NSW Register of Congenital Conditions - Reporting Requirements

Summary  This Policy Directive refers to the reporting of congenital conditions to the NSW Register of Congenital Conditions. It outlines the process for submitting paper-based and electronic notifications to the Ministry of Health, and presents information on data quality, security, access and dissemination. Compliance with this policy directive is mandatory for NSW Health. Information from the Register is used to monitor the occurrence of congenital conditions for service planning purposes and to identify changes in incidence that may warrant investigation.

Document type  Policy Directive
Document number  PD2018_006
Publication date  07 February 2018
Author branch  Centre for Epidemiology & Evidence
Branch contact  (02) 9391 9224
Replaces  PD2012_055
Review date  07 February 2023
Policy manual  Not applicable
File number  17/4482
Status  Active
Functional group  Clinical/Patient Services - Baby and Child, Maternity
Corporate Administration - Information and Data, Records
Distributed to  Ministry of Health, Private Hospitals and Day Procedure Centres, Public Health System
Audience  Administrative, Clinical and other staff involved in reporting congenital conditions to the Ministry of Health
NSW REGISTER OF CONGENITAL CONDITIONS – REPORTING REQUIREMENTS

PURPOSE
This Policy Directive provides guidance to NSW Health staff on the procedure to be followed for the reporting of congenital conditions to the NSW Register of Congenital Conditions.

MANDATORY REQUIREMENTS
All hospitals must notify the Register of Congenital Conditions (the Register) of scheduled congenital conditions detected in a fetus during pregnancy or in a child up to one year of age. This includes staff of obstetrics, neonatal and paediatric units, prenatal genetic services for chromosomal and DNA testing, feto-maternal units and anatomical pathology departments.

This Policy Directive outlines the process for submitting paper and electronic notifications to the Ministry of Health, and presents information on data quality, security, access and dissemination. Compliance with this directive is mandatory for NSW Health and is a condition of subsidy for public health organisations.

IMPLEMENTATION
This Policy Directive should be distributed to all LHD staff. Staff involved in the identification of scheduled congenital conditions during pregnancy or the post-natal period must follow the procedure set out in this policy directive.

REVISION HISTORY

<table>
<thead>
<tr>
<th>Version</th>
<th>Approved by</th>
<th>Amendment notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>February 2018</td>
<td>Deputy Secretary, Population and Public Health</td>
<td>Updated notification process.</td>
</tr>
<tr>
<td>(PD2018_006)</td>
<td></td>
<td>Included reference to NSW Health Privacy Manual for Health Information (IB2015_015)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Minor editorial updates.</td>
</tr>
<tr>
<td>(PD2012_055)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ATTACHMENT
1. NSW Register of Congenital Conditions - Reporting Requirements: Procedure
CONTENTS

1 BACKGROUND......................................................................................................................................... 1
  1.1 About this document .......................................................................................................................... 1
  1.2 Key definitions for scheduled congenital conditions ........................................................................ 1
  1.3 Legal and legislative framework ........................................................................................................ 2

2 REPORTING METHOD ................................................................................................................................ 2
  2.1 Notification types .................................................................................................................................. 2
  2.2 Methods of notification .......................................................................................................................... 2
    2.2.1 Paper notifications ............................................................................................................................ 2
    2.2.2 Electronic notifications ..................................................................................................................... 2
  2.3 Information to be notified ....................................................................................................................... 3

3 DATA QUALITY ........................................................................................................................................... 3

4 DATA SECURITY ......................................................................................................................................... 3

5 DATA ACCESS AND DISSEMINATION ........................................................................................................ 4

6 CONTACT INFORMATION ......................................................................................................................... 4
1 BACKGROUND

1.1 About this document

All hospitals must notify the Register of Congenital Conditions (the Register) of scheduled congenital conditions detected in a fetus during pregnancy or in a child up to one year of age. This includes staff of obstetrics, neonatal and paediatric units, prenatal genetic services for chromosomal and DNA testing, feto-maternal units and anatomical pathology departments.

The Register is located in the Centre for Epidemiology and Evidence of the NSW Ministry of Health. Information from the Register is used to monitor the occurrence of congenital conditions for service planning purposes and to identify changes in incidence that may warrant investigation.

1.2 Key definitions for scheduled congenital conditions

The Register is a state wide surveillance system that monitors the occurrence of scheduled congenital conditions to plan services for affected families, and identify changes in incidence that may warrant investigation.

Scheduled congenital conditions include:

1. All structural malformations. Examples include spina bifida, microcephaly, transposition of the great vessels, ventricular septal defects, pulmonary agenesis, polycystic lungs, duodenal atresia, exomphalos, hydronephrosis, cleft lip/palate, microphthalmia, limb reductions, polydactyly, birthmarks greater than 4cm diameter, cystic hygroma and multisystem syndromes including at least one structural malformation.

2. Chromosomal abnormalities. Examples include Down syndrome and unbalanced translocations.

3. Four medical conditions: cystic fibrosis, phenylketonuria, congenital hypothyroidism and thalassaemia major.

Congenital conditions that are not notifiable include:

1. Minor anomalies occurring in isolation.
   Examples of minor anomalies include skin tags, deviated nasal septum, tongue tie, benign heart murmurs, clicky non-dislocating hips, sacral dimples, positional talipes, abnormal palmar creases, and dysmorphic features.

2. Birth injuries.

3. Congenital infections which do not result in a structural malformation.

4. Tumours and cysts.

5. Conditions arising from prematurity or asphyxiation.
1.3 Legal and legislative framework

Congenital conditions occurring in a child under one year of age or pregnancies where the fetus has a congenital condition are required to be reported under the NSW Public Health Act 2010.

2 REPORTING METHOD

2.1 Notification types

1. *Notification of a scheduled congenital condition diagnosed in an infant*

   Information in this format should be supplied for congenital conditions detected in stillborn babies or live born babies up to one year of age.

2. *Notification of a scheduled congenital condition diagnosed by prenatal diagnosis*

   Information in this format should be supplied for congenital conditions detected in the fetus during pregnancy, regardless of whether the pregnancy continues.

Guidelines for notification are printed on the outside cover of each notification pad.

In the case of a multiple pregnancy or multiple birth where both babies are affected, a separate form or electronic record must be completed in full for each fetus or baby.

2.2 Methods of notification

Information may be supplied in paper or electronic format.

2.2.1 Paper notifications

For submission on paper forms, forms are provided in triplicate with the original sent to the NSW Ministry of Health, one copy for the hospital medical record and one copy for the parent or family. Information for parents and families concerning the Register is printed on the reverse side of the Parent Copy of both notification forms.

Paper notifications should be mailed to:

   The NSW Register of Congenital Conditions
   Centre for Epidemiology and Evidence
   Level 7
   NSW Ministry of Health
   Locked Mail Bag 961
   North Sydney NSW 2059

2.2.2 Electronic notifications

Electronic notifications of scheduled congenital conditions can be facilitated via a hospital’s Maternity Information System – the electronic system that captures birth notifications from hospitals. Notifications should be entered immediately following
diagnosis. Notifications should be sent to the Ministry of Health on at least a quarterly basis. For facilities interested in submitting notifications electronically, please contact: roccadmin@moh.health.nsw.gov.au.

2.3 Information to be notified

<table>
<thead>
<tr>
<th>Demographic details (mother)</th>
<th>Indigenous status (baby)</th>
</tr>
</thead>
<tbody>
<tr>
<td>First name</td>
<td>Plurality</td>
</tr>
<tr>
<td>Last name</td>
<td>Baby number</td>
</tr>
<tr>
<td>Date of birth</td>
<td>Birth weight</td>
</tr>
<tr>
<td>Hospital medical record number or laboratory number</td>
<td>Gestation</td>
</tr>
<tr>
<td>Residential address</td>
<td>Outcome</td>
</tr>
<tr>
<td>Country of birth</td>
<td>Autopsy/histopathology</td>
</tr>
<tr>
<td>Indigenous status (mother)</td>
<td>Date of death</td>
</tr>
<tr>
<td>Demographic details (live born or stillborn baby)</td>
<td>Pregnancy details (where applicable)</td>
</tr>
<tr>
<td>First name</td>
<td>Indication for prenatal diagnosis</td>
</tr>
<tr>
<td>Last name</td>
<td>Date of birth</td>
</tr>
<tr>
<td>Date of birth</td>
<td>Relevant medical or family history</td>
</tr>
<tr>
<td>Hospital medical record number or laboratory number</td>
<td>Congenital abnormality/syndrome</td>
</tr>
<tr>
<td>Hospital of birth</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>Sex</td>
<td>Laterality</td>
</tr>
<tr>
<td></td>
<td>Date of Diagnosis</td>
</tr>
<tr>
<td></td>
<td>Karyotype – balanced, unbalanced</td>
</tr>
</tbody>
</table>

3 DATA QUALITY

Data submitted to the Register is checked for any discrepancies and further information is requested from the hospital or reporting clinician if information received is inconsistent or incomplete.

4 DATA SECURITY

Data collected by the Register is protected under the NSW Public Health Act 2010. The NSW Health Privacy Manual for Health Information (previously known as the NSW Health Privacy Manual) must be observed for all data relating to the Register. This is located at: http://www.health.nsw.gov.au/policies/manuals/Pages/privacy-manual-for-health-information.aspx.

The Register database is held on the NSW Ministry of Health’s local area network, is password protected and is accessible only to the Register staff.

Paper forms submitted to the Register are securely stored and are destroyed no more than five years after the year of birth or completion of the pregnancy.
Personal identifiers (name, residential street number and name, and medical record number) are removed from the database five years after the year of birth or completion of the pregnancy.

5 DATA ACCESS AND DISSEMINATION

Information obtained from the Register is made available on request. Specific analyses of Register data, or access to unit record data from the Register, may be obtained on written request to the Executive Director, Centre for Epidemiology and Evidence (email: ceemail@moh.health.nsw.gov.au).

6 CONTACT INFORMATION

For further information about the Register of Congenital Conditions, or this Policy Directive, please contact: roccadmin@moh.health.nsw.gov.au.