

National congenital anomalies NBEDS 2016–

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National congenital anomalies NBEDS 2016–

Identifying and definitional attributes

Metadata item type:	Data Set Specification
METEOR identifier:	788219
Registration status:	Health, Recorded 17/07/2024
DSS type:	Data Set Specification (DSS)
Scope:	The scope of the National congenital anomalies national best endeavours data set (NCA NBEDS) is all births (both live births and stillbirths) with a congenital anomaly , and all terminations of pregnancy due to a congenital anomaly, in Australia during the reference period.

Excluded from the National congenital anomalies NBEDS are:

- Births where the baby has been diagnosed with a congenital anomaly after 12 months of age.
- Terminations of pregnancy before 20 weeks' gestation as this data is not available across all jurisdictions.
- Minor congenital anomalies that do not have significant medical, social, or cosmetic outcomes.

Collection and usage attributes

Statistical unit:	As there are two dimensions to the data, there are two statistical units: <ol style="list-style-type: none">1. Mother (Female)2. Baby (Product of conception) diagnosed with a congenital anomaly.
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In the case of multiple births, data are collected once for the mother and once for each baby that has been diagnosed with a congenital anomaly.

Collection methods:	National reporting arrangements:
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State and territory health authorities provide the data to the Australian Institute of Health and Welfare for national collation, on an annual basis (calendar year.) Data is based on cases of congenital anomalies reported to state and territory data collections, including congenital anomaly registers, perinatal data collections and admitted patient data collections.

Some baby and maternal data elements are sourced from the National Perinatal Data Collection (NPDC). Jurisdictions provide a common identifier so cases with congenital anomalies in the National Congenital Anomalies Data Collection (NCADC) can be linked to their respective NPDC record.

Implementation start date:	01/01/2016
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Comments: The terms 'product of conception' and 'baby,' and 'female' and 'mother' are used interchangeably throughout the NBEDS.

Glossary terms that are relevant to this NBEDS include:

[Birthweight](#)

[Congenital anomaly](#)

[Gender](#)

[Gestational diabetes mellitus](#)

[Hypertensive disorder during pregnancy](#)

[Live birth](#)

[Separation](#)

[Sex](#)

[Stillbirth \(fetal death\)](#)

[Termination of pregnancy](#)

[Urban Centre and Locality](#)

Source and reference attributes

Submitting organisation: Australian Institute of Health and Welfare

Relational attributes

Related metadata references: See also [Perinatal Mortality NBEDS 2024–25 Health, Standard 28/05/2024](#)

See also [Perinatal NBEDS 2024–25 Health, Standard 06/12/2023](#)

Metadata items in this Data Set Specification

Seq No.	Metadata item	Obligation	Max occurs
-	Congenital anomalies cluster	Mandatory	1
-	Classification system—edition, number code N{N}{.N}	Mandatory	1
	<i>DSS specific information:</i>		
	In the Congenital anomalies cluster this data element is used to record the edition number of the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM) used to classify (code) the congenital anomaly the baby (product of conception) has as reported in data element Person—congenital anomaly code (ICD-10-AM) ANN{.N{N}} .		
-	Diagnosis—identifier, N{N}	Mandatory	1
	<i>DSS specific information:</i>		
	In the Congenital anomalies cluster this data element is used to identify a specific congenital anomaly the baby (product of conception) has. A baby may have multiple congenital anomalies.		
-	Diagnosis—timing of diagnosis, congenital anomaly code N	Mandatory	1

Seq No.	Metadata item	Obligation	Max occurs
-	Person—congenital anomaly, diagnosis code (BPA 1979) ANN.N[N]	Conditional	1
	<p>Conditional obligation:</p> <p>This data element is collected on a Conditional basis with the data elements Person—congenital anomaly, diagnosis code (ICD-10-AM) ANN{.N[N]} and Person—congenital anomaly, text X[X(49)]. Data must be reported for at least one of these data elements. However, Person—congenital anomaly, diagnosis code (ICD-10-AM) ANN{.N[N]} is the preferred data element to use for the reporting of a baby's congenital anomaly.</p>		
-	Person—congenital anomaly, diagnosis code (ICD-10-AM) ANN{.N[N]}	Conditional	1
	<p>Conditional obligation:</p> <p>This data element is collected on a Conditional basis with the data elements Person—congenital anomaly, diagnosis code (BPA 1979) ANN.N[N] and Person—congenital anomaly, text X[X(49)]. Data must be reported for at least one of these data elements. This data element is the preferred data element to use for the reporting of a baby's congenital anomaly.</p> <p>DSS specific information:</p> <p>In the Congenital anomalies cluster the ICD-10-AM edition used for the diagnosis code should be recorded in the data element Classification system—edition, number code N[N]{.N}.</p>		
-	Person—congenital anomaly, text X[X(49)]	Conditional	1
	<p>Conditional obligation:</p> <p>This data element is collected on a Conditional basis with the data elements Person—congenital anomaly, diagnosis code (ICD-10-AM) ANN{.N[N]} and Person—congenital anomaly, diagnosis code (BPA 1979) ANN.N[N]. Data must be reported for at least one of these data elements. However, Person—congenital anomaly, diagnosis code (ICD-10-AM) ANN{.N[N]} is the preferred data element to use for the reporting of a baby's congenital anomaly.</p>		
-	Person—diagnosis date, DDMMYYYY	Mandatory	1
	<p>DSS specific information:</p> <p>In the Congenital Anomalies cluster this data element is used to report the date a congenital anomaly was diagnosed.</p>		
-	Person—person identifier, XXXXXX[X(14)]	Mandatory	1
-	Record—record source, congenital anomaly code N	Mandatory	1
-	Record—record source, text X[X(49)]	Conditional	1
	<p>Conditional obligation:</p> <p>In the Congenital Anomalies cluster this data element is reported only when CODE 5 'Other source' has been reported for Record—record source, congenital anomaly source code N.</p>		

Seq No.	Metadata item	Obligation	Max occurs						
-	Adult—body mass index, category code N	Mandatory	1						
	DSS specific information:								
	In the National Congenital Anomalies Data Collection this data element is a derived data element and is recorded for the mother only. It is derived from the data elements Person—weight (measured), total kilograms N[NN].N , Person—weight (self-reported), total kilograms NN[N] , Person—height (measured), total centimetres NN[N].N and Person—height (self-reported), total centimetres NN[N] collected in the National Perinatal Data Collection (NPDC).								
-	Birth event—state/territory of birth, code N	Mandatory	1						
	DSS specific information:								
	This data element is recorded for the mother only.								
-	Establishment—sector, code N	Mandatory	1						
	DSS specific information:								
	In the National Congenital Anomalies Data Collection this data element is used to report whether the baby diagnosed with the congenital anomaly was born in a hospital in the public or private sector.								
	The following supplementary codes are also used to report data for this data element.								
	A response of CODE 8 'Not applicable' is recorded where the baby diagnosed with the congenital anomaly was not born in a hospital.								
	<table border="1"> <thead> <tr> <th>Value</th> <th>Meaning</th> </tr> </thead> <tbody> <tr> <td>8</td> <td>Not applicable</td> </tr> <tr> <td>9</td> <td>Not stated</td> </tr> </tbody> </table>			Value	Meaning	8	Not applicable	9	Not stated
Value	Meaning								
8	Not applicable								
9	Not stated								
-	Female—age at time of childbirth, total years N[N]	Mandatory	1						
	Conditional obligation:								
	In the National Congenital Anomalies Data Collection this data element is used to record the mother's age at the time of the baby's birth.								
-	Female—diabetes mellitus during pregnancy indicator, yes/no/not stated/inadequately described code N	Mandatory	1						
	DSS specific information:								
	It is acceptable for jurisdictions to report only CODE 1 'Yes' and CODE 9 'Not stated/inadequately described' against this item.								
	This data element is recorded for the mother only.								

Seq No.	Metadata item	Obligation	Max occurs
-	Female—hypertensive disorder during pregnancy indicator, yes/no/not stated/inadequately described code N DSS specific information: It is acceptable for jurisdictions to report only CODE 1 'Yes' and CODE 9 'Not stated/inadequately described' against this item. This data element is recorded for the mother only.	Mandatory	1
-	Female—parity, total pregnancies N[N] DSS specific information: This data element is recorded for the mother only.	Mandatory	1
-	Female—tobacco smoking during pregnancy flag, yes/no/not stated/inadequately described code N DSS specific information: In the National Congenital Anomalies Data Collection this is a derived data element. It is derived from the data elements Female—tobacco smoking in the first 20 weeks of pregnancy indicator, yes/no/not stated/inadequately described code N and Female—tobacco smoking after 20 weeks of pregnancy indicator, yes/no/not stated/inadequately described code N collected in the National Perinatal Data Collection (NPDC).	Mandatory	1
-	Female—tobacco smoking in the first 20 weeks of pregnancy indicator, yes/no/not stated/inadequately described code N	Mandatory	1
-	Female—type of diabetes mellitus during pregnancy, code N Conditional obligation: In the Congenital Anomalies Data Collection this data element is reported only when CODE 1 'Yes' has been reported for Female—diabetes mellitus during pregnancy indicator, yes/no/not stated/inadequately described code N .	Conditional	1
-	Female—type of hypertensive disorder during pregnancy, code N Conditional obligation: In the National Congenital Anomalies Data Collection this data element is reported only when CODE 1 'Yes' has been reported for Female—hypertensive disorder during pregnancy indicator, yes/no/not stated/inadequately described code N . DSS specific information: This is a multiple response data element and is therefore operationalised for data collection across 3 individual data items (one data item per permissible value, excluding Code 9 (Not stated/inadequately described)).	Conditional	3

Seq No.	Metadata item	Obligation	Max occurs
-	Person—area of usual residence, Australian state/territory code N[N]	Mandatory	1
	DSS specific information:		
	In the National Congenital Anomalies Data Collection this data element is a derived data element and is recorded for the mother only. It is derived from the data element Person—area of usual residence, statistical area level 2 (SA2) code (ASGS Edition 3) N(9) collected in the National Perinatal Data Collection (NPDC)		
	In the National Congenital Anomalies Data Collection non-standard supplementary values for this data element are used as follows:		
	<ul style="list-style-type: none"> • CODE 0 = 'Non-Australian resident'. This value can be mapped to CODE 97 'Not applicable'. • NULL = 'Not stated'. This value can be mapped to CODE 99 'Not stated/inadequately described.' 		
-	Person—country of birth, code (SACC 2016) NNNN	Mandatory	1
	DSS specific information:		
	This data element is recorded for the mother only.		
-	Person—date of birth, DDMMYYYY	Mandatory	2
	DSS specific information:		
	This data element is recorded once for the mother and once for the baby with a congenital anomaly. In the case of multiple births, this data element should be recorded for each baby with a congenital anomaly.		
-	Person—date of birth, YYYY	Mandatory	1
	DSS specific information:		
	In the National Congenital Anomalies Data Collection this data element is used to record the baby's year of birth.		
-	Person—geographic remoteness, classification (ASGS edition 3) code N	Mandatory	1
	DSS specific information:		
	In the National Congenital Anomalies Data Collection this data element is a derived data element and is recorded for the mother only. It is derived from the data element Person—area of usual residence, statistical area level 2 (SA2) code (ASGS Edition 3) N(9) collected in the National Perinatal Data Collection (NPDC).		
-	Person—Indigenous status, code N	Mandatory	1
	DSS specific information:		
	In the National Congenital Anomalies Data Collection this data element is recorded only for the mother.		

Seq No.	Metadata item	Obligation	Max occurs
-	Person—person identifier, XXXXXX[X(14)]	Mandatory	2
	DSS specific information: This data element is recorded once for the mother and once for the baby with a congenital anomaly. In the case of multiple births, this data element should be recorded for each baby with a congenital anomaly.		
-	Person—sex, code X	Mandatory	1
	DSS specific information: This data element is recorded once for the baby with the congenital anomaly. In the case of multiple births, this data element should be recorded for each baby born with a congenital anomaly.		
-	Pregnancy—birth plurality, code N	Mandatory	1
	DSS specific information: This data element is recorded for the mother only.		
-	Product of birth—birth order, code N	Mandatory	1
	DSS specific information: This data element is recorded once for the baby with the congenital anomaly. In the case of multiple births, this data element should be recorded for each baby born with a congenital anomaly. Birth order is only assigned to births that are in scope for the Perinatal NMDS (i.e. births of at least 20 weeks gestation or 400 grams birthweight). In the case of multiple pregnancies, if one or more fetuses were removed from the mother's uterus before 20 weeks gestation, for example, by abortion (spontaneous, induced or fetal reduction), they are not considered in the assignment of birth order for any remaining fetuses that are born. For example, in a twin pregnancy, where one fetus is aborted before 20 weeks gestation, no birth order would be recorded for that twin. If the remaining twin is born and is in scope for the Perinatal NMDS, then their birth order would be recorded as CODE 1 'Singleton or first of a multiple birth.' If both twins are born and are in scope for the Perinatal NMDS, the first twin would be assigned a birth order of CODE 1 'Singleton or first of a multiple birth' and the second twin would be assigned a birth order of CODE 2 'Second of a multiple birth'. In the case of multiple births, this data element should be recorded for each baby born.		
-	Product of birth—birthweight, total grams N[NNN]	Mandatory	1
	DSS specific information: This data element is recorded once for the baby with the congenital anomaly. In the case of multiple births, this data element should be recorded for each baby born with a congenital anomaly. Weight is an important indicator of pregnancy outcome, is a major risk factor for neonatal morbidity and mortality and is required to analyse perinatal services for high-risk infants.		

Seq Metadata item No.

Obligation Max occurs

- [Product of conception—gestational age, code N](#)

Conditional 1

Conditional obligation:

In the National Congenital Anomalies Data Collection this data element is reported only when CODE 4 'Termination of pregnancy' has been reported for [Product of conception—pregnancy outcome code N](#).

DSS specific information:

In the National Congenital Anomalies Data Collection this data element is used to report the gestational age of the product of conception when the [termination of pregnancy](#) occurred.

- [Product of conception—gestational age, total completed weeks N\[N\]](#)

Mandatory 1

DSS specific information:

This data element is recorded once for the baby with the congenital anomaly. In the case of multiple births, this data element should be recorded for each baby born with a congenital anomaly.

The first day of the last menstrual period (LMP) is required to estimate gestational age, which is a key marker in pregnancy and an important risk factor for neonatal outcomes. Although the date of the LMP may not be known, or may sometimes be erroneous, estimation of gestational age based on clinical assessment may also be inaccurate. Gestational age is usually estimated based on available information on LMP and clinical assessment.

The following code has been agreed by the National Perinatal Data Development Committee (NPDDC) as a supplementary code for use in the Perinatal NMDS:

Value	Meaning
99	Not stated/inadequately described

- [Product of conception—pregnancy outcome, code N](#)

Mandatory 1

- [Record—linkage key flag, yes/no code N](#)

Mandatory 1

DSS specific information:

In the National Congenital Anomalies Data Collection this data element is used to report records in the National Congenital Anomalies Data Collection that cannot be linked to records in the National Perinatal Data Collection (NPDC).

- [Record—reason for linkage key absence, code N](#)

Conditional 1

Conditional obligation:

In the National Congenital Anomalies Data Collection this data element is reported only when CODE 2 'No' has been reported for [Record—linkage key flag, yes/no code N](#).

DSS specific information:

In the National Congenital Anomalies Data Collection this data element is used to report why records in the National Congenital Anomalies Data Collection cannot be linked to records in the National Perinatal Data Collection (NPDC).

**Seq Metadata item
No.**

**Obligation Max
occurs**

- [Record—reason for linkage key absence, text X\[X\(49\)\]](#)

Conditional 1

Conditional obligation:

In the National Congenital Anomalies Data Collection this data element is reported only when CODE 3 'Other' has been reported for [Record—reason for linkage key absence, code N](#).

DSS specific information:

In the National Congenital Anomalies Data Collection this data element is used to report the 'other reason' why records in the National Congenital Anomalies Data Collection cannot be linked to records in the National Perinatal Data Collection (NPDC).