National Perinatal Mortality Data Collection, 2020: Quality Statement

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# National Perinatal Mortality Data Collection, 2020: Quality Statement

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| Identifying and definitional attributes | |
| Metadata item type: | Data Quality Statement |
| Synonymous names: | Perinatal deaths; stillbirth; neonatal death |
| METEOR identifier: | 767675 |
| Registration status: | [AIHW Data Quality Statements](https://meteor.aihw.gov.au/RegistrationAuthority/5), Superseded 23/11/2023 |

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| Data quality | |
| Data quality statement summary: | **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. * Data reported to the NPMDC may differ from those of the National Perinatal Data Collection (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 2020, there was 1 death reported to the NPMDC that was 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 this death 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 Australian Institute of Health and Welfare (AIHW) is an independent corporate Commonwealth entity under the [*Australian Institute of Health and Welfare Act* 1987](http://www.comlaw.gov.au/Series/C2004A03450) (AIHW Act), governed by a [management Board](http://www.aihw.gov.au/aihw-board/) and accountable to the Australian Parliament through the Health portfolio.  The AIHW is a nationally recognised information management agency. Its purpose is to create authoritative and accessible information and statistics that inform decisions and improve the health and welfare of all Australians.  Compliance with the confidentiality requirements in the AIHW Act, the Privacy Principles in the [*Privacy Act* 1988](https://www.legislation.gov.au/Series/C2004A03712) (Cth) and AIHW’s data governance arrangements ensures that the AIHW is well positioned to release information for public benefit while protecting the identity of individuals and organisations.  For further information see the AIHW website [www.aihw.gov.au/about-us](https://www.aihw.gov.au/about-us), which includes details about the AIHW’s governance ([www.aihw.gov.au/about-us/our-governance](https://www.aihw.gov.au/about-us/our-governance)) and our role and strategic goals ([www.aihw.gov.au/about-us/our-vision-and-strategic-goals](https://www.aihw.gov.au/about-us/our-vision-and-strategic-goals)).  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 Clinical Expert 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 2020 was requested from states and territories on 13 May 2022 for submission to the AIHW by 13 July 2022. Data were received from 7 jurisdictions by this date. Final and useable data were received from 8 jurisdictions by 20 September 2022. 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: | Perinatal deaths data are published annually in the web-based [Australia's mothers and babies](http://www.aihw.gov.au/reports/mothers-babies/australias-mothers-babies/contents/summary) report available on the AIHW website.  Requests for unpublished data can be made by contacting the AIHW on (02) 6244 1000, by email to [info@aihw.gov.au](http://info@aihw.gov.au) or through the AIHW’s custom [Data on request](https://www.aihw.gov.au/our-services/aihw-custom-data-request-service) service. |
| Interpretability: | For perinatal deaths reporting, all statistical methods and concepts applied to the NPMDC can be found online at [Australia's mothers and babies, Data sources - Australian Institute of Health and Welfare (aihw.gov.au)](https://auth.aihw.gov.au/reports/mothers-babies/australias-mothers-babies/contents/technical-notes/data-sources). |
| 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 2020, there was 1 death reported to the NPMDC that was 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 this death 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. |
| Source and reference attributes | |
| Submitting organisation: | Australian Institute of Health and Welfare |
| Relational attributes | |
| Related metadata references: | Supersedes [National Perinatal Mortality Data Collection, 2019; Quality Statement](https://meteor.aihw.gov.au/content/749032)  [AIHW Data Quality Statements](https://meteor.aihw.gov.au/RegistrationAuthority/5), Superseded 29/11/2022  Has been superseded by [National Perinatal Mortality Data Collection, 2021; Quality Statement](https://meteor.aihw.gov.au/content/783855)  [AIHW Data Quality Statements](https://meteor.aihw.gov.au/RegistrationAuthority/5), Standard 23/11/2023 |