State and territory congenital anomaly data sources

	New South Wales(a)	Victoria	Queensland	Western Australia(c)	South Australia	Tasmania	Australian Capital Territory	Northern Territory
Collection name	1. NSW Register of Congenital Conditions 2. NSW Admitted Patient Data Collection	Victorian Congenital Anomalies Register (VCAR)	Congenital Anomaly Linked File (CALF) Data from the Queensland Perinatal Data Collection is linked with Hospital Admitted Patient Data Collection, ABS Cause of Death and Death Registration Data	Western Australian Register of Developmental Anomalies (WARDA)	South Australian Birth Defects Register (SABDR)	1. Tasmanian Perinatal Data Collection 2. Tasmanian Admitted Patient Data Collection	1. ACT Perinatal Data Collection 2. ACT Admitted Patient Data Collection 3. ACT Perinatal Deaths Data	Congenital Anomalies Register NT
Mandatory	Yes—under the NSW Public Health Act 2010	No	No	Yes—under the WA Register of Developmental Anomalies Regulations 2010	Yes—under the South Australian Health Care Act 2008, and South Australian Health Care Regulations 2008	No	No	Yes—under the NT Public and Environmental Health Act, and Public and Environmental Health Regulations 2014
Scope	Scheduled congenital conditions(c) detected in a fetus during pregnancy or in a child up to 1 year of age. Includes conditions detected in: • Stillborn babies or liveborn babies up to 1 year of age • the fetus during pregnancy regardless of whether the pregnancy continues or is terminated.	Notifications of congenital anomalies in children from before birth to 6 years of age. Includes structural, functional, genetic, chromosomal and biochemical abnormalities that can be detected before birth, at birth or days later, in either a liveborn or stillborn baby. All anomalies (major and minor) can be notified to the VCAR, however, reporting is based on major anomalies likely to contribute to perinatal and childhood mortality.	Includes: • terminations of pregnancy at any gestation performed because of a diagnosis of a birth defect • stillbirths and newborn babies with birth defects • children admitted and diagnosed with a birth defect after the neonatal period and prior to their 5th birthday • children who died prior to their 5th birthday, with a birth defect listed on their death record.	A developmental anomaly is defined as: cerebral palsy or a structural or functional anomaly which is present at conception or occurs before the end of pregnancy and is diagnosed during pregnancy, or after stillbirth or termination of pregnancy, or after live birth, but before 6 years of age.	A birth defect is any abnormality, structural or functional, identified up to 5 years of age, provided the condition had its origin before birth. Includes: • terminations of pregnancy at any gestation performed because of a diagnosis of a birth defect • late fetal deaths (stillbirths ≥20 weeks gestation) • newborn babies • children diagnosed after the neonatal period and prior to their fifth birthday.	Any structural or anatomical abnormalities of the baby that are present at birth, in either a liveborn or stillborn baby, and diagnosed before separation from care. Only anomalies diagnosed before discharge from the birthing hospital are included in the collection.	Includes congenital anomalies identified on the perinatal form and from hospital separations using relevant ICD-10-AM codes.	The diagnosis of a structural of functional abnormality in a child up to 12 months of age that was present from conception or that occurs before the end of pregnancy. Includes: • Diagnosed in pregnancy in the Northern Territory • Stillbirths and newborns • Children diagnosed up to 12 months of age

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Notification period	Before birth to 1 year of age	Before birth to 6 years of age	Birth to 5 years of age	Before birth to 6 years of age	Before birth to 5 years of age	Birth to discharge from birthing episode	Birth to 1 year of age	Before birth to 1 year of age
Classification system	ICD-9-BPA (for NSW Register of Congenital Conditions) ICD-10-AM (for Admitted Patient data)	ICD-10-AM	ICD-10-AM	ICD-9-BPA ICD-10-AM Orphacodes	ICD-9-BPA	ICD-10-AM	ICD-10-AM	ICD-10-AM
Source(s) of notification(s)	Primary source of notification is from 2 forms completed by paper or electronically: • notification of a scheduled condition diagnosed by prenatal diagnosis (detected in the fetus) • notification of a scheduled condition diagnosed in an infant (detected in stillborn or liveborn babies up to 1 year of age).	The Victorian Perinatal Data Collection (VPDC) is responsible for around 50% of notifications. The rest come from hospital inpatient and outpatient listings, maternal and child health nurses and cytogenetic laboratories. Notifications are made electronically or via a paper form.	The CALF combines records from the: • Queensland Perinatal Data Collection (QPDC) • Queensland Hospital Admitted Patient Data Collection (including terminations of pregnancy prior to 20 weeks' gestation) • ABS Cause of Death data where a congenital anomaly has been recorded. Data are primarily collected using electronic systems.	The medical practitioner making the diagnosis or providing care, and/or the chief executive officer of the hospital where the diagnosis is being made are responsible for notifications within 6 months. Paper or electronic notification cards can be used.	The primary sources of notification are the supplementary birth record form completed by midwives and the South Australian hospital inpatient listings. Notifications also come from other sources, including: • doctors and other health professionals • specialist paediatric assessment, treatment and rehabilitation centres • private practices • the Pregnancy Outcome Unit (SA Health) • the SA Perinatal Autopsy Service. Forms are completed electronically or via paper.	The Perinatal Data Collection Form is completed by all private hospitals and birth centres where the birth occurs, or by private midwifery and medical practitioners who deliver babies outside hospitals. The electronic perinatal system (ObstetrixTas) is used for all births in public and public contracted private maternity hospitals. A list of anomalies is provided and if any are selected a congenital abnormalities notification form and additional questions on ObstetrixTas are completed.	The primary source of notification is the ACT Perinatal Data Collection. The Perinatal Mortality Committee data and Admitted Patient Data Collection also provide some data on congenital anomalies.	The Primary source is the NT Perinatal Data Collection Congenital Anomaly. NT Health Hospital Admitted Patient Data Collection. NT Health Remote Community Patient Data Collection.

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Data quality/ ascertainment processes	Secondary sources used to improve case ascertainment include: • perinatal data collection form • pregnancy outcomes form • public pathology services • NSW Newborn Screening Program • review of electronic medical records for children up to 1 year of age who have attended a children's hospital in NSW and had an ICD-10-AM code for a congenital anomaly recorded on their admission. Register data is checked for discrepancies and information requested from the hospital or notifier if it is inconsistent or incomplete. Additional steps to confirm deduplication of notifications and other data quality checks are done on a calendar-year basis for each birth cohort.	The same case can be notified through multiple sources and this increases case ascertainment. Data submitted to the VPDC and the VCAR are checked for completeness and validity. Further cleaning is carried out when all data for the calendar year are submitted.	All recorded congenital anomalies are included for children up to 5 years. Reported rates do not include duplicates where an anomaly is reported in more than one collection. The quality of data from the QPDC depends on the accurate, consistent and timely completion of the forms. Completed forms and electronic extracts are validated and contradictory, ambiguous and missing data queried. Validation also occurs across data collections and the consistency of anomaly recording is checked across what is included in QPDC congenital anomalies tables and QPDC death tables.	Register staff ascertain new cases and confirm cases by reviewing medical records, records from antenatal ultrasonography clinics, cytogenetic laboratories, specialist clinics, community health clinics, the state newborn screening laboratory and newborn hearing and vision screening programs. Case ascertainment is strengthened by incorporation with the Western Australia Data Linkage System.	Register staff ascertain cases through electronic inpatient separation summaries from all hospitals with coded birth defects, and also via outpatient lists and databases. Ascertainment is incomplete in the first few years of life for each birth cohort. Data collection to 5 years of age, the use of multiple notification sources, and confirmation of diagnosis increases the accuracy of final diagnosis.	The Department of Health Tasmania undertakes reviews periodically and an extensive set of rules apply to the data. This triggers edits for records containing invalid data or data requiring confirmation. The hospital, birth centre, private midwifery and medical practitioners ensure corrections are made or further information is provided.	n.a.	Register staff validate NT Health clients notification from various sources by reviewing the NT Health electronic medical records. This includes pathology and radiology report, medical letters and remote clinic medical records. Additional information can be sort from Private hospital after the PDC notifications is received.

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Known limitations or issues	A data linkage project that linked NSW Register of Congenital Condition data with the NSW Admitted Patient Data Collection in 2009 showed that the quality and coverage of the register varied by condition.	VCAR includes both suspected and confirmed congenital anomalies. As reporting is not mandatory, it is likely Victorian anomalies are being under-reported. Data has been found to be comparable overtime.	CALF includes anomalies identified from a number of sources and over a longer period of time. The rates reported using CALF are not comparable to those in previous reports.	High quality and internally consistent data.	Data are comparable over time, and previous reports show no major changes in rates and prevalence of notified anomalies. Date of diagnosis was introduced in 2005, but was unavailable prior to this year.	Only anomalies diagnosed before discharge from the birthing hospital are included.	A congenital anomalies collection was available from 1994 to 2005.	Transfer of antenatal women interstate for fetal review and delivery are not identifiable in NT Health outpatient data set and unlikely be captured in other jurisdiction congenital anomaly registers.
More information	NSW Register of Congenital Conditions - Reporting Requirements	Victorian Congenital Anomalies Register	Statistical Services Branch | Queensland Health	Western Australian Register of Developmental Anomalies (healthywa.wa.gov.au) WA Register of Developmental Anomalies (WARDA) (health.wa.gov.au)	Women's and Children's Hospital, Adelaide (wch.sa.gov.au)	Tasmania does not routinely collate or report this data but has extracted for the NCADC. Council of Obstetric and Paediatric Mortality and Morbidity | Tasmanian Department of Health	The ACT does not routinely collate or report this data but has extracted for the NCADC. Data collections | Health (act.gov.au)	Perinatal registry | NT Health
Reports	HealthStats NSW Publications	Congenital anomalies in Victoria 2015–16 | Better Safer Care Congenital anomalies in Victoria 2013–2014	Statistical Services Branch Data Dashboards | Queensland Health	2014 Annual Report of the WA Register of Developmental Anomalies.pdf (health.wa.gov.au)	Birth Defects in South Australia 2016 (wch.sa.gov.au)	n.a.	n.a.	Nil to date Will include summary data in the new addition of NT Mothers and Babies Trends report.

(a) NSW use their register and admitted patient collection to report on notifications of congenital anomalies to the NCADC.

(b) Scheduled congenital conditions include: all structural malformations; chromosomal abnormalities; and 4 medical conditions (cystic fibrosis, phenylketonuria, congenital hypothyroidism and thalassaemia major). Conditions that are not notifiable include: minor anomalies occurring in isolation; birth injuries; congenital infections which do not result in a structural malformation; tumours and cysts; and conditions arising from prematurity or asphyxiation.

(c) Western Australia collects congenital anomalies data through the Western Australian Register of Developmental Anomalies, however, data for 2017 were not supplied to the NCADC in time for reporting.