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

Australian Centre for Asthma Monitoring
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Australian Centre for Asthma Monitoring
Woolcock Institute of Medical Research

December 2004

Australian Institute of Health and Welfare
Canberra
AIHW cat. no. ACM 3
The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is ‘better health and wellbeing for Australians through better health and welfare statistics and information’.
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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Contents

Foreword ............................................................................................................................................... v
List of tables and figures.............................................................................................................. viii
Contributors .................................................................................................................................. ix
Acknowledgments........................................................................................................................ x
Abbreviations............................................................................................................................... xi
Executive summary ....................................................................................................................... xiii
Recommendations......................................................................................................................... xiv

1 HRQoL measures .......................................................................................................................... xiv
2 Approaches to population monitoring of HRQoL ................................................................. xiv
3 HRQoL measures in children ....................................................................................................... xv
4 Further research .......................................................................................................................... xv

1 Introduction ...................................................................................................................................1
   1.1 Objectives ..........................................................................................................................1
   1.2 Health-related quality of life ...............................................................................................1
       1.2.1 Why measure HRQoL? .............................................................................................2
       1.2.2 Components of HRQoL ...........................................................................................2
       1.2.3 Relation to disability .................................................................................................3
   1.3 Population health monitoring .............................................................................................4
       1.3.1 Current monitoring activities in Australia .................................................................4
       1.3.2 Challenges in monitoring asthma .............................................................................5

2 Conceptual framework for measuring HRQoL in asthma.....................................................8
   2.1 How does asthma affect HRQoL? ......................................................................................8
   2.2 Purposes of measuring HRQoL ..........................................................................................10
       2.2.1 Discrimination ...........................................................................................................10
       2.2.2 Evaluation ................................................................................................................10
       2.2.3 Prediction ..................................................................................................................10
   2.3 Types of HRQoL measures ..................................................................................................11
       2.3.1 Generic and specific HRQoL measures ......................................................................11
       2.3.2 Utility scales .............................................................................................................12
   2.4 Attributes of HRQoL measures ..........................................................................................13
       2.4.1 Validity ......................................................................................................................13
       2.4.2 Reliability ..................................................................................................................14
       2.4.3 Responsiveness and sensitivity .................................................................................14
       2.4.4 Interpretability ..........................................................................................................15
       2.4.5 Feasibility and practical issues ..................................................................................16
List of tables and figures

Table 2.1: Impact of asthma on HRQoL for the individual and family.................................9
Table 2.2: Summary of attributes needed for the purposes of HRQoL measurements ......15
Table 2.3: Summary of key HRQoL elements for assessing the impact of asthma.........19
Table 3.1: Framework for assessing HRQoL measurement instruments.........................29
Table 3.2: Evaluation rating system for HRQoL instruments..........................................30
Table 3.3: Ratings of usefulness for population monitoring: generic adult measures ..........................................................32
Table 3.4: Ratings of usefulness for population monitoring: disease-specific adult measures ..........................................................................................................................33
Table 3.5: Generic multi-attribute utility indices................................................................34
Table 3.6: Ratings of usefulness for population monitoring: generic childhood measures 35
Table 3.7: Ratings of usefulness for population monitoring: asthma-specific childhood measures ..................................................................................................................................36
Table A1: Key to abbreviations and star rating system of usefulness for population monitoring ........................................41
Table A2: Generic adult HRQoL measures ........................................................................42
Table A3: Asthma-specific adult HRQoL measures..............................................................49
Table A4: Generic childhood HRQoL measures..................................................................58
Table A5: Asthma-specific childhood HRQoL measures.....................................................62
Table B1: Summary of measures excluded from evaluation: generic measures ............72
Table B2: Summary of measures excluded from evaluation: asthma-specific measures....72

Figure 1.1: Model of interrelationship between health, quality of life and health-related quality of life .................................................................3
Figure 1.2: Relationship between ‘severity’ and ‘control’ on outcomes............................6
Figure 2.1: Classification of HRQoL instruments by breadth and depth .........................17
Figure 2.2: Self-reported health status by asthma status, age 18 years and over, Australia 2001 .................................................................22
Figure 2.3: Satisfaction with life by asthma status, age 18 years and over, Australia 2001 ...23
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 ....24
Figure 2.5: SF-36 scores in people with asthma and the population norm, age 15 years and over, South Australia, 1998 .........................................................25
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Acknowledgments

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Valuable guidance was received from the members of the Management Committee of the Australian System for Monitoring Asthma during the drafting of this report. Their input is greatly appreciated.

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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
FEV₁  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
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ITG-ASF</td>
<td>Integrated Therapeutics Group Asthma Short Form</td>
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<tr>
<td>ITG-CASF</td>
<td>Integrated Therapeutics Group Child Asthma Short Form</td>
</tr>
<tr>
<td>LWAQ</td>
<td>Living with Asthma Questionnaire (Hyland)</td>
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<td>MAUI</td>
<td>Multi-attribute Utility Index</td>
</tr>
<tr>
<td>MCS</td>
<td>Mental components summary</td>
</tr>
<tr>
<td>Mini AQLQ-McMaster</td>
<td>Mini Asthma Quality of Life Questionnaire (McMaster)</td>
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<tr>
<td>NHP</td>
<td>Nottingham Health Profile</td>
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<tr>
<td>NHS</td>
<td>National Health Survey</td>
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<tr>
<td>PAQLQ</td>
<td>Paediatric Asthma Quality of Life Questionnaire</td>
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<tr>
<td>PCS</td>
<td>Physical components summary</td>
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<tr>
<td>PedsQL</td>
<td>Pediatric Quality of Life Inventory</td>
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<tr>
<td>PedsQL-Asthma Module</td>
<td>Pediatric Quality of Life Asthma Module</td>
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<tr>
<td>Pop.</td>
<td>Population</td>
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<tr>
<td>QALYs</td>
<td>Quality adjusted life years</td>
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<tr>
<td>QoL</td>
<td>Quality of life</td>
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<tr>
<td>QoLRIQ</td>
<td>Quality of Life for Respiratory Illness Questionnaire</td>
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<tr>
<td>RB</td>
<td>Respondent burden</td>
</tr>
<tr>
<td>S</td>
<td>Sensitivity</td>
</tr>
<tr>
<td>SA</td>
<td>South Australia</td>
</tr>
<tr>
<td>SF-36/12</td>
<td>Medical Outcomes Study Short-form 36/12</td>
</tr>
<tr>
<td>SIP</td>
<td>Sickness Impact Profile</td>
</tr>
<tr>
<td>SG</td>
<td>Standard gamble</td>
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<tr>
<td>SGRQ</td>
<td>St George’s Respiratory Questionnaire</td>
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<tr>
<td>TTO</td>
<td>Time trade-off</td>
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<tr>
<td>T-R</td>
<td>Test-retest</td>
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<tr>
<td>VAS</td>
<td>Visual analogue scale</td>
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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 evaluations that 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.