. The construct validity of this instrument as a measure of HRQoL is supported by comparison with the SF-12 and the SF-36 (Essink-Bot et al. 1997; Jenkinson et al. 1997; Johnson & Coons 1998; Johnson & Pickard 2000). Respondents who reported a problem on the EQ-5D scale also had lower mean scores in the corresponding dimensions of the SF-12 and SF-36. A major limitation identified in these studies was that the EQ-5D was prone to ceiling effects; that is, a high proportion of respondents had the highest possible score, which occurred when respondents reported no problem in all five dimensions. As a consequence, this instrument is relatively insensitive for discriminating differences in the general population where the majority of individuals do not have chronic illnesses (Guyatt et al. 1997). This represents a major limitation on the usefulness of the EQ-5D for population monitoring purposes, particularly in relation to asthma. The SF-6D is a relatively new instrument, but its derivation from the widely used SF-36 assures its wider use in the future. Disease-specific MAUIs have been developed to provide more sensitive measures for specific contexts. For example, the Asthma Symptom Utility Index (ASUI) was developed for clinical trials and cost-effectiveness studies in which reduction in symptom frequency and intensity is the primary clinical outcome (Revicki et al. 1998).

Table 3.5: Generic multi-attribute utility indices

	HUI Mark 3	EQ-5D	AQoL	SF-6D
Country of origin	Canada	United Kingdom	Australia	United Kingdom
Dimensions	8: hearing, speech, ambulation, dexterity, emotion, cognition, pain	5: self-care, usual activities, pain/discomfort, anxiety/depression	5: independent living, social relationships, physical senses, psychological wellbeing	6: role limitation, social function, bodily pain, mental health, vitality
No. of items	12	5	15	14
No. of response levels	4–6	3	4	2–6
No. of health states	972,000	243	1,073,741,824	9000
Sample for utility weights	General population	General population	General population	General population
Weights for Australia	No	No	Yes	No
Utility elicitation method	VAS/SG	TTO/VAS	TTO	VAS/SG
Utility algorithm form	Multiplicative	Regression/ Additive	Multiplicative	Additive
Range of utility weights	–0.36 to 1.00	–0.59 to 1.00	–0.04 to 1.00	+0.46 to 1.00

As noted previously, the validity of the MAUI within a specific population depends, in part, on the extent to which the weights are applicable to that population. The AQoL is the only MAUI with utility weights from an Australian sample. Thus, if any of the other MAUIs are used for Australian applications, subsequent decisions would be based on the utility weights of British, Canadian or American population samples and may not reflect the values of multicultural Australia. At this time, further work is required to develop a utility measure for use in people with asthma in Australian population monitoring.

3.3.4 Measuring HRQoL in children

Designing HRQoL indicators for children presents additional methodological challenges. A child's perspective on his or her wellbeing and functional status is dependent on the child's developmental stage and can differ greatly from the parents', carer's, or health professional's perspective (Jenney & Campbell 1997). Overall, the generic multi-item, multi-dimensional HRQoL scales that we reviewed (Table 3.6) were relatively long and, hence, had a substantial respondent burden, making them unsuitable for use in population monitoring surveys. They also tended to lack evidence for construct validity and test–retest reliability.

As for adults, there are circumstances in which it is important to measure HRQoL impacts that are specific to asthma. Several questionnaires that have been developed for this purpose are reviewed in Table 3.7. Probably the greatest challenge in measuring child and adolescent HRQoL is not only to capture the individual perspective, but also to accommodate the physical, emotional, and social changes that occur as the child develops and understands the concepts that are being addressed (Christie et al. 1993). The Childhood Asthma Questionnaires (French et al. 1998) are divided into three age groups: 4–7 years, 8–11 years and 12–16 years. This approach acknowledges that the issues relating to asthma and HRQoL are different in different stages of childhood. These measures rated moderately well in relation to other childhood measures for asthma. However, there may be insufficient power to detect differences for items that are relevant to a small age range in a sample from the general population, and none of the questionnaires rated well on the respondent burden criterion. Furthermore, the inclusion of self-completed and visual components in the administration of these surveys could be incompatible with some population health survey designs such as those administered by telephone. The particular advantages of this measurement instrument are that part of it can be administered to children without asthma, for comparison, and that it has been adapted for use in the Australian context (French 1996).

Table 3.6: Ratings of usefulness for population monitoring: generic childhood measures

Instrument	Respondent burden	HRQoL domains	Construct validity	Test–retest	Internal consistency	Sensitivity	Total (2☆=★)
Child Health and Illness Profile—Adolescent Edition (CHIP-AE)		★		☆	★	☆	★★★
Child Health Questionnaire Parent Form 50 (CHQ-PF50)		★		☆	☆	☆	★★☆
Child Health Questionnaire Parent Form 28 (CHQ-PF28)		★	☆			☆	★★
Pediatric Quality of Life Inventory (PedsQL)		★	☆		★	☆	★★★

Another example of an asthma-specific HRQoL instrument for use in children is the Pediatric Asthma Quality of Life Questionnaire (PAQLQ) (Juniper et al. 1996). This contains 23 items and takes approximately 10 minutes to complete, which, while rating low on the respondent burden criterion, is shorter than most childhood measures. It also has the advantage in population monitoring of being designed for children with asthma across a wide age range (7–17 years) and addresses the physical, psychological and social domains of health with scores for HRQoL dimensions in symptoms, activity limitations and emotional function. The child can self-complete the questionnaire (providing he or she has appropriate reading skills) or it can be administered via interview with the child.

The Adolescent Asthma Quality of Life Questionnaire (AAQLQ) (Rutishauser et al. 2001) also rates relatively highly, is designed for the 12–17 year age range, and has 32 items taking 5–7 minutes to complete. The instrument with lowest respondent burden in the evaluation of children's measures is the Integrated Therapeutics Group Child Asthma Short Form (ITG-CASF) (Bayliss et al. 2000) with only eight items. However, this instrument rates poorly in other criteria, including that the content is restricted to the physical and social domains.

The PAQLQ may be a preferable choice for population monitoring because, despite moderate respondent burden, it is designed for use across a wide age range. The AAQLQ may also be suitable for studies limited to the adolescent age range.

Table 3.7: Ratings of usefulness for population monitoring: asthma-specific childhood measures

Instrument	Respondent burden	HRQoL domains	Construct validity	Test–retest	Internal consistency	Sensitivity	Total (2☆=★)
About My Asthma		★		☆	★		★★☆
Adolescent Asthma Quality of Life Questionnaire (AAQLQ)		★	★	★	★		★★★★
Childhood Asthma Questionnaire A (CAQ-A)			★	☆	☆	☆	★★☆
Childhood Asthma Questionnaire B (CAQ-B)		★	★	★	☆	★	★★★★☆
Childhood Asthma Questionnaire C (CAQ-C)		★	☆	★	☆	★	★★★★
Children's Health Survey for Asthma (CHSA)		★	☆	☆	★		★★★
How Are You? (HAY)		★	☆	☆	★	☆	★★★☆
Integrated Therapeutics Group Child Asthma Short Form (ITG-CASF)	☆		☆		★	★	★★★
Paediatric Asthma Quality of Life Questionnaire (PAQLQ)		★	★	☆	★	☆	★★★★
Pediatric Quality of Life Asthma Module (PedsQL-Asthma Module)		★	☆		★		★★☆

4 Conclusions

The ideal instrument would be all things to all people: it would have both discriminative and evaluative power, being sensitive to differences between people and responsive to changes over time; it would be short enough for practical use in population health monitoring and precise enough for monitoring individual patients; and it would cover the complete range of real health states, from the sickest of the sick to the fittest of the fit. In this chapter we present alternative approaches to population monitoring using currently available HRQoL measures and then discuss the direction in which further developments of HRQoL measures for population monitoring purposes might usefully proceed.

4.1 Approaches to monitoring using currently available measures

Population health monitoring, for all purposes, traditionally involves measures that are implemented in large numbers of subjects: either in sample surveys, such as the National Health Survey, or in routine data collections, such as Health Insurance Commission data. This common feature has the important practical consequence that the cost of collecting HRQoL information (or any other information) increases substantially with the length and complexity of the data collection instrument. This tends to be the dominant factor in choosing the appropriate measure. Multi-item questionnaires and, in particular, multi-item, multi-dimensional questionnaires, are usually costly to implement in these large-scale monitoring activities and single item or very brief instruments are preferred.

However, it is important to recognise that there are costs, in terms of the value of the information, in using single item measures. The major costs are in loss of validity, reliability and sensitivity. Single item measures are limited in content validity because they do not sample adequately from each of the HRQoL domains. Single item global measures have a comprehensive scope. However, without explicit reference to the physical, psychological and social domains of HRQoL, these measures may not reflect all these domains in all respondents. Single item, single dimension questions clearly do not reflect all the domains of HRQoL impact. For example, questions about reduced activity days reflect the physical domain of HRQoL but give little information on other domains. Questions about school or work absence are even more limited in their coverage of HRQoL domains. Generally, single item measures also have a limited range of response options. Hence, the discriminant ability or sensitivity of these measures is generally poor and they are vulnerable to measurement error. This also explains the potential lack of reliability of single item measures. Even in very large surveys, these single item measures may be incapable of detecting differences that are smaller than the discriminating ability of the question.

Is there an alternative to using single item or brief measures in large health surveys to monitor the HRQoL impact of asthma? One alternative is to compromise and use shorter versions of the multi-item measures, for example the SF-12, that have intermediate cost and respondent burden and levels of validity, reliability and sensitivity that are usually adequate for population monitoring purposes.

Another alternative is to undertake more detailed surveys in smaller samples of the population using multi-item, multi-dimensional profiles or utility scales. These give a comprehensive coverage of the relevant domains of quality of life and are generally sensitive

to differences between subgroups and tend to be responsive to change over time. This increased sensitivity and responsiveness translates to greater study power and allows differences and changes to be detected with relatively small population samples.

The use of more comprehensive, multi-item questionnaires in relatively smaller population samples is particularly appropriate when the HRQoL issue to be addressed is specific to the population with asthma. An initial large survey may be used to identify a representative population of people with asthma, for whom a more detailed, asthma-specific multi-dimensional HRQoL questionnaire can be implemented. This approach is useful for measuring changes over time in the HRQoL impact of asthma and for measuring differences between subgroups of people with asthma.

Even when it is required to compare HRQoL impacts in people with and without asthma or with other diseases, this general approach may still be appropriate. A larger survey may be conducted to select smaller samples of subjects with asthma and without asthma (or with other conditions). However, for this purpose an asthma-specific questionnaire would not be suitable but a generic, multi-item, multi-dimensional profile would be appropriate. This nested design, with comprehensive multi-item questionnaires, is recommended for monitoring tasks that require comparisons between people with asthma and people without asthma.

Another solution to address the practical constraints of including multi-item HRQoL profile measures in large population surveys is to incorporate these measures in full, but with less frequency. It is likely that population measures of HRQoL every five years or so, for example, would be sufficient to monitor the impact of health status on HRQoL. This approach, using comprehensive HRQoL incorporated into population health surveys, is recommended for providing comparisons between different diseases and would eventually produce valuable time series. Of course, it would not necessarily be appropriate in cohort studies, particularly among children, as changes in individuals may occur over a much shorter time period.

4.2 Future directions

The limitations of using static questionnaires for population health monitoring relate to the trade-off between breadth and depth; that is, the range of aspects of health covered and the precision with which each aspect is measured. In population monitoring, long questionnaires that can measure HRQoL precisely are generally impractical. The solution has been to develop shorter questionnaires. However, these are less reliable and less sensitive or discriminatory.

Currently, there are research activities in 'modern psychometric methods' that are developing new approaches to testing HRQoL (Rosier et al. 1994). One of these approaches is termed 'dynamic health assessment' and has been described in Section 2.5.3. This approach combines item response theory (Ware et al. 1999) with a computer-aided selection from a battery of available questions to give maximum precision with maximum efficiency. These measures require sophisticated computerised algorithms to implement, referred to as 'computerised adaptive testing', which is still being developed in health outcomes applications. Also, further work is required in the application of the item response approach in relation to asthma-specific outcomes. Development of this methodology offers the promise of valid, precise and sensitive measures that will be feasible for implementation in large-scale population surveys administered with computer assistance.

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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