



Maternity data in Australia: a review of sources and gaps

Introduction

About 800 babies are born every day in Australia, with over 330 women becoming a mother for the first time (AIHW 2009). Maternity data, including information about maternal, fetal and neonatal deaths, are among the key indicators of health and wellbeing.

The United Nations named a reduction in child mortality and improvements in maternal health as two of the eight Millennium Development Goals (United Nations 2001). Australia's maternal and infant mortality rates are among the lowest in the world; however, there is significant inequality in outcomes for Aboriginal and Torres Strait Islander people in particular. In 2001–2004, babies born to Aboriginal and Torres Strait Islander mothers were almost twice as likely to be born pre-term, had almost twice the fetal death rate, and had twice the neonatal death rate of babies born to non-Indigenous women (AIHW 2007). The National Indigenous Reform Agreement provides an integrated framework for the achievement of the Closing the Gap targets for overcoming Indigenous disadvantage.

The Australian Government Department of Health and Ageing, led by the Commonwealth Chief Nurse and Midwifery Officer identified the need for consistent, comprehensive national maternity data to monitor progress towards achieving these and other key targets (Commonwealth of Australia 2009). A review of relevant Australian data collections was undertaken to determine the current depth and breadth of maternal data capture in Australia.

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What is maternity data?

The term 'maternity data' generally refers to information that is collected about pregnancy, labour, birth, the health of mothers up to 42 days after the birth, and babies up to 28 days after birth. For some types of information, the period of data collection is extended. The international definition of maternal mortality includes deaths in women up to a year after the birth (WHO 1993). Registers of congenital conditions have notification periods that vary by jurisdiction and range from one to sixteen years after birth.

Data are routinely collated for all births in Australia, in: national, state and territory perinatal data collections; vital registration collections; and hospital-admitted patient data collections. Information about rare events such as deaths and severe maternal and neonatal morbidity, is also included in specialist data collections, such as the Australasian Maternity Outcomes Surveillance System, the Australia and New Zealand Neonatal Network, and state/territory morbidity and mortality review committee collections.

Almost all (97%) births in Australia occur in hospitals (AIHW 2009). The collection of perinatal data is the responsibility of the health service providing care to the woman—usually a midwife or attending doctor. This information is obtained from the mother's antenatal records, and when the mother attends the maternity ward for the birth. Information is usually entered into the hospital maternity database or equivalent, or recorded on manual data collection forms. Both manual and electronic data are submitted to perinatal data collection units within state and territory health authorities.

Who uses maternity data, and what do they use it for?

Australian and state and territory governments require maternity data to track progress against national and international indicators, and targets for maternal and neonatal health in Australia.

Maternity data are used by researchers, clinical colleges, regional health authorities, hospitals, clinicians, policy-makers, statisticians, health administrators, non-government organisations and students. Data collection managers regularly receive requests for data from the media and members of the public.

Data are used for: routine reporting; service planning; performance monitoring, including setting points of reference and reporting of indicators; quality and safety initiatives, including clinical audit and morbidity and mortality review committees; epidemiological studies and other research; and reporting of Aboriginal and Torres Strait Islander health statistics. Data are used by state and territory maternal and perinatal morbidity and mortality review committees to investigate and classify deaths and sentinel events.

Review of maternity data collections

Scope of the review

The scope of the review was limited to national and state and territory (jurisdictional) data collections. It included key health, administrative and vital statistics data collected from conception to 28 days after the birth. For maternal deaths, the scope was extended to 1 year after the birth.

The following population data collections were included:

- ♦ National Perinatal Data Collection and all state/territory perinatal data collections
- ♦ AIHW National Perinatal Epidemiology and Statistics Unit collections: Australian Congenital Anomalies Monitoring System, National Maternal Deaths Database
- ♦ Australian Bureau of Statistics vital statistics collections: national births collection, national deaths collection, national perinatal deaths collection
- ♦ state and territory vital statistics collections—births, deaths, perinatal deaths
- ♦ state and territory collections for congenital anomalies in Western Australia, New South Wales, Victoria and South Australia.

The following collections containing data on specific subpopulations were included:

- ♦ Perinatal and Reproductive Epidemiology Research Unit collections held at the University of New South Wales: Australian and New Zealand Neonatal Network Register; and Australasian Maternity Outcome Surveillance System
- ♦ National Coroners Information System
- ♦ state and territory perinatal mortality review committees and maternal mortality review committees.

Australian data collections

Jurisdictional and national sources of information were documented at the data collection and data item levels. Findings were used to identify data collection issues, data gaps and opportunities for development.

A current list of data items, data collection forms, guidelines for data collection and/or data dictionaries were obtained from managers of each data collection. The following items were prepared as part of the review:

- ♦ a data collection overview that summarised information about each data collection's institutional environment, relevance and scope, timeliness, accuracy, accessibility, and interpretability
- ♦ the Maternity Information Matrix. The matrix is an electronic inventory of all data items in each data collection included in the review. In the matrix, currently collected data items are organised by topic, to correspond with each stage in the maternity pathway. Data items are grouped into subject areas and subtopics. For items included in multiple collections, definitions and characteristics of the data are summarised

to provide a complete picture of all the information currently collected on a specific topic. The matrix provides information on the scope, definitions, data availability and reporting of items for each collection included in the review

- ♦ a detailed report to the Australian Government Department of Health and Ageing, from which key findings and recommendations are summarised in this bulletin.

International data collection practices

Maternity data collection practices in a selection of countries were reviewed to investigate the scope and content of national collections, governance issues, challenges and barriers to data collection, and to identify examples of good practice. The review of international collections focused on countries with broadly similar health services to those in Australia. Common themes that emerged include: the use of record linkage; the availability of unique patient identifiers; the introduction of web-based reporting systems; and diverse governance arrangements.

Key data gaps

Gaps in national data were identified through a review of state and territory and national collections. There is a need for a systematic analysis of the information needs of key agencies involved in the shaping of policies on the nature and range of maternity services, to determine the significance of these gaps and other areas for development.

Maternity care

Models of maternity care and continuity of caregiver are important factors contributing to safety and quality, patient experience and outcomes. The availability of these data needs improvement, through the development of consistent and nationally agreed definitions that take account of local variations in service delivery. Definitions must align with models of care that will be implemented as a result of the Maternity Services Review. A data item on number of antenatal visits is being developed for inclusion in the National Perinatal Data Collection.

Maternal mortality

Although rare, maternal deaths are critical indicators of severe maternal morbidity. There is currently no nationally agreed method to review and report maternal deaths. Their monitoring is essential to ensure that any changes to the provision of maternity services do not adversely affect Australia's low maternal mortality ratio. The rarity of these events means that such monitoring is only feasible at a national level, using high-quality, consistent data.

Maternal conditions and morbidity

Substantial work is needed to develop national definitions of: the scope of conditions that comprise maternal morbidity; the period; and the conditions to be included. There are no mandatory national data items, nor is there consensus on nationally consistent definitions for common maternal conditions and complications such as gestational diabetes and hypertension.

Maternal characteristics and risk factors

National data on maternal characteristics and risk factors are limited, with only smoking during pregnancy available at a national level from 2010 onwards. National information about other modifiable risk factors, such as alcohol and substance use in pregnancy, and body mass index, are often requested but not currently available. These data would help monitor trends and evaluate interventions to improve outcomes, such as low birthweight and some congenital anomalies. A data item on alcohol use in pregnancy is being developed for inclusion in the National Perinatal Data Collection.

High-quality national data on psychosocial wellbeing and mental health are needed to inform strategies to improve detection and treatment of perinatal depression, puerperal psychosis and other psychiatric conditions.

Perinatal mortality

The quality and usefulness of national data on perinatal mortality is limited. This could be improved by including data items on neonatal death and cause of perinatal death in the Perinatal National Minimum Data Set, and standardising the classification, registration and reporting of perinatal deaths. In addition, reporting of perinatal deaths due to congenital anomaly separately from other perinatal deaths would be advantageous, as these conditions have a very different spectrum of risk and strategies for prevention.

Other gaps

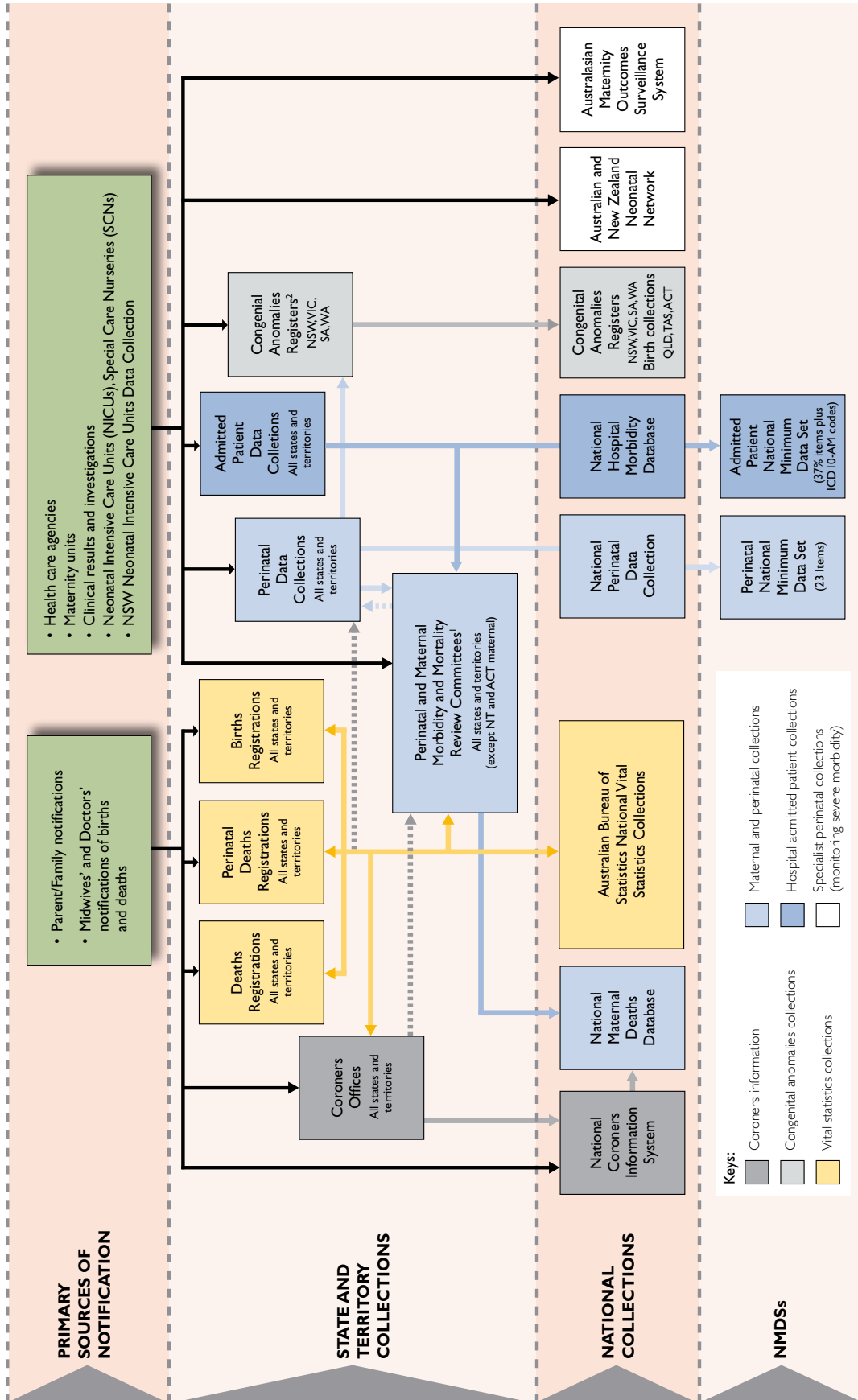
The review provided an overview of the system and process issues involved in the primary collection of maternal and perinatal data, including data quality issues and data development processes. At a national level, considerable time and resources are required for data items to be developed to national standards for inclusion in the Perinatal National Minimum Data Set and the National Health Data Dictionary, the register for national health data standards (National Health Information Standards and Statistics Committee 2010). This should be taken into account when planning future developments to national data collections.

Data flows

Figure 1 illustrates the relationship between data collections included in the review. Collections are grouped together using a colour key. For example, yellow represents vital statistics data collections, and blue represents perinatal data collections. A broken line indicates that there is a comparison of information between collections, and the arrow indicates the direction of flow if data are exchanged. However, there is inconsistency between states and territories in the information shared and what it is used for. For example, at the state and territory level, data from the Registrars of Births, Deaths and Marriages are used in some, but not all, jurisdictions to cross-check births and deaths, and to supplement deaths information.

Figure 1 highlights the absence of a national approach to analysing the detailed clinical data compiled by state and territory perinatal and maternal mortality and morbidity review committees, despite the significant input of information to these committees from the state and territory data collections.

At the national level, there are few links between data sets, and there is duplication of data collection. For example, the National Maternal Deaths Database is compiled through notifications from state and territory perinatal data collection units and maternal mortality review committees. Data from the National Coroners Information Service, state and territory coroners' offices and vital statistics collections are not routinely linked to the National Maternal Deaths Database. Similarly, data from the National Hospital Morbidity Database and Australian Congenital Anomalies Monitoring System are not routinely linked to the National Perinatal Data Collection.



1 In the NT, there is no PMMRC. Perinatal deaths are reviewed by the NT Child Deaths Review and Prevention Committee. In the ACT, the Maternal Perinatal Information Network is a steering group that has an advisory oversight of the ACT Perinatal Data Collection, but is not involved in a clinical review process. A Perinatal Mortality Committee conducts clinical reviews and reports to ACT Health on perinatal deaths. **(Perinatal and maternal morbidity and mortality review committees box)**

2 In some S/Ts, information on causes of perinatal and maternal deaths may be supplied to the Perinatal Data Collection by the PMMRC. **(Perinatal and maternal morbidity and mortality review committees box)**

3 In QLD, congenital anomalies identified during the birth episode (or recorded for deaths in the perinatal period) are recorded in the Perinatal Data Collection. The records in scope are then provided to ACAMS. **(Congenital anomalies registers box)**

4 In NSW, the Coroner's Office supplies data to the NSW Department of Health, which is subsequently submitted to the PMMRC but not the NSW Perinatal Data Collection. This is not routine practice in other states and territories. Data are submitted by the NSW Department of Health to the NMD. In QLD, the Registrar of Births, Deaths and Marriages supplies information on perinatal and maternal deaths to the Perinatal Data Collection, and this is subsequently supplied to the PMMRC along with the birth information. In SA, the Registrar of Births, Deaths and Marriages supplies data to the Perinatal Outcomes Unit to cross-check ascertainment of neonatal and post-neonatal deaths. **(Coroners offices all states/territories box)**

5 In the NT, the Registrar of Births, Deaths and Marriages supplies date of neonatal death to the NT Department of Health and Families. In 2010 approval was obtained for the Registrar to supply data to the Perinatal Data Collection for the purpose of validating the number of births in the latter collection. In the ACT, information in the Perinatal Data Collection on deaths is supplemented by the Registrar of Births, Deaths and Marriages. **(Perinatal Data collections all states/territories box)**

Figure 1: Relationship between data collections included in the review

Opportunities for future improvements

The review established several opportunities to improve national maternity data collection.

Review of information needs

The 'fitness for purpose' of current national maternity data could be assessed using a systematic analysis of the information needs of maternity policy makers and planners. Priorities for future data development at the national level could be established following a review of:

- the frameworks and policies guiding the work of maternity services, encompassing existing policy, reference and guidance documents
- information requirements for monitoring and reporting indicators and other national policy initiatives.

Data linkage

Countries with the best reputation for the quality of their maternity information systems, namely Sweden, Scotland and the Netherlands, and most recently New Zealand, all make use of record linkage to bring together information from birth registration, hospital and mortality data. As far as possible, development of the national maternity data collection in Australia should align with existing administrative data capture, to minimise the burden and cost of collecting additional data through maternity services. More timely, albeit limited, information about births could be reported using data from hospital collections. Such reports could then be improved by more detailed data from perinatal collections, containing information about both mother and baby. Linkage of perinatal and hospital data could also validate and improve the detection of maternal morbidity and interventions in labour. Linkage of birth records in the perinatal data collections to the state and territory perinatal deaths registries would enable more valid comparisons between the neonatal death data of states and territories. A feasibility study of options for perinatal data linkage would be required; however, there are data linkage capabilities at jurisdictional level—several states and territories already use linkage to validate and supplement their perinatal data collections.

Data in perinatal data collections are actively collected at the time of birth, relying on information in birth records, and where available, records of antenatal care. It is generally not practical to extend data collection beyond the date of discharge from hospital. Data linkage is particularly useful to ascertain later outcomes, such as perinatal mental health issues and other serious maternal morbidities, including pulmonary embolism, amniotic fluid embolism, and wound infections.

Health data linkage projects already undertaken in New South Wales, South Australia and Western Australia provide local evidence of the value this can bring. While much of this work could be done at jurisdictional level, some additional work would be needed to ensure that information about very ill babies who die in a different state or territory to their place of birth is not lost. In addition, it is important that standards are developed to maintain the integrity of a national collection.

Enhancing the Perinatal National Minimum Data Set

The Perinatal National Minimum Data Set for Australia currently contains 23 items. Additional items are supplied to the National Perinatal Data Collection by some or all states and territories voluntarily. But the scope and definitions used for many items are inconsistent, and as a result some of these data cannot be reported at a national level. These include items on previous pregnancies, the antenatal period, maternal morbidity, complications of labour, the puerperium, maternal mortality, fetal and neonatal morbidity, and perinatal deaths.

The National Perinatal Epidemiology and Statistics Unit is engaged in national data development projects in 2011 to add items about antenatal visits, and maternal alcohol consumption data to the Perinatal National Minimum Dataset following standard practices (AIHW 2010) and to undertake a review of maternal morbidity data available in state and territory perinatal collections. This work is a result of projects such as the Closing the Gap Initiative.

The quality and consistency of national reporting could be improved by reaching agreement on standardised definitions, scope and collection methods for these additional data items. A level of priority could be assigned to each of the current voluntary National Perinatal Data Collection items for their inclusion in the National Perinatal Data Development Committee work plan. This could be achieved using the 'fitness for purpose' analysis described above.

Maternity Information Matrix

The Maternity Information Matrix provides a snapshot of dynamic information systems. A mechanism is under development to maintain and update the matrix as a central index of maternity information in Australia, which will be widely accessible to stakeholders. The matrix is available for viewing electronically via the following link: <<http://www.aihw.gov.au/mothers-and-babies>>.

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The National Perinatal Epidemiology and Statistics Unit (NPESU) produces comprehensive statistics on mothers and babies. The NPESU is a collaborating unit of the Australian Institute of Health and Welfare and is based at The University of New South Wales. The NPESU manage several major national data collections.

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