

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

Australian Centre for Asthma Monitoring

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

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'*.

© Australian Institute of Health and Welfare 2004

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part may be reproduced without prior written permission from the Australian Institute of Health and Welfare. Requests and enquiries concerning reproduction and rights should be directed to the Head, Media and Publishing, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601.

A complete list of the Institute's publications is available from the Publications Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601, or via the Institute's web site (<http://www.aihw.gov.au>).

ISBN 1 74024 433 8

Suggested citation

Australian Centre for Asthma Monitoring 2004. Measuring the impact of asthma on quality of life in the Australian population. AIHW Cat No. ACM 3 Canberra: AIHW.

Australian Institute of Health and Welfare

Board Chair
Hon. Peter Collins, AM, QC

Director
Dr Richard Madden

Any enquiries about or comments on this publication should be directed to:

Australian Centre for Asthma Monitoring
Woolcock Institute of Medical Research
GPO Box M77
Missenden Road
Camperdown NSW 2050
Phone: (02) 9515 6578 (International +61 2 9515 6578)
Fax: (02) 9516 1207 (International +61 2 9516 1207)
Email: acam@asthmamonitoring.org.au

Cover design by Lauren Di Salvia, AIHW
Published by Australian Institute of Health and Welfare
Printed by Elect Printing

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.

Guy B Marks

Director

Australian Centre for Asthma Monitoring

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

2.4.6	Applicability to special populations	16
2.5	Breadth and depth of HRQoL measures	17
2.5.1	Single item and brief measures.....	18
2.5.2	Multi-item and multi-dimensional HRQoL profiles	18
2.5.3	Dynamic health assessment	20
2.6	Examples of population monitoring of HRQoL: two Australian health surveys	22
2.7	Selecting HRQoL measures for population monitoring.....	25
2.7.1	Comparisons of the impact of different diseases or health states	25
2.7.2	Monitoring changes over time.....	26
2.7.3	Resource allocation.....	26
3	Evaluation of HRQoL measures used in asthma	28
3.1	Review inclusion criteria.....	28
3.2	Framework for assessment of HRQoL measures	29
3.3	Evaluation of measures in relation to monitoring tasks.....	31
3.3.1	Generic measures.....	31
3.3.2	Disease-specific measures	32
3.3.3	Utility scales	34
3.3.4	Measuring HRQoL in children.....	35
4	Conclusions.....	37
4.1	Approaches to monitoring using currently available measures	37
4.2	Future directions	38
	Glossary.....	39
	Appendix A: Evaluation of HRQoL measurement instruments	41
	Appendix B: Excluded measures	72
	References.....	73

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

Contributors

The following staff were responsible for the preparation of this report:

From the Australian Centre for Asthma Monitoring:

Patricia Correll

Guy Marks

Leanne Poulos

Margaret Williamson

From the Centre for Health Economics Research and Evaluation:

Madeleine King

The following staff from the Australian Centre for Asthma Monitoring also provided input into this publication:

Rose Ampon

Deborah Baker

Anne Foyer

Acknowledgments

Australian System for Monitoring Asthma

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.

Committee members

Professor Norbert Berend, Woolcock Institute of Medical Research

Dr Kuldeep Bhatia, Australian Institute of Health and Welfare

Professor Donald Campbell, Asthma Australia

Dr Ching Choi, Australian Institute of Health and Welfare

Professor Peter Gibson (Chair), John Hunter Hospital, Newcastle

Professor Richard Henry, Sydney Children's Hospital, Randwick

Dr Christine Jenkins, National Asthma Reference Group

Ms Monica Johns, Department of Health and Ageing

Dr Paul Magnus, Australian Institute of Health and Welfare

Associate Professor Guy Marks, Australian Centre for Asthma Monitoring

Professor Charles Mitchell, University of Queensland

Mr David Muscatello, National Health Information Management Group

Mr Robin Ould, National Asthma Council

Professor Richard Ruffin, The Queen Elizabeth Hospital, University of Adelaide

Ms Anne Taylor, National Computer Assisted Telephone Interview Technical Reference Group

Other contributors

Peer reviewers

Valuable comments and suggestions were also received from the following individuals who reviewed the discussion paper that preceded this final report:

Ms Catherine Chittleborough, Department of Human Services, South Australia

Ms Ros Madden, Australian Institute of Health and Welfare

Ms Janet Sansoni, Australian Health Outcomes Collaboration

Dr Rima Staugas, National Asthma Reference Group

Associate Professor Theo Vos, Centre for Burden of Disease and Cost Effectiveness, University of Queensland

Associate Professor David Wilson, The Queen Elizabeth Hospital, University of Adelaide

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 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.

