

# National Perinatal Mortality Data Collection, 2013–2014; Quality Statement

## Identifying and definitional attributes

<b>Metadata item type:</b>	Quality Statement
<b>Synonymous names:</b>	Perinatal deaths
<b>METEOR identifier:</b>	696864
<b>Registration status:</b>	<ul style="list-style-type: none"><li>• <a href="#">AIHW Data Quality Statements</a>, Standard 29/05/2018</li></ul>

## Data quality

## Quality statement summary:

### Description

The National Perinatal Mortality Data Collection (NPMDC) is a data collection established within the Australian Institute of Health and Welfare (AIHW) and collates data from state and territory sources to be used in the preparation of national perinatal death reports. The data set contains information on the deaths of babies in hospitals and in the community within the scope of the collection, which includes all live births and stillbirths of at least 20 weeks' gestation or at least 400 grams birthweight, during pregnancy, birth or within 28 days of birth.

The NPMDC builds on the National Perinatal Data Collection (NPDC) managed by the AIHW and collates a broad data set from state and territory sources regarding all babies born in hospitals and in the community within the scope of that collection. Common identifier fields in the NPDC and NPMDC allow demographic information regarding perinatal death records in the NPMDC to be retrieved from the NPDC.

State and territory health authorities supply data to the AIHW under individual data agreements between AIHW and each state or territory health authority. The NPMDC and NPDC data are obtained from the birth hospitals and may not include information about deaths that occur among babies who died after transfer to a different hospital or after discharge home.

### Summary of key data quality issues

- The NPMDC provides national information for use in preparing a national report on the death of babies during pregnancy, birth or within 28 days of birth, from 2013. The NPMDC builds on mortality data collected at the time of birth and held in the NPDC from 1993.
- Institutional or regional perinatal mortality committees review perinatal deaths for causation and, in some circumstances, the presence of possible contributory factors; state or territory perinatal mortality committees or subcommittees also review some perinatal deaths.
- Perinatal death data reported by the Australian Bureau of Statistics (ABS) are not directly comparable with NPMDC data. ABS data are sourced from state and territory registrars of Births, Deaths and Marriages; NPMDC, as with NPDC data, are sourced from state and territory health authority data from midwives, and other staff, who collect information from mothers and perinatal administrative and clinical record systems.
- Data reported to the NPMDC may differ from those of the NPDC as delayed data submission to the NPMDC allows for data updates and corrections to have occurred prior to submission. Data for total births and live births are sourced from the NPDC while the data for perinatal deaths (comprising stillbirths and neonatal deaths) are sourced from the NPMDC. Therefore, the sum of the number of stillbirths plus the number of live births may not always be equal to the total number of births.
- Some data items are supplied voluntarily to the NPMDC, resulting in a relatively high number of 'Not stated' values. Data items that are particularly affected by this issue include Remoteness of usual residence, Socioeconomic status, Number of antenatal visits, Gestation at first antenatal visit and Smoking status (especially after 20 weeks of pregnancy). Maternal alcohol use was not reported for 95% of pregnancies.
- Common identifier information was missing from 117 records submitted from New South Wales, meaning that some demographic information regarding these deaths can not be retrieved from the NPDC.

**Institutional environment:** The Australian Institute of Health and Welfare (AIHW) is a major national agency set up by the Australian Government under the *Australian Institute of Health and Welfare Act 1987 (Cwth)* to provide reliable, regular and relevant information and statistics on Australia's health and welfare. It is an independent corporate Commonwealth entity established in 1987, governed by a management board, and accountable to the Australian Parliament through the Health portfolio.

The AIHW aims to improve the health and wellbeing of Australians through better health and welfare information and statistics. It collects and reports information on a wide range of topics and issues, from health and welfare expenditure, hospitals, disease and injury, and mental health, to ageing, homelessness, disability and child protection.

The AIHW also plays a role in developing and maintaining national metadata standards. This work contributes to improving the quality and consistency of national health and welfare statistics. The AIHW works closely with governments and non-government organisations to achieve greater adherence to these standards in administrative data collections to promote national consistency and comparability of data and reporting.

One of the main functions of the AIHW is to work with the states and territories to improve the quality of administrative data and, where possible, to compile national data sets based on data from each jurisdiction, to analyse these data sets and disseminate information and statistics.

The *Australian Institute of Health and Welfare Act 1987*, in conjunction with compliance to the *Privacy Act 1988 (Cwth)*, ensures that the data collections managed by the AIHW are kept securely and under the strictest conditions with respect to privacy and confidentiality.

For further information see the AIHW website <[www.aihw.gov.au](http://www.aihw.gov.au)>.

Under a Memorandum of Understanding with the Department of Health, the AIHW is responsible for the management of the NPMDC. The AIHW maintains a coordinating role in the collection, including providing secretariat duties to the National Maternal and Perinatal Mortality Advisory Group, undertaking data development and highlighting implementation and collection issues.

Australian state and territory health authorities supply data to the AIHW under individual data agreements between AIHW and each state and territory. The AIHW is the data custodian of the NPMDC and receives, compiles, edits and verifies the NPMDC data in collaboration with the state or territory health authority that supplied the data. State and territory health authorities retain ownership of the jurisdictional level data and must approve any jurisdictional level output before it is released.

**Timeliness:** NPMDC data are collected annually. Most jurisdictions need at least 12 months lead time to undertake post-mortem investigations, data entry and validation as required after the end of the data collection period. Perinatal deaths data for 2013–2014 were requested for submission to the AIHW by 3 February 2017. One jurisdiction supplied completed data by this date. Final and useable data were received from all jurisdictions by 18 September 2017. The AIHW is working with states/territories to transition reporting from 3 years to 18 months after the end of the data collection period.

**Accessibility:** *Perinatal deaths in Australia 2013–2014* is this first report using data from the NPMDC and is available on the AIHW website <<https://www.aihw.gov.au/reports-statistics/population-groups/mothers-babies/reports>>.

An interactive data display as well as supplementary tables accompany the report and are also available on the AIHW website <<https://www.aihw.gov.au/reports-statistics/population-groups/mothers-babies/reports>>

Requests for unpublished data can be made by contacting the AIHW on (02) 6244 1000, by email to [info@aihw.gov.au](mailto:info@aihw.gov.au) or through the AIHW's custom data request service at <https://www.aihw.gov.au/our-services/data-on-request>.

A cost-recovery charge may apply to requests that require substantial resources. Depending on the nature of the request, requests for access to unpublished data may require additional approval from jurisdictional data custodians or the AIHW Ethics Committee.

**Interpretability:** Since its inception, the NPDC has included some data regarding perinatal deaths. The Perinatal National Minimum Data Set (P–NMDS) was implemented in July 1998 to standardise data reported to the NPDC by states and territories and has undergone regular review and refinement since then. Data specifications and supporting metadata for the PNMDs are documented in the AIHW’s online metadata repository (METeOR) available at: <https://content/index.php/html/itemId/517456>.

Specific extra data elements regarding the events related to and the classified cause of perinatal deaths are requested from states and territories to populate the NPMDC. The NPDC and NPMDC contain common identifier information regarding the baby, to allow cross-referencing.

**Relevance:** Whilst the death of a baby during pregnancy, birth or within 28 days of birth is a rare event in Australian society such deaths are key indicators of the quality of maternity care.

Perinatal mortality data have been obtained, where available, for all babies born in Australia. Most perinatal deaths occur before or soon after birth and are captured within jurisdictional perinatal data collections, though deaths occurring after discharge of the mother’s care from the birth episode may not be captured.

The Perinatal Society of Australia and New Zealand (PSANZ) Perinatal Mortality Classification System, incorporating the Perinatal Death Classification (PSANZ-PDC) and Neonatal Death Classification (PSANZ-NDC), is applied as part of each state and territory’s perinatal mortality review process. Details of the PSANZ-PDC and NDC classification system are found in Section 5.1 and Supplementary tables A23 and A24. The PSANZ-PDC system classifies all perinatal deaths by the single most important factor seen as the antecedent cause of the perinatal death and is applied to both stillbirths (fetal deaths) and neonatal deaths (that is, to all perinatal deaths). The PSANZ-NDC classification system is applied only to neonatal deaths and classifies them by condition present in the baby in the neonatal period leading to the death.

**Accuracy:** Inaccurate responses may occur in all data provided to the AIHW. The AIHW does not have direct access to perinatal mortality committee records to determine the accuracy of the data provided. However, the AIHW undertakes validation on receipt of data. Data received from states and territories are checked for completeness, validity and logical errors. Potential errors are queried with jurisdictions, and corrections and resubmissions are made in response to these edit queries.

Errors may occur during the processing of data by the states and territories or at the AIHW. Processing errors prior to data supply may be found through the validation checks applied by the AIHW. The data are corrected when verification of an error is supplied. The AIHW does not adjust the data to correct for missing values.

A number of data items supplied to AIHW by states and territories for the NPMDC, regarding babies that died in the perinatal period in 2013–2014, were noticeably incomplete. Amongst the most crucial items of missing data were birthweight (missing or not stated in 256 perinatal deaths), maternal Indigenous status (missing or not stated in 186 perinatal deaths), gestational age (missing or not stated in 165 perinatal deaths), and age at neonatal death (missing in 117 neonatal deaths).

Some data items are supplied voluntarily to the NPMDC, resulting in a relatively high number of ‘Not stated’ values. Data items that are particularly affected by this issue include Remoteness of usual residence, Socioeconomic status, Number of antenatal visits, Gestation at first antenatal visit and Smoking status (especially after 20 weeks of pregnancy). Maternal alcohol use was not reported for 95% of pregnancies.

Common identifier information was missing from 117 records submitted from New South Wales, therefore demographic information regarding these deaths could not be retrieved from the NPDC.

Prior to the release or publication of any jurisdictional-level data, data are referred back to jurisdictions for checking and review. Note that because of data editing and subsequent updates of state/territory information, numbers reported may differ from those in reports published by the states and territories.

**Coherence:** The NPMDC is an ongoing data set collected specifically, in the first instance, for use in the *Perinatal deaths in Australia 2013–2014* report; it will be a continuing collection and will be available as it expands for future reports in that series.

State and territory health authorities compile statistics and publish reports on maternal deaths. Methodology, definitions, classifications and reference periods for these collections differ significantly across states and territories, and comparisons between states and territories should be made with caution.

Perinatal death data reported by the ABS are not directly comparable with NPMDC data. ABS data are sourced from state and territory registrars of Births, Deaths and Marriages; NPMDC, as with NPDC data, are sourced from state and territory health authority data from midwives, and other staff, who collect information from mothers and perinatal administrative and clinical record systems.

## Data products

**Implementation start date:** 14/05/2018

## Source and reference attributes

**Submitting organisation:** Australian Institute of Health and Welfare