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Maternal morbidity data in Australia: an assessment of the feasibility of standardised collection

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Authoritative information and statistics to promote better health and wellbeing

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Contents

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Abbreviations

ADIPS	Australian Diabetes in Pregnancy Society
AHMAC	Australian Health Ministers Advisory Council
AIHW	Australian Institute of Health and Welfare
AMOSS	Australasian Maternity Outcomes Surveillance System
ANZICS	Australian and New Zealand Intensive Care Society
APH	antepartum haemorrhage
BEACH	Bettering the Evaluation and Care of Health
DoHA	Department of Health and Ageing
GDM	gestational diabetes mellitus
GP	General Practitioner
ICD	international classification of disease
ICD-10 AM	International Classification of Diseases, version 10, Australian modification
ICU	intensive care unit
ISC	Inpatient Statistics Collection
METeOR	Metadata Online Registry
NDDWG	National Diabetes Data Working Group
NHDD	National Health Data Dictionary
NHMD	National Hospital Morbidity Database
NMDD	National Maternal Deaths Database
NMDS	National Minimum Data Set
NNAPEDCD	National Non-Admitted Patient Emergency Department Care Database
NOCD	National Outpatients Care Database
NPDC	National Perinatal Data Collection
NPDDC	National Perinatal Data Development Committee
NPESU	National Perinatal Epidemiology and Statistics Unit
PHEC	ABS Private Health Establishments Collection
PIH	Pregnancy-induced hypertension

PPH	postpartum haemorrhage
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
SLK	statistical linkage key
SOMANZ	Society of Obstetric Medicine of Australia and New Zealand
WHO	World Health Organization

Summary

Background

Maternal morbidity comprises medical conditions, risk factors and complications arising from or related to obstetric interventions. For this report, a priority list of 7 conditions have been identified based on prevalence and health burden: pre-existing diabetes, gestational diabetes, pre-existing hypertension, gestational hypertension, pre-eclampsia, antepartum haemorrhage and postpartum haemorrhage.

Each state and territory has a perinatal data collection, based on different collection and reporting practices, that includes information on all women who give birth within their jurisdiction. These differences have been cited as the main reason for the varied prevalence of the priority maternal morbidity conditions across states and territories.

Findings

- National guidelines exist for 6 of the 7 conditions. However, these are not endorsed or adhered to in every state and territory.
- Data on diabetes conditions affecting pregnancy have a high degree of standardisation across jurisdictions.
- Hypertensive conditions affecting pregnancy are routinely under-reported in perinatal data collections compared with hospital data collections.
- There is evidence of systematic misclassification of gestational hypertension and pre-eclampsia.
- Antepartum haemorrhage does not have a nationally endorsed guideline, although there are a number of reasonably consistent guidelines in use that could be used to formulate a national guideline.
- Data on postpartum haemorrhage is the most variable due to differences in definition as well as inconsistencies between jurisdictions in the assessment of blood volume loss.
- Not all jurisdictions publish perinatal data validation studies.

Recommendations

- Advise the National Perinatal Data Development Committee (NPDDC) to consider collection and reporting of data relating to pre-existing diabetes and gestational diabetes using the existing National Health Data Dictionary (NHDD) standard.
- Encourage the adoption by jurisdictions of the Society of Obstetric Medicine of Australia and New Zealand (SOMANZ) guidelines and NHDD definitions for pre-existing and gestational hypertension and pre-eclampsia.
- Promote discussion among clinical stakeholders, in particular obstetricians and midwives, to develop consensus definitions and guidelines for reporting antenatal and postnatal haemorrhage.
- Promote discussion among jurisdictional perinatal data managers about standardising the linkage of information about birth episodes in hospital data collections with perinatal data.

Introduction

1.1 Background to this report

In 2008 the Commonwealth Government Department of Health and Ageing (DoHA) conducted a national review of maternity services as the first step towards the development of the National Maternity Services Plan. The Report of the Maternity Services Review was released in February 2009 (Commonwealth of Australia 2009).

The Review noted that there was no consistent, national reporting of maternal morbidity, no standard national data and no nationally agreed definition of maternal morbidity conditions. It recommended that:

> 'The Australian Government, in consultation with states and territories and key stakeholders, agree and implement arrangements for consistent, comprehensive national data collection, monitoring and review, for maternal and perinatal mortality and morbidity.'

In response to this recommendation, two reviews of data collection practices were commissioned. The Commonwealth commissioned the Australian Institute of Health and Welfare (AIHW) and its collaborating unit the National Perinatal Epidemiology and Statistics Unit (NPESU) to undertake a review of perinatal and maternal mortality and morbidity data in Australia and the key findings have been published in a bulletin, *Maternity data in Australia: a review of sources and gaps* (Walker 2011) that describes data collection and reporting of maternal morbidity data in Australia in 2009.

This second review was commissioned by the Australian Health Ministers' Advisory Committee (AHMAC) and followed on from the previous review and focused exclusively on data relating to maternal morbidity collection practices in Australia. The purpose of the review was to assess the feasibility of standardising the collection and reporting of maternal morbidity within perinatal data collections. The review was tasked with:

- undertaking a review of current practices in maternal morbidity data collections
- identifying of the training and guidance provided to midwives about collection of maternal morbidity data
- identifying the processes used for maternal morbidity data validation in jurisdictions
- documenting the rationale for the collection and current uses of maternal morbidity data.

This report presents the findings of the second review.

1.2 Scope of the review

The scope of conditions that were considered relevant to the review includes 7 maternal medical conditions and obstetric complications affecting women that arise during 4 prescribed periods:

- before the pregnancy, that is a pre-existing condition
- arising during the pregnancy, that is an obstetric complication
- arising during labour or delivery, that is, a labour complication

- arising during the puerperium (defined as from birth to 42 days post-delivery), that is, a postnatal complication.

These 7 conditions are:

- pre-existing diabetes
- gestational diabetes
- pre-existing hypertension
- gestational hypertension
- pre-eclampsia
- antepartum haemorrhage
- postpartum haemorrhage.

Interventions are not considered within the scope of this review as there are already standardised data collection practices for the main interventions in labour and for birth. The data development of standard data elements such as episiotomy, use of analgesia and anaesthesia are at an advanced stage by the NPDDC and are thus not included in this review.

In considering the feasibility of expanding the Perinatal National Minimum Data Set (Perinatal NMDS) with standardised information about maternal morbidity, the report has focused on maternal morbidity data within perinatal data collections, while recognising that data about maternal morbidity is potentially available from other data sources.

1.3 Structure of this report

Section 2 sets out the methods for the review.

The findings of the review are presented in 3 sections.

Section 3 contextualises the maternal morbidity conditions under consideration and provides a summary of the key literature from Australia and internationally.

Section 4 describes the current maternal morbidity data available and collection practices for perinatal data.

Section 5 evaluates current maternal data within perinatal data collections. This section focuses on the prevalence and contribution to the burden on women and the health sector of each of the 7 priority conditions outlined above.

Section 6 describes alternative data collections as potential sources of maternal morbidity data.

The final section, **Section 7** discusses the findings and actions needed to progress the development of maternal morbidity data.

2 Maternal morbidity overview

Maternal morbidity is a broad term for ill health of women during pregnancy and/or as a consequence of giving birth. The incidence of maternal morbidity in Australia has been steadily rising in recent years (Haynes, Stone et al. 2004), (Nagle, Skouteris et al. 2011). It provides a useful indicator of community maternal health which supplements maternal mortality reporting and provides an evidence base for maternal health policy development. The incidence of specific types of maternal morbidity is low, but due to the range of possible conditions, the overall burden is significant.

There is a long-standing discourse in Australia and internationally about the scope and definition of maternal morbidity. This revolves around a lack of consensus on which aspects in the perinatal period should be included within the scope of the definition.

Maternal morbidity can be divided broadly into 4 components on the basis of severity and aetiology:

1. Conditions or complications that involve 'near miss' cases of women who nearly die. These conditions constitute serious maternal morbidity such as ruptured uterus, severe haemorrhage, septicaemia, organ failure, venous and coagulopathic conditions.
2. Medical conditions that arise during or are exacerbated by pregnancy that require increased surveillance, greater risks of intervention and may impact on the wellbeing of the baby at birth and the immediate and long term health of the mother. These conditions include diabetes, hypertension and obstetric haemorrhage.
3. Operative and non-operative interventions and their subsequent complications, such as caesarean section and episiotomy.
4. Minor complications such as vomiting, backache, urinary tract infections and haemorrhoids that may not considered serious by health professionals but may have significant impact upon a woman's daily functioning and wellbeing.

A number of studies have sought to empirically define the limits of severe maternal morbidity. A US-based systematic review identified 38 clinical variables, a large number of which were pre-existing conditions, both chronic and acute (Bruce, Berg et al. 2008). A South African study approached the definition of severe maternal morbidity from a different perspective. It recommended an indicator-based audit system, including indicators for conditions occurring frequently enough from a population-based monitoring perspective. These would not need to be wholly disease-based but should include indicators such as admission to intensive care units (Pattinson & Hall 2003).

The lack of consensus about the conditions that contribute to maternal morbidity overall, and for constituent conditions is reflected in international studies by the range of population-based prevalence rates for both grouped and specific conditions. A US study found 43% of women experience some type of morbidity during hospital-based labour and delivery, while 1 in 3 women had at least one obstetric complication or at least one pre-existing medical condition (Danel, Berg et al. 2003). A recent Irish study that investigated the incidence of maternal morbidities using a population-based 4-year retrospective methodology, found the incidence of maternal morbidities exclusive of caesarean delivery, was approximately 1 in 6 women (Lutomski, Morrison et al. 2011).

In Australia, studies have identified an increasing incidence of specific morbidity conditions and complications over the past 15-20 years. During this period there has been an increase in the average age of first delivery and the proportion of mothers aged 35 or older (Laws, Li et al. 2010). This, combined with an increase in community obesity, has been linked with the increased risk of maternal morbidities (Chu, Bachman et al. 2008), (Athukorala, Rumbold et al. 2008). The incidence of postpartum haemorrhage has increased significantly as has antepartum haemorrhage (Cameron, Roberts et al. 2006). The incidence of placenta praevia has increased with the rise in the number of caesarean sections and maternal age (Olive, Roberts et al. 2005). The rate of caesarean section increased from 18% of all women who gave birth in Australia in 1992 (Lancaster, Huang et al. 1994 to 31% in 2008 (Laws, Li et al. 2010). Caesarean section is a known risk factor for a range of morbidities, including major infection, uterine rupture in a subsequent pregnancy, haemorrhage, emergency hysterectomy and anaesthetic complications (Liu, Liston et al. 2007).

There is a continuing trend in Western countries for women to delay childbearing, with a threefold increase in the number of pregnant women of pregnancies in the over 35 age group now common in most jurisdictions compared with 20 years ago. One of the consequences of an increasing maternal age in the obstetric population is that providers are now experiencing a significant increase in the incidence of medical disorders in pregnancy. Hypertension, diabetes mellitus and renal disease have significant potential implications for the wellbeing of mother and foetus. As these disorders, per se, are associated with increased caesarean section rates, then a move to an older obstetric population will inevitably lead to a rise in caesarean section rates as a method of managing more complex pregnancies (Council of Obstetric and Paediatric Mortality and Morbidity 2010).

While there is a lack of consensus on what defines maternal morbidity, there is general agreement the incidence of some conditions is rising and the overall burden on the health system is substantial (Pollock, Sullivan et al. 2008).

3 Methods used

A Medline and PubMed literature search was conducted to review current epidemiological trends in relation to the maternal morbidity conditions under review. A search was also conducted to identify validation studies pertaining to the state and territory perinatal data collections.

Jurisdictions produce guidelines for the standardisation of data collection within their remit. These guidelines are aimed at midwives and other health personnel and in some cases provide the rationale for data collection in addition to information related to the collection and reporting of individual data items in the clinical setting.

A standardised request for information regarding current guidelines, data collection practices, notification forms and training was sent to all state and territory perinatal data managers in May 2011. Further information was sought directly from them regarding general training of staff in the collection of data items.

The guidance provided in jurisdictional documents was assessed against: peak-body guidelines produced by the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG); the Australian Diabetes in Pregnancy Society (ADIPS); the Society of Obstetric Medicine of Australia and New Zealand (SOMANZ); and the World Health Organization (WHO). Expert clinical information was provided by the Cardiovascular Disease Monitoring Advisory Committee (AIHW) with regard to the hypertension data items and the National Diabetes Data Working Group (AIHW) regarding the diabetes items.

Maternal morbidity data are also collected in a range of other information systems in addition to perinatal data collections. These include administrative data collections, such as hospital admitted patient collections, research data collections such as AMOSS and BEACH, and clinical registries such as the Australian and New Zealand Intensive Care Society (ANZICS). Information about data collections other than the state and perinatal collections was gathered directly by telephone and email from the custodians, and indirectly from web sources.

4 Maternal morbidity data in perinatal data collections

4.1 State and territory perinatal data collections

Each state and territory collects data relating to the perinatal period about all births, including those that take place at home or in the community. This data is mainly collected by midwives from both the antenatal record and the hospital record. Each jurisdiction uses its own unique data collection form, electronic and/or paper. There is considerable variation in the maternal morbidity data collected.

Maternal morbidity data collected

Each state and territory collects information about medical and obstetric conditions that arise during or as a result of pregnancy.

Data about maternal medical and obstetric conditions varies between jurisdictions. The range of conditions collected is not consistent. The full range of data items from each of the perinatal data collections can be viewed online (AIHW and UNSW 2011). The 7 maternal morbidity conditions have been selected for rigorous review because of their national health importance. Five of these conditions—pre-existing diabetes, pre-existing hypertension, gestational diabetes, gestational hypertension and pre-eclampsia—are identified National Health Priority Areas (NHPAC 2006). The remaining two conditions, collectively called obstetric haemorrhage, represent the leading cause of maternal mortality in Australia (Slaytor, Sullivan et al. 2004).

A core set of 6 conditions (pre-existing diabetes, pre-existing hypertension, gestational diabetes, gestational hypertension, pre-eclampsia, postpartum haemorrhage) are collected in all 8 jurisdictions and a seventh condition (antepartum haemorrhage) is collected in 7 jurisdictions. Information about these conditions is collected using tick boxes on paper-based or electronic forms.

Training for completion of perinatal notifications

New South Wales, Victoria, Queensland and South Australia perinatal data management units conduct training on an ad hoc basis. New South Wales arranges training when changes are made to the data collection form or process. Queensland has developed a training module, but all other states and territories rely on individual hospitals to provide training to midwives (and others) about how to collect and report this data. Tasmania, the Australian Capital Territory and the Northern Territory do not have the capacity to provide this function. In the Northern Territory, the commercial providers of the CareSys electronic database provide training on request. No information regarding training in Western Australia was received. Further information about training is provided in Appendix A.

Staff training is not a requirement in any jurisdiction, and in those that do provide training, none conduct regular training sessions in the identification, collection, reporting or recording of maternal morbidity in their perinatal notifications.

Guidelines

Each state and territory, with the exception of the Northern Territory, produce guidelines for perinatal data collection aimed at the midwifery workforce. Perinatal data for births in larger public hospitals in the Northern Territory use guidelines, but these are not specific to maternity. Guidelines are being developed in Northern Territory specifically for the collection of perinatal data that will include collection of data for births outside hospital. Maternal morbidity conditions are addressed specifically by each jurisdiction, with significant variation in the detail and specificity of information provided. Each of the seven conditions addressed include a summary of the guidelines relating to that condition for each jurisdiction. Further information about training is provided in Appendix A.

Data collation and validation

Depending on the jurisdiction, forms are submitted for each birth on a weekly or monthly basis, or within a specified time period after the birth of the baby (for example, 28 or 35 days). In the Northern Territory, perinatal data are extracted from the Northern Territory Hospital Information System every 6 weeks.

Before compilation, some health authorities may use a range of 'data check procedures' to fill in missing data, clarify inconsistent data and check validity. Information provided suggests that different jurisdictions use a varying combination of these:

- follow-up with hospital admissions, medical records staff and/or attending midwives (for missing data and for discrepancies or queries such as confirmation of pre-existing diagnoses)
- cross-checking with hospital-based administrative data collections or other administrative collections (such as Births, Deaths and Marriages) for missing data, inconsistent data and some general quality-control data checking
- validating cross-tabulations (for example, Indigenous status against country of birth)
- cross-checking with previous records for the mother in the perinatal database, if the mother has had a previous birth
- comparing against previous years' numbers to evaluate changes in reporting and potential errors (AIHW 2010b)
- Perinatal data for each year ending 31 December are sent annually, in electronic format, by health authorities in the various jurisdictions to the AIHW who supply it to the NPESU.

Data quality control

Validation studies of perinatal data have been conducted recently in 4 jurisdictions – New South Wales (Taylor, Travis et al. 2005), (Roberts, Bell et al. 2008; Bell, Ford et al. 2008), Victoria (Vagg, Taylor et al. 2000), Western Australia (Downey 2006) and South Australia (McLean, Scott 2001). These studies demonstrate that underreporting and misclassification of some conditions and complications occurred in all these jurisdictions. Table 4.1 describes the overall error rates found in the studies for the specified conditions as reported in these four jurisdictions.

Within the limits of available information these studies indicate that pre-existing and gestational diabetes are generally considered to be consistently and reliably reported. The

other 5 conditions are variously under-reported or misclassified to a greater extent. Caution should be taken in interpreting the proportion of incorrectly identified cases of all types of hypertension in this table as there are notable discrepancies between jurisdictions in the classification of these conditions (see Tables 5.4, 5.5 and 5.6 for descriptions of perinatal guideline definitions). This information is only available for those states where validation studies have been conducted, and highlights the need for ongoing validation of routine collections to be conducted in all jurisdictions.

Table 4.1: Incorrectly reported[(a)] cases of specified conditions as a percentage of validation study sample

	% NSW[(b)]	% Vic	% WA	% SA
Sample size	n=490	n=647	n=525	n=401
Pre-existing diabetes	n.a.	0.2	0.0	0.0
Gestational diabetes	0.4	n.a	0.0	n.a.
Pre-existing hypertension	0.4	0.8	1.1	0.7
Gestational hypertension	4.1	1.5	n.a	1.7
Pre-eclampsia	2.5	0.8	2.1	n.a
Antepartum haemorrhage	0.6	3.9	1.9	2.0
Postpartum haemorrhage	2.7	0.0	6.5	3.5

(a) Incorrectly reported cases combine the number of false positive and false negative cases and express these as a proportion of all cases.

(b) NSW data derived from hospital statistics.

n.a. not available.

Sources: Taylor, Travis et al. 2005 (NSW); Vagg, Taylor et al. 2000 (Victoria); Downey 2006 (WA); McLean, Scott 2001 (SA).

These 4 studies were designed to validate a broader cross-section of perinatal data than maternal morbidity conditions. The small overall error rates at a population level reflect in part the relatively small number of women that would have been affected with these conditions. The importance of these results lies in the relative magnitude of the rates for each condition rather than the absolute values.

Alternative measures, such as sensitivity and specificity, are widely used to assess reporting accuracy against a standard. Sensitivity is the proportion of 'true' cases correctly reported, while specificity is the proportion of 'true' non-cases correctly reported. These are presented in this report where available for these conditions, but were not universally available from these 4 studies.

4.2 National Perinatal Data Collection

National perinatal data are compiled for the National Perinatal Data Collection (NPDC), which comprises data items as specified in the Perinatal National Minimum Data Set (NMDS), plus additional items collected by the states and territories. The Perinatal NMDS is a specification for data collected on all live births and stillbirths of at least 20 weeks gestation or at least 400 grams birth weight, in hospitals, birth centres and in the community. These data elements are defined in the National Health Data Dictionary (NHDD) and standardised collection and reporting between the Commonwealth, states and territories is mandated by the National Health Agreement. The Perinatal NMDS has been implemented since 1997 and currently consists of 23 data items (Laws, Li et al. 2010).

There are currently no maternal morbidity conditions included in the Perinatal NMDS. This limits the development of clinical and performance indicators relating to maternal morbidity. However, some data have been included more recently into the NPDC. Annual data requests for data about births from the year 2006 onwards have included data on a series of maternal medical conditions, obstetric complications and complications of labour and the puerperium. These are outlined in Table 4.2. The aim of presenting this non-standardised data was to promote discussion and use this to initiate the process of data development for the inclusion of maternal morbidity data elements in the Perinatal NMDS (Laws, Sullivan 2008).

Table 4.2: Maternal morbidity data included in the National Perinatal Data Collection

Pre-existing conditions	Pregnancy complications	Labour complications	Puerperal complications
diabetes	gestational diabetes	fetal distress	postpartum haemorrhage
hypertension	pregnancy induced hypertension	cord prolapse	retained placenta
epilepsy	antepartum haemorrhage due to: placenta praevia; placental abruption; or other/unstated condition.	3rd/4th degree perineal tear	major puerperal infection

Source: National Perinatal Data Collection.

Information about each of the conditions listed in Table 4.2 is collected from states and territories as a series of data elements with dichotomous values to indicate whether the condition was present.

5 Standardised review of conditions in perinatal collections

This section deals with the 7 identified maternal morbidity items. Each of these conditions or data items is voluntarily supplied to the NPDC. All conditions are supplied by all jurisdictions with the exception of antepartum haemorrhage which is not supplied by New South Wales. These conditions were selected on the basis of their collective health importance, with the diabetes and hypertension conditions identified as national health priorities (NHPAC 2006).

The most recent guidelines that underpin the collection of these conditions, as used by each jurisdiction, were examined in conjunction with published reports.

Information about the prevalence, the definitions available and used in each state and territory, data collection practices, validation studies, training issues and the rationale behind the collection of each morbidity condition are presented.

Table 5.1 summarises the key findings presented in this section. Existing collection of condition data in all jurisdictions is an advantage, and Table 5.1 indicates that 6 out of the 7 conditions are currently collected by all states and territories. Variation in prevalence between jurisdictions is likely to be due to a combination of differences in data collection practices and true differences in prevalence (Laws, Li et al. 2010). However, external validation studies bear out that more of the variation is due to data collection practices. A review of the NHDD has identified data elements for the conditions which could be adapted for use within the Perinatal NMDS. The availability of national guidelines from a peak body that incorporate a clear definition of the given condition is necessary to standardise data collection across jurisdictions.

Table 5.1: Key points for maternal morbidity conditions

	Collected by all states and territories	Range of reported prevalence between jurisdictions[(a)]	Does a NHDD item exist?	National guideline available
Pre-existing diabetes	Yes	Minor	Yes	Yes
Gestational diabetes	Yes	Minor	Yes	Yes
Pre-existing hypertension	Yes	Major	No	Yes
Gestational hypertension	Yes	Major	No	Yes
Pre-eclampsia	No	Major	No	Yes
Antepartum haemorrhage	Yes	Major	No	No
Postpartum haemorrhage	Yes	Major	No	Yes

(a) The range of reported prevalence is used here as an indicator of the quality of data collection practices.

5.1 Diabetic conditions

Background

Diabetes mellitus is a chronic medical condition that results from a body's impaired ability to metabolise blood glucose, which is normally used for energy production at the cellular level.

An excess of blood glucose results in complications to the normal function of the cardiovascular system and has particularly damaging effects on the kidneys and eyesight.

Diabetes affects both the mother and baby in the short– and long–term. Short-term effects include: increased risk of premature delivery, macrosomic fetal growth, increased risk of miscarriage and fetal congenital malformations (AIHW 2010a; Correa, Gilboa et al. 2008). Long-term effects include: increased risk of cardiovascular and renal disease for both the mother and child, as well as increased risk of developing diabetes in the offspring and future obesity (Clausen, Mathiesen et al. 2008), (AIHW 2010a). Due to its growing prevalence and the health burden associated with it, diabetes mellitus has been identified as a National Health Priority Area.

In relation to maternal morbidity, diabetes can take two forms: pre-existing diabetes mellitus (Type 1 and Type 2) and gestational diabetes mellitus.

Pre-existing diabetes

Recent research evidence suggests the type of pre-existing diabetes (Type 1 or Type 2) may account for differences in the incidence and type of adverse outcomes experienced by the child in adult life (Clausen, Mathiesen et al. 2009). The Australasian Diabetes in Pregnancy Society (ADIPS) has produced guidelines for the identification and management of women with pre-existing diabetes (McElduff, Cheung et al. 2005).

Box 5.1: Summary of main findings for pre-existing diabetes

- The ADIPS has produced guidelines for identification and management of women with pre-existing diabetes.
- There is some minor variation in the timing of the diagnosis between jurisdictions. ADIPS recommends a diagnosis of diabetes mellitus made during the first trimester should be classified as pre-existing diabetes.
- There is a need for common nomenclature to be used across jurisdictions to avoid inconsistency in national reporting.
- A National Health Data Dictionary item currently exists (Person—diabetes mellitus status, code NN) that could be used in the Perinatal NMDS.

Population health burden

Based on NPDC data for 2008, the estimated mean prevalence for pre-existing diabetes of all women who gave birth in the five most populous states was 0.6% (Laws, Li et al. 2010). This aligns with other national estimates of population prevalence for this condition, of 0.3% for women aged 25-34 and 0.9% for women aged 35-44 (Hadfield, Lain et al. 2008). The most at-risk populations are women who are more likely to have type 2 diabetes compared to other Australian women, including women who identify as being of Aboriginal or Torres Strait Islander origin, or who were born in Polynesia, southern Asia or the Middle East, (AIHW 2010a).

Definitions and codes

While all jurisdictions collect data for pre-existing diabetes, the condition encompasses subset conditions that are not collected by all jurisdictions. This complexity is reflected in the range of terms used to describe the same condition. The broadest division is Type 1 and Type

2 diabetes mellitus. Type 1 is also known as insulin dependent diabetes while Type 2 is known as non-insulin dependent diabetes. Patients with non-insulin dependent diabetes may use insulin in combination with oral hypoglycaemic medications and others will be diet controlled.

In addition to these nomenclature issues, the complexity is exacerbated by the inappropriate application, in hospital morbidity data, of the general condition ICD-10 AM E codes (E10, E11, E13, E14) to pregnant women. The O24 codes which are specific to the obstetric population should be used. The National Hospital Morbidity Database (NHMD) reports both set of codes within its collection (by principal diagnosis and additional diagnoses) while the jurisdictional midwife data collections (and by extension, the NPDC) only report O24 codes (AIHW 2010a). An algorithm has been developed by the NHMD to determine the most appropriate ICD-10 AM diagnostic code where both sets of codes exist in a single record.

The AIHW National Diabetes Data Working Group (NDDWG) recommend that a diagnosis of Type 1 or Type 2 diabetes made before conception or during the first trimester of pregnancy be identified and recorded as pre-existing diabetes in pregnancy (AIHW 2010a). This recommendation has not been universally adopted by the state and territory perinatal data groups.

Collection methods

All jurisdictional midwives' data collections use a tick box method to record pre-existing diabetes. The tick box may be either on a paper-based form or in an electronic form. Victoria, Queensland, Western Australia and the Australian Capital Territory collect diabetes information according to ICD-10 AM codes, that is, in these jurisdictions, computer data entry for given conditions is linked directly to an ICD-10 AM code. This process is more streamlined, thereby reducing data error. Of these jurisdictions, Queensland and Western Australia collect the information about the presence of pre-existing diabetes from perinatal data sources, normally the patient held antenatal record, while the other two jurisdictions take this information from hospital medical records. In the other four jurisdictions, New South Wales, South Australia, Tasmania and the Northern Territory, clinical coders separately assign the relevant codes (AIHW 2010a).

All state and territory midwives data collections collect and report pre-existing diabetes. There is however, some variation in the specific diabetes conditions each state and territory report, as well as some variation in the way these data are collected. Only Victoria and Queensland collect anything other than simple pre-existing diabetes. Victoria collects diabetes Type 1 and diabetes Type 2 while Queensland collects insulin treated, oral hypoglycaemic therapy and other under the heading pre-existing diabetes mellitus. This other is explained in the relevant guideline manual as including diet, exercise or, lifestyle management.

Guidelines

Guidelines are produced for 6 of 8 jurisdictions for data entry personnel who are principally, but not exclusively, midwives (Table 5.2). The Australian Capital Territory and the Northern Territory do not produce guidelines. South Australia produces a guideline but it does not provide a definition of pre-existing diabetes. The guidelines are in all cases easy to understand and apply. None of the guidelines indicate whether any other information source (other than asking the women) is to be utilised. The AIDPS (McElduff, Cheung et al.

2005) has produced an evidence-based guideline that defines the condition and provides explicit guidance for its management.

Table 5.2: Guideline definitions for coding pre-existing diabetes

Jurisdiction	Guideline definition
NSW	Pre-existing diabetes before pregnancy
Vic	Pre-existing maternal diseases and conditions that are not directly attributable to the pregnancy but may significantly affect care during the pregnancy and or the outcome
Qld	Diabetes pre-existing prior to pregnancy. Indicate whether insulin treated, oral hypoglycaemic therapy treated or other (includes diet, exercise, lifestyle management)
WA	Pre-existing diabetes before pregnancy
SA	n.a.
Tas	Pre-existing maternal diseases and conditions that are not directly attributable to the pregnancy but may significantly affect care during the pregnancy and or the outcome
ACT	n.a.
NT	n.a.

n.a. not applicable (that is, the jurisdiction does not produce a guideline for the perinatal data collection).

Source: State and territory perinatal data collection guidelines.

Data validation

Consistency in the prevalence for pre-existing diabetes in pregnancy across jurisdictions suggests reliable data collection practices occur for this condition. Four jurisdictions—New South Wales, Victoria, Western Australia and South Australia—have conducted data validation studies at various times, all finding high levels of accuracy in their respective perinatal data collections. In each study, data was validated against hospital medical records which are considered the gold standard. The New South Wales study based on 1998 data (Taylor, Travis et al. 2005) found 99.7% agreement for pre-existing diabetes and a more recent study found 100% agreement (Hadfield, Lain et al. 2008). The Victorian study found 100% accuracy for this condition (AIHW 2010a). The Western Australian study also found 100% ascertainment (Downey 2006). The South Australian study also demonstrated a 100% ascertainment, significantly improved upon since the previous validation study in 1986, by the addition of a specific tick box option for pre-existing diabetes (McLean, Scott et al. 2001). A recent academic validation study conducted in New South Wales also using hospital medical records as the reference standard, found accurate reporting of pre-existing diabetes in hospital data when compared with birth data records with a slight but not significant under-ascertainment of Type 2 pre-existing diabetes in the hospital data (Bell, Ford et al. 2008).

Rationale for data collection

Some guidelines provide a rationale for data collection. For example, the section referring to pre-existing diabetes in the New South Wales guideline states 'Diabetes mellitus is associated with higher rates of maternal and perinatal morbidity and mortality'. Others, such as the Victorian guideline, give a broad rationale for the collection of all pre-existing maternal morbidity conditions specified on their notification form, 'Pre-existing maternal diseases and conditions that are not directly attributable to pregnancy but may significantly affect care during the current pregnancy and/or pregnancy outcome'.

Gestational diabetes

Box 5.2: Summary of main findings for gestational diabetes

- ADIPS have produced a national guideline for gestational diabetes mellitus (GDM).
- There is a need for standardised timing of diagnosis of GDM. Options include the ADIPS guideline (between 26-28 weeks) or ICD-10 AM coding (O24.4, O24.9) which specifies diagnosis after 24 weeks.
- There is a need for jurisdictional guidelines to reflect a standardised approach to diagnosis and data collection to include greater specificity of information than is currently provided.
- A NHDD item currently exists (Person—diabetes mellitus status, code NN) that can be used in the Perinatal NMDS with relatively minor revision needed.

Background

GDM is a transient form of diabetes that arises or is first diagnosed during pregnancy and resolves soon after the end of pregnancy. A diagnosis of GDM signals a heightened risk of developing chronic diabetes mellitus in later life. For some women, a diagnosis of GDM in pregnancy is the means by which previously unrecognised chronic diabetes is exposed (AIHW 2010a). In either case, GDM is a serious problem, and it has many of the same risks and potential complications as pre-existing diabetes.

Definitions and codes

The NDDWG recommends GDM be defined as any degree of glucose intolerance with onset or first recognition during pregnancy (Metzger & Coustan 1998). This is at odds with the ADIPS position which recommends screening between 26 and 28 weeks gestation and defines GDM as carbohydrate intolerance of variable severity with onset or first recognition during pregnancy (Hoffman, Nolan et al. 1998). A 2002 updated version of the ADIPS guidelines was endorsed by RANZCOG in 2003. The Australian College of Midwives recommend referring cases of GDM requiring insulin to secondary or tertiary medical care. These guidelines only address referral mechanisms and do not address the management of women with GDM (ACM 2008).

All state and territory midwives data collections use a standardised nomenclature, gestational diabetes or GDM on their respective notification forms, however guideline definitions are discrepant. ADIPS guidelines for screening, diagnosis and follow-up testing are widely used, but what guides practice in this area rests with the individual hospital. A one-size fits all approach may not be suitable for hospitals managing populations with specific needs. The relevant ICD-10 AM codes closely reflect the ADIPS guidelines and inform the NHDD data element (Person—diabetes mellitus status, code NN) which incorporates a coding value for GDM. Standardisation of this data is not complete however. An O24 code for GDM may be applied for a diagnosis made at or after 24 weeks gestation rather than at or after 26 weeks (and before 28 weeks) as described in the ADIPS guidelines.

Population health burden

Based on figures from the NHMD for 2007-2008, an estimated 5% of females aged 15-49 who gave birth in hospital were diagnosed with GDM, with more than one-third of these cases among females aged 35 and older (AIHW 2010a). Perinatal data collection incidence rates for

the 2008 reporting period for each state and territory vary considerably. According to 2008 NPDC data (Laws, Li et al. 2010), Tasmania reported a GDM incidence rate of 28.0 per 1,000 women who gave birth, while the Northern Territory reported a rate of 62.1 per 1,000 women giving birth. In the most populous 4 states, the range was from 44.7 per 1,000 women who gave birth in Western Australia to 54.9 in Victoria. This is not wholly explained in terms of population differences and suggests a lack of standardised data collection practices for this condition. Because of this, NHMD data has been preferred over jurisdictional midwives data collection data for reporting purposes at a national level, despite historical concerns over the underreporting of morbidity in administrative data sets (AIHW 2010a).

Collection methods

All states and territories collect GDM using a tick box method, with data collected on a paper or electronic form, or a combination of both. Victoria and Queensland include tick boxes to differentiate the management of GDM. Victoria requires either diet or insulin data items to be ticked to affirm a record of GDM. There are no options for 'neither' or 'unknown'. Queensland has three tick box options for GDM – insulin treated, oral hypoglycaemic therapy, other – to establish a report of GDM. The South Australian birth notification form has a tick box located directly below gestational diabetes, which states Other (specify, including impaired glucose tolerance). This Other is intended for additional obstetric complications not elsewhere reported on the form and does not solely relate to diabetic conditions, though the wording may be misleading.

Data validation

No jurisdiction routinely conducts validation studies for GDM in their midwives data collection (Laws, Li et al. 2010). Validation studies of data in hospital collections have been conducted in 3 jurisdictions (New South Wales, Victoria and Western Australia), with most finding a high degree of accuracy in reporting for this condition. The New South Wales study based on 1998 data (Taylor, Travis et al. 2005) found 99.1% agreement between hospital case notes and perinatal data for GDM while the Victorian study found 99.7% accuracy (AIHW 2010a). A fourth validation study conducted in South Australia (McLean, Scott et al. 2001) did not address GDM. The Western Australian study (Downey 2006a) found 100% accuracy between the reference standard and the perinatal data collected for this condition.

A recent independent validation study conducted in New South Wales found GDM was more completely and more accurately reported in the hospital data than in the birth data. It also found that more severe forms of diabetes were more likely to be reported than less severe (Bell, Ford et al. 2008).

Guidelines

Guidelines are provided to hospital and homebirth midwives to assist with uniform completion of the midwives' notification form in 6 of 8 jurisdictions. These are set out in Table 5.3. The ADIPS have produced a reliable evidence-based guideline that defines this condition and its management (Nankervis 2012).

Table 5.3: Guideline definitions for coding gestational diabetes

Jurisdiction	Guideline definition
NSW	Diabetes diagnosed during the current pregnancy
Vic	The manifestation of diabetes mellitus during pregnancy that resolves post birth; Insulin dependent or diet controlled
Qld	Diabetes specifically occurring during pregnancy. Indicate whether insulin-treated, oral hypoglycaemic therapy-treated or other (includes diet, exercise, and lifestyle management)
WA	Diabetes in pregnancy as confirmed by clinical investigations (e.g. Glucose Tolerance Test)
SA	There is still no universal agreement on the criteria for gestational diabetes and impaired glucose tolerance. Place a tick in the box for gestational diabetes if the clinician has documented that this woman has gestational diabetes based on the criteria of the hospital or laboratory where the test was performed. (The criteria currently used by the ADIPS and the WHO for the 75g oral glucose tolerance test are reproduced in full).
Tas	Impaired glucose tolerance occurring during pregnancy, demonstrated by fasting 75gm OGTT (oral glucose tolerance test) plasma glucose levels of fasting ≥ 5.5, and/or 2 hr level ≥8.0
ACT	n.a.
NT	n.a.

n.a. not applicable (that is, the jurisdiction does not produce a guideline for the perinatal data collection).

Source: State and territory perinatal data collection guidelines.

Rationale for data collection

There is no difference in the rationale for pre-existing diabetes and GDM, as provided by any of the 6 jurisdictions that currently produce guidelines. See Appendix B for a general description of the rationale for collecting maternal morbidity data, supplied by jurisdiction data managers.

5.2 Hypertensive conditions

Background

Pregnancies complicated by hypertension are associated with increased risk of maternal morbidity outcomes, including obstetric haemorrhage and maternal death. The Society of Obstetric Medicine of Australia and New Zealand (SOMANZ) endorse the International Society for the Study of Hypertension in Pregnancy classification of hypertension in pregnancy (SOMANZ 2008). Box 5.3 identifies the major classifications for this condition in pregnancy. In addition to these classifications, SOMANZ has also defined severe hypertension in pregnancy as a systolic blood pressure ≥ 140mmHg and/or diastolic blood pressure ≥ 90mmHg.

Box 5.3: SOMANZ classification of hypertension in pregnancy

- Chronic hypertension defined as: essential; secondary; or white coat (elevated blood pressure exhibited in a clinical setting only).
- Gestational hypertension
- Pre-eclampsia – eclampsia
- Pre-eclampsia superimposed on chronic hypertension

Source: Lowe, Brown et al. 2009.

Pre-existing hypertension

Box 5.4: Summary of main findings for pre-existing hypertension

- SOMANZ has produced a useable national guideline for this condition
- There is a need for common nomenclature to be used across jurisdictions to avoid inconsistency in national reporting.
- Validation studies have found systematic underreporting of this condition in both the perinatal and the hospital admissions data.
- Jurisdictional perinatal data collection guidelines reflect wide variation in the required specificity for this condition.
- No suitable NHDD item exists for this condition.

Background

Pregnancies complicated by pre-existing hypertension have been found to be at substantially greater risk of fetal death compared with pregnancies complicated by pre-eclampsia (Roberts, Algert et al. 2005). Studies differ in their estimates of the risk of women with pre-existing hypertension of developing superimposed pre-eclampsia, from 16% to 40% (Lydakis, Beevers et al. 2001). One study in South Australia found this latter condition is strongly associated with placental abruption. The same study found that women with pre-existing hypertension had a significantly higher risk of having an elective caesarean compared with other types of hypertension in pregnancy but that some increase in maternal systemic blood pressure is at worst benign and at best is associated with some protection against perinatal mortality (Heard, Dekker et al. 2004).

Generally, the reproductive-aged female population is young and healthy and will not have overt symptoms of chronic conditions. Because of this, they are often unlikely to have been screened or diagnosed prior to pregnancy. Therefore, the differential diagnosis of pre-existing and pregnancy-induced hypertension can be difficult to make with certainty until after the pregnancy, when gestational hypertension is expected to resolve.

Definitions

The synonymous terms used in perinatal data collections for this condition varies between hypertension, chronic hypertension, pre-existing hypertension and essential hypertension. The SOMANZ guidelines affirm that chronic hypertension predates the pregnancy or has onset before 20 weeks' gestation. The reason for the loose application of a definitive time of onset is because some women with pre-existing hypertension will not be diagnosed with the condition until pregnancy, this often being the first time that many women will be fully screened and tested for hypertensive disorders. Three jurisdictions refer to essential hypertension—Queensland, Western Australia and the Australian Capital Territory. For comparative purposes, the NHDD defines an individual in the general population with hypertension as '...a person (who) is currently being treated for hypertension (high blood pressure) using antihypertensive medication' (AIHW 2012).

Population health burden

A large population-based study conducted in New South Wales found 0.6% of all births were to mothers with pre-existing hypertension (Roberts, Algert et al. 2005). Another New South Wales study in 2008 confirmed a rate of 1.3% for this condition in their validated

sample, compared with a rate of 0.5% for the same women in the midwives' data (Roberts, Bell et al. 2008). The prevalence rates for this condition differ markedly between states and territories, depending on data collection definitions and practices (see Table 5.4).

Prevalence rates for this condition reported in the most recent Australia's Mothers and Babies series (Laws, Li et al. 2010) show a higher degree of variance between the states with the largest populations (New South Wales, Victoria, Queensland, Western Australia) than would be expected from demographic differences, suggesting inconsistent data collection practices between the jurisdictions. Western Australia reported a rate for this condition of 13.6 cases per 1,000 women, while Queensland reported a rate of 6.1 cases per 1,000 women.

Collection methods

All state and territory perinatal data collections include pre-existing hypertension in pregnancy. The mode of collection for all jurisdictions is by a tick box option on their notification forms—paper or electronic. In addition to a tick box, Victoria, Queensland and the Australian Capital Territory provide a free text field or a separate tick box for, variously, cardiovascular condition or circulatory condition or renal condition, all of which might plausibly be used for pre-existing hypertension.

Western Australia requires specific conditions to be met over 2 visits for a woman to be assigned this condition, but counter intuitively reports a higher rate. Queensland has no specific requirements to be met. The Queensland procedure for assigning pre-existing hypertension to the woman's record is determined by asking the woman her known hypertension status.

In the hospital data, hypertension is reported using the 6 major ICD-10 AM codes for hypertension in pregnancy (O11-O16). A maximum of 40 diagnoses can potentially be assigned for each hospital admission (Roberts, Bell et al. 2008).

Guidelines

Guidelines are provided to hospital and homebirth midwives to assist with the uniform completion of the perinatal notification form in 6 of 8 jurisdictions. These are set out in Table 5.4.

Table 5.4: Guideline definitions for coding pre-existing hypertension

Jurisdiction	Guideline definition
NSW	Chronic hypertension diagnosed prior to, or in the first half, of the current pregnancy Definitions of chronic hypertension follow those recommended by the Australasian Society for the Study of Hypertension in Pregnancy and described in the Society's Consensus Statement on the Management of Hypertension in Pregnancy
Vic	Maternal diseases and conditions that are not directly attributable to pregnancy but may significantly affect care during the current pregnancy and/or pregnancy outcome
Qld	Pre-existing maternal conditions, hypertension or diabetes, and other diseases, illnesses or conditions arising during the current pregnancy, that are not directly attributable to pregnancy but may significantly affect care during the current pregnancy and/or pregnancy outcome
WA	Diastolic blood pressure of 90 mmHg or more recorded on at least 2 occasions before 24 weeks of pregnancy and not due to any identifiable aetiology factor
SA	Hypertension that is pre-existing
Tas	Known hypertension requiring medical treatment prior to pregnancy or occurring in the first half of the pregnancy before 20 weeks
ACT	n.a.
NT	n.a.

n.a. not applicable (that is, the jurisdiction does not produce a guideline for perinatal data collection).

Source: State and territory perinatal data collection guidelines.

Data validation

Validation studies conducted on perinatal data have been published by 4 jurisdictions: New South Wales, Victoria, Western Australia and South Australia. The most rigorous type of validation study involves the direct comparison of perinatal data derived from the midwives' data collection form with gold standard hospital records. This type of study was conducted in Victoria (Vagg, Taylor et al. 2000), Western Australia (Downey 2006) and South Australia (McLean, Scott et al. 2001). All states and territories report perinatal data in their hospital discharge data and there have been a number of validation studies comparing perinatal data derived from admitted patient data collection data with gold standard hospital records. This type of study has been conducted in New South Wales on 3 occasions since 2000 (Lain, Roberts et al. 2008), (Taylor, Travis et al. 2005), (Hadfield, Lain et al. 2008). New South Wales routinely conducts data linkage between the NSW Admitted Patient Data Collection and the NSW Midwives Data Collection, and one study (Roberts, Bell et al. 2008) has compared this combined perinatal data with the reference standard.

The Victorian validation study data estimated 71% agreement for pre-existing hypertension—between the Perinatal Morbidity Statistics form data and the medical record—in their sample. The error was in all cases due to misclassification of gestational hypertension as pre-existing hypertension, though the total number of true cases was small (Vagg, Taylor et al. 2000b).

The South Australian study found only one case of inaccurate reporting of this condition in their sample. This study was conducted prior to the introduction of a standardised patient held antenatal medical record, which may have since further improved the accuracy of this data (McLean, Scott et al. 2001).

The Western Australian study found a 98.9% agreement for pre-existing hypertension between the perinatal data and the medical records data (Downey 2006).

A recent New South Wales study (Hadfield, Lain et al. 2008) investigated the validity of reported pre-existing perinatal medical condition data found in the hospital discharge data (NSW Admitted Patients Data Collection) compared with the reference standard hospital medical records and found there was systematic underreporting of pre-existing hypertension. This conclusion supported an earlier study (Taylor, Travis et al. 2005) which found variable under-enumeration of a range of pre-existing medical conditions in NSW data. Another New South Wales validation study (Roberts, Bell et al. 2008) sought to assess the accuracy of the hypertensive disorders of pregnancy in single and linked population health datasets—perinatal data and hospital discharge data—compared with data from medical records. The outcome of this study suggested rates of all types of hypertension are routinely underreported in both perinatal and hospital discharge data, but that the underreporting is more significant in the perinatal data. It also found greater accuracy in the reporting of more severe hypertensive conditions (Roberts, Bell et al. 2008).

While relatively few validation studies have been conducted on the quality of this perinatal morbidity data, there is evidence to suggest a trend toward the misclassification of pre-existing hypertension and gestational hypertension. The New South Wales and Victorian studies were statistically more robust because of their sampling methods and in both these jurisdictions there was evidence of underreporting and misclassification for this condition.

Rationale for data collection

Only New South Wales and Victoria provide a rationale for the collection of pre-existing hypertension in pregnancy. Instructions for New South Wales Midwives Data Collection (2006) states, 'hypertension is associated with higher rates of maternal and perinatal morbidity and mortality'. The Victorian Perinatal Data Collection User Manual—paper and electronic (2009) states, 'About 1 in 10 pregnancies is complicated by hypertension: about 3-4% have pre-eclampsia, a similar proportion have gestational hypertension and 1-2% have pre-existing chronic hypertension'.

Gestational hypertension

Box 5.5: Summary of main findings for gestational hypertension

- SOMANZ has produced a useable national guideline for this condition.
- There is a need for common nomenclature to be used in jurisdictions to avoid inconsistencies in national reporting. Gestational hypertension (or pregnancy-induced hypertension (PIH)) and pre-eclampsia (or PIH with proteinuria) are terms used interchangeably by some jurisdictions and are collected as one condition.
- The South Australia perinatal data collection guideline provides the most specific information, making a clear distinction between the two conditions.
- There is discrepancy between jurisdictions about the timing of diagnosis of this condition: either after 20 weeks or after 24 weeks gestation.
- Validation studies have repeatedly found substantial under ascertainment of gestational hypertension in the perinatal data collections.
- Training has been identified as a way to improve data quality.

Definitions and codes

Gestational hypertension is variously known and recorded as pregnancy induced hypertension or PIH. The Society of Obstetric Medicine of Australia and New Zealand (SOMANZ) recommend using the term gestational hypertension (Lowe, Brown et al. 2009). This corresponds to ICD-10 AM codes O13 and O14.

The SOMANZ definitions for gestational hypertension are set out in Box 5.6.

Box 5.6: SOMANZ definitions for gestational hypertension

Gestational hypertension is the new onset of hypertension after 20 weeks gestation, with a systolic blood pressure greater than or equal to 140mgHg and/or diastolic blood pressure greater than or equal to 90mmHg (Lowe, Brown et al. 2009).

Severe gestational hypertension is systolic blood pressure greater than or equal to 170 mmHg and diastolic blood pressure greater than or equal to 110mmHg.

Population health burden

The incidence rates of this condition vary dramatically across jurisdictions. The rate (per 1,000 women who gave birth) of gestational hypertension in 2008 was 63.1 in New South Wales, 48.1 in Victoria and 4.0 in Western Australia (Laws, Li et al. 2010). An independent New South Wales study estimated incidence rate to be 83.4 per 1,000 women who gave birth, where 'pregnancy hypertension' included all types of pregnancy induced hypertension with onset after 20 weeks gestation (Hadfield, Lain et al. 2008).

Collection methods

All states and territories collect and report pregnancy hypertension in some form and all perinatal data collection forms include a tick box option for these conditions. The specific diagnostic term used for this condition however is not standard and only 3 jurisdictions (New South Wales, Queensland and Tasmania) make a distinction between gestational hypertension and pre-eclampsia, raising issues about the specificity and reliability of data across jurisdictions. Note that non-proteinuric pregnancy-induced hypertension is the term used for gestational hypertension in New South Wales (see Table 5.5).

Data validation

New South Wales validation studies have found significant under ascertainment of gestational hypertension cases (high number of false negatives) and that the corresponding hospital data was substantially more accurate than the perinatal data (Roberts, Bell et al. 2008), (Hadfield, Lain et al. 2008). The Victorian validation study found 40% of true cases were missed in the perinatal data (Vagg, Taylor et al. 2000a).

A South Australian study found the highest number of false negatives among all the obstetric complications examined was for gestational hypertension. That is, they identified that a significant number of the midwives data notification forms had erroneously excluded gestational hypertension.

Table 5.5: Guideline definitions and data items for gestational hypertension

Jurisdiction	Data item on form	Guideline
NSW	Non-proteinuric	Hypertension developing after 20 weeks gestation without proteinuria Pregnancy-induced hypertension (non-proteinuric) is also referred to as gestational hypertension
Vic	Pre-eclampsia	A serious disorder of human pregnancy that carries a severe morbidity and mortality risk for both mother and child About one in ten pregnancies is complicated by hypertension: about 3-4 % have pre-eclampsia, a similar proportion have gestational hypertension and 1-2 % have pre-existing chronic hypertension (MJA 2003; 179 (4): 182-184)
Qld	PIH/PE: Mild Moderate Severe	Complications of pregnancy arising up to the period immediately preceding labour and delivery that are directly attributable to the pregnancy and may significantly affect care during the current pregnancy and/or the outcome
WA	Pre-eclampsia	A rise in the systolic BP to 140mm Hg or more and /or a rise in the diastolic BP to 90mm Hg or more in a woman who has been normotensive before the 24th week of pregnancy, with or without proteinuria
SA	Pregnancy hypertension (all types)	BP ≥140/90 on two occasions at least 4 hrs apart, or BP ≥170/110 on one occasion; ± proteinuria, ± generalised oedema This specifically excludes essential hypertension or other categories of pre-existing hypertension occurring alone but include if there was superimposed pre-eclampsia Proteinuria: A trace of protein occurring once would best be ignored from the point of view of these statistics. Include if ≥1+ or ≥0.3g/24 hours Eclampsia: Should be separately identified under 'Other' as a specified complication
Tas	Pregnancy-induced hypertension	PIH: Hypertension occurring for the 1st time in pregnancy, not associated with proteinuria >300mg/24hrs
ACT	Pre-eclampsia	n.a.
NT	Pre-eclampsia	n.a.

n.a. not applicable (that is, the jurisdiction does not produce a guideline for perinatal data collection).

Source: State and territory perinatal data collection forms and guidelines.

Rationale for data collection

Only New South Wales and Victoria provide a justification for the collection of this data. In New South Wales all hypertensive syndromes in pregnancy include the same rationale, that is, 'hypertension is associated with higher rates of maternal and perinatal morbidity and mortality'. In Victoria, where gestational hypertension is grouped together with pre-eclampsia, the guidelines provide an epidemiological justification for data collection. Although the conditions are not separated in the data collection, the rationale makes a clear distinction between gestational hypertension and pre-eclampsia. It states, 'a serious disorder of human pregnancy that carries a severe morbidity and mortality risk for both mother and child. About 1 in 10 pregnancies is complicated by hypertension: about 3–4% have pre-eclampsia, a similar proportion have gestational hypertension and 1–2% have pre-existing chronic hypertension' (Davey, Taylor et al. 2008).

Pre-eclampsia

Box 5.7: Summary of main findings for pre-eclampsia

- SOMANZ guideline available for national application.
- There is a need for common nomenclature to be used across jurisdictions to avoid inconsistencies in national reporting.
- Gestational hypertension (or PIH) and pre-eclampsia (or PIH with proteinuria) are terms used interchangeably by some jurisdictions and are also collected as one condition in some cases.
- There is a discrepancy between jurisdictions in relation to the timing of diagnosis of this condition: either after 20 weeks or after 24 weeks gestation.
- The South Australia perinatal data collection guideline provides the most specific information, making a clear distinction between the two conditions.
- Validation studies have repeatedly found substantial under ascertainment and misclassification of pre-eclampsia in the perinatal data collections.
- Training has been identified as a way to improve data quality.

Background

Pre-eclampsia is a severe maternal morbidity with potentially fatal consequences for the fetus if left untreated. The SOMANZ guidelines for hypertension in pregnancy describe pre-eclampsia as a multi-system disorder unique to human pregnancy characterised by hypertension and involvement of one or more other organ systems and/or the fetus. Raised blood pressure is commonly but not always the first manifestation. Proteinuria is the most commonly recognised additional feature after hypertension. These guidelines also describe a further classification that of pre-eclampsia superimposed on chronic hypertension (Lowe, Brown et al. 2009). Data for this classification do not need to be collected through the perinatal data collection systems, as the condition may be ascertained from cross-tabulation of confirmed pre-eclampsia cases with confirmed pre-existing hypertension cases. Currently, the NPDC does not collect or report pre-eclampsia in its annual report. It reports pregnancy-induced hypertension only, which includes cases of pre-eclampsia.

Definitions and codes

Some jurisdictions use the term pre-eclampsia specifically for the condition as described by the SOMANZ guidelines, while others use it to generally refer to pregnancy-induced hypertension or to a severe form of the same. Table 5.6 shows the ways this diagnostic term is used in each jurisdiction. Only New South Wales and the Australian Capital Territory report separate statistics for gestational hypertension and pre-eclampsia. The remaining jurisdictions report hypertension arising in pregnancy, including pre-eclampsia.

The relevant ICD-10 AM codes for this condition are the O14 codes. These codes make a distinction between mild and severe forms of pre-eclampsia.

The ANZICS clinical registry data base reports a code for pre-eclampsia/eclampsia. This data is not reported nationally and is not currently linked with other hospital data sets.

Population health burden

A New South Wales study found a fivefold increased risk for developing major maternal morbidities for women with pre-eclampsia (Roberts, Algert et al. 2005). There is a large variability in the estimated rates for this condition between jurisdictions. One study estimated a prevalence of 1.5% ranging to 7.7% based on different health data sets (Roberts, Bell et al. 2008). As mentioned previously (see Gestational hypertension: Collection methods), there is a lack of uniformity in how this condition is differentiated from other types of hypertension in pregnancy, despite there being national guidelines in place providing a clear definition and distinction. The lack of a standardised definition suggests these population estimates are not comparable between jurisdictions.

Collection methods

Only New South Wales, Queensland and Tasmania collect data sensitive enough to exclude less severe forms of pregnancy hypertension in their data (see Table 5.6). Using a tick box option, New South Wales collects Pregnancy-induced hypertension: proteinuric and bases its collection practices on SOMANZ guidelines. Under the heading of PIH/PE (pre-eclampsia), Queensland also uses a tick box option but increases the specificity of its data collection by having data collected by severity of hypertension. However, there are no guidelines to support these different options. Tasmania also uses a tick box option and, unlike the other two states, calls this data item pre-eclampsia. All other states and territories collect pre-eclampsia but use this data item for all types of pregnancy hypertension, therefore losing some specificity and sensitivity to the data that is reported.

Table 5.6: Guideline definitions and data items for pre-eclampsia

Jurisdiction	Data item on form	Guideline
NSW	Pregnancy-induced hypertension (proteinuric)	Pregnancy-induced hypertension (proteinuric) includes pre-eclampsia and eclampsia This field is equivalent to the following ICD-10 AM codes: O14 (0,1,9) O15 (0,1,2,9) Hypertension developing after 20 weeks gestation (with proteinuria). Pregnancy-induced hypertension (proteinuric) includes pre-eclampsia and eclampsia
Vic	Pre-eclampsia	Pre-eclampsia: a serious disorder that carries a severe morbidity and mortality risk for both mother and child. About one in ten pregnancies is complicated by hypertension: about 3-4 % have pre-eclampsia, a similar proportion have gestational hypertension and 1-2 % have pre-existing chronic hypertension. (MJA 2003; 179 (4): 182-184)
Qld	PIH/PE: Mild Moderate Severe	Complications of pregnancy arising up to the period immediately preceding labour and delivery that are directly attributable to the pregnancy and may significantly affect care during the current pregnancy and/or the outcome
WA	Pre-eclampsia	The development of hypertension with either proteinuria, oedema or both, induced by pregnancy after the 24 week. It is a specific disease of pregnancy Superimposed pre-eclampsia is defined as the development of pre-eclampsia in a woman with chronic hypertension
SA	Pregnancy hypertension (all types)	BP ≥140/90 on 2 occasions at least 4 hrs apart, or ≥170/110 on 1 occasion; ± Proteinuria; ± generalised oedema. This specifically excludes essential hypertension or other categories of pre-existing hypertension occurring alone but include if there was superimposed pre-eclampsia Proteinuria: A trace of protein occurring once would best be ignored from the point of view of these statistics. Include if ≥1+ or ≥0.3g/24 hours

(continued)

Table 5.6 (continued): Guideline definitions and data items for pre-eclampsia

Jurisdiction	Data item on form	Guideline
Tas	Pre-eclampsia	Hypertension occurring after 20 weeks of pregnancy (as defined by systolic BP ≥140 and/or diastolic ≥ 90mmHg) in association with urinary protein excretion >300mg/24 hrs
ACT	Pre-eclampsia	n.a.
NT	Pre-eclampsia	n.a.

n.a. not applicable (that is, the jurisdiction does not produce a guideline for perinatal data collection).

Source: State and territory perinatal data collection forms and guidelines.

Data validation

No state or territory conducts routine validation of their pre-eclampsia data. In the past decade ad hoc data perinatal data validation has been conducted in 4 jurisdictions—New South Wales (Roberts, Bell et al. 2008; Taylor, Travis et al. 2005), Victoria (Vagg, Taylor et al. 2000a), Western Australia (Downey 2006), and South Australia (McLean, Scott et al. 2001). The methodology for selecting a representative sample was similar in each case. Each study looked at a range of conditions including pre-eclampsia and compared perinatal data with gold standard medical records (Victoria, Western Australia, South Australia) or perinatal data found in hospital statistics collections and the gold standard (New South Wales).

The first of the New South Wales studies found a statistically significant underreporting of pre-eclampsia in linked hospital collection and midwives 'collection perinatal data (Roberts, Bell et al. 2008). The second study in this jurisdiction compared data from the NSW Inpatient Statistics Collection and medical records and found twice as many women had pre-eclampsia as were reported in the midwives and hospital data collections. The accuracy of this data increased if all types of gestational hypertension were grouped together suggesting systematic misclassification of this condition was occurring (Taylor, Travis et al. 2005).

The Victorian study found roughly the same number of false positives as false negatives in the perinatal data and estimated that ascertainment of this condition was 87% (Vagg, Taylor et al. 2000a).

In the Western Australian validation study pre-eclampsia was also under ascertained in the perinatal data collection with a sensitivity of 0.23 , indicating that only 23% of true cases in the sample (n=525) were identified correctly (Downey 2006).

The South Australian study examined a sample of 2.1% of all births in the study period and found 5 cases of women diagnosed with pre-eclampsia whose condition was not reported in the perinatal data. The study concluded that, overall, conditions were accurately reported in the perinatal data collection but could be improved by articulating the definitions of some conditions. (McLean, Scott et al. 2001a).

Training

The SOMANZ guidelines indicate that the classification of pre-eclampsia is more accurate if clinicians are trained in the interpretation of dipstick proteinuria testing. Dipstick testing for proteinuria is a screening test with very high false positive and negative rates. The guidelines recommend the use of automated dipstick readers where available as this can significantly improve detection of proteinuria. In the absence of automatic readers, clinicians may benefit from further training in accurate reading methods (Lowe, Brown et al. 2009).

Rationale for data collection

Only New South Wales and Victoria provide a justification for collecting data about hypertension in pregnancy (see Gestational hypertension: Rationale for data collection) and only Victoria specifically refers to pre-eclampsia. In reference to pre-eclampsia, the Victorian guidelines state:

[It is] a serious disorder of pregnancy that carries a severe morbidity and mortality risk for both mother and child. About 1 in 10 pregnancies is complicated by hypertension: about 3–4% have pre-eclampsia, a similar proportion have gestational hypertension and 1-2% have pre-existing chronic hypertension (MJA 2003).

5.3 Obstetric haemorrhage conditions

Background

All states and territories collect data relating to obstetric haemorrhage, which includes bleeding arising in pregnancy, in labour and delivery and in the puerperium.

There are 3 broad subdivisions included within this term: threatened miscarriage, antepartum haemorrhage (APH) and postpartum haemorrhage (PPH). A fourth subdivision intrapartum haemorrhage is only collected by the Northern Territory and is normally considered part of PPH.

PPH is measured in terms of blood volume loss and represents an immediate life-threatening event. An associated data item, transfusion, and the units of blood product the woman receives, may also measure PPH severity. PPH includes bleeding up to 24 hours after delivery.

All types of obstetric haemorrhage are underreported in admitted patient data collections (Lain, Roberts et al. 2008).

Antepartum haemorrhage

Box 5.8: Summary of main findings for antepartum haemorrhage

- All states and territories collect antepartum haemorrhage (APH) data but NSW does not report this data to the NPDC.
- Most jurisdictions collect causes of APH (including an option for unknown cause).
- Victoria and Tasmania apply different volume of blood loss specifications to qualify APH.
- There are variations in the definitions of placenta praevia (a leading cause of APH) between jurisdictions.
- There is a significant under ascertainment of cases of APH found in some validation studies, highlighting the need for other sources (Outpatients, Emergency Department, General Practitioner (GP)) of information to be used for this data.
- While no national guideline has been identified, individual women's hospital and jurisdictional guidelines share a high degree of uniformity.

Definitions and codes

Antepartum haemorrhage usually refers to per vaginal bleeding that occurs after 20 weeks gestation, but in some jurisdictions includes bleeding before 20 weeks. Bleeding before 20 weeks is generally defined as threatened miscarriage. Except for New South Wales, all states and territories report this information to the NPDC. APH normally involves relatively small volumes of blood loss but is indicative of potential intrapartum complications particularly related to placental positioning. There are three types of placental positioning that are commonly reported: placenta praevia, placental abruption, and placenta accreta.

The principal relevant ICD-10 AM codes for this condition are the O42-O46 codes.

Population health burden

According to a recent Australian study, the estimated population incidence for any antepartum haemorrhage was 18 per 1,000 women who gave birth (Lain, Roberts et al. 2008). The NPDC report estimates for this condition as a composite (with placenta praevia and abruptio placenta) in a range from 23 (Tasmania) to 107 (Northern Territory) per 1,000 women. When these placental complication conditions are excluded from the estimate, the adjusted range is from 13 (Queensland) to 31 (Northern Territory) per 1,000 women. This figure is consistent with a New South Wales study that found a rate of 2.2% of women who gave birth experiencing APH during their pregnancy (Roberts, Ford et al. 2009b). Research has found that 1 in 7 women with placenta praevia will suffer a major adverse outcome related to obstetric haemorrhage, and half of this morbidity will occur among women who have an elective caesarean section (Roberts, Ford et al. 2008).

Collection methods

As shown in Table 5.7, nomenclature and classification of APH is generally standard across jurisdictions. The main exceptions relate to bleeding that occurs before 20 weeks gestation. The most populous states do not collect threatened miscarriage data—New South Wales and Victoria—and the other jurisdictions collect threatened abortion, threatened miscarriage or APH <20 wks. Unlike other jurisdictions, Victoria specifies a minimum amount of blood loss to qualify for this diagnosis.

Table 5.7: Guideline definitions and data items for antepartum haemorrhage

Jurisdiction	Data item on form	Guideline
NSW	Not collected	
Vic	Antepartum haemorrhage (APH): Placenta praevia – with haemorrhage Placental abruption Other APH	Where the placenta is located over or very near to the cervical os[(a)], which may result in haemorrhage
Qld	APH (<20 weeks)	
	APH (20 weeks or later) abruption	APH (antepartum haemorrhage) resulting from the placenta becoming totally or partially detached from the uterine wall whilst the foetus is still in utero
	APH (20 weeks or later) placenta praevia	An antepartum haemorrhage resulting from the placenta being located over or very near to the internal os[(a)]
	APH (20 weeks or later) other	Any other antepartum haemorrhage, or cause unknown

(continued)

Table 5.7 (continued): Guideline definitions and data items for antepartum haemorrhage

Jurisdiction	Data item on form	Guideline
WA	Threatened abortion (<20 weeks)	Uterine bleeding in pregnancy before 20th week
	APH - placenta praevia	Antepartum haemorrhage resulting from the placenta being located over or very near to the internal cervical os[(a)]
	APH – abruption	Antepartum haemorrhage resulting from the placenta becoming totally or partially detached from the uterine wall whilst the fetus is still in utero
		Abruption without antepartum haemorrhage should be recorded under 'other' in text
	APH – other	Antepartum haemorrhage resulting from causes other than placenta praevia or placental abruption
SA	Threatened miscarriage	Bleeding before 20 weeks gestation
	APH - Abruption	APH = bleeding at 20 weeks or later in pregnancy
	APH - Placenta praevia	If placenta praevia without bleeding, include only under 9 Other - specify placenta praevia
	APH - Other & unknown cause	
Tas	Bleed < 20 weeks (threatened miscarriage)	Any vaginal bleeding occurred before 20 weeks gestation
	Placenta previa	Ultrasound diagnosis of a placenta that is located partly or completely in the lower uterine segment of the uterus after 28 weeks gestation
	APH (undetermined origin)	Any bleeding from the genital tract occurring after 20 weeks, with estimated blood loss greater than 20ml for which no known cause can be found
	Placental abruption	Premature separation of the placenta with wither or both of revealed (vaginal) or concealed bleeding between the placenta and the uterine wall
ACT	APH-Placenta praevia	n.a.
	APH-Abruption placenta	
	APH-other (unspecified)	
	Threatened Abortion	
NT	Labour complications other	Includes antepartum haemorrhage

n.a. not applicable (that is, the jurisdiction does not produce a guideline for perinatal data collection).

Note: NSW does not collect this data as part of their Midwives' Data Collection. Information about APH is collected as part of the NSW Admitted Patients Data Collection but this data is not provided to the NPDC.

(a) Explanatory note: cervical os: the opening of the cervix.

Source: State and territory perinatal data collection forms and guidelines.

Data validation

No jurisdiction routinely conducts validation of their data. A validation of perinatal data in the New South Wales hospital statistics (NSW Inpatient Statistics Collection) data identified sensitivities of 88% for placenta praevia data and 50% for placental abruption data in their sample. This poor result for placental abruption was due to the underreporting of half of the true cases with this condition (Taylor, Travis et al. 2005).

A Victorian validation study found a significant under ascertainment of APH, with 42% of their sample records accurately reporting this condition. The researchers found evidence of confirmed APH in previous admission records, emergency department attendances and GP

shared care documentation that had not been recorded on the midwives' data collection form (Vagg, Taylor et al. 2000).

A Western Australian study looked at threatened abortion and found a sensitivity of 66% for this condition. This estimate was mainly due to the high number of cases that were incorrectly identified as threatened abortion. The study also examined APH (APH-placenta praevia, APH-placental abruption, APH-other) and found generally adequate recording of these conditions (Downey 2006).

A South Australian validation study found the second most missed (false negative; after gestational hypertension) obstetric complication recorded in the perinatal data collection was APH closely followed by threatened miscarriage (McLean, Scott et al. 2001).

Rationale for data collection

No specific rationale is provided by any jurisdiction for the collection of data on this condition. See Table 8.2 for a general description of why jurisdictions collect maternal morbidity data, as provided by the data managers in each state and territory.

Postpartum haemorrhage

Box 5.9: Summary of main findings for postpartum haemorrhage

- RANZCOG produced a College Statement in 2011 for this condition and has endorsed the WHO definition of PPH.
- There is significant variation in the volume of blood loss criteria used by different jurisdictions.
- New South Wales alone uses a proxy measure (units of blood infused) rather than relying on quantifying the volume of blood lost by the woman. This method is supported by independent research.
- A New South Wales validation study found significant under ascertainment of PPH cases especially where caesarean section occurs.
- Training of clinical staff will improve case ascertainment and improve accuracy of individual case severity.

Definitions and codes

The principal relevant ICD-10 AM diagnostic codes for this condition are the O71 and O72 codes. These codes lack the ability to reflect differences in severity of PPH, with the same code being used for a 600ml haemorrhage as for a 3500ml haemorrhage (Pollock, Sullivan et al. 2008). The Australian Coding Standards permit clinical coders to code a condition only if the diagnosis is documented in the medical record or otherwise confirmed by a clinician. The Coding Standards state that PPH is a haemorrhage of 500mls or more in the case of a vaginal delivery and 750mls or more in the case of a caesarean section. However, if the diagnosis of PPH is not documented in the medical record, it must be confirmed with a clinician, specifically a doctor, before it is coded. In practice, confirmation is rarely conducted due to workloads (Lain, Roberts et al. 2008). The NHDD uses the ICD-10 AM codes for its value domains (AIHW 2012).

The ANZICS data collection uses a code for this condition (see Chapter 6 for information about data sources). The utility of this as a data source is limited because there is no requirement that clinicians fill in details for known cases, thus allowing for systematic underreporting.

The WHO guidelines for PPH state this condition is defined as blood loss greater than or equal to 500ml within 24 hours after birth, whereas severe PPH is blood loss greater than or equal to 1,000ml within 24 hours (WHO 2009). This definition is endorsed by the Royal Australian and New Zealand College of Obstetricians and Gynaecologist in their College Statement C-Obs 43 (RANZCOG 2011).

Population health burden

PPH is a major cause of maternal mortality and morbidity worldwide and a number of evidence-based studies have found an increasing incidence of PPH in developed countries over the past 15–20 years (Knight, Callaghan et al. 2009). The estimated Australian population incidence for any postpartum haemorrhage was 7.2 per 100 women who gave birth (Lain, Roberts et al. 2008). One Australian study found the recent rise in the rate of PPH was not explained by increasing maternal age or rates of caesarean section (Cameron, Roberts et al. 2006), a position supported by international studies (Knight, Callaghan et al. 2009). A later study has demonstrated the increase in total maternal morbidity rates in Australia was exclusively due to the rise in the incidence of PPH (Roberts, Ford et al. 2009a).

An international review of PPH found the observed increase in PPH in Australia (also Canada and the United States of America) was limited solely to immediate/atonic PPH. The review also noted increasing rates of severe adverse outcomes due to haemorrhage in Australia and some other developed countries. Two of the recommendations from this study of particular relevance were: (1) to standardise measures for the assessment of severity of PPH and (2) training should be provided to all staff involved in care in the assessment of blood loss (Knight, Callaghan et al. 2009).

Collection methods

PPH is collected and reported in all jurisdictional perinatal data collections, though there is a marked difference in how this data is collected. Table 5.8 indicates the range of specificity for this condition in terms of the volume of blood lost as a measure of severity of the condition, with a cut-off of 500ml and 600mls used to differentiate between mild and moderate PPH. Additionally, some jurisdictions do not make any differentiation, by only recording volumes greater than 500mls.

New South Wales has taken a different approach in using a proxy value for this condition: units of blood products used. This makes intuitive sense in terms of reliably reporting the severity of the condition as the clinical assessment of blood loss is difficult to make accurately. By measuring unit of transfused blood products, New South Wales has avoided this problem, however the New South Wales guidelines are restrictive in that they do not include other blood products such as volume expanding colloids. Victoria collects PPH data in terms of blood loss in millilitres within an anticipated error range of 50mls. It also includes a categorical yes/no for transfusion received by the mother, but does not collect the number of units transfused.

Data validation

A validation study conducted in New South Wales that compared obstetric haemorrhage data in the NSW Admitted Patient Data Collection with gold standard medical records, found all forms of obstetric haemorrhage diagnosis and procedure codes were under ascertained, with sensitivities ranging from 28.3% to 100% (Lain, Roberts et al. 2008). Another study conducted in New South Wales found PPH is under ascertained for women delivered by caesarean section (Roberts, Ford et al. 2009b). This same study recommends the use of transfused units of blood, as a more reliable and accurate indicator of PPH.

Training

Studies both in Australia and internationally have identified the need for training in the assessment of blood loss for midwifery and nursing staff (Cameron, Roberts et al. 2007), (Knight, Callaghan et al. 2009). Previous studies have shown the lack of reliability between assessors of blood loss volume.

Table 5.8: Guideline definitions and data items for postpartum haemorrhage

Jurisdiction	Data item on form	Guideline
NSW	Postpartum haemorrhage requiring blood transfusion: Yes/No	Requiring transfusion of whole blood or packed cells
Vic	Blood loss (mls)	The definition of postpartum haemorrhage varies between institutions. Estimated blood loss is recorded in mls in the medical record at all hospitals. Collecting the volume of blood lost enables analysis of the predictors and sequelae of excessive blood loss, however defined. An estimate of the amount of blood lost at the time of birth and in the following 24 hours (whether the loss is from the vagina, from an abdominal incision, or retained for example, broad ligament haematoma). Report the best estimate of the amount of blood lost in millilitres (mls). This is usually reported to the nearest 50ml, but may be more accurate than this if desired for example when there is very small amount of bleeding
Qld	Primary PPH (500-999ml)	Medical and obstetric complications (necessitating intervention) arising after the onset of labour and before the completed delivery of the baby and placenta
	Primary PPH (≥1,000ml)	As above
	Other (specify)	Retained placenta with manual removal with haemorrhage / without haemorrhage
WA	Postpartum haemorrhage	Bleeding from the genital tract after delivery of 500ml of blood or more
SA	PPH (Primary)	A blood loss of 600ml or more. Please note this option is only for primary postpartum haemorrhage occurring within 24 hours of birth
	Please tick the appropriate box as to the estimated blood loss: 600-999ml 1,000ml or more	If the woman has a secondary postpartum haemorrhage, specify under 'Other'
Tas	Primary PPH >500ml in the first 24 hours	Postpartum haemorrhage (PPH): Estimated blood loss of ≥ 500ml after vaginal birth or ≥1,000ml after caesarean delivery
ACT	PPH	None
NT	PPH	None

Source: State and territory perinatal data collection forms and guidelines.

Rationale for data collection

The only identified rationale for the collection of this data was found in the New South Wales guidelines (Instructions for the New South Wales Midwives Data Collection 2006 Edition, p. 68), which states, 'Postpartum haemorrhage is one of the most common complications of the early postpartum period. The need for blood transfusion indicates a serious level of morbidity'.

6 Maternal morbidity in other data collections

6.1 Background and main sources of maternal morbidity data

The majority of women in Australia receive some or all of their antenatal care with public health providers, particularly hospital antenatal clinics. The remainder receive care from private providers, principally obstetricians and more recently from independent midwives. A small proportion of women will receive no antenatal care. Information from the antenatal period is commonly entered on a patient-held antenatal record.

Most women deliver in a hospital environment and the information from both their antenatal record and from their hospital stays are selectively recorded in 3 datasets: the jurisdictional perinatal data collection, the jurisdictional hospital inpatient statistics collection and births registration data. For the purposes of this review, only the perinatal and the hospital data are relevant, as birth data does not contain any clinical information. The information that is recorded in the hospital maternity database and the categories used for some of the items may differ to those contained on the perinatal data collection forms (AIHW 2010b).

6.2 Other potential data sources

Other potential sources of information about episodes of maternal morbidity care and treatment are held in specialised administrative and clinical data sets (see Table 6.1). These include intensive care unit (ICU) admissions in the ANZICS CORE database, emergency department visits in the National Non-Admitted Patient Emergency Department Care Database (NNAPEDC) and other outpatients' visits in the National Outpatients Care Database (NOCD). The most comprehensive national data collection regarding diagnoses and procedures for women with maternal morbidities is the National Hospital Morbidity Database (NHMD). This administrative collection contains records from all the state and territory admitted patient collections.

This section critically looks at the capacity for these data sets to provide information about maternal morbidity. Included in this section are the National Maternal Deaths Database (NMDD) and the national, research-based Australian Maternity Outcomes Surveillance System (AMOSS).

Table 6.1: Maternal morbidity available from other data sources

Maternal morbidity type	Characteristics	Potential data sources
Severe morbidity/maternal deaths	Very rare Resource intensive Variable risk of long-term sequelae for survivors May arise at any time, but most common in intrapartum or postnatal periods May occur after discharge from hospital	Maternal mortality data collections Hospital data collections AMOSS (selected conditions) ANZICS (if admitted to intensive care unit)
Serious medical conditions	Rare or uncommon Resource intensive – often includes screening whole pregnant population Early intervention can reduce complications Potential for serious complications and long-term sequelae May arise at any time, but often disease severity increases as gestation advances	Hospital data collections Specific condition registers or collections (e.g. diabetes)
Complications of interventions	Applies only to women who had one or more interventions Wide range of relevant conditions Range in frequency from common to very rare Range in severity from serious to minor ailments	Hospital data collections AMOSS
Minor ailments	Common Occur during all four periods Many conditions Rarely long term sequelae	Primary care data collections e.g. BEACH, Hospital Emergency Data Medicare and Pharmaceutical Benefits Scheme

Notes

1. Condition frequency: very rare conditions affect less than 1 per 1,000 women; rare conditions affect less than 1 per 100 women; uncommon conditions affect less than 5 per 100 women; common conditions affect more than 10 per 100 women.
2. Condition onset: pre-pregnancy (chronic condition present before conception); antenatal (during pregnancy and up to the onset of labour); intrapartum (from the onset of labour to the completion of the process of birth, that is, expulsion of all products of conception —the baby, the placenta and the membranes); postnatal (up to 42 days after the birth).

National Hospital Morbidity Database

The National Hospital Morbidity Database (NHMD) is a collection of electronic summary records for hospital inpatient separations in Australia (AIHW 2012b) and includes separations from high care obstetric environments and intensive care units (ICU). The NHMD is maintained by the AIHW and annual data are compiled from data supplied by the state and territory hospital in-patient data collections. The database contains information relating to admitted patients in almost all hospitals, including public acute hospitals, public psychiatric hospitals, private acute hospitals, private psychiatric hospitals and private free standing day hospital facilities. Public sector hospitals that are not included are those not within the jurisdiction of a state or territory health authority (for example, hospitals operated by the Department of Defence or correctional authorities and hospitals located in offshore territories). The minority of private hospitals that did not provide data were mostly free-standing day hospital facilities. A comparison of private hospital data from the NHMD and the ABS Private Health Establishments Collection (PHEC) indicates there were 107,563 more separations reported in the PHEC than the NHMD, the bulk of which were separations from

private free-standing day hospitals. Admission during pregnancy or for birth is not usual in these hospitals.

Principal and other diagnoses, procedures and external causes of injury are recorded using the current Australian modified version of the international classification of disease (ICD) and other data elements are supplied using definitions from the National Health Data Dictionary. By agreement all births in hospital are coded with ICD-10 AM codes. The NHMD reported 482,195 separations in 2009-2010 for principal diagnoses falling within the (ICD-10 AM chapter XV) Pregnancy, Childbirth and the Puerperium classification (AIHW 2011). The leading cause for hospitalisation within this category was perineal laceration during delivery. NHMD principal diagnosis data is freely available on the AIHW data cube website (NHMD data cubes). This information is not available in published paper format and is not reported in the Australian Hospital Statistics series.

The strength of the NHMD rests in it being an established validated collection based on a national minimum data set. It is useful because it collects information on hospitalised obstetric episodes of care including pregnancy, and intrapartum information and, to a lesser extent, the puerperium. The weakness of this database rests in its being an episode-based data collection. This means it is unable to distinguish multiple presentations for the same woman. Data linkage where an individual is assigned a unique identifier that is then used to link between different data collections would improve this aspect of the NHMD.

National Maternal Deaths Database

The National Maternal Deaths Database (NMDD) contains information on maternal deaths in Australia. It is an ad hoc collection compiled from state and territory maternal mortality committees. These committees receive notifications of maternal deaths from medical practitioners and midwives, hospitals, health departments, coronial and post mortem investigations, perinatal and hospital morbidity collections and from the Registrar of Births, Deaths and Marriages. Data from this report specific database have been reported on a triennial basis in the Maternal Deaths in Australia report published by AIHW. The most recent report was for the 2003–2005 period. The dataset includes factors related to the pregnancy, labour and birth and information about the classification and cause of death are included. Causes of death are recorded using ICD-10-AM employing definitions from the NHDD.

Maternal mortality is the most severe endpoint in the spectrum of maternal morbidity. It is a rare/sentinel event in Australia. Maternal death is not included as a perinatal NMDS data item. The leading causes of direct maternal deaths were: amniotic fluid embolism, thromboembolism and hypertension. Cardiac disease, psychiatric related causes and non-obstetric haemorrhage were the main indirect causes of maternal deaths. (Sullivan, Hall et al. 2007). Maternal mortality is an essential data item in any collection on maternal morbidity. The utility for data linkage would need to be explored.

Australasian Maternity Outcomes Surveillance System

The Australasian Maternity Outcomes Surveillance System (AMOSS) is a national surveillance mechanism that studies rare and potentially fatal maternal morbidities in pregnancy, childbirth and the postnatal phase. It was developed as a response to the gap in the data available from routine sources regarding obstetric morbidity. AMOSS provides information on the incidence, risk factors and the outcomes of severe morbidity in

pregnancy, thus providing a mechanism to improve the knowledge of rare serious obstetric disorders and their management in Australia and New Zealand. Reports and publications are available from the AMOSS website at <www.amoss.com.au>.

This National Health and Medical Research Council-funded project commenced in Australia in 2009 and has subsequently been extended to New Zealand. It now covers 96% of births in Australia and all births in New Zealand.

AMOSS conducts incidence and case control studies of a rolling set of selected rare and severe maternal conditions each year. Completed and current studies include: extreme morbid obesity, influenza A with intensive care admission, eclampsia, placenta accrete, peripartum hysterectomy, amniotic fluid embolism and antenatal pulmonary embolism. New conditions for review commencing in 2012 include rheumatic heart disease, gestational breast cancer and vasa previa. Planned conditions in 2013-2017 include: massive obstetric haemorrhage, selected admission to ICU, peripartum cardiomyopathy, cerebral vascular accidents, cardiac arrest, group A streptococcal puerperal sepsis, adrenal therapy under 20 years of age, pregnancy in non-renal solid organ transplants, puerperal psychosis, Hodgkin lymphoma and stillbirth.

Data is collected voluntarily from Australasian maternity units with under 50 births per year. A negative reporting mechanism is used, with monthly reporting by participating sites. Nearly 300 hospital sites actively participate in AMOSS.

ANZICS CORE Adult Patient Database

The Australian and New Zealand Intensive Care Society (ANZICS) Adult Patient Database (ANZICS Adult Patient Database) receives data submissions on a voluntary basis from intensive care units throughout Australia. These provide information about individual episodes of care in ICU. The dataset data dictionary—APACHE II—follows the format of the National Health Data Dictionary (AIHW 2012b). Data from this data collection are not publicly reported and the system is largely designed for measuring performance outcomes for health service provision purposes. All Australian tertiary referral ICUs currently contribute to the database. This is the only specifically ICU-reporting dataset and as such is a valuable source of data for severe maternal morbidity data. However, admission to ICU as a measure of severe maternal morbidity would only capture about one-third of cases of interest, with most cases of severe maternal morbidity not involving an ICU admission (Pollock, Sullivan et al. 2008). Table 6.2 shows the extent of the ANZICS database coverage in each jurisdiction as well as its sensitivity to identifying pregnancy or pregnancy-related admissions. While the great majority of ICUs are involved in data collection (except in Western Australia), there is significant variation across jurisdictions in the accuracy of reporting pregnancy status.

As with the NHMD, this is an episode-based system that cannot, at present, associate multiple presentations in different hospitals by the same woman for the same presenting condition or complication. It is also limited by being subscribed on a voluntary basis. There are only 2 specific codes in the ANZICS coding classification relating to pregnancy related conditions—pre-eclampsia and postpartum haemorrhage. In 2010, the database introduced the routine identification of pregnant women in its dataset. While limited in the conditions it addresses, it may fulfil a valuable role in identifying cases of severe morbidity conditions that are presently not collected or reported in the perinatal or hospital collections, and will include ICU-specific information not otherwise found in the NHMD.

Table 6.2: ANZICS Adult Patient Data pregnancy identified, by state and territory 2010

Jurisdiction	Per cent of units recording pregnancy status	Per cent of records with a pregnancy status recorded	Per cent of records with a pregnancy status unknown
NSW	95	91	10
Vic	94	92	8
Qld	97	91	23
WA	60	92	2
SA	100	70	13
Tas	100	63	20
ACT	100	100	12
NT	100	>99	28

Source: Australian and New Zealand Intensive Care Society.

National Non-Admitted Patient Emergency Department Care Database

The National Non-Admitted Patient Emergency Department Care Database (NNAPEDCD) is compiled from data supplied by the state and territory health authorities. It is a collection of electronic summary records for non-admitted patients treated in public hospital emergency departments. The primary purpose of this dataset is for administrative performance measure comparison with a focus on triage categories and waiting times.

The scope of the collection includes occasions of service at tertiary referral public hospitals and specialist women's and children's hospitals, as well as level B or Large Hospitals. There were 7.2 million emergency department services provided in public hospitals in 2008–09 (AIHW 2011).

This data source has the potential for identifying acute, but less serious conditions treated in the community that may negatively impact on the woman's wellbeing, such as excessive vomiting in pregnancy and threatened miscarriage.

This data set has limited value at the present time, as principal diagnosis for the occasion of service is not reported at the national level. At the emergency department level where principal diagnosis is recorded (either ICD-9 or ICD 10 AM) anecdotal evidence suggest principal diagnosis of non-admitted emergency department presentations lack sensitivity. Emergency doctors routinely enter data prior to receiving confirmatory test results (for example, x-rays or blood tests) and may oversimplify the presenting problem. There is little scope for correcting the original diagnosis once entered (Mr J Agla, New South Wales Department of Health, by email 24 June 2011).

The AIHW is in the process of reviewing this aspect of the NNAPEDCD and is considering adding principal diagnosis to the reported data.

National Outpatient Care Database

The National Outpatient Care Database (NOCD) is a compilation of summary data for outpatient clinic occasions of service in public hospitals, excluding emergency departments. The data supplied are based on counts of individual occasions of service and group sessions for 24 types of outpatient clinics, including obstetric and antenatal outpatient clinics.

The scope for the NOCD was for services provided to non-admitted, non-emergency patients registered for care in outpatient clinics of public hospitals that were classified as either tertiary referral and specialist women's and children's hospitals (peer group A) or Large Hospitals (peer group B). In the financial year 2009-10, there were a total of 1,948,704 occasions of service for women seeking obstetric-related care.

This data set is limited in value because its focus is largely on sector performance outcomes and does not record principal diagnosis for occasions of service.

Bettering the Evaluation of Care and Health Survey

Information about general practice activity is available from the Bettering the Evaluation and Care of Health (BEACH) survey, which is owned and managed by the University of Sydney. For each year's data collection, a random sample of about 1,000 general practitioners each report details of 100 consecutive general practice encounters of all types on structured encounter forms. On each form, the general practitioner records information about the consultation (for example, date and type of consultation), the patient (for example, date of birth, sex and reasons for encounter), the problems managed and the management of each problem (for example, treatment provided, prescriptions and referrals). Data on patient risk factors, health status and general practitioners' characteristics are also collected.

With an increasing proportion of low-risk pregnancy care being provided via GP shared care arrangements in Australia, the relevance of this dataset lies in its accessibility to data of women presenting with pre-existing conditions, gestational diabetes, gestational hypertension and antepartum haemorrhage. As it is a sample-based collection, data linkage would not be appropriate.

Table 6.3 summarises the relative relevance and limitations of the potential data sources.

Table 6.3: Summary of other potential data sources

Database	Advantages	Limitations
NHMD	Well validated	Episode based data
	Good coverage of women who give birth and their babies	Not all women identified
		No link between mothers and their babies
NMDD	Important conditions i.e. resulting in death	Maternal deaths are rare
AMOSS	Important conditions. Near complete coverage	Can be used to validate rare conditions in NHMD and improve data quality
ANZICS	Severe morbidity	Voluntary data entry by clinicians
	Includes pregnancy indicator	Limited to two conditions only: pre-eclampsia and PPH
NNAPEDCD	Captures acute antenatal problems	Potential data quality issues
NOCD		Does not record principal diagnosis
		Incomplete coverage
BEACH	Captures less serious morbidity	Rolling sample unsuitable for data linkage

7 Main findings of the review

This report has looked at three major areas of maternal morbidity: diabetes, hypertension and obstetric haemorrhage. It has shown significant differences in data collection practices across jurisdictions, related to differences in definitions. It has also identified substantial statistical error in the reported prevalence data for the hypertension and haemorrhage data as borne out in the validation studies published in this area. Methods for improving the quality of national maternal morbidity data have been suggested.

Even small changes to perinatal data collection processes can be a costly and complex exercise.

National and international guidelines currently exist for diabetes (pre-existing and gestational diabetes), hypertension (pre-existing, gestational and pre-eclampsia) and postpartum haemorrhage conditions in pregnancy. Agreement on and integration of these guidelines into the supporting documents for states and territory perinatal data collection is an essential first step towards development of nationally standardised data elements and data collection practices for maternal morbidity.

7.1 Standardising data collection: Diabetic conditions

The collection and reporting of pre-existing and gestational diabetes mellitus from perinatal collections appears consistent across all jurisdictions. All states that have conducted validation studies have found full or near-full agreement in their data sample with their gold standard for these conditions.

Application of the ADIPS guideline would expand data collected about pre-existing diabetes to distinguish between Type 1 and Type 2. This information is currently collected in some, but not all jurisdictions.

7.2 Standardising data collection: Hypertensive disorders

In contrast to diabetes, under-reporting of hypertensive disorders has been demonstrated in those states that have conducted validation. Perinatal data had poorer ascertainment than hospital in-patient data, due in large part to midwives not recording less severe forms of the disease. Furthermore, inconsistent data collection practices have been demonstrated between jurisdictions. The use of non-standard categories for data collection has contributed to misclassification, particularly for data collected on pre-existing and gestational hypertension, and pre-eclampsia. Application of the SOMANZ guidelines provides a clear pathway for the development of consistent data collection and reporting in this area.

In addition, the ability to distinguish between gestational hypertension and pre-eclampsia relies on the accurate testing for proteinuria and interpretation of results by clinical staff in antenatal settings using appropriate equipment. Failure to do so has the potential to misclassify these two hypertensive conditions.

7.3 Standardising data collection: Obstetric haemorrhage

There is substantial variation between jurisdictions in reported prevalence of antepartum haemorrhage based on current data collection practices. No agreed national definition for antepartum haemorrhage has been found, however there are a number of consistent guidelines in use by individual hospitals and other bodies that could formulate a national guideline for this condition (Haynes 2004, SA Perinatal Practice Guidelines, Workgroup 2012, KEMH Guidelines 2009). Standardisation of the collection of data on postpartum haemorrhage also poses a significant challenge in terms of data collection and reporting practices. There are two issues: (1) standardising the definition of PPH, and (2) standardising the assessment of blood loss.

The WHO and the RANZCOG define primary PPH as blood loss greater than or equal to 500ml within 24 hours after birth, while severe PPH is greater than or equal to 1,000ml within 24 hours (WHO 2012, RANZCOG 2011). At present, jurisdictional perinatal data collections make a distinction for bleeding due to type of delivery—normal vaginal (500ml, 600ml), caesarean section (750ml, 1,000ml)—but this distinction is not articulated in the WHO guidelines. The Australian Coding Standard requires a clinician—usually a doctor—to record a diagnosis of PPH before an episode can be data coded. In practice, doctors will often only document the principal intervention (for example, caesarean section) that gave rise to the blood loss rather than PPH itself. This may partially explain the reason why PPH is routinely underreported in the perinatal data collections.

The second challenge relates to finding a valid and reliable assessment tool for blood volume loss that can be used in all clinical settings where PPH occurs. Considerable research has been conducted in this area with no international consensus reached. The WHO PPH guideline discourages the normal practice of visual estimation as unreliable. Some states and territories use total blood volume transfused as a proxy measure of blood loss in PPH. Issues around this measure being too restrictive need to be investigated, so that not only whole blood but also all blood products and synthetic volume expanders can also be included.

7.4 Data collection and reporting tools

A standard data element already exists within the NHDD for diabetes that has detailed guidance and incorporates the national guidelines recommended by ADIPS (Appendix C). This includes a category for gestational diabetes and could, with dataset specific guidance, be applied to the collection of diabetes in perinatal collections. No comparable data elements exist for other significant maternal obstetric and medical conditions.

Three data elements have been developed to report ICD data related to maternal medical conditions, obstetric complications and postnatal complications (Appendix C). The use of these is limited in the absence of standard protocols for including diagnostic information. Conditions currently coded to ICD-10 AM within perinatal collections are varied both in the methods for selecting conditions and the way in which the information is coded. These have the potential to be of value if a standard protocol for data capture from a standard source, such as hospital inpatient collections, can be developed.

7.5 Data linkage

Linkage of data from different collections that include the condition of interest can help overcome under-ascertainment or misclassification, and enables the capture of important longitudinal outcomes (Roberts, Algert et al. 2007), (Roberts, Bell et al. 2008). Record linkage is also a good validation tool for the individual datasets (Roberts, Ford et al. 2008). Data linked by person can include antenatal, delivery, and postnatal events for each woman. Identifying cases from more than one dataset improves the ascertainment of data compared with identifying cases from a single dataset.

In Western Australia and New South Wales, there has been linkage of perinatal data over time to examine outcomes for the same woman and with other collections, including death registration data, hospital admission data and special registers (such as birth defects). The data are available for research purposes as well as contributing data to NPDC and validation of data in the NHMD (Roberts, Ford et al. 2008). All other states and territories conduct data linkage to a lesser degree and the capability for record linkage is progressing. As part of the National Maternity Services Plan (Commonwealth of Australia 2011), a standardised antenatal patient held record will be introduced that will complement the national electronic health records. One of the benefits of standardised clinical records of this nature is the prospective documentation of maternal morbidity conditions and the potential to obtain a means of gold standard validation checking, with statistical records collected by jurisdictional and national perinatal data collections.

The AIHW is well placed to provide data linkage between the range of national data sets in its custody. Linking perinatal data with state and territory hospital data could be used to validate sentinel clinical conditions collected through perinatal collections and provide the means to ascertain a range of maternal complications of pregnancy and maternal morbidity conditions that result in hospital admission during pregnancy or re-admission in the postnatal period.

Linking between these two jurisdictionally derived data sets could be achieved through the application of a statistical linkage key (SLK). An SLK is a variable used to link data for statistical and research purposes, generated from elements of an individual's personal demographic data, and attached to de-identified data relating to diagnostic outcomes and interventions received for that individual. This is in accordance with AIHW privacy protocols to protect individuals from direct and indirect misuse of personal information. The key features of this privacy protocol are the separation of personal identifying information from service information, and the absence of any record identifiers which would allow linkage back to the source data (AIHW 2005).

7.6 Use of maternal morbidity data from other data sources

The data sources of principal interest for valid and reliable data collection and reporting of maternal morbidities are the state and territory midwife data collections and the NPDC. The NNAPEDDC and the NOCD potentially provide additional sources of data if linked with existing state and territory perinatal data collections. This is particularly relevant for conditions such as antepartum haemorrhage in emergency department or outpatient clinics that do not appear in other data collections. As stand-alone sources, the NOCD and the

NNAPEDDC have limited value because of the low standard of clinical data (sensitivity and specificity) collected and reported in both.

The NHMD has the potential to provide significant improvement in our understanding of the scope and impact of maternal morbidity. Linking hospital inpatient data with the state and territory midwife data collections, outpatient, and emergency department data would provide the most comprehensive understanding of maternal morbidity.

7.7 Actions to progress development of standardised maternal morbidity data

In response to AHMAC's commissioning of this report, the AIHW advises a number of possible actions to improve the consistency of maternal morbidity data:

- For diabetes, the existing NHDD standard should be used to collect and report data relating to pre-existing diabetes and gestational diabetes
- For pre-existing and gestational hypertension, and pre-eclampsia, the SOMANZ guidelines and NHDD definitions should be used by all jurisdictions
- For obstetric haemorrhage, clinical stakeholders (obstetricians and midwives in particular) need to develop consensus definitions and guidelines for reporting antenatal haemorrhage and post-natal haemorrhage. This will inform the national data development process for these conditions.

In addition, standardising data linkage practices for the linkage of diagnostic information in birth, and postnatal episodes in hospital in-patient data and perinatal data is recommended.

The development of standardised maternal morbidity data will progress as part of the National Maternal Data Development project. The AIHW has been commissioned by DoHA to undertake this project over a 3 year period to develop the collection and availability of nationally consistent and comprehensive maternity data in Australia. This project addresses action 4.1.5 under the National Maternity Services Plan and will address national data requirements through scoping national information needs, identification of data gaps and inconsistencies in relation to meeting these needs, and assessing and recommending options for improved maternity data collection and data development to address the identified data requirements.

Appendix A: Guidelines for perinatal data collection

Table A1: Training and guidelines for midwives collecting data, by state and territory

S/T	Guidelines	Training	Comment
NSW	Perinatal data collection policy: <www.health.nsw.gov.au/policies/> State-wide surveillance system which monitors patterns of pregnancy care, services and pregnancy outcomes	No specific training requirements Round of training at maternity hospitals when content of policy changes Last change/training was 1 January 2011 Training conducted by team of clinical nurse consultants who organise the content and then travel around the state conducting the training	
Vic	No guideline manual VPDC Bulletin (available at <www.health.vic.gov.au/ccopmm/publications/index>) is the primary method by which amendments to standards and reporting timelines are published:	No training requirements VPDC Bulletin Annual Clinician Midwifery Conference Regular midwifery education sessions held at all Victorian Universities Hospital midwives are also offered education and this occurs on an ad hoc basis	Uses paper and electronic
Qld	Perinatal data collection instruction manual: <www.health.qld.gov.au/hic/> Manual provided to all hospital midwives and independent practitioners Instructions to midwives on the scope of the collection and how to complete the sections Included are medical conditions, pregnancy complications, labour and delivery complications and puerperium complications	Training provided on ad hoc basis to any hospital that requests it Training can be done via face-to-face, video conference or teleconference The PDC tries to be in contact with every maternal hospital face-to-face or via video conference at least once every year Provides updates an information about changes to the collection Information is provided in quarterly newsletter to all hospitals 'Facts of Life'	
WA	Guidelines for Completion of the Notification of Case Attended Health Act (Notification by Midwife) Regulations Form No.2 Provided for use by midwives but also doctors where midwife not present at birth		

(continued)

Table A1 (continued): Training and guidelines for midwives collecting data, by state and territory

S/T	Guidelines	Training	Comment
SA	Guidelines for the supplementary birth record: <www.sahealth.sa.gov.au/wps/wcm/guidelines> Preferred method for data collection may vary from hospital to hospital, i.e. in some hospitals all midwives are responsible for completing the supplementary birth record, and in others there are specific midwives for this task	Each service provider is responsible for providing training for their midwife data collectors POU staff provide in-services/training at public and private hospitals when invited to do so Where data validations reveal systematic error, the person/hospital is contacted for discussion/review	SA Pregnancy Record Handheld record completed for women birthing in public hospitals (contains information on maternal morbidity) Hospitals contribute to AMOSS
Tas	Statement on paper based collection manual for 'pre-pregnancy conditions': 'Conditions, diseases or illnesses present prior to pregnancy or arising during pregnancy, which are not directly attributable to the pregnancy but may significantly affect care during pregnancy and/or pregnancy outcome. Hypertension is defined as: *Known hypertension requiring medical treatment prior to pregnancy, or occurring in first half of pregnancy (before 20 weeks).* Indicate if the mother suffered from any of the listed conditions. If more than one option is appropriate, tick ALL appropriate options, these being None, cardiovascular, thyroid, diabetes mellitus, mental health, renal disease, epilepsy, hypertension, other'	Each hospital has responsibility in training medical practitioners in the collection of data. With the move to an electronic entry system training remains the responsibility of each hospital but there is work happening creating an overarching training package	Conditions, diseases or illnesses present prior to pregnancy or arising during pregnancy, which are not directly attributable to the pregnancy but may significantly affect care during pregnancy and/or pregnancy outcome. Hypertension is defined as: Known hypertension requiring medical treatment prior to pregnancy, or occurring in first half of pregnancy (before 20 weeks). Indicate if the mother suffered from any of the listed conditions. If more than one option is appropriate, tick ALL appropriate options. These being: cardiovascular, thyroid, diabetes mellitus, mental health, renal disease, epilepsy, hypertension, other'
ACT	Produce year-by-year update guidelines describing changes to midwives data collection form	Historically relied on hospitals to conduct own training but Epidemiology Branch are planning to take a more proactive role	Only involves three hospitals
NT	Three manuals for perinatal data collection (currently being updated): CareSys NT - Birthing Suite Manual (Maternity Unit Module) (2002); CareSys – A Self Directed Learning Package and Reference Guide for Midwives (2000); Perinatal Data Collection – Procedures manual (2002)	No available training manual for web base system The public hospital system does not offer formalised group training for the birthing suite module Training is attended on an ad hoc basis by CareSys trainers. Most midwives receive training from midwifery colleagues	Manuals are currently being updated along with the Health Gains Planning perinatal data dictionary Items missing in this dictionary include maternal morbidity definitions such as PPH and APH

Source: State and territory perinatal data managers, by email May 2011.

Appendix B: Rationale for collecting maternal morbidity

Table B1: Rationale for collecting maternal morbidity data, by state and territory perinatal data collection managers

S/T	Rationale
NSW	We collect this data is to monitor the most important factors that affect the health of mothers and newborns.
Vic	We collect this data is for analysis: maternal medical conditions may influence the course and outcome of the pregnancy and may result in antenatal admission to hospital and/or treatment that could have adverse effects on the fetus and perinatal morbidity. Complications often influence the course, management and outcome of pregnancy, possibly resulting in hospital admissions and/or adverse effects on the mother, the fetus and perinatal morbidity.
Qld	The data is collected to monitor patterns of obstetric and neonatal practice in the state and to provide statistical information on specific topics within these fields to assist with the planning of Queensland Health services. It is also intended to be a basic source of information for research in obstetric and neonatal care and to be used in the education of students of midwifery and medicine.
WA	The data is collected to monitor maternal events, assist in the planning of obstetric services, assist with ongoing research in the areas of obstetrics and maternity services, provide a continuing source of information for ongoing education in clinical practice and to provide Western Australian perinatal data for inclusion in the national perinatal statistics reports. Statutory requirement is specified in Section 335 of the Health Act 1911 (Part X111): • Required to assist Department of Health in monitoring cases and developing appropriate health responses and policies. • Assists research and education. • Supports mandatory national requirements • Assists with requests from researchers, Department of Health units, consumers and the media
SA	As part of the Health Care Act, the SA Health Department has responsibilities to improve the health of South Australians, and perceives the collection of perinatal data as an important contribution to this. SA Regulations state the information that is to be provided. Determination of the data items to be collected occurs in a number of ways, but is mostly based on research evidence as to what should be collected at a State population level. Each time NPESU would like to add another data item to the SA collection, we have to provide evidence as to why this should be collected, and then apply to have our Regulations amended. It is entirely possible that the requested amendment could be rejected, although this has not happened to date. The collection can be used to provide a Statewide picture of pregnancy characteristics and outcomes, obstetric problems and characteristics of perinatal care, as well as trends over time. It may also be used to provide regional or individual hospital profiles or profiles of groups of women e.g. Aboriginal women, or obstetric practice, e.g. caesarean section. Risk factors for adverse outcome may be identified and monitoring of pregnancy outcomes may be undertaken.
Tas	
ACT	The reasons the ACT PDC collect maternal morbidity data is because it is requested by the national statistics and the ACT Maternal Perinatal Information Network – which includes representation from obstetricians, midwives and policy areas.
NT	The NT perinatal collection is considered the most flexible and reliable method for the collection of maternal morbidity data. This collection captures morbidity data from a variety of setting in which care had been received, such as community health centres and home births. The data set also collects health issues that were managed prior to the birthing admission episode, for example threatened premature labour.

Appendix C: Maternal morbidity elements in the NHDD

Person—diabetes mellitus status, code NN

Identifying and definitional attributes

Metadata item type:	Data Element
Short name:	Diabetes status
METeOR identifier:	270194
Registration status:	Health, Standard 01/03/2005
Definition:	Whether a person has or is at risk of diabetes, as represented by a code.
Data element concept:	Person—diabetes mellitus status

Value domain attributes

Representational attributes

Representation class:	Code
Data type:	String
Format:	NN
Maximum character length:	2

Permissible values:

Value	Meaning
01	Type 1 diabetes
02	Type 2 diabetes
03	Gestational diabetes mellitus (GDM)
04	Other (secondary diabetes)
05	Previous gestational diabetes mellitus (GDM)
06	Impaired fasting glucose (IFG)
07	Impaired glucose tolerance (IGT)
08	Not diagnosed with diabetes
09	Not assessed

Supplementary values:	99	Not stated/inadequately described

Collection and usage attributes

Guide for use:

Note that where there is a Gestational diabetes mellitus (GDM) or Previous GDM (i.e. permissible values 3 & 5) and a current history of Type 2 diabetes then record 'Code 2' Type 2 diabetes.

This same principle applies where a history of either Impaired fasting glycaemia (IFG) or Impaired glucose tolerance (IGT) and a current history and Type 2 diabetes, then record 'Code 2' Type 2 diabetes.

CODE 01 Type 1 diabetes

Beta-cell destruction, usually leading to absolute insulin deficiency. Includes those cases attributed to an autoimmune process, as well as those with beta-cell destruction and who are prone to ketoacidosis for which neither an aetiology nor pathogenesis is known (idiopathic). It does not include those forms of beta-cell destruction or failure to which specific causes can be assigned (e.g. cystic fibrosis, mitochondrial defects). Some subjects with Type 1 diabetes can be identified at earlier clinical stages than 'diabetes mellitus'.

CODE 02 Type 2 diabetes

Type 2 includes the common major form of diabetes, which results from defect(s) in insulin secretion, almost always with a major contribution from insulin resistance.

CODE 03 Gestational diabetes mellitus (GDM)

GDM is a carbohydrate intolerance resulting in hyperglycaemia of variable severity with onset or first recognition during pregnancy. The definition applies irrespective of whether or not insulin is used for treatment or the condition persists after pregnancy. Diagnosis is to be based on the Australian Diabetes in Pregnancy Society (ADIPS) Guidelines.

CODE 04 Other (secondary diabetes)

This categorisation include less common causes of diabetes mellitus, but are those in which the underlying defect or disease process can be identified in a relatively specific manner. They include, for example, genetic defects of beta-cell function, genetic defects in insulin action, diseases of the exocrine pancreas, endocrinopathies, drug or chemical-induced, infections, uncommon forms of immune-mediated diabetes, other genetic syndromes sometimes associated with diabetes.

CODE 05 Previous GDM

Where the person has a history of GDM.

CODE 06 Impaired fasting glycaemia (IFG)

IFG or 'non-diabetic fasting hyperglycaemia' refers to fasting glucose concentrations, which are lower than those required to diagnose diabetes mellitus but higher than the normal reference range. An individual is considered to have IFG if they have a fasting plasma glucose of 6.1 or greater and less than 7.0 mmol/L if challenged with an oral glucose load, they have a fasting plasma glucose concentration of 6.1 mmol/L or greater, but less than 7.0 mmol/L, AND the 2 hour value in the Oral Glucose Tolerance Test (OGTT) is less than 7.8 mmol/L.

CODE 07 Impaired glucose tolerance (IGT)

IGT is categorised as a stage in the natural history of disordered carbohydrate metabolism; subjects with IGT have an increased risk of progressing to diabetes. IGT refers to a metabolic state intermediate between normal glucose homeostasis and diabetes. Those individuals with IGT manifest glucose intolerance only when challenged with an oral glucose load. IGT is diagnosed if the 2 hour value in the OGTT is greater than 7.8 mmol/L. and less than 11.1 mmol/L AND the fasting plasma glucose concentration is less than 7.0 mmol/L.

CODE 08 Not diagnosed with diabetes

The subject has no known diagnosis of Type 1, Type 2, GDM, Previous GDM, IFG, IGT or Other (secondary diabetes).

CODE 09 Not assessed

The subject has not had their diabetes status assessed.

CODE 99 Not stated/inadequately described

This code is for unknown or information unavailable.

Collection methods: The diagnosis is derived from and must be substantiated by clinical documentation.

Source and reference attributes

Origin: Developed based on Definition, Diagnosis and Classification of Diabetes Mellitus and its Complications Part 1: Diagnosis and Classifications of Diabetes Mellitus Provisional Report of a World Health Organization Consultation (Alberti & Zimmet 1998).

Data element attributes

Collection and usage attributes

Collection methods: Diabetes (clinical):

A type of diabetes should be recorded and coded for each episode of patient care.

Source and reference attributes

Submitting organisation: Cardiovascular Data Working Group

National Diabetes Data Working Group

Relational attributes

Related metadata references: Supersedes Diabetes status, version 1, DE, NHDD, NHIMG, Superseded 01/03/2005.pdf (27.3 KB)

Pregnancy (current)—complication, code (ICD-10-AM 7th edn) ANN{.N[N]}

Identifying and definitional attributes

Metadata item type:	Data Element
Short name:	Complications of pregnancy
METeOR identifier:	405823
Registration status:	Health, Standard 22/12/2009
Definition:	Complications arising up to the period immediately preceding delivery that are directly attributable to the pregnancy and may have significantly affected care during the current pregnancy and/or pregnancy outcome, as represented by a code
Data element concept:	Pregnancy (current)—complication

Value domain attributes

Classification Scheme:	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification 7th edition

Representational attributes

Representation class:	Code
Data type:	String
Format:	ANN{.N[N]}
Maximum character length:	6

Collection and usage attributes

Guide for use:	Complications and conditions should be coded within the Pregnancy, Childbirth, Puerperium chapter 15 of Volume 1, ICD-10-AM.

Data element attributes

Collection and usage attributes

Guide for use:	Examples of these conditions include threatened abortion, antepartum haemorrhage, pregnancy-induced hypertension and gestational diabetes. There is no arbitrary limit on the number of complications specified.

Comments:	Complications often influence the course and outcome of pregnancy, possibly resulting in hospital admissions and/or adverse effects on the fetus and perinatal morbidity.

Source and reference attributes

Submitting organisation:	National Perinatal Data Development Committee

Relational attributes

Related metadata references:	Supersedes Pregnancy (current)—complication, code (ICD-10-AM 6th edn) ANN{.N[N]} Health, Superseded 22/12/2009

Birth event—complication, code (ICD-10-AM 7th edn) ANN{.N[N]}

Identifying and definitional attributes

Metadata item type:	Data Element
Short name:	Complication of labour and delivery
METeOR identifier:	391338
Registration status:	Health, Standard 22/12/2009
Definition:	Medical and obstetric complications (necessitating intervention) arising after the onset of labour and before the completed delivery of the baby and placenta, as represented by a code.
Data element concept:	Birth event—complication

Value domain attributes

Classification Scheme:	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification 7th edition

Representational attributes

Representation class:	Code
Data type:	String
Format:	ANN{.N[N]}
Maximum character length:	6

Collection and usage attributes

Guide for use:	Complications and conditions should be coded within the Pregnancy, Childbirth, Puerperium chapter 15 of Volume 1, ICD-10-AM.

Data element attributes

Collection and usage attributes

Guide for use:	There is no arbitrary limit on the number of conditions specified.
Comments:	Complications of labour and delivery may cause maternal morbidity and may affect the health status of the baby at birth.

Source and reference attributes

Submitting organisation: National Perinatal Data Development Committee

Relational attributes

Related metadata references: Supersedes Birth event—complication, code (ICD-10-AM 6th edn) ANN{.N[N]} Health, Superseded 22/12/2009

Birth event—complication (postpartum), code (ICD-10-AM 7th edn) ANN{.N[N]}

Identifying and definitional attributes

Metadata item type:	Data Element
Short name:	Postpartum complication
METeOR identifier:	391336
Registration status:	Health, Standard 22/12/2009
Definition:	Medical and obstetric complications of the mother occurring during the postnatal period up to the time of separation from care, as represented by a code.
Data element concept:	Birth event—complication (postpartum)

Value domain attributes

Classification Scheme:	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification 7th edition

Representational attributes

Representation class:	Code
Data type:	String
Format:	ANN{.N[N]}
Maximum character length:	6

Collection and usage attributes

Guide for use:	Complications and conditions should be coded within the Pregnancy, Childbirth, Puerperium chapter 15 of Volume 1, ICD-10-AM.

Data element attributes

Collection and usage attributes

Guide for use:	There is no arbitrary limit on the number of conditions specified.
Comments:	Examples of such conditions include postpartum haemorrhage, retained placenta, puerperal infections, puerperal psychosis, essential hypertension, psychiatric disorders, diabetes mellitus, epilepsy, cardiac disease and

chronic renal disease.

Complications of the puerperal period may cause maternal morbidity, and occasionally death, and may be an important factor in prolonging the duration of hospitalisation after childbirth.

Source and reference attributes

Submitting organisation: National Perinatal Data Development Committee

Origin: International Classification of Diseases - 10th Revision, Australian Modification (7th Edition 2010) National Centre for Classification in Health, Sydney.

Relational attributes

Related metadata references: Supersedes Birth event—complication (postpartum), code (ICD-10-AM 6th edn) ANN{.N[N]} Health, Superseded 22/12/2009

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The following are a selection of national and hospital guidelines relevant to the maternal morbidity conditions covered in this report.

- ADIPS (Australian Diabetes in Pregnancy Society) 1998. Gestational diabetes mellitus: Management guidelines. Linda Hoffman, Chris Nolan, J Dennis Wilson, Jeremy JN Oats and David Simmons. Revised 2012: <www.adips.org/images/stories/documents/2012_adips_guidelines.pdf>
- RANZCOG (Royal Australian and New Zealand College of Obstetricians and Gynaecologists) 2011 College statement: Diagnosis of gestational diabetes (C-Obs 7): < www.ranzcog.edu.au/component/content/article/270-revised-statement-guidelines/417--diagnosis-of-gestational-diabetes-mellitus-c-obs-7.html>
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- Government of South Australia, Perinatal Practice Guideline: <www.health.sa.gov.au/ppg/Default.aspx?tabid=58>
- King Edward Memorial Hospital, Perth, Western Australia, Women's and Children's Health Service Clinical Guidelines: Complications of Pregnancy: <www.kemh.health.wa.gov.au/development/manuals/O&G_guidelines/sectionb/2/5157.pdf>
- Australian College of Midwives, National Midwifery Guidelines: <www.midwives.org.au/scripts/cgiip.exe/WService=MIDW/ccms.r?pageid=10037>
- Royal Hospital for Women guidelines: <www.seslhd.health.nsw.gov.au/rhw/Manuals/documents/Antenatal_Pregnancy%20Care/Antepartum%20Haemorrhage%20(APH)%20Guideline.pdf>

This report presents the results of a review of current practices in maternal morbidity data collection. Definitions, data collection guidelines, validation and uses of the maternal morbidity data by jurisdictions are described. Further action is needed to standardise data collection.

Maternal morbidity data in Australia: an assessment of the feasibility of standardised collection

AIHW