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Australian Institute of
Health and Welfare

Foundations for
enhanced maternity
data collection
and reporting in
Australia

*National Maternity Data
Development Project*

Stage 1

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Stage 1

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Australian Institute of Health and Welfare
Board Chair
Dr Andrew Refshauge

Director
David Kalisch

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

Media and Strategic Engagement Unit
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Tel: (02) 6244 1032
Email: info@aihw.gov.au

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Acknowledgments

Abbreviations

ABS	Australian Bureau of Statistics
ACM	Australian College of Midwives
AIHW	Australian Institute of Health and Welfare
AHMAC	Australian Health Ministers' Advisory Council
APC	Admitted Patient Care (collection)
DSS	Data Set Specification
GP	general practitioner
MaCCS	Maternity Care Classification System
METeOR	Metadata Online Registry
MIM	Maternity Information Matrix
NCIS	National Coronial Information System
NHMD	National Hospital Morbidity Database
NMDDP	National Maternity Data Development Project
NMDR	National Maternal Death Report
NMDS	National Minimum Data Set
NMMAC	National Maternal Mortality Advisory Committee
NMSP	National Maternity Services Plan
NPDC	National Perinatal Data Collection
NPESU	National Perinatal Epidemiology and Statistics Unit
PPH	postpartum haemorrhage
PSANZ	Perinatal Society of Australia and New Zealand
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
SOMANZ	Society of Obstetric Medicine of Australia and New Zealand
STMMC	state and territory maternal mortality committee
UNSW	University of New South Wales

Summary

Investment in more comprehensive and consistent national data collection for maternal and perinatal morbidity and mortality was recommended by the *Report of the maternity services review*—a review conducted in 2008 by the then Australian Government Department of Health and Ageing in response to concerns that maternity care was not meeting the needs of all Australian women. Its findings led to the development of the National Maternity Services Plan (NMSP). The NMSP is a strategic national framework to guide policy and program development and reflects the joint understanding and commitment of health ministers in all jurisdictions. The National Maternity Data Development Project (NMDDP) was established in response to Action 4.1.5 of the NMSP: *The Australian Government funds the development of nationally consistent maternal and perinatal data collection.*

This report presents the findings of Stage 1 of the NMDDP which was conducted between May 2011 and June 2013, under the expert guidance of a project advisory group and with extensive stakeholder consultation. Major components included:

- identifying national information needs for maternity data and assessing options to meet these needs through enhanced data collection and reporting
- conducting a range of data development activities, including developing a classification system for models of maternity care
- reaching agreement on the national requirements for maternal mortality reporting, including developing a standardised data collection form
- investigating issues with collecting and reporting national perinatal mortality data.

One outcome of the project has been an agreed set of priority data items for improving national data collection and reporting. These data items fall into three main categories:

- improvement of maternal morbidity data items (such as diabetes and hypertension) that are currently inconsistently collected across Australia
- addition of data items relating to lifestyle and risk factors in the antenatal period, including obesity and maternal mental health
- addition of data items on indications for caesarean section and other interventions, reflecting a need for consistent and accurate information about interventions before and during labour.

Another outcome is the development of the Maternity Care Classification System (MaCCS) to classify the diverse range of models of maternity care in Australia. Once implemented, this system is designed to support analysis of outcomes of maternity care provided in different ways.

Stage 1 of the NMDDP also involved in-depth examination of the current collection of data on maternal mortality. While maternal deaths are rare in Australia, they are still an important indicator of the quality of maternity services and obstetric care. A national report on maternal mortality in Australia for 2006–2010 will be published in 2014.

A second stage of the NMDDP has now begun and will focus on continuing the development of priority data items and of the MaCCS, extending maternal mortality reporting work, developing methods to better capture and report on national perinatal mortality, and providing greater access to maternal and perinatal data through web tools.

1 Introduction

1.1 The need for better maternity data

In recent years, several reports have highlighted the need for more comprehensive and consistent national data collection for maternal and perinatal mortality and morbidity. They include *Improving maternity services in Australia: the report of the Maternity Services Review* (the Review) (Commonwealth of Australia 2009), the National Maternity Services Plan (NMSP) (AHMC 2011) and a review of sources and gaps in maternity data in Australia (AIHW 2011).

Findings of the *Improving maternity services in Australia* report

The aims of the Review, which was conducted by the then Australian Government Department of Health and Ageing in response to concerns that maternity care was not meeting the needs of all Australian women, were to: canvass a wide range of perspectives on maternity services in Australia; identify key gaps and determine where change was required and how it could occur; and inform the priorities for national action, including the development of a national plan for maternity services (Commonwealth of Australia 2009).

The Review received numerous submissions advocating improved national data collection and review, including good governance arrangements, in the areas of maternal and perinatal morbidity and mortality, as well as in the area of women's experiences. Submissions identified 'the need for a nationally agreed, consistent and standardised minimum dataset that could provide an evidence-based platform upon which a national benchmarking program for maternity services could be built' (Commonwealth of Australia 2009). The Review's conclusions included that:

- Australia's strong record of safety in maternity services is an acknowledged strength of our maternity system
- changes to maternity services need to be guided by evidence
- stable, ongoing arrangements for national maternity data collection, analysis and review must be a priority.

The Review recommended that the Australian Government, in consultation with states and territories and key stakeholders:

- agree on and implement arrangements for consistent, comprehensive national data collection, monitoring and review for maternal and perinatal mortality and morbidity

- initiate targeted research aimed at improving the quality and safety of maternity services in select key priority areas, such as evidence around interventions, particularly caesarean sections, and maternal experience and outcomes, including from postnatal care.

The National Maternity Services Plan

The NMSP incorporated recommendations of the Review. The NMSP provides a strategic national framework to guide policy and program development over 5 years (2011 to 2015) and reflects the joint understanding and commitment of all jurisdictions (AHMC 2011). The Australian Health Ministers' Conference (now the Standing Council on Health [SCoH]) endorsed the NMSP in November 2010 and the Commonwealth and all state and territory governments are required to report to SCoH on progress against the Plan over its five year life (AHMC 2011).

Maternity data in Australia: a review of sources and gaps

A review of Australian maternal and perinatal data collections found that the quality and consistency of national reporting could be improved by developing and implementing national data standards for non-standardised data items in the National Perinatal Data Collection (NPDC). A review of frameworks and policies guiding the work of maternity services and associated information requirements for monitoring and reporting indicators and other national policy initiatives was recommended (AIHW 2011). This work was incorporated into the National Maternity Data Development Project (NMDDP).

1.2 The National Perinatal Data Collection—overview of collection and reporting

National reporting on pregnancy and childbirth for mothers, and the characteristics and outcomes for their babies, is currently based on the NPDC, held at the Australian Institute of Health and Welfare (AIHW). The NPDC is specified by the Perinatal National Minimum Data Set (NMDS) which at June 2013 contained 29 mandatory data items supplied by each jurisdiction (see Appendix A), as well as over 80 voluntary data items supplied by some of the jurisdictions.

The NPDC includes data on all live births and stillbirths of at least 400 grams birthweight, or at least 20 weeks gestation—that is, nearly 300,000 births per annum—resulting in a large and very rich data set. Collection of perinatal data occurs in each state and territory and is undertaken by midwives. The data are obtained from clinical and administrative records and information systems, including records of antenatal care, the care provided during labour and the delivery, and care provided after birth, as well as self-reported information from the mothers themselves. Several maternity information systems are used in hospitals across Australia and, while their primary purpose is clinical management, they are also feeder systems for the perinatal data collection.

The collection form (either paper or computerised) is usually completed at, or shortly after, the birth episode and may be reviewed and updated before the mother's discharge. The collection is not designed to record information after discharge even if the woman, or her baby, is re-admitted to the same hospital within the puerperium.

Each jurisdiction maintains its own perinatal data collection. All jurisdictions except South Australia have electronic data capture systems for at least a proportion of their perinatal data collection. Hospitals with small numbers of births and some private hospitals may use paper forms. Electronic data capture systems are at different stages of implementation, with Western Australia and the Northern Territory almost fully electronic—the number of paper forms in use is less than 3%—while the others remain hybrid systems, with up to 20% of forms paper-based, although this should reduce over time as more hospitals move to electronic reporting. The South Australian Department of Health is currently implementing a new electronic system in the major public hospitals and this will include a maternity module in the future.

The jurisdictions collate and forward the perinatal data to the data custodian (the AIHW) where they are incorporated in the NPDC. The AIHW National Perinatal Epidemiology and Statistics Unit (NPESU) analyses the NPDC and compiles an annual report containing national information for births and the women who give birth in *Australia's mothers and babies* (for example, Li et al. 2013). The jurisdictions also compile their own comprehensive reports.

Data items in the Perinatal NMDS are collected by all states and territories according to mandated national data definitions. However, data quality can vary markedly for voluntary items. There are a number of data gaps and inconsistencies, meaning that data cannot be aggregated to provide a national picture. See Appendix B for an example.

1.3 The National Maternity Data Development Project

The NMDDP was established in response to the NMSP's recommendations around improved data collection and reporting. The primary aim of the NMDDP is to ensure Action 4.1.5 of the NMSP is addressed: *The Australian Government funds the development of nationally consistent maternal and perinatal data collection.*

This report presents the findings of Stage 1 of the NMDDP which was conducted between May 2011 and June 2013. A second stage has now begun.

Stage 1 consisted of three interrelated components—the scoping of national information needs for maternity data; options to meet information needs through enhanced data collection and reporting; and a range of data development activities, including developing a nomenclature for models of maternity care. The components of Stage 1 are described in more detail in Table 1.1.

Table 1.1: Stage 1 overview of project components

Component	Subcomponents
Scoping and mapping of national information needs in relation to maternal and perinatal morbidity and mortality	1. Identify and prioritise national information needs for maternity data
	2. Update a resource for perinatal data—the Maternity Information Matrix (MIM)
Identify options to meet current and future information needs	1. Identify options to meet information needs, including jurisdictional capacity to modify existing, or implement new data items, and to report on data items
	2. Investigate options for local-level reporting and access by maternity services to data for quality assurance
	3. Report on maternal deaths and conduct data linkage to improve ascertainment of these deaths
	4. Develop a prototype for national perinatal mortality reporting
Data development	1. Assess data development options for priority data items and develop national definitions where required
	2. Develop a nomenclature to describe models of maternity care

1.4 Related data projects and initiatives

The NMDDP has linkages with a number of other maternity data projects and alignment of these projects, where feasible, was an important consideration.

- The AIHW is undertaking the National Core Maternity Indicators project. The National Core Maternity Indicators (see Appendix C) are clinical indicators that apply to the field of maternity care. Some of the data for these will be made available through work undertaken as part of the NMDDP to improve the NPDC.

- National evidence-based antenatal care guidelines are being developed (AHMAC 2012), providing direction for what is important in antenatal care provision. The first module was published in April 2013 and a second is under development. The guidelines are broader in scope than the NPDC, nevertheless much of what the NMDDP identified as important for national data collection aligns with the guidelines.

1.5 Project governance and consultation

The NMDDP is guided by a project advisory group. Key experts in the fields of obstetrics, midwifery, research, statistics and health policy were represented on the group.

The main role of the NMDDP Advisory Group during Stage 1 was to provide:

- advice and guidance on current and emerging perinatal and maternal mortality and morbidity issues

- advice on perinatal and maternal mortality and morbidity data collections and data collection practices

- assistance in identifying information gaps, overlaps and priority areas for national maternal and perinatal data collection.

NMDDP Advisory Group members bring not only their subject matter knowledge and expertise to the project but also their extensive connections to other networks, people, organisations and projects. This assists greatly to ensure alignment with other relevant projects and to avoid duplication of effort.

Reference and working subgroups were also established during Stage 1 to guide and inform specific components of the project. The National Maternal Mortality Advisory Committee (NMMAC) and subcommittees assisted with the work on maternal mortality. The Nomenclature for Models of Care Working Party advised on developing a classification system for models of maternity care in Australia, and the Clinical and Data Reference Group guided the data development work for clinical data items.

A list of members of these groups is provided in Appendix D and the relationship between the groups as well as higher-level reporting pathways are illustrated in

Figure 1.1. The NMDDP Advisory Group and subcommittees act in an advisory capacity to the AIHW. The National Perinatal Data Development Committee consists of jurisdictional perinatal data collection managers who consider and approve changes to the NPDC which are then submitted to the National Health Information Standards and Statistics Committee (NHISSC). The NHISSC makes recommendations to the National Health Information Performance and Principal Committee (NHIPPC) which reports to the Australian Health Ministers' Advisory Council (AHMAC) and to all Health Ministers via the Standing Council on Health (incorporating the former Australian Health Ministers' Conference).

Recognising the importance and value in consultation for a project impacting many stakeholders across all jurisdictions, extensive consultations occurred over the duration of the project. In addition to the committees mentioned above, state and territory stakeholders from health departments and hospitals, including obstetric and midwifery advisers, maternity services managers, data custodians, information systems administrators and members of clinical committees were particularly important for consultation about the key information gaps (see Chapter 2) and the nomenclature for models of care project (see Chapter 3). Members of professional health bodies and consumer organisations were also involved in many consultation processes.

Consultation was conducted using a range of methods, including face-to-face meetings and workshops, teleconferences, and electronic and online surveys.

1.6 Structure of this report

This report describes the outcomes of Stage 1 of the NMDDP as follows:

- the development of a set of data items agreed to be of the highest priority for improving national maternity data collection and reporting (Chapter 2)

- the design of a classification system for collecting data on models of maternity care (Chapter 3)

- agreed data items for prospective national reporting of maternal mortality (Chapter 4)

- an update to the Maternity Information Matrix and the release of an online version (Appendix E).

Work in progress is described in Chapter 5 including:

- data development for agreed priority data items

- a maternal mortality report for 2006–2010

- a data linkage study to better ascertain the number and causes of maternal death

- investigating a common approach to reporting national perinatal mortality data

- exploring user-friendly formats for reporting of maternity data.

*Membership of the NMDDP AG

Royal Australian and New Zealand College of Obstetricians and Gynaecologists

Australian College of Midwives

Maternity Services Inter Jurisdictional Committee

National Perinatal Data Development Committee

Obstetrics expert

Midwifery expert

Department of Health

Australian Institute of Health and Welfare

National Perinatal Epidemiology and Statistics Unit

SCoH
Standing Council on Health

AHMAC
Australian Health Ministers' Advisory Council

NHIPPC
National Health Information and Performance Principal Committee

CCPHPC
Community Care and Population Health Principal Committee

NHISSC
National Health Information Standards and Statistics Committee

MSIJC
Maternity Services Inter-jurisdictional Committee

NPDDC
National Perinatal Data Development Committee

NMDDP AG*
National Maternity Data Development Project Advisory Group

NMMAC
National Maternal Mortality Advisory Committee

NMoC WP
Nomenclature for Models of Care Working Party

CDRG
Clinical and Data Reference Group

Note: Light purple boxes represent NMDDP AG and direct reporting committees; blue box represents indirect reporting lines; dark purple boxes are for higher level committees.

Figure 1.1: Governance structure for Stage 1 of the National Maternity Data Development Project (NMDDP)

2 The NMDDP priority data items

The first step in the project was to identify the main information priorities and gaps in maternal and perinatal data. The starting point for this work was the key national policy documents discussed in Chapter 1—the Review and the NMSP. Much of the groundwork in identifying the key information needs had been established through the many submissions that were received as part of the Review. Building on this work, a scoping exercise was conducted, consisting of:

- a desktop review of other national policy documents, state and territory policy documents, and indicator frameworks (see Appendix F for a summary of results)

- consultation with external stakeholders via a questionnaire (see Appendix G) and with the NMDDP Advisory Group. The questionnaire asked respondents to rate the importance of the information needs sourced through the desktop review for national data collection as well as seeking to elicit any information needs not previously identified.

Information needs were considered in the context of the maternity pathway encompassing the following areas:

- pre-conception and the antenatal period
- maternal and paternal demographics and characteristics
- models of maternity care
- maternal morbidity
- labour and delivery
- complications of labour and delivery
- puerperium
- baby characteristics
- neonatal morbidity
- perinatal mortality
- health systems as they impact on all of the above.

The work led to the development of a draft NMDDP priority data item list. Many more items were suggested by stakeholders than could be included in the priority list. Prioritising data items recognised the necessity to limit the total number of new items and topics for collection, in an environment of increasing competition for resources, and

also acknowledged the need to achieve a balance between data collection and respondent burden. The items were prioritised through analysis of the questionnaire results, and consultation with the NMDDP Advisory Group.

The items were mapped against existing data collections, using the Maternity Information Matrix (MIM) (see Box 2.1 and Appendix E) and other information sources, to identify data gaps and inconsistencies. The mapping involved examining the current status of each item in terms of: its collection and recording in perinatal and related collections; the type of data gap that existed and the type of improvements needed to achieve national reporting; data linkage possibilities to assist national reporting; and priorities and comments from the consultation. This work identified the key issues for development for each of the prioritised data items, considering such factors as feasibility, practicality and potential time frames for achieving national consistency.

Box 2.1: The Maternity Information Matrix

The Maternity Information Matrix (MIM) is a comprehensive interactive tool that lists and describes data elements in national and jurisdictional data collections in Australia with information relevant to maternal and perinatal health. It allows comparisons of data items across collections and provides valuable information for identifying data gaps and inconsistencies.

The MIM was revised and updated to reflect data collection practices as at July 2011 and a web version provides online access to information about all maternity data collections existing in Australia. The MIM currently describes the data items in 45 collections, some of which are national and others jurisdiction-based (see Appendix E for more information and latest update).

The NMDDP priority data item list went through a number of consultation processes and revisions. Visits were conducted to all jurisdictions and meetings held with government and clinical stakeholders to discuss the items.

The final list of priority data items is shown in Table 2.1, together with a rationale and expected time frame for data development. In particular, the list reflects a number of areas of focus:

- Maternal morbidity items—these are inconsistently collected yet are considered by stakeholders as some of the most important items to collect in terms of monitoring maternal and perinatal outcomes.

- Risk or lifestyle factors in the antenatal period—many items relate to these factors that are usually, or should be, identified in the antenatal period and have potentially serious impacts on mothers and babies. Stakeholders identified these as a high priority for national data collection. Their poor collection to date means there is a significant gap in critical maternity information that could provide evidence to enable services and governments to develop and implement early intervention policies and programs.

- Indications for interventions—given the debate over increasing rates of induction and operative birth, without apparent explanation, the need for more consistent and accurate information about the reasons for these interventions is seen to be of high importance.

The data items vary in their dimensions and complexity. For some items, the process is more straightforward than for others. For example, where clinical guidelines exist, these will be used to develop the items, as is the case for hypertension in pregnancy (Lowe et al. 2008) and gestational diabetes mellitus (Nankervis et al. 2013). This is not to say these are universally accepted, but they do provide a starting point for discussion and, because a national and in some cases international process has taken place, there is much wider acceptance of this starting point.

For other data items, such as the mental health and screening for domestic violence items, these may need to be captured through a set of data items rather than an individual data item. Currently, they have no clear definition or agreed parameters. Data on screening for domestic violence alone, for example, may not result in useful information at the national level and additional data items for risk assessment and referral to services might also need to be considered. Such complex items require further investigation, discussion and pilot testing before an item or set of items to capture the data can be recommended.

While the NMDDP priority data items were agreed in principle in Stage 1 of the project by jurisdictional perinatal data custodians, who are ultimately responsible for implementation and resourcing of new and modified items in their data collections, the actual data elements, definitions and data collection methods were not finalised or agreed. This forms part of the data development process that is discussed in Chapter 5.

Table 2.1: Final national maternity data item priority list

Area for action/ priority data item	Rationale	Expected time frame for data development[a]
Maternal demographics		
Maternal education	The relationship between health outcomes and socioeconomic status (SES) is well documented (Kubzansky et al. 1999). Higher maternal education is associated with better outcomes for mother and baby. Educational attainment is considered one of the best individual-level indicators of SES (National Research Council 2006) and could assist with analysis of pregnancy outcome data and trends.	Long term
Interpreter service required[b]	This item was selected as a proxy for English language proficiency which is an indicator of potential barriers to communication in the health-care setting and could be analysed together with health outcomes. The National Maternity Services Plan (NMSP) identifies communication strategies to assist with women's awareness of available information which in turn enables them to make informed decisions and choices (AHMC 2011).	Short term
Maternal and perinatal risk factors		
Maternal height and maternal weight (maternal body mass index [BMI])	Maternal obesity is a significant risk factor for adverse outcomes for both mother and baby during pregnancy and childbirth, e.g. gestational diabetes, thromboembolism, hypertension, risk of operative births including caesarean, postpartum haemorrhage, higher risk of fetal death, birth injury, admission to neonatal intensive care unit and a higher risk of childhood obesity. High BMI may also limit various antenatal assessments that rely on ultrasound screening, such as accurate determination of gestational age in early pregnancy and assessments of fetal growth and wellbeing in later pregnancy (AHMC 2011). On the other hand, low BMI may indicate poor nutritional status which may also put mother and baby at risk (AHMAC 2012).	Short term

Table 2.1 (continued): Final national maternity data item priority list

Area for action/ priority data item	Rationale	Expected time frame for data development[a]
Maternal and perinatal risk factors (continued)		
Mental health	Identified in the NMSP as well as in the National Perinatal Depression Initiative, a goal of which is improved early detection of antenatal and postnatal depression (by the routine and universal screening of women during the perinatal period). This will enable early intervention for women experiencing perinatal depression (beyondblue 2008; AHMC 2011).	Medium term
Alcohol in pregnancy	Risk of poorer perinatal outcomes which can lead to fetal alcohol spectrum disorders (FASD) (House of Representatives Standing Committee on Social Policy and Legal Affairs 2012).	Medium term
Domestic violence	Increased risk of maternal and fetal morbidity and mortality (Nelson et al. 2012; VicHealth & Department of Human Services, Victorian Government 2004). Also an element of the NMSP—access for vulnerable women to appropriate services and models of care (AHMC 2011).	Long term
Substance use	Increased risk of maternal and fetal morbidity, including lower birthweight, small for gestational age, smaller head circumference and neonatal abstinence syndrome; women are less likely to seek antenatal care and have higher rates of infectious diseases (Wong et al. 2011).	Long term
Maternal morbidity		
Hypertensive disorders in pregnancy, including chronic hypertension, gestational hypertension, pre-eclampsia and eclampsia	There is a substantially greater risk of fetal death and higher risk of caesarean section. Hypertension in pregnancy generally is associated with increased risk of obstetric haemorrhage and maternal death (Heard et al. 2004; Roberts et al. 2005; Sullivan et al. 2008).	Short term
Diabetes mellitus, including pre-existing diabetes, gestational diabetes mellitus and diabetes therapy/control	Diabetes affects mother and baby in both the short and long term. Short-term risks include premature delivery, macrosomic fetal growth, miscarriage and fetal congenital malformations. Long-term effects include increased risk of cardiovascular disease and renal disease for mother and child and increased risk of developing diabetes and future obesity in the offspring (AIHW 2010; Clausen et al. 2009; Correa et al. 2008).	Short term
Severe primary postpartum haemorrhage (PPH)	A major cause of maternal death and 'near miss' cases, often leading to severe maternal morbidity. Complications include anaemia and fatigue, need for blood transfusion, hysterectomy, cardiac and other organ dysfunction (Anderson & Etches 2007; WHO 2012).	Short term
Peripartum hysterectomy and its indications	Although peripartum hysterectomy is rare, incidence is increasing, possibly due to an increase in the rate of caesarean sections (Haynes et al. 2004). The primary indication for peripartum hysterectomy is haemorrhage, mostly due to uterine rupture, retained placenta, or atony of uterus (Bodelon et al. 2009).	Medium term
Febrile morbidity in labour	Febrile morbidity in labour is associated with adverse neurological outcomes for the baby, including seizures, cerebral palsy and encephalopathy (Grether & Nelson 1997; Impey et al. 2001; Reilly & Oppenheimer 2005).	Medium term
Indications for intervention		
Indications for caesarean section	The reasons for the rise in interventions such as caesarean section and their impact on women are subjects of considerable debate (AHMC 2011). Caesarean birth is safer now than in the past and serious complications are uncommon, particularly for healthy women, but a small risk of serious morbidity and mortality for both the mother and the baby remains, and can complicate a subsequent pregnancy. Caesarean section is now one of the most common interventions in pregnancy. Caesarean birth in a first pregnancy makes a subsequent caesarean likely, and currently 4 out of 5 pregnant women with a history of caesarean birth have a further caesarean birth (AIHW NPESU & AIHW 2013).	Short term

Table 2.1 (continued): **Final national maternity data item priority list**

Area for action/ priority data item	Rationale	Expected time frame for data development[a]
Indications for intervention		
Indications for induction	Induction of labour is an intervention to end the pregnancy before the spontaneous onset of labour that may be recommended for women with pre-eclampsia, diabetes mellitus, pregnancies complicated by restricted fetal growth and other medical conditions. There is debate about acceptable use of induction of labour at term for non-medical conditions. Induction of labour is associated with risk of fetal distress, uterine hyper-stimulation and postpartum haemorrhage and can be the start of a cascade of further medical interventions (AIHW NPESU & AIHW 2013).	Medium term
Indications for instrumental vaginal birth	Instruments such as vacuum or forceps can be used to assist a mother at the end of labour or expedite the birth if the baby is showing signs of distress. The use of instruments is associated with both short-term and long-term complications for the mother and the baby, some of which can be serious (AIHW NPESU & AIHW 2013).	Medium term
Baby anthropometrics		
Head circumference	Important in terms of late growth restriction and the only way to pick up late placental insufficiency. Head circumference measurements at birth reflect intrauterine brain development and fetal growth. Failure to detect growth restriction is a common contributor to perinatal death (Barbier et al. 2013; Kuban et al. 2009; Kurtoglu et al. 2012).	Medium term
Perinatal mortality		
Coding of cause of perinatal death	Perinatal mortality is a key outcome indicator of maternity care. Accurate deaths information is critical for monitoring outcomes. Perinatal mortality surveillance has been recognised as necessary for monitoring the safety and quality of maternity care in the NMSP (AHMC 2011).	Medium term
Timing of fetal death	This item would help understand more about the population risk profile for perinatal death. Currently, population risk data cannot be adjusted accurately for antepartum and intrapartum deaths that are not preventable, such as those due to lethal congenital anomalies, and those that might be preventable (Li et al. 2012). The distinction between antepartum and intrapartum deaths may assist with greater understanding of whether changes in clinical practice are needed (Kramer et al. 2002).	Long term

(a) Time frames for data development are relative, and do not include the time it would take before all jurisdictions implement and could report on the items.

(b) This item was subsequently dropped from the list due to data quality concerns (see page 20).

3 A classification system for models of maternity care

The Review (see Chapter 1) highlighted consumer dissatisfaction with the limited range of models of maternity care available to women in Australia. A maternity model of care refers to the way in which a woman is cared for during pregnancy, birth and the postnatal period. The Review noted the lack of standardised terminology and definitions for identifying and differentiating models of maternity care (Commonwealth of Australia 2009). Recognising these needs, the NMSP advocated increasing availability and access to a range of models of maternity care and the provision of evidence-based information to both consumers and health services to enable informed decision making (AHMC 2011).

The Maternity Care Classification System (MaCCS) was developed during Stage 1 of the NMDDP. The MaCCS is a standardised nomenclature or classification system enabling identification and description of the models of maternity care currently provided in Australia, as well as catering for those developed into the future. The MaCCS, if fully implemented, will allow for collection of data nationally to facilitate meaningful analysis and comparisons of maternal and perinatal outcomes under differing models of care.

3.1 Literature review

The first step in development of a system to define and describe models of maternity care was a comprehensive literature review. This was guided by an initial data framework proposed through the NMDDP Advisory Group that suggested the nomenclature should encompass the characteristics of women, carers and care.

The literature review found no previous attempts in Australia or internationally to develop a standard classification system for models of maternity care. Most literature focused on care models delivered predominantly by midwives and there was little available literature on obstetric models of care such as private obstetric or general practitioner (GP) shared-care models. The literature provided evidence about the different characteristics that define models of maternity care but did not examine which characteristics are better than others or which characteristics influence outcomes more than others.

The literature review found that, as proposed in the initial framework, the characteristics that differentiate models of care could be meaningfully grouped into three broad domains which are described below.

Characteristics of the women cared for

Although every woman's pregnancy is unique and women's pathways through maternity care can also differ (even in the same model), models of care are designed for particular groups of women, not each individual woman. Based on the literature review, the two main characteristics about the women in a model of care that differentiate between models are risk category and target group.

Women's risk status is usually based on a combination of factors, including previous medical and obstetric history, assessment of her psychosocial situation and any current pregnancy complications (Kennedy 2006; Symon 2006). The literature review showed that, if outcomes from different models of care were to be compared using a classification system, then it would be important that women from similar groups were compared according to their risk status.

Closely related to the issue of risk status is whether models of care are designed for, or restricted to, certain target groups of women that share particular characteristics. These target groups may be focused on commonalities of culture or ethnicity (for example, models for Aboriginal and Torres Strait Islander women); obstetric or medical conditions (models for diabetes, next birth after caesarean section); social circumstances (models for young mothers or refugees); or other vulnerable groups (models for victims of domestic violence or socioeconomic disadvantage). Differentiating whether a model of care is for a particular target group would allow analysis of similar models.

Characteristics of care providers

The literature review identified many variations between different models in the professional affiliation of carers in a model, the number of carers and the industrial organisation (rostering or self-managed caseload) of the carers working in a model.

The professional affiliation of the carers involved in a model of care was found to influence how that model is structured and the philosophy of care that underpins the care provided (Hatem et al. 2008).

The number of carers was found to be particularly important when examining continuity of care/carer and differentiating between different models that are identified as 'teams'. The literature review revealed that there are significant differences in the number of carers that may be involved in a 'team' model of care, with some models having as few as 4 and others as many as 20 (Hatem et al. 2008; Homer et al. 2008).

There has been a move to one-to-one and small-team models in recent years and this has meant that midwives are expected to be on call for the women under their care to ensure continuity of care. The term 'caseload' or 'group practice' is often used to identify models that work in this way. However, the attributes of models using this terminology are not necessarily the same; hence, the names alone may not be relied upon to enable classification. It may be necessary to drill down further into the organisation of care providers' work, such as the number of women per carer (caseload size), to assist in identifying each model of care.

Characteristics of the care provided

The literature review revealed a number of aspects of care that could be important for a classification system, including level of continuity, location of care and mode of antenatal and postnatal care delivery (individual or group sessions).

Without being able to identify differences in continuity of care across the stages of pregnancy, labour and birth and the postnatal period, comparisons between models will not be accurate. There are a multitude of variations in continuity of care and these cannot be accounted for by the name or category of the model alone. The level of continuity can affect outcomes for mothers and babies, both in a physical and psychosocial sense.

The location of care is increasingly thought to influence a woman's experience of her care and her progress in labour (Birthplace in England Collaborative Group 2011; Hatem et al. 2008). The literature review highlighted variations in location within the same type of model with antenatal, intrapartum and postnatal care being provided in the community (including the home), birth centres (freestanding and hospital) and in public and private hospitals. It is important to identify not just the location of the birth (as, for some women who live in remote areas, this may be a metropolitan hospital) but also the location of where their antenatal and postnatal care is provided.

The way care is delivered, either as individual one-on-one sessions or group sessions, has also been shown to have some effect (Ickovics et al. 2003; Palmer et al. 2010;

Queensland Government 2012). For some vulnerable groups of women, a model of care utilising group antenatal care has been shown to improve outcomes for mothers and babies (Ickovics et al. 2003; Palmer et al. 2010). Identifying how care is delivered will allow differentiation between models that may be part of the same broad category, such as midwifery caseload models.

Justification for a classification system

The results of the literature review showed that, while there were broad categories of models of care in Australia, there were significant variations within those categories, thereby highlighting the difficulty in being able to compare models of care based on their name alone. Models of care were found to be evolving, hence a classification system that did not allow for changes and varying characteristics would not be meaningful or useful. Models of care are a complex concept and are built with many contributing components, all of which may impact on the quality and outcomes of maternity care experienced by women and their babies.

Based on the literature review and an examination of the variables of models of care that contribute to different outcomes for mothers and babies, a draft models of care framework incorporating the elements described above was developed as the basis of a system for classifying models of maternity care.

The full literature review is available in a companion volume to this report, *Nomenclature for models of maternity care: literature review, July 2012—Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1*, accessed at <http://www.aihw.gov.au/>.

3.2 Building on the literature review—development of the Maternity Care Classification System

Following the literature review and development of the data framework, there was ongoing consultation with an expert working party, the Nomenclature for Models of Care Working Party, a subcommittee of the NMDDP Advisory Group (see Appendix D for members), and with jurisdictional stakeholders. As a result of consultation, the data elements of the framework went through a number of modifications. The framework and data elements that were agreed by the end of Stage 1 of the NMDDP are shown in Table 3.1. It is possible further modifications could occur during Stage 2. The framework will be used as the basis for developing a data set of component data items, the Models of Care Data Set Specification (DSS). The consultation report is available in *Nomenclature for models of maternity care: consultation report, December 2012—Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1*, accessed at <http://www.aihw.gov.au/>.

During the development phase, a proposal was developed to combine the concepts of the data framework with the broad groupings for models of care (Major Model Categories; see Table 3.2). The resulting MaCCS would allow maternity services to classify their models of care based on individual characteristics (identified through the data framework) as well as to allocate the model to a broad group. The Major Model Categories were mostly identified in the literature and refined based on wider consultation. They can be used as a high-level classification system that broadly describes the type of model but which does not provide the detailed delineation between the aspects of woman, carer and care shown in Table 3.1.

Implementation of the MaCCS would involve the annual completion of a questionnaire based on the Models of Care DSS by each maternity service to define the characteristics of each maternity model of care at that service. Based on the characteristics of the model, a Major Model Category would then be assigned to that particular model at that maternity service. The Major Model Category code would be recorded in clinical records and data collections that include information about maternity care within the hospital or health authority. For example, the Major Model Category would be recorded in the perinatal data collection in each state and territory.

The MaCCS would capture data at the service level about the intentions of a model of care, rather than aspects of each individual woman's care. It aims to capture the characteristics of a model of care as it is intended for the majority of women who are cared for under this model. Not all women within a defined model of care will experience exactly the same attributes of the model in the same way.

Ideally, the Major Model Category would be recorded on each woman's record at various reference points in pregnancy, such as at booking, at term and at onset of labour. If the model of care changed during the pregnancy, this could also be recorded, including when the model changed and the reason why. Such information combined with information about the woman's individual pregnancy journey (as recorded in the perinatal data collection) would provide a powerful tool to describe and analyse the outcomes of different models of care. An example of how data from the Models of Care DSS database could be linked to data from the perinatal data collection is shown in Figure 3.1.

There has been significant interest from the maternity community in seeing the MaCCS taken forward as a system for classifying different models of care in Australia.

Table 3.1: Final data items for classifying models of maternity care

Dimension	Data element	Description	Data values
Women	Entry restrictions	Are there restriction criteria for entry into this model of care or is it open to all women? For example, does the model restrict entry to women with 'low risk' pregnancies or only women with diabetes, or high medical risk etc. If the model is available to all women, then the answer is 'no'.	Yes; No
	Target group	Is this model designed primarily for a specific target group of women; for example, women with diabetes, vaginal birth after caesarean (VBAC), Aboriginal and Torres Strait Islander women, young mothers, low risk women etc.	Diabetes; VBAC; Breech; Aboriginal and/or Torres Strait Islander; Drug and alcohol; Bariatric; Multi-fetal pregnancy; Vulnerable woman; Young mother; Migrant or refugee; Mental health; Low risk/normal pregnancy; Complex/high risk pregnancy; Planned homebirth; Other cultural; Other medical; Other social; Other (text) Multiple selections allowed
Carers	Profession of designated maternity carer(s)	Many models of care are defined by the professional who is the designated maternity carer, sometimes known as the 'lead carer', 'maternity care coordinator' or 'primary carer', e.g. midwifery-led models, GP-led models. The available data values also include whether there is more than one type of designated carer in a shared-care model.	Specialist obstetrician—public; Specialist obstetrician – private; GP obstetrician; Midwife—public; Midwife—private; GP; Maternal-fetal medicine subspecialist; Nurse; Aboriginal Maternal Infant Care practitioner; Shared care; Multidisciplinary team; Other (text)
	Midwifery caseload	Is care in this model provided by midwives who are working within a caseload structure with a monthly or annual capped caseload of women per full-time-equivalent carer?	Yes; No

(continued)

Dimension	Data element	Description	Data values
Carers (continued)	Size of caseload	If this is a midwifery caseload model, what is the usual capped number of women per annum per full-time-equivalent carer? If the model does not have a caseload or there is no cap, then select N/A.	<=30; 31–35; 36–40; 41–45; 46–50; 51–55; 56–60; >60; N/A
	Continuity of designated carer	This element describes the extent of planned continuity of the designated or primary carer across the different stages of maternity care. Continuity is defined by the majority of care being provided by a single designated (named) carer with a maximum of three other carers involved in the provision of care. For example, a midwife in a group midwifery caseload practice might offer continuity of designated carer throughout the duration of maternity care, but a team midwifery model may involve continuity only in the antenatal and postnatal period.	Duration of maternity care; Antenatal period; Antenatal and intrapartum; Antenatal and postpartum; Intrapartum and postpartum; No continuity
	Profession of other planned collaborative carer(s)	This is designed to capture the scope of other recognised and named carers in professional roles who routinely collaborate with the designated care provider in the model of care. These professionals have a designated role in the model as opposed to being referred to on an ad hoc basis as required for some women.	Specialist obstetrician—public; Specialist obstetrician—private; GP obstetrician; Midwife—public; Midwife—private; GP; Maternal-fetal medicine subspecialist; Aboriginal Health Practitioner; Medical specialist (other than obstetric); Nurse; Perinatal mental health worker; Other allied health practitioner; Other (text); Nil Multiple selections allowed
Care	Planned transfer for birth	Do all women in this model of care require transfer to another location for intrapartum care and birth? This is a planned transfer for all women and not just for those women who require a higher-level facility for birth or in an emergency. For example, a remote maternity care model may require all women to be transferred from their remote community to an urban hospital at 36 weeks to wait for labour and birth.	Yes; No
	Planned location of antenatal care	This element describes the scope of location that is offered within this model of care for the provision of antenatal care. Some models of care offer multiple options and all applicable locations may be selected. This is the location(s) where the majority of antenatal care is provided. For example, a caseload midwifery model might offer antenatal care at a hospital clinic or home. This is a multiple-value field so all locations provided in the model can be selected.	Hospital clinic—on-site; Hospital clinic—outreach; Clinician's rooms/ Medicare Local; Community facility; Aboriginal Community Controlled Health Organisation facility; Home; Other Multiple selections allowed
	Planned location for birth	This element describes the scope of location that is offered within this model of care for birth. Some models of care offer multiple options and all applicable locations may be selected. This is the location(s) where the majority of care is provided for birth. For example, a team midwifery model may offer birth in a hospital or birth centre.	Home; Birth centre—stand alone; Birth centre—in hospital; Hospital—excluding birth centre; Aboriginal Community Controlled Health Organisation facility; Other Multiple selections allowed
	Planned location of postnatal care	This element describes the scope of location that is offered within this model of care for the provision of postnatal care. Some models of care offer multiple options and all applicable locations may be selected. This is the location(s) where the majority of postnatal care is provided. For example, a shared-care model may offer postnatal care in hospital or home.	Home; Birth centre—stand alone; Birth centre—in hospital; Hospital—excluding birth centre; Aboriginal Community Controlled Health Organisation facility; Hotel/hostel; Community facility; Clinician's rooms/Medicare Local; Other Multiple selections allowed

Table 3.1 (continued): Final data items for classifying models of maternity care

Dimension	Data element	Description	Data values
Care (continued)	Individual or group care	This element identifies whether the model of care offers antenatal and/or postnatal care in individual or group sessions. Group sessions include both education AND clinical care in a group setting and not just education. For example, a team midwifery model offering group antenatal care, such as CenteringPregnancy®.	Individual one-to-one care; Group sessions; Mix
	Planned scheduled medical visits	The number of planned visits with an obstetrician (specialist or GP) scheduled for all women in the model. For example: A midwifery group practice caseload model may include 2 planned visits to a specialist obstetrician for all women. A public hospital maternity care model run by midwives may not schedule medical visits for all women and only refer them to a specialist obstetrician when needed.	0; 1; 2; 3; 4; 5; 6; 7; 8; 9; 10; >10
	Additional antenatal services	Are additional antenatal and/or postnatal services provided in this model of care, particularly for women in remote or rural areas who reside at a significant distance from a maternity service? For example: A high-risk maternity clinic that offers telehealth services to remote communities. A public hospital maternity care model that provides fly-in fly-out clinicians to remote communities.	N/A; Fly-in fly-out clinicians; Telehealth; Community-based remote-area clinicians; Other (text) Multiple selections allowed
	Model completion	How long after discharge does planned postnatal care within this model end? If the model does not include an inpatient stay, then count the time from the birth. For example: A GP obstetrician model may provide ongoing regular postnatal care to women for 2 weeks after birth. A public hospital maternity care model may complete care for women in that model at discharge.	At discharge; 1–3 days; 4–7 days; 8–14 days; 15–28 days; 29–42 days; >42 days

Table 3.2: Major Model Categories

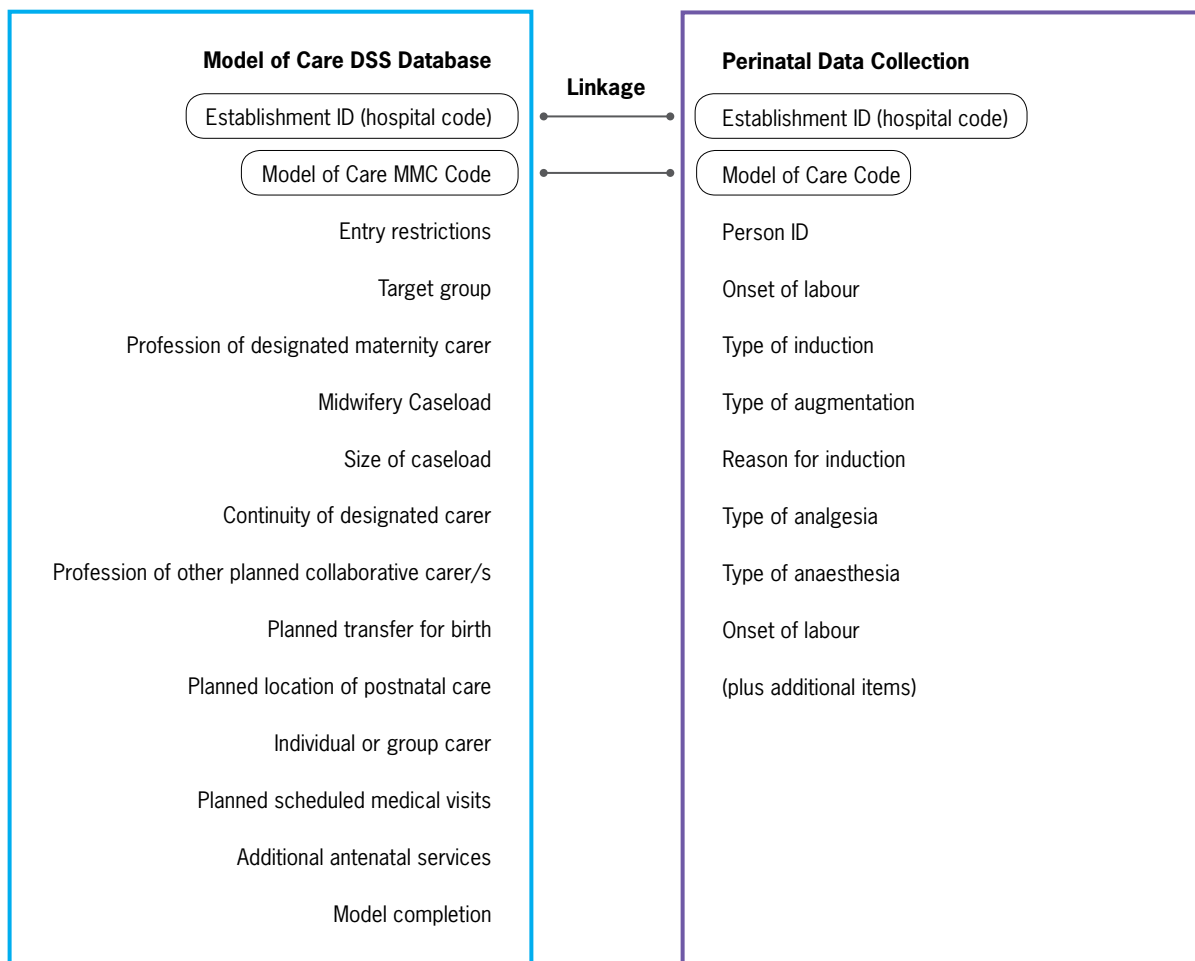| Major Model Category	Description
Private obstetrician (specialist) care	Antenatal care provided by a private specialist obstetrician. Intrapartum care is provided in either a private or public hospital by the private specialist obstetrician and hospital midwives in collaboration. Postnatal care is usually provided in the hospital by the private specialist obstetrician and hospital midwives and may continue in the home, hotel or hostel.
Private midwifery care	Antenatal, intrapartum and postnatal care is provided by a private midwife or group of midwives in collaboration with doctors in the event of identified risk factors. Antenatal, intrapartum and postnatal care could be provided in a range of locations, including the home.
GP obstetrician care	Antenatal care provided by a GP obstetrician. Intrapartum care is provided in either a private or public hospital by the GP obstetrician and hospital midwives in collaboration. Postnatal care is usually provided in the hospital by the GP obstetrician and hospital midwives and may continue in the home or community.
Shared care	Antenatal care is provided by a community maternity service provider (doctor and/ or midwife) in collaboration with hospital medical and/or midwifery staff under an established agreement and can occur both in the community and in hospital outpatient clinics. Intrapartum and early postnatal care usually takes place in the hospital by hospital midwives and doctors often in conjunction with the community doctor or midwife (particularly in rural settings).
Combined care	Antenatal care provided by a private maternity service provider (doctor and/or midwife) in the community. Intrapartum and early postnatal care provided in the public hospital by hospital midwives and doctors. Postnatal care may continue in the home or community by hospital midwives.
Public hospital maternity care	Antenatal care is provided in hospital outpatient clinics (either on-site or outreach) by midwives and/or doctors. Care could also be provided by a multidisciplinary team. Intrapartum and postnatal care is provided in the hospital by midwives and doctors in collaboration. Postnatal care may continue in the home or community by hospital midwives.
Public hospital high-risk maternity care	Antenatal care is provided to women with medical high risk/complex pregnancies by maternity care providers (specialist obstetricians and/or maternal-fetal medicine subspecialists in collaboration with midwives) with an interest in high-risk maternity care in a public hospital. Intrapartum and postnatal care is provided by hospital doctors and midwives. Postnatal care may continue in the home or community by hospital midwives.
Team midwifery care	Antenatal, intrapartum and postnatal care is provided by a small team of rostered midwives (no more than 8) in collaboration with doctors in the event of identified risk factors. Intrapartum care is usually provided in a hospital or birth centre. Postnatal care may continue in the home or community by the team midwives.
Midwifery group practice caseload care	Antenatal, intrapartum and postnatal care is provided within a publicly funded caseload model by a known primary midwife with secondary backup midwife/midwives providing cover and assistance in collaboration with doctors in the event of identified risk factors. Antenatal care and postnatal care is usually provided in the hospital, community or home with intrapartum care in a hospital, birth centre or home.
Remote area maternity care	Antenatal and postnatal care is provided in remote communities by a remote area midwife (or a remote area nurse) or group of midwives, sometimes in collaboration with a remote area nurse and/or doctor. Antenatal care may also be provided via telehealth or fly-in fly-out clinicians in an outreach setting. Intrapartum and early postnatal care is provided in a regional or metropolitan hospital (involving temporary relocation prior to labour) by hospital midwives and doctors.
No formal care	Not strictly a 'model' of care, but this category includes women who have received no formal antenatal care and present to hospital late in pregnancy or in labour.

Model of Care DSS Database

Establishment ID (hospital code)

Model of Care MMC Code

Entry restrictions

Target group

Profession of designated maternity carer

Midwifery Caseload

Size of caseload

Continuity of designated carer

Profession of other planned collaborative carer/s

Planned transfer for birth

Planned location of postnatal care

Individual or group carer

Planned scheduled medical visits

Additional antenatal services

Model completion

Linkage

Perinatal Data Collection

Establishment ID (hospital code)

Model of Care Code

Person ID

Onset of labour

Type of induction

Type of augmentation

Reason for induction

Type of analgesia

Type of anaesthesia

Onset of labour

(plus additional items)

Figure 3.1: **Example of potential data linkage between the Models of Care DSS database and perinatal data collections**

4   Prospective national reporting of maternal mortality

The maternal mortality project was conducted as a subcomponent of the NMDDP. It aimed to develop a nationally consistent and confidential maternal death enquiry system and develop a national report on maternal mortality (see Chapter 5).
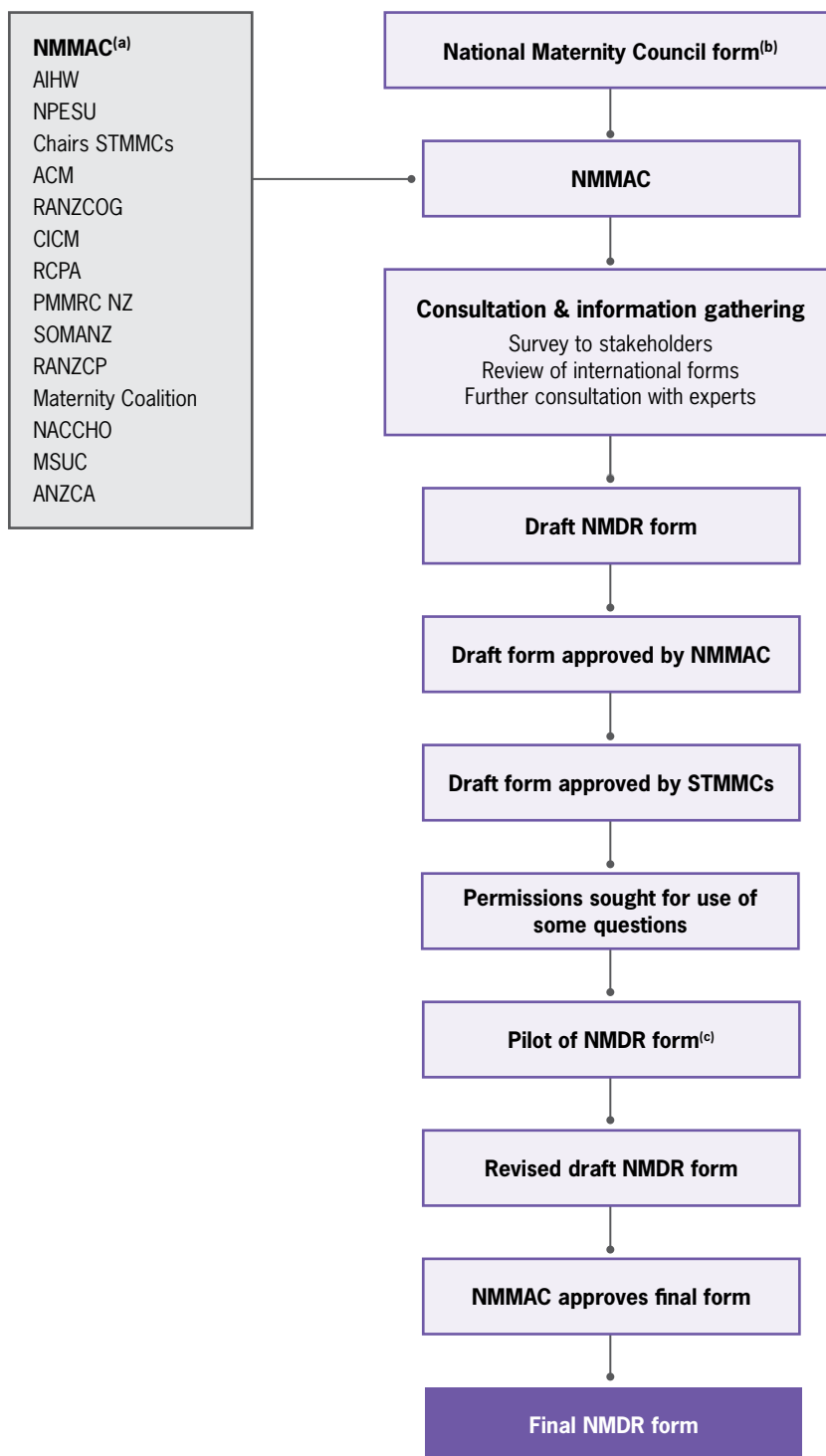
Australian maternal death reporting relies on collation of information about maternal deaths from each state and territory maternal mortality committee (STMMC). There is no nationally agreed standard method for reporting and reviewing maternal deaths. Each STMMC is responsible for conducting confidential death enquiries to determine primary and contributory causes of maternal deaths as well as assigning the classification of the maternal death. Deaths are notified to each committee by clinicians, midwives and obstetricians, hospitals, health departments and through coronial and post-mortem investigations as well as other avenues such as multimedia review. Maternal deaths are further ascertained from state and territory perinatal and hospital morbidity collections, from death certificate data supplied to the Registrars of Births, Deaths and Marriages, or from the Australian Bureau of Statistics (ABS) mortality data (derived from Registers of Births, Deaths and Marriages). The roles and responsibilities of the STMMC vary by jurisdiction and there is no national minimum data set. The processes and definitions vary across jurisdictions, making meaningful comparisons difficult.

Throughout the course of the maternal mortality project, work proceeded to develop a prospective National Maternal Death Report (NMDR) form as part of the national process of review to standardise the collection of maternal death information in Australia. The aim was to generate a form to improve the quality and utility of maternal death data collection and include information that could inform policy, clinical guidelines and educational resources.

The draft prospective NMDR form, which was based initially on a form provided by the National Maternity Council, has undergone several rounds of consultation and refinement, under the guidance of the National Maternal Mortality Advisory Committee (NMMAC), a subcommittee of the NMDDP Advisory Group (Figure 4.1). The form has been developed to collect the information required at a national level, with jurisdictions determining use of the form locally. It is not intended to replace local review processes or data collection, however states and territories can elect to use it as a primary data collection tool if desired. The strength of the form is that it is the first nationally agreed form and its implementation would facilitate the collection of nationally consistent information. This is the first step in moving towards a standardised national collection.

The new form will collect detailed information on the underlying health status of women who die, such as: their past obstetric and medical history; health conditions or events occurring in pregnancy, such as antenatal visits and procedures and complications of pregnancy; risk factors associated with the pregnancy, including body mass index (BMI), smoking, alcohol and other drug use; details of labour and birth, such as induction, caesarean section and use of analgesia or anaesthesia; details of the death, such as place of death, and hospital transfers; and particular health conditions, such as thromboembolism.

Piloting of the prospective NMDR form is being conducted in several jurisdictions. Depending on the findings of the pilot, the form will be revised. Implementation of the form depends on agreement by jurisdictions and availability of local funding to implement it.

NMMAC[a]

AIHW
NPESU
Chairs STMMCs
ACM
RANZCOG
CICM
RCPA
PMMRC NZ
SOMANZ
RANZCP
Maternity Coalition
NACCHO
MSUC
ANZCA

National Maternity Council form[b]

↓

NMMAC

↓

Consultation & information gathering
Survey to stakeholders
Review of international forms
Further consultation with experts

↓

Draft NMDR form

↓

Draft form approved by NMMAC

↓

Draft form approved by STMMCs

↓

Permissions sought for use of some questions

↓

Pilot of NMDR form[c]

↓

Revised draft NMDR form

↓

NMMAC approves final form

↓

Final NMDR form

(a) CICM: College of Intensive Care Medicine; RCPA: Royal College of Pathologists of Australasia; PMMRC NZ Perinatal & Maternal Mortality Review Committee New Zealand; RANZCP: Royal Australian & NZ College of Psychiatrists; NACCHO: National Aboriginal Community Controlled Health Organisation; ANZCA: Australian & NZ College of Anaesthetists. See also Abbreviations list.

(b) The NMMAC used this form as a starting point for development of the National Maternal Deaths Reporting form.

(c) Underway 2013–14.

Figure 4.1: Development of the prospective National Maternal Deaths Reporting (NMDR) form

5 Progress with other components of the NMDDP

This chapter outlines progress with work that commenced during Stage 1 of the NMDDP and is ongoing at the time of publication. The work is of a long term nature and will not produce definable outputs for several years however it establishes the foundations for future reporting.

5.1 Data development for agreed priority data items

Having determined the NMDDP priority data item list (Chapter 2), the project moved to assessing how to capture the information in such a way as to add value to the data collection without unreasonably adding to respondent burden.

An assessment of data collections was undertaken to ascertain whether any of the data items could or should be collected through data collections or surveys other than the NPDC. There were potentially a number of different collections, such as research collections, administrative data and surveys that could be used to meet the reporting needs of revised or expanded maternity data collections arising as a result of the NMDDP. In reviewing the most feasible options for collection, it was important to consider the purpose of each of the data collections and whether they:

- collected data at the national level
- could provide relevant information for the whole population of interest
- were regularly and systematically collected
- were accessible.

The NPDC was found to meet the above criteria and be the most suitable collection for the purpose of improving nationally standardised maternity information. Above all, it offers relevance, being collected at source (from the mother and clinicians, and in the primary health-care setting) and is a census of detailed information about mothers and their babies. The NPDC is a large and very rich data set.

The primary purpose of the NPDC is population health information, population monitoring and surveillance and research. The data can be used to explore patterns, trends over time, for jurisdictional and international comparisons,

and may provide insight into the effects of, or the need for, particular policy or program changes. Another important and emerging use of the NPDC is reporting against clinical indicators. This is potentially useful for service quality investigation or improvement, although not the primary purpose of this national collection. A national collection needs to meet national analysis and reporting needs and will not be able to collect every item of potential interest. A national collection is unlikely to provide the immediate clinical feedback that some maternity services may require, however can be very useful over the longer time period to explore trends.

The Admitted Patient Care (APC) collection was the only other collection considered potentially suitable as a collection vehicle for some of the priority data items. The APC collection (different names are used in different jurisdictions) is a collection of data on separations (that is, episodes of care) in public and private hospitals in Australia. Data are available on principal and additional diagnoses, procedures and diagnosis-related groups, mode of separation, length of stay, demographics and other variables. Each jurisdiction provides these data to the AIHW for collation and reporting in the national hospital statistics collection, known as the National Hospital Morbidity Database (NHMD).

However, after investigation, the APC collection did not appear to be a suitable substitute data source, despite its possible convenience in terms of cost and lower respondent burden, because:

- Health conditions are usually only recorded in APC data if they affect the current hospital admission. For example, if a woman's hypertension condition is well controlled and does not impact on the birth, this health condition may not be recorded in the woman's hospital separation record.

- The notes and information sources that clinical coders have available to them may provide insufficient detail to satisfy the level of detail required of the NMDDP priority data items, such as the distinction between different types of hypertension affecting the pregnancy. Or, while a blood loss of over 500 mL may be recorded on the clinical notes, unless the doctor has written 'postpartum haemorrhage', the coder is not permitted to record it as such.

- Even if a condition is recorded, and sufficient detail is available, there may not be an International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM) code that aligns with the NMDDP priority data item. The classification of hypertensive disorders in the ICD-10-AM (8th edition), for example, aligns poorly with current clinical guidelines for these disorders, such as those of the Society of Obstetric Medicine in Australia and New Zealand.

Limitations to collecting priority data items in the perinatal data collection

While the NPDC was found to be the most suitable data collection for national maternity information, there are some limitations that affect data quality. Many of the NMDDP priority data items relate to medical conditions or risk factors that are usually identified in the antenatal period. This may occur in a range of settings, such as at GP, specialist or hospital antenatal clinics. However, as noted previously, the NPDC was designed as a 'birth episode' collection and involves the completion of a form at or shortly after birth. Data collection for events and conditions in the antenatal period therefore poses particular challenges as the midwife attending the birth may not have access to information that was recorded in the antenatal period. Currently, to obtain such information, the midwife uses sources available to her at the time of the birth episode and/or mother's discharge from hospital, such as doctors' notes, medical records, discharge summaries and the woman's self-reported information. Information availability and access can be improved through the use of woman-held pregnancy records and electronic maternity information systems which are in operation in many hospitals, allowing data to be recorded throughout the antenatal period. A national woman-held pregnancy record, including an electronic version, is under development.

The NPDC has some scope limitations in that it does not cover pre-conception or post-discharge events. Some information needs initially scoped as important for national collection, such as pre-conception maternal nutrition, consumer experience and access to postnatal care, therefore had to be excluded from the priority data list on the grounds of feasibility of data collection. It is becoming more common for mothers to be discharged within 2 days of giving birth (Li et al. 2012), therefore the opportunity to collect information about what happens to the woman and her baby in the days following birth is diminishing. Perinatal data collections and the NPDC are not updated retrospectively for information about events occurring post-discharge—for example if the woman was re-admitted for a postpartum haemorrhage and subsequent hysterectomy, or with new information that may emerge, such as coroners' records about a maternal or neonatal death.

Private hospital data, particularly antenatal data, are more difficult to collect because the clinical environment is different to that of public hospitals and the midwife may have less access to information than in public hospitals. In addition, in some cases, data provision may be beyond the scope of licensing or other regulatory arrangements.

It remains the case therefore that, where records are not available or only partial records are available to the midwife, she may have to rely on the mother's self-reported information at the birth episode to complete some items on the perinatal data collection form, including some of the new national priority items arising through the NMDDP. The perinatal data collection, like all data collections, has some imperfections, however its benefits far outweigh the limitations.

Achieving national consistency

Many jurisdictional stakeholders emphasised the need for the NMDDP priority data items to be included in the Perinatal NMDS to achieve national consistency in data collection. However, they also raised the potential for considerable implications for jurisdictions in terms of incorporating the revised and new data items in their collections, and expressed concern that the inclusion of so many data items in the Perinatal NMDS, within a short time frame, was unlikely to be achievable.

Because of these concerns, the NMDDP Advisory Group agreed that the best way to progress the priority data items into the NPDC would be to initially include them in a Perinatal Data Set Specification (DSS). A DSS is a set of data items to be collected according to standardised definitions (national data standards), however there is no obligation to collect or report the items. This is different to an NMDS which is for mandatory collection and national reporting. An NMDS is dependent upon agreement from every state and territory to collect and supply data according to the national definitions; that is, to implement the data items in their perinatal data collection.

A DSS therefore allows development of national data standards to proceed but takes pressure off jurisdictions in terms of implementation time lines and resources. The process of data development for items being added to a DSS or NMDS is the same. National data standards must be created and agreed to, and endorsed by relevant national data and standards committees.

The aim of the NMDDP is for priority data items to become national data standards and to progressively move into the Perinatal NMDS. This is the only way for standardised national collection to occur. It is anticipated that some data items on the priority list will be able to be added with relative ease to the Perinatal NMDS, while a longer time frame will be required for other items, dependent on jurisdictional time frames and resources.

Figure 5.1 sets out the projected future NPDC, with all NMDDP priority data items incorporated into the collection. It includes the priority data items (new DSS/NMDS items), existing NMDS items, and items from the broader NPDC that are provided to the national data custodian on a voluntary and non-standardised basis. The items are grouped along the maternity pathway, from the antenatal to the postnatal period.

The development of national data standards follows a formal process. A national data standard specifies the nationally agreed name, definition, response categories and other characteristics of the data as well as guidelines for its collection. The standards are created and stored in the AIHW's Metadata Online Registry (METeOR), which is an electronic repository and registry that operates according to international standards for data development (see <http://meteor.aihw.gov.au/content/index.phtml/itemId/181162>).

The NMDDP priority data items have been grouped into work batches that align with the expected relative time frame for development:

- Batch 1 consists of hypertension, diabetes, diabetes therapy, maternal height, maternal weight, indications for caesarean section, severe primary postpartum haemorrhage and interpreter service required.
- Batch 2 items are peripartum hysterectomy and its indications, indications for induction, indications for instrumental vaginal birth, and mental health.
- Batch 3 includes head circumference, timing of fetal death, febrile morbidity in labour, maternal education, alcohol consumption in pregnancy and screening for domestic violence.
- Batch 4 consists of one item, substance use, which will require a lengthier data development time frame due to its considerable dimensions and complexity.

To date, all Batch 1 items other than interpreter service required have been recommended for the Perinatal DSS by the National Health Information Standards and Statistics Committee (NHISSC) and have been submitted to the National Health Information Performance and Principal Committee (NHIPPC) for endorsement. The item interpreter service required was removed from the priority list due to stakeholder concerns about data quality and interpretation of the data. The recommended items can be viewed in METeOR <http://meteor.aihw.gov.au/content/index.phtml/itemId/510127>.

5.2 Maternal mortality report for 2006–10

A comprehensive report, *Maternal deaths in Australia 2006–10*, is being prepared and will be published later in 2014.

The purpose of the report, the fifteenth in the series of Australian maternal mortality reporting, is to identify trends in maternal mortality and to develop an evidence base for maternal deaths that can be used to inform maternity services policy and practice. The NMDDP has provided the opportunity to review all processes involved with compilation of such a report, with the aim of achieving greater consistency in national reporting.

Collection of consistent data from STMMCs (see Chapter 4) for the 2006–2010 maternal mortality report was achieved using a standardised form agreed through consultation. The prospective NMDR form will replace the current form in future years once it has been finalised (see Chapter 4).

Ethics committee approvals for the report were obtained from 14 committees, including the AIHW Ethics Committee, University of New South Wales Human Research Ethics Committee, ethics committees in each state and territory, the National Coronial Information System Ethics Committee and Aboriginal health ethics committees in New South Wales, South Australia, Western Australia and the Northern Territory.

Case summaries have been incorporated to make the report more accessible to clinicians working in maternity services. Care has been taken to remove information that could potentially identify any individual.

5.3 Data linkage study on maternal and late maternal deaths

A national population data linkage study is being undertaken to determine the incidence of maternal and late maternal deaths in Australia. A late maternal death is defined as the death of a woman from direct or indirect obstetric causes more than 42 days but less than 1 year after the end of pregnancy.

Late maternal deaths are believed to be under-ascertained in Australia. For the period 1997–2002, only 13 late maternal deaths were reported nationally. This probably in part reflects the fact there is no national agreement or process to review or report on late maternal deaths, as well as the difficulty in identifying these deaths using existing health information and surveillance systems.

This study is retrospective and uses data linkage to identify deaths of women aged 15–49 years occurring within 1 year of a birth. These deaths are classified as maternal or non-maternal. Maternal deaths are defined as maternal and late maternal deaths that occurred during a pregnancy or within 1 year of giving birth/termination of a pregnancy as evidenced by linkage with a birth record and death record for the same individual. Additionally, deaths due to early pregnancy loss where there is no perinatal or STMMC record (unlinked death records) but with an obstetric-related cause of death are included in some of the analyses of maternal mortality.

Scope of data collection

	Pre-conception	ANTENATAL PERIOD	LABOUR & DELIVERY	IMMEDIATE POSTPARTUM OUTCOME	POSTNATAL PERIOD (prior to/at discharge)	Post-discharge
New DSS/NMDS[1]		Maternal education; Height; Weight; Mental health; Alcohol consumption; Domestic violence screening; Substance use; Pre-existing & gestational hypertension & pre-eclampsia; Pre-existing & gestational diabetes; Diabetes therapy; Woman's model of care (from Models of Care DSS)	Indications for induction; Indications for instrumental vaginal birth; Indications for caesarean section; Febrile morbidity in labour; Timing of fetal death	Baby head circumference; Coding of cause of perinatal death; Severe primary postpartum haemorrhage; Peripartum hysterectomy; Indications for peripartum hysterectomy		
Existing NMDS[2]		Date of birth; Indigenous status (mother); Person identifier (mother); Establishment identifier; Country of birth; State; Usual residence; Smoking (before/after 20 weeks; quantity); Antenatal visits (number; gestation at first visit); *Parity; Most recent previous caesarean birth*	Labour onset type; Birth method; Birth presentation; Setting of birth; Analgesia (administered; type); Anaesthesia (administered; type); *Labour induction type*	Postpartum perineal status; Baby date of birth; Sex; Person identifier (baby); Birth weight; Apgar score at 5 mins; Gestational age; Birth order; Birth status; Plurality; Indigenous status (baby); *Resuscitation (indicator; method)*	Separation date (mother; baby)	
NPDC[3]		Marital status; Assisted reproductive technology; Previous pregnancies/outcomes; Gravidity; Intended place of birth; Maternal medical conditions (various); Obstetric complications (various); Antenatal length of stay	Induction/augmentation; No labour; Hospital sector; Accommodation status; Admission date; Complications of labour; Cord prolapse; Retained placenta; Fetal distress in labour	Major puerperal infection; Baby length; Resuscitation drug therapy; Fetal death; Neonatal death; Maternal death; Date of death; Autopsy; Classification of death; Main cause of death	Postnatal length of stay (mother; baby); Mode of separation (mother; baby)	

Notes

1. NMDDP priority data items for future inclusion in the NMDS.
2. Items in italics are in the process of incorporation into the NMDS. This work pre-exists the NMDDP.
3. Additional NPDC (voluntary; non-standardised) items.

Figure 5.1: The expanded National Perinatal Data Collection (NPDC)

Data used for this study include: all births in the perinatal data collections in 1998–2009; all deaths of women in 1999–2010 recorded in the National Death Index (NDI) and in the National Coronial Information System; and all maternal deaths reported to STMMCs.

Recognising the importance of maintaining confidentiality and respecting the privacy of the individuals to whom the data relate, ethical approval from the states and territories for this study and permission from each of the source data custodians was sought at the outset.

The report development and data linkage processes are illustrated in Figures 5.2 and 5.3 and a detailed description of the data linkage study methodology is available in *Maternal mortality: data linkage methodology—Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1*, accessed at <http://www.aihw.gov.au/>. The results of the data linkage study will be published in 2015.
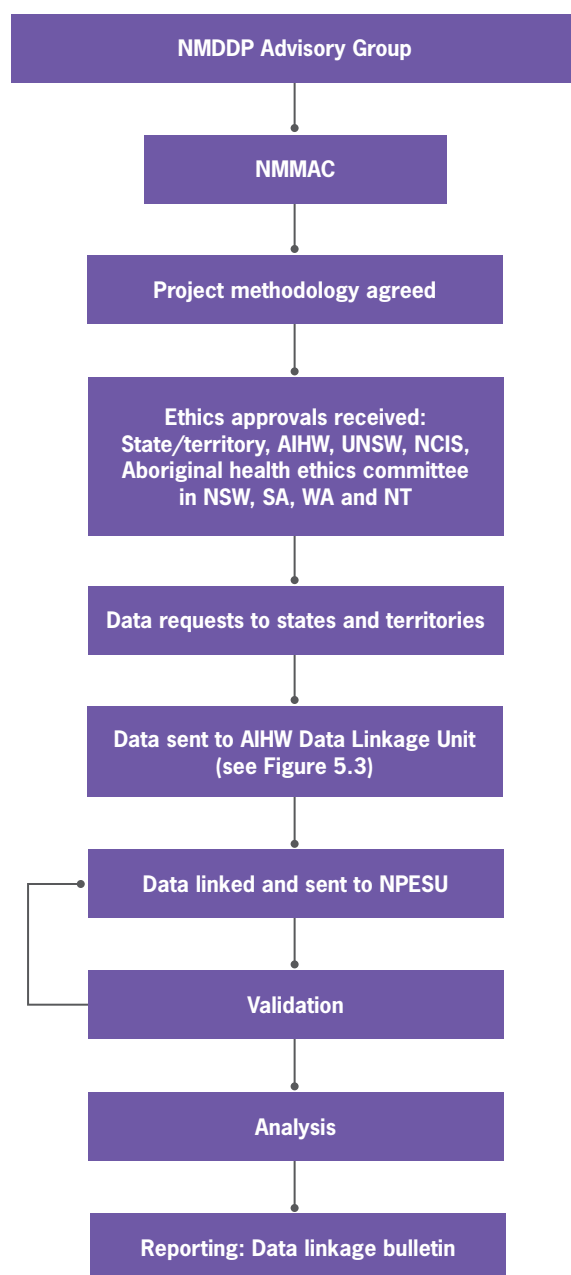
Figure 5.2: Development process for the data linkage study

Figure 5.3: Data linkage summary
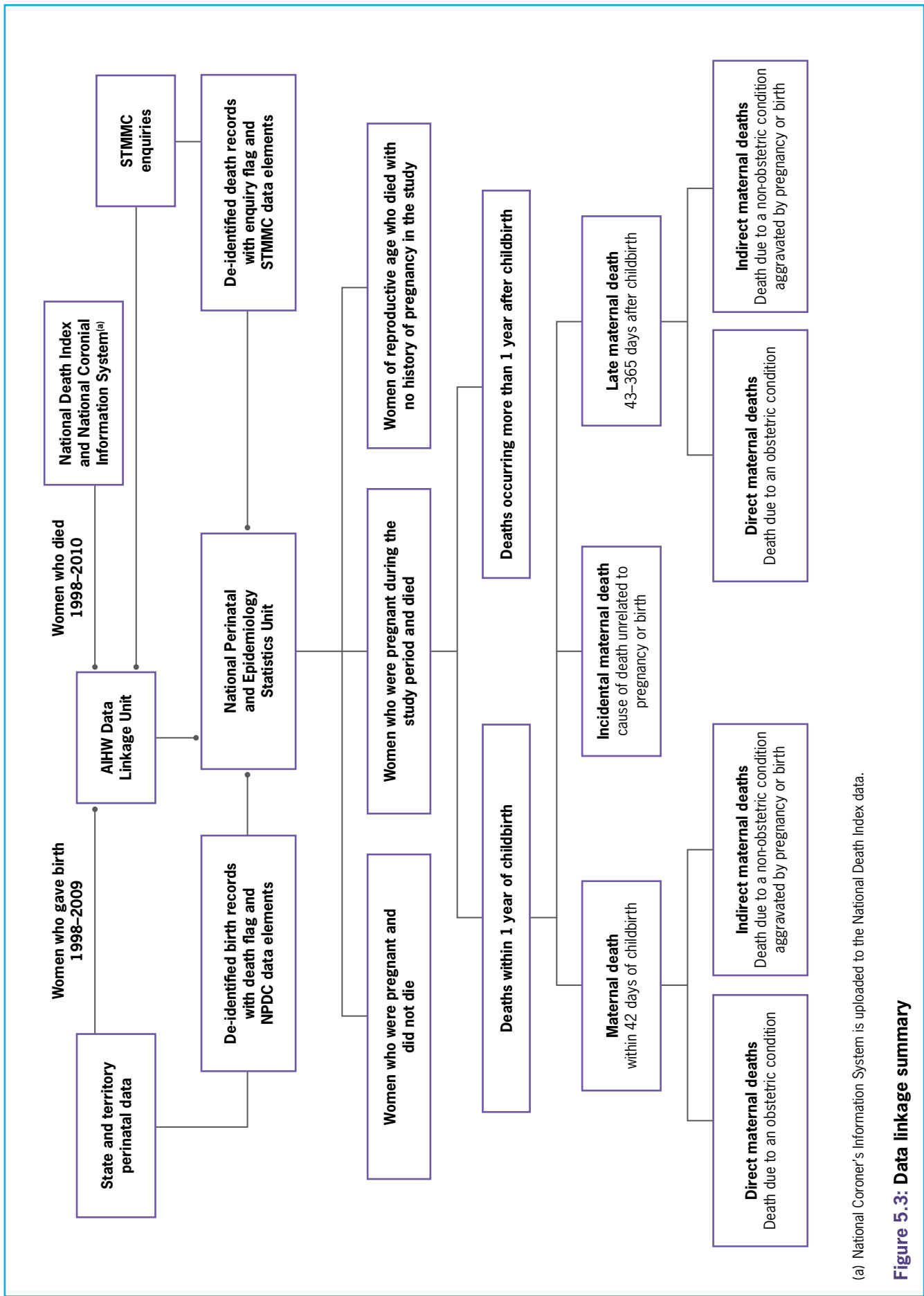
(a) National Coroner's Information System is uploaded to the National Death Index data.

5.4 Investigation of a common approach to reporting national perinatal mortality data

Options have been investigated for standardised national reporting of perinatal mortality, using data from the NPDC and other data sets containing information about perinatal deaths. Perinatal deaths are stillbirths (also known as fetal deaths) and neonatal deaths (deaths of liveborn babies up to the age of 28 days). These sentinel events in maternity care point to the health and wellbeing of women and the care they received during pregnancy and childbirth.

There were 2,609 perinatal deaths reported in Australia in 2010. This equates to 1 in every 115 women giving birth (ABS 2012).

There is currently no nationally standardised data collection that allows comprehensive reporting of perinatal mortality in relation to maternity services. An issues paper on the feasibility of, and way forward for, national perinatal mortality reporting is available in *National perinatal mortality data reporting project: issues paper, October 2012—Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1*, accessed at <http://www.aihw.gov.au/>, and a summary provided here.

Current collection and reporting mechanisms

Jurisdictional collection and reporting

Perinatal mortality reporting is undertaken in all jurisdictions. Data sources used in the ascertainment of perinatal deaths vary between jurisdictions, as does the level and scope of reporting. Perinatal mortality may be included with reports that focus on mortality, with or without maternal mortality included, or may be a chapter in the jurisdiction's birth report. Each jurisdiction also has, or is instituting, a committee process for multidisciplinary review of all perinatal deaths. These committees review clinical information regarding perinatal deaths, including the results of post-mortem investigations, and assign a classification of cause of death using the Perinatal Society of Australia and New Zealand (PSANZ) classification system. Procedures for perinatal death reviews and reporting vary between jurisdictions, reflecting differences in the size of their populations, legislative arrangements and possibly also the resources available for these activities.

National collection and reporting

Currently, there are two independent systems for national perinatal death data collection and reporting that operate in Australia: the ABS vital registration data collection and the NPDC. These collections are separately reported, and are not reconciled as a matter of course, and because their underlying collection methods differ, they report different numbers and causes of deaths.

ABS vital registration data

Perinatal mortality reported from vital registrations by the ABS are the official national statistics used for national performance indicators and international reporting.

Notifications of perinatal deaths are lodged with the Registrar of Births, Deaths and Marriages in each jurisdiction. Birth and death registration is mandatory but statutory forms and practices differ. However in all jurisdictions, at least two forms of notification of a death are required for full registration of a perinatal death: the Medical Certificate of Cause of Perinatal Death (MCCPD); and a statement from either the funeral director in the case of a neonatal death or from the parents in the case of a stillbirth. A perinatal death must be certified by either a doctor using the MCCPD or by a coroner. The MCCPD form separately lists maternal causes and fetal causes of death, and may specify the main cause of death. If a main cause is not specified, the first-listed condition on the certificate is used. The MCCPD is usually completed soon after death and does not take into consideration later findings from post-mortem pathology or autopsy results.

Only information about fully registered deaths is sent to the ABS, although the Registrar of Births, Deaths and Marriages will partially register a death if some, but not all, information is received. Details of fully registered deaths, including information from the MCCPD are sent to the ABS where coding of cause of death is carried out. These data are coded to the International Classification of Diseases, Tenth Revision (ICD-10; WHO 1992).

The ABS reports these data annually in its *Causes of death, Australia* series (see ABS cat. no. 3303.0).

The NPDC

Data for the NPDC are collected by states and territories as part of their perinatal data collections (see Section 1.2 of this report). Stillbirths are reported as a mandatory data element as part of the Perinatal NMDS, but neonatal death, age at neonatal death, cause(s) of death and autopsy status are voluntary data elements supplied by most, but not all, jurisdictions.

Information in the NPDC about neonatal deaths is known to be incomplete as there may be no knowledge of deaths that occur outside the birth hospital. There is currently no facility to update the collection with information about deaths that are notified at a later date.

The AIHW reports perinatal deaths annually in its *Australia's mothers and babies* publications.

The ABS and NPDC reporting processes are illustrated in Figure 5.4.
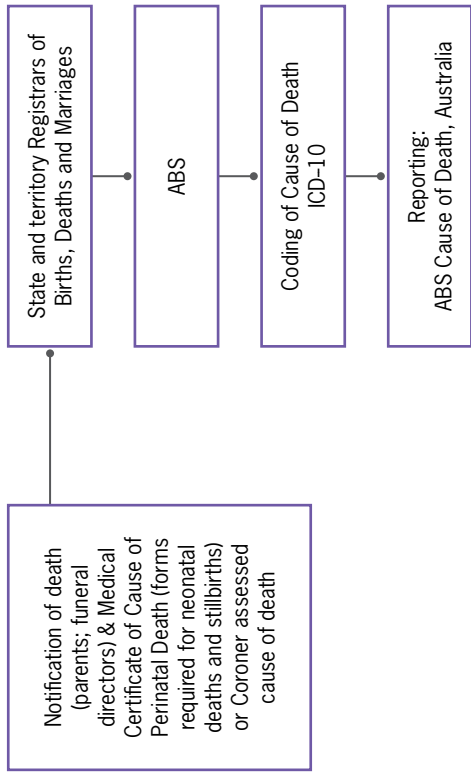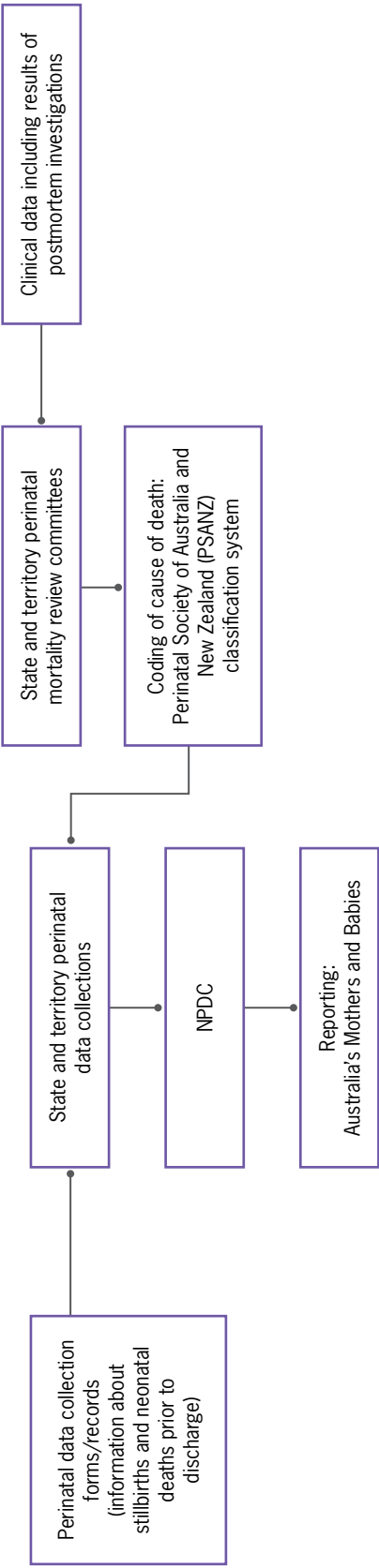
Figure 5.4: Jurisdictional and national perinatal mortality collection, review and reporting

VITAL REGISTRATIONS

State and territory Registrars of Births, Deaths and Marriages

ABS

Coding of Cause of Death
ICD–10

Reporting:
ABS Cause of Death, Australia

Notification of death (parents; funeral directors) & Medical Certificate of Cause of Perinatal Death (forms required for neonatal deaths and stillbirths) or Coroner assessed cause of death

PERINATAL DATA COLLECTION

State and territory perinatal data collections

NPDC

Reporting:
Australia's Mothers and Babies

Perinatal data collection forms/records (information about stillbirths and neonatal deaths prior to discharge)

State and territory perinatal mortality review committees

Coding of cause of death: Perinatal Society of Australia and New Zealand (PSANZ) classification system

Clinical data including results of postmortem investigations

Considerations for national perinatal mortality reporting

Ascertainment

Incomplete data

The use of different reporting methods by the ABS (vital registrations) and the AIHW (NPDC) obscures the differences in the numbers of perinatal deaths available for national reporting from these two sources. When data are aggregated over several years, it becomes apparent that ABS perinatal data do not include information about 15% of stillbirths and the NPDC data are missing information for about 8% of neonatal deaths.

Cross-border issues

Provision needs to be made for transfer of information for neonates who die in a state/territory other than that of their birth to avoid under-reporting. There is no standard process for notification and review when a perinatal death occurs in a different jurisdiction to where the baby was born, resulting in patchy coverage of these deaths. These cross-border-flow cases are often not reported to the health authority in which the babies were born and, together with different jurisdictional definitions of what constitutes a reviewable death, contributes to some neonatal deaths being excluded from review.

Classification and coding cause of death

The ICD is the recognised standard for national and international mortality classification. The ICD code applied to registered cause of death by ABS is reported nationally in Australia and used for comparisons between countries. However, there are recognised limitations in the ICD classification. ICD-10 codes are not always easily applied to stillbirths due to the range and detail of codes available. The registered cause of death, which is determined from information available at the time of death, often needs to be revised as results of post-mortem investigations become available, but depends on the clinician notifying amendments to the Registrar of Births, Deaths and Marriages, who notifies ABS of the change.

The PSANZ classification is applied by clinicians following a review of all the results related to a perinatal death, as this provides more clinically relevant information and descriptions of the death. The PSANZ cause of death classification is used by perinatal review committees in all Australian states and territories.

Both PSANZ and ICD coding have value in their respective arenas to provide information on the cause of death. The feasibility of dual reporting, using PSANZ and ICD, would have to be further explored but would increase the utility of a national perinatal mortality report.

New Zealand experience

Recent New Zealand experience of instituting a system for reporting perinatal mortality can inform the development of perinatal mortality reporting in Australia. In New Zealand, a national perinatal death data set is compiled using data from a number of sources. New Zealand uses the PSANZ classification system for reporting perinatal deaths. Critical to the success of New Zealand mortality reporting processes, for both maternal and perinatal deaths, has been the legislation put in place to support data supply and review, with legal privilege status protecting the proceedings and significant penalties in place if requests for information are not adhered to.

Developing an integrated perinatal mortality data collection

The number of data items specific to perinatal death needed for national reporting purposes is relatively small: place of death; timing of fetal death in relation to onset of labour; age in hours and days at neonatal death; and cause of death.

Consultation with stakeholders, including the NMDDP Advisory Group, confirmed that the best way for developing an integrated perinatal mortality data collection nationally is to extend the Perinatal NMDS to include standardised perinatal mortality data items. Information about perinatal deaths is already voluntarily provided by most jurisdictions for the NPDC, including PSANZ cause of death. Delayed supply of these items could be agreed so that the timeliness of the main collection is not compromised.

Stakeholders agreed that the most important factor was the standardisation of data collected across jurisdictions. A degree of standardisation of the process for investigation of the causes of death and examination of preventability issues is also necessary. There need to be strategies in place for ensuring complete ascertainment of perinatal deaths, determination of cause of death using multidisciplinary review of all clinical and post-mortem information and the means to integrate later supply of perinatal deaths data with births data.

There was universal support from jurisdictional, professional and clinical stakeholders for a national perinatal mortality report.

5.5 Improving the availability of maternity data

Currently, the main purpose of the NPDC is to report at a national and, to a lesser extent, jurisdictional level in the annual *Australia's mothers and babies* reports. However, given the potential of data to feed into improvements to the quality of maternity care, making these data more readily available could assist services to more easily identify and respond to their local needs.

Options for local-level reporting of maternity data items were explored. 'Local level' in this context was defined as including lower geographical levels, such as regions, or administrative levels (Medicare Locals; Local Hospital Networks; hospital peer groupings) or individual hospitals. Several existing reporting models were reviewed to see whether they might provide useful structures or processes that could be adapted for local-level reporting of maternity data.

The models were found to be quite different. The purpose of some was continuous quality improvement, while others were for benchmarking or for performance monitoring. Most provided information down to the individual service or hospital level, although some of this information was not publicly available. Such information allows hospitals or services to compare their performance with other hospitals or services in their peer group and to an average for all participating hospitals or services, which may help to identify areas for investigation and possible improvements in practice.

Jurisdictional stakeholders were consulted about the current reporting of clinical indicators at the local level in their state or territory. Several jurisdictions already report at a local health district and/or hospital level, however this reporting varies considerably across jurisdictions in terms of its scope and availability. The New South Wales Ministry of Health publishes hospital-level data for clinical indicators in its *New South Wales mothers and babies* report (for example, Centre for Epidemiology and Evidence 2012). The Department of Health Victoria publishes hospital level data for 16 indicators in its *Victorian maternity services performance indicators* reports (for example, Department of Health, Victorian Government 2010). Others have a more limited set of indicators that they report for selected hospitals or report at the health administrative area level. Jurisdictions will usually provide confidential reports to individual hospitals on request.

When jurisdictional stakeholders were asked whether they supported the idea of national coordination and reporting of hospital-level maternity data reporting, they expressed limited support for this, with a number of issues being raised, including:

- attaining appropriate clearance from hospitals and data custodians
- maintaining the confidentiality of detailed data and hospital profiles
- duplication of reporting; that is, a number of hospitals already participate in other indicator reporting, such as that done by Women's Healthcare Australasia (see <http://women.wcha.asn.au>) and the Australian Council on Healthcare Standards (see <http://www.achs.org.au>).

- hesitation of private hospitals to be included, generally due to resource implications
- timeliness and frequency of updates to data affect the ability of local services to respond to unfavourable trends and change outcomes.

Nationally coordinated hospital-level reporting of maternity data therefore appears to be some way off. However, with so much variation in current reporting, there may be scope for national reporting of selected maternity data items by a range of local-level categories. A web-based platform could make up-to-date maternity information readily available.

Investigation of such a product has begun using the set of 10 National Core Maternity Indicators (see Appendix C). Data are available on the AIHW website in an interactive data portal. Currently, this provides national data disaggregated by state, size of hospital, public/private sector, Indigenous status, socioeconomic status and remoteness (see <http://www.aihw.gov.au/ncmi>).

Over time, a web portal could be extended to include reporting of the National Core Maternity Indicators and other maternity data from the NPDC with disaggregation at regional levels (for example, ABS statistical areas; Medicare Locals) or groups of hospitals (such as peer groupings) and eventually, with appropriate agreements, privacy and confidentiality checks in place, to individual hospitals.

6 Conclusions

The NMDDP Stage 1 laid the foundations for enhanced national maternity data collection through:

- identifying and prioritising data gaps and inconsistencies in the existing NPDC and developing a plan to address them
- developing a classification system for defining models of maternity care that has broad support from key stakeholders
- achieving progress towards national agreement on standardised reporting of maternal mortality, collaborating on a national maternal mortality report for 2006–10, and piloting a data linkage study to achieve better ascertainment of maternal deaths
- progressing towards standardised national data collection and reporting for perinatal deaths.

The project's long-term goal is to expand the existing Perinatal NMDS significantly. Investigations during the course of the project revealed this was the only way to ensure the implementation of new data items in jurisdictional perinatal data collections. The project also aims to develop new data collections, such as the Models of Care DSS, to complement and integrate with existing systems.

Respondent burden for the enhanced maternity data collection will be minimised by a phased introduction of new standardised data items, which will be included in a Perinatal DSS. This will allow data development work, such as reaching agreement on national definitions, and developing national standards to proceed while concurrently jurisdictions can investigate the most efficient ways of incorporating these items into their forms and systems, and any implications for education and training among clinicians. In the meantime, AIHW will also progress complex and lengthy development work for data items, such as 'screening for domestic violence'.

Much work remains to be done to bring an enhanced national maternity data collection to fruition. With the assistance of relevant experts, and the collective and continued commitment of government, maternity service providers and jurisdictional health authorities, enhanced data collection will provide a richer and stronger evidence base so that maternity service delivery and maternal and perinatal outcomes can be monitored reliably and improved over time.

Appendix A: Perinatal National Minimum Data Set

Table A1: Perinatal NMDS items[a]

Metadata item	METeOR identifier
Birth event—anaesthesia administered indicator, yes/no code N	495466
Birth event—analgesia administered indicator, yes/no code N	495381
Birth event—birth method, code N	295349
Birth event—birth plurality, code N	269994
Birth event—birth presentation, code N	299992
Birth event—labour onset type, code N	269942
Birth event—setting of birth (actual), code N	269937
Birth event—state/territory of birth, code N	270151
Birth event—type of anaesthesia administered, code N[N]	422383
Birth event—type of analgesia administered, code N[N]	471867
Birth—Apgar score (at 5 minutes), code NN	289360
Birth—birth order, code N	269992
Birth—birth status, code N	269949
Birth—birth weight, total grams NNNN	269938
Episode of admitted patient care—separation date, DDMMYYYY	270025
Establishment—organisation identifier (Australian), NNX[X]NNNNN	269973
Female (mother)—postpartum perineal status, code N[N]	423659
Female (pregnant)—number of cigarettes smoked (per day after 20 weeks of pregnancy), number N[NN]	365445
Female (pregnant)—tobacco smoking indicator (after twenty weeks of pregnancy), yes/no code N	365417
Female (pregnant)—tobacco smoking indicator (first twenty weeks of pregnancy), yes/no code N	365404
Female—number of antenatal care visits, total N[N]	423828
Person—area of usual residence, statistical area level 2 (SA2) code (ASGS 2011) N(9)	469909
Person—country of birth, code (SACC 2011) NNNN	459973
Person—date of birth, DDMMYYYY	287007
Person—Indigenous status, code N	291036
Person—person identifier, XXXXXX[X(14)]	290046
Person—sex, code N	287316
Pregnancy—estimated duration (at the first visit for antenatal care), completed weeks N[N]	379597
Product of conception—gestational age, completed weeks N[N]	298105

(a) For details of the Perinatal NMDS 2013–14, see the METeOR webpage <http://meteor.aihw.gov.au/content/index.phtml/itemId/489433>.

The National Perinatal Data Collection (NPDC) consists of data items collected as part of the Perinatal National Minimum Data Set (NMDS) and a number of voluntary items that are collected by some jurisdictions. Data items that are part of the Perinatal NMDS are collected by all states and territories according to mandated national data definitions. However, definitions can vary markedly for voluntary data items. This means that some data cannot be aggregated to provide a national picture. For example, maternal morbidity conditions such as hypertension are collected and reported by all jurisdictions, however Figure B1 shows that the rate of gestational hypertension, as reported to the NPDC, varies markedly across jurisdictions. Two years of data are provided to allow the inclusion of Victoria which could not report these data more recently due to an information system transition. There is no attempt here to explain differences between the two reporting periods within jurisdictions however ACT

supplied information to say that the increase in rates in the ACT between 2008 and 2011 likely reflects improved matching to obtain missing information from the Admitted Patient Care (APC) data in 2011.

Different definitions and terminology are used for gestational hypertension. There is lack of consistency also in the time periods for hypertension to be 'pre-existing', such as 'first half of pregnancy', 'before 24 weeks' and 'before 20 weeks'. In some jurisdictions, there is no distinction between gestational hypertension and pre-eclampsia, and in Western Australia, the data item gestational hypertension is not specified for collection. Different definitions may not be the only reason for differing rates, however there is no obvious explanation for different population rates for these conditions, particularly across the larger population jurisdictions.

Rate per 1,000 women who gave birth

Notes

1. Because of differences in definitions and methods used for data collection, these data are not comparable across jurisdictions.
2. In Western Australia, gestational hypertension was not specified for collection during the period shown, which is reflected in the rates presented.
3. Data not available for Victoria for 2011.

Source: Laws et al. 2010; Li et al. 2013.

Figure B1: **Gestational hypertension by state and territory, 2008 and 2011**

Figure B2 shows that the reported rates of postpartum haemorrhage vary significantly across the states and territories. This is not surprising, given the different definitions used in the jurisdictions as shown in Table B1. New South Wales rates differ to those of other states because of the narrow definition based on blood transfusion exclusively. Variations may also be caused by the different blood volume thresholds used to report a blood loss as PPH e.g. in Queensland, 600 mL and in South Australia, 500mL; and a loss of 500mL associated with caesarean section may be defined as a PPH in some settings and not others. Some rates may reflect the 'true' population rate of this condition; for example, the high rate in the Northern Territory may reflect a high proportion of complex births among the Indigenous population.

Notes
1. Because of differences in definitions and methods used for data collection these data are not comparable across jurisdictions.
2. May include primary and secondary postpartum haemorrhage.
3. Data not available for Victoria for 2011.
Source: Laws et al. 2010; Li et al. 2013

Figure B2: Postpartum haemorrhage by state and territory, 2008 and 2011
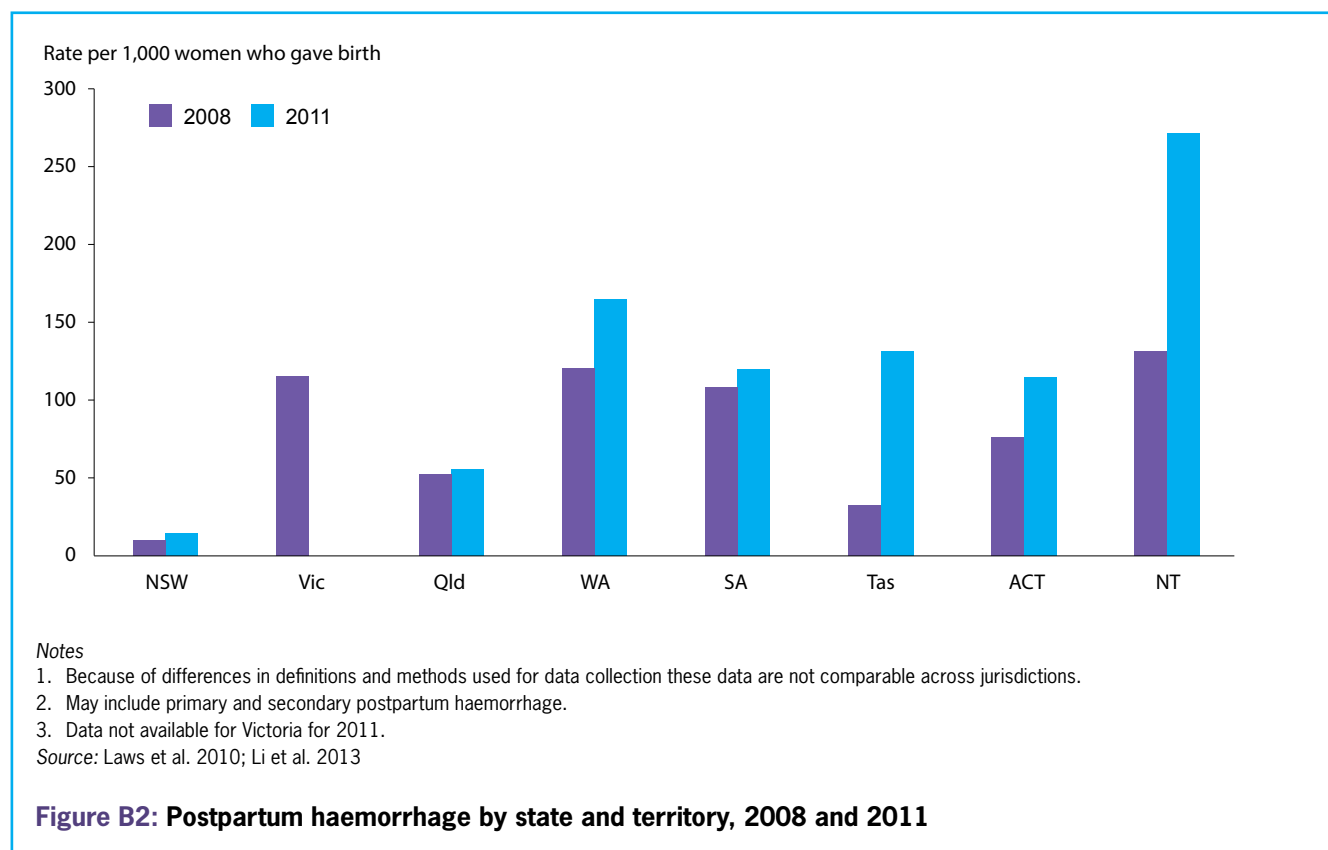
Table B1: Postpartum haemorrhage response categories used in jurisdictions

Response category	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Postpartum haemorrhage (PPH) requiring blood transfusion—no units specified	X	X						
Open numeric field—mL		X						
PPH/Blood loss—one volume category for >500 mL or ≥500 mL[a]				X		X	X	X
PPH/Blood loss (mL)—with 2 or more volume categories			X[b]		X[c]			
Notes								
Can distinguish between severe and non-severe [d]		X	X		X			
Also collects secondary PPH				X				

(a) Without specifying volume categories, it is not currently possible to distinguish severe PPH from PPH (except in Victoria where there is an open numeric field for entering the volume in mL).

(b) Queensland collects primary PPH with volume categories of 500–999 mL and ≥1,000 mL under *Labour and delivery complications* but collects secondary PPH under *Discharge details* with only a tick box and no volume.

(c) South Australia collects primary PPH with volume categories of 600–999 mL and ≥1,000 mL.

(d) This depends on how 'severe' is defined. For the purposes of the table above, 'severe' is ≥1,000 mL and non-severe is <1,000 mL.

Appendix C: National Core Maternity Indicators

The National Core Maternity Indicators are a set of 20 maternity indicators that are recommended for national reporting (Table C1). They are the result of extensive consultation and refinement and have been endorsed by the Australian Health Ministers' Advisory Council (AHMAC). The indicators will assist with improving the quality of maternity services in Australia by establishing baseline data for future monitoring and evaluation of practice change.

A report was published in 2013 (AIHW NPESU & AIHW 2013) on the first 10 indicators for which standardised national data are available. Indicators 11–20 require further data development. The AIHW commenced investigatory work in 2013 for indicators 11 to 18 and a report of the findings will be released later in 2014. Indicator 19 has been partially met through the Australian National Infant Feeding Survey. Indicator 20: Models of care is being progressed through the NMDDP (see chapter 3).

Table C1: National Core Maternity Indicators

No.	Indicator
1	Smoking in pregnancy for all women giving birth
2	Antenatal care in the first trimester for all women giving birth
3	Episiotomy for women having their first baby and giving birth vaginally
4	Apgar score of less than 7 at 5 minutes for births at term
5	Induction of labour for selected women giving birth for the first time
6	Caesarean section for selected women giving birth for the first time
7	Non-instrumental vaginal birth for selected women giving birth for the first time
8	Instrumental vaginal birth for selected women giving birth for the first time
9	General anaesthetic for women giving birth by caesarean section
10	Small babies among births at or after 40 weeks gestation
11	High risk women undergoing caesarean section who receive appropriate pharmacological thromboprophylaxis
12	Babies born ≥37 completed weeks gestation admitted to a neonatal intensive care nursery or special care nursery for reasons other than congenital anomaly
13	Third and fourth degree tears for (a) all first births and (b) all births
14	Significant blood loss of (i) > 1,000 mL and < 1,500 mL and (ii) ≥ 1,500 mL during first 24 hours after the birth of the baby (i.e. major primary PPH) for (a) vaginal births and (b) caesarean sections
15	Women having their second birth vaginally whose first birth was by caesarean section
16	Separation of baby from the mother after birth for additional care
17	One-to-one care in labour
18	Caesarean sections without compelling medical indication <39 weeks (273 days)
19	Supporting breastfeeding
20	Models of care

Appendix D: Members of groups and committees as at June 2013

Table D1: NMDDP Advisory Group members

Name	Organisation/expertise
Dr Fadwa Al-Yaman (Chair)	Australian Institute of Health and Welfare
Ms Sue Cornes	Chair, National Perinatal Data Development Committee
Professor Caroline Homer	Clinical expert—midwifery
Ms Ann Kinnear	Australian College of Midwives
A/Professor Michael Nicholl	Clinical expert—obstetrics
Professor Jeremy Oats	Maternity Services Inter-jurisdictional Committee
Professor Michael Permezel	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
Ms Melinda Petrie	Australian Institute of Health and Welfare
Professor Elizabeth Sullivan	National Perinatal Epidemiology and Statistics Unit
Ms Nicole Symes	Department of Health[a]
Ms Meredeth Taylor	Department of Health[a]

(a) Inaugural Department of Health and Ageing (now the Department of Health) representatives were Ms Sharon Appleyard and Ms Bronia Rowe. Other members have included Dr Masha Somi and Ms Hope Darby.

Table D2: NMDDP Clinical and Data Reference Group members

Name	Organisation/expertise
Dr Fadwa Al-Yaman	Australian Institute of Health and Welfare
Ms Mary Beneforti	Australian Institute of Health and Welfare
Ms Helen Cooke	Australian College of Midwives
Ms Sue Cornes	Chair, National Perinatal Data Development Committee
Dr Lisa Hilder	National Perinatal Epidemiology and Statistics Unit
Dr Janet Hornbuckle	Expert in maternal fetal medicine
Ms Maureen Hutchinson	Western Australian Department of Health
A/Professor Michael Nicholl	Clinical expert—obstetrics
Professor Jeremy Oats (Chair)	Maternity Services Inter-jurisdictional Committee
Professor Michael Permezel	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
Ms Melinda Petrie	Australian Institute of Health and Welfare
Professor Elizabeth Sullivan	National Perinatal Epidemiology and Statistics Unit
Ms Desley Williams	Northern Territory midwife

Table D3: National Perinatal Data Development Committee members

Name	Organisation/expertise
Mr Andrew Affleck	Australian Bureau of Statistics
Dr Fadwa Al-Yaman	Australian Institute of Health and Welfare
Ms Bhanu Bhatia	Northern Territory
Ms Sue Cornes (Chair)	Queensland
Ms Danielle Cosgriff	Victoria
Dr Mary-Ann Davey	Victoria
Ms Joanne Ellerington	Queensland
Ms Louise Freebairn	Australian Capital Territory
Dr Lisa Hilder	National Perinatal Epidemiology and Statistics Unit
Mr Paull Hoffmann	Australian Bureau of Statistics
Ms Maureen Hutchinson	Western Australia
Mr Alan Joyce	Western Australia
Ms Zhuoyang Li	National Perinatal Epidemiology and Statistics
Mr Elvis Maio	New South Wales
Mr Peter Mansfield	Tasmania
Ms Lee O'Neill	Northern Territory
Ms Melinda Petrie (secretariat)	Australian Institute of Health and Welfare
Dr Wendy Scheil	South Australia
Ms Joan Scott	South Australia
Ms Rosalind Sexton	Australian Capital Territory
Ms Diana Stubbs	Victoria
Professor Elizabeth Sullivan (Deputy Chair)	National Perinatal Epidemiology and Statistics Unit
Dr Lee Taylor	New South Wales

Table D4: National Maternal Mortality Advisory Committee

Name	Organisation/expertise
Dr Fadwa Al-Yaman	Head, Social and Indigenous Group, Australian Institute of Health and Welfare
Dr Peter Chapman	Maternity Services Inter-jurisdictional Committee
A/Professor Amanda Dennis	Chair, Tasmanian Council of Obstetric & Paediatric Mortality & Morbidity Maternal Mortality Subcommittee
Professor Jodie M Dodd	Chair, South Australian Maternal & Neonatal Clinical Network
Ms Kate Dyer	Australian College of Midwives, with expertise in maternal mortality and high-risk pregnancy
Professor David Ellwood	Chair, Australian Capital Territory Maternal Perinatal Data Collection
Professor Cynthia Farquhar	Chair, Perinatal and Maternal Mortality Review Committee New Zealand
Professor Michael Humphrey	Chair, Queensland Maternal and Perinatal Quality Council
Dr Jenny Hunt	National Aboriginal Community Controlled Health Organisation (NACCHO)
Ms Rebecca Jenkinson	Consumer representative, The Maternity Coalition
A/Professor Steven Katz	Associate Professor, Australian and New Zealand College of Anaesthetists
Professor Yee Khong	The Royal College of Pathologists Australasia
Ms Ann Kinnear	Executive Officer, Australian College of Midwives
Professor Marie-Paule Austin	The Royal Australian and New Zealand College of Psychiatrists
Ms Rachael Lockey	Midwifery Co-Director Integrated Maternity Services, Northern Territory Department of Health and Families
Dr Karin Lust	Council Member, Society of Obstetric Medicine Australia and New Zealand
Dr Nhi Nguyen	The College of Intensive Care Medicine
Professor Jeremy Oats	Victorian Consultative Council on Obstetric and Paediatric Mortality and Morbidity; Representative for Maternity Services Inter-jurisdictional Committee
Professor Michael Permezel	Victorian Consultative Council on Obstetric and Paediatric Mortality and Morbidity
A/Professor John Smoleniec	New South Wales Perinatal and Maternal Mortality Committee
Professor Elizabeth Sullivan (Chair)	Director, National Perinatal Epidemiology and Statistics Unit
Clinical A/Professor Barry Walters	The Royal Australian and New Zealand College of Obstetrics and Gynaecology and Western Australian Perinatal and Infant Mortality Committee

Table D5: Nomenclature for Models of Care Working Party

Name	Organisation/expertise
Dr Fadwa Al-Yaman	Australian Institute of Health and Welfare
Ms Hazel Brittain (1/5/12–12/11/12)	Maternity Services Inter-jurisdictional Committee
Ms Joanne Ellerington	Expert—health information management
Ms Natasha Donnolley	National Perinatal Epidemiology and Statistics Unit
Dr Lisa Hilder	National Perinatal Epidemiology and Statistics Unit
Prof Caroline Homer	Expert—midwifery
Ms Rachael Lockey	Expert—working with Aboriginal and Torres Strait Islander women
Dr Belinda Maier	Maternity Services Inter-jurisdictional Committee
Mr Peter Mansfield	National Perinatal Data Development Committee
A/Prof Michael Nicholl	Expert—obstetrics
Ms Margaret O'Brien	Indigenous representative—Danila Dilba Health Service
Professor Michael Permezel	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
Ms Melinda Petrie	Australian Institute of Health and Welfare
Ms Ann Robertson (until 11/2/12)	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
Ms Anne Robertson (until 1/5/12)	Maternity Services Inter-jurisdictional Committee
Dr Ruth Stewart	Australian College of Rural and Remote Medicine
Prof Elizabeth Sullivan (Chair)	National Perinatal Epidemiology and Statistics Unit
Ms Jocelyn Toohill	Australian College of Midwives

Appendix E: The Maternity Information Matrix

The Maternity Information Matrix or MIM was first developed in 2010 and then updated for the National Maternity Data Development Project (NMDDP) and published as an online resource in February 2012, reflecting data collection practices as at July 2011. A new version reflecting data collection practices as at July 2013 will be released in 2014 and will be available at <www.maternitymatrix.aihw.gov.au>. The following screenshots (figures E1–E3) provide some examples of components of the MIM as they will appear in the new version.
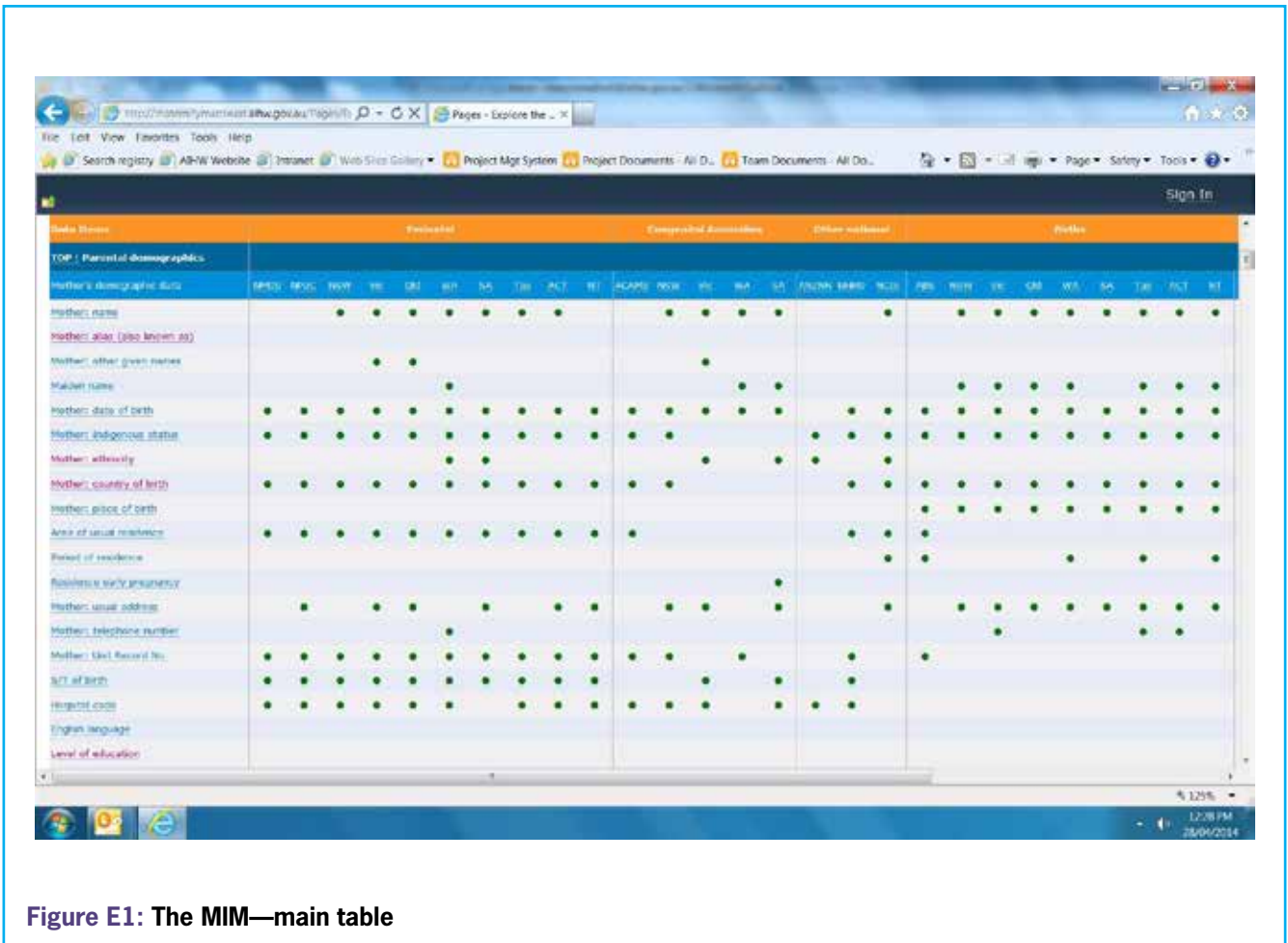
Figure E1: The MIM—main table
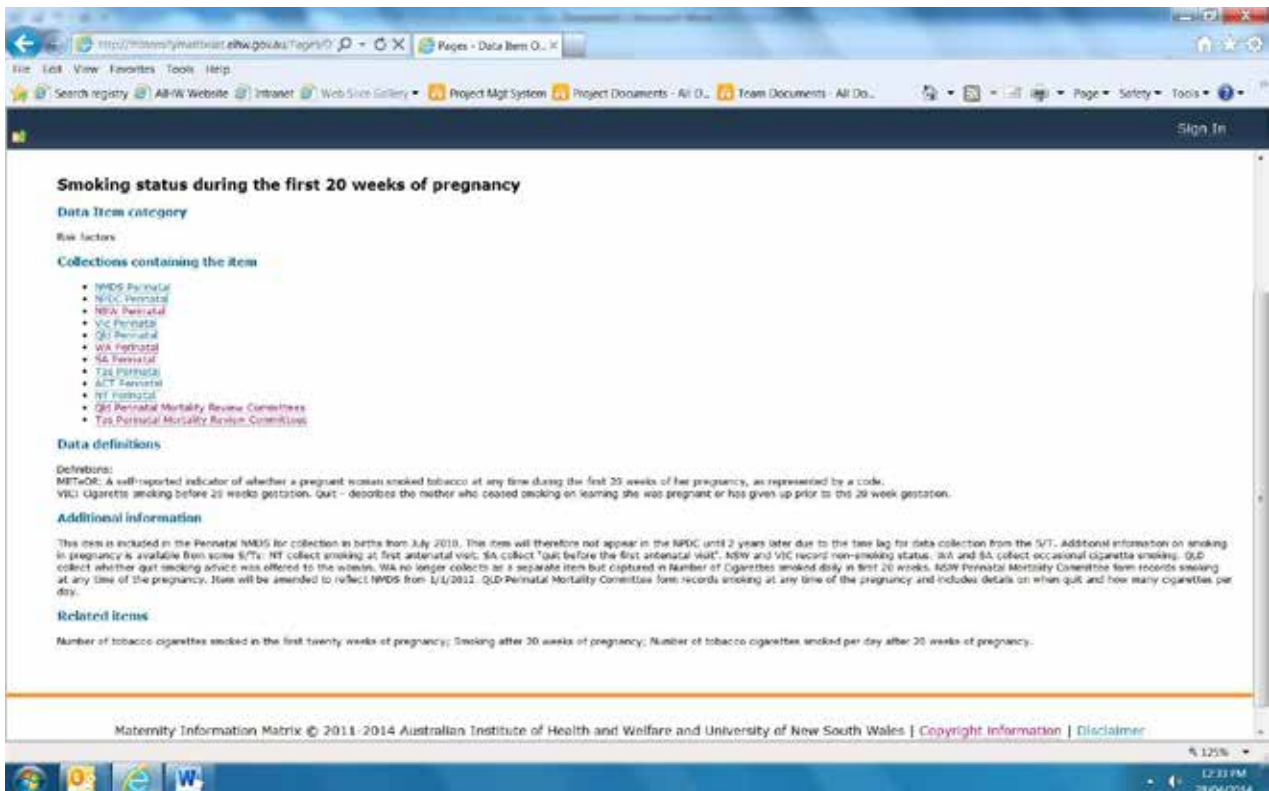
Figure E2: A sample metadata page from the MIM
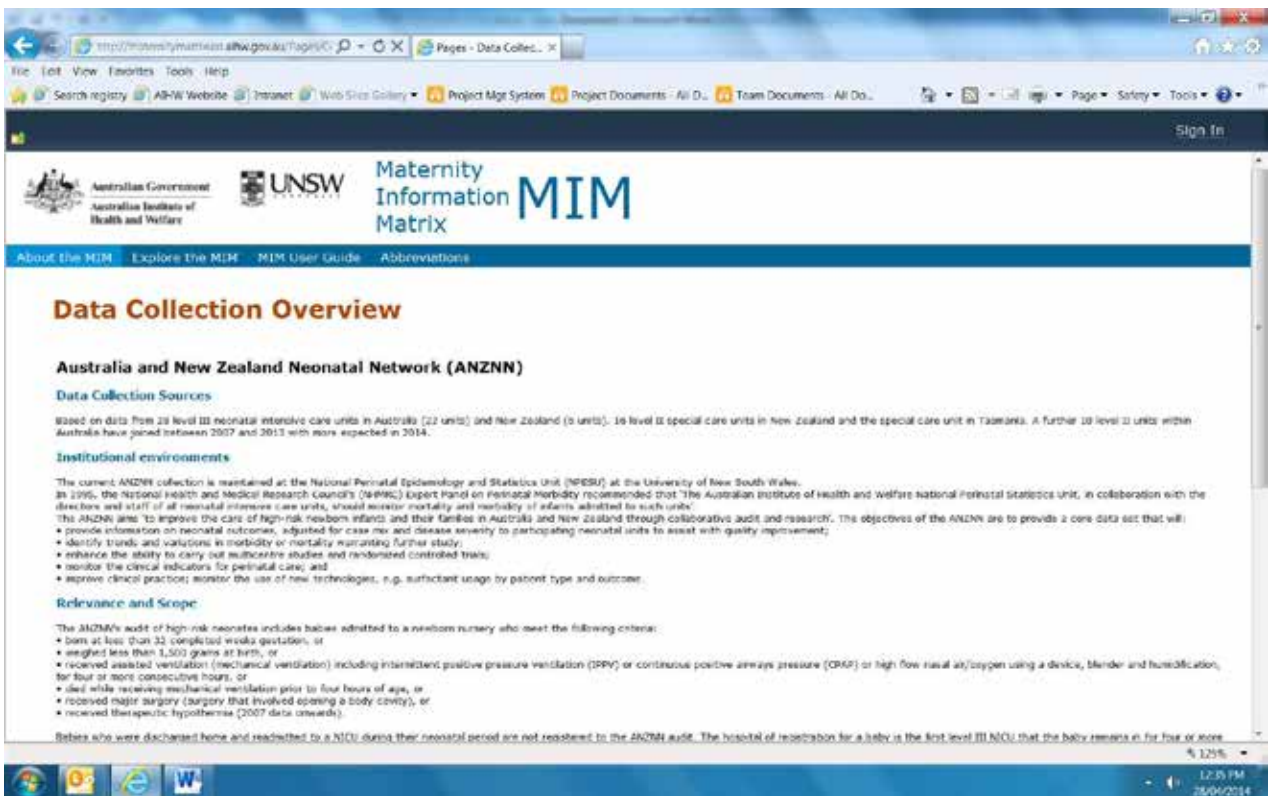
Figure E3: A sample data collection overview

Appendix F: National information needs— summary from the desktop review

The items and topic areas in tables F1 to F12 were sourced from the desktop review and formed the basis for the stakeholder questionnaire (see Appendix G), the results of which were used to draft the National Maternity Data Development Project (NMDDP) priority data item list (see Chapter 2). Data items in bold font in the tables represent broad areas for which more detailed stakeholder input was sought.

Table F1: Demographics

Data item	Rationale	Data collection issues
Ethnicity of parents	Ethnicity can be used to study equity of access to health care and outcomes and provides more specific information than just country of birth. For example, an increase in the caesarean section rate has been recorded in the Australian immigrant population, particularly women from South-East Asia. This may be due to a number of factors, including altered diet, higher rates of gestational diabetes, and genetic influences on fetal size where parents are of different ethnic origins.	Country of birth is collected for mothers in the Perinatal National Minimum Data Set (NMDS). The issue is whether country of birth is specific enough or if ethnicity should be captured in other data, or in addition to country of birth. Ethnicity can be considered to indicate lifestyle and can be distinct from country of birth. For example, a women may have been born in Australia but follow the cultural practices of her parents' area of origin. One state collects ethnicity of both parents. However, paternal information on ethnicity and country of birth is lacking.
Maternal education	It could be useful to control for this variable in analyses as there is evidence to suggest that higher maternal education is associated with better outcomes for mother and baby.	Maternal education is currently not collected in any jurisdictional perinatal data collection or any other maternity data collection.
Maternal occupation	Maternal occupation is currently not included in any perinatal data collection and therefore cannot be routinely controlled for in analyses. Occupation is related to education and income which are both social determinants of health.	Only one jurisdiction includes information about maternal occupation. However, this information is captured in births and deaths registrations, so opportunities for data linkage may exist.
Maternal main language spoken at home	An indicator of cultural background and potential cultural barriers and communication issues which may indicate equity in access to services. Such information potentially assists to assess the need for interpreter services to ensure that women of culturally and linguistically diverse (CALD) backgrounds can make informed decisions about their health care.	This is not collected in the perinatal data collections. A variable around whether English is the main language spoken at home is collected in the Australasian Maternity Outcomes Surveillance System.
Maternal English language proficiency	As above. Proficiency in the English language may affect access to services as well as understanding of information communicated by clinicians and others about pregnancy and labour.	This is not collected in the perinatal data collections. A variable around English language proficiency is collected by the Queensland Maternal and Perinatal Quality Council.
Paternal demographics	Father's socioeconomic, language background or Indigenous status may influence outcomes for mother and baby.	Information on paternal age, address, occupation and Indigenous status are potentially relevant. Paternal obesity may also be important as some early research shows it may affect fertility. Paternal age and obesity have also been linked to birth defects. Some states collect some items about the father. Some of this information can also be obtained through linkage to birth registration data.

Table F2: **Maternal characteristics**

Data item	Rationale	Data collection issues
Maternal height	Maternal obesity is a significant risk factor for adverse outcomes for both mother and baby during pregnancy and childbirth, e.g. gestational diabetes; thromboembolism; hypertension; risk of operative births, including caesarean; a higher risk of fetal death; birth injury; admission to neonatal intensive care unit; and a higher risk of childhood obesity. High body mass index (BMI) may also limit various antenatal assessments that rely on ultrasound screening, such as accurate determination of gestational age in early pregnancy and assessments of fetal growth and wellbeing in later pregnancy. On the other hand, low BMI may indicate poor nutritional status which may also put mother and baby at risk.	Some jurisdictions collect height and/or weight separately. Maternal BMI is a National Perinatal Data Collection (NPDC) item but only one jurisdiction collects it. Collecting height and weight separately may be preferable as height is a predictor of baby size and weight has practical and workforce implications. Obesity/BMI is not reported at a national level and there are limited numerical data on mortality and morbidity outcomes for obese women and their babies.
Maternal weight	As above.	As above
Maternal mental health	Identified in the National Maternity Services Plan (NMSP) and listed as action item: options for evidence-based maternity care for women receiving mental health care are developed. In addition, an outcome of the National Perinatal Depression Initiative is that there will be improved early detection of antenatal and postnatal depression (by the routine and universal screening of women during the perinatal period). This will enable early intervention for women experiencing perinatal depression.	Two jurisdictions collect information on pre-existing maternal mental health or psychosocial wellbeing. One of these jurisdictions records an Edinburgh Depression Scale score. Others may capture this through free-text fields for maternal conditions. National Perinatal Depression Initiative indicators: the proportion of the target population (e.g. women in the perinatal period) who have been screened for antenatal depression; the proportion of the target population (e.g. women in the perinatal period) who have been screened for postnatal depression.
Illicit drug use during pregnancy	Increased risk of maternal and fetal morbidity.	Women may present late in pregnancy; don't want to disclose illegal drug use; legal and other problems can complicate provision of maternity care for women who use illegal drugs. However, this can also be an opportunity to provide education and support services. Healthy for Life collects this information for services funded by the Office for Aboriginal and Torres Strait Islander Health (OATSIH).
Women offered appropriate interventions in relation to smoking	Smoking cessation interventions during pregnancy can contribute to higher rates of smoking cessation, decreased smoking relapse and increased mean birth weight of babies born to women receiving advice and assistance.	Differs to the tobacco smoking items collected in the Perinatal NMDS which capture whether the mother smoked during pregnancy before/after 20 weeks and the number of cigarettes smoked. This item is concerned with interventions in relation to smoking during pregnancy. One jurisdiction asks whether smoking cessation advice is offered to mothers.
Alcohol use during pregnancy	Risk of poorer perinatal outcomes which can lead to fetal alcohol spectrum disorders (FASD). A known teratogen.	This item is currently being developed for inclusion in the Perinatal NMDS. Further development requires consideration around issues including dose, frequency, timing and data collection method. Three jurisdictions ask about alcohol consumption and two ask the number of standard drinks per day/week.
Women in prison	Element of the NMSP—access for vulnerable women to appropriate services and models of care.	Prison may be picked up through address/usual residence as a demographic identifier.
Women experiencing domestic violence	Element of the NMSP—access for vulnerable women to appropriate services and models of care.	Currently, this may be something that is written in free-text fields, if the midwife becomes aware of it; otherwise data collection methods are unknown.
Women who have experienced genital cutting	Element of the NMSP—access for vulnerable women to appropriate services and models of care.	Currently, this may be something that is written in free-text fields, if the midwife becomes aware of it; otherwise data collection methods are unknown.

Table F3: Pre-conception and antenatal period

Data item	Rationale	Data collection issues
Pre-conception planning	Pre-conception is the time to prepare for pregnancy and parenthood. This can help reduce problems during pregnancy and assist in recovery from birth. Diet, iron and folate intake, weight, physical activity, smoking, alcohol use and pre-existing medical conditions are some factors prospective parents should talk about with their doctor.	Not collected.
Intended place of birth	Consistent information about the intended place of birth is essential to assess the safety of different models of care and places for birth. If the actual place of birth differs from the intended place of birth, this may reflect complications arising during the pregnancy. Capturing this information at the time of onset of labour is particularly critical.	Jurisdictions collect this differently—five use this item to describe the intention at onset of labour and three to describe the intention at booking. These are two different, but both useful, points of collection of this information. It is not possible to aggregate nationally to determine when a change of intention occurred. In the absence of information about why the intended place of delivery changed, it is not possible to determine whether change in intended place of birth was the choice of the pregnant woman, the result of a change in address or altered clinical circumstances. The reason for, and timing of, changes to the intended place of birth denotes a significant data gap.
Termination of pregnancy	This item is important for understanding the burden of congenital anomalies as well as in relation to the reporting of screening outcomes and perinatal deaths.	National consistency in the data would more accurately report the burden of congenital anomalies in Australia. Only two jurisdictions have mandatory reporting of terminations and, therefore, a change in legislation would be required before national reporting could be done.
Antenatal screening	Encompasses testing for a wide variety of conditions, most commonly fetal congenital anomalies, maternal infection and maternal hypertension.	There is no national policy framework or guidelines that set standards to assist in monitoring performance of antenatal-testing service providers. No data items are in the NPDC and the majority of relevant data items are not published in jurisdictional reports. Screening for Down syndrome is recorded by two jurisdictions and seven record chorionic villus sampling.
Antenatal diagnosis	Identification of a major congenital anomaly assists with planning the most appropriate place for birth and may enable early intervention to reduce the extent of potential compromise to the baby and/or assist women to make a decision regarding termination.	Some antenatal diagnoses are included in births defects registers. However, only some jurisdictions have births defects registers. Notifiable conditions vary between jurisdictions.

Table F4: Models of care

Data item	Rationale	Data collection issues
Pregnancy risk indicator	Clinical risk is an important factor in recommending the appropriate model of care for women. The NMSP states the need to have accurate assessments of clinical risk in relation to homebirth in particular. Women with certain conditions, either solely or in combination, can be 'at risk' during pregnancy as risks of maternal and perinatal morbidity and mortality are increased. Consideration of the model of care and care management plans for women who have certain risk factors guide decision-making about the appropriate place of maternity care.	There is a lack of clarity around definitions of clinical risk and what constitutes low risk. 'At risk' may relate to the following stages of conception/pregnancy and birth: – pre-conception or in early pregnancy – during the pregnancy – maternal disease – previous obstetric history – complications in present pregnancy – at labour and birth Many data items related to maternal conditions are captured in some form by some jurisdictions in their perinatal data collections. However, to categorise risk, it would be necessary to pull out various data items individually and/or combine them into a 'risk' measure.
Pregnancy care option	The NMSP has a strong focus on women's choices and about care being woman-centred; as well as identifying women at risk and safety and quality of outcomes. With accurate data, options around preferred, recommended and actual models of care could be compared to examine women's pathways through care and to analyse these in conjunction with outcomes for women and babies.	Items for preferred and recommended pregnancy care option appear on the Victorian Maternity (hand-held) Record. Capturing information about planned model of care at booking, planned at term (37 weeks) and planned at onset of labour, and comparing these with the actual model of care at the end of labour, could assist with understanding transition points in the woman's care.
Continuity of caregiver	The NMSP notes that fragmentation of care can adversely affect the maternity experience and outcomes for women and their families. Continuity of care has been identified as an important feature of maternity care in New Zealand and United Kingdom reforms.	Data are not collected in the NPDC, although some states/territories provide a free-text field for 'model of antenatal care' which may capture caseload midwifery (an indicator of continuity of care). However, there is no consistent or organised collection of the model of care.
One-to-one care in labour	This is related to continuity of caregiver and may be important for promoting and supporting vaginal birth and greater satisfaction for the mother.	One state aims to implement one-to-one care for all women experiencing their first labour or undertaking a vaginal birth after caesarean (VBAC), vaginal breech or vaginal twin birth, by 2015, however it is not known nationally how many women experience one-to-one care in labour. This field could be recorded by the midwife completing the labour ward summary.
Homebirths	There is a need to understand more about the clinical experiences and health outcomes of mothers and babies for homebirth. The outcomes should include morbidity for women who choose a home or hospital birth so that accurate comparisons can be made. Outcomes for planned and unplanned homebirths, and publicly and privately funded homebirths need further investigation.	Data limitations mean that women's choices and the outcomes of different models of care (e.g. planned homebirth) cannot be accurately tracked or reported. Accurate comparisons between women who choose homebirth early in pregnancy and those who choose hospital birth are difficult to make. Identifying planned homebirths in routine data collections is not always possible.

Table F5: Maternal morbidity

Data item	Rationale	Data collection issues
Pre-existing diabetes	Diabetes affects mother and baby in both the short and long term. Short-term risks include risk of premature delivery, macrosomic fetal growth, increased risk of miscarriage and fetal congenital malformations. Long-term effects include increased risk of cardiovascular disease and renal disease for mother and child and increased risk of developing diabetes and future obesity.in the offspring.	All jurisdictions collect data on pre-existing diabetes in the NPDC but the condition has a range of subset conditions that are not collected. This complexity is reflected in the range of terms used to describe the same condition. Also, various coding issues exist. Some jurisdictions collect information about types 1 and 2, insulin-treated, oral hypoglycaemic therapy.
Pre-existing hypertension	There is a substantially greater risk of fetal death and higher risk of caesarean section. Hypertension in pregnancy is generally associated with increased risk of obstetric haemorrhage and maternal death.	Collected as part of the NPDC, however very different rates of the condition are reported among jurisdictions and this is not explained solely in terms of population differences. This suggests a lack of standardised collection practices. Both the National Hospital Morbidity Database (NHMD) and perinatal collections under-report the condition.
Gestational diabetes mellitus	As for pre-existing diabetes above.	Reported in the NPDC by all jurisdictions. It is suggested that very different rates of the condition reported among jurisdictions are not explained solely in terms of population differences. This suggests a lack of standardised collection practices. Data can also be extracted from the NHMD. These data may be more accurate than the midwives collection, although there is concern over possible under-reporting in the NHMD.
Gestational hypertension	Hypertension in pregnancy is generally associated with increased risk of obstetric haemorrhage and maternal death.	Data specification and collection are not standard across jurisdictions, e.g. all jurisdictions collect this in the NPDC but only three distinguish between gestational hypertension and pre-eclampsia. This means that rates cannot be compared across jurisdictions.
Pre-eclampsia	Pre-eclampsia is a multi-system disorder characterised by hypertension and involvement of one or more other organ systems, and may result in fetal death.	One of the issues in data collection is the lack of distinction between this condition and other forms of less serious hypertension in pregnancy. There are large differences in reported prevalence rates.
Placenta accreta	There is progressive increasing risk of this condition with previous caesarean section.	This is a reason for caesarean section and is not collected in the NPDC but is collected in the Australasian Maternity Outcomes Surveillance System.
Postpartum haemorrhage (PPH)	A major cause of maternal death.	All jurisdictions collect this and it is an item in the NPDC, but currently there is no standardised measurement for the severity of PPH in terms of blood loss.

Table F6: **Labour**

Data item	Rationale	Data collection issues
Reasons for induction of labour	Induction of labour may increase the risk of operative vaginal birth or caesarean section. Induction of labour in nulliparous women of low risk should be unnecessary and the rate should be zero. Increasing rates of intervention, such as induction in labour, are of concern and may be related to increasing rates of late pre-term birth and other impacts on women and their babies. The NMSP states there is a need for 'agreement of identified clinical indicators for specified interventions that are compared across maternity services of the same service capability'.	Data are not comparable across jurisdictions. There is variability in both the definitions and methods used for data collection and reporting across jurisdictions, e.g. some collect psychosocial reasons. Data are only published for four states.
Lead intrapartum care provider	This may be related to exploring outcomes from various models of care.	Some jurisdictional perinatal data collections record the lead intrapartum care provider for the birth, while others collect the birth attendant only, which provides limited information on the care provided. Lead intrapartum provider is also collected through vital registrations and the perinatal death registrations.
Fetal monitoring during labour	There appears to be debate over continuous electronic fetal surveillance.	Four jurisdictions collect this information but not in the same way. Items recorded include continuous electronic fetal heart rate monitoring, fetal scalp electrode and lactate levels. There is no consistent definition of the related item of 'fetal distress'.
Vaginal birth after caesarean (VBAC)	This reflects appropriate clinical management for women with a history of primary caesarean section who are offered VBAC and/or who achieve a term vaginal birth. Reducing the number of avoidable caesarean sections minimises risks and costs associated with the intervention, such as complications in subsequent pregnancies, prolonged recovery after delivery and the small risk of serious morbidity after birth. It may be useful to distinguish between planned VBAC, attempted VBAC and achieved VBAC.	Collected by some hospitals. Clarification of the definition may be required as some hospitals may interpret this differently. It would be important to capture information not just about the most recent delivery but any previous deliveries where a caesarean was performed.
Reasons for instrumental vaginal births	The reasons for the rise in interventions and their impact on women are subjects of considerable debate.	There is currently no information in the NPDC on indication or urgency of instrumental delivery.
High-risk women undergoing caesarean section who receive appropriate pharmacological thromboprophylaxis	There is a higher risk of thromboembolism among women having caesarean section, especially if it is an emergency procedure.	Currently there is no national data source. Data are collected by some hospitals for accreditation purposes.

Table F7: Complications of labour

Data item	Rationale	Data collection issues
Fetal distress	Early detection of fetal distress may result in better neonatal outcomes. Fetal distress is a broad term and can be indicated by various signs: decreased movement felt by the mother, meconium in the amniotic fluid, increased or decreased fetal heart rate and biochemical signs in the baby such as fetal metabolic acidosis.	Currently, there is no consistent definition of fetal distress. There is a lack of consistency in the way fetal distress is collected, e.g. some states collect it in a free-text field and others as a defined field. However; most jurisdictions collect this item as both a complication arising during labour and a reason for caesarean section.
Cord prolapse	This is a rare, serious obstetric condition that may result in fetal death and is often a reason for emergency caesarean section being performed. The item is a subset of conditions arising during labour and/or reasons for caesarean section.	Five jurisdictions collect this item under complications arising during labour. Two jurisdictions collect this as a reason for caesarean.
Retained placenta	This can be a cause of infection, PPH and hysterectomy. It can be caused by placenta accreta.	Six jurisdictions collect this information under complications arising during labour. The information is not collected in a consistent way, e.g. free-text fields are sometimes used.
Reasons for caesarean section	The NMSP notes rising rates of caesareans as an area of considerable debate.	Data on reasons for caesarean section are not consistently collected across jurisdictions. Issues include the collection of data relating to the main reason for caesarean section compared with several reasons, use of free-text fields and differences in definitions of the individual categories; in particular, the 'other' category. National data on caesarean section can differentiate between where 'labour' and 'no labour' occurred, and document a selection of specific main reasons for caesarean section. Some items collected as complications of labour and reasons for caesarean section use outdated terminology.
Third and fourth degree perineal tears	These tears are a significant delivery-related complication with the potential for long-term disability or morbidity. They may reflect quality of intrapartum care or differences in identification and classification rates.	Tears and episiotomies are already in the NPDC and are collected by most jurisdictions, but the degree of tear is not recorded. The degree of tear is an item under consideration for inclusion in the Perinatal NMDS (postpartum perineal status).

Table F8: Puerperium

Data item	Rationale	Data collection issues
Provision of appropriate breastfeeding support or advice	Some health-care practices may interfere with the uptake of breastfeeding. The World Health Organization and the National Health and Medical Research Council recommend that all babies are exclusively breastfed until 6 months of age. There is a national breastfeeding strategy with an implementation plan that includes data collection for this item.	Six jurisdictions collect some information on breastfeeding in their perinatal data collections. There is substantial variation in the type and timing of data collected, and data are not comparable.
Breastfeeding	As above.	As above. The Australian National Infant Feeding Survey was run in 2010 for the first time and results will help meet some information needs around breastfeeding.
Separation of baby from mother after birth for additional care	Separating newborn babies from their mothers could reflect unnecessary health practices and may interfere with breastfeeding practices and bonding.	Not collected.
Postnatal sepsis	Untreated infection can cause severe illness and death.	Major puerperal infection is an item in the NPDC but only one jurisdiction collects data.
Postnatal home visits	The aim of postnatal care is to provide convalescence from the birthing process, parenting and breastfeeding education and support, and clinical care to promote maternal and infant health. Home visits could relate to continuity of care, transferral of information and models of care.	Not collected.
Postnatal complications	Many women suffer some level of morbidity postpartum.	Two jurisdictions collect information on maternal morbidities arising during the puerperium up until separation date. Identification of common postnatal complications in routine data collections is difficult because complications arising after discharge generate a new hospital admission record and may not be at the hospital where the birth took place. It is not currently possible to link perinatal data with information about maternal morbidity and other events during the postnatal period unless these resulted in re-admission to the same hospital.
Postnatal care and plans	There has been a lack of research on the way postnatal care is delivered. Breastfeeding and depression are two priority areas of the NMSP. Issues identified by the Royal Australian and New Zealand College of Obstetricians and Gynaecologists include: early discharge from hospital; fragmented care; poor hospital outreach into community; busy and under-funded child health clinics; lack of family support; lack of support for Indigenous and culturally and linguistically diverse (CALD) women; and poor breastfeeding rates. It has been suggested that all women should have a postnatal care plan.	Postnatal care should include clinical examination and observation of both woman and her baby; support for infant feeding; routine infant screening to detect rare medical disorders; advice about infant vaccination; and continuing provision of advice and support for the mother—usually extending to at least 6 weeks after birth or longer. Some items are collected by jurisdictions about breastfeeding and conditions arising during the puerperium but these are inconsistent. The move toward community-based, primary health-care models will see more postnatal care being delivered in the community. The capacity to assess the number of home visits, number of days of care and transition to other services, such as child health, is likely to be required in the future.
Baby items during the puerperium	Screening and assessment during this time may allow for early identification of problems, referral for further medical assessment and the opportunity to administer prophylactic vaccinations.	Data are not routinely or uniformly collected across jurisdictions or published; examples of items collected in some jurisdictions include vaccinations for hepatitis B and vitamin K and assessment items such as discharge weight. Neonatal hearing screening is conducted in most jurisdictions and could be included in national data collection.

Table F9: Baby characteristics

Data item	Rationale	Data collection issues
Term babies admitted to a neonatal intensive care nursery (NICU) or special care nursery for reasons other than congenital anomaly	These are babies who would be expected to be well but become ill in the immediate postnatal period. Reasons for admission to NICU range from minor (e.g. jaundice) to serious (e.g. seizures, growth restriction, sepsis). Such admissions may reflect the balance of unnecessary separation of the infant from its mother versus the benefit of dedicated neonatal care in a nursery. This information can be used by hospitals to review their practices and protocols for nursery admissions.	These data are collected by some hospitals for accreditation or for quality improvement purposes. There are difficulties in obtaining reliable data as although data are collected through the NPDC, jurisdictions use different definitions. In addition, one data source for this item shows a range of 0 to 53% of normal term babies being admitted to an NICU, which means the item may need refinement to be useful.
Small for gestational age (SGA)	It is important to distinguish babies who are pre-term (and may be of appropriate weight) from those who have intrauterine growth retardation (IUGR). Some of the outcomes for these babies overlap, but not all, and it is important to monitor IUGR babies over time. SGA babies who have IUGR are at greater risk of perinatal morbidity and mortality, and long-term morbidity.	In terms of data reporting, 'small for gestational age' has been proposed as a better measure than low birthweight. It currently can be derived from the NPDC but is not the main indicator for reporting. There may be issues with definitions and normalised birth charts.
Length	Accurate measurement of birth weight, head circumference and length is important in order to establish growth relative to gestational age.	This would be useful for percentiles and for research projects. There may, however, be significant issues around collecting high quality data for this item.
Head circumference	Accurate measurement of birth weight, head circumference and length is important in order to establish growth relative to gestational age.	As above.

Table F10: Fetal and neonatal morbidity

Data item	Rationale	Data collection issues
Intrauterine growth restriction (IUGR)	Intrauterine growth restriction is associated with a number of modifiable risk factors and can be an indicator of antenatal health. IUGR is associated with adverse fetal and neonatal outcomes. Babies who are small for gestational age need to be assessed for IUGR.	There is no agreed definition at the national level as well as a lack of national consistency in data collections. Some jurisdictions collect information in a free-text field. Accurate measurement of birth weight, head circumference and length is important for babies suspected of IUGR in order to establish growth relative to gestational age.
Congenital anomalies	Many congenital conditions may be diagnosed later than the birth episode and are therefore not included in perinatal data collections. Termination of pregnancy may also occur for some congenital anomalies diagnosed during pregnancy.	There is variation in the period of detection used by state and territory congenital anomalies registers, ranging from 1 year to 18 years of life. Further data development is needed on the jurisdictional coverage and quality of termination of pregnancy data to support national reporting of congenital anomalies. Only four states collect and provide data on terminations of pregnancy at less than 20 weeks with diagnoses of congenital anomalies. Only South Australia and Western Australia have mandatory notification of termination of pregnancy irrespective of gestational age.

Table F11: Perinatal mortality

Data item	Rationale	Data collection issues
Timing of fetal deaths	This item would help understand more about the population risk profile. Currently, analyses of fetal deaths are limited because timing is not recorded.	Fetal death is included in the Perinatal NMDS under 'birth status' but additional detail on timing and cause of death are not.
Perinatal deaths due to congenital anomaly	Reporting these deaths separately from other perinatal deaths is increasingly recognised as advantageous as these conditions have a very different spectrum of risk and strategies for prevention.	Data on cause of death, particularly for congenital anomalies, are sometimes incomplete. Cause of death assigned after committee review, and including the results of post-mortem results, is likely to be more accurate than the certified cause of death since the latter is completed before the post-mortem examination and may be completed by any registered medical practitioner.
Coding of cause of fetal or neonatal death	Perinatal mortality is a key outcome indicator of maternity care. Accurate deaths information is critical for monitoring outcomes.	Not all fetal deaths are able to be classified by cause. Information about causes of death is obtained from the medical certificate completed by a medical practitioner or a coroner and is required for the registration of a stillbirth or a death. Information on the certificate is usually completed before the results of post-mortem investigations are available. Deaths are coded by some jurisdictions using the Perinatal Society of Australia and New Zealand Perinatal Death Classification (PSANZ–PDC) for stillbirths and the PSANZ-NDC (Neonatal Death Classification) for neonatal deaths. These classifications have been developed and are widely accepted by clinicians but are different to those used by statistical agencies such as the Australian Bureau of Statistics (ABS). The ABS gets deaths data from the Registrars of Births, Deaths and Marriages and codes the data to the International Classification of Diseases, Tenth Revision (ICD-10).
Other issues around perinatal mortality	Perinatal mortality is a key outcome indicator of maternity care. Accurate deaths information is critical for monitoring outcomes, with cause-specific information, definitions and consistent coding being important for both national and international comparisons. Accurate and complete data are required for fetal and neonatal deaths separately.	Birth and death registration is compulsory in each jurisdiction, but registration practices vary. Not all stillbirths are registered but they are recorded by the hospitals. Registrars of Births, Deaths and Marriages also receive notifications from the hospitals even though the parents may not register the stillbirth. There may also be difficulties around ascertainment of neonatal deaths occurring after hospital discharge. There are different definitions in Australia for registering and reporting perinatal deaths. Definitions in Australia are also different from those used by the World Health Organization in terms of birthweight, gestational period and the neonatal period, making international comparisons difficult.

Table F12: Health systems

Data item	Rationale	Data collection issues
Level of capability of maternity service	A national capability framework is under development, recognising the importance of consistent benchmarking of clinical indicators and consistent language for describing health services. This will also enable more consistent comparison of maternal and perinatal health outcomes.	Once the framework is finalised and a capability level consistently assigned to all maternity services, it should be possible to include a capability indicator to maternity data sets. However, it would be most useful to have the capability level for both the intended and actual hospital/facility for the birth.
Consumer satisfaction/ sentiment	It is important to monitor the consumer sentiment and response to changes in models of care for delivery of maternity services. The NMSP aims to increase choice and control for women and there is a strong focus on woman-centred maternity care. The National Healthcare Agreement includes measurement of patient experience through nationally comparative information about levels of patient satisfaction with care received	There is no systematic process for data collection for customer satisfaction, so it cannot be adequately assessed. However, there are also limitations associated with customer satisfaction surveys. Consumer reviews may provide a useful barometer of overall satisfaction and assist in identifying areas for improvement in service provision. In addition to satisfaction with services and various models of care, other issues mentioned include finding out whether women believe the rates of caesarean section are too high and what should be done about it, and what levels of risk women are prepared to accept.

Appendix G: Questionnaire

SECTION 1—Specific data items

REFER TO QUESTIONS 1–4 BELOW AS YOU COMPLETE THE TABLE. **ANSWER ALL OF QUESTION 1 FIRST (DOWN THE PAGE) BEFORE PROCEEDING TO QUESTION 2**

Q1. (a) For each item, please select if you 'Agree' or 'Disagree' that it should be collected nationally in a standardised way. If not in your area of expertise, select 'Unable to comment'.

   (b) If you disagree that the item should be collected nationally in a standardised way, you may give a reason(s).

Q2. For each item that you selected 'Agree' in Q1a, select a priority for this item to be collected nationally in a standardised way, relative to other items you also consider are important.

Q3. If you are able to do so, please provide more information on:

   • the best way for the data item to be collected (e.g. as part of the NMDS*, NPDC* or another existing data sets; through linking two or more existing data sets; as part of a new collection; some other way)

   • barriers to collection

   • any additional comments

   * see Appendix 2 in the information paper for further information

COMPLETE SHADED SECTION FIRST (down the page)

Item for data collection	Q1a. Item should be collected nationally?	Q1b. If you disagree, why? (optional)	Q2. Priority (relative to all other items) FOR ITEMS YOU CHOSE AGREE IN Q1	Q3. Please provide more information, if possible
DEMOGRAPHICS				
Ethnicity	○ Agree ○ Disagree ○ Unable to comment		○ Essenti ● High ○ Medium ○ Low	
Maternal education	○ Agree ○ Disagree ○ Unable to comment		○ Essenti ○ High ○ Medium ○ Low	
Maternal occupation	○ Agree ○ Disagree ○ Unable to comment		○ Essenti ○ High ○ Medium ○ Low	
MATERNAL CHARACTERISTICS				
Maternal obesity	○ Agree ○ Disagree ○ Unable to comment		○ Essenti ○ High ○ Medium ○ Low	
Illicit drug use during pregnancy	○ Agree ○ Disagree ○ Unable to comment		○ Essenti ○ High ○ Medium ○ Low	
Mother's mental health	○ Agree ○ Disagree ○ Unable to comment		○ Essenti ○ High ○ Medium ○ Low	
Women offered appropriate interventions for smoking	○ Agree ○ Disagree ○ Unable to comment		○ Essenti ○ High ○ Medium ○ Low	
Alcohol use during pregnancy	○ Agree ○ Disagree ○ Unable to comment		○ Essenti ○ High ○ Medium ○ Low	
Women in prison	○ Agree ○ Disagree ○ Unable to comment		○ Essenti ○ High ○ Medium ○ Low	
Women experiencing domestic violence	○ Agree ○ Disagree ○ Unable to comment		○ Essenti ○ High ○ Medium ○ Low	
Women who have experienced genital cutting	○ Agree ○ Disagree ○ Unable to comment		○ Essenti ○ High ○ Medium ○ Low	

(continued)

ANTENATAL PERIOD

	Agree	Disagree	Unable to comment		Essenti	High	Medium	Low	
Intended place of birth	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Termination of pregnancy	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	

MATERNAL MORBIDITY

	Agree	Disagree	Unable to comment		Essenti	High	Medium	Low	
Gestational diabetes mellitus (GDM)	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Pre-existing diabetes	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Pre-existing hypertension	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Gestational hypertension	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Pre-eclampsia	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Placenta accreta	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Post-partum haemorrhage	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	

LABOUR

	Agree	Disagree	Unable to comment		Essenti	High	Medium	Low	
Fetal monitoring during labour	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Vaginal birth after caesarean (VBAC)	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Lead intrapartum care provider	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Reasons for induction of labour	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Reasons for Instrumental vaginal births	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	

COMPLICATIONS OF LABOUR

	Agree	Disagree	Unable to comment		Essenti	High	Medium	Low	
Cord prolapse	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Fetal distress	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Retained placenta	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
High risk women undergoing caesarean section who receive appropriate pharmacological thromboprophylaxis	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
3rd and 4th degree perineal tears	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	
Reasons for caesarean section (includes elective)	○ Agree	○ Disagree	○ Unable to comment		○ Essenti	○ High	○ Medium	○ Low	

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PUERPERIUM

Breastfeeding	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment
Provision of appropriate breastfeeding support or advice	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment
Postnatal home visits	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment
Separation of baby from mother after birth for additional care	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment
Postnatal sepsis	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment

BABY CHARACTERISTICS

Term babies admitted to a neonatal intensive care nursery or special care nursery for reasons other than congenital abnormality	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment
Small for gestational age	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment

FETAL AND NEONATAL MORBIDITY

Intrauterine growth restriction	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment

PERINATAL MORTALITY

Timing of fetal deaths	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment
Perinatal deaths due to congenital anomaly	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment

MODELS OF CARE

Continuity of caregiver indicator	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment
One to one care in labour	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment
Pregnancy risk indicator	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment
Preferred pregnancy care option	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment
Recommended pregnancy care option	○ Essenti ○ High ○ Medium ○ Low	○ Agree ○ Disagree ○ Unable to comment

SECTION TWO – broad areas

Considerable data gaps at the national level are evident in the literature for several broad topic areas, however we found little specific information to enable us to select or prioritise data items or indicators.
In some cases, information is already collected nationally through one or more permanent or research collections, but we have not been able to determine the coverage, consistency, accessibility, or priority of information needs.
We need your help based on your expertise to identify the relevant items for these areas.

For each broad area in which you have expertise, please provide as much information as you can, including:

- any information needs or data items that, in your opinion, are important for national standardised collection and that haven't been captured in Section 1 of this questionnaire.
- reasons for any information needs you list e.g. high prevalence, high cost, emerging condition, need to know more about condition, impact on maternal outcomes etc.
- any data issues pertaining to the information needs or data items e.g. whether this is a data gap (no data); or an issue of data quality or accessibility; whether there are particular barriers or limitations to collection of the items; whether there are ways of improving the information such as through data linkage.
- any other information you think is relevant.

Refer to Appendix 1 in the information paper for reasons for the inclusion of these broad areas.

Item for data collection	Reason for item inclusion	Priority (relative to all other items)	Please provide more information, if possible
PATERNAL DEMOGRAPHICS			
		○ Essenti ○ High ○ Medium ○ Low	
		○ Essenti ○ High ○ Medium ○ Low	
ANTENATAL SCREENING			
		○ Essenti ○ High ○ Medium ○ Low	
		○ Essenti ○ High ○ Medium ○ Low	
ANTENATAL DIAGNOSIS			
		○ Essenti ○ High ○ Medium ○ Low	
		○ Essenti ○ High ○ Medium ○ Low	

BABY ITEMS DURING THE PEURPERIUM

	Rating
	○ Essenti ○ High ○ Medium ○ Low
	○ Essenti ○ High ○ Medium ○ Low

POSTNATAL COMPLICATIONS

	Rating
	○ Essenti ○ High ○ Medium ○ Low
	○ Essenti ○ High ○ Medium ○ Low
	○ Essenti ○ High ○ Medium ○ Low

POSTNATAL CARE AND PLANS

	Rating
	○ Essenti ○ High ○ Medium ○ Low
	○ Essenti ○ High ○ Medium ○ Low
	○ Essenti ○ High ○ Medium ○ Low

CONGENITAL ANOMALIES

	Rating
	○ Essenti ○ High ○ Medium ○ Low
	○ Essenti ○ High ○ Medium ○ Low
	○ Essenti ○ High ○ Medium ○ Low

HOMEBIRTHS

	Rating
	○ Essenti ○ High ○ Medium ○ Low
	○ Essenti ○ High ○ Medium ○ Low

CONSUMER SENTIMENT/SATISFACTION

	Rating
	○ Essenti ○ High ○ Medium ○ Low
	○ Essenti ○ High ○ Medium ○ Low

PERINATAL MORTALITY

	Rating
	○ Essenti ○ High ○ Medium ○ Low
	○ Essenti ○ High ○ Medium ○ Low

SECTION 3

LIST BELOW ANY ADDITIONAL DATA ITEMS THAT YOU CONSIDER SHOULD BE COLLECTED NATIONALLY IN A STANDARDISED WAY

SECTION 4

Thinking about all the data items across this questionnaire, list your top priorities (up to 10) for national data collection in a standardised way.

If you include a broad area topic from Section 2 as a top priority, please list the specific item(s)—not just the broad area.

1. _____   6. _____

2. _____   7. _____

3. _____   8. _____

4. _____   9. _____

5. _____   10. _____

Additional comments

_____

THANK YOU. YOU HAVE NOW COMPLETED THE QUESTIONNAIRE ☺

Appendix H: Additional material

The following project documents are available as companion volumes to this report, accessed through the Additional materials tab in the publications catalogue on the AIHW website at <http://www.aihw.gov.au/>.

- AIHW 2014. Nomenclature for models of maternity care: literature review, July 2012—Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1. Cat. no. PER 62. Canberra: AIHW

- AIHW 2014. Nomenclature for models of maternity care: consultation report, December 2012—Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1. Cat. no. PER 64. Canberra: AIHW

- AIHW 2014. Maternal mortality: data linkage methodology—Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1. Cat. no. PER 65. Canberra: AIHW.

- AIHW 2014. National perinatal mortality data reporting project: issues paper, October 2012—Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1. Cat. no. PER 66. Canberra: AIHW.

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The report presents findings of Stage 1 of the National Maternity Data Development Project which was established in response to the National Maternity Services Plan. The aim of the project is to build a more comprehensive and consistent national data collection for maternal and perinatal health. National information needs for maternity data were identified and data development commenced. A system for classifying models of maternity care was developed and improved coordination of national maternal mortality data collection was implemented.