



Australian Government

**Australian Institute of
Health and Welfare**



Enhancing maternity data collection and reporting in Australia

***National Maternity Data
Development Project***

Stage 2



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The Australian Institute of Health and Welfare is a major national agency which provides reliable, regular and relevant information and statistics on Australia's health and welfare. The Institute's mission is *authoritative information and statistics to promote better health and wellbeing.*

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ISBN <9781742498867>

Suggested citation

Australian Institute of Health and Welfare 2016. Enhancing maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 2. Cat. no. PER 73. Canberra: AIHW.

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Published by the Australian Institute of Health and Welfare

Please note that there is the potential for minor revisions of data in this report.
Please check the online version at <www.aihw.gov.au> for any amendments.

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Acknowledgments

This report was written by various past and current AIHW staff including Mary Beneforti, Lisa Gaal, Jude Luzuriaga, Charlotte Ramage and Michelle Quee.

Contributions were made by Natasha Donnelly and Amy Monk of the AIHW National Perinatal Epidemiology and Statistics Unit (NPESU).

Fadwa Al-Yaman (AIHW) and Conan Liu (AIHW) are thanked for their guidance and assistance. Thanks are also extended to the following people who reviewed the research briefs on National Maternity Data Development Project (NMDDP) priority data items (available online): Ross Haslam, Michael Humphrey, Michael Nicholl and Jeremy Oats.

The AIHW would also like to thank the following groups for their advice and assistance:

- the NMDDP Advisory Group—Fadwa Al-Yaman (Chair), Belinda Barnett, Georgina Chambers, Sue Cornes, Ross Haslam, Caroline Homer, Michael Humphrey, Ann Kinnear, Conan Liu, Peter Mansfield, Marisa Monaco Michael Nicholl, Jeremy Oats, Michael Permezel and Adrian Riches

- the Advisory Group's subcommittees—the National Maternal Mortality Advisory Committee, the Maternity Care Classification System Working Party, the National Perinatal Mortality Reporting Advisory Group, the NMDDP Clinical and Data Reference Group and the Screening for domestic violence working party
- members of the National Perinatal Data Development Committee led by Sue Cornes (Chair) are also acknowledged for their guidance and support in developing data items for the Perinatal Data Set Specification.

Special thanks are extended to the numerous stakeholders involved in consultations for several major components of the NMDDP, including perinatal data staff and other staff members of state and territory health authorities, clinicians, hospital information managers, and researchers. This project would not have been possible without their assistance and advice.

The Australian Government Department of Health funded this project.

Abbreviations

ABS	Australian Bureau of Statistics	MCU	Metadata and Classifications Unit
AIHW	Australian Institute of Health and Welfare	MSIJC	Maternity Services Inter Jurisdictional Committee
AHMAC	Australian Health Ministers' Advisory Council	NCMI	National Core Maternity Indicator
APC	Admitted Patient Care collection	NHIPPC	National Health Information and Performance Principal Committee
BMI	Body Mass Index	NHISSC	National Health Information Standards and Statistics Committee
CDRG	Clinical and Data Reference Group	NHMD	National Hospital Morbidity Database
DSS	Data Set Specification	NMDDP	National Maternity Data Development Project
DV	Domestic Violence	NMDS	National Minimum Data Set
FASD	Fetal Alcohol Spectrum Disorders	NMMAC	National Maternal Mortality Advisory Committee
HARK	Humiliation, Afraid, Rape, Kick Screening Tool	NMSP	National Maternity Services Plan
HITS	Hurt, Insult, Threaten, Scream Screening Tool	NPDC	National Perinatal Data Collection
ICD-10	International Classification of Diseases, Tenth Revision	NPDDC	National Perinatal Data Development Committee
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification	NPESU	National Perinatal Epidemiology and Statistics Unit
MaCCS	Maternity Care Classification System	PDC	Perinatal data collection
METeOR	Metadata Online Registry	PPH	Postpartum haemorrhage
MIM	Maternity Information Matrix	PSANZ	Perinatal Society of Australia and New Zealand
MoC	Model of Care	RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
MoC DSS	Maternity Model of Care Data Set Specification	SOMANZ	Society of Obstetric Medicine of Australia and New Zealand
MMC	Major Model Category		

Summary

Over the past 4 years, the AIHW has been working to consolidate national maternal and perinatal data collection and reporting in Australia. This has been made possible through the National Maternity Data Development Project (NMDDP) at the AIHW, funded by the Australian Government Department of Health. The NMDDP was established in response to recommendations of the Commonwealth's 2008 Maternity Services Review, as well as the 2010–2015 National Maternity Services Plan, both of which advocate improved national maternity data collection and reporting.

Stage 1 of the NMDDP was conducted over 2011–2013, and included scoping of national information needs for maternity data, and the setting out of a range of data development activities. The report, *Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1* is available on the AIHW website <www.aihw.gov.au>.

This report presents the outcomes of Stage 2 of the NMDDP, which was carried out between July 2013 and June 2015. The second stage focused on:

- continuing the data development of NMDDP priority maternity data items and creating a Perinatal Data Set Specification (DSS)
- developing and piloting the Maternity Model of Care (MoC) DSS
- producing a national report on maternal mortality for 2008–2012
- developing methods to better capture and report on national perinatal mortality
- producing a first national perinatal mortality report
- providing greater access to maternal and perinatal data and metadata through web tools.

The Perinatal DSS is a major component of Stage 2 of the NMDDP, and currently contains—in addition to the Perinatal National Minimum Data Set—16 new nationally standardised data elements corresponding to clinical data items on the NMDDP priority list. Data development for non-clinical (psychosocial) data items is in progress. A report on screening for domestic violence in the antenatal period was published in August 2015.

The MoC DSS has been created to underpin the Maternity Care Classification System (MaCCS). The MaCCS is a unique national data collection system for maternity models of care that will, once fully implemented, enable detailed examination as well as provide summary national statistics on models of care in Australian maternity services. The MoC DSS has been piloted and revised, and is now a national data standard. This work is described in full in a supplementary publication to this report.

The 2006–2010 and 2008–2012 *Maternal deaths in Australia* reports have revived national reporting in this critical area. The first national report on perinatal mortality, *Perinatal mortality in Australia 1993–2012*, to be released in 2016, will be a major advancement in the provision of national information on this important topic. States and territories and the Commonwealth need to continue to work together to maintain the commitment to, and build a system for, ongoing national maternal and perinatal mortality reporting.

An important and continuing aspect of the NMDDP has been to consolidate and streamline reporting of maternity data and metadata while providing more contemporary and user-friendly access to the data. The perinatal data portal and the Maternity Information Matrix are web-based tools that have been developed and/or expanded during the NMDDP.

A third stage of the NMDDP has commenced and will run until June 2016.



1 Introduction

Over 300,000 women give birth in Australia each year. Much is known about the characteristics of women giving birth, their labour and delivery experiences, and their babies, because of the perinatal data collections in each state and territory and the national perinatal data collection that collates this information. Generally, Australian women have normal pregnancies and deliver healthy babies, and Australian maternity services and professionals are considered among the best in the world.

However, important information gaps remain, and these can hinder the development of quality improvement practices. There is insufficient understanding of why caesarean section rates are so high, and whether repeat caesarean section deliveries are contributing to the apparently increasing rates of postpartum haemorrhage and peripartum hysterectomy. Rising maternal obesity rates may be affecting these events, but more information is needed to understand these relationships. Tragically, some mothers take their own lives each year, before or soon after giving birth—hence it is imperative to continue to monitor trends in maternal mortality to examine whether anything could be done to prevent these and other maternal deaths. Meanwhile, accurate statistics on perinatal deaths are still hard to obtain.

The National Maternity Data Development Project (NMDDP) aims to fill some of these data gaps to better inform decision making. In Stage 1 of the NMDDP, an assessment of national information needs for maternity data collection was undertaken for this purpose. Stage 2 has centred on consolidating the work undertaken during Stage 1 and establishing ongoing data collections and reporting mechanisms.

The National Maternity Data Development Project

The NMDDP was established in response to recommendations of the Maternity Services Review (Department of Health and Ageing 2009), as well as the

subsequent National Maternity Services Plan (NMSP) (AHMC 2011), both of which advocate improved national maternity data collection and reporting. The primary aim of the NMDDP is to ensure Action 4.1.5 of the NMSP is carried out, namely: *The Australian Government funds the development of nationally consistent maternal and perinatal data collection.* The Australian Government funded the Australian Institute of Health and Welfare (AIHW) to undertake this project.

Stage 1 of the NMDDP was conducted between May 2011 and June 2013 and aimed to:

- identify and prioritise data gaps and inconsistencies in the existing National Perinatal Data Collection (NPDC) and develop a plan to address them
- develop a nomenclature for defining and categorising models of maternity care
- achieve progress towards national agreement on standardised reporting of maternal mortality, and produce a national maternal mortality report for 2006–10, and pilot a data linkage study to increase ascertainment of late maternal deaths
- progress standardised national data collection and reporting for perinatal deaths.

For a full report on Stage 1 see *Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1* (AIHW 2014a).

NMDDP Stage 2

This report presents the outcomes of Stage 2 of the NMDDP, which was conducted between July 2013 and June 2015. The second stage focused on continuing the development of priority data items and 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. Table 1.1 outlines the components of Stage 2.

Table 1.1: Overview of project components in NMDDP Stage 2—July 2013 to June 2015

Component	Subcomponents	Status	Chapter in this report
Continuation of data development work commenced in Stage 1 of the NMDDP	Data development of priority information needs identified in Stage 1 for a nationally consistent and comprehensive maternal and perinatal data collection in Australia.	Development of most clinical priority data items complete. Report released on options for a data item on screening for domestic violence in the National Perinatal Data Collection. Data items for perinatal mental health workshopped and recommended for the Perinatal Data Set Specification (DSS).	2, 3
	Progress implementation of new data items for collection and inclusion in the Perinatal NMDS.	Perinatal DSS created with future planned implementation of items in the Perinatal National Minimum Data Set (NMDS).	2, 3
	Continued development of the Maternity Care Classification System (MaCCS) for models of maternity care.	Maternity Models of Care DSS created, piloted and endorsed.	4
National reporting on perinatal and maternal mortality	Maternal mortality—produce an updated report on maternal deaths for the period 2008–2012.	<i>Maternal deaths in Australia 2008–2012</i> published in June 2015.	5
	Perinatal mortality—investigate ways of improving perinatal mortality reporting in Australia.	Draft report written and will be published in 2016.	6
	Perinatal mortality—produce a national report on perinatal mortality.	Draft report under preparation and will be published in 2016.	6
Expansion of reporting options	Expand reporting options to enable better use of enhanced maternal and perinatal data.	Perinatal data portal developed with Module 1 (demography) released in Dec 2014 and Module 2 (antenatal period) in June 2015.	7
	Investigate options for reporting of perinatal and maternal data in the new information environment.	As above. In addition, new format proposed for Australia's Mothers and Babies series.	7
	Updating of the Maternity Information Matrix (MIM), an online repository of perinatal metadata.	MIM updated to version 3 and uploaded to AIHW website.	7

The National Perinatal Data Collection

National reporting on pregnancy and childbirth for mothers, and the characteristics of 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 31 mandatory data items supplied by each jurisdiction (see Appendix A), as well as numerous voluntary data items supplied to varying degrees by some jurisdictions.

The NPDC includes data on all live births and stillbirths of at least 400 grams birthweight, or at least 20 weeks gestation. 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. Various 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. The jurisdictions collate and forward the perinatal data to the data custodian (the AIHW) where they are incorporated in the NPDC. The AIHW compiles

an annual report, *Australia's mothers and babies* (for example, AIHW 2015a), containing national information for births and the women who give birth. The jurisdictions also publish 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.

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 during both Stages 1 and 2 of the project.

- National evidence-based antenatal care guidelines have been developed (AHMAC 2012), providing direction for what is important in antenatal care provision. The first module was published in April 2013, and a second in February 2015. These clinical guidelines are broader in scope than the NPDC and have a different audience and purpose; however most of what the NMDDP specifies as important for national data collection aligns with the guidelines. The guidelines provide research evidence, relevance and context to the data

collection, and for some issues in antenatal care provision, provide direction as to which data collection tools or methods should be employed.

- The Maternal Sentinel Events and Postpartum Haemorrhage (PPH) Working Group has been advising the Australian Commission on Safety and Quality in Healthcare (ACSQHC) on the definition of a maternal sentinel event and severe acute maternal morbidity, including postpartum haemorrhage (PPH). The definitions are relevant for hospital reporting, but consistency with related NPDC definitions is desirable, as well as an understanding of the reasons for any differences.
- The AIHW has been undertaking the National Core Maternity Indicators (NCMI) project. The NCMI (see Table 1.2 for status), as suggested by their name, are clinical indicators that apply to the field of maternity care. Ten indicators have already been reported (see <<http://www.aihw.gov.au/publication-detail/?id=60129542685>>). A further eight have been investigated as to their reporting feasibility and/or need for further data development (see <<http://www.aihw.gov.au/publication-detail/?id=60129549627>>). Some of the data for the core maternity indicators will become available as a result of work undertaken as part of the NMDDP to improve the NPDC, such as work on primary postpartum haemorrhage data elements.

Table 1.2: National Core Maternity Indicators

No.	Indicator	Status
1	Smoking in pregnancy for all women giving birth	Data for 2004–2009 reported in online data portal ^(a) and in <i>National core maternity indicators</i> publication ^(b) , and will be updated in 2016 to include 2004–2013 data.
2	Antenatal care in the first trimester for all women giving birth	Data for 2007–2009 reported in online data portal ^(a) and in <i>National core maternity indicators</i> publication ^(b) , and will be updated in 2016 to include 2004–2013 data.
3	Episiotomy for women having their first baby and giving birth vaginally	Data for 2004–2009 for indicators 3–8 reported in online data portal ^(a) and in <i>National core maternity indicators</i> publication ^(b) , and will be updated in 2016 to include 2004–2013 data.
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	

(continued)

Table 1.2 (continued): National Core Maternity Indicators

No.	Indicator	Status
9	General anaesthetic for women giving birth by caesarean section	Data for 2007–2009 reported in online data portal ^(a) and in <i>National core maternity indicators</i> publication ^(b) , and will be updated to include 2004–2013 data.
10	Small babies among births at or after 40 weeks gestation	Data for 2004–2009 reported in online data portal ^(a) and in <i>National core maternity indicators</i> publication ^(b) , and will be updated in 2016 to include 2004–2013 data.
11	High risk women undergoing caesarean section who receive appropriate pharmacological thromboprophylaxis	This indicator was not recommended for further progression due to data quality issues.
12	Babies born ≥ 37 completed weeks gestation admitted to a neonatal intensive care nursery or special care nursery for reasons other than congenital anomaly	Further data development is required. This work is on the AIHW work plan for the NCMI.
13	Third and fourth degree tears for (a) all first births and (b) all births	This indicator will be reported for the first time in 2016. It will be added to the online data portal, with data for 2007–13.
14	Significant blood loss of (i) $>1,000$ mL and $<1,500$ mL and (ii) $\geq 1,500$ mL during first 24 hours after the birth of the baby (that is, major primary PPH) for (a) vaginal births and (b) caesarean sections	This data item was added to the Perinatal DSS 2014–15 (see Chapter 2). Once data become available, this indicator will be added to the online data portal.
15	Women having their second birth vaginally whose first birth was by caesarean section.	This indicator will be added to the online data portal in 2016, with data for 2007–2013.
16	Separation of baby from the mother after birth for additional care.	This indicator was not recommended for further progression due to data quality issues.
17	One-to-one care in labour	This indicator was not recommended for further progression due to data quality issues.
18	Caesarean sections without compelling medical indication <39 weeks (273 days)	A data item, 'Main indication for caesarean section', was added to the Perinatal DSS 2014–15 (see Chapter 2). Once data become available, this indicator will be added to the online data portal.
19	Supporting breastfeeding	This indicator has been referred elsewhere for further development. Breastfeeding is currently collected in the Australian Bureau of Statistics (ABS) Australian Health Survey 2011–12 ^(c) and will again be collected in 2014–15.
20	Models of care	'Models of care' work is a component of the NMDDP. A comprehensive method for collecting models of care information has been developed but is yet to be implemented. See Chapter 4.
21	Skin-to-skin contact between mother and baby after birth	This indicator was added to the original set of 20 NCMI. Further data development is required. This work is on the AIHW work plan for the NCMI.

(a) NCMI data portal at <http://www.aihw.gov.au/ncmi/>.

(b) NCMI publication at <http://www.aihw.gov.au/publication-detail?id=60129542685>.

(c) See the ABS website: <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/20F4417FB21B3704CA257B8D00229E75?opendocument>.

Project governance and consultation

The NMDDP is guided by a project advisory group. Key experts in the fields of obstetrics, midwifery, research, statistics, consumer advocacy, and health policy are represented on the group. The NMDDP Advisory Group (AG), now in its fifth year of existence, and consisting of a core set of members who have been part of the group from the outset, operates as a central coordinating point for all activities of the NMDDP. The involvement of the AG has been one of the most robust features of the NMDDP,

servicing to unite different sectors of the maternity, academic and government workforce, and provide a high level forum for discussion and decision making.

The role of the NMDDP AG during Stage 2 was similar to that of Stage 1 in terms of: providing advice and guidance on current and emerging perinatal and maternal mortality and morbidity issues, and data collection practices; facilitating communication with stakeholders; identifying linkages with other projects; and providing feedback on project documents and

draft reports. Greater focus was given to advice on the data development work such as for the NMDDP priority data items and the models of care. This slight change in focus provided the opportunity to include additional members on the AG such as jurisdictional representatives of the National Perinatal Data Development Committee (NPDDC), a neonatologist and a consumer representative.

Reference and working subgroups were established or extended during Stage 2 to guide and inform specific components of the project. Continuing groups included:

- the National Maternal Mortality Advisory Committee (NMMAC), which assists with the work on maternal mortality
- the Clinical and Data Reference Group, which guides the data development work for clinical data items.

New groups consisted of:

- the National Perinatal Mortality Reporting Advisory Group (NPMRAG), to advise on the perinatal mortality reporting components
- the MaCCS Working Party, for advice on further developing a classification system and data set specification for maternity models of care in Australia
- the Screening for Domestic Violence Working Party, which provided valuable input to the data development work for this complex area.

A list of members of these groups is provided in Appendix B, 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 NPDDC 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 (SCoH) (previously the Australian Health Ministers' Conference). (See Chapter 2 and Figure 2.1 for more information on the data development process.)

In addition to these committees, 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 MaCCS.

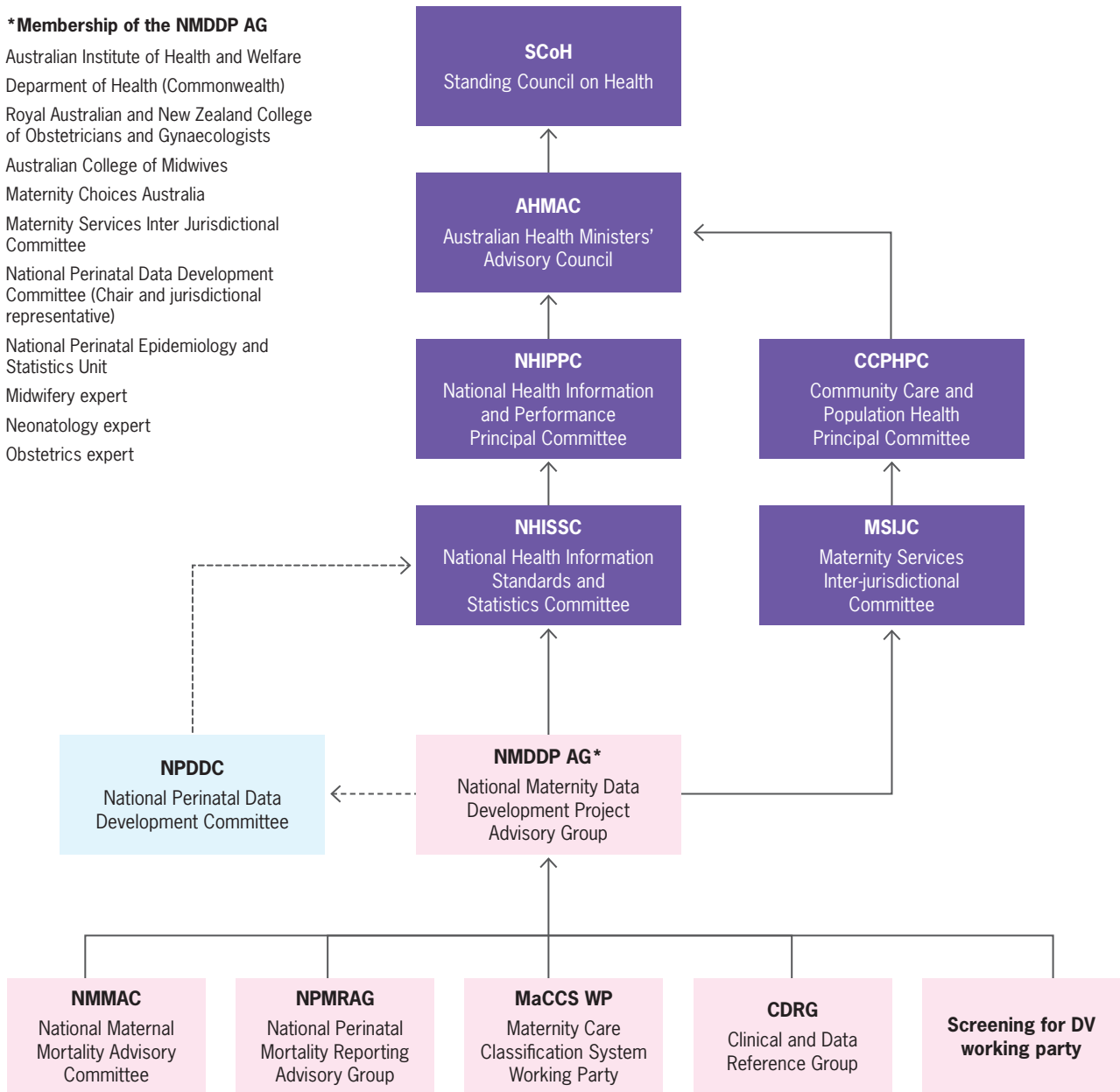
Structure of this report

This report describes the outcomes of Stage 2 of the NMDDP, as follows:

- the development of a Perinatal Data Set Specification for data items agreed to be of the highest priority for improving national maternity data collection and reporting (Chapter 2), and ongoing data development for psychosocial data items (Chapter 3)
- the development and piloting of a Maternity Model of Care Data Set Specification, and the development of web specifications for an electronic data collection tool (Chapter 4)
- national reporting of maternal mortality (Chapter 5)
- national reporting of perinatal mortality including ways to better integrate national data from different sources (Chapter 6)
- the release of web-based platforms for perinatal data and metadata to provide user-friendly and interactive access to data (Chapter 7).

***Membership of the NMDDP AG**

- Australian Institute of Health and Welfare
- Department of Health (Commonwealth)
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists
- Australian College of Midwives
- Maternity Choices Australia
- Maternity Services Inter Jurisdictional Committee
- National Perinatal Data Development Committee (Chair and jurisdictional representative)
- National Perinatal Epidemiology and Statistics Unit
- Midwifery expert
- Neonatology expert
- Obstetrics expert



Note: Pink boxes represent NMDDP AG and direct reporting committees. Blue box represents indirect reporting; purple boxes are for higher level AHMAC committees.

Figure 1.1: Governance structure for Stage 2 of the National Maternity Data Development Project (NMDDP)



2 Data development—clinical items

Stage 1 outcomes

The main national information priorities and gaps in maternal and perinatal data were investigated during Stage 1 of the NMDDP, through a review of national and jurisdictional statistics, policies and frameworks, and through extensive consultation with stakeholders.

This work led to the development of an NMDDP priority data item list that reflected a number of key areas of focus:

- *Maternal morbidity items*—these were found to be 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 related 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 a significant gap in this critical maternity information.
- *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 was seen to be of high importance.

The data items were subsequently mapped against existing data collections, and other information sources, to determine data gaps and inconsistencies. This helped elicit the key issues for data development for each of the prioritised data items, considering factors such as feasibility, practicality and potential time frames for achieving national consistency. The items were also grouped into work batches that aligned with the expected relative time frame for development. (See Appendix C for the list as finalised at the end of Stage 1.)

Stage 2

The Perinatal Data Set Specification

The creation of a Perinatal Data Set Specification (DSS) has been a major component of Stage 2 of the NMDDP. It currently contains 17 data elements corresponding to data items on the NMDDP priority list (Table 2.1).

The data development process

Data development began during Stage 1 under the expert guidance of the NMDDP Clinical and Data Reference group (CDRG), and has been a continuing focus of Stage 2. The project aims for priority data items to become national data standards and to progressively move into the Perinatal NMDS to achieve national consistency in data collection.

There are considerable implications for jurisdictions in terms of incorporating the new data items in their collections, hence the priority data items are initially included in a 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. An NMDS, on the other hand, is for mandatory collection and national reporting and is dependent upon agreement from every state and territory to collect and supply data according to the national definitions.

The process of data development for items being added to a DSS or NMDS is the same. National data standards are created and must be agreed to, before being endorsed by relevant national data and standards committees. Hence, while not all jurisdictions can currently implement all of the Perinatal DSS items in their collections, they have agreed to the national standards and in principle, to future collection.

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>>).

Formal approval processes by national health standards committees including the National Health Information Standards and Statistics Committee (NHISSC) and the National Health Information Performance and Principal Committee (NHIPPC) are required for the registration of national data standards and the creation and modification of DSSs and NMDSs.

This comprehensive and rigorous process is illustrated in Figure 2.1.

Clinical data items

The new data elements in the Perinatal DSS relate to seven clinical areas of the NMDDP priority data item list (Table 2.1).

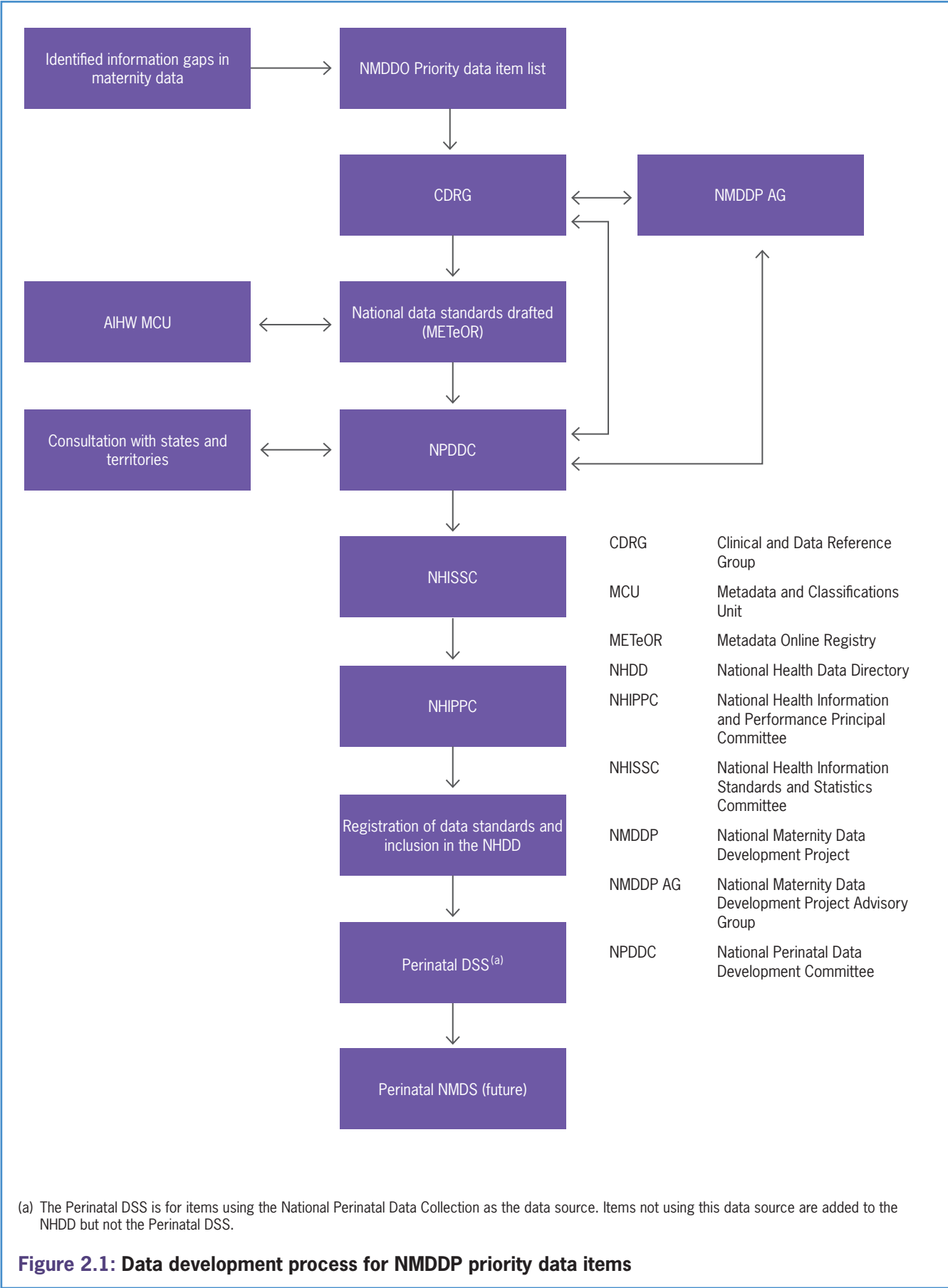
Short research briefs provide more information about each of the above data items and are available on the AIHW website <<http://www.aihw.gov.au/publication-detail?id=60129554606>>.

Table 2.1: The Perinatal Data Set Specification (DSS)

Clinical area	Metadata item ^(a)	Implementation start date ^(b)
Diabetes	Female—diabetes mellitus during pregnancy indicator, yes/no/not stated/inadequately described code N	01/07/2014
	Female—type of diabetes mellitus during pregnancy, code N	01/07/2014
	Female—type of diabetes mellitus therapy during pregnancy, code N	01/07/2014
Head circumference	Birth—head circumference, total centimetres, code NN[N].N	01/07/2016
Hypertension	Female—hypertensive disorder during pregnancy indicator, yes/no/not stated/inadequately described code N	01/07/2014
	Female—type of hypertensive disorder during pregnancy, code N	01/07/2014
Indications for caesarean section	Birth event—additional indication for caesarean section, code N[N]	01/07/2014
	Birth event—main indication for caesarean section, code N[N]	01/07/2014
Indications for induction of labour	Birth event—additional indication for induction of labour, code N[N]	01/07/2015
	Birth event—main indication for induction of labour, code N[N]	01/07/2015
Primary postpartum haemorrhage	Female—blood transfusion due to primary postpartum haemorrhage indicator, yes/no/not stated/inadequately described code N	01/07/2014
	Female—estimated blood loss indicating primary postpartum haemorrhage, estimated blood loss volume category, code N	01/07/2014
	Female—primary postpartum haemorrhage indicator, yes/no/not stated/inadequately described code N	01/07/2014
Maternal height and weight	Person—height (measured), total centimetres NN[N].N	01/07/2014
	Person—height (self-reported), total centimetres NN[N]	01/07/2014
	Person—weight (measured), total kilograms N[NN].N	01/07/2014
	Person—weight (self-reported), total kilograms NN[N]	01/07/2014

(a) The items can be viewed in METeOR at: <<http://meteor.aihw.gov.au/content/index.phtml/itemId/568380>>.

(b) Implementation start date refers to when an item was first incorporated in the Perinatal DSS. Items with an implementation start date of 01/07/2014 were first incorporated in the Perinatal DSS in 2014–15. The most current version of the Perinatal DSS at the time of publication was 2016–17.



The NMDDP priority data item list

The priority data item list developed in Stage 1 of the NMDDP was revised during Stage 2. Table 2.2 shows the status of the list at the time of publication. Decisions about revisions to items and additions to, or removal of items from the list, were made by the CDRG and the NMDDP AG (see Figure 2.1 above).

Some data items were removed from the list including *Interpreter service required* and *Febrile morbidity in labour* due to data quality concerns, and *Indications for instrumental vaginal birth* due to reconsideration of its usefulness as an item for national data collection.

New items were also considered, including *Screening for diabetes* and *Previous gestational diabetes mellitus*. However, after discussion with stakeholders, it was agreed that the former would not yield useful data and the latter was too specialised for national data collection.

Asthma in pregnancy and female genital mutilation (FGM) were assessed for addition to the NMDDP priority data item list—however it was not possible to accommodate them, due to the many competing priorities. Asthma is an important health condition that needs to be managed in pregnancy, but it was not considered feasible to collect data because it was unlikely that data around review and management of the condition would be available to midwives attending the birth. There would also be a need to understand more about the degrees of asthma severity

and what information could be collected accurately without adding significantly to respondent burden.

The Australian Government Department of Health has been funding a variety of projects in the FGM area, including projects specifically aimed at improving the evidence base on FGM in Australia, which should assist with the current information gaps.

An initial investigation into the collection of data on maternal education (Batch 3 item) indicated it would be difficult to incorporate into the perinatal data collection due to perceived lack of relevance by clinicians. The NHMD was also considered a possibility for sourcing these data, but maternal education would need to be added to the Admitted Patient Care NMDS, and this was not considered feasible, particularly because the data item would only be relevant for a small subset of the 8 million annual hospital separations occurring in Australia. As a proxy measure for maternal education, it is possible to report the national perinatal data by socioeconomic status using the Australian Bureau of Statistics (ABS) Socioeconomic Index for Areas (SEIFA). SEIFA has some limitations in that it relates to the socioeconomic status of an area rather than an individual.

For more information on the Batch 3 data item, *Model of care*, see Chapter 4, which describes data development for the Maternity Care Classification System (MaCCS), a classification system for maternity models of care.

Table 2.2: NMDDP priority data items

Batch	Priority data items ^(a)	Current status ^(a)
1	Hypertension Diabetes Maternal height Maternal weight Indications for caesarean section Severe primary postpartum haemorrhage	Perinatal DSS 2014–15 onwards
	Screening for diabetes Previous gestational diabetes mellitus	Added to the NMDDP priority list for consideration but subsequently removed
	Interpreter service required	Removed from the NMDDP priority list

(continued)

Table 2.2 (continued): NMDDP priority data items

Batch	Priority data items ^(a)	Current status ^(a)
2	Indications for induction of labour	Perinatal DSS 2015–16 onwards
	Head circumference	Perinatal DSS 2016–17 onwards
	Peripartum hysterectomy	Ongoing data development
	Indications for peripartum hysterectomy	
	Mental health	
2	Indications for instrumental vaginal birth	Removed from the NMDDP priority list
	Febrile morbidity in labour	
3	Timing of stillbirth ^(b)	Ongoing data development
	Screening for domestic violence	
	Alcohol use in pregnancy	
	Substance use	
	Model of care	
	Maternal education	Deferred data development

(a) Current at November 2015.

(b) Previous name was 'Timing of fetal death'.

Data development for remaining clinical data items

Peripartum hysterectomy

Peripartum hysterectomy is one of only two data items that will not use the perinatal data collection as its data source (the other is *Timing of stillbirth*). Instead, data will be sourced from the National Hospital Morbidity Database (NHMD) according to agreed criteria. The item has also been broadened to encompass hysterectomies occurring in early pregnancy, for example, as a result of ectopic pregnancy or abortion. Therefore, data elements for pregnancy-associated hysterectomy, peripartum hysterectomy (as a subset of the former), and indications for pregnancy-associated hysterectomy, are under development.

The proposed data elements are:

- Female—pregnancy-associated hysterectomy, yes/no code N
- Female—peripartum hysterectomy, yes/no code N
- Female—related condition contributing to pregnancy-associated hysterectomy, code N[N].

Subject to agreement, these data elements could be added to the National Health Data Dictionary as a data element cluster and be linked to the Perinatal DSS.

A working paper on peripartum hysterectomy examining NHMD data from 2003–04 to 2013–14 is also under development and will be published in 2016. A short research brief about the importance of peripartum hysterectomy is available on the AIHW website at <<http://www.aihw.gov.au/publication-detail/?id=60129554606>>.

Timing of stillbirth

This item forms part of the set of data items for reporting on perinatal mortality which comes under another component of the NMDDP, outlined in Chapter 6. Data will be sourced from clinical review committee data in each state and territory. A short research brief on this item can be found on the AIHW website at <<http://www.aihw.gov.au/publication-detail/?id=60129554606>>.

Summary

Figure 2.2 illustrates the status of the expanded National Perinatal Data Collection, showing new Perinatal DSS data items, those still under development, Perinatal NMDS items and voluntarily-provided non-standard NPDC items. Challenges lie ahead with development of the psychosocial data items, which are discussed in the next chapter.

		Scope of data collection			
		Antenatal period	Labour & delivery	Immediate postpartum outcome	Postnatal period (prior to/at discharge)
Pre-conception	Post-discharge	Perinatal DSS^(a) Maternal height Maternal weight Hypertensive disorders Diabetes (type; therapy) Ongoing data development Woman's model of care (principal; prior to birth) (from Maternity Model of Care DSS) Mental health Alcohol use in pregnancy Screening for domestic violence Substance use Deferred data development Maternal education	Perinatal DSS^(a) Indications for induction of labour Indications for caesarean section Ongoing data development Timing of stillbirth	Perinatal DSS^(a) Baby head circumference Primary postpartum haemorrhage Data element cluster under development^(b) Peripartum hysterectomy Indications for peripartum hysterectomy	
		Existing NMDS^(c) Date of birth Indigenous status (mother) Person identifier (mother) Establishment identifier Country of birth State/territory of birth Area of usual residence Smoking (before/after 20 weeks; quantity) Antenatal visits (number; gestation at first visit) Parity Caesarean section for most recent previous birth	Existing NMDS^(c) Labour onset type Birth method Birth presentation Place of birth Analgesia (administered; type) Anaesthesia (administered; type) <i>Labour induction type</i>	Existing NMDS^(c) 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) <i>Resuscitation (indicator; method)</i>	Existing NMDS^(c) Separation date (mother; baby)
		NPDC (voluntary items)^(d) Marital status Previous pregnancies/outcomes Assisted reproductive technology Gravidity Intended place of birth Maternal medical conditions (various) Obstetric complications (various)	NPDC (voluntary items)^(d) Induction/augmentation No labour Hospital sector Accommodation status Admission date Complications of labour Cord prolapse Retained placenta Fetal distress in labour	NPDC (voluntary items)^(d) Major puerperal infection Baby length Resuscitation drug therapy Fetal death Neonatal death Maternal death Date of death (baby) Autopsy (baby) Classification of death Main cause of death (baby)	NPDC (voluntary items)^(d) Postnatal length of stay (mother; baby) Mode of separation (mother; baby)

(a) A DSS is a set of data items to be collected according to standardised definitions (national data standards), however they are not mandatory for collection. These data items are intended to be progressively moved into the Perinatal NMDS.
 (b) Linked to Perinatal DSS (data source: hospital morbidity).
 (c) Mandated national data standards. Items in italics are in the process of incorporation into the NMDS. This work pre-exists the NMDDP.
 (d) Additional NPDC (voluntary; non-standardised) items.

Figure 2.2: Status of the expanded National Perinatal Data Collection, November 2015



3 Data development—non-clinical data items

Four psychosocial data items, *Screening for domestic violence*, *Mental health*, *Alcohol use in pregnancy*, and *Substance use* are on the NMDDP priority data item list. They are complex items to develop and accordingly have a long-term time frame for inclusion in the Perinatal NMDS, if feasible. There are many factors to consider in deciding whether or not data development should proceed collectively for some or all of these psychosocial items. For example, strong evidence has been found for a dependent relationship between domestic violence (DV) and women's mental health. Impacts include depression, suicidal tendencies, post-traumatic stress disorder, and drug and alcohol misuse. To date, the data items have each been investigated in their own right, rather than as a set of psychosocial items, partly because of the way the project has evolved and partly because the concept of 'psychosocial' is in itself quite complex. This chapter provides a summary of work that has occurred during Stage 2 of the NMDDP.

Stage 1

The four psychosocial data items were confirmed as priority areas during Stage 1, although work on alcohol use in pregnancy pre-dated the NMDDP as part of the Council of Australian Governments (COAG) work in relation to the National Indigenous Reform Agreement (NIRA).

Scoping work for screening for domestic violence, including a literature review and consultation with state and territory stakeholders, commenced in Stage 1.

The former National Perinatal Depression Initiative (NPDI) set the stage for mental health with a strong focus on screening for depression in the antenatal period. However the NPDI has not continued and this work has lost some momentum.

Substance use in pregnancy was a late addition to the NMDDP priority data item list, and was out of scope in both Stages 1 and 2. Therefore it is only briefly touched on here.

Stage 2

Screening for domestic violence

Domestic violence (DV) is a leading preventable contributor to death, disability and illness for women of reproductive age (15 to 44 years old). Estimates from the ABS 2012 Personal Safety Survey (ABS 2013) indicate that around 5% of women (aged 18 years and over) experienced violence during pregnancy from their previous or current partner.

Pregnancy has been identified as a period of high risk for the onset or worsening of DV, which is dangerous to both pregnant women and their babies (Taft 2002; WHO 2000). DV may cause pregnant women to suffer with breast and genital injury, miscarriage, antepartum haemorrhage and infection, blunt or penetrating abdominal trauma and death. Babies may suffer with fetal fractures, low birthweight, injury and suppressed immune system (Walsh 2008). Pregnancy outcomes for abused women, both in Australia and globally, are worse compared with those of non-abused women (Taft et al. 2004; WHO 2013).

Pregnancy, however, can also be an important time for screening for DV. In addition to being a time when DV may be more prevalent, pregnancy also presents an opportunity for identification of DV, as many women will have contact with health-care services and will meet with health-care professionals on a regular basis during the antenatal period.

Despite feasibility concerns with implementing *Screening for domestic violence* in perinatal data collections, stakeholders consulted during the NMDDP believed DV was sufficiently important to warrant further investigation, and recommended that a data item be developed.

Data development process

The data development process involved several steps. Initially, existing literature on DV in pregnancy, and screening for DV in pregnancy was reviewed to determine:

- the importance of routine screening and what data would be possible to collect
- data gaps and the potential of the NPDC in filling data gaps
- how screening for DV could be measured and/or reported in the NPDC.

Relevant jurisdictional tools and data practices currently in use were also reviewed. A discussion paper was developed and used to support a national workshop with key experts and stakeholders to consider: whether it would be possible to collect national information on screening for DV as part of the NPDC; what information would be collected; and how the data would be used. Subsequently, a working party was formed to resolve issues raised in the discussion paper and at the workshop. The AIHW developed an information paper, *Screening for domestic violence during pregnancy: options for future reporting in the National Perinatal Data Collection*, which is available on the AIHW website at <www.aihw.gov.au/publication-detail/?id=60129551956>. A summary of that report is provided.

Rationale for collecting information on screening for DV

The rationale for collecting data on screening for domestic violence was developed by drawing on the literature review and stakeholder consultation, and was extensively reviewed by stakeholders. The rationale set out in the information paper is detailed in Appendix D, and covers four main areas:

Why screening should occur

There are multiple purposes for screening during pregnancy, including: poorer pregnancy outcomes for abused women; the unique opportunity of pregnancy for women to receive help due to more frequent contact with health services; and there is evidence to support that antenatal screening for DV may be more beneficial than screening in other health settings.

The need for data

There is currently no comprehensive approach to national data collection on DV in pregnancy. National data are important for population-level surveillance, clinical care and outcomes, and for informing research on the association of DV with other maternal and perinatal outcomes.

Why the NPDC is an appropriate collection

The NPDC is a census of women who give birth in any given year across Australia, and who predominantly fall within the 15–44 years age range where the highest levels of disease burden are attributable to DV. Collecting data in the NPDC could be valuable because no other data source can provide such comprehensive coverage of the target population.

How the data could be used

The primary uses for NPDC data on DV would include: annual reporting on rates and patterns of DV in pregnancy; analysis on correlations between DV and other clinical characteristics or perinatal risk factors (such as low birthweight); and disaggregations to show high risk groups.

Definition for DV and screening

Challenges around terminology and definitions of DV and screening need to be considered before national measurement for DV in pregnancy can begin.

The following definition was agreed as suitable for the NPDC, and is adapted from the National Plan to Reduce Violence Against Women (COAG 2011):

‘Domestic violence refers to acts of violence that occur between people who have, or have had, an intimate relationship. The central element is a pattern of behaviour aimed at controlling a partner through fear, for example by using behaviour which is violent or threatening any act that might cause harm or suffering. Domestic violence can include physical, sexual, emotional or psychological abuse.’

Screening was seen as a process by which an organisation or professional attempts to identify victims of violence or abuse in order to offer interventions that can lead to beneficial outcomes. An important element of routine screening is that all clients attending a service should be asked questions related to the existence of DV, regardless of whether it is suspected or not.

Data context and gaps

Data on DV in pregnancy in Australia are currently limited and inconsistent across jurisdictions, with variations in what is captured, counted and reported, and how it is collected. There is also known under-reporting of DV due to the complex and sensitive nature of DV, including patients’ reluctance to report, and under-identification by health workers.

Screening for DV in the antenatal period already occurs in most Australian jurisdictions. While jurisdictions vary in relation to the types of data they collect and record, there are some commonalities among the approaches taken and screening questions used.

Potential approaches to obtaining national data in the NPDC

Potential approaches to obtaining national data in the NPDC include:

- developing and implementing a minimum set of standard questions, based on the questions currently in use across jurisdictions
- seeking to implement a nationally consistent screening approach by encouraging all midwives to use a recommended validated DV screening tool
- maintaining a flexible screening approach consistent with the National Antenatal Care Guidelines that enables jurisdictions to screen in different ways for different populations.

The preferred approach is the second one. Health-care providers can sometimes struggle to interpret a client's answers, and without clear questions and answers incorrect recording of responses can occur. A validated tool provides clear direction about how to assess and interpret answers to questions about DV, and a scoring system for determining positive responses for DV.

The HARK (Humiliation, Afraid, Rape, Kick) and the HITS (Hurt, Insult, Threaten, Scream) are two recommended tools for consideration (outlined in Appendix E).

Further consultation and pilot testing would be required before any national data standards could be developed. The data item could include 3 indicators, specifying (a) whether screening occurred, (b) whether DV was disclosed, and (c) whether additional follow-up was offered due to disclosure of DV.

It is also likely that certain pre-conditions for screening would need to be in place before the start of any DV data collection in the NPDC. These pre-conditions would include: funding for sustained training and staff support; a need for referral pathways for women who disclose;

and assured maintenance of confidentiality and privacy. In addition, it would be important to consider issues that disclosure of DV would have for Aboriginal and Torres Strait Islander women.

Mental health

Mental health issues such as depression, anxiety and related disorders can affect the wellbeing of the mother and baby during pregnancy, a period that is critical to the future health of the child (Beck 1998; Halligan et al. 2007 in AHMAC 2012). Suicide is a leading cause of indirect maternal mortality in Australia (Johnson et al. 2014). While screening for perinatal depression has been conducted in maternity clinical settings in all jurisdictions in recent years, few data are available on screening rates or outcomes, and there are no national data.

National evidence-based clinical guidelines for the antenatal period were developed under the Plan (AHMAC 2012). The guidelines, which draw on published evidence, make recommendations on key areas of antenatal care, including mental health and depression and anxiety, and aim to promote consistency of care, thereby improving the experience and outcomes of antenatal care for women and their babies. Nationally consistent data are needed to describe and monitor these outcomes.

The guidelines recommend use of the Edinburgh Postnatal Depression Scale (EPDS) to detect depression and provide information on how to administer it and act upon it, including cross-cultural considerations (AHMAC 2012).

To date, three data elements associated with perinatal mental ill health risk in the antenatal period have been recommended for further data development and inclusion in the NPDC (Table 3.1). The data elements arose from findings, provided to the NMDDP, of a concurrent University of New South Wales project.

The work to develop these data elements included producing a discussion paper and holding a workshop involving a broad range of stakeholders followed by meetings of a working party. The elements have been endorsed by the NMDDP Advisory Group for further data development.

Table 3.1: Data elements associated with perinatal mental ill health risk in the antenatal period

Data element	Values
1 Antenatal depression/anxiety screening conducted	Yes; Not offered; Declined; Unknown or not stated
2 Additional follow-up indicated due to the identification of perinatal mental health risk factors	Yes; No; Not applicable; Unknown or not stated
3 Presence or history of mental health condition	Yes; No; Unknown or not stated

Data element 1 was seen to be of value in measuring the implementation of screening for depression and anxiety, recognising that the tool currently recommended and endorsed nationally is the Edinburgh Postnatal Depression Scale (EPDS). This data element was also seen as being useful at a population level when assessing outcomes of women and babies (differences between women screened and not screened).

Data element 2 was seen to be of value as a proxy for a screening or assessment result, and is independent of individual tools or the timing of screening or assessment. It acknowledges that there is a range of different risk factors for perinatal mental health, as well as means of identifying them. It is an indicator showing that a woman required some additional care due to a deviation from 'normal' because of the presence of perinatal mental health risk factors. It does not show or specify what additional action or care was required or whether the woman received it. Additional follow-up may cover a range of actions such as re-screening, referral, increased antenatal visits, multidisciplinary case reviews, and so on.

Data element 3 was seen as an important identifier of risk for perinatal mental health. Although this data element is by either self-report (which can lower data quality) or documentation, it was viewed as still being of high value. A data element incorporating a specific mental health diagnosis was not feasible, so data element 3 was seen as an appropriate and valuable alternative.

These proposed data elements would need to undergo further consultation and testing. Steps involved in progressing this complex work include:

- pilot testing the proposed questions and data elements, and incorporating refinements
- development of national data standards and inclusion in the Perinatal DSS
- preparation of an information paper.

Alcohol use in pregnancy

High-level and/or frequent intake of alcohol in pregnancy increases the risk of miscarriage, stillbirth and premature birth (O'Leary 2004, in AHMAC 2012). Alcohol use in pregnancy can have adverse effects on a developing fetus, resulting in a spectrum of harm to the fetus that can last a lifetime. These adverse effects are referred to collectively as fetal alcohol spectrum disorders (FASD). People with FASD experience lifelong problems such as learning difficulties, mental illness, drug and alcohol problems, and trouble with the law (Streissguth et al. 2004, in AHMAC 2012). The lack of coherent national data about alcohol use in pregnancy has been recognised (AIHW 2010).

Alcohol use in pregnancy is a Batch 3 NMDDP priority data item. Currently, three jurisdictions collect some data in the NPDC; however, the information is collected differently in each of these jurisdictions (Table 3.2).

Table 3.2: Summary of state and territory perinatal data collections that include alcohol use in pregnancy

State/territory	Data about alcohol use included	Amount of alcohol consumed (options available on the form)
Tasmania	Consumed alcohol Y/N	<1 standard drink/day >1 standard drink/day (tick boxes)
Northern Territory	Alcohol: 1st antenatal visit and 36 weeks antenatal visit, with a blank field next to each gestation or 'Yes/No/Unknown' response	No prompt given to indicate what information should be collected
Australian Capital Territory	Alcohol consumption during pregnancy: 'Yes/No'	The number of standard drinks per week

Tasmania collects information on alcohol use in pregnancy and has published the results annually since 2007 in the *Council of Obstetric & Paediatric Mortality & Morbidity annual report* (Department of Human Services and Health Tasmania 2014).

The Northern Territory has collected and reported on alcohol use in pregnancy since 2003 in their annual *Mothers and babies* publication. Data are collected by midwives at the first antenatal visit, and again at around 36 weeks' gestation. However, while recent reports note that the collection of these data has improved, in 2011, 8% of data from the first antenatal visit and 18% of data at 36 weeks were reported to be missing. Missing data for alcohol use was said to be more prevalent among the antenatal records of Indigenous women. Rates of alcohol use are calculated after removing missing data (Thompson 2014).

Alcohol use data have been included in the ACT Perinatal Data Collection since 2002. However, alcohol use was not reported in the most recent ACT perinatal health publication, *Maternal and perinatal health in the ACT 1999–2008* (Epidemiology Branch, ACT Health 2011).

Jurisdictional collection of data on alcohol use in pregnancy is not practised in the remaining Australian states. However, there does appear to be widespread data recording at the clinical level, with all jurisdictions including at least one question about alcohol consumption in their pregnancy hand-held records or electronic databases. Anecdotally, clinicians talk to most if not all mothers about alcohol use when they attend for antenatal care, as they do about other psychosocial issues.

Between 2010 and 2012, the AIHW conducted work to develop a nationally agreed uniform method for measuring and recording alcohol use in pregnancy. As noted earlier in this chapter (page 16), the work arose originally in relation to the NIRA, and pre-dates the NMDDP. COAG agreed to the enhancement of perinatal data to capture additional information in relation to antenatal care and alcohol use during pregnancy, and provided funding to the AIHW to facilitate the development of data items for inclusion in the Perinatal NMDS.

The work involved a literature review, consultation and a workshop with key stakeholders, a review and assessment of current collection measures, and a review and assessment of collection instruments. A discussion paper was also prepared for the NPDDC.

As a result of this work, the AIHW recommended the 'AUDIT-C' as the preferred instrument for capturing alcohol use in pregnancy. The AUDIT-C (see Appendix E) is a modified and shortened version of the Alcohol Use

Disorders Identification Test (AUDIT)—the full version of the AUDIT is a 10-question test that determines if personal alcohol use is harmful or 'risky'. The test was developed and is recommended by the World Health Organization (Babor et al. 2000).

The AUDIT-C consists of three questions relating to consumption, dependence and alcohol related problems. The AUDIT-C is recommended for international use in clinical settings.

International studies have verified AUDIT-C as effective for testing alcohol dependency and risky drinking (Dawson et al. 2005; Frank & DeBenedetti 2008). These studies included a systematic review of brief screen questionnaires that seek to identify problem drinking during pregnancy. This study determined that AUDIT-C had one of the highest sensitivities for identifying prenatal risk drinking (Burns et al. 2010). Additionally, this study further noted that asking women directly about their drinking presents an opportunity for intervention and advice.

The Royal Australian College of GPs (RACGP) also recommends the AUDIT-C in general medicine (see <<http://www.racgp.org.au/your-practice/guidelines/snap/3-applying-the-5as-to-each-risk-factor/34-alcohol/>>

For its latest survey in 2013, the National Drug Strategy Household Survey (NDSHS) collected data regarding alcohol use in pregnancy using the AUDIT-C. This survey currently represents the only source of national data on alcohol use in pregnancy, and the data are quite limited. Key findings in 2013 were that the proportion of pregnant women abstaining from alcohol increased slightly between 2010 and 2013 (from 49% to 53%) but this increase was not statistically significant. Of those that did consume alcohol, most (96%) usually consumed 1–2 standard drinks on that drinking occasion.

There are methodological limitations associated with data collections derived from self-report such as response and recall bias, which can result in the under-reporting of alcohol consumption. Research suggests that self-report methods are currently the only practical way of measuring alcohol consumption during pregnancy in relation to dose, timing and frequency, while also yielding information on alcohol use in the first trimester. The AIHW also collects other self-reported data in the Perinatal NMDS related to smoking in pregnancy.

Data development for alcohol use in pregnancy was interrupted in mid-2012 when agreement could not be reached with state and territory perinatal data custodians about including the item in the Perinatal NMDS. Jurisdictions agreed about the importance of

capturing alcohol use in pregnancy, but did not agree to use of the AUDIT-C without further trial. They were also concerned about: the response burden in the clinical setting; the accuracy of the data; sensitivities around questioning women about their alcohol consumption; and the use of the data, including whether the information would be linked to other data collections and used to diagnose FASD.

The AIHW will pilot the AUDIT-C in 2015–16 in conjunction with researchers at the Murdoch Childrens Research Institute. The pilot will test the AUDIT-C among focus groups of midwives to explore their opinions on the feasibility of collecting data on pregnancy alcohol intake in the context of the routine perinatal data collection process; and with groups of pregnant women to explore their considerations about providing information on alcohol consumption in the context of their own maternity care and for the purposes of a national data collection. Investigation of the use of the AUDIT-C in the Indigenous context is also part of the study.

Substance use in pregnancy

There is limited information on women who use illicit drugs in pregnancy. Burns and others (2006) found that mothers who use illicit substances in pregnancy were generally younger than other mothers, more likely to be smokers, less likely to present early to antenatal services and more likely to have a premature baby. Babies of mothers who use illicit substances in pregnancy are also more likely to be of low birthweight and have smaller head circumferences (Abdel-Latif et al. 2007). Parents of these babies may experience a multitude of interrelated problems such as mental health issues,

socioeconomic disadvantage, homelessness, social isolation and violence (Cousins 2005).

The data item *Substance use in pregnancy* was not included in the work program for Stage 2 of the NMDDP due to its considerable complexity, meaning that a long-term time frame would be required. Its importance is acknowledged, and it remains on the NMDDP priority data item list for progression in 2015–16. First steps include a literature review to explore issues of substance use in pregnancy, defining the item and its scope, gathering information about what jurisdictions and clinicians are already doing, and exploring data quality issues.

Summary of data development work on psychosocial data items

While none of the psychosocial items have progressed to become endorsed national standards, this is due to the complexity of the work, the need for piloting and associated resources, and the lack of conviction on the part of some stakeholders that these items should be incorporated in the NPDC. Some progress has been made with *Screening for domestic violence*, *Mental health* and *Alcohol use in pregnancy*, and action will continue in 2015–16. Data development for *Substance use in pregnancy* will also commence in 2015–16. Consideration should be given to focus group testing for the *Screening for domestic violence and Mental health* items in a similar study to that underway for *Alcohol use in pregnancy*. Advice should also be sought on the feasibility of a psychosocial screen in the perinatal context that would potentially encompass all the areas discussed in this chapter.



4 Data development—Maternity Care Classification System

Stage 1

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 maternity models of 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.

The work in Stage 1 consisted of a comprehensive literature review, development of the initial data framework, and extensive consultation with relevant stakeholders, resulting in the draft MaCCS. The processes and results of this work have been reported elsewhere (AIHW 2014, 2014a, 2014b).

The MaCCS is designed to 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.

Implementation of the MaCCS would involve the annual completion of a questionnaire by each maternity service to capture the characteristics of each model of maternity care at that service. The characteristics of models would be collected in a nationally consistent way by defining them in a new Maternity Model of Care Data Set Specification (MoC DSS).

Based on the characteristics of the model, a Major Model Category (MMC) and Model ID would then be assigned to that particular model at that maternity service. The MMC and Model ID codes would be recorded in clinical records and data collections that include information about maternity care within the hospital or health authority. For

example, the appropriate codes would be recorded in the perinatal data collection record for each woman to reflect the model of care she was receiving throughout her pregnancy and prior to birth.

Assigning an MMC to each model would facilitate reporting on the range of models of care available to women in each jurisdiction using common terminology such as *Team midwifery care*, *Private obstetrician (specialist) care*, *Shared care* and so on. It will also, through linkage with the Perinatal Data Collection (PDC), allow for more in-depth analysis based on characteristics of models, such as the extent of continuity of carer, whether the model is targeted for a specific group of women (such as Aboriginal and Torres Strait Islander women) or whether care was offered in a certain location (such as at home, or at a birth centre or Aboriginal Community Controlled Health Organisation).

Stage 2

Stage 2 of the NMDDP sought to develop the theoretical framework of the MaCCS into a working classification system based on a new Maternity Model of Care Data Set Specification (MoC DSS) and the specifications for a web-based data collection tool.

Development of the MaCCS during Stage 2 was undertaken with guidance from the MaCCS Working Party (see Appendix B).

The Maternity Model of Care Data Set Specification

To ensure that data collected through the MaCCS would be comparable and consistent across all users and jurisdictions, the data elements needed to be developed in a standardised way using established data development practices. The AIHW's Metadata Online Registry (METeOR), which enables nationally comparable and consistent data to be produced, was agreed the most appropriate way to standardise the MaCCS data elements. Hence the MoC DSS was developed.

National data standards for the data elements in the MaCCS specified in Stage 1 of the NMDDP were drafted in METeOR. These data standards used the definitions and data values endorsed by stakeholders consulted during Stage 1 of the project, but they required further validation via a national pilot to ensure that they were comprehensive and exhaustive.

National pilot of the MoC DSS

It was intended that the pilot would specifically test the technical aspects of the data elements developed in METeOR, that is, the data standards, rather than test the MaCCS as a classification system.

The aims of the MoC DSS national pilot were to:

- ensure that the value domains were correct and exhaustive
- test the Guide for Use for each data element and ensure there were sufficient instructions for users
- ensure that the values for the 10 Major Model Categories (MMCs) were correct and exhaustive and all models could be assigned to a single MMC.

A range of maternity services in each jurisdiction were nominated as suitable pilot sites by the health departments of each state and territory to ensure a representative mix of birthing services of different size, geographical location, casemix and models of care. The pilot was conducted between June and September 2014 via SurveyMonkey®. Participants were asked to complete a new survey for each of the models of maternity care offered to pregnant women at their maternity service. A total of 49 sites across Australia were invited to participate, of which three declined. A total of 217 surveys classifying models of maternity care using the MoC DSS were received and analysed.

Analysis of the surveys received focused on four different areas:

1. Identification of errors made by participants in recording the values for each data element (such as not following conditional obligations or other instructions contained in the data standards, and inconsistent values between different data elements).
2. Data elements and standards that needed amending, deleting or replacing.

3. Functionality required in a future web-based electronic data collection tool.
4. Foci for education and training as part of the MaCCS implementation.

Overall there were very few suggestions for additional instructions or comments from users on how the data standards could be improved or whether additional values were needed, which suggested that the existing value sets were comprehensive. It was clear however from the number and types of errors that not all participants read or understood the data standards or instructions well.

Outcomes included:

- confirmation that the 10 MMCs included in the MaCCS are suitable for classifying all models of care currently in use in Australia, with the exception of one emerging model for private obstetrician/private midwife care that will be added to the list of MMCs
- demonstration that the use of data standards alone is not enough to ensure high quality data collection, particularly when novel concepts are being introduced
- confirmation of the need for a purpose-built electronic data collection tool to improve the accuracy of data collected; and a comprehensive education program to support it.

Over 50 recommendations resulting from the pilot were reviewed and endorsed by the MaCCS Working Party. Four data elements were replaced with new, related data elements; additional values were added for three data elements; and seven data elements were provided with additional Guide for Use or DSS-specific instructions. Other recommendations related to functionality and validation rules for a future MaCCS data collection tool.

Following the pilot, the data elements of the MoC DSS were revised and finalised (Table 4.1). The MoC DSS was subsequently endorsed by NHPPC and added to the National Health Data Dictionary. The full set of specifications for the MoC DSS, as well as the full report of the national pilot, can be found in the companion volume to this report, *Maternity Care Classification System: Maternity Model of Care Data Set Specification national pilot report—National Maternity Data Development Project Stage 2*, accessed at <<http://www.aihw.gov.au/publication-detail/?id=60129554606>> and on METeOR at <<http://meteor.aihw.gov.au/content/index.phtml/itemId/559937>>

Table 4.1: Final Maternity Model of Care Data Set Specification data elements by short name

Data element short name
Establishment identifier
Target group indicator
Maternity target group
Profession of designated maternity carer
Midwifery caseload indicator
Midwifery caseload size
Extent of continuity of carer
Planned collaborative maternity carer
Routine relocation for intrapartum care and birth indicator
Expected setting for an antenatal care visit
Expected setting of birth
Postnatal visits in a residential setting
Individual or group care
Planned medical visit indicator
Additional remote or rural services offered indicator
Type of additional antenatal/postnatal remote or rural service
Expected length of time for postnatal visits in a residential setting
Major Model Category
Maternity model of care identifier (<i>not used in the pilot</i>)

Model of Care data elements for addition to the Perinatal DSS

The MMC and unique Model ID code generated by the MaCCS and assigned to each model of care can be recorded on each woman's health record (and in particular her record in the PDC) to capture the model of care received. In order to make meaningful use of this, a data element or elements need to be added to the Perinatal DSS, and eventually NMDS, to record the model of care for each woman.

In determining the appropriate data elements, the MaCCS Working Party considered the difficulty experienced in collecting data relevant to the antenatal period in the absence of an electronic pregnancy record, as well as

the issue of women moving between different hospitals during pregnancy (the Model ID code is hospital-specific). The following points were also considered:

- What is important to know about models of care and why?
- What will give the best quality data that is also of the most value in answering the questions about models of care?
- At what time does the model of care make the most difference to outcomes or have the most influence for women and their babies?

Subsequently, two data elements were recommended for development for addition to the Perinatal DSS (Box 4.1)

Box 4.1 Data elements on model of care for the Perinatal DSS/NMDS

Short name: Principal model of care

Definition: The model of maternity care a woman received for the majority of her pregnancy care or, where time is uncertain or of similar duration for more than one model of care, then the model of care that was most significant in the woman's pregnancy.

Value domain: This is populated using the MaCCS, and would be the value of the unique model of care code for that model of care that had been entered into the MoC DSS database or one of a set of generic model codes (such as 'no formal care').

(continued)

Box 4.1 (continued) Data elements on model of care for the Perinatal DSS/NMDS

Note: Further information will be required in the Guide for Use (for this data element) that allows the clinician some judgment in selecting which model was the principal model. The principal model of care should be selected based on both duration of care as well as the significance of the care. For example if a woman was in a low-risk General Practitioner Shared care model from 12–24 weeks and then developed hypertension and pre-eclampsia and was in a high risk model from 24–36 weeks, then we would expect the clinician recording the data to select the second model of care.

Short name: Model of care prior to birth

Definition: The model of maternity care a woman is under at the onset of labour or at the time of non-labour caesarean section. This may be different to the model of care she received throughout her pregnancy or the Principal model of care.

Value domain: This is populated using the MaCCS, and would be the value of the unique model of care code that had been entered into the MoC DSS database for that model of care or one of a set of generic model codes (such as 'no formal care').

Ideally, when information systems in the future allow it, the model of care at all stages of pregnancy should be recorded. This would involve recording whenever a woman commenced and changed a model of care throughout pregnancy. This will not be possible until there is a single contemporaneous or 'real time' electronic pregnancy record in each state or territory.

The MaCCS Data Collection Tool

Jurisdictional stakeholders provided in-principle support for the MaCCS and agreed that an electronic data collection tool would increase the likelihood of it being implemented. The national pilot further highlighted that the data elements in the MaCCS were a new concept to staff working in maternity services and to data custodians, and an electronic data collection tool would help to ensure the data collected on maternity models of care were easily collected and of high quality.

The functionality, business rules and interoperability requirements of a data collection tool (DCT) have since been developed, informed by a range of sources, including consultation with jurisdictional and national stakeholders, consultation with industry specialists, and examination of the results of the MoC DSS national pilot and the metadata contained in the DSS itself.

The DCT will translate a questionnaire, based on the data elements of the MoC DSS (see Table 4.1), into an electronic format with a web interface (hosted by each jurisdiction, or nationally, via the internet or intranet), and a back end to collate the data (stored on a secure server). Maternity services staff will use the DCT to classify their models of care by answering

the questionnaire about each model of maternity care at the service. Programmed functionality will guide users through the process, and business rules will be incorporated to restrict the data fields that could record inconsistent values for different data elements in the MoC DSS, thereby reducing errors. The MaCCS DCT will allocate a unique Model ID code for each model of care entered via the questionnaire.

The data collected by the MaCCS DCT, including the Model ID codes, will be stored centrally, either at the national or jurisdictional level. Figure 4.1 provides a visual representation of how data might flow through the system, the data collection points, storage databases, and where the DCT fits into this bigger picture. The figure shows a national solution, whereby MoC questionnaire response data are provided directly by hospitals to the AIHW, where model IDs would be assigned and provided back to jurisdictions and hospitals.

Once models are classified, clinicians can enter the appropriate Model ID code into each woman's perinatal data record at the maternity service. The centrally held MoC database will be searchable, enabling staff to find the Model ID code retrospectively if necessary. Similarly, if a woman presented to a different hospital for intrapartum care than the one where she received her antenatal care, staff will use the search function of the DCT to locate the relevant Model ID code. The Model ID code will be used to populate two data fields in the woman's perinatal data record—*Principal model of care* and *Model of care prior to birth*, and two new corresponding data elements will be added into the Perinatal DSS to record the model of care for each woman (see Box 4.1).

The future of reporting on maternity models of care

The NMDDP has seen the development of a unique method for classifying maternity models of care based on the underlying characteristics of the woman, the carers and the care provided. The MaCCS proposes a national data collection system for maternity models of care that would enable detailed examination of models of care together with maternal and perinatal characteristics and

outcomes, as well as summary national statistics on the models of care being offered in Australia.

The MoC DSS has been created to underpin the MaCCS. It has been piloted and revised, and endorsed by NHIPPC as a national standard. A number of administrative, resourcing and testing processes are still required before development and implementation of the MaCCS DCT can become a reality, allowing models of care to be accurately classified according to the MaCCS. Work will continue in 2015–16.

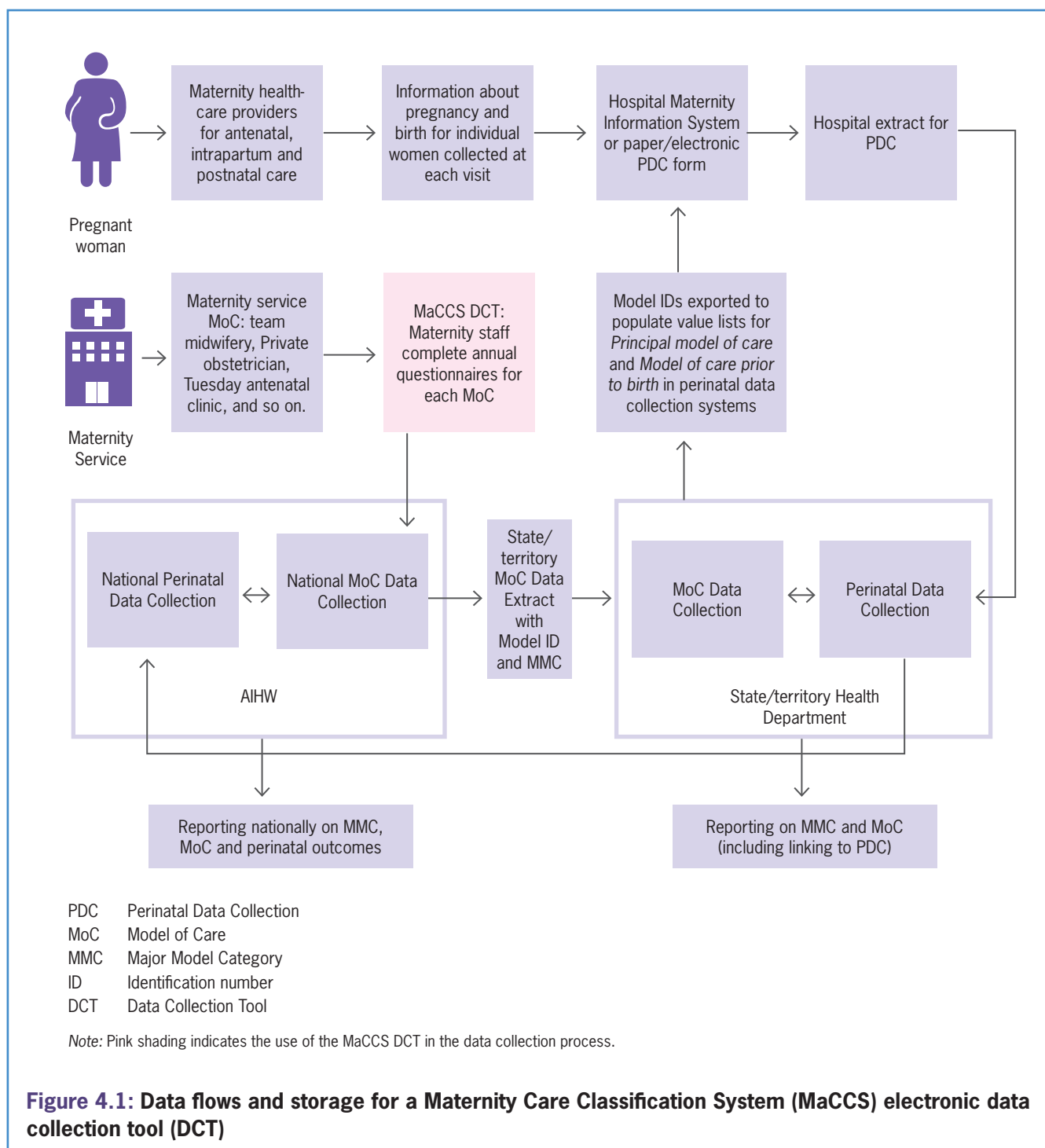


Figure 4.1: Data flows and storage for a Maternity Care Classification System (MaCCS) electronic data collection tool (DCT)



5 Maternal mortality

The NMDDP has facilitated the production of two comprehensive reports on maternal mortality, *Maternal deaths in Australia 2006–10* (AIHW: Johnson et al. 2014), and *Maternal deaths in Australia 2008–2012* (AIHW: Humphrey et al. 2015). These reports were the 15th and 16th in the Australian maternal mortality reporting series. The purpose of the series is to show trends in maternal mortality and to develop an evidence base for maternal deaths that can be used to inform maternity services policy and practice.

Maternal deaths are fortunately rare in Australia. Nevertheless, between 2006 and 2012, on average, 20 women died each year from causes related to pregnancy or birth, a rate of around 7 deaths per 100,000 women who gave birth. The rate is twice as much in Aboriginal and Torres Strait Islander women. While the death rate has decreased since 1972–1975, when it was 12.7 deaths per 100,000 women who gave birth, the rate has not significantly changed since 1982–1984, with fluctuations over the years reflecting the volatility of rare death reporting (Figure 5.1) (AIHW: Johnson et al. 2014). The review of maternal deaths remains an important measure of maternity services and obstetric care.

A maternal death is defined as ‘the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes’ (WHO 1992).

Key causes of maternal death include cardiovascular disease, obstetric haemorrhage, thromboembolism, hypertensive disorders and deaths due to psychosocial causes.

Primary data collection for, and review of, maternal deaths in Australia is undertaken by state and territory health departments with initial notification and significant input from the relevant Registrars of Births, Deaths and Marriages, and Coroners.

State and Territory Maternal Mortality Committees (STMMCs) are convened via state and territory health departments to conduct reviews of these deaths. Each STMMC is responsible for case findings, determined after conducting confidential death enquiries to establish primary and contributory causes of the maternal death, and assigning a classification to the death.

Data from the jurisdictions are subsequently provided to AIHW for collation into a national data set and preparation of a national report on maternal deaths.

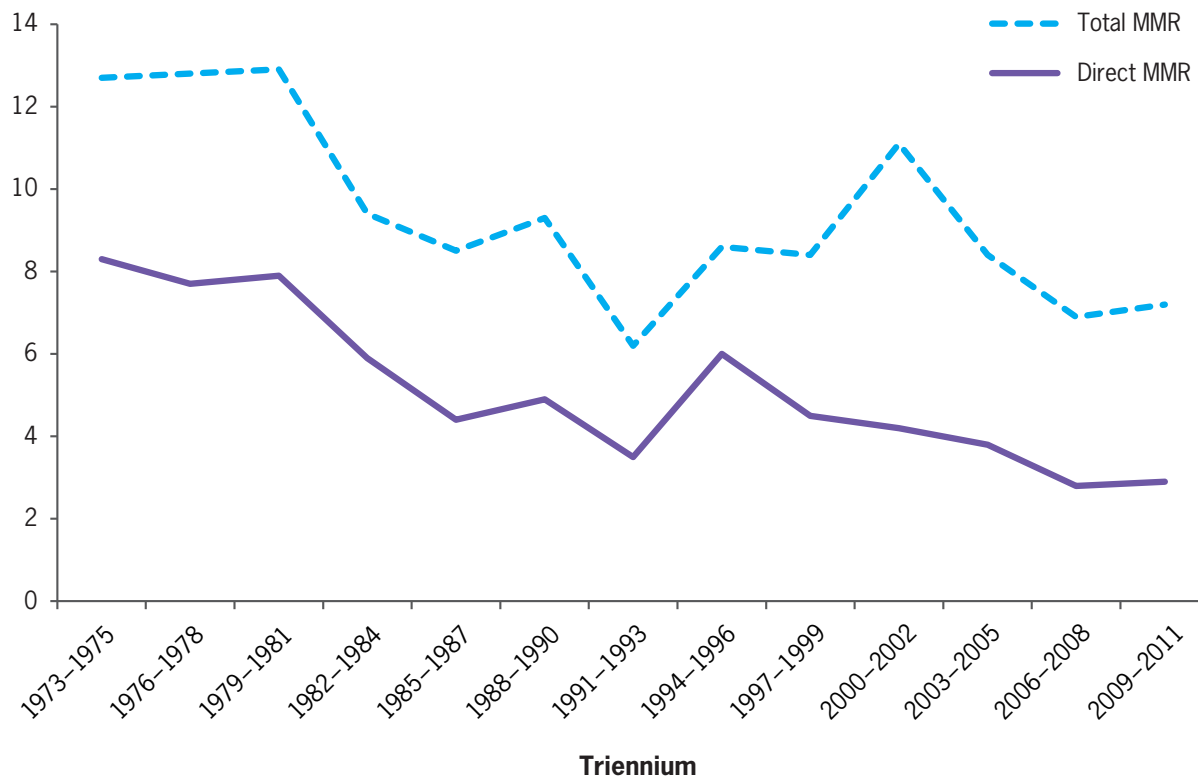
Stage 1

The NMDDP provided the opportunity to review all processes involved with compilation of a national maternal mortality report, with the aim of achieving greater consistency in national reporting. There had been a hiatus in reporting in previous years due to uncertainty around the best way to compile and report high quality national maternal mortality statistics.

Australia has lacked a nationally agreed uniform method for reviewing and reporting information about maternal deaths that is applied across all jurisdictions. Good progress has been made during the NMDDP. Collection of consistent data from STMMCs for the 2006–2010 maternal mortality report was achieved using a standardised form agreed through consultation. A new National Maternal Death Reporting form was also developed and is proposed to replace the current form in future years once it has been finalised (see next section). A national committee of relevant experts and stakeholders, the National Maternal Mortality Advisory Committee (NMMAC) (see Chapter 1) has guided the work throughout the NMDDP.

The publication *Maternal deaths in Australia 2006–10* (AIHW: Johnson et al. 2014), was prepared during Stage 1 of the NMDDP.

Deaths per 100,000 women giving birth



Source: Maternal deaths in Australia 2008-2012 (AIHW: Humphrey et al. 2015).

Figure 5.1: Maternal mortality ratios, Australia, by triennium, 1973-2011

Stage 2

Maternal mortality reporting

Maternal mortality reporting continued during Stage 2 with the preparation of *Maternal deaths in Australia 2008-2012*, published in June 2015 (AIHW: Humphrey et al. 2015). A similar methodology was followed as for the previous report, including epidemiological data on maternal deaths, the use of illustrative vignettes known as 'case summaries', clinical commentary, and references to published guidelines for further education on specific clinical management where available and relevant.

Over the 5-year period 2008-2012, there were 105 maternal deaths in Australia that occurred within 42 days of the end of pregnancy, representing a maternal mortality ratio (MMR) of 7.1 deaths per 100,000 women who gave birth in Australia. There were 49 maternal deaths directly related to the pregnancy, while 53 deaths were indirect maternal deaths, due to non-pregnancy-related conditions aggravated by the pregnancy or

its management. Three maternal deaths could not be classified as either direct or indirect deaths.

The women who died were aged between 17 and 50. Women aged 40 and over, women who are obese with a body mass index (BMI) of 30 or more, and women of Aboriginal and Torres Strait Islander origin, were among those at increased risk of maternal death.

Obstetric haemorrhage, thromboembolism and hypertensive disorders were the leading causes of direct death and accounted for 6 in 10 direct maternal deaths, while the leading cause of indirect maternal death was cardiovascular disease. There were 16 deaths due to psychosocial causes, including 12 due to suicide.

National Maternal Death Report form

A prospective National Maternal Death Report (NMDR) form was developed in Stage 1 of the NMDDP (see AIHW 2014a). Its purpose is to collect more detailed risk factor, pregnancy and clinical information on maternal deaths than previously. The use of a standard form will improve the quality and utility of data collection, and

can also help to minimise the number of additional data requests to jurisdictions for the development of national maternal death reports. The NMDR form is designed to be used at a national level and is not intended to replace local review or data collection processes.

During Stage 2, the NMDR form was piloted in Queensland and South Australia, and subsequently also reviewed by jurisdictional coroners. The content was found to be relevant and fit-for-purpose. The form needs further development, including production of an electronic version. A national implementation plan for the form is also required.

Data linkage study on late maternal deaths

A national population data linkage study was 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, most likely reflecting the fact that 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.

The data linkage study was retrospective and used linkage techniques to find deaths of women aged 15–49 years occurring within 1 year of giving birth.

The report's development and data linkage processes were described in the NMDDP Stage 1 report (AIHW 2014), 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/publication-detail/?id=60129548679>>.

Due to the complex processes involved in this study, it has taken time to extract, validate and interpret the data and present the results in a way that is easily understood and meaningful. The results of the data linkage study will be published in 2016 in a forthcoming AIHW publication, *Mothers who die: a national population data linkage study of women who died within one year of giving birth*.

The future of maternal mortality reporting

The 2006–2010 and 2008–2012 maternal deaths reports (AIHW: Johnson et al. 2014; AIHW: Humphrey et al. 2015) have revived national reporting in this critical area and it is important that the work continues. The Commonwealth, and the states and territories need to continue to work together to maintain the commitment to national reporting.

Legislative barriers prohibit the sharing of information across some state and territory borders and this can affect some aspects of reporting. For example, data elements such as maternal place of residence (and hence remoteness of residence) cannot be presented with the necessary degree of accuracy. Formal mechanisms are needed for more effective data sharing among jurisdictional maternal mortality registration authorities and maternal mortality data collection and review committees.

Future reporting will be improved if information related to the assessment of avoidable factors or preventability surrounding the deaths can be included. Currently this is not incorporated in the national reports due to the absence of a nationally consistent approach to assessment of preventability of deaths, and the retrospective nature of the data collection. This information is not readily available or routinely collected in all jurisdictions.



6 Perinatal mortality

About 1% of maternities end in a perinatal death, that is, a stillbirth (also known as fetal death) or a neonatal death (deaths of liveborn babies up to the age of 28 days). In 2013, there were 2,998 perinatal deaths reported in Australia, equating to 1 in every 100 births (ABS 2015c). The death of a baby is a tragic event for the mother and her family, and, while recognising that not all perinatal deaths can be avoided, investigation and reporting of deaths may inform preventative management strategies for maternity care.

Stage 1

During Stage 1 of the NMDDP, options were investigated for standardised national reporting of perinatal mortality using data from the NPDC and other data sets containing information about perinatal deaths. There was universal support from stakeholders for a regular national perinatal mortality report. Stakeholders also recommended that a DSS or NMDS of national data standards for perinatal mortality be developed.

Stakeholders agreed that it would be necessary to standardise the process for investigation of causes of death and examination of preventability issues. In particular there would need to be agreed strategies in place across all jurisdictions for ensuring complete ascertainment of perinatal deaths, and determination of cause of death using multidisciplinary review of all clinical and post-mortem information. Integration of finalised perinatal death records (for example, after coronial review) with birth records would also need to occur in order to keep the perinatal data collection up to date.

The Stage 1 work has been reported in detail 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*, available at <<http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129548686>>.

Stage 2

Issues with ascertainment of neonatal deaths

During Stage 2, an investigation was conducted into how to overcome the gaps and the key issues set out in Stage 1 of the NMDDP. The results of this investigation will be reported in *Improving perinatal mortality data collection and reporting in Australia (AIHW 2016 forthcoming)*. Meanwhile, preliminary findings are included in this chapter.

Neither vital registration collections (ABS) nor the NPDC (AIHW) have complete ascertainment and reporting of perinatal mortality in Australia. These collections are separately reported, are not reconciled, and have different underlying collection methods.

Information in the NPDC on fact of stillbirth is considered to be near complete, but neonatal deaths have been found to be incompletely captured by jurisdictional Perinatal Data Collections (PDCs). The level of under-ascertainment has been estimated at 8% in the NPDC, with the difference varying according to jurisdiction (AIHW 2014d). This is likely due to a lack of information about deaths that occur outside the hospital of birth or outside the birth episode.

Generally, once closed off for the reporting year, the PDCs and consequently the NPDC are not updated retrospectively with information about events occurring post-discharge, for example where a baby aged less than 28 days is either discharged or transferred from the birth hospital and subsequently dies, or when later information emerges, such as a coroner's report about a neonatal death. All jurisdictions have implemented some processes to cross-check vital registration data from the RBDM with PDC data, which helps improve ascertainment, but the regularity and type of process (for example manual or electronic), and any updating of the PDC, may vary from place to place.

Preliminary reconciliation of neonatal deaths between the ABS cause-of-death unit record file (CODURF) and the NPDC show differences in the numbers of reported deaths by age of death. In total, there were more neonatal deaths in the CODURF than in the NPDC—however, at a state and territory level, Victoria and Western Australia recorded more neonatal deaths in the NPDC than were registered in the CODURF. Day 1 neonatal deaths were found to be captured more comprehensively in the NPDC than the CODURF, but for day 2 to day 27 neonatal deaths, CODURF registrations exceeded the NPDC. This accords with the known limitation of birth data collections to capture deaths of babies after they leave the birth hospital. The forthcoming AIHW report (2016) shows that some neonatal deaths may in fact be missing from the NPDC because the neonate was never registered in the PDC, such as would occur with an unreported community birth.

There is a need to explore reconciliation of cross-border deaths data because there is no standard process for notification and review when a perinatal death occurs in a different jurisdiction to where the baby was born. Some neonatal deaths are therefore excluded from review altogether. New South Wales and the Northern Territory are the only jurisdictions that include neonatal deaths of babies born elsewhere in their reports.

To improve ascertainment, legislative changes might be needed for more effective data sharing, both between jurisdictional RBDMs, PDCs and PMRCs, and across borders. In some states and territories, data sharing is more extensive and well-established, but procedures vary among jurisdictions due to differences in population size, legislative arrangements and the resources available for these activities. A legal review could help overcome issues in data sharing among statutory authorities within a jurisdiction (including the RBDM, Coroner, the PDC and the PMRC). Ideally, data-sharing capabilities among all jurisdictional health authorities in Australia could be formalised to improve ascertainment and review of cross-border deaths.

A proposal for national reporting of perinatal mortality

The report, *Improving perinatal mortality data collection and reporting in Australia* (AIHW 2016 forthcoming),

proposes a model for national reporting of perinatal mortality. Establishing this model has two main elements:

- enhancing the existing perinatal data collection by improving the supply of existing elements and supplementing the collection with new elements
- data linkage between vital registrations, review committee data and the PDC, either at the jurisdictional or national levels.

Potential enhancements to the perinatal data collection

Existing data

Each jurisdiction already collects some information on perinatal deaths in its PDC and provides this to the NPDC:

- Fact of perinatal death is available from two data items:
 - *Birth status*, which has been a data element in the Perinatal NMDS since 1997
 - *Baby outcome*, a voluntary item not consistently reported by all jurisdictions to the NPDC. *Baby outcome* is the only variable that reports neonatal death status.
- Voluntary (non-NMDS) data items are supplied to varying levels of completeness and quality including:
 - Baby's date of death
 - Cause of death and disease classified by:
 - International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian modification (ICD-10-AM or ICD-10), the World Health Organization's internationally accepted classification system for death and disease.
 - Perinatal Society of Australia and New Zealand–Perinatal Death Classification (PSANZ–PDC) and/or the PSANZ–Neonatal Death Classification (PSANZ–NDC).
 - Autopsy status
 - Age of neonatal death in days at time of death.

The completeness of voluntary items supplied by the PDCs to the NPDC varies greatly, and overall is currently inadequate as a means of providing national information on neonatal mortality. Improving the supply of this information, perhaps by working with states and territories to add data items to the NMDS or a DSS could improve data quality in the NPDC.

Supplementary data

The addition of supplementary data elements to the NPDC, such as the timing of perinatal death in relation to labour, autopsy status, and the results of post-mortem investigations, would also enhance current information collected on perinatal mortality.

These supplementary data can be sourced from state and territory perinatal mortality review committees (PMRCs). The PMRCs (different names are used in each jurisdiction) have a multidisciplinary membership with expert representation from obstetricians, midwives, neonatologists and dedicated perinatal pathologists. Procedures for perinatal death reviews vary between jurisdictions, reflecting differences in population size, legislative arrangements and resources available for these activities. Clinical information relating to each perinatal death is collated and revised, including the results of post-mortem investigations (where available), and classification of cause of death is assigned.

PMRCs are currently convened by health authorities in all jurisdictions except the Northern Territory where perinatal deaths are reviewed by the Northern Territory's two main health services.

Useful supplementary data from PMRCs include:

- State/territory of death review
- Year of death review
- Termination of pregnancy flag
- Baby's date of death
- Autopsy status
- Other post-mortem investigations
- PSANZ–Perinatal Death Classification
- PSANZ–Neonatal Death Classification
- Place of death
- Timing of stillbirth in relation to labour
- Time of birth
- Time of death
- Age of neonate at time of death in hours (death at less than 1 completed day of life)
- Age of neonate at time of death in days up to less than 28 days
- ICD-10 or ICD-10-AM cause of death after perinatal review primary
- ICD-10 or ICD-10-AM cause of death after perinatal review other.

The PMRCs supplied supplementary data to the above specifications for a forthcoming AIHW report: *Perinatal deaths in Australia: 1993–2012* (outlined in more detail later in this chapter). The analysis of these data will help determine their usefulness for future and regular reporting.

In some states and territories, information on the causes of perinatal deaths may be supplied back to the PDC by the PMRC. Factors contributing to the availability and provision of supplementary data, such as jurisdictional legislation and resources, require further investigation. Additional burden on state and territory perinatal data collection activities would also need to be considered.

Data linkage

Data linkage would provide an appropriate method to improve the ascertainment of perinatal deaths at a jurisdictional or national level in Australia. In particular, data linkage could detect the estimated 8% of neonatal deaths missing from the NPDC. Incorporating these deaths into the NPDC would produce a more integrated national pregnancy, childbirth and maternity data collection. Linking of data from two or more administrative data collections would extend the scope, coverage and quality of perinatal data in Australia.

Two data linkage strategies that could potentially be used to generate such a national collection are:

- *national linkage* performed by the AIHW of each jurisdiction's PMRC data with the National Death Index (NDI). The NDI has been specifically set up for the purposes of data linkage, while CODURF data are de-identified and are used for statistical reporting. The NDI holds information about both fact of death (whether a person died) and cause of death (what the person died from), supplemented with information from CODURF.
- *jurisdictional linkage* performed by each state and territory health authority of the jurisdictions' PMRC data with the NDI.

The AIHW holds the NDI, which is a catalogue of deaths specifically set up for the purposes of research. Fact-of-death data are received monthly from the RBDMs and collated into the NDI, and as part of this process a monthly national fact-of-death file is returned to the RBDMs (see Figure 6.1 for an illustration of how registered deaths are incorporated in data collections). The NDI is supplemented annually with cause-of-death information from the CODURF (this is compiled through ABS coding of cause of death and through the RBDMs—see Figure 6.1). Researchers and other agencies can

have data linked to the NDI to ascertain fact and/or cause of death. For more information about the NDI, see <<http://www.aihw.gov.au/deaths/aihw-deaths-data/>>.

The national linkage option outlined above involves the states and territories sending identifiable PMRC data to the AIHW Data Linkage Unit for data linkage with the NDI. This step would potentially add deaths that were missing from the PMRC data (for example for babies born in one jurisdiction and dying in another, who may not have had a review). The linked file, with identifying information removed, would then be provided to the AIHW analysis unit where it could be merged with other, non-identifiable data supplied by PMRCs to create one national data set of perinatal deaths. Records that could not be fully linked would be returned to the states and territories for investigation, identification and establishment of the cause of death. The updated records would then be re-supplied to the national data set. This national data set could also then be linked to the NPDC to form a fully integrated national collection. Linkage keys based on the state/territory perinatal data record ID and PMRC ID would enable the linkage to occur across the different data sets, and a mix of linkage methods may need to be employed.

The second option involves each state and territory health authority linking PMRC data and data from the NDI within their jurisdiction. The states and territories would then send the resulting perinatal death data set, with identifiable information removed, to AIHW for compilation into one national data set. Linkage to the PDC or NPDC data, at the state/territory or national levels, would facilitate the incorporation of maternal and birth data into the national collection.

There are advantages and disadvantages of both methods and these would need to be further investigated. For example, the national linkage option would assist with identification of babies born in one jurisdiction who die in another whereas the jurisdictional linkage option might be more straightforward in terms of privacy and legislation issues around sharing of data.

More information on these options will be available in *Improving perinatal mortality data collection and reporting in Australia* (AIHW 2016 forthcoming).

Web-based data capture

Researchers at the Mater Medical Research Institute in Queensland have been piloting the use of a web-based system for collecting standardised data on stillbirths (with the option to extend to neonatal deaths) in hospitals. The three-year research project is funded by the National Health and Medical Research Council (NHMRC). The

system uses the National Perinatal Death Clinical Audit Tool developed by PSANZ and the Australian and New Zealand Stillbirth Alliance (ANZSA), and based on a system currently used in New Zealand for collecting information in hospitals about each perinatal death (see the ANZSA website for more information about the tool <<http://www.stillbirthalliance.org.au>>).

The purpose of this data collection system is to provide the critical data needed for hospital or regional reviews of perinatal deaths in conjunction with the results of post-mortem investigations, for local audit or submission to state/territory health authorities. The data collection includes fields for the PSANZ Perinatal Death Classification and the PSANZ Neonatal Death Classification, with both coded and text fields to incorporate the outcome of multidisciplinary review of the circumstances of the death.

The output data were not designed to be part of a data collection for national reporting of perinatal mortality, therefore these data items do not necessarily align with data items in the Perinatal NMDS or other National Health Data Dictionary (NHDD) data items. Investigation is needed to determine whether the collection could be adapted for this function and/or whether a core set of items could be used as a supplementary source of information. This standardised web-based data collection system may have value as the basis for validation and quality control of cause-of-perinatal-death at a jurisdictional or national level—if it is taken up by all state and territory health departments (AIHW 2014d).

Other findings and recommendations of NMDDP work on perinatal mortality—classification issues

The NPDC holds data that are coded using the PSANZ classification system, applied to the reviewed cause of perinatal death by the PMRCs, while the ABS holds perinatal death information coded using the ICD-10 classification system, without taking into account the investigations of the perinatal death and the subsequent multidisciplinary clinical PMRC review.

Both classification systems have benefits and limitations. While the PSANZ classification system can provide more specific clinical information than available from ICD-10 codes, PSANZ is predominantly used only in Australia and New Zealand, which makes international comparisons problematic. ICD-10 codes are, on the other hand, widely used internationally. The data-linkage options discussed in this chapter, however, could create a national data collection that includes both types of cause-of-death code for each death without the need for double coding.

Whether a linked data set is compiled or not, it may be worth examining the concurrent use of ICD-10 and PSANZ codes for reviewed perinatal deaths. In addition, the feasibility of developing an algorithm for mapping ICD-10 and PSANZ cause-of-death codes could be explored, to increase the utility of existing perinatal mortality data.

National Perinatal Mortality 1993–2012 report

A *Perinatal deaths in Australia 1993–2012 report* is under development. This first national report on perinatal mortality will be a major advance in the provision of national information on this important topic. It will include a statistical analysis of perinatal deaths in Australia, and may also include a discussion on the definitions and classification systems in use, the various jurisdictional perinatal death classification methodologies, causation of perinatal deaths and demographic and clinical characteristics of perinatal deaths.

Depending on the quality of the available data, analyses will be undertaken of: mortality rates, including trends in stillbirth, and neonatal and perinatal mortality, for 1993 to 2012; and stillbirth, neonatal and perinatal mortality rates by Indigenous status, birthweight, gestation and by whether an autopsy was conducted or not. Analyses of cause-of-perinatal-death by year and Indigenous status, and by maternal risk factors (where available), will be undertaken using both the PSANZ and ICD-10 classifications of cause-of-death where possible. Timing of birth for both stillbirths and neonatal deaths is another variable of interest that will be explored. Demographic and clinical characteristics such as maternal age, maternal smoking and parity will also be reported.

The future of perinatal mortality reporting

In addition to the first national report on perinatal mortality, developing a national data collection that incorporates data linkage methods to improve ascertainment of deaths would greatly enhance information availability and quality. Such a data repository would be invaluable for informing clinical practice improvement and evidence-based policy development, and, ultimately, improving the health of Australia's mothers and babies.



7 Improving the availability of maternity data and metadata

An important and continuing aspect of the NMDDP has been to consolidate and streamline reporting of maternity data. Figure 7.1 depicts the publications and products that are or will be produced from the NPDC, and the associated information flows and source data collections.

The NPDC is collated from state and territory perinatal data collections and provides a rich data source for the annual *Australia's mothers and babies* publication, which has traditionally been published in hard copy with a mix of national and state and territory tables. The series continued in 2015 with a change of format to cater for a wider variety of audiences. A hard copy 'in brief' report presented national data tables and brief commentary so that the main points could quickly be grasped. The perinatal data portal—described below—complements and supplements the publication by providing more detailed breakdowns for many variables of interest, and presents these in a dynamic, interactive format. Online data tables provide state and territory and other data for users who require this level of detail.

Maternal and perinatal mortality reports will continue to be produced, drawing on data from state and territory maternal and perinatal mortality collections as well as the NPDC (see Figure 7.1). As described in earlier chapters, the aim is to establish ongoing national collections in both these areas so that knowledge and expertise is not lost each time a national database needs to be compiled, as has been the situation up until now.

While the MaCCS is still under development, data from this collection will feed into the NPDC. A detailed data set is another output of the future MaCCS that researchers will find of value. In addition, the MaCCS will meet the reporting requirements of NCMI 20.

The National Hospital Morbidity Database (NHMD), collated from state and territory hospital morbidity

collections, is the data source for NMDDP priority data items *Peripartum hysterectomy* and *Indications for peripartum hysterectomy*, and can also be a useful source of additional or validation data on mothers.

Metadata such as the national data standards in the Perinatal NMDS and DSS underpin the NPDC and other perinatal data collections, and are catalogued in the Maternity Information Matrix (MIM).

The perinatal data portal and the MIM are web-based tools that were developed and/or expanded during the NMDDP—more detail on both products is provided below.

Perinatal data portal

The perinatal data portal, developed in Stage 2 of the NMDDP, offers a contemporary presentation of maternal and perinatal data in a user-driven format that includes graphs and downloadable data tables. The data portal complements the scope of material traditionally published in hard copy as part of the *Australia's mothers and babies* series of reports.

The portal adds value to the existing report by providing an interactive method of accessing the data and by including (data quality permitting) trend information and additional data disaggregations by state, maternal age group, parity, Indigenous status of mother, country of birth, remoteness and SEIFA, hospital sector, and hospital accommodation status.

Data are being progressively released module by module following the maternal pathway, commencing with maternal demographics (first release), antenatal care and maternal risk factors (second release), labour and delivery (third release), and baby outcomes (future release).

Future plans include:

- new data items developed during the NMDDP as data become available
- multiple data sources, for example reporting pregnancy-associated hysterectomy from hospital morbidity data
- reporting at lower levels of geography such as regions or primary care health networks
- reporting at the service level.

The portal is accessible on the AIHW website at <<http://www.aihw.gov.au/perinatal-data/>> or via a link from the Mothers and Babies overview page on the same website at <<http://www.aihw.gov.au/mothers-and-babies/>>. (Some screenshots from these pages are included in Appendix G.)

Maternity Information Matrix

The Maternity Information Matrix (MIM) is a metadata collection providing a summary of data items in Australian national and jurisdictional data collections relevant to maternal and perinatal health. It allows comparisons to

be made of data items across collections and shows existing data gaps and inconsistencies (see Appendix F for sample screenshots).

The first prototype of the MIM was developed in 2010 and was then revised and updated during Stage 1 of the NMDDP to reflect data collection practices as at July 2011. The first web version was released in February 2012.

The MIM is a dynamic tool that requires regular, preferably biennial, updating to ensure it accurately reflects changes to data items that inevitably occur in all data collections. During Stage 2, the metadata were updated to reflect practice as at July 2013.

The MIM currently describes the data items in 43 collections (see Table 7.1). Some of these collections have national coverage while many are jurisdiction-based collections.

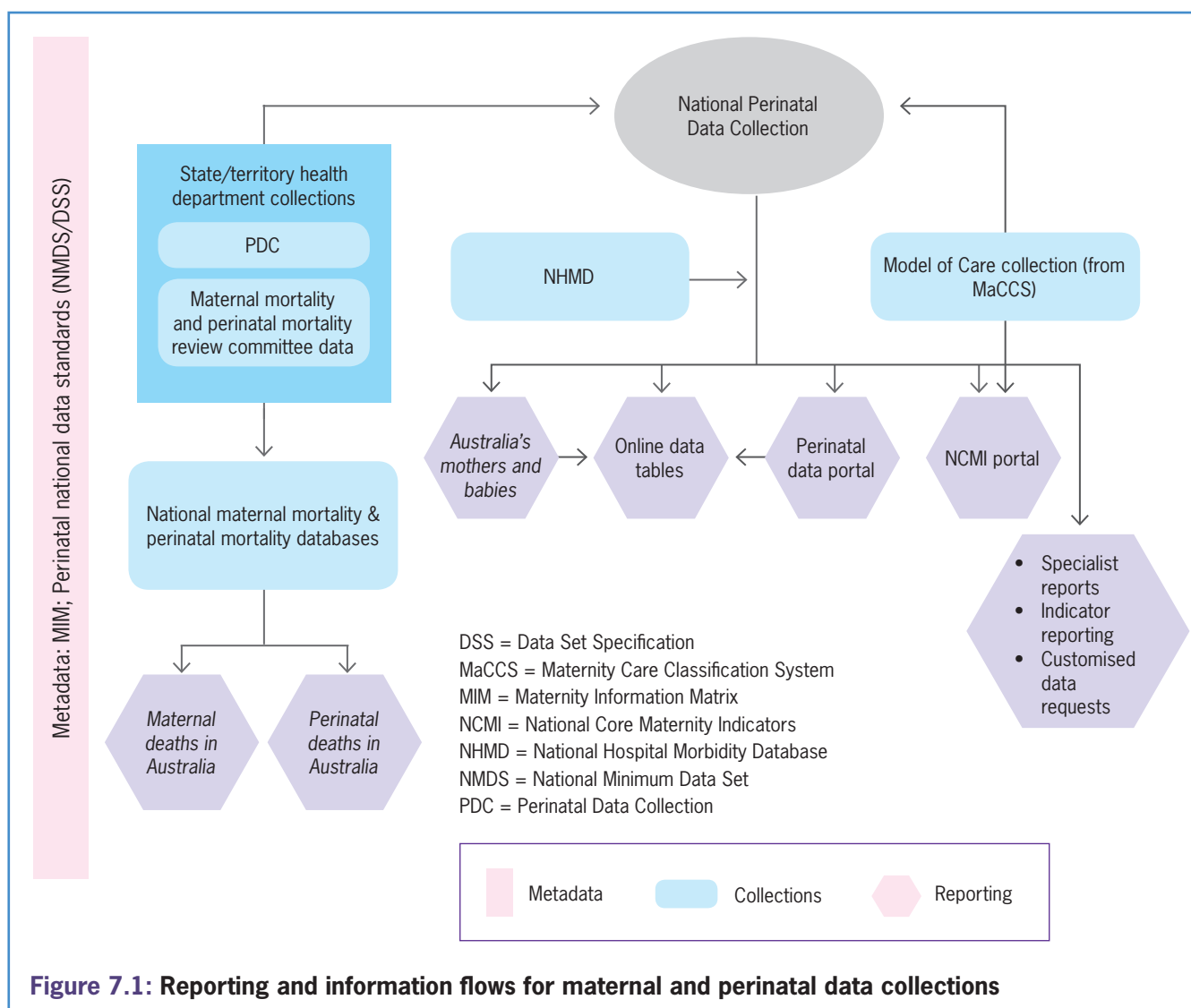
Table 7.1: Data collections in the Maternity Information Matrix

Data collections	Data collections
National	NSW
National Perinatal Data Collection (NPDC)	NSW Perinatal Data Collection
Perinatal National Minimum Data Set (NMDS)	NSW Register of Congenital Conditions
Australian Congenital Anomalies Monitoring System (ACAMS)	NSW Maternal and Perinatal Committee
National Maternal Deaths Database (NMDD)	NSW Births Registration collection
National Coroners Information System (NCIS)	NSW Deaths Registration collection
National Hospital Morbidity Database (NHMD)	Victoria
Australian and New Zealand Neonatal Network (ANZNN) Register	Victorian Perinatal Data Collection (VPDC)
Australasian Maternity Outcomes Surveillance System (AMOSS)	Victorian Birth Defects Register
Australian Bureau of Statistics, Births	Victorian Consultative Council on Obstetric and Paediatric Mortality and Morbidity (CCOPMM)
Australian Bureau of Statistics, Causes of Death	Victoria Births Registration collection
Australian Bureau of Statistics, Perinatal Deaths	Victoria Deaths Registration collection
Queensland	WA
Queensland Perinatal Data Collection	Western Australian Midwives Notification System (WAMNS)
Queensland Maternal and Perinatal Quality Council (QMPQC)	Western Australian Register of Developmental Anomalies (WARDA)
Queensland Births Registration collection	Western Australia Births Registration collection
Queensland Deaths Registration collection	Western Australia Deaths Registration collection

(continued)

Table 7.1(continued): Data collections in the Maternity Information Matrix

Data collections	Data collections
SA	Tasmania
South Australian Perinatal Statistics Collection	Tasmanian Perinatal Data Collection
South Australian Birth Defect Register	Tasmanian Council of Obstetric and Paediatric Mortality and Morbidity (COPMM)
South Australian Maternal, Perinatal and Infant Mortality Committee (MPIMC)	Tasmania Births Registration collection
South Australia Births Registration collection	Tasmania Deaths Registration collection
South Australia Deaths Registration collection	
ACT	NT
ACT Perinatal Data Collection	Northern Territory Perinatal Data Collection
ACT Perinatal Mortality Committee	Northern Territory Births Registration collection
ACT Births Registration collection	Northern Territory Deaths Registration collection
ACT Deaths Registration collection	
Special purpose collections	
Australian Maternity Outcomes Surveillance System (AMOSS)	
National Maternal Deaths Database	



Conclusions

Stage 2 of the NMDDP has seen substantial progress in the areas of data development, maternal and perinatal mortality reporting, and online dissemination of perinatal data.

Two new data set specifications have been developed: the Perinatal DSS and the Maternity Model of Care DSS. Data development for psychosocial items continues to press ahead in sensitive areas such as screening for domestic violence, and an information paper on this topic is forthcoming. A second maternal deaths report has been published, and the first national report on perinatal mortality will be released later in 2016.

While progress has been steady and moving in the right direction, work needs to continue on:

- finalising data development for the remaining clinical items, and progressively implementing these items into state and territory perinatal data collections
- data development for psychosocial data items, to map a clear direction for the future
- building and testing an electronic tool for the MaCCS and implementing it

- establishing ongoing national collections for maternal and perinatal mortality to guarantee future consistent and regular national reporting on these important areas
- integrating and streamlining maternity data reporting through developing the online perinatal data portal further, updating the Maternity Information Matrix to provide users with timely information in user-friendly formats, and publishing the *Australia's mothers and babies*, maternal mortality and perinatal mortality reports.

The Maternity Services Review that led to the development of the National Maternity Services Plan recommended that 'stable, ongoing arrangements for national maternity data collection, analysis and review... be a priority' (Commonwealth of Australia 2009). National governance has been a key feature of this project. The NMDDP Advisory Group and its subcommittees, representing clinical, academic, health information, consumer, and Commonwealth and state and territory government sectors, is a driving force for the project.

Stage 3 will encompass further consolidation of the gains made in the first 4 years, and embedding of sound processes and systems for the future.

Appendix A: Perinatal National Minimum Data Set

Table A.1: Perinatal NMDS items

Metadata item ^(a)	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 20 weeks of pregnancy), yes/no code N	365417
Female (pregnant)—tobacco smoking indicator (first 20 weeks of pregnancy), yes/no code N	365404
Female—caesarean section at most recent previous birth indicator, code N	422187
Female—number of antenatal care visits, total N[N]	423828
Female—parity, total pregnancies N[N]	501710
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 2014–, see <<http://meteor.aihw.gov.au/content/index.phtml/itemId/517456>>.

Table A.2: Perinatal DSS items

Metadata item ^(a)	METeOR identifier
Perinatal NMDS 2014–	517456
Birth—head circumference, total centimetres NN[N].N	568380
Birth event—additional indication for caesarean section, code N[N]	587048
Birth event—additional indication for induction of labour, code N[N]	573654
Birth event—main indication for caesarean section, code N[N]	587046
Birth event—main indication for induction of labour, code N[N]	569595
Female—blood transfusion due to primary postpartum haemorrhage indicator, yes/no/not stated/inadequately described code N	522211
Female—diabetes mellitus during pregnancy indicator, yes/no/not stated/inadequately described code N	504291
Female—estimated blood loss indicating primary postpartum haemorrhage, estimated blood loss volume category, code N	522192
Female—hypertensive disorder during pregnancy indicator, yes/no/not stated/inadequately described code N	516807
Female—primary postpartum haemorrhage indicator, yes/no/not stated/inadequately described code N	504959
Female—type of diabetes mellitus during pregnancy, code N	516668
Female—type of diabetes mellitus therapy during pregnancy, code N	516185
Female—type of hypertensive disorder during pregnancy, code N	504548
Person—height (measured), total centimetres NN[N].N	270361
Person—height (self-reported), total centimetres NN[N]	270365
Person—weight (measured), total kilograms N[NN].N	270208
Person—weight (self-reported), total kilograms NN[N]	302365

(a) For details of the Perinatal DSS 2016–17, see <<http://meteor.aihw.gov.au/content/index.phtml/itemId/605250>>.

Appendix B: Members of groups and committees as at June 2015

Table B.1: NMDDP Advisory Group members

Name ^(a)	Organisation/expertise
Dr Fadwa Al-Yaman (Chair)	Australian Institute of Health and Welfare
Ms Belinda Barnett	Maternity Choices Australia
A/Professor Georgina Chambers	National Perinatal Epidemiology and Statistics Unit
Ms Sue Cornes	Chair, National Perinatal Data Development Committee
Professor Ross Haslam	Australian and New Zealand Neonatal Network
Professor Caroline Homer	Clinical expert—midwifery
Professor Michael Humphrey	National Perinatal Epidemiology and Statistics Unit
Ms Ann Kinnear	Australian College of Midwives
Mr Conan Liu	Australian Institute of Health and Welfare
Mr Peter Mansfield	Perinatal data collection manager Tasmania
Ms Marisa Monaco	Department of Health
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
Mr Adrian Riches	Department of Health

(a) Former members: Ms Bec Waqanikolu (Maternity Choices Australia), Professor Elizabeth Sullivan (University of Technology Sydney), Ms Danielle Cosgriff (Victorian Department of Health), Ms Louise Riley (Health), Ms Melinda Petrie (AIHW). New members: Stage 3 NMDDP are Mr Louis Young (Health), Ms Ann Burgess (MSIJC), Dr Suellen Allen (ACSQHC) and Professor Yee Khong (Clinical expert, pathology).

Table B.2: 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
Professor Christine East	Perinatal Society of Australia and New Zealand
Dr Donna Hartz	Women's Healthcare Australasia
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
Mr Conan Liu	Australian Institute of Health and Welfare
Mr Peter Mansfield	Perinatal data collection manager Tasmania
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
Professor Elizabeth Sullivan	University of Technology Sydney
Ms Desley Williams	NT midwifery representative

Table B.3: National Perinatal Data Development Committee members

Name	Organisation/expertise
Dr Fadwa Al-Yaman	Australian Institute of Health and Welfare
Ms Kirsty Anderson	Victoria
Mr Wayne Anderson	Western Australia
A/Professor Georgina Chambers	National Perinatal and Epidemiology Statistics Unit
Ms Sue Cornes (Chair)	Queensland
Dr Mary-Ann Davey	Victoria
Ms Karen Dempsey	Northern Territory
Ms Joanne Ellerington	Queensland
Ms Louise Freebairn	Australian Capital Territory
Mr Tim Harrold	New South Wales
Mr Paull Hoffmann	Australian Bureau of Statistics
Ms Maureen Hutchinson	Western Australia
Mr Peter Mansfield	Tasmania
Ms Lee O'Neil	Northern Territory
Dr Wendy Scheil	South Australia
Ms Joan Scott	South Australia
Ms Rosalind Sexton	Australian Capital Territory
Ms Diana Stubbs	Victoria
Dr Lee Taylor	New South Wales
Ms Vickie Veitch	Victoria

Table B.4: National Maternal Mortality Advisory Committee members

Name	Organisation/expertise
Dr Steven Adair	Chair, Australian Capital Territory Maternal Perinatal Data Collection
Dr Fadwa Al-Yaman	Senior Executive, Indigenous and Children's Group, Australian Institute of Health and Welfare
Professor Marie-Paule Austin	The Royal Australian and New Zealand College of Psychiatrists
A/Professor Georgina Chambers	Director, National Perinatal and Epidemiology Statistics Unit
A/Professor Alicia Dennis	Australian and New Zealand College of Anaesthetists
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
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)	Chair, Queensland Maternal and Perinatal Quality Council
Dr Jenny Hunt	National Aboriginal Community Controlled Health Organisation
Ms Rebecca Jenkinson	Consumer representative, The Maternity Coalition
Professor Yee Khong	The Royal College of Pathologists Australasia
Ms Ann Kinnear	Executive Officer, Australian College of Midwives
Dr Karin Lust	Council Member, Society of Obstetric Medicine Australia and New Zealand
Professor John Newnham	Western Australian Maternal Mortality Committee
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

(continued)

Table B.4 (continued): National Maternal Mortality Advisory Committee members

Name	Organisation/expertise
A/Professor John Smoleniec	New South Wales Perinatal and Maternal Mortality Committee
Professor Elizabeth Sullivan	University of Technology Sydney
Dr Nikki Whelan	Chair, Maternal Mortality Sub-Committee, Queensland Maternal and Perinatal Quality Council

Table B.5: Maternity Care Classification System Working Party

Name ^(a)	Organisation/expertise
Ms Mary Beneforti	Australian Institute of Health and Welfare
Ms Jo Borrman	Expert—Health Information Management
A/Professor Georgina Chambers (Chair)	National Perinatal Epidemiology and Statistics Unit
Ms Natasha Donnoley (Secretariat)	National Perinatal Epidemiology and Statistics Unit
Ms Joanne Ellerington	NPDDC and Qld representative
Mr Mark Gill	Vic representative
Professor Caroline Homer	Expert—midwifery
Ms Maureen Hutchinson	WA representative
Professor Sue Kruske	Expert—rural and remote maternity care
Ms Penny Maher	ACT representative
Mr Peter Mansfield	Tasmania representative
Ms Gail Mondy	MSIJC representative
A/Professor Michael Nicholl	Expert—obstetrics and NSW representative
Ms Maggi Richardson	NT representative
Dr Wendy Scheil	SA representative

(a) Former members and proxy members include Professor Elizabeth Sullivan (former Chair), Ms Kate Gibson (NPDDC representative), Ms Marie Hughes (NT representative), Ms Jan White (Proxy for MSIJC), Ms Helen Perkins (Proxy for ACT).

Table B.6: Screening for Domestic Violence Working Party

Name	Organisation/expertise
Ms Tamsin Anderson	NSW Department of Health
Ms Mary Beneforti (Chair)	Australian Institute of Health and Welfare
Ms Fiona Blackshaw	Australian Bureau of Statistics
Dr Donna Hartz	University of Western Sydney
Ms Megan Howitt	NT Department of Health
Ms Stephanie Kelly	Australian Bureau of Statistics
Mr Conan Liu	Australian Institute of Health and Welfare
Mr Peter Mansfield	Tasmanian Department of Health and Human Services
Mr William Milne	Australian Bureau of Statistics
Mr George Neale	Private hospitals representative
Dr. Michelle Quee	Australian Institute of Health and Welfare (formerly of)
Dr Jo Spangaro	University of New South Wales—expert in DV
Dr Angela Taft	La Trobe University— expert in DV

Table B.7: National Perinatal Mortality Reporting Advisory Group

Name	Organisation/expertise
A/Professor Georgina Chambers	National Perinatal and Epidemiology Statistics Unit
Ms Joanne Ellerington	National Perinatal Data Development Committee
Professor David Ellwood	Australian and New Zealand Stillbirth Alliance
A/Professor Vicki Flenady	Perinatal Society of Australia and New Zealand
Ms Vivien Gee	Department of Health WA
Dr Adrienne Gordon	NSW Maternal and Perinatal Committee
Dr Lisa Hilder	National Perinatal and Epidemiology Statistics Unit
Professor Michael Humphrey (Chair)	National Perinatal and Epidemiology Statistics Unit consultant adviser
Professor Alison Kent	ACT Maternal and Perinatal Mortality Committee
Professor Yee Khong	The Royal College of Pathologists Australasia
Mr Graham Kraak	Maternity Services Inter-Jurisdictional Committee
Mr Conan Liu	Australian Institute of Health and Welfare
Ms Sam Paior	Consumer representative
Ms Vickie Veitch	Consultative Council on Obstetric and Paediatric Mortality & Morbidity (VIC)
Ms Sue Walker	Health Information Management
Ms Jane Warland	Australian College of Midwives (SA)
Ms Jeanine Young	SIDS and KIDS

Appendix C: Stage 1 NMDDP priority data item list

Table C.1: Priority data items for inclusion/standardisation in perinatal data collections, Stage 1 NMDDP 2011–13 ^(a)

Batch 1 (short term) ^(b)	Batch 2 (medium term) ^(b)	Batch 3 (long term) ^(b)
<p>Maternal morbidity</p> <p>Pre-existing hypertension</p> <p>Gestational hypertension</p> <p>Pre-eclampsia</p> <p>Pre-existing diabetes</p> <p>Gestational diabetes</p> <p>Maternal height</p> <p>Maternal weight</p> <p>Maternal demographics</p> <p>Whether interpreter required</p>	<p>Maternal morbidity</p> <p>Severe primary PPH</p> <p>Peripartum hysterectomy</p> <p>Indications for intervention</p> <p>Indications for caesarean section</p> <p>Indications for induction</p> <p>Indications for instrumental vaginal birth</p> <p>Indications for peripartum hysterectomy</p> <p>Maternal and perinatal risk factors</p> <p>Mental health</p>	<p>Maternal morbidity</p> <p>Febrile morbidity in labour</p> <p>Maternal and perinatal risk factors</p> <p>Alcohol in pregnancy</p> <p>Screening for domestic violence</p> <p>Substance use</p> <p>Baby anthropometrics</p> <p>Head circumference</p> <p>Maternal demographics</p> <p>Maternal education</p> <p>Perinatal mortality</p> <p>Timing of fetal death ^(c)</p> <p>Coding of cause of perinatal death ^(c)</p>

(a) Note this list has been updated during Stage 2 of the National Maternity Data Development Project (NMDDP).

(b) Time frames are a relative estimate of how long the data development process might take for items, and incorporate concepts of both feasibility and priority. The endpoint for the proposed time frames is approval by National Health Information Standards and Statistics Committee (NHSSC)/ National Health Information Performance and Principal Committee (NHIPP). Collection of data would commence at some time after this, depending on jurisdictional ability to incorporate the data items into their systems and collections. Reporting of data to the AIHW would be possible 18 months to 2 years after the commencement of collection of the data.

(c) To be actioned as part of the investigation into national perinatal mortality reporting in Stage 3.

Appendix D: Rationale—screening for domestic violence data

Table D.1: Rationale for collecting screening for domestic violence data in the NPDC

Issue	Rationale
Why screen?	<p>There are multiple purposes for screening during pregnancy including:</p> <ul style="list-style-type: none"> (a) Pregnancy is a unique time for women to receive help due to more frequent contact with health services and opportunities for women isolated by DV to discuss this with a health care provider (Spangaro et al. 2010a). (b) Increasing opportunities for safety planning, awareness (Chang et al. 2010), support and ongoing care. (c) Decreasing the acceptability of DV among both health professionals and patients (that is, helping to change social norms) (Spangaro et al. 2010b). (d) Screening is not harmful to women, and antenatal screening may be more beneficial than screening in other health settings (Taft et al. 2013). (e) Pregnancy outcomes for abused women (in Australia and globally) are worse compared with those of non-abused women (WHO 2013; Taft et al. 2004). For example, abused women are at increased risk of miscarriage (Morland et al. 2008), pre-term labour and birth (Shah et al. 2010) and having low birthweight infants (Shah et al. 2010; Silverman 2006; Yost et al. 2005; El Kady et al. 2005). Women assaulted during pregnancy also have higher risks of placental abruption, caesarean delivery, haemorrhage and infection compared to women without a history of assault (El Kady et al. 2005). In addition, DV prior to pregnancy is a significant, independent risk factor for hypertension, edema, vaginal bleeding, placental problems, severe nausea and vomiting, dehydration, diabetes, kidney infection and/or urinary tract infection, as well as premature rupture of membranes (Silverman 2006). <p>Not all women will disclose DV, and of those who do disclose, not all will want help or referral. However, referral is not the only reason for conducting screening and if awareness is the only outcome, this can still be beneficial.</p>
Need for the data	<p>For women aged 15–44, DV is responsible for greater disease burden than many well-known health risk factors such as high blood pressure, smoking and obesity (Vos et al. 2006). Pregnancy can be a period of high risk for the onset or worsening of DV incidents (Taft 2002; WHO 2000).</p> <p>Despite this, there is currently no comprehensive approach to national data collection on DV in pregnancy. The only source of national data is the ABS Personal Safety Survey (PSS), which helps to measure the prevalence of violence during pregnancy; however the PSS does not collect data annually, nor routinely from the entire population of interest as the NPDC does. Without routine and consistent national collection, Australia is unable to monitor the extent of DV in pregnancy, its associations with pregnancy events and outcomes for mothers and babies, and service provision for responding. This is a serious barrier to informing and developing policy and program responses.</p> <p>While recognising that the benefits of DV screening for women and their babies are not always clear or simple to evaluate, collecting screening and disclosure data via the NPDC may help to better understand women's pregnancy and health outcomes.</p>
Why collect in the NPDC?	<p>The NPDC is a large data set (a census of mothers with about 300,000 records per year) and is the main source of national reporting on pregnancy and childbirth for mothers, and the characteristics and outcomes of their babies. The NPDC includes a sample of women (that is, pregnant women only) who predominantly fall within the age range of 15–44, where the highest levels of disease burden attributable to DV have been shown to occur (Vos et al. 2006).</p> <p>Collecting data in the NPDC could be valuable because:</p> <ul style="list-style-type: none"> (a) No routine national data collection for DV exists for pregnant women and no other data source (for example, the PSS) can provide such comprehensive coverage of the population and the subject matter area. (b) Population level data are needed to drive policies, programs, and service planning and delivery. (c) While aggregated de-identified data would be used for routine reporting, the NPDC also provides opportunities for data linkage to explore individual women's outcomes (using other variables within the NPDC) as well children's longer term outcomes if linkage to childhood data sets later becomes possible. (d) Identifying violence as an issue for health care is necessary for reducing it, and the NPDC can provide data of relevance to the National Plan to Reduce Violence against Children. (e) It could provide data on the sustainability of screening programs. <p>However, a range of data quality issues exist, so before any reliable national data are collected, pilot studies are needed to determine the best type of data to collect, as well as how to collect such data.</p>

(continued)

Table D.1: Rationale for collecting screening for domestic violence data in the NPDC (continued)

Issue	Rationale
How the data will be used?	<p>The primary uses for NPDC data on DV include:</p> <p>Annual reporting to show DV rates and patterns in pregnancy.</p> <p>Analysis to examine correlations between DV and other clinical characteristics or perinatal risk factors. For example: low birthweight, premature labour and birth, miscarriage and haemorrhage (which are already included in the NPDC), as well as maternal mental health, inadequate weight gain and models of care (which are not currently part of the NPDC but are being considered for inclusion).</p> <p>Disaggregations to examine different geographic levels and sub-populations to identify high risk groups (survey data are unlikely to provide adequate sample sizes for generating reliable data for Aboriginal and Torres Strait Islander people or other specific sub-populations).</p>

References

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Appendix E: Psychosocial screening measurement instruments

Depression and anxiety

Table E.1: Edinburgh Postnatal Depression Scale (EPDS)

Questions	Scoring system				Score
	0	1	2	3	
I have been able to laugh and see the funny side of things	As much as I always could	Not quite so much now	Definitely not so much now	Not at all	
I have looked forward with enjoyment to things	As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all	
I have blamed myself unnecessarily when things went wrong	No, never	Not very often	Yes, some of the time	Yes, most of the time	
I have been anxious or worried for no good reason	No, not at all	Hardly ever	Yes, sometimes	Yes, very often	
I have felt scared or panicky for no very good reason	No, not at all	No, not much	Yes, sometimes	Yes, quite a lot	
Things have been getting on top of me	No, I have been coping as well as ever	No, most of the time I have coped quite well	Yes, sometimes I haven't been coping as well as usual	Yes, most of the time I haven't been able to cope at all	
I have been so unhappy that I have had difficulty sleeping	No, not at all	Not very often	Yes, sometimes	Yes, most of the time	
I have felt sad or miserable	No, not at all	Not very often	Yes, quite often	Yes, most of the time	
I have been so unhappy that I have been crying	No, never	Only occasionally	Yes, quite often	Yes, most of the time	
The thought of harming myself has occurred to me	Never	Hardly ever	Sometimes	Yes, quite often	
Total					

Source: Cox et al. 1987.

A score of 13 and above is often considered to be a marker for detecting possible major depression (Beyondblue 2011).

Alcohol use in pregnancy

Table E.2: AUDIT-C Screening Test

Questions	Scoring system					Score
	0	1	2	3	4	
How often do you have a drink containing alcohol?	Never	Monthly or less	2–4 times per month	2–3 times per week	4+ times per week	
How many standard drinks of alcohol do you drink on a typical day when you are drinking?	1–2	3–4	5–6	7–9	10+	
How often do you have 5 or more drinks on one occasion?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
Total						

Sources: Babor et al. 2000; Foundation for Alcohol Research & Education 2014.

Advice is provided to the individual based on the total AUDIT-C score (out of 12). A total score of 0–3 is rated as low risk of harm; a score of 4–7 is medium risk of harm; and a score of 8 and above is high risk of harm.

Screening for domestic violence

Table E.3: HARK and HITS DV screening tools—tool properties, advantages and disadvantages

HARK (Humiliation, Afraid, Rape, Kick)	HITS (Hurt, Insult, Threaten, Scream)
<p>Tool properties</p> <p>4 items assess physical, sexual, and emotional abuse by a partner or ex-partner within the last year:</p> <ol style="list-style-type: none"> 1. 'Within the last year, have you been humiliated or emotionally abused in other ways by your partner or ex-partner?' 2. 'Within the last year, have you been afraid of your partner or ex-partner?' 3. 'Within the last year, have you been raped or forced to have any kind of sexual activity by your partner or ex-partner?' 4. 'Within the last year, have you been kicked, hit, slapped or otherwise physically hurt by your partner or ex-partner?' <p>Response categories: Yes/no for all questions.</p> <p>Scoring procedure: If any questions are answered affirmatively, the HARK can be considered positive for abuse.</p> <p>Self-report.</p>	<p>Tool properties</p> <p>4 items assess the frequency of physical or emotional abuse by a partner:</p> <ol style="list-style-type: none"> 1. 'How often does your partner physically hurt you?' 2. 'How often does your partner insult you or talk down to you?' 3. 'How often does your partner threaten you with harm?' 4. 'How often does your partner scream or curse at you?' <p>Response categories: Each question is answered on a 5-point scale:</p> <p>1 = never, 2 = rarely, 3 = sometimes, 4 = fairly often, 5 = frequently.</p> <p>Scoring procedure: Responses are summed to form a total score which can range from 4 to 20. A cut-off score of 10 or greater can be used to classify participants as victimised.</p> <p>Self-report or clinician-administered.</p>
<p>Advantages</p> <p>Covers most aspects of recommended NPDC definition.</p> <hr/> <p>Most closely aligns with what jurisdictions already collect.</p> <hr/> <p>Simplicity and directness.</p>	<p>Advantages</p> <p>Recommended by many reviews that show it has good sensitivity and specificity.</p> <hr/> <p>Can be either clinician-administered or self-report.</p> <hr/> <p>Responses ranging from 'never' to 'frequently' allow space for women to not feel locked in to admitting abuse.</p>
<p>Disadvantages</p> <p>Does not include anything about controlling behaviour.</p> <hr/> <p>More recently developed and not included in as many reviews (however is based on the AAS which is better tested and recommended).</p> <hr/> <p>Only a self-report tool.</p> <hr/> <p>Questions on sexual violence mean a higher level of intrusiveness, and some health professionals may have reservations about asking such questions.</p> <hr/> <p>Women may be reluctant to provide simple yes/ no answers to questions, and commonly provide partial or vague answers (disclosure can be a process that involves shame associated with admitting abuse). Midwives can struggle to know how to treat vague or partial answers and whether they should be classified as DV or not. A lack of guidance on interpreting answers can lead to diverse practice among midwives in recording responses.</p>	<p>Disadvantages</p> <p>Does not include anything about controlling behaviour.</p> <hr/> <p>More time required to score.</p> <hr/> <p>Wording around frequency may be less well understood.</p> <hr/> <p>Asks about current violence, not violence in the last 12 months.</p>

Sources: Sohal et al. 2007; Sherin et al. 1998.

Appendix F: 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 was released in 2014 and is available at <www.maternitymatrix.aihw.gov.au>. The following screenshots (figures F.1–F.3) provide some examples of components of the MIM.

Data Items	Perinatal								Congenital Anomalies				Other national			Births												
	NMDS	NTDC	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	ACAMS	NSW	Vic	WA	SA	AR/NTM	NTM/D	NCIS	ABS	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	
TOP: Parental demographics																												
Mother's demographic data																												
Mother: name			●	●	●	●	●	●	●	●		●	●	●	●			●		●	●	●	●	●	●	●	●	●
Mother: alias (also known as)																												
Mother: other given names				●	●								●															
Maiden name						●								●	●					●	●	●	●	●	●	●	●	●
Mother: date of birth	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			●	●	●	●	●	●	●	●	●	●	●
Mother: indigenous status	●	●	●	●	●	●	●	●	●	●	●	●						●	●	●	●	●	●	●	●	●	●	●
Mother: ethnicity						●	●						●		●			●		●	●	●	●	●	●	●	●	●
Mother: country of birth	●	●	●	●	●	●	●	●	●	●	●	●						●	●	●	●	●	●	●	●	●	●	●
Mother: place of birth	●	●	●	●	●	●	●	●	●	●	●	●						●	●	●	●	●	●	●	●	●	●	●
Area of usual residence	●	●	●	●	●	●	●	●	●	●	●	●						●	●	●	●	●	●	●	●	●	●	●
Period of residence																		●		●				●		●		●
Residence early pregnancy																		●										
Mother: usual address		●		●	●		●		●	●		●	●		●			●		●	●	●	●	●	●	●	●	●
Mother: telephone number						●												●										
Mother: Lunit Record No.	●	●	●	●	●	●	●	●	●	●	●	●		●				●	●									
S/T of birth	●	●	●	●	●	●	●	●	●	●	●	●	●		●			●	●									
Hospital code	●	●	●	●	●	●	●	●	●	●	●	●	●		●			●	●									
English language																		●										
Level of education																		●										

Figure F.1: The MIM—main table

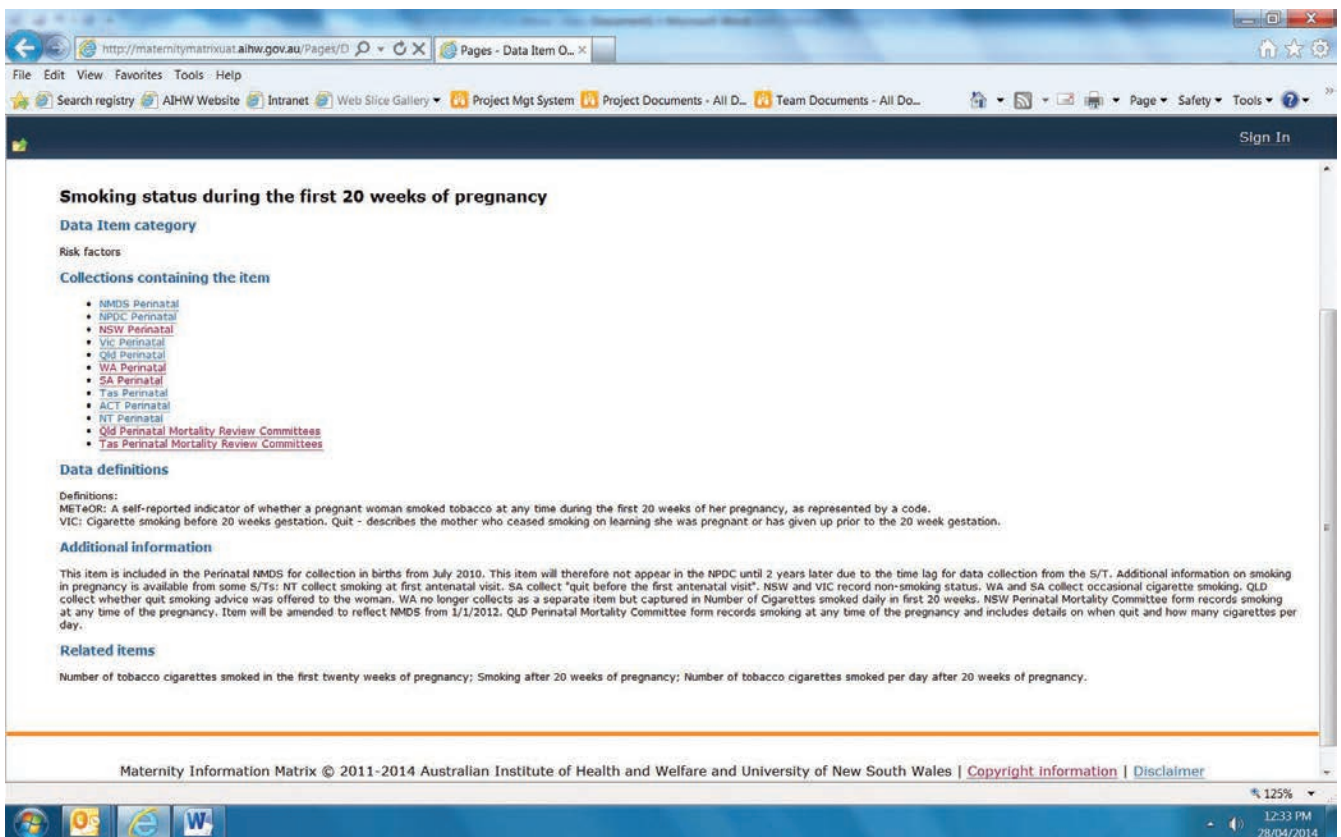


Figure F.2: A sample metadata page from the MIM

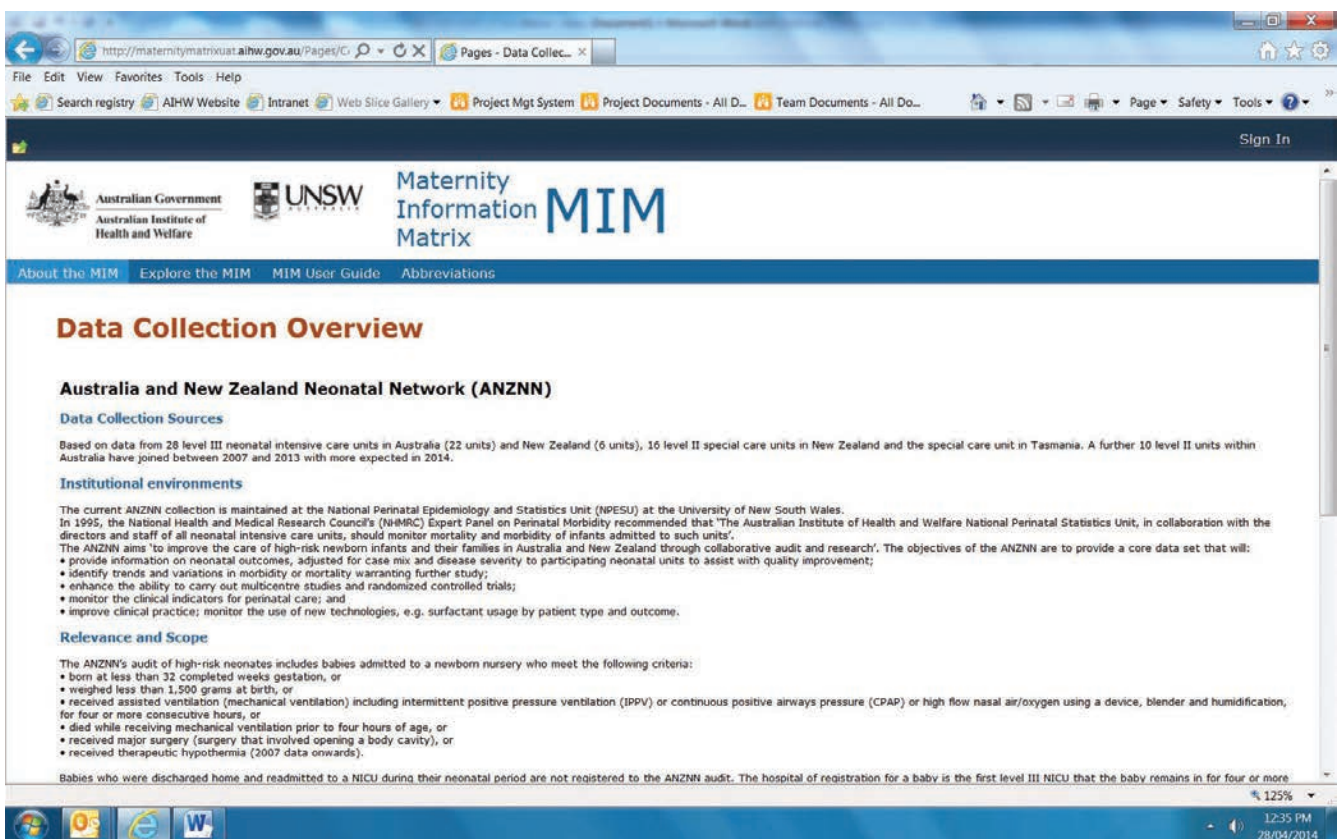


Figure F.3: A sample data collection overview

Appendix G: Perinatal data portal

Figure G.1: Perinatal data portal screenshot, home page

Figure G.2: Perinatal data portal screenshot, method of birth by state and territory



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Related publications

AIHW 2014. Foundations for enhanced maternity data collection and reporting in Australia: National Maternity Data Development Project Stage 1. Cat. no. PER 60. Canberra: AIHW.

AIHW 2015. Screening for domestic violence during pregnancy: options for future reporting in the National Perinatal Data Collection. Cat. no. PER 71. Canberra: AIHW

AIHW 2016. Maternity care classification system: maternity model of care data set specification national pilot report—National Maternity Data Development Project Stage 2. Cat. no. PER 74. Canberra: AIHW.

Short research briefs

The following research briefs, which support the NMDDP priority clinical data items, are available on the AIHW website at <http://www.aihw.gov.au/publication-detail?id=60129554606>

- Body mass index
- Diabetes in pregnancy
- Head circumference
- Hypertensive disorders of pregnancy
- Indications for induction of labour
- Indications for caesarean section
- Peripartum hysterectomy
- Postpartum haemorrhage
- Timing of stillbirth

This report presents findings of Stage 2 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. Stage 2 has seen substantial progress in: data development for clinical data items and maternity models of care; maternal and perinatal mortality reporting; and online dissemination of perinatal data.