# National Perinatal Mortality Data Collection, 2017; Quality Statement

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# National Perinatal Mortality Data Collection, 2017; Quality Statement

# Identifying and definitional attributes

Metadata item type:	Data Quality Statement
Synonymous names:	Perinatal deaths; stillbirth; neonatal death.
METEOR identifier:	729106
Registration status:	AIHW Data Quality Statements, Superseded 19/05/2021

## **Data quality**

#### Summary of key data quality issues

The National Perinatal Mortality Data Collection (NPMDC) collates state and territory information on the deaths during pregnancy, birth or within 28 days of birth, of babies of at least 20 weeks' gestation or at least 400 grams birthweight. Key quality issues to consider for the collection include:

- Data items are supplied voluntarily to the NPMDC, resulting in a relatively high number of 'Not supplied/stated' values for some data items. In 2017, data items particularly affected by this issue include Reason autopsy not performed (95.2% not supplied/stated), Contributory factors: Assessment of factors performed (66.5% not supplied/stated), Post-mortem investigations performed indicator (48.0% not supplied/stated), and Place of death (41.8% not supplied/stated).
- 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.
- In 2017, there were 2 deaths that were reported to the NPMDC that were unable to be matched to a record in the NPDC due to the lack of common identifier information. This means that some demographic information cannot be retrieved from the NPDC for these deaths and are recorded as 'not stated' where information is not available.
- 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; while NPMDC 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.

#### Description

The 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 or birth or within 28 days of birth.

State and territory health authorities supply data to the AIHW under individual data agreements between AIHW and each state or territory health authority. Data are collected annually by calendar year. The NPMDC contains data from 2013.

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.

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.

#### Institutional environment:

The AlHW is a national agency set up by the Australian Government under the <u>Australian Institute of Health and Welfare Act 1987</u> 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 <u>board</u>, and accountable to the Australian Government 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 <u>Australian Institute of Health and Welfare Act 1987</u>, in conjunction with the <u>Privacy Act 1988</u> (*Cwlth*), 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 <u>www.aihw.gov.au</u>.

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. Data cannot be finalised for a calendar year until all Jurisdictional Mortality Review Committee reports that apply to that period are complete. Jurisdictions coordinate and facilitate data collection procedures from service providers and the updating of records. 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. NPMDC data for 2017 was requested from states and territories on 31 May 2019 for submission to the AIHW by 31 July 2019. Data were received from 3 jurisdictions by this date. Final and useable data were received from 8 jurisdictions by 18 December 2020. Data suppliers in some jurisdictions have given feedback that a request for data 17 months after the end of the collection period is unachievable as some data (particularly pertaining to PSANZ classification codes and contributory factors) are still waiting to be compiled at this stage. The AIHW continues to work on a number of strategies to improve the timeliness of data publication and has a goal of finalising national data and reporting within 2 years after the end of the data collection period.

Accessibility:	The Stillbirths and neonatal deaths in Australia report uses data from the NPMDC and is available on the AIHW website, providing online interactive data displays, supplementary data tables and technical notes at <a href="https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths-in-australia">https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths-in-australia</a> .
	Requests for unpublished data can be made by contacting the AIHW on (02) 6244 1000, by email to info@aihw.gov.au or through the AIHW's custom data request service at <a href="https://www.aihw.gov.au/our-services/data-on-request">https://www.aihw.gov.au</a> or through the AIHW's custom data request service at <a href="https://www.aihw.gov.au/our-services/data-on-request">https://www.aihw.gov.au</a> or through the AIHW's custom data request service at <a href="https://www.aihw.gov.au/our-services/data-on-request">https://www.aihw.gov.au</a> or through the AIHW's custom data request service at <a href="https://www.aihw.gov.au/our-services/data-on-request">https://www.aihw.gov.au/our-services/data-on-request</a> .
Interpretability:	For Stillbirths and neonatal deaths in Australia reporting, all statistical methods and concepts applied to NPMDC can be found in technical notes accompanying the report online at <a href="https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths-in-australia">https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths-in-australia</a> .
Relevance:	The death of a baby during pregnancy, birth or within 28 days of birth can be 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. 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 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.
	Data items are supplied voluntarily to the NPMDC, resulting in a relatively high number of 'Not supplied/stated' values for some data items. In 2017, data items particularly affected by this issue include Reason autopsy not performed (95.2% not supplied/stated), Contributory factors: Assessment of factors performed (66.5% not supplied/stated), Post-mortem investigations performed indicator (48.0% not supplied/stated), and Place of death (41.8% not supplied/stated).
	In 2017, there were 2 deaths that were reported to the NPMDC that were unable to be matched to a record in the NPDC due to the lack of common identifier information. This means that some demographic information cannot be retrieved from the NPDC for these deaths and are recorded as 'not stated' where information is not available.

Coherence:

The NPMDC is an ongoing data set collected specifically, in the first instance, for use in AIHW perinatal mortality reports such as Stillbirths and neonatal deaths in Australia. The NPMDC is an ongoing 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.

Data reported to the NPMDC may differ from those of the National Perinatal Data Collection 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.

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: 14/07/2020

### Source and reference attributes

Submitting organisation: Australian Institute of Health and Welfare

### **Relational attributes**

Related metadata references:	Supersedes National Perinatal Mortality Data Collection, 2015–2016; Quality Statement AIHW Data Quality Statements, Superseded 28/07/2020
	Has been superseded by <u>National Perinatal Mortality Data Collection, 2018;</u> <u>Quality Statement</u> <u>AIHW Data Quality Statements</u> , Superseded 18/11/2021