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# Monitoring asthma in pregnancy

## A discussion paper

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**ACAM**  
Australian Centre for  
Asthma Monitoring



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# **Monitoring asthma in pregnancy**

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Australian Institute of Health and Welfare  
Canberra

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# Contents

- Acknowledgments ..... iv
- Abbreviations ..... v
- Summary ..... vi
- 1 Introduction.....1**
- 2 What does good care for asthma in pregnancy look like? .....3**
  - Effects of pregnancy on asthma outcomes.....3
  - Effects of asthma on pregnancy outcomes.....5
  - Evidence about adverse effects of therapy for asthma during pregnancy .....6
  - Management of asthma during pregnancy .....6
- 3 Developing a monitoring approach for asthma in pregnancy .....10**
  - Existing indicators that are relevant to asthma in pregnancy.....10
  - Proposed additional indicators specific to pregnancy .....10
- 4 Data sources that could be used within a monitoring approach .....13**
  - Existing data sources .....13
  - Emerging possibilities for data collection .....15
  - Specific local studies .....16
- 5 Discussion .....18**
  - Options for data development .....18
  - Relevance to other common, chronic and complex conditions managed during pregnancy .....19
- Glossary .....21**
- References.....24**
- List of tables.....28**
- List of boxes .....29**

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# Abbreviations

ABS	Australian Bureau of Statistics
ACAM	Australian Centre for Asthma Monitoring
AIHW	Australian Institute of Health and Welfare
BEACH	Bettering the Evaluation and Care of Health
DoHA	Department of Health and Ageing
GINA	Global Initiative for Asthma
GP	general practitioner
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, Tenth revision, Australian Modification
ICS	inhaled corticosteroid
LABA	long-acting beta-agonists
NAC	National Asthma Council
NAEPP	National Asthma Education and Prevention Program
NHMRC	National Health and Medical Research Council
MIM	Maternity Information Matrix
NHMD	National Hospital Morbidity Database
NMDS	National Minimum Data Set
NPDC	National Perinatal Data Collection
PCEHR	personally controlled electronic health record
SABA	short-acting beta-agonists
SHS	Shared Health Summary

# Symbols

n.a.      not available

# Summary

Pregnant women with poorly controlled asthma are at increased risk of experiencing pregnancy-induced hypertension and pre-eclampsia. They are also at increased risk of having infants that are premature or small for their gestational age.

Clinical guidelines emphasise the importance of pregnant women with asthma using their asthma medications as prescribed. Taking prescribed preventer medicines for asthma is safer for pregnant women and their infants than having uncontrolled asthma.

Asthma can be controlled, and exacerbations of asthma can be prevented, with good care during pregnancy. If asthma control is maintained during pregnancy, the outcomes for the woman and infant are no different than for women who do not have asthma.

Currently, in Australia, there is no nationally consistent collection of asthma-management data in pregnant women. Improved information about management practices among pregnant women with asthma would enable us to:

- ascertain who is getting good care for asthma during pregnancy
- identify opportunities for improving care for pregnant women with asthma.

This report recommends the following indicators of good care for asthma during pregnancy:

- proportion of pregnant women who have their asthma status documented
- proportion of pregnant women with asthma who had a review of their asthma during the first trimester
- proportion of pregnant women with asthma who have a 4- to 6-weekly review of their asthma during pregnancy.

Improving data on the management of asthma during pregnancy could be achieved by:

- augmenting existing national perinatal data
- enhancing general practice data
- conducting periodic surveys in the antenatal setting.

The problems and solutions that have been identified for asthma may have analogous application in relation to other common chronic diseases that require management during pregnancy, such as diabetes and epilepsy.

# 1 Introduction

Asthma is a chronic inflammatory condition of the airways associated with episodes of wheezing, breathlessness and chest tightness. Asthma is an important condition in pregnant women because:

- asthma is common
- asthma may have adverse effects on the course of pregnancy and on fetal and infant outcomes
- pregnancy may have adverse effects on asthma control and exacerbations, and asthma changes unpredictably in pregnancy
- some pregnant women and health professionals have concerns about potential adverse effects of medicines used to treat asthma during pregnancy.

Asthma is one of the most common chronic disorders that affect pregnant women. In Australia, it was estimated that 11.4% of women aged 15–49 had current asthma in 2011–12 (ABS 2013). Studies of pregnant women in Western Australia, Newcastle and Melbourne have shown that about 12% have current asthma (Clifton et al. 2009; Kurinczuk et al. 1999; Sawicki et al. 2011).

The presence of asthma in pregnant women is associated with an increased risk of adverse maternal outcomes, including worsening asthma and pre-eclampsia (see Box 2.1 for pregnancy-related terms), and an increased risk of adverse fetal and infant outcomes, particularly if the mother experiences an exacerbation of asthma while she is pregnant (Murphy et al. 2011). Clinical practice guidelines, based on evidence (Murphy et al. 2006) recommend careful management of asthma during pregnancy to reduce these risks (NAC 2006).

Little information is available at present on the management of asthma in pregnancy in Australia. Population-level monitoring of pregnant women with asthma would support assessment of the extent to which management of asthma in pregnancy in Australia is consistent with clinical practice guidelines. It would also allow evaluation of the impact of asthma on maternal and fetal outcomes.

The purpose of this report is to:

- describe a rationale for monitoring asthma in pregnancy
- develop a proposed approach to monitoring asthma in pregnancy
- describe the data sources proposed for use within a monitoring approach
- outline options for further data development required to inform such monitoring.

Chapter 2 describes what good care for asthma in pregnancy looks like. The chapter first examines how pregnancy may have an impact on asthma control and how asthma may affect pregnancy and fetal outcomes. This is followed by a review of evidence about possible adverse effects of asthma therapy during pregnancy and finally by a summary of clinical practice guidelines relevant to the management of asthma in pregnancy, to provide context for the identification of appropriate indicators and measures.

Chapter 3 describes the elements of an approach designed to assess who is getting good care for asthma during pregnancy. This chapter also describes how this approach could be used to identify opportunities for improving care for pregnant women with asthma.



Chapter 4 describes existing data sources that could, potentially, be used within a monitoring approach for pregnant women with asthma, and evaluates their suitability for this purpose.

Chapter 5 outlines options for further data development to inform the monitoring approach. This chapter also discusses the relevance of these findings to monitoring care for other chronic diseases that affect maternal and child outcomes of pregnancy.

## 2 What does good care for asthma in pregnancy look like?

### Effects of pregnancy on asthma outcomes

Although there is currently no established cure for asthma, good management of the condition can control the disease and prevent symptoms from occurring or worsening. The assessment of asthma control includes assessment of the patient's current status (for example, symptoms, medication use and lung function), as well as their risk of experiencing future adverse outcomes such as reduced lung function and episodes of worsening symptoms (exacerbations).

Many women with a history of asthma experience a change in asthma control during pregnancy, independent of any change in medication use. It has been estimated that one-third of pregnant women with asthma experience an improvement in their symptoms, one-third experience an overall worsening of their symptoms and the remaining one-third are overall unchanged (Gluck 2004). This change is most evident between 25 and 32 weeks of gestation (Murphy et al. 2005b; Schatz et al. 1988).

Even among women whose asthma control is unchanged or improved during pregnancy, exacerbations of asthma are common. Over half of pregnant women with asthma experience an exacerbation of their condition and one-third experience a severe exacerbation (Murphy et al. 2005b). Hence, both overall deterioration in asthma control and exacerbations are common among pregnant women.

Women who have severe asthma before they are pregnant are most likely to suffer an exacerbation of their asthma during pregnancy (Murphy et al. 2005b; Schatz et al. 2006). Other factors increasing the likelihood of exacerbations during pregnancy are mainly related to inadequate asthma management before the pregnancy, such as:

- lack of self-management skills
- absence of an asthma action plan
- poor adherence to prescribed inhaled corticosteroids (ICS) use
- obesity (Hendler et al. 2006).

These factors increase the risk of deterioration in asthma control during pregnancy (Chambers 2003).

Mechanical, neuro-hormonal and behavioural changes that occur in pregnancy may all contribute to the observed changes in asthma control. Some of these changes may cause a sensation of breathing difficulty in pregnant women, with or without asthma. Mechanical changes to the shape of the chest wall and position of the diaphragm alter the efficiency of breathing during pregnancy, particularly in the third trimester (Gluck & Gluck 1976, 2006).

Stimulation of the respiratory centre in the brain by the hormone progesterone, particularly during the first or second trimester, causes a sensation of breathing difficulty (that is, shortness of breath) in many women. In pregnant women with asthma, this may be perceived as deterioration in asthma control (Gluck & Gluck 2006; Murphy et al. 2011). However, progesterone may have more specific effects on airway muscle tone and on airway inflammation in women with asthma (Tan & Thomson 2000). The direct mechanism of these

changes and the explanation for improvement in some women and deterioration in others has not been fully explained.

Deterioration of asthma symptoms may also arise as an indirect consequence of behavioural change during pregnancy. Concerns about the effects of prescribed medication on the fetus cause many women to reduce or discontinue their asthma medication during pregnancy, either on their own initiative or on medical advice (Beckmann 2002; Chambers 2003; Lim et al. 2011a, 2012).

In a study of women of child-bearing age in the United States, 82% of respondents who used ICS were concerned about the perceived risks to their unborn child if they became pregnant and, of this group, 36% said that they would discontinue their ICS if they became pregnant (Chambers 2003). Similar findings have been found in Australia where almost one-third of pregnant women self-reported non-adherence to prescribed ICS before a severe exacerbation of asthma (Murphy et al. 2005a).

Non-adherence to asthma medication may lead to a loss of asthma control and increased risk of exacerbations (Murphy et al. 2005a; Schatz & Leibman 2005). Hence, non-adherence to asthma medications due to the perceived risk of harm to the developing fetus may lead to loss of control of asthma. Evidence about the risk to the fetus associated with medications used in the treatment of asthma is presented in Chapter 2 *Evidence about adverse effects of therapy for asthma during pregnancy*.

Viral respiratory tract infections are also a common cause of exacerbations of asthma during pregnancy (Murphy et al. 2006; Schatz & Leibman 2005). Pregnant women appear to be particularly susceptible to viral respiratory infections (Cox et al. 2006; Murphy et al. 2005a).

Pregnant women comprised 7% of people requiring hospital care in the United States during the 2009 H1N1 influenza pandemic. Among pregnant women who were hospitalised at that time, 22% also had asthma (Jain et al. 2009). Similar observations were made in Australia and New Zealand, where 31% of pregnant women admitted to hospital with H1N1 influenza had asthma (that is, three times the population prevalence of asthma in women of child-bearing age) (Knight et al. 2011).

#### **Box 2.1: Definitions of pregnancy terms used**

- **Pregnancy-induced hypertension:** characterised by the onset of hypertension after 20 weeks gestation without any maternal or fetal features of pre-eclampsia followed by return of normal blood pressure 3 months after birth.
- **Pre-eclampsia:** a multi-system disorder unique to human pregnancy, which is characterised by hypertension and involvement of one or more other organ systems and/or the fetus.
- **Small for gestational age:** describing a fetus or baby that has failed to reach the birthweight expected for its gestational age; that is, below the 10th percentile.
- **Pre-term delivery:** birth before 37 weeks of gestation

# Effects of asthma on pregnancy outcomes

## Outcomes for the mother

Overall, there is an increased risk of pregnancy-induced hypertension and pre-eclampsia among pregnant women who have asthma (Liu et al. 2001; Stenius-Aarniala et al. 1996). However, there is some variation among studies. Some studies have shown that women with well-controlled asthma are not at increased risk of pre-eclampsia compared with women without asthma (Mihirshahi et al. 2007; Murphy et al. 2005c; Stenius-Aarniala et al. 1996).

Although there is no evidence that exacerbations of asthma during pregnancy are associated with an increased risk of pre-eclampsia, the severity of asthma before pregnancy is correlated with the risk of gestational hypertension and pre-eclampsia (Murphy & Gibson 2011). This provides an additional rationale for monitoring asthma and asthma management during pregnancy.

## Outcomes for the fetus and infant

Maternal asthma is associated with an increased risk of low birthweight, small for gestational age and pre-term delivery (Enriquez et al. 2007; Murphy et al. 2011). All three outcomes are considered adverse for the infant.

A recent meta-analysis has shown that the birthweight of infants born to mothers with asthma is, on average, 93 grams lower than the birthweight of those born to women without asthma (Murphy et al. 2011). Furthermore, the risk of having a low birthweight infant was 2.5 fold higher in mothers who experienced a severe exacerbation of asthma during pregnancy than in mothers without asthma (Murphy et al. 2006), and 3 fold higher in mothers with an exacerbation of asthma compared with those with no exacerbations during pregnancy (Namazy et al. 2013). The magnitude of the effect of severe exacerbations of asthma on birthweight is similar to that of maternal smoking during pregnancy (Murphy & Gibson 2011).

Women with asthma have a 1.2 fold increased risk of having a baby who is small for gestational age compared with women without asthma (Murphy et al. 2011). Another, more recent meta-analysis comparing women with mild to those with moderate/severe asthma demonstrated a 1.2 fold increased risk of having a small-for-gestational-age infant for women with moderate/severe asthma (Namazy et al. 2013). Among women with asthma during pregnancy, regular use of ICS protects against the risk of having a small-for-gestational-age infant (Jana et al. 1995; Murphy & Gibson 2011).

Maternal asthma is associated with a 1.4 fold increased risk of pre-term delivery (Murphy et al. 2011). This effect was evident only in women who had no active asthma management during the pregnancy and was not evident in the women whose asthma was actively managed during pregnancy (Murphy et al. 2011).

Furthermore, maternal asthma is associated with a small, but significantly increased, risk of congenital malformations (rate ratio 1.11; 95% confidence interval 1.02–1.21), a 45% increased risk of death within the first 28 days of life and a 50% increased risk of neonatal hospitalisations (Murphy et al. 2011).

## Evidence about adverse effects of therapy for asthma during pregnancy

Although the safety of medications used to treat asthma in pregnant women cannot be unequivocally proven (GINA 2011), there is unambiguous evidence for adverse perinatal outcomes in women with poorly controlled asthma who do not take regular preventer treatment. A recent meta-analysis found that use of medicines such as ICS, long-acting beta-agonists (LABAs) and cromones during pregnancy was not associated with any particular adverse events, although the fluticasone/salmeterol combination had been associated with poor outcomes in some post-marketing studies (Lim et al. 2011b). The authors concluded that, although some negative outcomes of these medications have been reported, their direct link with medication use is inconclusive due to the confounding effect of asthma severity. They recommended that selection of therapy should be based on a balance of the risks and benefits of medication use versus the risks of poor asthma control (Lim et al. 2011b).

One study found that high doses of ICS ( $>1000\mu\text{g}/\text{day}$ ) during the first trimester may be linked to a risk of congenital malformations. However, when the dose in the first trimester was below  $1000\mu\text{g}/\text{day}$ , there was no greater risk of congenital malformations than for the general population (Blais et al. 2009). There are few data on the risk of adverse outcomes attributable to use of LABA, combination ICS/LABA therapy, leukotriene receptor antagonists or cromones during pregnancy (GINA 2011; Lim et al. 2011b).

Despite limited evidence of adverse effects of treatment for asthma during pregnancy, many women and their doctors remain concerned. A qualitative study of pregnant mothers with asthma at John Hunter Hospital, Newcastle, revealed that perception of risk of asthma medication to their unborn baby was overestimated compared with the actual risk (Powell et al. 2011). There is also evidence of under-prescribing of asthma medications during pregnancy (Lim et al. 2011a).

## Management of asthma during pregnancy

### Clinical practice guidelines

There are several current national and international guidelines and recommendations that are relevant to the management of asthma during pregnancy; these are summarised in Boxes 2.2 and 2.3.

**Box 2.2: Summary of current Australian guidelines and recommendations for asthma management relevant to management during pregnancy**

***Standards for Maternity Care in Australia and New Zealand (Royal Australian and New Zealand College of Obstetricians and Gynaecologists 2011)***

- Women with complex medical conditions which include asthma must be managed by a consultant obstetrician.
- A system of clear referral guidelines and pathways should be established so that pregnant women who require additional care are cared for and treated by the appropriate specialist.
- Multidisciplinary care, provided through well-understood clinical and local social service networks, should be available for all women with pre-existing medical conditions.

***Asthma Management Handbook (National Asthma Council Australia 2006)***

- Close cooperation between all health professionals caring for the pregnant patient is important to ensure the best asthma management.
- Peak expiratory flow monitoring and regular review of asthma every 4–6 weeks is recommended. This can provide reassurance for the pregnant woman and her healthcare providers.
- The pharmacological treatment of asthma during pregnancy should be the same as for non-pregnant women.
- Doses of ICS should be the minimum necessary to control symptoms and maintain normal or best lung function. Trigger factors should be avoided or minimised where possible. Minimise exposure to known allergens and irritants.
- Acute asthma exacerbations may reduce the amount of oxygen available to the fetus. Any deterioration in symptoms should be managed promptly.

**Box 2.3: Summary of current international guidelines and recommendations for asthma management relevant to management during pregnancy**

*British Guideline on the Management of Asthma: A National Clinical Guideline (British Thoracic Society 2012)*

- Counsel women with asthma regarding the importance and safety of continuing asthma medications in pregnancy to ensure good asthma control.
- Use ICS, LABA and short acting beta agonists (SABA) as normal during pregnancy.
- Give drug therapy for acute asthma as for the non-pregnant patient.
- During acute asthma, give high flow oxygen to maintain saturation between 94–98% to prevent maternal and fetal hypoxia.

*American College of Obstetricians and Gynaecologists Practice Bulletin: Clinical Management Guidelines for Obstetrician-Gynecologists no. 90 (Dombrowski et al. 2008)*

- The ultimate goal of asthma therapy in pregnancy is maintaining adequate oxygenation of the fetus by preventing hypoxic episodes in the mother.
- Optimal management of asthma during pregnancy includes objective monitoring of lung function, avoiding or controlling asthma triggers, educating patients, and individualizing pharmacologic therapy to maintain normal pulmonary function.
- It is safer for pregnant women with asthma to be treated with asthma medications than it is for them to have asthma symptoms and exacerbations.
- ICS are first-line controller therapy for persistent asthma in pregnancy.
- The step-care therapeutic approach uses the lowest amount of drug intervention necessary to control a patient's severity of asthma.

*Global Strategy for Asthma Management and Prevention (GINA 2012)*

- Focus treatment on control of symptoms and maintenance of normal lung function.
- Pregnant patients with asthma need to be advised that the greater risk to their baby lies with poorly controlled asthma and the safety of most modern treatments should be stressed. Provide printed material in relation to this for additional reassurance.
- ICS have been shown to prevent exacerbations of asthma during pregnancy.
- Acute exacerbations of asthma should be treated aggressively to avoid fetal hypoxia.

*Working group report on managing asthma during pregnancy: recommendations for pharmacologic treatment (NAEPPA and Pregnancy Working Group 2004)*

- Assess and monitor asthma on a monthly basis, evaluating asthma history, lung auscultation and objective measures of lung function. Spirometry is recommended at initial assessment, with spirometry or peak flow at subsequent visits.
- Control factors contributing to asthma severity by identifying and avoiding exposure to allergens and irritants that lead to asthma exacerbations.
- Patient education; asthma control is enhanced by ensuring access to education about asthma and skills necessary to manage it. This includes self-monitoring, correct use of inhalers and following a plan for managing asthma long term and for promptly handling signs for of worsening asthma.
- Stepwise approach to pharmacologic therapy; the dose and number of medications and frequency of administration are increased as necessary and decreased where possible.



Key elements of these guidelines are:

- review of asthma status every 4–6 weeks during the pregnancy; this includes assessment of symptoms, measurements of lung function (peak flow or spirometry) and medications review if necessary. This differs from the recommended frequency of asthma review every 3–12 months for non-pregnant patients with asthma (NAC 2006).
- education for the pregnant patient on the use and safety of asthma medications during pregnancy and the importance of maintaining good asthma control in order to reduce the chance of exacerbations
- ensuring the pregnant patient knows to avoid relevant asthma triggers and allergens where possible to prevent exacerbations
- appropriate management of worsening asthma in pregnancy, through provision of a written asthma action plan, and use of appropriate medications and monitoring for exacerbations managed in primary or secondary care.

Among pregnant women with asthma, regular use of ICS reduces the risk of severe exacerbations of asthma (Dombrowski et al. 1996; Murphy et al. 2006). Cessation of regular use of ICS during pregnancy increases the risk of deterioration in asthma control and the occurrence of severe exacerbations of asthma (Murphy et al. 2005a).

ICS are recommended as first-line therapy for asthma in pregnancy (Dombrowski et al. 2008; GINA 2011; NAC 2006). The report of the National Asthma Education and Prevention Program (NAEPP) in the United States finds that ‘it is safer for pregnant women with asthma to be treated with asthma medications than it is for them to have asthma symptoms and exacerbations’ (NAEPP 2007).

Exacerbations of asthma that occur during pregnancy should be managed in the same way as these exacerbations are managed in non-pregnant women (NAC 2006). However, in the United States, it has been shown that pregnant women are less likely to receive appropriate treatment during an asthma exacerbation than non-pregnant women (McCallister et al. 2011).

Existing guidelines recommend that pregnant women have an annual influenza vaccination, as they are more susceptible to seasonal influenza (DoHA 2013). As smoking has adverse effects on pregnancy outcomes, and also on the control of the asthma, advice on smoking cessation is an important part of management of pregnant women with asthma.

The first module of new National Evidence-Based Antenatal Care Guidelines was released in 2012 to support Australian maternity services to provide high-quality, evidence-based antenatal care to healthy pregnant women. These guidelines refer only briefly to asthma care during pregnancy, noting the importance of providing additional care for severe asthma in the antenatal period (AHMAC 2012).

Currently, in Australia, there is no nationally consistent collection of asthma-management data in pregnant women, which makes it difficult to assess if there is a gap between recommended clinical management of asthma in pregnancy and clinical practice, and, if so, to identify and assess the implications of any such gap.



# 3 Developing a monitoring approach for asthma in pregnancy

## Existing indicators that are relevant to asthma in pregnancy

The Australian Centre for Asthma Monitoring (ACAM) was established in 2002, with one of its objectives being to provide advice on the development of national indicators to monitor asthma. The initial work on indicators led to 24 recommended indicators for population monitoring (ACAM 2004, 2007; AIHW 2000). Further rigorous work in indicator development through a consultative process with asthma experts and stakeholders refined the list to 10 core items (ACAM 2009)(Table 3.1). These were considered the most important indicators for monitoring asthma at a national level. In addition to these, smoking status is important for pregnant women with asthma, and its adverse effects on mother and fetus have been well described in the literature (Boulet et al. 2012; Nathan et al. 2012). The list does not preclude the use of other indicators where they are relevant to a specific purpose.

**Table 3.1: Core asthma indicators for general population**

Indicator	Description
1 Prevalence of current asthma	Reporting doctor-diagnosed asthma as well as symptoms of or treatment for asthma in the last 12 months
2 Death (all ages)	Death due to asthma
3 Death (5 to 34 years)	Death due to asthma among people aged 5 to 34
4 Hospitalisations	Episodes of hospitalisation for asthma
5 Asthma control	A composite indicator developed from measures of symptoms and medication use to impute the proportion of people with asthma who have poor clinical control
6 General practice encounters	General practice encounters for asthma
7 Asthma action plans	People with asthma who have a written asthma action plan
8 Quality of life	People with asthma who report poor health-related quality of life
9 Preventer use	People with asthma who use preventers (ICS and other similar medicines)
10 Cost due to asthma	An index derived from expenditure and burden of disease data to examine the costs of asthma to individuals
11 Smoking <sup>(a)</sup>	Current smoking status

(a) No consensus was reached on smoking status during development of core indicators, but the importance of identifying smoking status in pregnant women has been well described in the literature.

Source: ACAM 2009

## Proposed additional indicators specific to pregnancy

Building on the ACAM's earlier work, this report proposes three additional indicators specific to asthma management in pregnancy for consideration (briefly summarised in Table 3.2). These indicators can be used in planning and implementation of interventions to reduce

the burden of asthma on this subpopulation as well as community at large. These three indicators are described in more detail below.

**Table 3.2: Proposed additional asthma indicators for pregnant women**

Indicators	Description
1 Proportion of pregnant women who have the presence or absence of current asthma documented	Documented doctor-diagnosed asthma as well as symptoms of or treatment for asthma during antenatal care
2 Proportion of pregnant women with asthma who have a review of their asthma during the first trimester	Provision of asthma review among the pregnant women with asthma in the first trimester
3 Proportion of pregnant women with asthma who have a 4- to 6-weekly review of their asthma in pregnancy	Provision of asthma review among the pregnant women with asthma throughout pregnancy

Source: ACAM analysis of literature.

## Proportion of pregnant women who have the presence or absence of current asthma documented

### Description

Proportion of women who have their clinical record indicating the presence or absence of asthma.

**Numerator:** Number of pregnancy clinical records where the presence or absences of asthma are recorded.

**Denominator:** Number of pregnancy clinical records.

### Rationale

As reported in the preceding chapter, there is evidence that, among pregnant women: asthma is common; it may have adverse effects on the course of pregnancy and on fetal and infant outcomes; it may be adversely affected by pregnancy; and appropriate management is important to ensure optimal pregnancy and asthma outcomes.

The first step to initiating appropriate management for asthma in pregnancy is to record the diagnosis of asthma during antenatal care. This indicator is designed to measure the extent to which the diagnosis of asthma is sought and recorded during antenatal care.

## Proportion of pregnant women with asthma who have a review of their asthma during the first trimester

### Description

The proportion of pregnant women with asthma who have documented evidence of a review of their asthma status (level of control) and management (prescription of appropriate preventer medications, avoidance of trigger factors, possession of a written asthma-management plan, and education about use and safety of medications) during the first trimester of pregnancy.

**Numerator:** Number of pregnant women who have a documented review of their asthma within their first trimester of pregnancy.

**Denominator:** Number of pregnancy clinical records.

### **Rationale**

As outlined in the previous chapter, there is evidence that asthma control may change during pregnancy and that effective asthma management improves both asthma outcomes and pregnancy outcomes. The aspects of assessment and management measured by this indicator are important elements of caring for patients with asthma during pregnancy and are recommended in clinical practice guidelines.

## **Proportion of pregnant women with asthma who have a 4- to 6-weekly review of their asthma in pregnancy**

### **Description**

The proportion of pregnant women with asthma who have documented evidence of a review of their asthma control at 4- to 6-weekly intervals between the initial assessment and delivery.

**Numerator:** Number of pregnant women with asthma who have documented reviews on their pregnancy clinical record

**Denominator:** Number of pregnancy clinical records.

### **Rationale**

As outlined in the previous chapter, there is evidence that asthma control may change during pregnancy and that effective asthma management improves both asthma outcomes and pregnancy outcomes. Exacerbations or worsening control may occur at any time during pregnancy, particularly during the second trimester. Clinical practice guidelines recommend that asthma is reviewed at 4- to 6-weekly intervals during pregnancy, whereas for the general asthma population, review at 3- to 12-monthly intervals is recommended.

## 4 Data sources that could be used within a monitoring approach

### Existing data sources

#### **AIHW National Perinatal Data Collection and National Maternity Data development project**

The National Perinatal Data Collection (NPDC) is a national population-based collection of data on pregnancy and childbirth. The NPDC is derived from data reported to the perinatal data collections in each state and territory in Australia. Midwives and other staff complete notification forms for each birth, usually at the time of delivery, using information obtained from mothers and from hospital or other records. Selected data from these state and territory collections are compiled annually into the national data set by the AIHW's National Perinatal Epidemiology and Statistics Unit (Perinatal and Reproductive Epidemiology Research Unit 2012).

The Perinatal National Minimum Data Set (NMDS) specifies perinatal data elements for mandatory collection and reporting at a national level, and depends on national agreement to collect the data in a standardised way (Perinatal and Reproductive Epidemiology Research Unit 2012). The Perinatal NMDS was first specified in 1997. It includes data items relating to the mother, including demographic characteristics, factors relating to the pregnancy, labour and birth, and data items relating to the baby, including birth status, sex and birthweight (Perinatal and Reproductive Epidemiology Research Unit 2012).

The National Maternity Data Development Project being carried out by AIHW in collaboration with National Perinatal Epidemiological Statistics Unit aims to develop a nationally consistent maternity data collection in Australia. One aspect of this project was to update the Maternity Information Matrix (MIM): an electronic inventory of maternity data collections in Australia. The MIM was formed from a review of existing national and jurisdictional data collections and reporting practices nationwide in 2010. The MIM provides a list of data collections, data items, and a comparison of metadata and data collection overviews.

The MIM was reviewed to determine whether asthma status was recorded in any of the maternity data collections in Australia, as information on the presence of asthma in pregnancy is not included in the Perinatal NMDS.

The presence of asthma during pregnancy is recorded in the maternity data collections of three states (Queensland, Western Australia and South Australia) (Maternal Information Matrix 2012). If this practice were to be extended to the other states and territories, it would be possible to monitor the first of the proposed indicators: the proportion of pregnant women who have their asthma status documented.

Western Australia is able to link the data from the Midwives Notification of Case Attended (which asks specifically about asthma) with other data sources such as the state hospital morbidity data collection and the emergency department data collection. This could provide valuable information on the prevalence of current asthma among pregnant women and, potentially, the rate of attendance at emergency departments and rate of hospitalisations

among pregnant women with asthma. However, the validity of these data as an indicator of the prevalence of asthma in pregnancy has not been assessed. The validity would be limited by the accuracy of information that is available to the midwife at the time of delivery.

**Table 4.1: Proportion of pregnant women who had their asthma status recorded in Qld, WA and SA**

State	Disease recorded	Asthma recorded	
		Count	per cent
Queensland, 2009	Asthma	1,294	2.1
Western Australia, 2009	Respiratory system diseases	3,463	11.3
South Australia, 2010	Asthma	1,217	6.2

*Note:* The Western Australia midwives notification system asks specifically about asthma, but the annual report only contains respiratory disease.

*Source:* Personal communication between ACAM and state/territory health authorities.

## National Hospital Morbidity Database

The National Hospital Morbidity Database (NHMD) is an administrative data set maintained by the AIHW. It is a collection of information about care provided to patients admitted to Australian hospitals. The NHMD contains information on diagnosis, demographic characteristics, procedures performed and duration of stay for episodes of care for patients admitted to hospital. In addition, states and territories hold identifiable, unit record data on hospitalisations that can be used for data linkage purposes.

The validity of these data as an indicator of the proportion of pregnant women who have had their asthma status documented is limited by the fact that hospital admissions are counted per separation and they do not equate to individuals. The diagnostic information is only relevant to the current presentation to hospital. Any conditions that were not actively managed during the episode of hospital care are not recorded.

Over the period from 1 July 2008 to 30 June 2011, asthma (defined using the ICD-10-AM codes J45 and J46) was recorded as a principal or additional diagnosis in 0.21% of all pregnancy-related admissions (defined using the ICD-10-AM codes O10 to O99 and Z33 to Z39) in women aged 15–49. This confirms the under-enumeration of asthma among pregnant women in the NHMD.

A further constraint on the use of this data set is that, at a national level, maternal characteristics, such as asthma status, cannot be linked to child characteristics and therefore analysis of the impact of maternal asthma on the infant cannot be analysed. Systematic linkage of maternal and infant records using the NHMD alone is not possible, as it would require linking episodes of care for the same woman during pregnancy, childbirth and postnatally. This can only be achieved by linking sets of maternal pregnancy records and infant records with the perinatal data collection that has records identifying both the mother and the baby. In this way, the NHMD could contribute to monitoring asthma and pregnancy outcomes. This has been suggested for evaluation of other maternal comorbidities but it is not a current feature of this database (AIHW 2010.)

# Emerging possibilities for data collection

## Hand-held pregnancy record

The hand-held pregnancy record is a personal copy of notes taken during antenatal and medical visits that is maintained by the woman. This system of recording visits is currently being used in Western Australia and is the main system in South Australia. At each visit, routine checks are recorded in the hand-held pregnancy record. The record is created and issued by either the woman's general practitioner (GP) or other health-care provider at the first antenatal visit after confirmation of her pregnancy (NHMRC 2010).

There is evidence to suggest that this method of record keeping enables greater access to information, supports continuity of care, facilitates communication and promotes greater responsibility and control by the woman.

These records are then transferred into the clinical notes of the woman at the hospital where she gives birth. The South Australian Department of Health is investigating an opportunity to create a web-based format complementing the hard copy version to provide a real-time patient record (NHMRC 2010).

This hand-held record could provide an opportunity to record information such as the asthma indicators as detailed in Chapter 3 *Proposed additional indicators specific to pregnancy* and could contribute to greater information on management of other comorbidities in pregnant women (NHMRC 2010)

## General practice data

Despite its critical importance, national data development in Australian primary health-care system has not been as well advanced as other parts of the health system. As a result, only limited national statistics are available to describe how asthma is managed in the primary health-care system.

The existing Bettering the Evaluation and Care of Health (BEACH) Survey is currently the only national data source describing what occurs during patient visits with GPs. The BEACH Survey was assessed for its potential to support measurement of the proposed asthma management in pregnancy indicators. However, the survey methodology (including how problems managed during GP-patient encounters are recorded and resulting underestimation of pregnant women with asthma) means it is not suitable for this purpose. For further information on the BEACH Survey, see AIHW: Britt et al. (2010) and AIHW (forthcoming).

The vast majority of general practices in Australia use clinical information software to record selected details of GP-patient encounters (AIHW 2008). This information is not currently collated in a systematic way at the national level. However, the Australian Primary Care Collaboratives Program (run by the Improvement Foundation) has been improving data collection according to an established methodology for some time. Although this process does not produce fully standardised data, it illustrates that collation of primary health-care information is feasible. Various Medicare Locals are also collating such data, together with other relevant data sources, to understand and improve the quality of services in their jurisdiction. Further standardisation and sharing of such information, in keeping with patient privacy and confidentiality, and with appropriate standardisation of data items, could support much greater understanding of management of asthma and other chronic



diseases during pregnancy in future (del Fante et al. 2006; Kelly et al. 2009; Pearce et al. 2011).

In July 2012 the Australian Government launched the National eHealth Record System and associated Personally Controlled Electronic Health Record (PCEHR) system. One of the key clinical documents shared via the PCEHR System is an individual's Shared Health Summary (SHS), which aims to make health-care information available to consumers and all of their health-care providers across place and time (AIHW 2008). It is possible that future developments in this area, particularly associated with the SHS, will enhance availability of information about asthma management in pregnancy. The SHS is created by the patient's regular medical practitioner (for example, GP, registered nurse or Aboriginal health worker) and is designed to be a curated record of the patient's current medical conditions, medications, allergies and immunisations at a point in time. There are a number of issues that would need to be resolved (such as increases in uptake of the SHS and standardised collation of information) before such information would be useful for monitoring purposes.

## Specific local studies

There are few local studies that describe the management of asthma in pregnancy. A population-based survey conducted at the Royal Women's Hospital, Melbourne, collected information about changes in use of asthma medicines during pregnancy. Pregnant women with self-reported asthma were invited to complete an anonymous questionnaire during their 36th week antenatal visit. Women aged 18 or under and those were unable to communicate in English were excluded (Sawicki et al. 2012) (see Table 4.2).

A study conducted at John Hunter Hospital, Newcastle, collected information on asthma self-management skills (Murphy et al. 2005a) among pregnant women with doctor-diagnosed asthma who were assessed between 20 and 33 weeks gestation.

The Childhood Asthma Prevention Study, conducted in western and south-western Sydney, has reported data on ICS among pregnant women with asthma (Mihirshahi et al. 2007). Mothers were assessed in late pregnancy.

**Table 4.2: Australian studies that have data relevant to proposed indicators**

Study	Region or hospital	Asthma recorded (per cent)	Action plan	Proportion using ICS
Sawicki et al. 2012 ( <i>n</i> = 819)	Royal Women's Hospital, Melbourne	104 (12.7%)	n.a.	19/102 (18.6%)
Murphy et al. 2005 ( <i>n</i> = 211)	John Hunter Hospital, Newcastle	All subjects had asthma	32 (15.2%)	135 (64.0%)
Mihirshahi et al. 2003 (South West Sydney, <i>n</i> = 616)	South West Sydney	340/611 (55.6%) <sup>(a)</sup>	n.a.	95/314 (30.3%)

<sup>(a)</sup> Pregnant women recruited for study by Mihirshahi et al. were those whose unborn children were at high risk of developing asthma (that is, pregnant women with asthma or pregnant women whose partners or other children had current symptoms of asthma), hence the high proportion of asthma recorded in this population.

Sources: Mihirshahi et al. (2003); Murphy et al. (2005a); Sawicki et al. (2012).

These data are limited by their small sample size, local population base and single instance of study. However, it is likely that they do provide useful information about the management of asthma during pregnancy in Australia.



# 5 Discussion

## Options for data development

In the preceding chapters, this report has described what good care for asthma during pregnancy looks like and how this is related to important outcomes for both the mother and infant. The report has also described the information that would be required in a monitoring approach designed to ascertain who is getting good care for asthma during pregnancy and to identify opportunities for improving care for pregnant women with asthma. Finally, the report has described the currently available data sources that might inform a monitoring approach for asthma in pregnancy.

At present, most of the identified indicators in the proposed monitoring approach cannot be measured using the available data sources.

One option for measuring existing core asthma indicators on deaths, hospitalisations and preventer medication use among pregnant women would be to investigate the feasibility of linking existing perinatal data collections to the National Death Index (AIHW 2013), hospital morbidity data (AIHW 2012) and Pharmaceutical Benefits Scheme data (ACAM 2011), respectively. At present, this type of linkage is undertaken in some jurisdictions, but not nationally. Options for measuring the other key indicators – namely asthma control, GP visits, possession of written asthma action plans, recording of asthma status and the frequency and timing of asthma reviews – include:

- augmenting data collection by midwives for the NPDC
- enhancing general practice data
- conducting periodic surveys in the antenatal setting.

### Augmenting existing national perinatal data

It may be feasible to ask midwives to provide the following information to the NPDC:

- for all pregnant women:
  - whether or not the woman has ever had asthma
- for women with asthma:
  - their asthma status (current asthma, past asthma)
  - the date on which asthma was first documented during antenatal care
  - the date of first asthma review.

The NPDC could then report:

- for all pregnant women:
  - whether asthma status has been documented
  - asthma status (current asthma, past asthma, no asthma), if asthma status has been documented.
- for women with current asthma:
  - gestational age when asthma was first documented
  - gestational age when asthma was first reviewed.

The validity of these data would be limited by the variable availability of complete antenatal records at the time of delivery, when the perinatal data collection is usually completed. It seems unlikely that other information about asthma could feasibly be recorded by midwives.

## **Enhancing general practice data**

One possible option for improving general practice data is to conduct targeted surveys of GPs to record information about asthma status, control and management (that is, use of preventer medications and possession of written asthma management plans) in all pregnant women with asthma. A survey such as this could also collect information on the timing and frequency of asthma status reviews during pregnancy.

Other options to enhance Australian general practice data are to consider systematically collating information from GP software systems, particularly focusing on information that is targeted for inclusion on the Shared Health Summary to reduce burden on information suppliers and leverage off existing investments in GP information.

## **Conducting periodic surveys in the antenatal setting**

Surveys of pregnant women with asthma, such as those previously reported from antenatal care settings in Melbourne, Newcastle and Sydney, may be the most efficient way to collect information on the management and control of asthma during pregnancy.

## **Conclusion regarding data collection**

Based on currently available information, it seems that the most feasible, and probably the most cost-effective, method of collecting data to monitor asthma and the management of asthma during pregnancy would be to enhance data collection by midwives. Other potentially feasible methods would be periodic surveys in general practice or antenatal settings. However, formal assessment of the relative feasibility and cost of these data collection vehicles was not within the scope of this project.

The NPDC is currently undergoing enhancements to support information needs required under the Maternity Services Plan 2010–2015. A number of items related to morbidity during pregnancy will be captured through these enhancements. On the basis of this report, the relevant information committee will be approached to determine the feasibility of adding asthma as an additional comorbidity as part of these data collection enhancements.

## **Relevance to other common, chronic and complex conditions managed during pregnancy**

Diabetes and hypertension are long-term and complex conditions that are common in pregnant women. Like asthma, they have an important interaction with pregnancy in that they may be triggered or exacerbated by pregnancy and they may have an adverse effect on pregnancy outcomes, both for the mother and the infant. Also, like asthma, their management may be complicated by pregnancy. Other conditions such as heart disease, epilepsy and renal failure have a similar relationship to pregnancy, but are less common than asthma, diabetes and hypertension among pregnant women.

The monitoring approach that has been proposed here for asthma in pregnant women, as well as the options for implementing this approach, may be of assistance in developing

approaches for monitoring other chronic conditions in pregnant women. Examining these conditions in detail with a view to extending the proposed data development options to include these conditions may produce cost efficiencies. If a suite of conditions could be measured by the same instrument, the data collected would also enable ascertainment of who is getting good care for all these conditions during pregnancy, and identification of opportunities for improving care for pregnant women with these conditions.

# Glossary

**asthma:** A chronic inflammatory disorder of the airways. Chronically inflamed airways are hyperresponsive; they become obstructed and airflow is limited (by bronchoconstriction, mucus plugs and increased inflammation) when airways are exposed to various risk factors (GINA 2010).

**asthma severity:** Severity is defined by the intensity of treatment required to achieve good asthma control. Mild asthma is asthma that can be well-controlled with reliever medications alone or with low-dose inhaled corticosteroids. Severe asthma is asthma that requires high-intensity treatment with inhaled corticosteroids and long-acting beta<sub>2</sub>-agonists to maintain good control, or that is not well controlled despite such treatment (Reddel et al. 2009) Several different definitions of asthma severity have been used in the past (Taylor et al. 2008).

**auscultation:** The action of listening to sounds of the heart, lungs or other organs, typically with a stethoscope.

**BEACH (Bettering the Evaluation and Care of Health) survey:** A continuous cross-sectional paper-based data collection that collects information for individual patient visits about the reasons for seeking medical care, the type of patients seen, the types of problems managed and treatment provided in general practice across Australia.

**birthweight:** The first weight of the baby (stillborn or live born) obtained after birth. Birthweight is usually measured to the nearest 5 g and obtained within 1 hour of birth.

**confidence interval (CI):** A statistical term describing a range (interval) of values within which we can be 'confident' that the true value lies, usually because it has a 95% or higher chance of doing so.

**current asthma:** Reporting ever being diagnosed asthma by a doctor or nurse, and reporting having any symptoms of asthma or taking treatment for asthma in the previous 12 months. Other definitions have been used in some surveys, but this is the definition recommended by the Australian Centre for Asthma Monitoring (ACAM 2009).

**cromones:** Medication (which includes nedocromil sodium and sodium cromoglycate) administered by inhalation and used as a prophylactic treatment of asthma. Cromones must be taken regularly to produce optimal effect, but they will not relieve acute symptoms. Although the mechanism of action of these drugs is not fully understood, they are thought to block allergen-induced bronchoconstriction and may be useful in asthma associated with allergic factors. They may also be used to prevent exercise-induced bronchoconstriction.

**diabetes:** A chronic condition in which the body cannot properly use its main energy source, the sugar glucose. This is either due to the pancreas not producing enough of the hormone insulin, or the body being unable to effectively use the insulin produced. Insulin helps glucose enter the body's cells from the bloodstream and then be processed by them. Diabetes is marked by an abnormal build-up of glucose in the blood and it can have serious short-term and long-term effects on many of the body's systems, especially the blood vessels and nerves.

**fetus:** An unborn child from its 8th week of development.

**gestational age:** The time measured from the first day of the woman's last menstrual cycle to the current date. It is measured in completed weeks. A term pregnancy can range from 37 to 42 weeks

**gestational hypertension:** characterised by the onset of hypertension after 20 weeks gestation without any maternal or fetal features of pre-eclampsia followed by return of normal blood pressure 3 months after birth.

**infant:** A child aged under 12 months.

**inhaled corticosteroids (ICS):** Medications widely used in the treatment of airways disease to reduce bronchial inflammation and hyperresponsiveness. They reduce symptoms, improve lung function and reduce the risk of exacerbations. Inhaled corticosteroids are most effective when used on a regular basis, either daily or twice daily. In Australian asthma guidelines, inhaled corticosteroids are termed 'preventers'; in many other countries, they are called 'controllers'. See also *preventer medication*.

**leukotriene receptor antagonists:** Orally administered medications resulting in relaxation of smooth muscle and some reduction of the inflammation mediated by leukotrienes. This type of treatment may have a place in prevention or treatment of exacerbations of asthma in children, but should not be used for acute relief of symptoms. It may also have a role in the management of aspirin-sensitive asthma and exercise-induced bronchoconstriction.

**long-acting beta-agonist (LABA):** Medication that relaxes the muscles that surround the airways and allows for easier breathing. In asthma management, long-acting beta<sub>2</sub>-agonists are recommended for use only in combination with inhaled corticosteroids therapy. The action of long-acting beta<sub>2</sub>-agonists lasts at least 12 hours.

**morbidity:** Refers to ill health in an individual and to levels of ill health in a population or group.

**mortality:** Death.

**outcome (health outcome):** A health-related change due to a preventive or clinical intervention or service. The intervention may be single or multiple and the outcome may relate to a person, group or population or be partly or wholly due to the intervention.

**perinatal:** Pertaining to, or occurring in, the period shortly before or up to up to 28 completed days after birth.

**pre-eclampsia:** A complication of pregnancy characterised by high blood pressure and protein in the urine.

**pregnancy:** The period during which a woman carries a developing fetus in the uterus.

**prescription drugs:** Drugs available only on the prescription of a registered medical practitioner and available only from pharmacies.

**pre-term delivery:** Birth before 37 weeks of gestation

**prevalence:** The number or proportion (of cases, instances, and so forth) present in a population at a given time.

**preventer medication:** A type of medication used to treat asthma to control the disease in order to minimise symptoms and exacerbations.

**progesterone:** A steroid hormone secreted by the corpus luteum of the ovary, the placenta, and also (in small amounts) by the adrenal cortex and testes. It is responsible for preparing the inner lining (endometrium) of the uterus for pregnancy. If fertilisation occurs, progesterone maintains the uterus throughout pregnancy and prevents the further release of eggs from the ovary.

**reliever medication:** A type of medication used in the treatment of asthma to relieve symptoms when they occur.

**small for gestational age:** Describes a fetus or baby that has failed to reach the birthweight expected for its gestational age. This is usually defined as less than the 10th percentile as measured on customised charts according to maternal and paternal characteristics.

**spirometry:** Measurement of lung function performed by a spirometer. Spirometry is used to establish the presence of airflow limitation and its reversibility in response to bronchodilator, which is an important feature for the diagnosis of asthma.

**statistical significance:** An indication from a statistical test that an observed difference or association may be significant, or 'real', because it is unlikely to be due just to chance. A statistical result is often said to be 'significant' if it would occur by chance only once in 20 times or less often.

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# List of tables

Table 3.1: Core asthma indicators for general population.....10

Table 3.2: Proposed additional asthma indicators for pregnant women.....11

Table 4.1: Proportion of pregnant women who had their asthma status recorded in Qld, WA, and SA.....14

Table 4.2: Australian studies which have data relevant to proposed indicators.....16

# List of boxes

- Box 2.1: Definitions of pregnancy terms used.....4
- Box 2.2: Summary of current Australian guidelines and recommendations for asthma management relevant to management during pregnancy .....7
- Box 2.3: Summary of current international guidelines and recommendations for asthma management relevant to management during pregnancy .....8

Asthma in pregnant women may have adverse effects on maternal, fetal and infant outcomes, particularly if expectant mothers experience an exacerbation of asthma while pregnant. Pregnancy, in turn, may have adverse effects on asthma control among expectant mothers. This report outlines a proposed approach to monitoring asthma during pregnancy by capitalising on existing data sources as well as identifying data development opportunities.