Enhancing asthma-related information for population monitoring

Asthma data development plan
2005
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Enhancing asthma-related information for population monitoring

Asthma data development plan 2005

Australian Centre for Asthma Monitoring
Woolcock Institute of Medical Research

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**Abbreviations**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AAP</td>
<td>asthma action plan</td>
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<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<td>ACAM</td>
<td>Australian Centre for Asthma Monitoring</td>
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<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>BEACH</td>
<td>Bettering the Evaluation and Care of Health</td>
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<tr>
<td>CATI</td>
<td>Computer-Assisted Telephone Interview</td>
</tr>
<tr>
<td>CATI TRG</td>
<td>Computer-Assisted Telephone Interview Technical Reference Group</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
</tr>
<tr>
<td>ED</td>
<td>emergency department</td>
</tr>
<tr>
<td>GP</td>
<td>general practitioner</td>
</tr>
<tr>
<td>HIC</td>
<td>Health Insurance Commission</td>
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<tr>
<td>ICD</td>
<td>International Classification of Diseases</td>
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<tr>
<td>ICD-9</td>
<td>International Classification of Diseases version 9</td>
</tr>
<tr>
<td>ICD-9-CM</td>
<td>International Classification of Diseases version 9, Clinical Modification</td>
</tr>
<tr>
<td>ICD-10</td>
<td>International Classification of Diseases version 10</td>
</tr>
<tr>
<td>ICD-10-AM</td>
<td>International Classification of Diseases 10th revision, Australian Modification</td>
</tr>
<tr>
<td>NAC</td>
<td>National Asthma Council</td>
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<tr>
<td>NHPA</td>
<td>National Health Priority Area</td>
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<tr>
<td>NHS</td>
<td>National Health Survey</td>
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<tr>
<td>SAND</td>
<td>Supplementary Analysis of Nominated Data</td>
</tr>
<tr>
<td>VAED</td>
<td>Victorian Admitted Episodes Dataset</td>
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<td>VEMD</td>
<td>Victorian Emergency Management Dataset</td>
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Executive summary

This document proposes a plan for further development of asthma-related data for population monitoring purposes. It extends the Review of proposed National Health Priority Area asthma indicators and data sources (Baker et al. 2004), published in February 2004. That review assessed the value of a range of indicators for asthma and produced a set of recommended indicators for monitoring asthma in Australia. Some of these indicators are able to be monitored using currently available data. However, for others, more data development is required. This document identifies the steps necessary to enable monitoring of those indicators.

Indicators have been categorised into two groups based on the level of development required:

- **Level 1**: Indicator definition established and nationwide data source identified.
- **Level 2**: Indicator definition established but no existing nationwide data source identified.

For several Level 1 indicators, further studies and analyses are recommended to validate data. For Level 2 indicators, a range of projects is proposed that will develop and assess data sources for these indicators. These issues are summarised in Tables 1 and 2.

The plan proposes the establishment of collaborative links between the Australian Centre for Asthma Monitoring (ACAM) and other agencies, where appropriate, to facilitate the process of asthma data development. In many instances, several indicators have similar data development issues involving the same agency. At the end of this document, the projects that are relevant to each of the key data users and data providers are listed. It is strongly recommended that data development be driven through the formation of collaborative groups involving these users and providers of data. For example, six of the indicators have projects proposed that require development of cross-sectional survey questions for implementation in state health surveys (Computer-Assisted Telephone Interviews) and the National Health Survey. This highlights the need for a working group with the relevant parties and ACAM to oversee a coordinated approach to the development of survey questions that will provide data for these indicators.

The Review of proposed National Health Priority Area asthma indicators and data sources (Baker et al. 2004) highlights the importance of monitoring the incidence of occupational asthma, the prevalence of airway hyperresponsiveness (an objective marker of asthma prevalence), the costs of asthma to individuals with the disease, the extent of utilisation of lung function measurements in people with asthma and the level of asthma control in people who have the disease. As it is not feasible to measure any of these potential indicators on a nationwide scale at present, they are not assessed in this document.

The process described here represents a stage in the development of asthma data. As our knowledge about asthma, its risk factors, and improved management strategies develops, other indicators may be required to address new issues.
<table>
<thead>
<tr>
<th>Indicator</th>
<th>Description</th>
<th>Data source</th>
<th>Suggested approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence of ever having doctor-diagnosed asthma</td>
<td>The prevalence rate of ever having doctor-diagnosed asthma per 100,000 resident population</td>
<td>ABS NHS and CATI surveys</td>
<td>No further development required</td>
</tr>
<tr>
<td>Death rate for asthma, ages 5 to 34 years</td>
<td>Death rate in people aged 5 to 34 years where the underlying cause of death is asthma (ICD-10-AM codes: J45, J46) per 100,000 resident population</td>
<td>AIHW National Mortality Data Collection</td>
<td>Examination of multiple causes of death data Coding validation studies</td>
</tr>
<tr>
<td>Death rate for asthma, all ages</td>
<td>Death rate in people all ages where the underlying cause of death is asthma (ICD-10-AM codes: J45, J46) per 100,000 resident population</td>
<td>AIHW National Mortality Data Collection</td>
<td>Examination of multiple causes of death data Coding validation studies</td>
</tr>
<tr>
<td>Hospital separations for asthma</td>
<td>Hospital separation rate for asthma (ICD-10-AM codes: J45, J46) per 100,000 resident population</td>
<td>AIHW National Hospital Morbidity Database</td>
<td>Assessment of the impact of coding changes on hospital admissions for asthma as primary and secondary diagnoses</td>
</tr>
<tr>
<td>Hospital patient days for asthma</td>
<td>Hospital patient days attributable to asthma (ICD-10-AM codes: J45, J46) per 100,000 resident population per year</td>
<td>AIHW National Hospital Morbidity Database</td>
<td>Assessment of the impact of coding changes on hospital patient days for asthma as primary and secondary diagnoses</td>
</tr>
<tr>
<td>Rate of smoking in people with asthma</td>
<td>The proportion of people aged 18 years or over who have current asthma and who smoke any tobacco product weekly or more frequently per 100,000 resident population</td>
<td>State CATI surveys</td>
<td>Support the use of survey questions that have been shown to be reliable and can be used in conjunction with questions to monitor the prevalence of current asthma</td>
</tr>
<tr>
<td>Rate of asthma-related general practice encounters</td>
<td>Rate of asthma-related general practice encounters per 100 resident population</td>
<td>BEACH data and HIC MBS statistics</td>
<td>No further development required</td>
</tr>
<tr>
<td>Rate of Asthma 3+ Visit Plan Practitioner Incentive Program payments</td>
<td>Rate of payments for completed Asthma 3+ Visit Plan Practitioner Incentive Program payments per 100,000 resident population</td>
<td>HIC health statistics</td>
<td>No further development required</td>
</tr>
<tr>
<td>Proportion of schools using the Asthma Friendly Schools Program</td>
<td>Proportion of schools recognised as using the Asthma Friendly Schools Program</td>
<td>State Departments of Education Australian Department of Health and Ageing Asthma Australia</td>
<td>No further development required</td>
</tr>
</tbody>
</table>
Table 2: Development of NHPA asthma indicators proposed by ACAM, 2004: Level 2 indicators

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Description</th>
<th>Suggested approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevalence of current asthma</td>
<td>Prevalence rate of people ever diagnosed with asthma who have experienced symptoms of asthma (wheeze, shortness of breath or chest tightness) or taken treatment for asthma in the last 12 months per 100,000 resident population</td>
<td>Development of survey questions to monitor ACAM definition</td>
</tr>
<tr>
<td>Prevalence of wheeze in the preceding 12 months</td>
<td>Prevalence rate of wheeze or whistling in the chest in the previous 12 months per 100,000 resident population</td>
<td>Development of survey questions</td>
</tr>
<tr>
<td>Prevalence of smoking in households where children with asthma reside</td>
<td>The proportion of children aged under 15 years who live in a household where people smoke and who (a) have current asthma or (b) have had wheeze in the previous 12 months</td>
<td>Development of survey questions and National Health Data Dictionary definitions</td>
</tr>
<tr>
<td>Individuals with one or more hospital separations for asthma</td>
<td>Rate of having one or more hospital separations for asthma in a year per 1,000 resident population</td>
<td>Obtain and analyse linked data sets</td>
</tr>
<tr>
<td>Hospital re-admissions for asthma</td>
<td>Hospital re-admission rate for asthma per 1,000 resident population</td>
<td>Obtain and analyse linked data sets</td>
</tr>
<tr>
<td>Hospital re-attendance for asthma within 28 days</td>
<td>Number of people discharged with a principal diagnosis of asthma (ICD-10-AM J45 or J46) who re-attend at an emergency department (ED) and/or are re-admitted to hospital within 28 days with a diagnosis of asthma</td>
<td>Obtain and analyse linked hospital and ED data and improve ED data coverage</td>
</tr>
<tr>
<td>Asthma-related ED attendance</td>
<td>Rate of hospital ED attendances for asthma per 100,000 resident population</td>
<td>Improve ED data coverage</td>
</tr>
<tr>
<td>Proportion of people with asthma who have an asthma action plan</td>
<td>Proportion of people with current asthma who have an individualised, written asthma action plan with the four essential components, developed in consultation with a health professional, per 100,000 resident population</td>
<td>Development of survey questions</td>
</tr>
<tr>
<td>Proportion of people with asthma who use preventers regularly</td>
<td>Proportion of people with asthma who use a preventer medication regularly</td>
<td>Development of survey questions</td>
</tr>
<tr>
<td>Impact of asthma on quality of life</td>
<td>Proportion of people with asthma who report poor health-related quality of life</td>
<td>Identification of appropriate data sources to measure quality of life measures as recommended in separate ACAM report on this subject</td>
</tr>
</tbody>
</table>
Introduction

Asthma was made a National Health Priority Area (NHPA) in Australia in 1999, and the Australian Centre for Asthma Monitoring (ACAM) was established in 2002 to develop a system for population-based monitoring of asthma. As an initial step, ACAM undertook a review of NHPA asthma indicators that had been proposed from a workshop conducted in August 2000 by the Australian Institute of Health and Welfare (AIHW) (AIHW 2000). ACAM also accessed a wide range of administrative and research data collections from federal and state agencies and other sources, including industry, and published the most comprehensive record of asthma statistics ever compiled in Australia (ACAM 2003).

The outcomes of the indicator review and the lessons learnt through the compilation of asthma data were published in *Review of proposed National Health Priority Area asthma indicators and data sources* in February 2004 (Baker et al. 2004). This report assessed the feasibility and value of the proposed indicators, and where possible, provided data definitions and identified data sources. In addition, the report proposed a number of new indicators for monitoring asthma and highlighted issues that need to be resolved before appropriate indicators can be incorporated into an asthma-monitoring system.

This data development plan follows on from the two previous reports and presents proposals for projects to enable the development of appropriate indicators and/or data sources to inform asthma-monitoring needs.

It is important to note here that this report does not present an exhaustive and permanently relevant listing of indicators for asthma monitoring. There are many environmental and lifestyle factors that are linked to the occurrence of asthma or to exacerbations of asthma and there will be circumstances in which it is appropriate to measure these in populations. Similarly, there will be situations in which information is required on specific aspects of asthma management. The design of tools to collect this information will be guided by the aims of investigation. In addition, some of the indicators that we have currently recommended may become obsolete with the evolution of knowledge and with changes in asthma-related public health and clinical practice. The list of indicators provided here will need to be periodically revised.

Why the need for enhanced asthma-related information?

During the work conducted to assess the feasibility and value of the proposed asthma indicators and their potential data sources, a number of issues were identified that need to be resolved before appropriate indicators can be incorporated into the monitoring system. These issues include:

- inability to define an indicator that meets the monitoring objective in a valid, sensitive and/or readily interpretable manner
- inability to identify existing, reliable sources of data to measure a proposed indicator.

ACAM is responsible for advising on the development and management of special projects and collaborations to ensure the integration and enhancement of asthma-related information. This document presents proposals for such projects to enable the further
development of appropriate indicators and/or data sources to inform asthma monitoring needs.

Indicators are discussed in this plan according to the level of data development required:

- **Level 1**: Indicator definition established and nationwide data source identified.
- **Level 2**: Indicator definition established but no existing nationwide data source identified.

The data development issues and projects to deal with these issues are proposed for each indicator.

The Review of proposed National Health Priority Area asthma indicators and data sources (Baker et al. 2004) highlights the importance of monitoring the incidence of occupational asthma, the prevalence of airway hyperresponsiveness (an objective marker of asthma prevalence), the costs of asthma to individuals with the disease, the extent of utilisation of lung function measurements in people with asthma and the level of asthma control in people who have the disease. As it is not feasible to measure any of these potential indicators on a nationwide scale at present, they are not assessed in this document.

### Monitoring risk groups

The planning and implementation of interventions to reduce the burden of asthma in the community is enhanced by targeting risk groups or population strata who have the most to gain. These groups may be distinguished as having a high prevalence of asthma or asthma-like symptoms, increased exposure to risk factors, poor asthma management or self-management, or worse outcome of asthma, including higher death and hospitalisation rates. Disadvantaged or otherwise disengaged groups in society, such as the elderly, people from non-English-speaking backgrounds, Indigenous people, and those living in remote areas and in socioeconomically disadvantaged areas may be at risk of some or all of these adverse situations. For example, Asthma in Australia 2003 (ACAM 2003) highlighted the elevated prevalence of asthma or asthma-like symptoms in Indigenous people, low rates of use of preventer medications in young adult males, and relatively higher rates of death due to asthma among people from non-English-speaking backgrounds. In further developing data for asthma monitoring, it will be important to enhance our capacity to identify target groups for specific interventions to reduce the burden of asthma.

### Objectives of this plan

This plan aims to:

- identify data development issues for the monitoring of asthma
- recommend enhancements to existing data sources to enable valid and reliable measurement of asthma indicators
- identify and assess alternative sources of data relevant to the asthma indicators
- propose the development of methods to improve data collection and data analysis (e.g. data linkage analysis tools)
- propose collaborative activities in the health sector to develop data for indicators that are useful nationally and in local health-care settings.
Framework for data development to monitor asthma indicators

In this report indicators have been grouped according to the two identified levels of development required.

For each indicator, the data development issues are reviewed. Projects are proposed to develop the indicator definition, if required, and to identify and develop data sources. The data development plan for each indicator is based on the following framework.

Description
A quantitative description of how ACAM recommends measuring the indicator.

Intent of indicator
The potential purposes for which the indicator was developed. Includes a description of target population and setting.

Asthma-monitoring issue
States the problem or problems that need to be dealt with in order for the indicator to be monitored effectively.

Background
Presents background information relevant to the asthma-monitoring issue as well as information on the current availability of data, its limitations and any actions in progress to enhance the data.

Suggested data development approach
Identifies projects that can be undertaken to resolve the asthma-monitoring issue and enhance or further investigate the validity and feasibility of data for the indicator.

Descriptive title of project

Responsibility
The organisation responsible for each project is identified where possible.

Feasibility of the approach
Deals with issues relevant to the feasibility of the proposed data development task and the practicalities related to the data development approach in each project (e.g. capacity of the data agency, funding sources).
Level 1: Indicators with accepted definitions and nationwide data sources

The following Level 1 indicators, from the *Review of proposed National Health Priority Area asthma indicators and data sources* (Baker et al. 2004) have been omitted in this section because there are no further data development issues to be resolved:

- prevalence of ever having doctor-diagnosed asthma
- rate of smoking in people with asthma
- rate of asthma-related general practice encounters
- rate of Asthma 3+ Visit Plan Practitioner Incentive Program payments
- proportion of schools using the Asthma Friendly Schools Program.

1.1 Death rate for asthma among persons aged 5–34 years and all ages

Description
Death rate in people aged 5–34 years and all ages where the underlying cause of death is asthma (ICD-10-AM codes: J45, J46) per 100,000 resident population.

Intent of indicator
- To evaluate interventions to prevent and manage exacerbations of asthma.
- To monitor adverse events related to asthma.
- To monitor the impact and costs of asthma for the individual and community.

Asthma-monitoring issue
The extent to which diagnostic confusion and coding changes currently influence the enumeration of deaths from asthma in Australia is unknown.

Background
There is evidence that asthma mortality may change in response to changes in prevalence, disease severity (Jalaludin et al. 1999) and treatment (Beasley et al. 1999). A number of other factors related to the classification of asthma deaths complicate the interpretation of trends in asthma mortality statistics. These include:
• modifications to asthma classifications with International Classification of Diseases (ICD) version changes
• changes to coding practice
• the propensity of attending medical practitioners to diagnose and label patients as having asthma who actually have other respiratory conditions
• diagnostic confusion between asthma and chronic obstructive pulmonary disease (COPD) when completing death certification, particularly in older people (over 35 years).

The effect of coding changes mainly due to ICD version changes has been well documented and ‘comparability factors’ are now available for ‘all ages’ for most conditions to allow comparison between versions. However, although these data are available, little is known about how coding changes affect the enumeration of deaths from asthma for specific age groups. Comparability factors to adjust for comparison of data coded with ICD-9 and ICD-10 have been calculated and applied to asthma statistics according to age groups (1.00, i.e. no conversion, for 0–34 years; 0.84 for 35–64 years; and 0.68 for 65 years and over) (ACAM 2003). However, we have little understanding about which coding changes contribute to these variations.

The extent to which diagnostic confusion affects the enumeration of asthma deaths was demonstrated in the late 1980s by studies in South Australia and Victoria (Campbell et al. 1992; Jenkins et al. 1992). These studies showed marked over-enumeration of asthma deaths in older people who had other chronic obstructive airways diseases. No similar studies have been published in Australia since. Evidence from the United Kingdom shows that the attribution of death to asthma is less accurate in older people (Jones et al. 1999) and is most accurate among persons aged 5–34 years. In older age groups COPD, heart failure, and other respiratory illnesses have clinical features that overlap with asthma and misclassification among all these diagnoses is relatively common (Beasley et al. 1999; Guite & Burney 1996; Jalaludin et al. 1999; Sidenius et al. 2000).

Currently, there is no method to assess the impact of diagnostic confusion on Australian asthma death statistics, and data users are advised to take care when interpreting asthma mortality data in people over 35 years because of possible diagnostic inaccuracies. Quantifying the impact of changes in diagnostic practice on death certification would assist in the interpretation of trends in asthma death statistics.

Before 1998, Australian Bureau of Statistics (ABS) mortality statistics only contained ‘underlying cause of death’. Since 1999, multiple causes of death fields are now available. The availability of data on both associated and underlying causes of death may enhance the value of information on asthma mortality. In particular, it will enable examination of:
• the associated causes of death in people where asthma is identified as the underlying cause
• the underlying causes of death in people where asthma is identified as an associated cause, and therefore the potential additional mortality burden of this disease.

An understanding of these effects will assist in interpreting changes in data trends.
Suggested data development approach

Project 1.1.1
Examination of data on multiple causes of death

_Responsibility:_ ACAM and AIHW.

_Feasibility of the approach:_ Can be undertaken by ACAM.

Project 1.1.2
Continued assessment of the impact of coding changes on certification of asthma as underlying cause of death

_Responsibility:_ ACAM.

_Feasibility of the approach:_ Able to be conducted by ACAM or organisation with similar expertise in the future.

Project 1.1.3
Validation studies of coding accuracy

_Responsibility:_ ABS in collaboration with ACAM.

_Feasibility of the approach:_ Will require additional funding.

1.2 Rate of hospital separations and hospital patient days for asthma

Description
Hospital separation rate for asthma and hospital patient days (ICD-10-AM codes: J45, J46) per 100,000 resident population.

Intent of indicator
- To evaluate interventions for the prevention and management of exacerbations of asthma.
- To monitor adverse events related to asthma.
- To monitor the impact and costs of asthma for the individual and community.
- To monitor accessibility of hospital care for people with asthma.
Asthma-monitoring issue

The accuracy of the coding of hospital diagnoses for asthma in Australia is unknown.

Background

There are a number of factors that can affect the coding of hospital diagnoses for asthma:

- modifications to asthma classifications with ICD version changes
- changes in local coding practice
- the propensity of attending medical practitioners to diagnose and label patients as having asthma who actually have other respiratory conditions.

Revisions of the ICD classification are known to have implications for disease classification and the consistency of time series data. ICD-10-AM was phased in across the states for hospital separation data in 1998–1999 and 1999–2000. The instructions to coders changed in ICD-10-AM, which has implications for continuity across time series. Under ICD-10-AM, where asthma and COPD are both recorded, COPD is selected.

Comparability factors for the transition from ICD-9-CM to ICD-10-AM have been calculated using a sample of hospital separations from 1995-1996 that were coded according to both classifications. This was applied to asthma statistics according to age groups (1.00, i.e. no conversion, for 0–34 years; 0.64 for 35–64 years; and 0.53 for 65 years and over).

As for the mortality data, multiple diagnosis fields are available for the hospitalisation data. The implications of the additional diagnoses, where asthma is the principal diagnosis, have not been explored. Furthermore, the meaning of asthma as an additional diagnosis may be important for monitoring purposes. The instruction to coders in relation to COPD and asthma, referred to above, is an example of the importance of these additional fields. It is important to fully understand the information on hospital utilisation as it relates to asthma.

Suggested data development approach

Project 1.2.1

Assessment of the impact of coding changes on diagnosis of asthma

This would enhance the work on comparability factors via mapping studies for the changeover from ICD-9-CM to ICD-10-AM.

Responsibility: ACAM.

Feasibility of the approach: Able to be conducted by ACAM or organisation with similar expertise in the future.
Project 1.2.2

Examination of secondary diagnoses attached to primary diagnosis to investigate the issues around diagnosis and diagnostic confusion

Responsibility: ACAM.

Feasibility of the approach: Able to be conducted by ACAM or organisation with similar expertise in the future.
Level 2: Indicators with no nationwide data source available

2.1 Prevalence of current asthma

Description
Prevalence rate of people ever diagnosed with asthma who have experienced symptoms of asthma (wheeze, shortness of breath or chest tightness) or taken treatment for asthma in the last 12 months per 100,000 resident population.

Intent of indicator
- To evaluate population health interventions to prevent the onset of asthma.
- To monitor exposure to and the impact of environmental and other risk factors for asthma.
- To monitor the impact and costs of asthma for the community.

Asthma-monitoring issue
There are no nationwide data on the prevalence of current asthma, ascertained in accordance with the proposed indicator definition.

Background
Monitoring the prevalence of asthma is complex, with a wide range of subjective and objective criteria that can be used to define asthma. The proposed indicator definition for current asthma is: ever having been diagnosed with asthma AND having experienced symptoms of asthma or taken treatment for asthma in the last 12 months (Baker et al. 2004). The definition of current asthma implemented in the 2001 National Health Survey (NHS) (ABS 2001) is not consistent with the definition of current asthma proposed by ACAM (Baker et al. 2004). The ABS has subsequently field-tested questions to identify current asthma (Daly & Taylor 2004). However, the questions tested were not consistent with ACAM’s proposed definition. The questions that were field-tested asked respondents to exclude times when they had a cold or respiratory infection.

Currently the prevalence of asthma, measured according to the proposed indicator definition, can only be monitored in some, but not all, state-based health survey programs.
Suggested data development approach

Project 2.1.1

Development of questions for use in health surveys using wording that will ensure consistency with the definition for the indicator recommended by ACAM for the prevalence of current asthma.

Responsibility: ACAM in collaboration with the Computer-Assisted Telephone Interview Technical Reference Group (CATI TRG) and the NHS development team.

Feasibility of the approach: Can be undertaken within the current resources of ACAM.

2.2 Prevalence of wheeze in the preceding 12 months

Description
Prevalence rate of wheeze or whistling in the chest in the previous 12 months per 100,000 resident population.

Intent of indicator
- To evaluate population health interventions to prevent the onset of asthma.
- To monitor exposure to and the impact of environmental and other risk factors for asthma.
- To monitor the impact and costs of asthma for the community.

Asthma-monitoring issue
There are no nationwide data available that will allow the prevalence of recent wheeze to be monitored.

Background
Wheeze is a respiratory symptom that occurs in people with asthma but also arises from many other causes, particularly in young children and in older people. In assessing the prevalence of asthma, information on the prevalence of wheeze should be considered along with information on other asthma-related indicators.

Currently, the only nationwide population data on the prevalence of wheeze are those collected in the 2001 NHS, for adults aged 18–44 years. Several local surveys have measured the prevalence of wheeze in children (Downs et al. 2001; Glasgow et al. 2001; Robertson et al. 1998; Toelle et al. 2003).
Suggested data development approach

Project 2.2.1

Development of a question for use in health surveys to investigate the prevalence of wheeze in the preceding 12 months.

Responsibility: ACAM in collaboration with the NHS development team and the CATI TRG.

Feasibility of the approach: Can be undertaken within the current resources of ACAM.

2.3 Prevalence of smoking in households where children with asthma reside

Description

The proportion of children aged under 15 years who live in a household where people smoke and who (a) have current asthma or (b) have had wheeze in the previous 12 months.

Intent of indicator

- To monitor exposure to, and impact of, environmental and other risk factors for asthma.
- To evaluate population health interventions to prevent the onset and exacerbations of asthma.
- To monitor the provision of a safe environment for people with asthma.

Asthma-monitoring issue

There are no data available on actual exposure to tobacco smoke in households where children reside.

Background

In order to monitor household smoking, a number of issues must be considered to determine the most reliable method of measuring exposure. These include what constitutes a household in which there is exposure to tobacco smoke and what constitutes exposure to tobacco smoke.

Some state health surveys regularly collect data on households where tobacco is smoked occasionally or frequently in the household. Many do not collect data on the quantity of tobacco consumed in the household. Data from the 2001 NHS can only be used to estimate the proportion of children with asthma who are residing with a regular smoker, not the proportion of children exposed to environmental tobacco smoke inside their home because smoking within the home is not specified in the questions.
Two questions have been used by New South Wales Health Survey Program and have been tested for the Chronic Disease and Behavioural Risk Factor Surveillance Survey Module (Second Field Test). These questions have been shown to have acceptable reliability and validity during field testing (Daly & Taylor 2004). They are:

Which of the following best describes your smoking status?

1 I smoke daily
2 I smoke occasionally
3 I don’t smoke now, but I used to
4 I’ve tried it a few times but never smoked regularly
5 I’ve never smoked
X Don’t know
R Refused

Which of the following best describes your home situation?

1 My home is smoke free (includes smoking is allowed outside only)
2 People occasionally smoke in the house
3 People frequently smoke in the house
X Don’t know
R Refused

Suggested data development approach

Project 2.3.1

Development and implementation of a question module to determine the number of children with asthma who are residing with a smoker that smokes inside the house, and the child’s estimated level of exposure in the house.

Responsibility: ACAM in collaboration with the NHS development team and the CATI TRG.

Feasibility of the approach: Can be undertaken within the current resources of ACAM.

2.4 Number of individuals with a hospital separation for asthma and hospital re-admissions for asthma within 28 days

Description

Number of individuals with a hospital separation for asthma

Rate of having one or more hospital separation for asthma in a year per 1,000 resident population.

Hospital re-admissions for asthma within 28 days

Hospital re-admission rate for asthma per 1,000 resident population.
Intent of indicator

• To evaluate interventions for the prevention and management of exacerbations of asthma.
• To monitor return to normal function after an exacerbation of asthma.
• To monitor adverse events related to asthma.
• To develop structures to support effective and accessible asthma care.
• To monitor the impact and costs of asthma for the individual and community.

Asthma-monitoring issue

‘Linked’ national hospital data are not currently available to identify individuals with multiple hospitalisations.

Background

In order to monitor individuals with one or more hospital separations, including those who are re-admitted within 28 days, ‘linked’ hospital separation data are required to identify multiple separations for the same person. The National Hospital Morbidity Database compiles data from all states and territories and, therefore, represents a national data source. However, these data do not contain unique patient identifiers and the patient identifying information in these data may be too limited for recognising multiple hospitalisations for the same individual. Further investigation is needed to determine whether accurate linkage of records pertaining to individual patients is feasible with these data.

Currently, linked hospital separation data have only been produced in three states:

• New South Wales linkage of hospital separations: Currently hospital separation data linked within the years 1996–97 to 2000–01 are available.

• Linkage of Victorian Admitted Episodes Data (VAED): The Victorian Department of Human Services Ethics Committee has approved this project and linkage has been completed. Linked data sets for the four-year period 1999–2000 to 2002–2003 for people with asthma and related respiratory conditions have been provided to ACAM.

• Western Australian linkage of metropolitan hospital separations: Western Australia routinely link hospital data to identify individuals for all metropolitan public and private hospital separations, and rural public hospital separations. Discussions have been held with the relevant department within Western Australia Health regarding access to linked data for asthma. Linkage is to be further developed and costed in conjunction with Western Australia Health.
Suggested data development approach

Project 2.4.1
Utilisation of state-based linked hospital data to monitor individuals with one or more hospitalisations, and re-admissions for asthma.

Responsibility: ACAM in collaboration with state health authorities in New South Wales, Victoria and Western Australia.

Feasibility of the approach: Can be undertaken by ACAM in collaboration with other agencies.

Project 2.4.2
Investigation of linkage capacity within National Hospital Morbidity Database.
Linked Inpatient Statistics Collection data in New South Wales are to be used to compare the sensitivity of linkage using linkage strategies. This will involve comparing linkage that uses variables equivalent to those available in the National Hospital Morbidity Database with a more ‘optimal’ linkage strategy that uses variables such as name and address.

Responsibility: ACAM and AIHW.

Feasibility of the approach: Can be undertaken within the existing resources of ACAM.

2.5 Hospital re-attendance rate for asthma within 28 days

Description
Number of people discharged with a principal diagnosis of asthma (ICD-10-AM J45 or J46) who re-attend at an emergency department (ED) and/or are re-admitted to hospital within 28 days with a diagnosis of asthma.

Intent of indicator
- To evaluate interventions for the prevention and management of exacerbations of asthma.
- To monitor return to normal function after an exacerbation of asthma.
- To monitor adverse events related to asthma.
- To develop structures to support effective and accessible asthma care.
- To monitor the impact and costs of asthma for the individual and community.
Asthma-monitoring issue

‘Linked’ national hospital and ED data are not currently available to identify individuals who re-attend at an ED for asthma within 28 days of a hospital separation.

Background

This indicator would use ‘linked’ hospital separation and ED data, which are required to identify attendances for the same person. Formal assessment of this indicator is yet to be undertaken to determine whether it has added value for monitoring system-wide quality of asthma management.

Currently, ED data are only available at a state level, and linkage with hospital data must be negotiated with each jurisdiction. In addition, asthma attendances at EDs are under-enumerated because data with diagnostic labels attached is limited to three states (New South Wales, Victoria and Western Australia), and in these states only a sample of EDs contribute to the collection. Three states have hospital separation and ED data with diagnostic information attached:

- In New South Wales, linked hospital separations are currently available and have been accessed. Linkage has also been carried out between NSW hospital separations data and ED data and a data set provided to ACAM.
- In Victoria, linkage has been carried out between the Victorian Admitted Episodes Data (VAED) and Victorian Emergency Management Data (VEMD).
- Western Australia has a unique patient identifier for all people admitted to metropolitan hospitals. ED data are also available with diagnostic information and the unique patient identifier for a sample of metropolitan EDs that can be linked to hospitalisation data. Further discussions with the relevant department are needed to explore the options for accessing this data.

Suggested data development approach

Project 2.5.1

Assessment of the feasibility and value of state-level projects to link individuals between hospital separation and emergency department data.

Responsibility: ACAM in collaboration with state health authorities in New South Wales, Victoria and Western Australia.

Feasibility of the approach: Can be undertaken within the current resources of ACAM.
2.6 Asthma-related emergency department attendance

Description
Rate of hospital emergency department (ED) attendances for asthma per 100,000 resident population.

Intent of indicator
• To monitor the frequency and severity of asthma exacerbations.
• To monitor adverse events related to asthma.
• To monitor the impact and costs of asthma for the community (in terms of use of ED services) and the individual.

Asthma-monitoring issue
Data collections of asthma attendances at EDs in Australia do not cover all hospitals and in some states do not contain diagnostic labels.

Background
ED attendance data with diagnostic labels attached are only available in New South Wales, Victoria and Western Australia, and in these states there is not comprehensive coverage of EDs in the data collection. Rural and remote areas are underrepresented in the sample. Without comprehensive coverage, it is not possible to accurately establish a denominator population to allow an estimate of attendance rates.

Access to New South Wales and Victorian data has been approved for ACAM. At the national level, negotiations are proceeding with states and territories for a national minimum data set for EDs. The agreed variables at this time are administrative only, and there is no agreement on the collection of diagnostic information or presenting problem.
Suggested data development approach

Project 2.6.1

Utilisation of ED data in states recording diagnoses to assess ED attendance for asthma.

Responsibility: ACAM.

Feasibility of the approach: Can be undertaken within the current resources of ACAM

Project 2.6.2

Contribution to the national process for the development of a minimum data set and inclusion of diagnostic information into the collection, via collaboration with the AIHW.

Responsibility: ACAM and AIHW.

Feasibility of the approach: Able to be conducted by ACAM or organisation with similar expertise in the future.

2.7 Proportion of people with current asthma with an asthma action plan

Description

Proportion of people with current asthma who have an individualised, written asthma action plan (AAP) with the essential components, developed in consultation with a health professional.

Intent of indicator

- To evaluate interventions for the prevention and management of exacerbations of asthma.
- To develop structures to support effective and accessible asthma care.

Asthma-monitoring issue

There are no data sources that provide information on the possession of an AAP that contains the specific elements that have been shown to be beneficial.

Background

AAPs may be provided in various formats. The following features, which are common to most of the AAPs that have been shown to be beneficial, are considered to be the four essential components of an AAP:
• The AAP must be written.
• The AAP must be individually prescribed and not generic.
• The AAP must contain information to allow the patient to recognise the onset of an exacerbation.
• The AAP must contain information on what action to take in response to that exacerbation (usually increase or commence steroids and/or seek urgent medical care).

The NHS and state health surveys have included questions about the possession of an AAP. Although these provide some information on the four essential components of an AAP, the questions were found to be unreliable in field testing by the CATI TRG.

**Suggested data development approach**

**Project 2.7.1**

Development of more reliable questions to monitor possession of AAPs that contain the four essential elements listed above, and identify appropriate use of AAPs at the time of exacerbations.

*Responsibility:* ACAM in collaboration with the NHS development team and the CATI TRG.

*Feasibility of the approach:* Can be undertaken within the current resources of ACAM.

**2.8 Proportion of people with asthma who use preventers regularly**

**Description**

Proportion of people with asthma who use a preventer medication regularly.

**Intent of indicator**

• To evaluate interventions for the management of asthma, the control of symptoms of asthma, and the prevention of exacerbations of asthma.

**Asthma-monitoring issue**

There are no national data sources that identify people who meet criteria for being prescribed preventer medication and the rate of regular preventer usage.

**Background**

Preventer medications, predominantly inhaled corticosteroids, are the recommended treatment for moderate and severe asthma (NAC 2002). Their use is directed at improving
control, improving lung function and preventing exacerbations. However, these drugs are also used in the management of other respiratory conditions, including COPD.

There are two potential data sources for this indicator—Supplementary Analysis of Nominated Data (SAND) and health survey data. SAND modules are *ad hoc* add-on surveys to the Bettering the Evaluation and Care of Health (BEACH) survey of general practice. Four SAND modules have collected data on asthma prevalence, GP-assessed asthma severity (based on National Asthma Council criteria) and asthma education.

State health surveys have been used to assess preventer use in people with current asthma and can be used to identify people with asthma who meet the criteria for being prescribed preventer medication (Marks et al. 2000). Cognitive and field testing of questions by the CATI TRG to ascertain the proportion of people with asthma who use preventers regularly have found that further testing is needed to develop questions that can reliably measure this indicator.

**Suggested data development approach**

**Project 2.8.1**

Analysis of the current SAND data modules to compare preventer use according to severity as assessed by the general practitioner and possibly develop a SAND module to collect further information.

*Responsibility:* ACAM in collaboration with the GP Statistics and Classification Unit.

*Feasibility of the approach:* Can be undertaken by ACAM, subject to the approval of the General Practice Statistics and Classification Unit and the sponsors of the relevant SAND module.

**Project 2.8.2**

Development of national consistency in the inclusion of questions that can identify people with current asthma who meet the criteria for being prescribed preventer medication and provide information about use of asthma medication.

*Responsibility:* ACAM in collaboration with the NHS development team and the CATI TRG.

*Feasibility of the approach:* Can be undertaken by ACAM.
2.9 Impact of asthma on quality of life

Description
Proportion of people with asthma who report poor health-related quality of life.

Intent of indicator
- To monitor the impact and costs of asthma for the community.
- To monitor the impact and costs of asthma for the individual.

Asthma-monitoring issue
The validity and reliability of various forms of this indicator needs to be evaluated.

Background
ACAM has produced a document titled *Measuring the impact of asthma on quality of life in the Australian population* (ACAM 2004). This evaluates the characteristics of instruments for measuring the impact of asthma on health-related quality of life. The document has identified limitations in the current approaches to measuring health-related quality of life in population-based studies in Australia and recommends changes to the current strategies.

Currently, the impact of asthma on quality of life can be monitored through cross-sectional surveys of the Australian population such as the NHS and individual state health surveys. In general, these surveys have already implemented various measures that could contribute to this indicator, such as measures of health status, reduced activity days and life satisfaction. However, the measures used have usually been single-item or very brief questionnaires.

ACAM’s report has supported the use of more comprehensive measurement instruments than have generally been used in these surveys to improve information about the impact of asthma on quality of life (ACAM 2004). The report has also recommended the development of dynamic health assessment for monitoring asthma-specific outcomes in population health surveys.

Suggested data development approach

Project 2.9.1

Implementation of measures of health-related quality of life in national and state health surveys in line with the recommendations in *Measuring the impact of asthma on quality of life in the Australian population* through:
- the development of nested surveys within larger surveys that employ comprehensive quality of life measures on a subset of participants with and without asthma using:
  - generic measures to compare different diseases
- asthma-specific measures to monitor the impact of asthma over time
- child-specific measures to monitor asthma impacts in children
- the use of more comprehensive and validated quality of life measurements that are suitable for implementation in large population surveys.

Responsibility: ACAM in collaboration with the NHS development team and the CATI TRG.

Feasibility of the approach: Further resources will need to be identified to implement survey changes.

**Project 2.9.2**

Participation in research to develop the application of dynamic health assessment for asthma-specific outcomes.

Responsibility: ACAM in collaboration with researchers in dynamic health assessment methods.

Feasibility of the approach: Able to be conducted by ACAM or organisation with similar expertise in the future.
Conclusions and recommendations

This data development plan presents a strategic approach to enhancing population data for monitoring asthma in Australia by identifying a range of strategies, and where possible, projects that would either build on available data or establish new sources of data. In most cases the Australian Centre for Asthma Monitoring (ACAM) would accept responsibility for driving the projects. However, most projects are collaborative, and involve other groups such as the Computer-Assisted Telephone Interview Technical Reference Group (CATI TRG) and the National Health Survey (NHS) development team at the Australian Bureau of Statistics. The time required to complete the projects proposed in this plan may extend beyond ACAM’s current contractual agreement. Therefore, it has been suggested that some projects are to be conducted by ACAM or an organisation with similar expertise at a future time.

A number of the projects for different indicators are very closely aligned. Therefore, some data development activities are able to fulfil the development requirements for more than one indicator. An example is the development of internally linked hospital data sets. Establishing this resource will enable monitoring of the number of individuals with hospital separations for asthma as well as the number of individuals with re-admissions for asthma. In Table 3, projects are grouped according to the organisations who are likely to be involved in collaborative data development.

There are six indicators that require the development of questions suitable for administration in cross-sectional surveys. As both CATI TRG and the NHS development team have already undertaken substantial data development in this field, we propose the establishment of a collaborative working group including representatives of both these groups, together with ACAM. This group would manage the process of final development of an appropriate and agreed set of questions to enable consistent monitoring of these questionnaire-based asthma indicators in Australia. Between May and July 2004, ACAM conducted a series of consultation workshops with asthma stakeholders throughout Australia, and this suggestion has received wide support.

A number of other indicators relevant to monitoring asthma have been identified (Baker et al. 2004). These include:

- prevalence of airway hyperresponsiveness
- proportion of people with asthma who have had recent spirometry
- index of asthma control
- incidence rate of asthma initiated (caused) by occupational exposure
- costs of asthma to individuals.

However, feasible strategies for comprehensive monitoring of these indicators have not yet been established. Some data relevant to these indicators have been included in previous reports (ACAM 2003) and will be included in future reports.
### Table 3: Summary of projects for asthma data development by collaborating organisations

<table>
<thead>
<tr>
<th>Collaborating groups</th>
<th>Indicator</th>
<th>Project</th>
<th>Project Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CATI Technical Reference Group and NHS Development Team</strong></td>
<td>Prevalence of current asthma</td>
<td>2.1.1 Development of questions for use in health surveys using wording that will ensure consistency with the definition for the indicator recommended by ACAM for the prevalence of current asthma.</td>
<td></td>
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<tr>
<td></td>
<td>Prevalence of wheeze in the preceding 12 months</td>
<td>2.2.1 Development of a question for use in health surveys to investigate the prevalence of wheeze in the preceding 12 months.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Prevalence of smoking in households where children with asthma reside</td>
<td>2.3.1 Development and implementation of a question module to determine the number of children with asthma who are residing with a smoker that smokes inside the house, and the child’s estimated level of exposure in the house.</td>
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<td>Proportion of people with current asthma with an asthma action plan (AAP)</td>
<td>2.7.1 Development of more reliable questions to monitor possession of AAPs that contain the four essential elements, and identify appropriate use of AAPs at the time of exacerbations.</td>
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<td>Proportion of people with asthma who use preventers regularly</td>
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<td></td>
<td>Impact of asthma on quality of life</td>
<td>2.9.1 Implementation of measures of health-related quality of life in national and state health surveys in line with the recommendations in Measuring the impact of asthma on quality of life in the Australian population.</td>
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<tr>
<td><strong>Australian Bureau of Statistics</strong></td>
<td>Death rate for asthma among persons aged 5–34 years and all ages</td>
<td>1.1.3 Validation studies of coding accuracy</td>
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(continued)
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<td>Number of individuals with hospital separations for asthma within 28 days</td>
<td>2.4.1 Utilisation of state-based linked hospital data to monitor individuals with one or more hospitalisations, and re-admissions for asthma.</td>
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<td>Hospital re-attendance rate for asthma within 28 days</td>
<td>2.5.1 Assessment of the feasibility and value of state-level projects to link individuals between hospital separation and emergency department data.</td>
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<td></td>
<td>Asthma-related emergency department (ED) attendance</td>
<td>2.6.1 Utilisation of ED data in states recording diagnoses to assess ED attendance for asthma.</td>
</tr>
<tr>
<td><strong>State health authorities</strong></td>
<td>Death rate for asthma among persons aged 5–34 years and all ages</td>
<td>1.1.1 Examination of data on multiple causes of death.</td>
</tr>
<tr>
<td></td>
<td>Rate of hospital separations and hospital patient days for asthma</td>
<td>1.2.2 Examination of secondary diagnoses attached to primary diagnosis to investigate the issues around diagnosis and diagnostic confusion</td>
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<td>Number of individuals with hospital separations for asthma and hospital re-admissions for asthma within 28 days</td>
<td>2.4.2 Investigation of linkage capacity within National Hospital Morbidity Database.</td>
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<td>2.6.2 Contribution to the national process for the development of a minimum data set and inclusion of diagnostic information into the collection, via collaboration with the AIHW.</td>
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<td><strong>To be determined</strong></td>
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<td>2.9.2 Participation in research to develop the application of dynamic health assessment for asthma-specific outcomes.</td>
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References


