**Register of Congenital Conditions**

NSW Ministry of Health

# Background

The NSW Register of Congenital Conditions (formerly known as the NSW Birth Defects Register) is a population-based surveillance system established to monitor congenital conditions detected during pregnancy or at birth, or diagnosed in infants up to one year of age. The Register of Congenital Conditions (RoCC) was established in 1990 and, under the *NSW Public* *Health Act 1991*, from 1 January 1998 doctors, hospitals, and laboratories have been required to notify certain congenital conditions to the Register.

The Register is administered by the Centre for Epidemiology and Research of the NSW Ministry of Health. The collection is based on the date of pregnancy outcome (i.e. date of termination of pregnancy, date of birth, date of stillbirth).

There are three types of conditions that are reported to the Register:

* Conditions that affect the growth, development and health of the baby that are present before birth, such as cleft lip, dislocated hip and problems with the development of the heart, lungs or other organs;
* Conditions due to changes in the number of the baby’s chromosomes, such as Down Syndrome; and
* Four conditions due to changes in the baby’s inherited genetic information: cystic fibrosis, phenylketonuria, congenital hypothyroidism and thalassaemia major.

Functional conditions such as deafness and blindness are not captured in the RoCC.

There is evidence that terminations of pregnancy where a congenital condition is present are under-reported to the RoCC.

Information from the RoCC is published by the NSW Ministry of Health in the annual *NSW Mothers and Babies Report,* which can be found on the Ministry of Health website at<http://www.health.nsw.gov.au/hsnsw/Pages/mothers-and-babies-reports.aspx>.

Congenital conditions are coded using the British Paediatric Association Classification of Diseases: Modified Classification for NSW Register of Congenital Conditions. Where necessary, consultation should be undertaken with RoCC staff to determine the optimal disease codes to capture the condition in question.

# Access to information on Aboriginal and Torres Strait Islander peoples

An application to the Aboriginal Health and Medical Research Council (AH&MRC) ethics committee should be made for research projects for which one or more of the following apply:

* The experience of Aboriginal people is an explicit focus of all or part of the research
* Data collection is explicitly directed at Aboriginal peoples
* Aboriginal peoples, as a group, are to be examined in the results
* The information has an impact on one or more Aboriginal communities
* Aboriginal health funds are a source of funding

Research that is not specifically directed at Aboriginal people or communities, such as for the total population or a sub-population (eg. rural NSW, people over 50 years old) can still potentially impact on Aboriginal people.

However, an application for such research need only be made to the Committee if *any* one of the following applies:

* Any of the five factors listed above are present; or
* Aboriginal people are known, or are likely, to be significantly over-represented in the group being studied (eg. compared to the 2.1% of the total NSW population as shown in the 2006 Census); or
* The Aboriginal experience of the medical condition being studied is known, or is likely, to be different from the overall population; or
* There are Aboriginal people who use the services being studied in distinctive ways, or who have distinctive barriers that limit their access to the services; or
* It is proposed to separately identify data relating to Aboriginal people in the results.

The AH&MRC ethics committee have some specific requirements, including evidence of community engagement in the research. Relevant documents can be found on the AH&MRC website at: <http://www.ahmrc.org.au>. If you are unsure whether an application to the AH&MRC Ethics Committee is required, please seek the advice of the Ethics Committee secretariat (T: 02 9212 4777).

# Tips for using RoCC data in linkage studies

* Personal identifiers are removed from the RoCC after a period of five years; that is, names and other identifying variables are removed from the database. Data from the Register can therefore only be linked for the five year period for which identifiers remain on each record.
* The CHeReL regularly links RoCC data for linkage studies; however the RoCC dataset is not part of the Master Linkage Key. Therefore in your application for linked data, please list RoCC data as an external (ad hoc) dataset.
* A recent validation study that assessed the quality and coverage of reporting to the NSW Register of Congenital Conditions was published by the NSW Ministry of Health and is available here: <http://www.health.nsw.gov.au/hsnsw/Publications/rocc-apd-linkage-study.pdf>. One of the key findings of the study was that the quality and coverage of the Register was condition specific. It is strongly recommended that users who are considering using records from the Register review the report, and consider whether the Register is an appropriate data source for their study.

# Data custodian

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# Register of Congenital Conditions – Variable information

| Variable | Description/Notes | Codes |
| --- | --- | --- |
| Baby’s date of birth | Date of birth for live births and stillbirths.  Date of pregnancy outcome for spontaneous abortions and terminations of pregnancy.  Full date of birth will only be supplied if sufficient justification is supplied that age and month/year of birth is insufficient. Date of birth may otherwise be supplied as MMYYYY. |  |
| Mother’s date of birth | Full date of birth will only be supplied if sufficient justification is supplied that age is insufficient. Date of birth may otherwise be supplied as MMYYYY. |  |
| Mother’s age | Mothers age in years |  |
| Mother’s SLA of residence | SLA of residence | Codes are according to the Australian Standard Geographical Classification (ASGC) issued by the Australian Bureau of Statistics <http://www.abs.gov.au/ausstats/abs@.nsf/mf/1216.0> |
| Health Area of residence | Health Area of residence | See Attachment 1 – Area Health Services |
| Local Health District of residence | Local Health District of residence | See Attachment 2 – Local Health Districts |
| Mother’s Indigenous status | Mother’s Indigenous status. See notes above regarding access to this variable. | 1 = Aboriginal  2 = Torres Strait Islander  3 = Aboriginal and Torres Strait Islander  4 = None of the above  9 = Not stated |
| Mother’s country of birth | Mother’s country of birth | Codes are according to the Standard Australian Classification of Countries (SACC) issued by the Australian Bureau of Statistics <http://www.abs.gov.au/ausstats/abs@.nsf/mf/1269.0> |
| Baby’s Indigenous status | Baby’s Indigenous status. See notes above regarding access to this variable. | 1 = Aboriginal  2 = Torres Strait Islander  3 = Aboriginal and Torres Strait Islander  4 = None of the above  9 = Not stated |
| Hospital of birth | Hospital of birth for live births and stillbirths. Hospital of pregnancy outcome for spontaneous abortions and terminations of pregnancy. | Code lists are updated regularly. If information on specific facilities is required, these should be specified by name. |
| Health Area of hospital | Health Area of hospital | See Attachment 1 – Area Health Services |
| Local Health District of hospital | Local Health District of hospital | See Attachment 2 – Local Health Districts |
| Previous pregnancy > 20 weeks | Whether the mother has had a previous pregnancy of 20 completed weeks gestation or more. | 0 = No  1 = Yes  9 = Not stated |
| Number of previous pregnancies | Number of previous pregnancies of 20 completed weeks gestation or more. |  |
| Baby’s Sex | Sex of fetus or baby | 1 = Male  2 = Female  3 = Indeterminate  9 = Unknown |
| Pregnancy outcome | Spontaneous abortions: most spontaneous abortions are not tested for chromosomal abnormalities. The cases reported to the RoCC usually arise from testing following repeated spontaneous abortions.  Neonatal and post-neonatal deaths: these are under-reported to the RoCC. | 1 = Spontaneous abortion  2 = TOP (<20 weeks)  3 = Stillbirth (>20 weeks)  4 = Liveborn/neonatal death  5 = Liveborn/postneonatal death  6 = Liveborn surviving  9 = Unknown outcome |
| Birth weight | Birth weight measured in grams for live born and still born infants |  |
| Gestational age | Gestational age measured in weeks, based on the best clinical estimate |  |
| Baby’s date of death | Full date of birth will only be supplied if sufficient justification is supplied that age and month/year of birth is insufficient. Date of birth may otherwise be supplied as MMYYYY. |  |
| Plurality | The number of fetuses or babies from the pregnancy. On this basis pregnancy may be classified as single or multiple. | 1 = Singleton  2 = Twins  3 = Triplets  etc  9 = Not stated |
| Birth order | The order of birth. | 1 = First  2 = Second  3 = Third  etc  9 = Not stated |
| Congenital condition code | Congenital condition code | British Paediatric Association Classification of Diseases: Modification Classification for NSW Register of Congenital Conditions |
| Congenital condition position | Congenital condition position | 1 = Right  2 = Left  3 = Bilateral  4 = Unilateral (NOS)  5 = Anterior  6 = Posterior  7 = Central/Midline  8 = Not applicable  9 = Not stated |

# Attachment 1 – Area Health Services (AHS)

|  |  |
| --- | --- |
| Code | Description |
| X160 | Children’s Hospital at Westmead |
| X170 | Justice Health |
| X500 | Sydney South West AHS |
| X510 | South Eastern Sydney & Illawarra AHS |
| X520 | Sydney West AHS |
| X530 | Northern Sydney & Central Coast AHS |
| X540 | Hunter & New England AHS |
| X550 | North Coast AHS |
| X560 | Greater Southern AHS |
| X570 | Greater Western AHS |
| X900 | Ambulance Service of NSW |
| X910 | NSW Not Further Defined |
| X920 | Victoria |
| X930 | Queensland |
| X940 | South Australia |
| X950 | Western Australia |
| X960 | Tasmania |
| X970 | Northern Territory |
| X980 | Australia Capital Territory |
| X990 | Other Australian Territories |
| X997 | Overseas Locality |
| X998 | No Fixed Locality |
| X999 | Not Stated/Other |

# Attachment 2 – Local Health Districts (LHD)

|  |  |
| --- | --- |
| Code | Description |
| X700 | Sydney LHD |
| X710 | South Western Sydney LHD |
| X720 | South Eastern Sydney LHD |
| X730 | Illawarra Shoalhaven LHD |
| X740 | Western Sydney LHD |
| X750 | Nepean Blue Mountains LHD |
| X760 | Northern Sydney LHD |
| X770 | Central Coast LHD |
| X800 | Hunter New England LHD |
| X810 | Northern NSW LHD |
| X820 | Mid North Coast LHD |
| X830 | Southern NSW LHD |
| X840 | Murrumbidgee LHD |
| X850 | Western NSW LHD |
| X860 | Far West LHD |
| X630 | Sydney Children’s Hospitals Network |
| X690 | St Vincent’s Health Network |
| X180 | Forensic Mental Health Network |
| X170 | Justice Health |
| X910 | NSW not further specified |
| X920 | Victoria |
| X921 | Albury (Victoria in-reach) |
| X930 | Queensland |
| X940 | South Australia |
| X950 | Western Australia |
| X960 | Tasmania |
| X970 | Northern Territory |
| X980 | Australian Capital Territory |
| X990 | Other Australian Territories |
| X997 | Overseas Locality |
| X998 | No Fixed Address |
| 9999 | Missing |