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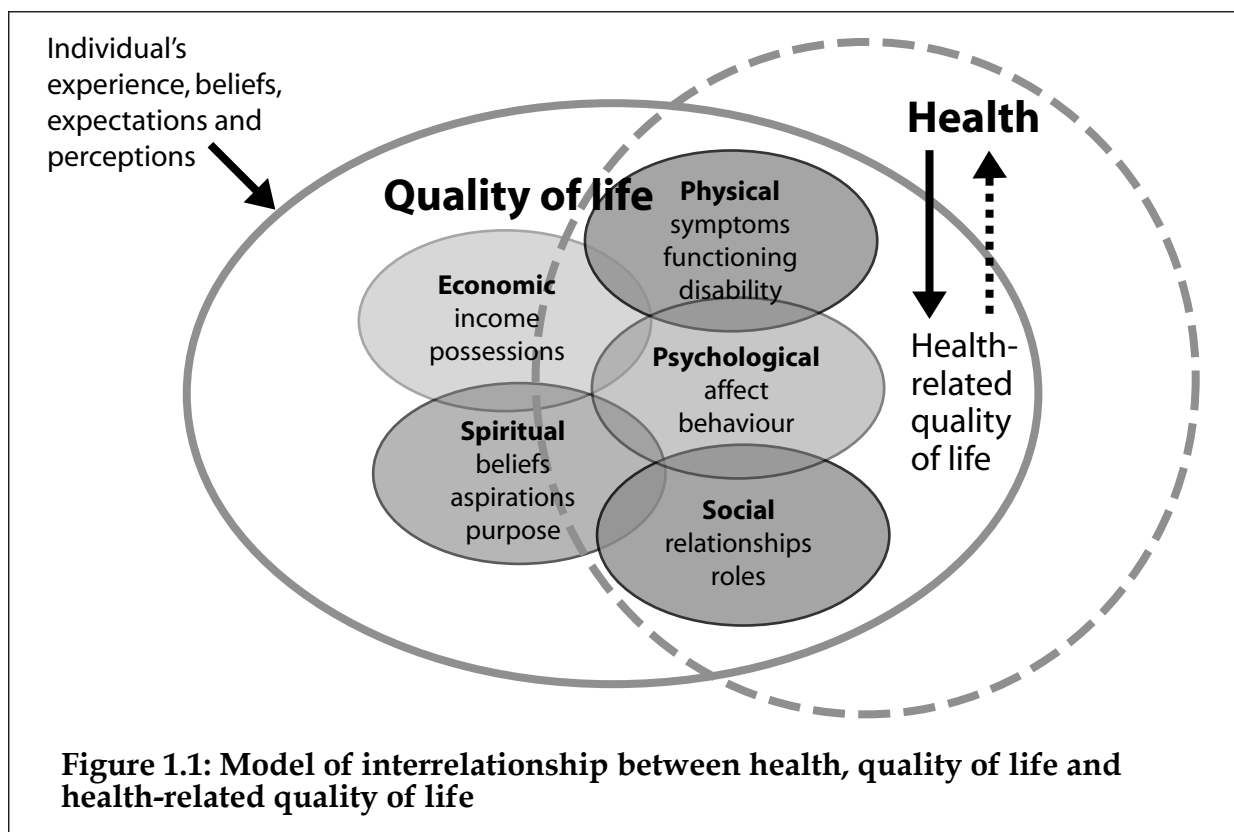
It has been suggested that some measures of HRQoL are really measuring how people assess the 'quality of their health' or 'health status' and are not measuring how health impacts on their wellbeing (Bradley 2001). For example, a woman who is aware that she has a chronic illness may assess her health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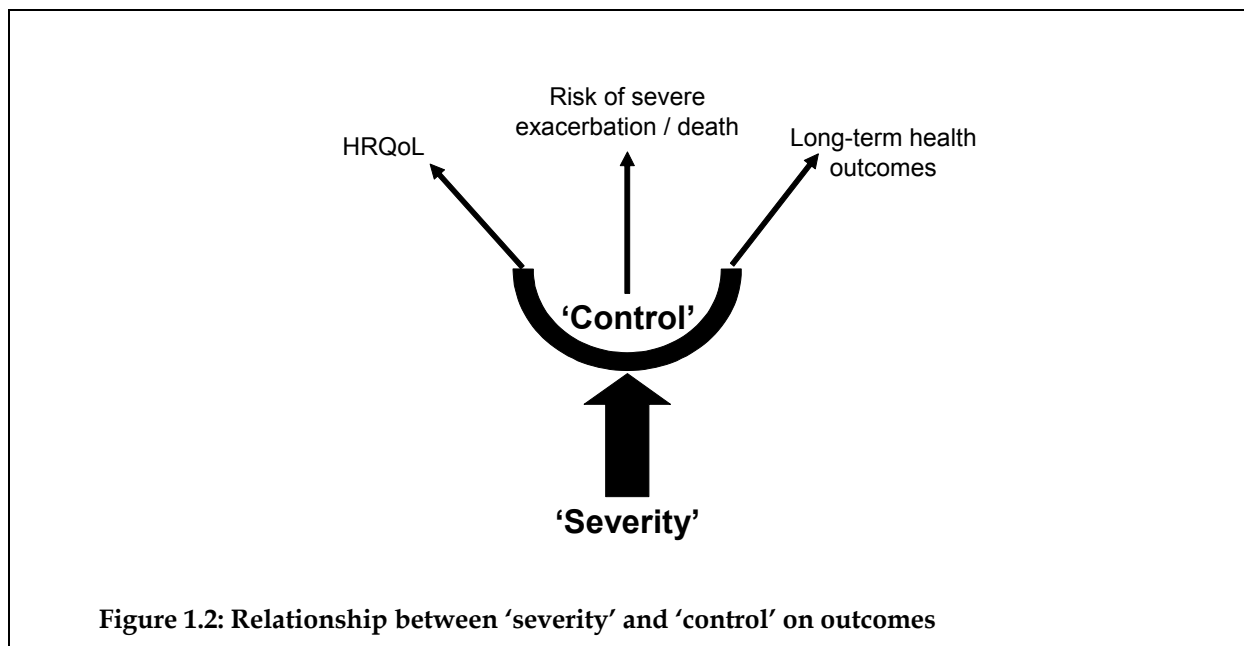

Figure 1.2: Relationship between 'severity' and 'control' on outcomes

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.