National Congenital Anomaly Data Collection, 2023; Quality Statement

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Identifying and definitional attributes

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Data quality

Data quality statement summary:

The National Congenital Anomalies Data Collection (NCADC) is an Australian Institute of Health and Welfare (AIHW) collection of data relating to babies with a congenital anomaly. The AIHW collates data supplied from the states and territories of Australia and harmonises this data for national reporting. The AIHW does not source data on congenital anomalies independently.

The NCADC contains information on babies with diagnosed congenital anomalies and includes live births, stillbirths and terminations of pregnancy (where this data is available). Some baby and maternal data elements in the NCADC are sourced from the National Perinatal Data Collection (NPDC) and cases with congenital anomalies in the NCADC are linked to their respective NPDC record (for those cases that are in scope for the NPDC). This increases the range of information available about cases in the NCADC.

Summary of key issues

Data availability

- Data for the 2017 birth cohort are the most recent data available across 7 reporting jurisdictions (New South Wales, Victoria, Queensland, South Australia, the Australian Capital Territory, Tasmania and the Northern Territory) and have been used to update the current web report.
- Data for the 2016 birth cohort informed the first web report released in 2022 and remain available as data tables in the Data section of the current web report. These data were from 6 reporting jurisdictions (New South Wales, Victoria, Queensland, South Australia, the Australian Capital Territory and Tasmania).
- Data for the 2018 birth cohort are published as preliminary data tables only and do not include Victoria or Western Australia.

Data sources

Data for the NCADC comes from various state and territory data collections. These may vary, for example with respect to: whether they are mandated for collection; the collection methods used; the classification system used to code anomalies; the notification period in use (ranging from the perinatal period only to up until 6 years of age); and the sources of notifications, including, congenital anomaly registers, perinatal collections and hospital admitted patient data collections. Some collections may incorporate notifications from pathology and cytogenetics laboratories, GPs and other health professionals.

More information about jurisdictional data sources can be found in *Congenital anomalies in Australia*.

Data quality and interpretation

Every effort has been made to collect and report national congenital anomalies data consistently, by using common data specifications and reporting using a similar notification period and classification system—in this case the relevant edition of the International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian Modification (ICD-10-AM). However, there are differences in the scope and methods used to collect congenital anomalies data across jurisdictions that may impact national counts and comparability between jurisdictions.

The scope for reporting from the NCADC is different to the scope for reporting from jurisdictional congenital anomaly collections. Over 400 congenital anomalies are counted as inclusions for reporting in the NCADC. Reporting focuses on anomalies that have significant medical, social or cosmetic outcomes for an individual that were diagnosed in babies up to 12 months of age only. The numbers and rates presented will therefore underestimate the overall prevalence of congenital anomalies in Australia and may differ from those reported by individual jurisdictions. More information is available in *Congenital anomalies in Australia*.

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* (AIHW Act), governed by a management 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 confidentiality requirements in the AIHW Act, Privacy Principles in the *Privacy Act 1988*, (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, which includes details about the AIHW's governance (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).

Data for the NCADC are supplied to the AIHW by state and territory health authorities, under individual agreement between AIHW and each state and territory.

The AIHW is the data custodian of the NCADC and receives, compiles, and validates the NCADC 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.

The AIHW is responsible for managing the NCADC and coordinates the National Congenital Anomaly Advisory Group (NCAAG). The NCAAG was set up in 2019 to oversee the process of data collection and reporting for the NCADC and the AIHW works closely with NCAAG members on the collection and reporting of congenital anomalies data and data development.

Timeliness:

Data for the 2017 birth cohort is the most recent data available across all reporting jurisdictions. The NCADC are sourced from various state and territory data collections and there are different processes involved in each jurisdiction to collect, compile, link and validate data from multiple sources. Some congenital anomalies collections have long notification periods (for example up to 5 or 6 years of age), so data for a particular birth cohort may take years to finalise. Jurisdictions have noted the following issues in the supply of congenital anomalies data:

1. Complexity of case ascertainment and data linkage processes

Cases are difficult to accurately ascertain due to their low prevalence rates. Jurisdictions have different methods of case ascertainment and rely on multiple data sources to identify cases of anomalies. There may be timeliness issues due to delays in the receipt of data from these different sources and a need to follow up sources for case ascertainment. Linkage with other data collections takes time and is resource intensive but improves case ascertainment.

2. Notification period

Timeliness and availability of data is also dependent on the notification period used. For some congenital anomaly collections (for example in those that collect data until 6 years of age), the birth cohort data are incomplete for the first few years.

The AIHW aims to collect and publish data from jurisdictions on an annual basis. The first web report based on 2016 birth cohort data was released 1 April 2022. An update using 2017 birth cohort data was released 29 June 2023, see *Congenital anomalies in Australia*.

The AIHW will continue to work with jurisdictional data custodians and the NCAAG to develop strategies to improve the timeliness of the annual collection and reporting of data for the NCADC.

Accessibility:

Congenital anomalies in Australia is available for viewing on the AIHW website and is the second national report based on data from the NCADC. It is a web report with interactive data visualizations, data tables and technical notes. Information about the various jurisdictional congenital anomaly collections and reporting is also available in this report.

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 on request service. Requests that take longer than half an hour to compile are charged for on a cost-recovery basis. Requests for access to unpublished data may require additional approval from jurisdictional data custodians or the AIHW Ethics Committee.

Interpretability:

All statistical methods and concepts applied to the NCADC can be found in the 'Technical notes' in the web report *Congenital anomalies in Australia*. Every effort has been made to collect and report congenital anomalies data consistently, by using common data specifications and reporting using a similar notification period across jurisdictions. However, there are differences in the scope and methodologies used to collect congenital anomalies data across jurisdictions and the NCADC reflects these differences. This may impact national counts and comparability between jurisdictions. See the 'Technical notes' for more information about jurisdictional data sources and AIHW processes to integrate and harmonize the data for reporting.

Relevance:

The purpose of the NCADC is to collect data relating to babies with congenital anomalies to inform policy development and planning and to drive improvements in healthcare outcomes. The NCADC data are compiled from various state and territory data collections. Data for the 2017 birth cohort are the latest data available across the states and territories and were supplied by all jurisdictions, except Western Australia. Data were requested on all cases of congenital anomalies in the 2017 birth cohort including among livebirths, stillbirths, and terminations of pregnancy (where data were available). This includes conditions in the tenth edition of the ICD-10-AM, including Chapter 17 (Q00-Q99), P35 (congenital viral diseases) and P371 (congenital toxoplasmosis).

In practice, what could be supplied varied by jurisdiction, and this had an impact on national reporting. National reporting includes over 400 congenital anomaly condition codes at the 4-character level of the ICD-10-AM, that have significant medical, social or cosmetic outcomes for an individual, and were diagnosed in the 2017 birth cohort up to 12 months of age. Anomalies that did not pose significant health issues for a baby were excluded. The anomaly inclusions and exclusions for reporting were agreed to by the NCAAG and are listed in the web report. To improve consistency, national data were harmonised for reporting, for example:

- AIHW mapped all 2017 congenital anomaly data, including some records from New South Wales supplied in International Statistical Classification of Diseases and Related Health Problems Version 9 British Paediatric Association extension (ICD-9-BPA), to ICD-10-AM (tenth edition) to report data on a single classification.
- Most jurisdictions (except Tasmania) have a notification period for congenital anomaly collections up to 12 months of age, so this is used as the notification period for inclusion for reporting, even though some jurisdictions provided data based on notification periods greater than 12 months.
- Some anomalies were excluded from national reporting because data could not be supplied from all reporting jurisdictions or because they did not pose significant health issues (these are sometimes referred to in other literature as minor anomalies).
- Terminations under 20 weeks were excluded as this data were not available for all reporting jurisdictions.
- Only records able to be linked to the NPDC were included for reporting and records where state of birth was unknown were excluded.

Accuracy:

State and territory health departments are primarily responsible for the quality of the data they provide. The AIHW does not have access to state and territory congenital anomalies records to determine the accuracy of the data provided and relies on jurisdictions to undertake quality assurance processes. The AIHW does however validate the data provided by the states and territories as a whole. Data received from the states and territories are checked for completeness, validity and logic errors. Potential errors are queried with jurisdictions, and corrections and resubmissions made in response to these queries.

Congenital anomalies data for the 2017 birth cohort were not available from Western Australia.

Before publication, data are referred back to jurisdictions for checking and review. The numbers reported based on the NCADC may differ from those published by individual jurisdictions, because the scope of NCADC reporting may be different from the scope of reporting from jurisdictional data collections. Data from the NCADC is standardised across reporting jurisdictions. There are differences in the way cases of congenital anomalies are identified across jurisdictions, and this may affect both jurisdictional and national counts.

The scope of this collection means the numbers and rates presented will underestimate the overall prevalence of congenital anomalies in Australia (see the 'Methods' section in *Congenital anomalies in Australia* for more information).

Some cases are excluded from reporting for data quality reasons. These include:

- cases where the baby's state of birth is unknown, to ensure there are no duplicates being included in the data set
- cases where the baby's outcome is unknown, because it cannot be determined if they are in scope for reporting
- cases that cannot be linked with data from the NPDC.

See the 'Technical notes' for more information.

Coherence:

The NCADC is an ongoing collection to report on congenital anomalies. The AIHW will collect and publish data from jurisdictions on an annual basis.

State and territory health authorities compile statistics and publish reports on congenital anomalies. The collection methods, definitions, classifications, and reference periods used in these collections may differ across states and territories and from the NCADC, and comparisons should be made with caution.

The current NCADC data collection differs in scope from the previous AIHW collection, the Australian Congenital Anomalies Monitoring System (ACAMS). Data presented are not directly comparable to previous reports published in 2006 and 2008 due to differences in scope, including the anomalies reported on and the period of notification used for reporting.

Congenital anomalies information is also available in the AIHW National Hospitals Morbidity Database (NHMD) as part of the National Hospitals Data Collection. This is restricted to anomalies diagnosed in hospital and relates to episodes of care rather than individuals. As such, comparisons with this data source should be made with caution.

Data products

Implementation start date: 18/01/2022

Source and reference attributes

Submitting organisation: Australian Institute of Health and Welfare

Relational attributes

Related metadata references:

Supersedes National Congenital Anomaly Data Collection, 2021; Quality Statement

AIHW Data Quality Statements, Superseded 29/06/2023