**Neonatal Intensive Care Units’ (NICUS) Data Collection**

Neonatal Intensive Care Units’ Data Collection

NSW Pregnancy and Newborn Services Network

# Background

The Neonatal Intensive Care Units’ (NICUS) Data Collection contains information on infants admitted to one of the 10 neonatal intensive care units in NSW or the ACT or one of five level 4 special care units in NSW during the first 28 completed days of life and who meet any of the following eligibility criteria: gestation < 32 weeks, birth weight </= 1500g, need for assisted ventilation (mechanical ventilation, continuous positive airways pressure [CPAP], high flow oxygen/air >1L/min), major surgery (opening of a body cavity), insertion of a central line, intentional hypothermia for infants with hypoxic ischaemic encephalopathy, exchange transfusion.

The 10 participating Intensive Care units are sited at the Canberra Hospital, Children's Hospital at Westmead, John Hunter Children’s Hospital, Liverpool Hospital, Nepean Hospital, Royal Prince Alfred Hospital, Royal Hospital for Women, Royal North Shore Hospital, Sydney Children's Hospital, Westmead Hospital, and the five Level 4 special care units are sited at Blacktown Hospital, Campbelltown Hospital, Gosford Hospital, St George Hospital and Wollongong Hospital.

# Information recorded on the database includes:

* Infant identifying details including name, date of birth, address, hospital of birth, hospital record number
* Mother’s identifying details
* Father’s identifying details if available
* Mother’s demographics: aboriginality, ethnicity, usual residence at birth of baby
* Neonatal details: gestation, birth weight, head circumference, birth order and plurality, APGAR Scores
* Resuscitation details including exposure to oxygen
* Respiratory status including ventilation details
* Morbidities and treatment e.g. bronchopulmonary dysplasia, necrotizing enterocolitis, retinopathy of prematurity, intraventricular hemorrhage
* Sepsis
* Age and growth parameters at discharge from hospital
* Death prior to discharge from hospital including cause of death
* Pregnancy and delivery details
* Developmental outcome of infants at 1 and 2-3 years of age, corrected for prematurity

# Previous linkage projects conducted through CHeReL include:

Using hospital discharge data for determining neonatal morbidity and mortality: a validation study. Principal researcher Dr Jane Ford, University of Sydney. Published 2007

Outcomes of children admitted to neonatal intensive care units between 1998 and 2006. Project commenced in 2009. Principal Researcher Dr Julee Oei, Royal Hospital for Women.

Evaluating appropriate use of blood products in mothers and babies. Project commenced in 2011. Principal researcher Dr Jane Ford, University of Sydney.

# Availability of data for studies:

These data are available to researchers for further study, subject to approval from the Data Custodian, the Directors of all participating units and appropriate ethics committees. For further information and a list of variables available for data linkage projects please contact the Data Custodian, Ms Barbara Bajuk or CHeReL staff on [cherel@cancerinstitute.org.au](mailto:cherel@cancerinstitute.org.au). A list of variables available for data linkage projects can also be accessed on the CHeReL website at: <http://www.cherel.org.au/external-datasets>

# Data custodian

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