

# 2013

REPORT OF THE  
**AUSTRALIAN AND  
NEW ZEALAND  
NEONATAL NETWORK**



**UNSW**  
AUSTRALIA

**ANZNN**

# 2013

---

## REPORT OF THE AUSTRALIAN AND NEW ZEALAND NEONATAL NETWORK

Sharon S.W. Chow, Renate Le Marsney,  
Sadia Hossain, Ross Haslam and Kei Lui

***ANZNN Executive:***

Ross Haslam (Chairman)

Kei Lui (Operations Manager)

Barbara Bajuk

Roland Broadbent

Adam Buckmaster

Lee Carpenter

Georgina Chambers

Koert de Waal

Andy Gill

Jim Holberton

Guan Koh

Jane Pillow

Shelley Reid

Jutta van den Boom



**UNSW**  
A U S T R A L I A

**ANZNN**

© Australian and New Zealand Neonatal Network 2015

This work is copyright. Apart from any use as permitted under the Copyright Act 1968, no part may be reproduced without prior written permission from the Australian and New Zealand Neonatal Network (ANZNN). Requests and enquiries concerning reproduction and rights should be directed to the Coordinator, Australian and New Zealand Neonatal Network at the National Perinatal Epidemiology and Statistics Unit, Level 1, AGSM Building (G27), UNSW Australia, Sydney NSW 2052 Australia.

This publication is part of the Australian and New Zealand Neonatal Network annual reports series. A complete list of the ANZNN's publications is available from the Network's website < <http://www.anznn.net> >.

ISBN: 978-0-9807290-6-1

Suggested citation:

Chow, S.S.W., Le Marsney, R., Hossain S., Haslam, R., Lui, K., 2015. Report of the Australian and New Zealand Neonatal Network 2013. Sydney: ANZNN.

Any enquiries about or comments on this publication should be directed to:

Coordinator

Australian and New Zealand Neonatal Network

At the National Perinatal Epidemiology and Statistics Unit

Level 1, AGSM Building (G27)

UNSW Australia

Sydney NSW 2052

Australia

**Phone:** +61 2 9385 9158

**Email:** [anznn@unsw.edu.au](mailto:anznn@unsw.edu.au)

Published by the Australian and New Zealand Neonatal Network 2015

Designed and printed by Green Print Centre at UNSW

Please note that there is the potential for minor revisions of data in this report.

Please check the online version at < <http://www.anznn.net> > for any amendments.

# Contents

<b>Acknowledgements.....</b>	<b>vi</b>
<b>Structure of this report .....</b>	<b>vii</b>
<b>Abbreviations.....</b>	<b>viii</b>
<b>Participating units and supporting staff.....</b>	<b>ix</b>
<b>1. Organisation of the ANZNN .....</b>	<b>1</b>
History .....	1
Purpose of this report.....	1
Structure of the ANZNN .....	1
Registration criteria .....	2
Funding support .....	3
Data set variables.....	3
<b>2013 Report of the Australian and New Zealand Neonatal Network .....</b>	<b>4</b>
Babies born in Australia .....	5
Babies born in New Zealand.....	5
<b>2. Babies registered to level III units.....</b>	<b>6</b>
<b>3. Mothers of level III registrants .....</b>	<b>9</b>
Maternal age.....	9
Previous antenatal history .....	9
Assisted conception.....	9
Presenting antenatal problem .....	10
Antenatal corticosteroid use .....	11
Magnesium sulphate .....	12
Multiple births .....	13
Method of birth.....	13
Place of birth .....	14
Transport after birth to a level III NICU .....	15
Breastfeeding at discharge .....	15
<b>4. Characteristics of level III registrants .....</b>	<b>16</b>
Baby gender .....	16
Resuscitation in delivery suite.....	16
Apgar score at birth .....	16
Admission temperature .....	17

Indication for respiratory support .....	17
Exogenous surfactant .....	18
Type of assisted ventilation .....	19
Ventilation in babies born at less than 32 weeks gestation.....	21
Ventilation in babies born at 32 to 36 weeks gestation .....	21
Ventilation in babies born at term .....	21
Respiratory support .....	21
Nasal high flow therapy .....	22
Parenteral nutrition.....	23
Chronic lung disease.....	24
Pulmonary air leak.....	24
Neonatal sepsis.....	25
Retinopathy of prematurity .....	26
Intraventricular haemorrhage .....	27
Late cerebral ultrasound.....	28
Therapeutic hypothermia.....	28
Necrotising enterocolitis .....	29
Spontaneous intestinal perforation.....	29
Neonatal surgery.....	29
Congenital anomalies.....	30
Transfer from level III NICUs to other units .....	31
Length of stay until discharge home .....	31
Survival of the ANZNN registrants .....	32
<b>5. Babies registered to level II units.....</b>	<b>35</b>
Overview .....	35
Maternal, pregnancy and birth characteristics .....	36
Characteristics of level II babies .....	38
Eye examination.....	39
Cerebral ultrasound .....	39
Other morbidities .....	39
Level II transfers .....	39
Survival .....	39
<b>6. Extremely preterm follow-up, 2009–2010 births .....</b>	<b>41</b>
Introduction .....	41
Follow-up rate.....	41
Assessment and tools .....	43
Neurological outcome .....	43
Vision and hearing.....	44
Congenital anomalies.....	44

Developmental testing .....	45
Functional impairment.....	47
Moderate to severe functional impairment .....	48
Growth – weight, height and head circumference .....	49
Respiratory and gastrointestinal tract .....	52
<b>APPENDICES .....</b>	<b>53</b>
<b>Appendix 1: Trends .....</b>	<b>53</b>
<b>Appendix 2: Data tables by birthweight.....</b>	<b>62</b>
<b>Appendix 3: Methods used in this report .....</b>	<b>70</b>
<b>Appendix 4: Confidentiality guidelines .....</b>	<b>71</b>
Principles of ownership and maintenance of data.....	71
Conditions for data collection .....	71
Conditions for data security .....	72
Small numbers .....	72
<b>Appendix 5: Minimum Data Set variables.....</b>	<b>73</b>
Neonatal Minimum Data Set .....	73
Extremely Preterm Follow-up Minimum Data Set.....	89
<b>Glossary .....</b>	<b>95</b>
<b>References .....</b>	<b>97</b>
<b>List of Tables .....</b>	<b>98</b>
<b>List of Figures .....</b>	<b>100</b>

# Acknowledgements

This is the eighteenth report of the Australian and New Zealand Neonatal Network (ANZNN), the sixth report in the new format and the second to include a report on 2 to 3 year follow-up. The ANZNN has endeavoured to retain the information provided in previous reports to allow comparative reporting over time. Details of the current format can be found under 'Structure of this report'.

The number of Australian level II units continues to increase with a total of ten units contributing data for this report, with more units joining the ANZNN the number will continue to rise.

We would like to acknowledge all the units involved in the provision of data for this report. The ANZNN appreciates the contribution of all participating units and we thank them for their ongoing support together with our data managers for their hard work and attention to detail.

The ANZNN greatly values the time, effort and expertise of the members of the ANZNN Advisory Council and their conceptual, intellectual and financial contributions, all of which have helped make this network a respected and world-recognised organisation.

We thank the following members of the ANZNN Executive: Ross Haslam (Chairperson), Barbara Bajuk, Roland Broadbent, Adam Buckmaster, Lee Carpenter, Georgina Chambers, Koert de Waal, Andy Gill, Jim Holberton, Guan Koh, Kei Lui, Jane Pillow, Shelley Reid and Jutta van den Boom for their commitment and guidance for all the activities of the ANZNN. Particular thanks to the ANZNN Data Collection Operation Committee, namely Kei Lui (Chairperson), Georgina Chambers, Deborah Donoghue, Andy Gill, Jim Holberton, Timothy Hong, John Hyland, Caroline Karskens and Peter Marshall. The Follow-up Subcommittee of Kei Lui (Chairperson), Lex Doyle, Liza Edmonds, Peter Gray, Noel French, Elizabeth Hurron, Michael Stark and Crista Wocadlo were instrumental in advising the data collection and analysis for the 2-3 year follow-up chapter. Thanks also to Peter Anderson for his advice regarding the analysis of follow-up outcomes. Particular acknowledgement goes to Renate Le Marsney for leading the data analysis and writing the chapter on 2-3 year follow-up of extremely preterm infants, and to Sadia Hossain for her assistance in the production of this report.

We thank Emerge Health (Australia), Douglas Pharmaceuticals (New Zealand) and Ikaria Australia for their ongoing support and for helping us to achieve our aims. We acknowledge our colleagues from the National Perinatal Epidemiology and Statistics Unit for their continued support and encouragement.

# Structure of this report

- Chapter 1:** This chapter presents the structure and organisation of the ANZNN together with some historical information related to its establishment. Also included is information on funding, selection criteria as well as a brief synopsis of level III registrants in Australia and New Zealand for 2013.
- Chapter 2:** ‘Babies registered to level III units’ provides information and characteristics on the ANZNN registrants in 2013 who are either born in a hospital with a level III unit or who are born elsewhere and then transferred to a level III unit within the first 28 days of life.
- Chapter 3:** ‘Mothers of level III registrants’ provides information on the mothers of level III registrants registered to the ANZNN in 2013.
- Chapter 4:** ‘Characteristics of level III registrants’ provides information about the babies admitted to a level III neonatal unit during 2013.
- Chapter 5:** ‘Babies registered to level II units’ provides information about babies registered to the level II special care baby units during 2013.
- Chapter 6:** ‘Extremely preterm follow-up, 2009-2010 births’ provides 2 to 3 year follow-up information about extremely preterm and/or extremely low birthweight babies registered to the level III neonatal units during 2009 and 2010.
- Appendices:** Appendix 1 presents 10-year trends  
Appendix 2 presents data tables by birthweight for 2013  
Appendix 3 presents the methods employed for this report  
Appendix 4 contains confidentiality guidelines, and conditions for data collection, use and security  
Appendix 5 presents the Minimum Data Sets for the ANZNN.



# Abbreviations

ABS	Australian Bureau of Statistics	IVF	<i>in vitro</i> fertilisation
ANZNN	Australian and New Zealand Neonatal Network	IVH	intraventricular haemorrhage
APH	antepartum haemorrhage	LOS	length of stay
CI	confidence interval	MgSO <sub>4</sub>	magnesium sulphate
CLD	chronic lung disease	NEC	necrotising enterocolitis
CP	cerebral palsy	NHFT	nasal high flow therapy
CPAP	continuous positive airways pressure	NHMRC	National Health and Medical Research Council
CRIB	Clinical Risk Index for Babies	NICU	neonatal intensive care unit
ECMO	extracorporeal membrane oxygenation	NPESU	National Perinatal Epidemiology and Statistics Unit
g	gram	NO	nitric oxide
GIFT	gamete intra-fallopian transfer	O <sub>2</sub>	oxygen – normal air is 21% oxygen
GIT	gastrointestinal tract	PMA	post menstrual age (completed weeks)
GMFCS	gross motor function classification system	PPROM	preterm pre-labour rupture of membranes
HFNC	high flow nasal cannulae	PVL	periventricular leukomalacia
HFOV	high frequency oscillatory ventilation	RD	respiratory distress
HMD	hyaline membrane disease	RDS	respiratory distress syndrome
ICD-10-AM	The International Statistics Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification	ROM	rupture of membranes
IPPV	intermittent positive pressure ventilation	ROP	retinopathy of prematurity
IQR	interquartile range	SD	standard deviation
IUGR	intrauterine growth restriction	TPN	total parenteral nutrition
		UNSW	University of New South Wales
		WHO	World Health Organization

# Participating units and supporting staff

## Level III nurseries:

### Australia

#### New South Wales

##### Children's Hospital at Westmead

*(NICU & special care beds: 24)*

Nadia Badawi (Co-director), Rob Halliday (Co-director), Alison Loughran-Fowlds, Caroline Karskens

##### John Hunter Hospital

*(NICU & special care beds: 42)*

Paul Craven (Director), Chris Wake, Rebecca Glover, Larissa Korostenski, Susanne Wooderson, Lynne Cruden, Alissa Argomand

##### Liverpool Health Service

*(NICU & special care beds: 31)*

Jacqueline Stack (Director), Ian Callander, Kathryn Medlin, Kaye Marcin

##### Nepean Hospital

*(NICU & special care beds: 36)*

Vijay Shingde (Director), Lyn Downe (Clinical Director), Basiliki Lampropoulos, Jacqueline Furey, Mee Fong Chin, Kerrie Bonzer

##### Royal Hospital for Women

*(NICU & special care beds: 44)*

Kei Lui (Director), Lee Sutton, Vikki Biggs, Diane Cameron

##### Royal North Shore Hospital

*(NICU & special care beds: 25)*

Mary Paradisis (Director), Jennifer Bowen, Martin Kluckow, Amy Sparks, Claire Jacobs

##### RPA Women and Babies

*(NICU & special care beds: 34)*

Ingrid Rieger (Director), Tracey Lutz (Clinical Director), Nick Evans, David Osborn, Crista Wocadlo, Shelley Reid

##### Sydney Children's Hospital

*(NICU & special care beds: 4)*

Andrew Numa (Director), Janelle Young

#### Westmead Hospital

*(NICU & special care beds: 41)*

Melissa Luig (Director), Mark Tracy, Melissa Ross, Tracey Anne Goyen, Jane Baird

#### Neonatal Intensive Care Units' (NICUS) Data Collection

*(New South Wales and Australian Capital Territory)*

Barbara Bajuk, Sara Sedgley, Mark Leckie

### Australian Capital Territory

#### The Canberra Hospital

*(NICU & special care beds: 25)*

Hazel Carlisle (Director), Zsuzsoka Kecskes, Alison Kent, Alana Carter, Judith Smith

### Victoria

#### Mercy Hospital for Women

*(NICU & special care beds: 56)*

Dan Casalaz (Director), Andrew Watkins, Jim Holberton, Elizabeth Noble, Emily Burke

#### Monash Medical Centre

*(NICU & special care beds: 56)*

Elizabeth Carse (Acting Director), Andrew Ramsden, Kenneth Tan, Kaye Bawden, Rose Li, Marie Hayes

#### Royal Children's Hospital

*(NICU & special care beds: 32)*

Rod Hunt (Director), Jo Brooks

#### Royal Women's Hospital

*(NICU & special care beds: 58)*

Carl Kuschel (Director), Lex Doyle (Professor of Neonatology), Esther Wong, Alison Martin, Melissa Drew, Frances Darmanin

### Tasmania

#### Royal Hobart Hospital

*(NICU & special care beds: 26)*

Tony De Paoli (Director), Peter Dargaville, Karen Butterley

## Queensland

### Mater Mothers' Hospital

*(NICU & special care beds: 79)*

Lucy Cooke (Director), David Knight, Peter Gray, Elizabeth Hurron, Dion Hattersley, Leith Poulsen

### Royal Brisbane and Women's Hospital

*(NICU & special care beds: 71)*

David Cartwright (Director), Pieter Koorts, Paul Colditz (Professor of Perinatal Medicine), Tim Donovan

### The Townsville Hospital

*(NICU & special care beds: 44)*

Guan Koh (Director), Gary Alcock, Jenny Binney, Louise McIlldowie, Kathleen Pirard

## South Australia

### Flinders Medical Centre

*(NICU & special care beds: 35)*

Peter Marshall (Director), Rebecca Davis

### Women's and Children's Hospital

*(NICU & special care beds: 49)*

Chad Andersen (Director), Andy McPhee, Michael Stark, Ann Fitzgerald, Cindy Golding, Ros Lontis, Meg Bater

## Western Australia

### King Edward Memorial and Princess Margaret Hospitals

*(NICU & special care beds: 107)*

Karen Simmer (Director and Professor of Neonatal Medicine), Annette Butler, Noel French, Rolland Kohan, Shripada Rao, Andy Gill, Jane Pillow, Damber Shrestha

## Northern Territory

### Royal Darwin Hospital

*(NICU & special care beds: 25)*

Charles Kilburn (Director of Perinatal Services), Manbir Chauhan (Director of Unit), Rakesh Seth, Deborah Ribbon, Sarah Thomas, Connie Yii

## Newborn emergency transport services

### NETS NSW (Newborn & Paediatric Emergency Transport Service)

Andrew Berry (Director)

### Newborn Emergency Transport Service (Victoria)

Michael Stewart (Director)

### Western Australia Neonatal Transport Service

Steven Resnick (Director)

## New Zealand

### Christchurch Women's Hospital

*(NICU & special care beds: 38)*

Nicola Austin (Director), Brian Darlow (Professor of Paediatrics), Nina Mogridge, Trish Graham

### Dunedin Hospital

*(NICU & special care beds: 16)*

Roland Broadbent (Director), Liza Edmonds, Carole Chettleburgh, Frances McCaffrey

### Middlemore Hospital

*(NICU & special care beds: 30)*

Lindsay Mildenhall (Director), Maisie Wong, David Hou

### National Women's Health (at Auckland City Hospital)

*(NICU & special care beds: 46)*

Malcolm Battin (Director), Coila Bevan

### Waikato Hospital

*(NICU & special care beds: 41)*

David Bouchier (Director), Phil Weston, Deborah Harris, Arun Nair, Claire West

### Wellington Women's Hospital

*(NICU & special care beds: 40)*

Vaughan Richardson (Director), Keith Fisher, Helen Miller, Michael Hewson, Harshad Patel, Bronwyn Cook

## Level II nurseries:

### Australia

#### New South Wales

##### Blacktown Hospital

*(Special care beds: 24)*

Anjali Dhawan (Director), Therese Freeman

##### Campbelltown Hospital

*(Special care beds: 15)*

Raymond Chin (Director), Kellie Gear

##### Gosford District Hospital

*(Special care beds: 25)*

Hassan Sharifi Savojbolaghi (Director), Adam Buckmaster, Kerry Field, Jane Wardle

##### St George Hospital

*(Special care beds: 8)*

Bob Fonseca (Director), Anne Hurst

##### Wollongong Hospital

*(Special care beds: 20)*

Susie Piper (Director), Ian Wright, Sylvia Lees

### Victoria

##### Sunshine Hospital

*(Special care beds: 21)*

Martin Wright (Director), Thao Lu, Jennifer Francis, Rosalynn Pszczola

### Queensland

##### Cairns Base Hospital

*(Special care beds: 22)*

Ross Messer (Director), Sue McMahon

##### Gold Coast Hospital

*(Special care beds: 22)*

Peter Schmidt (Director), Timothy Hong, John Hyland

##### Mackay Base Hospital

*(Special care beds: 4)*

Michael Williams (Director), Kerry Topping

### Tasmania

##### Launceston General Hospital

*(Special care beds: 12)*

Chris Bailey (Director), Jennifer James, Robyn Morey, Frances McCarroll, Christine Coker

##### Timaru Hospital

*(Special care beds: 3)*

Philip Morrison (Director), Bid Esler, Mark Liddy

##### Wairau Hospital

*(Special care beds: 4)*

David Bond (Director)

### Northern Territory

##### Alice Springs Hospital

*(Special care beds: 8)*

David Green (Director), Marion Bates

### New Zealand

##### Gisborne Hospital

*(Special care beds: 6)*

Heinrich Stander (Director), Graeme Lear, Barbara Reid

##### Hawkes Bay Hospital

*(Special care beds: 12)*

Oliver Grupp (Director), Jenny Corban, Kay Hodson, Mercy Jenson

##### Lower Hutt Hospital

*(Special care beds: 12)*

Robyn Shaw (Director), Debbie Bashaw, Anne Mitchell

##### Nelson Hospital

*(Special care beds: 10)*

Peter McIlroy (Director), Nathalie Robinson, Maureen Higgs

##### North Shore Hospital

*(Special care beds: 12)*

Jutta van den Boom (Director), Diane Chesney

##### Palmerston North Hospital

*(Special care beds: 17)*

Jeff Brown (Director), Amy Hinder

##### Rotorua Hospital

*(Special care beds: 10)*

Stephen Bradley (Director), Jacquie Koberstein, Gaye France

**Southland Hospital**

*(Special care beds: 6)*

Ian Shaw (Director), Paul Tomlinson, Liz Hanning-Baird

**Taranaki Base Hospital**

*(Special care beds: 8)*

John Doran (Director), Jane Bocock

**Tauranga Hospital**

*(Special care beds: 10)*

Hugh Lees (Director), Heather McAlley, Anna Moore

**Wanganui Hospital**

*(Special care beds: 4)*

David Montgomery (Director), Barbara Hammond

**Whakatane Hospital**

*(Special care beds: 5)*

Chris Moyes (Director), Margret Norris, Lee Willetts

**Whangarei Area Hospital**

*(Special care beds: 8)*

Ransford Addo (Director), Janine Whale, Lynne Clarke, Merophy Brown

**Waitakere Hospital**

*(Special care beds: 12)*

Jutta van den Boom (Director), Janis Stockman

**ANZNN Program and Secretariat****National Perinatal Epidemiology and Statistics Unit (NPESU)**

Georgina Chambers (Director), Sharon Chow, Sadia Hossain, Renate Le Marsney

# 1. Organisation of the ANZNN

## History

A prospective audit commenced in 1994 with all level III units in Australia and New Zealand contributing data on babies from 1 January 1995. Level II units in New Zealand joined in 1998, followed by one level II unit in Tasmania, Australia in 1999. Level II units within Australia continue to join with a total of ten units contributing data in 2013.

## Purpose of this report

The purpose of the *Report of the Australian and New Zealand Neonatal Network* is ‘to improve the care of high-risk newborn infants and their families in Australia and New Zealand by enabling benchmarking and so collaborative audit, plus facilitating research’.

This is achieved through:

- providing a core data set that will:
  - provide information on neonatal outcomes, adjusted for case mix and disease severity, to participating neonatal units to assist with quality improvement
  - identify trends and variations in morbidity or mortality
  - assist with the identification of areas of priority for research
  - enhance the ability to carry out multicentre studies and randomised controlled trials through collaboration
- monitoring the clinical indicators for perinatal care and improving clinical practice while maintaining national standards of evidence-based care
- monitoring the use of new technologies, e.g. high flow/oxygen air usage by patient type and outcome
- consistency in national data collections.

## Structure of the ANZNN

The ANZNN is located in the National Perinatal Epidemiology and Statistics Unit (NPESU) within the University of New South Wales (UNSW). The arrangement is outlined in the memorandum of understanding (MOU) between ANZNN and UNSW.

The governance structure of the ANZNN (Figure 1) consists of the Advisory Council (formerly Advisory Committee), the Executive Committee (formerly Management Committee), and the Data Collection and Operations Committee. The Advisory Council is the governing body of ANZNN and includes the directors (or their nominee) of each participating unit, the academic neonatologists and neonatal nurses in the region. The Director of NPESU, who is the data custodian for ANZNN, is also a member of the Advisory Council. The purpose of the Advisory Council is to monitor the progress of ANZNN, discuss current issues and agree on new variables for inclusion in the minimum data set and to approve the use of the data for research – all as recommended by the Executive Committee.

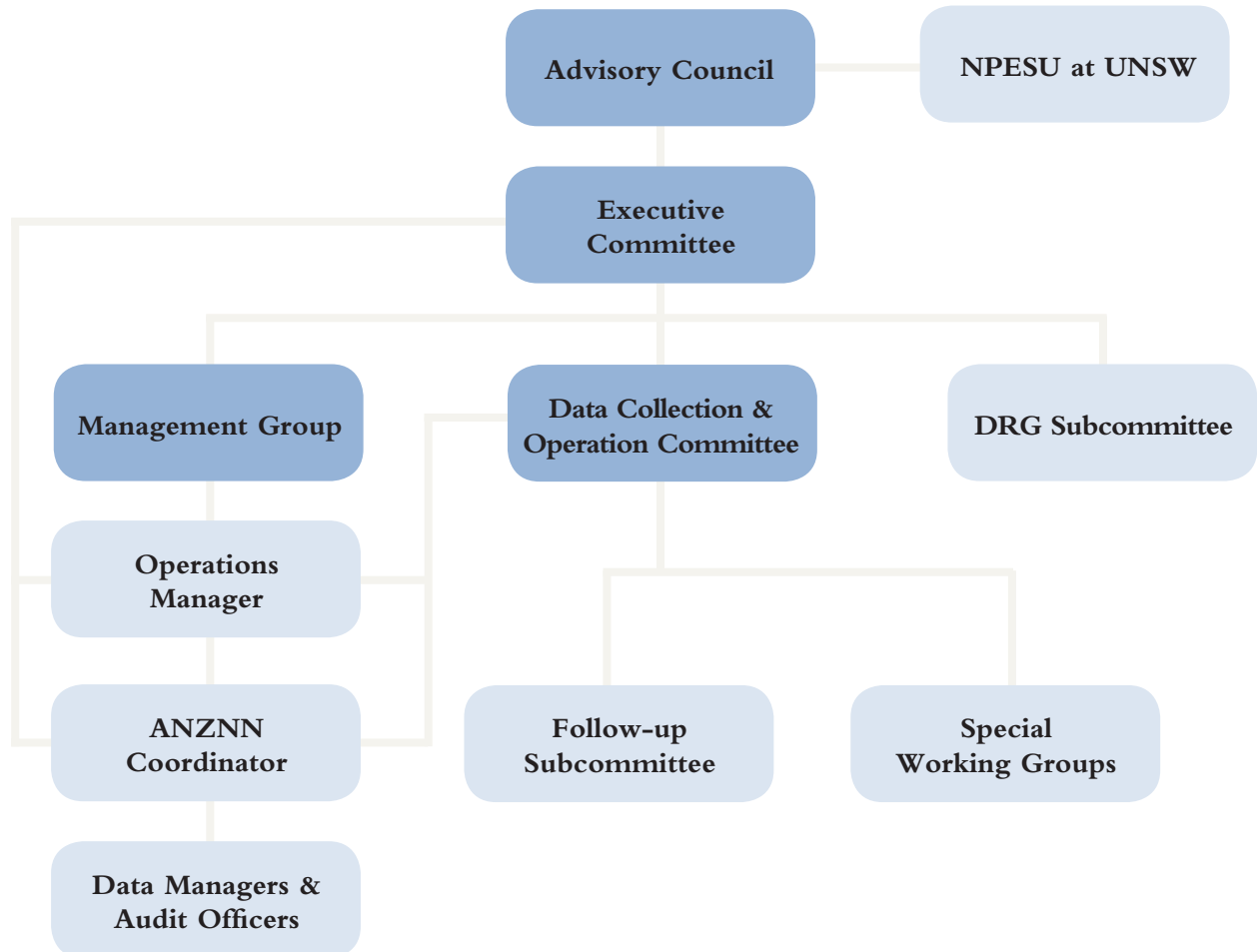
The Executive Committee is an elected committee that has regional representation from directors, a data manager group representative and neonatal nurse representatives from across the network. It is concerned with the general functioning of the network, finance and decision-making, as reported by the Chairman and Operations Manager.

The Data Collection and Operation Committee coordinates the operations of the ANZNN data collection, monitors the workload and progress of the annual report and reports through the Executive Committee to the Advisory Council.

The Operations Manager and Coordinator deal with day-to-day business and report to the Executive Committee and Data Collection and Operation Committee.

The data managers and audit officers are responsible for the collection and submission of data for ANZNN. The ANZNN Coordinator is the point of contact for the ANZNN and liaises with the ANZNN committees, NPESU, data managers and audit officers.

**FIGURE 1: Schematic flow chart of ANZNN**



## Registration criteria

Babies who meet one or more of the following criteria are eligible for registration with the audit:

- born at less than 32 weeks gestation, or
- weighed less than 1,500 grams at birth, or
- received assisted ventilation (mechanical ventilation) including intermittent positive pressure ventilation (IPPV) or continuous positive airways pressure (CPAP) or high flow for four or more consecutive hours, or died while receiving mechanical ventilation prior to four hours of age, or
- received major surgery (surgery that involved opening a body cavity), or
- received therapeutic hypothermia.

Babies who were discharged home and readmitted to a neonatal intensive care unit (NICU) during their neonatal period were not eligible for registration in the ANZNN audit. The hospital of registration was the first level III NICU in which the baby, aged less than 28 days, stayed for four or more hours. Babies who received their entire care in a level II hospital or who were not transferred to a level III NICU during the first 28 days were registered to the first level II centre that they remained in for four or more hours.

## Funding support

Currently the major share of funding is from annual registration of level III units. The registration fee is determined annually by the Advisory Council. In return individual units receive a feedback report that enables them to benchmark their unit against the combined ANZNN data set.

Emerge Health (Australia), Douglas Pharmaceuticals (New Zealand) and Ikaria Australia make an annual contribution and the ANZNN thanks them for their generosity and support.

## Data set variables

The variables used for the 2013 audit are listed in Appendix 5 and are also available on the website <<http://www.anznn.net>>.



# 2013

---

REPORT OF THE  
**AUSTRALIAN AND  
NEW ZEALAND  
NEONATAL NETWORK**

## Babies born in Australia

There were 7,887 babies registered to the ANZNN from 22 level III NICUs in Australia, representing 2.6% of notified live births in 2013 (Australian Bureau of Statistics 2013). Of these registrants, 76.6% were born in a hospital with tertiary care facilities. There were 2,971 babies born before 32 weeks gestation representing 37.7% of Australian registrants.

Maternal ethnicity was provided for 96.1% of mothers: 78.1% of the mothers of these babies identified as Caucasian and 11.1% as Asian. Over one in twenty mothers (6.0%) identified as Aboriginal or Torres Strait Islander, which was the same proportion reported in all births in Australia in 2013 (6.0%) (Australian Bureau of Statistics 2013).

Among Australian NICU admissions registered to the ANZNN, 1,600 were from multiple births representing 20.3% of ANZNN admissions in Australia in 2013.

Male babies were over-represented among NICU admissions – 58.0% of the Australian ANZNN registrants, compared with 51.5% among live births in Australia (Australian Bureau of Statistics 2013).

Assisted ventilation was provided for 7,211 babies (2.3% of live births) and continuous positive airways pressure (CPAP) was the only form of respiratory assistance for 3,815 babies.

## Babies born in New Zealand

There were 1,834 babies who met ANZNN registration criteria from six level III NICUs in New Zealand representing 3.1% of the 58,717 live births registered in New Zealand in 2013 (Statistics New Zealand 2013). Of these registrants, 89.0% were born in a hospital with tertiary care facilities. There were 530 babies born before 32 weeks gestation representing 28.9% of New Zealand registrants.

Maternal ethnicity was reported for 98.7% of the New Zealand registrants. The percentage of Caucasian mothers was 52.6%. A higher proportion of mothers identified themselves as Maori (18.8%) compared to 13.5% of mothers identified as Pacific Islander and 12.9% as Asian.

Among New Zealand NICU admissions registered to the ANZNN, 287 were from multiple births representing 15.6% of ANZNN admissions in New Zealand in 2013.

Male babies were also over-represented among NICU admissions in New Zealand – 59.7% of the New Zealand registrants compared to 51.3% of total live births in New Zealand (Statistics New Zealand 2013).

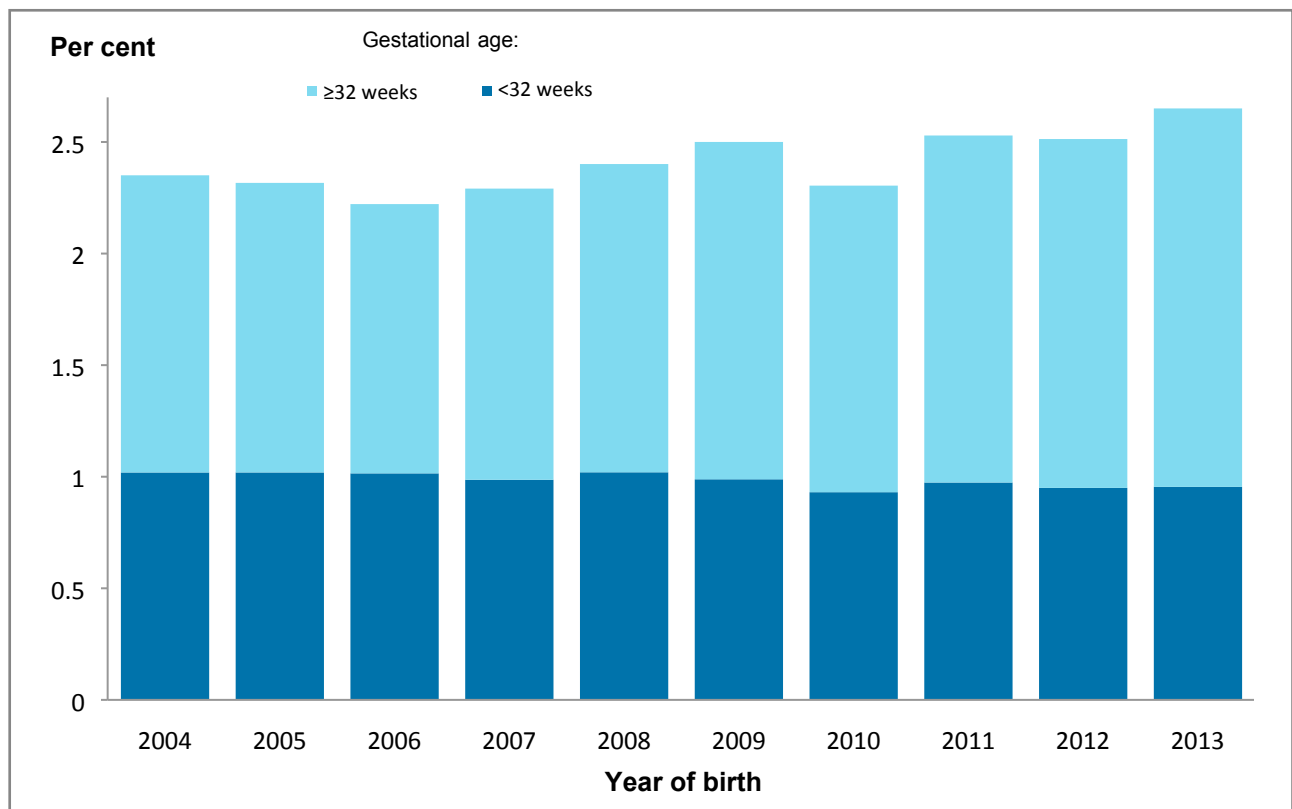
Assisted ventilation was given to 1,782 babies representing 3.0% of all live births with 1,211 babies receiving CPAP as the only form of respiratory assistance (2.1% of all live births).

## 2. Babies registered to level III units

This section includes data on the ANZNN registrants from 28 of the level III NICUs in Australia and New Zealand. Registrants also include babies born in other hospitals and transferred to a level III NICU within the first 28 days of life.

Of the babies admitted to an NICU in Australia and New Zealand in 2013, 9,721 fulfilled the registration criteria for inclusion in the ANZNN audit. The population represents 2.7% of the 366,782 live births in the two countries in 2013 (Australian Bureau of Statistics 2013; Statistics New Zealand 2013) (Figure 2) illustrating an increase of 405 registrants from 2012 (2.5% of all live births).

**FIGURE 2: Babies registered to ANZNN audit of level III units each year as a percentage of liveborn babies in Australia and New Zealand 2004-2013**



**Note:** Data on the ANZNN registrants from two level III NICUs were not included in 2010.

There were 3,501 (36.0 %) babies born before 32 weeks gestation and 6,220 babies born at 32 weeks or more (64.0%). Of the registrants born before 32 weeks gestation 92.8% received assisted ventilation. The major indication for assisted ventilation in this age group was hyaline membrane disease.

The largest level III NICU in Australia and New Zealand registered just under 1,150 babies in 2013, the smallest just over 40 (Figure 3). The median number of babies registered to an ANZNN unit was 293.

The gestational age group at birth and birthweight for babies qualifying for inclusion in the ANZNN 2013 level III audit is set out in Tables 1 and 2 respectively. The 10-year trend (2004–2013) in gestational age at birth is presented in Figure 11 in Appendix 1.

FIGURE 3: Number of level III registrants born at each neonatal intensive care unit, 2013

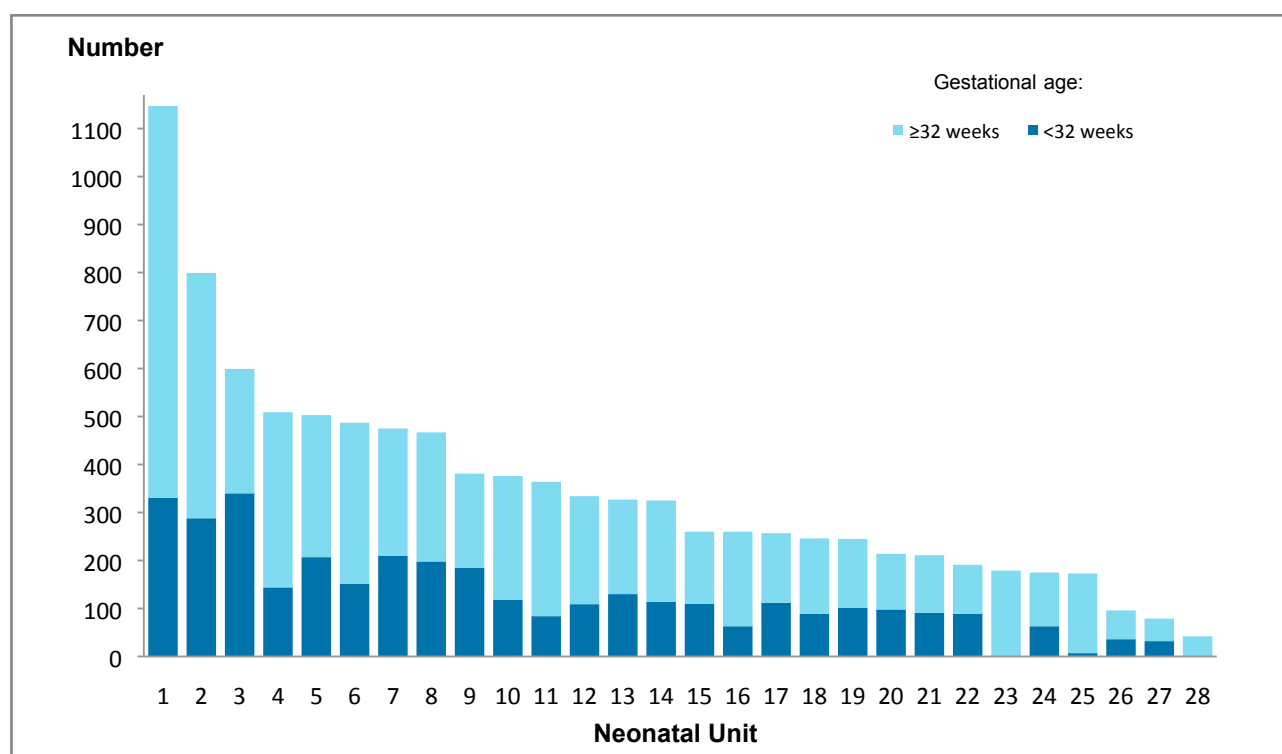


TABLE 1: Level III registrants born at each completed week of gestation, 2013

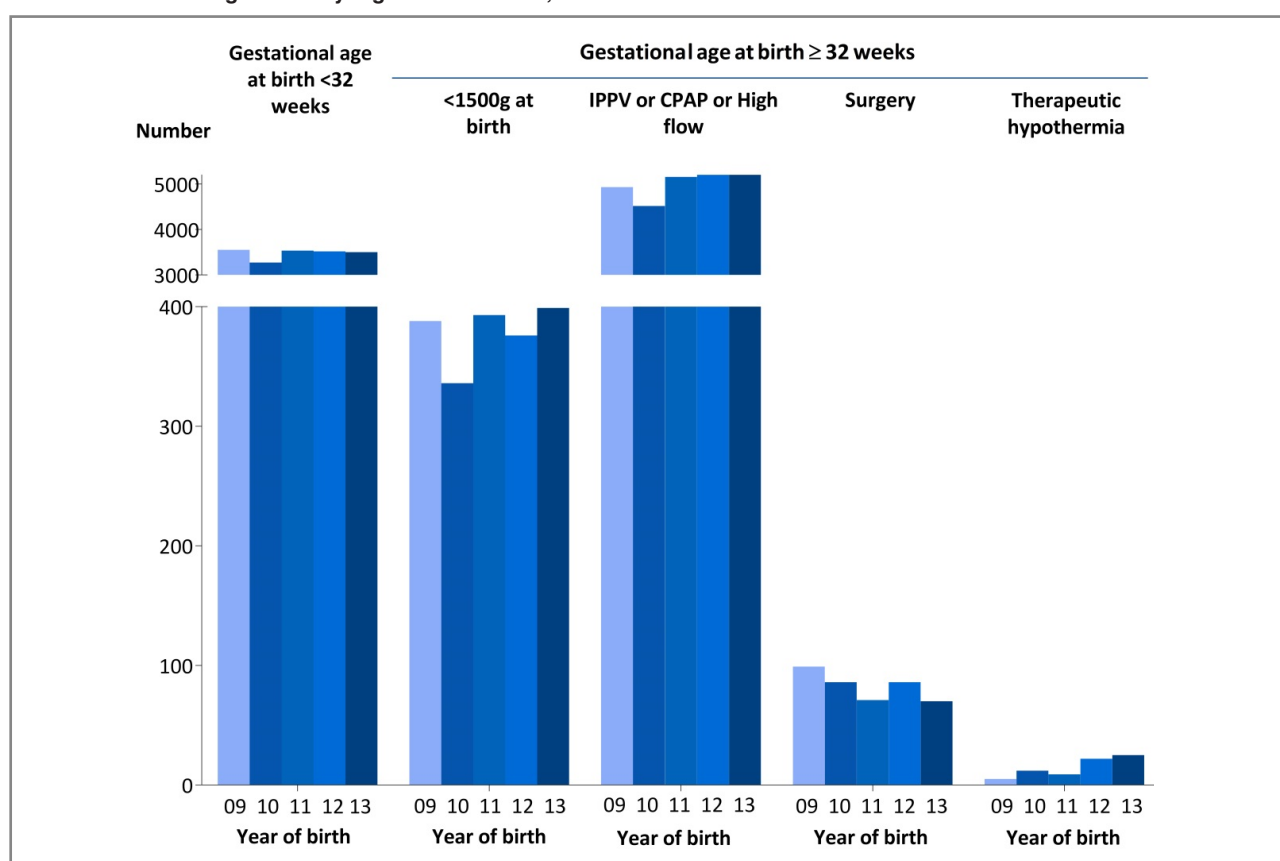
Gestational age (completed weeks)	Number of babies	Percent	Cumulative percent
<24	51	0.5	0.5
24	181	1.9	2.4
25	230	2.4	4.8
26	312	3.2	8.0
27	316	3.3	11.2
28	400	4.1	15.3
29	493	5.1	20.4
30	684	7.0	27.4
31	834	8.6	36.0
<b>All babies &lt;32 weeks</b>	<b>3,501</b>	<b>36.0</b>	
32	766	7.9	43.9
33	709	7.3	51.2
34	672	6.9	58.1
35	560	5.8	63.9
36	529	5.4	69.3
37	567	5.8	75.1
38	676	7.0	82.1
39	700	7.2	89.3
40	629	6.5	95.8
41	383	3.9	99.7
≥42	29	0.3	100.0
<b>Total</b>	<b>9,721</b>	<b>100.0</b>	

**Note:** Gestational ages ≥42 weeks have been combined to maintain confidentiality of small numbers.

**TABLE 2: Level III registrants in each birthweight group, 2013**

Birth weight (grams)	Number of babies	Percent	Cumulative percent
<500	20	0.2	0.2
500–599	108	1.1	1.3
600–699	189	1.9	3.3
700–799	213	2.2	5.5
800–899	253	2.6	8.1
900–999	316	3.3	11.3
1,000–1,099	283	2.9	14.2
1,100–1,199	333	3.4	17.6
1,200–1,299	372	3.8	21.5
1,300–1,399	433	4.5	25.9
1,400–1,499	442	4.5	30.5
<b>All babies &lt;1,500g birthweight</b>	<b>2,962</b>	<b>30.5</b>	
1,500–1,999	1,675	17.2	47.7
2,000–2,499	1,322	13.6	61.3
2,500–2,999	1,207	12.4	73.7
3,000–3,499	1,262	13.0	86.7
3,500–3,999	885	9.1	95.8
≥4,000	408	4.2	100.0
<b>Total</b>	<b>9,721</b>	<b>100.0</b>	

**FIGURE 4: Level III registrants by registration criteria, 2009–2013**



*Note: Data on the ANZNN registrants from two level III NICUs were not included in 2010.*

## 3. Mothers of level III registrants

### Maternal age

While there are many determinants of perinatal outcome, an important one is maternal age. In 2013, the age of mothers of neonates registered as high-risk ranged from less than 15 years to just under 55 years. The highest proportion of registrant mothers was aged 30–34 years (30.5%) followed by mothers aged 25–29 years (25.4%). Together they accounted for more than half of the mothers (55.9%) of ANZNN registrants in 2013 (Table 3). In 2013, the proportion of babies born to teenage mothers decreased slightly (0.4%) from 2012, while those born to mothers in the 35–39 age group increased by 0.4%, from 18.9% in 2012 to 19.3%.

Two in five of the babies born to teenage mothers (40.9%) were born at less than 32 weeks completed gestation, while 34.8% of babies born to mothers 30–34 years were less than 32 weeks gestation at birth (Table 3).

**TABLE 3: Age group of mothers of level III registrants by gestational age group, 2013**

Maternal age (years)	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Less than 20	n.p.	n.p.	36	46	68	49	75	130	430
20–24	11	78	91	130	213	179	219	421	1,342
25–29	12	105	162	233	351	368	424	778	2,433
30–34	11	118	167	266	456	487	544	873	2,922
35–39	6	63	126	143	311	283	359	555	1,846
40 and over	<5	n.p.	41	68	104	88	109	160	599
Not stated	1	2	5	7	15	21	31	67	149
<b>Total</b>	<b>51</b>	<b>411</b>	<b>628</b>	<b>893</b>	<b>1,518</b>	<b>1,475</b>	<b>1,761</b>	<b>2,984</b>	<b>9,721</b>
	Per cent								
Less than 20	n.p.	n.p.	5.8	5.2	4.5	3.4	4.3	4.5	4.5
20–24	22.0	19.1	14.6	14.7	14.2	12.3	12.7	14.4	14.0
25–29	24.0	25.7	26.0	26.3	23.4	25.3	24.5	26.7	25.4
30–34	22.0	28.9	26.8	30.0	30.3	33.5	31.4	29.9	30.5
35–39	12.0	15.4	20.2	16.1	20.7	19.5	20.8	19.0	19.3
40 and over	n.p.	n.p.	6.6	7.7	6.9	6.1	6.3	5.5	6.3
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

Maternal data for babies of a multiple birth are presented for each registrant.

### Previous antenatal history

In 2013, a previous preterm delivery was reported by 1,031 mothers (10.6%) of babies registered to ANZNN while 293 mothers (3.0%) reported a previous perinatal loss.

### Assisted conception

Assisted conception refers to any infertility treatment used in this pregnancy. Types of infertility treatment include ovulation induction, *in vitro* fertilisation (IVF), intrauterine insemination and other infertility treatments not already mentioned.

There were 818 (8.4%) pregnancies resulting from assisted conception in the ANZNN 2013 cohort with most (84.4%) the result of IVF treatment. Of the pregnancies resulting from assisted conception, 50.7% of the mothers were more than 34 years of age at the time of giving birth, compared with 52.4% in 2012.

## Presenting antenatal problem

Many mothers of ANZNN registrants were admitted to hospital with complications prior to the baby's birth. The presenting antenatal problem refers to the antenatal complication that led to the baby's birth and subsequent admission to an NICU. There may be other complications related to this pregnancy but they are not reported here. Information about the presenting antenatal problem was available for 98.8% of 2013 ANZNN registrants. The mothers of nearly one-quarter of registrants (23.0%) presented with preterm labour while fetal distress was the second highest (13.3%) presenting antenatal problem (Table 4).

The maternal antenatal complications for registrants born at 37–44 weeks, 32–36 weeks and less than 32 weeks gestational age are set out in Figure 5. For women who gave birth before 32 weeks gestation and women who gave birth at 34–36 weeks gestation, the most common presenting antenatal problem was preterm labour (36.8% and 29.2% respectively) followed by preterm pre-labour rupture of membranes (20.7% and 14.8% respectively).

Overall 86.7% of mothers of registrants had a pregnancy complication recorded. Among women who gave birth at term, two in five (39.1%) were recorded as having no maternal presenting antenatal problem.

**TABLE 4: Mother's presenting antenatal problem for level III registrants by gestational age group, 2013**

Presenting antenatal problem	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
No antenatal problems	0	0	0	0	0	0	10	1,166	1,176
Preterm pre-labour rupture of membranes (PROM)	10	88	131	175	318	230	258	40	1,250
Preterm labour	28	211	237	311	498	403	511	6 <sup>(a)</sup>	2,205
Hypertension in pregnancy	<5	22	53	124	229	254	204	n.p.	1,013
Antepartum haemorrhage (APH)	8	46	82	79	138	137	147	59	696
Intrauterine growth restriction (IUGR)	0	<5	22	34	77	112	124	n.p.	462
Fetal distress	<5	25	n.p.	105	152	148	156	635	1,279
Other problem	<5	13	43	56	95	170	230	n.p.	1,062
Congenital anomalies	0	<5	<5	7	9	15	109	317	461
Not stated	0	2	3	2	2	6	12	90	117
<b>Total</b>	<b>51</b>	<b>411</b>	<b>628</b>	<b>893</b>	<b>1,518</b>	<b>1,475</b>	<b>1,761</b>	<b>2,984</b>	<b>9,721</b>
Per cent									
No antenatal problems	0.0	0.0	0.0	0.0	0.0	0.0	0.6	40.3	12.2
Preterm pre-labour rupture of membranes (PROM)	19.6	21.5	21.0	19.6	21.0	15.7	14.8	1.4	13.0
Preterm labour	54.9	51.6	37.9	34.9	32.8	27.4	29.2	0.2	23.0
Hypertension in pregnancy	n.p.	5.4	8.5	13.9	15.1	17.3	11.7	n.p.	10.5
Antepartum haemorrhage (APH)	15.7	11.2	13.1	8.9	9.1	9.3	8.4	2.0	7.2
Intrauterine growth restriction (IUGR)	0.0	n.p.	3.5	3.8	5.1	7.6	7.1	n.p.	4.8
Fetal distress	n.p.	6.1	n.p.	11.8	10.0	10.1	8.9	21.9	13.3
Other problem	n.p.	3.2	6.9	6.3	6.3	11.6	13.2	n.p.	11.1
Congenital anomalies	0.0	n.p.	n.p.	0.8	0.6	1.0	6.2	11.0	4.8
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

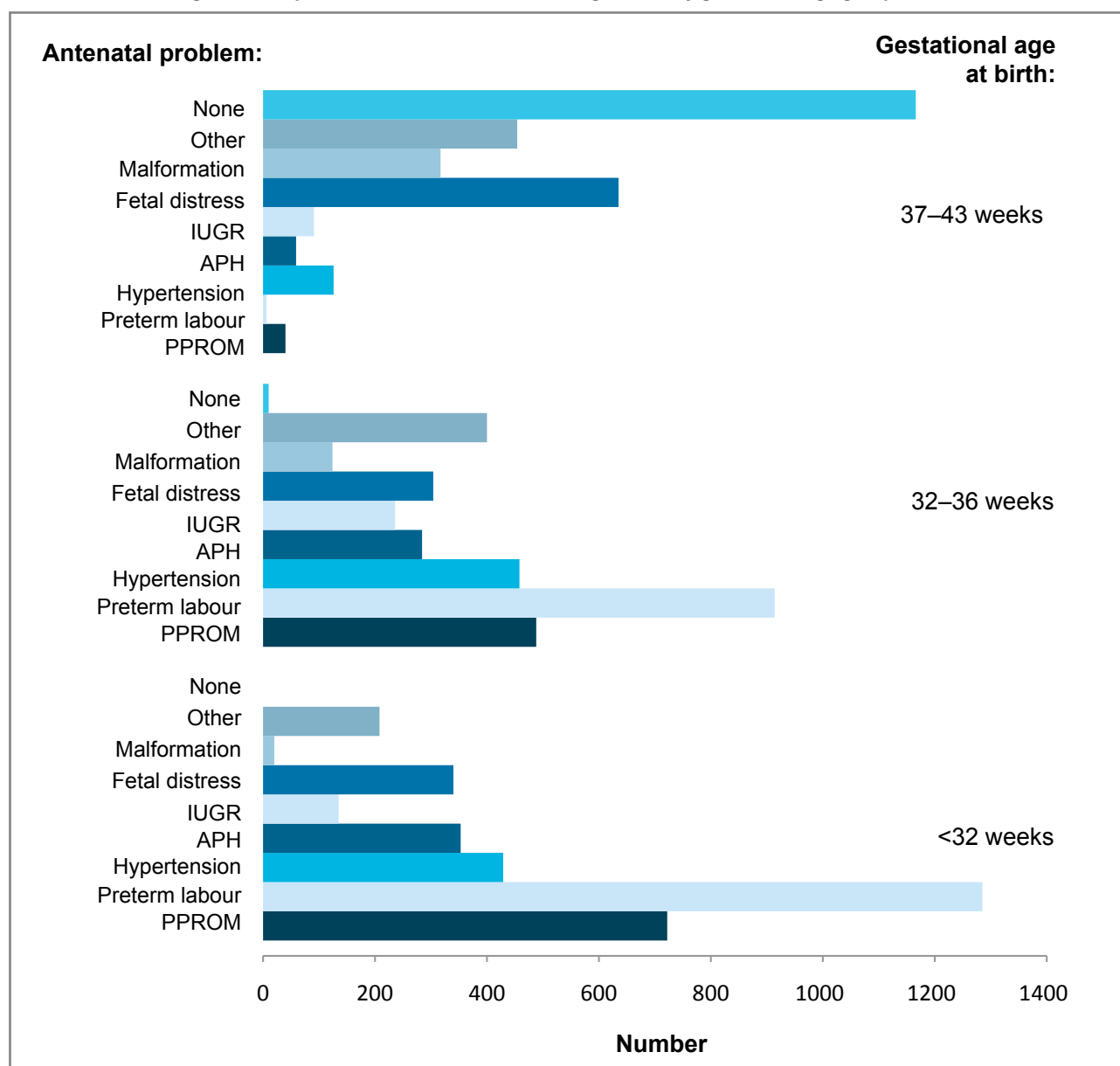
*n.p.* Data not published to maintain confidentiality of small numbers.

*(a)* These mothers presented with preterm labour, then went on to deliver at term.

**Note:** Not stated data are excluded from per cent calculations.

Maternal data for babies of a multiple birth are presented for each registrant.

FIGURE 5: Presenting antenatal problem for mothers of level III registrants by gestational age group, 2013



## Antenatal corticosteroid use

Corticosteroids given to the mother during the antenatal period, via any route at a time likely to enhance fetal maturation, are recorded for ANZNN registrants.

Since 1997, consideration has been given to administering maternal antenatal corticosteroids before the 34th completed week of gestation with the aim of improving neonatal outcomes by enhancing newborns' maturation. The preferred regimen is more than one dose of antenatal corticosteroids, with the first dose given more than 24 hours and less than eight days before the baby's birth (Crowley 1995).

Table 5 presents antenatal corticosteroids use for mothers of ANZNN registrants in each gestational age group. In 2013, 86.4% of mothers of ANZNN registrants born before 34 weeks of gestation received one or more doses of antenatal corticosteroids leaving 13.6% of mothers of registrants in this group who did not report receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 16.8% received them more than seven days prior to giving birth.

For mothers of ANZNN registrants born before 32 weeks of gestation, 88.8% received one or more doses of antenatal corticosteroids and 11.2% of mothers of registrants in this group did not report receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 16.3% received them more than seven days prior to giving birth (Table 5). The 10-year trend (2004–2013) for maternal corticosteroids is represented by Figure 12 in Appendix 1.



**TABLE 5: Antenatal corticosteroid use for mothers of level III registrants by gestational age group, 2013**

	Gestational age group								
Antenatal corticosteroids	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
None	17	40	53	88	143	253	922	2,358	3,874
Incomplete course	16	117	155	197	369	353	179	13	1,399
Course completed	18	211	314	465	740	623	368	38	2,777
Completed >7 days prior to birth	0	34	101	129	242	217	180	46	949
Not stated	0	9	5	14	24	29	112	529	722
<b>Total</b>	<b>51</b>	<b>411</b>	<b>628</b>	<b>893</b>	<b>1,518</b>	<b>1,475</b>	<b>1,761</b>	<b>2,984</b>	<b>9,721</b>
Per cent									
None	33.3	10.0	8.5	10.0	9.6	17.5	55.9	96.0	43.0
Incomplete course	31.4	29.1	24.9	22.4	24.7	24.4	10.9	0.5	15.5
Course completed	35.3	52.5	50.4	52.9	49.5	43.1	22.3	1.5	30.9
Completed >7 days prior to birth	0.0	8.5	16.2	14.7	16.2	15.0	10.9	1.9	10.5
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*Note:* Not stated data are excluded from per cent calculations.

Maternal data for babies of a multiple birth are presented for each registrant.

## Magnesium sulphate

Babies born at less than 32 weeks gestation are at the highest risk of neurologic injury during labour and immediately after birth. Antenatal administration of magnesium sulphate (MgSO<sub>4</sub>) to very preterm babies has been demonstrated to provide neuroprotection (Crowther et al 2003, Rouse 2009, Conde-Agudelo and Romero 2009). The recommended timeframe for it to be given to high risk mothers is the six hours preceding birth. An infusion of 4 hours is optimal but a loading dose and shorter course still provides useful prophylaxis. The NHMRC published a National Clinical Practice Guideline in 2010.

For mothers of ANZNN registrants born at less than 32 weeks of gestation, 46.9% were given antenatal MgSO<sub>4</sub> (Table 6). Of these, 24.0% received a complete course by infusion over 4 hours or more within 6 hours of birth. MgSO<sub>4</sub> administration is an emerging trend among the member units. Care should be taken in interpretation of these data as this is only the second year of collection for the ANZNN.

**TABLE 6: Magnesium sulphate use for mothers of level III registrants by gestational age, 2013**

	Gestational age									
Magnesium sulphate	<24	24	25	26	27	28	29	30	31	Total
Number										
None	n.p.	53	58	100	113	117	164	329	n.p.	1,449
Complete course	9	42	54	54	52	71	81	68	55	486
Incomplete course or intramuscular injection	5	25	34	52	57	65	69	89	38	434
Given but details unknown	<5	29	35	45	34	65	70	49	n.p.	362
Not stated	14	32	49	61	60	82	109	149	214	770
Total	51	181	230	312	316	400	493	684	834	3,501
Per cent										
None	n.p.	35.6	32.0	39.8	44.1	36.8	42.7	61.5	n.p.	53.1
Complete course	24.3	28.2	29.8	21.5	20.3	22.3	21.1	12.7	8.9	17.8
Incomplete course or intramuscular injection	13.5	16.8	18.8	20.7	22.3	20.4	18.0	16.6	6.1	15.9
Given but details unknown	n.p.	19.5	19.3	17.9	13.3	20.4	18.2	9.2	n.p.	13.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

*n.p.* Data not published to maintain confidentiality of small numbers.

*Note:* Not stated data are excluded from per cent calculations.

## Multiple births

Multiple birth pregnancies are often associated with labour and delivery complications, an increased risk of premature birth, low birthweight infants as well as an increased risk of perinatal mortality and morbidity. In 2013, 19.4% of ANZNN registrants were reported as being from a multiple pregnancy, and of these, the greatest percentage were twins (91.0%). Of the 2013 ANZNN registrants from multiple births, 54.1% were born before 32 weeks gestation and 97.5% were born before 37 weeks gestation (Table 7). The 10-year trend (2004–2013) for multiple births is represented by Figure 13 in Appendix 1.

**TABLE 7: Plurality of level III registrants by gestational age group, 2013**

Plurality	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Singletons	44	315	440	638	1,041	996	1,420	2,935	7,829
Twins	7	n.p.	n.p.	243	425	414	329	48	1,718
Triplets and higher orders	0	<5	n.p.	11	52	63	12	0	169
Not stated	0	0	1	1	0	2	0	1	5
<b>Total</b>	<b>51</b>	<b>411</b>	<b>628</b>	<b>893</b>	<b>1,518</b>	<b>1,475</b>	<b>1,761</b>	<b>2,984</b>	<b>9,721</b>
	Per cent								
Singletons	86.3	76.6	70.2	71.5	68.6	67.6	80.6	98.4	80.6
Twins	13.7	n.p.	n.p.	27.2	28.0	28.1	18.7	1.6	17.7
Triplets and higher orders	0.0	n.p.	n.p.	1.2	3.4	4.3	0.7	0.0	1.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

## Method of birth

Data on method of birth are presented for each baby. Method of birth can be dependent upon gestational age, presenting part of the baby and maternal factors. For more than half of the 2013 registrants (58.8%) the method of birth was caesarean section with 63.0% of caesarean sections occurring before the onset of labour. One-third of registrants (34.8%) were non-instrumental vaginal births (Table 8). The rate of birth by caesarean section has gradually increased from 49.8%, since the first data collection in 1995, to 58.8% in 2012. The 2013 data shows no change from 2012.

The most common method of birth for registrants born before 24 weeks gestation was vaginal birth (86.3%) (Table 8). The 10-year trend (2004–2013) for method of birth is represented by Figure 14 in Appendix 1.

**TABLE 8: Method of birth for level III registrants by gestational age group, 2013**

	Gestational age group								
Method of birth	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
Vaginal	44	204	201	299	466	375	558	1,215	3,362
Vaginal instrumental birth	0	12	6	13	54	55	106	377	623
Caesarean section in labour	0	98	156	206	323	288	333	698	2,102
Caesarean section no labour	7	94	263	371	675	750	756	662	3,578
Not stated	0	3	2	4	0	7	8	32	56
<b>Total</b>	<b>51</b>	<b>411</b>	<b>628</b>	<b>893</b>	<b>1,518</b>	<b>1,475</b>	<b>1,761</b>	<b>2,984</b>	<b>9,721</b>
Per cent									
Vaginal	86.3	50.0	32.1	33.6	30.7	25.5	31.8	41.2	34.8
Vaginal instrumental birth	0.0	2.9	1.0	1.5	3.6	3.7	6.0	12.8	6.4
Caesarean section in labour	0.0	24.0	24.9	23.2	21.3	19.6	19.0	23.6	21.7
Caesarean section no labour	13.7	23.0	42.0	41.7	44.5	51.1	43.1	22.4	37.0
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*Note:* Not stated data are excluded from per cent calculations.

## Place of birth

In line with standard clinical practice guidelines, clinicians endeavour to have all births at less than 33 weeks gestation occur in a perinatal centre equipped with an NICU. In 2013, 79.0% of all babies and 87.9% of babies less than 32 weeks gestation at birth were born in a tertiary centre equipped with an NICU; 20.4% of all ANZNN registrants were born in a non-tertiary hospital; while 0.7% of registrants were not born in a hospital (Table 9).

**TABLE 9: Level of hospital of birth for level III registrants by gestational age group, 2013**

	Gestational age group								
Level of birth hospital	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
Tertiary hospital	42	356	543	787	1,347	1,255	1,319	2,023	7,672
Non-tertiary hospital	9	n.p.	78	101	161	211	n.p.	930	1,979
Not born in a hospital <sup>(a)</sup>	0	<5	6	5	10	7	n.p.	28	64
Not stated	0	0	1	0	0	2	0	3	6
<b>Total</b>	<b>51</b>	<b>411</b>	<b>628</b>	<b>893</b>	<b>1,518</b>	<b>1,475</b>	<b>1,761</b>	<b>2,984</b>	<b>9,721</b>
Per cent									
Tertiary hospital	82.4	86.6	86.6	88.1	88.7	85.2	74.9	67.9	79.0
Non-tertiary hospital	17.6	n.p.	12.4	11.3	10.6	14.3	n.p.	31.2	20.4
Not born in a hospital <sup>(a)</sup>	0.0	n.p.	1.0	0.6	0.7	0.5	n.p.	0.9	0.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

<sup>(a)</sup> These babies were either born before arrival to hospital or born at home.

*Note:* Not stated data are excluded from per cent calculations.

## Transport after birth to a level III NICU

Transport after birth to a level III NICU is required if there is insufficient time before birth to allow the mother to be transferred to a tertiary centre; if a cot is not available in the hospital of birth or if the hospital of birth is unable to manage the degree of immaturity and/or compromise of the newborn.

In 2013, 23.5% of ANZNN registrants were transferred to an NICU after birth. Of these the greatest percentage (81.7%) were transported by a specialist team with 14.8% transported by a non-specialist team (Table 10). The 10-year trend (2004–2013) for mode of transport to level III unit is represented by Figure 16 in Appendix 1.

**TABLE 10: Mode of transport to level III NICU after birth for level III registrants by gestational age group, 2013**

	Gestational age group								
Mode of Transport	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
Not transported	41	347	535	779	1,334	1,236	1,263	1,884	7,419
Specialist retrieval team	9	49	71	83	148	199	423	876	1,858
Non-specialist team	0	5	14	21	27	26	53	191	337
Other	1	10	7	8	8	12	11	21	78
Not stated	0	0	1	2	1	2	11	12	29
Total	51	411	628	893	1,518	1,475	1,761	2,984	9,721
Per cent									
Not transported	80.4	84.4	85.3	87.4	87.9	83.9	72.2	63.4	76.5
Specialist retrieval team	17.6	11.9	11.3	9.3	9.8	13.5	24.2	29.5	19.2
Non-specialist team	0.0	1.2	2.2	2.4	1.8	1.8	3.0	6.4	3.5
Other	2.0	2.4	1.1	0.9	0.5	0.8	0.6	0.7	0.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

**Note:** Not stated data are excluded from per cent calculations.

## Breastfeeding at discharge

Data on breastfeeding at discharge were available for 95.3% of the babies born at less than 32 weeks gestation and/or less than 1,500 grams at birth who survived to go home. Among registrants who provided data on breastfeeding, 73.4% were breastfed at discharge. The rate of breastfeeding at discharge of surviving extremely preterm babies (born at less than 28 weeks gestation) was 63.7% compared to 76.3% for surviving very preterm babies (born at least 28 weeks and less than 32 weeks gestation).

## 4. Characteristics of level III registrants

### Baby gender

Male births exceeded female births in both Australia and New Zealand and accounted for 51.5% of combined live births in both countries in 2013 (Australian Bureau of Statistics 2013; Statistics New Zealand 2013). The percentage was higher among ANZNN registrants with male births representing 58.3%. For births at less than 32 weeks gestation, 53.6% were male; of births at term, 62.2% were male.

### Resuscitation in delivery suite

The type of resuscitation given to babies immediately after birth ranges from the least severe, suction to the most severe, external cardiac massage and ventilator support. For the purpose of this audit ANZNN only collected data on babies on whom endotracheal intubation was performed; 21.8% of registrants were intubated in the delivery suite to establish independent respiration and heart rate. For babies born before 32 weeks the percentage was 39.1% and for babies born at term the percentage was 15.2%.

### Apgar score at birth

The Apgar score gives a clinical indication of a baby's condition immediately after birth. It is a numerical score based on five characteristics: heart rate, respiratory condition, muscle tone, reflexes and colour with a maximum possible score of 10. A low score (less than 4) at one minute of age indicates a baby is considerably compromised and requires specialised resuscitation.

An Apgar score of less than 4 at one minute of age was recorded for 16.8% of ANZNN registrants, with 4.1% of registrants recording an Apgar score of less than 4 at five minutes of age. Among the babies who had low Apgar scores at one minute, 40.5% of babies were born at less than 32 weeks and 38.4% were born at term (Table 11).

**TABLE 11: Apgar scores at birth for level III registrants by gestational age group, 2013**

Apgar scores at birth for level II registrants by gestational age group, 2010									
	Gestational age group								
Apgar score	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
Apgar at 1 minute									
Apgar < 4	26	146	152	163	169	154	187	622	1,619
Apgar 4-7	n.p.	241	386	478	717	n.p.	672	1,023	4,235
Apgar ≥ 8	<5	19	80	241	619	n.p.	892	1,312	3,781
Not stated	0	5	10	11	13	10	10	27	86
Total	51	411	628	893	1,518	1,475	1,761	2,984	9,721
Number									
Apgar at 5 minutes									
Apgar < 4	7	31	32	22	27	35	45	197	396
Apgar 4-7	29	214	267	274	351	303	407	885	2,730
Apgar ≥ 8	15	158	320	586	1,126	1,128	1,299	1,875	6,507
Not stated	0	8	9	11	14	9	10	27	88
Total	51	411	628	893	1,518	1,475	1,761	2,984	9,721

*n.p.* Data not published to maintain confidentiality of small numbers.

## Admission temperature

The temperature at admission to the NICU, or temperature nearest to admission to the registration unit, was reported for 93.1% of ANZNN registrants in 2013. The rectal temperature is preferred; however, if it is not available the axilla temperature is recorded.

For babies born before 32 weeks gestation the admission temperature together with the base excess is used to calculate the Clinical Risk Index for Babies (CRIB) II score. CRIB II score is a risk-adjustment instrument widely used in NICUs to measure initial illness severity and is a predictor of survival until discharge.

The median temperature at admission to the NICU was 36.5°C; the median temperature increased slightly with increasing gestational age at birth. The lowest median temperature recorded was 35.9°C by the youngest babies, i.e. those born at less than 24 weeks gestation (Table 12).

**TABLE 12: Median admission temperature and interquartile ranges for level III registrants by gestational age group, 2013**

Gestational age group	Number of babies	Temperature	
		Median	Inter quartile range
<24	51	35.9	35.2–36.5
24–25	411	36.1	35.5–36.7
26–27	628	36.4	35.8–36.9
28–29	893	36.4	35.9–36.8
30–31	1,518	36.4	35.9–36.7
32–33	1,475	36.4	35.9–36.7
34–36	1,761	36.5	36.1–36.8
37–43	2,984	36.6	36.2–37.0
<b>Total</b>	<b>9,721</b>	<b>36.5</b>	<b>36.0–36.8</b>

## Indication for respiratory support

In 2013, only 5.0% of all ANZNN registrants did not receive any form of respiratory support. For the remaining registrants, hyaline membrane disease (HMD) remained the most common indication for respiratory support at 42.3%. Non-specific respiratory distress accounted for 33.3% of babies, surgery for 4.6%, while meconium aspiration syndrome accounted for 3.5% (Table 13).

For babies born before 37 weeks gestation, HMD (57.1%) remained the most common indication for respiratory support. For babies born at term, non-specific respiratory distress (42.4%) was the most common indication followed by meconium aspiration (11.2%) and surgery (10.5%) (Table 13). The 10-year trend (2004–2013) for mode of assisted ventilation is represented by Figure 17 in Appendix 1.

**TABLE 13: Indication for respiratory support for level III registrants by gestational age, 2013**

Indication for respiratory support	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
No respiratory support	0	0	<5	15	177	126	n.p.	87	475
Non-specific respiratory distress	<5	n.p.	26	109	446	558	803	1,230	3,187
Hyaline membrane disease	46	381	577	743	832	700	569	205	4,053
Meconium aspiration syndrome	0	0	0	0	<5	0	n.p.	324	331
Pneumonia	0	0	<5	<5	<5	<5	18	82	107
Persistent pulmonary hypertension	0	<5	<5	0	<5	<5	13	95	119
Apnoea	0	11	9	10	21	22	27	55	155
Congenital anomaly	0	<5	<5	6	8	15	56	190	281
Other	n.p.	0	n.p.	n.p.	7	11	35	133	190
Peri-surgery	0	0	0	<5	5	n.p.	108	304	442
Newborn encephalopathy	0	0	0	0	<5	n.p.	32	196	236
Not stated	0	4	4	6	14	8	26	83	145
<b>Total</b>	<b>51</b>	<b>411</b>	<b>628</b>	<b>893</b>	<b>1,518</b>	<b>1,475</b>	<b>1,761</b>	<b>2,984</b>	<b>9,721</b>
Per cent									
No respiratory support	0.0	0.0	n.p.	1.7	11.7	8.5	n.p.	2.9	5.0
Non-specific respiratory distress	n.p.	n.p.	4.2	12.3	29.7	38.0	46.3	42.4	33.3
Hyaline membrane disease	90.2	93.6	92.5	83.8	55.3	47.7	32.8	7.1	42.3
Meconium aspiration syndrome	0.0	0.0	0.0	0.0	n.p.	0.0	n.p.	11.2	3.5
Pneumonia	0.0	0.0	n.p.	n.p.	n.p.	n.p.	1.0	2.8	1.1
Persistent pulmonary hypertension	0.0	n.p.	n.p.	0.0	n.p.	n.p.	0.7	3.3	1.2
Apnoea	0.0	2.7	1.4	1.1	1.4	1.5	1.6	1.9	1.6
Congenital anomaly	0.0	n.p.	n.p.	0.7	0.5	1.0	3.2	6.5	2.9
Other	n.p.	0.0	n.p.	n.p.	0.5	0.7	2.0	4.6	2.0
Peri-surgery	0.0	0.0	0.0	n.p.	0.3	n.p.	6.2	10.5	4.6
Newborn encephalopathy	0.0	0.0	0.0	0.0	n.p.	n.p.	1.8	6.8	2.5
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

## Exogenous surfactant

Exogenous surfactant administered to babies with moderate to severe HMD has been shown to reduce the severity of the disease, the ventilation requirements and the risk of air leaks. Exogenous surfactant can be administered for both prevention and cure. For babies born at less than 31 weeks gestation most benefit is gained by early administration of exogenous surfactant (within two hours of birth). For babies born at 31 or more weeks gestation exogenous surfactant is usually only administered to those with a confirmed diagnosis of HMD. There is some evidence that a bolus dose of exogenous surfactant given to babies with meconium aspiration syndrome can reduce ventilation requirements.

In 2013, nearly one-third of ANZNN registrants (29.2%) were administered exogenous surfactant (Table 14). There were 2,276 babies who received intermittent positive pressure ventilation for HMD in 2013. Exogenous surfactant was given to 2,134 of these babies (93.8%). There were 142 babies diagnosed with HMD who were not given exogenous surfactant.

**TABLE 14: Exogenous surfactant use for level III registrants by gestational age group, 2013**

Exogenous surfactant	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
None	<5	17	n.p.	343	1,044	1,166	1,449	2,743	6,867
Curosurf	41	339	427	424	341	232	225	174	2,203
Survanta	n.p.	48	94	123	126	74	80	n.p.	607
SurvCuro	0	6	<5	0	<5	0	<5	<5	17
Other or unknown surfactant	0	0	0	2	n.p.	1	n.p.	3	12
Not stated	0	1	1	1	0	2	2	8	15
<b>Total</b>	<b>51</b>	<b>411</b>	<b>628</b>	<b>893</b>	<b>1,518</b>	<b>1,475</b>	<b>1,761</b>	<b>2,984</b>	<b>9,721</b>
Per cent									
None	n.p.	4.1	n.p.	38.5	68.8	79.2	82.4	92.2	70.8
Curosurf	80.4	82.7	68.1	47.5	22.5	15.8	12.8	5.8	22.7
Survanta	n.p.	11.7	15.0	13.8	8.3	5.0	4.5	n.p.	6.3
SurvCuro	0.0	1.5	n.p.	0.0	n.p.	0.0	n.p.	n.p.	0.2
Other or unknown surfactant	0.0	0.0	0.0	0.2	n.p.	0.1	n.p.	0.1	0.1
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

## Type of assisted ventilation

Assisted ventilation requires specialised nursing, medical and paramedical care and utilises a large component of the available resources. Of the babies registered to the ANZNN in 2013, 92.5% required assisted ventilation for four or more hours.

The two major forms of assisted ventilation used are intermittent positive pressure ventilation (IPPV) and continuous positive airways pressure (CPAP). IPPV is assisted ventilation given via an endotracheal tube, while CPAP can be administered via an endotracheal tube or via nasopharyngeal prongs (nasal CPAP). For the purposes of this audit CPAP is recorded via any route. The 10-year trend (2004–2013) for assisted ventilation is represented in Figures 17 to 19 in Appendix 1.

In 2013, IPPV was given for a total of 583,556 hours to ANZNN registrants and CPAP was given for 1,442,086 hours. The total number of hours of ventilation equates to each baby receiving 8.7 days of assisted ventilation. The median number of hours of assisted ventilation is inversely related to the gestational age at birth (Table 15).

The most common form of ventilation given to ANZNN registrants in 2013 remains CPAP with 51.7% of registrants receiving CPAP only, 12.1% receiving IPPV only and 28.7% receiving both CPAP and IPPV.

In addition to IPPV and CPAP babies may have received high frequency oscillatory ventilation (HFOV), nitric oxide (NO) or extracorporeal membrane oxygenation (ECMO). HFOV is administered via an endotracheal tube, and is usually given in conjunction with IPPV. The use of HFOV had been relatively



stable at 12–14% since 1999, with the exception of 2007 (11.2%). In 2013, 15.4% of registrants who received IPPV also received HFOV. However, 18 babies received HFOV without at least four hours of IPPV. The use of HFOV among individual units varied between 1.1% and 14.5% with the highest percentage of babies receiving HFOV born at 24–25 weeks (46.2%) followed by babies born at less than 24 weeks gestation (46.0%) (Table 16). The 10-year trend (2004–2013) for HFOV is represented in Figure 20 in Appendix 1.

**TABLE 15: Duration of assisted ventilation use by level III registrants by gestational age group, 2013**

Median & Interquartile range	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
IPPV (hours)									
Median	407	310.5	52	24	23	22	43	52	45
IQR	70–840	115–696	15–240	11–72.5	10–56	10–55	20–104	21.5–108.5	17–132
CPAP (hours)									
Median	1,154	937	804	212	51	29	24	17	40
IQR	213–1,449	558–1,294	381–1,128	76–555	21–119	14–72	11–53	8–39	14–128

*Note: IQR = Interquartile range*

In 2013, 18 registrants received ECMO of whom the majority were born at term. The percentage of ANZNN registrants who received nitric oxide (NO) was 4.6%. The use of NO continues to have a U-shaped distribution with the highest percentage of babies to receive NO born at less than 24 weeks (18.0%) (Table 16). The 10-year trend (2004–2013) for NO is represented in Figure 21 in Appendix 1.

**TABLE 16: Assisted ventilation for level III registrants by gestational age group, 2013**

	Gestational age group								
Ventilation type	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
CPAP given	24	345	582	843	1,252	1,242	1,421	2,106	7,815
Invasive ventilation	50	396	504	484	449	335	543	1,215	3,976
▪ IPPV given	49	396	502	483	449	334	542	1,212	3,967
▪ HFOV given	23	183	106	68	40	17	55	129	621
NO given	9	54	44	45	24	19	40	215	450
Total in each age group	51	411	628	893	1,518	1,475	1,761	2,984	9,721
Per cent									
CPAP given	47.1	83.9	92.7	94.4	82.5	84.2	80.7	70.6	80.4
IPPV given	96.1	96.4	79.9	54.1	29.6	22.6	30.8	40.6	40.8
Per cent of babies given invasive ventilation									
HFOV given	46.0	46.2	21.0	14.0	8.9	5.1	10.1	10.6	15.6
NO given	18.0	13.6	8.7	9.3	5.3	5.7	7.4	17.7	11.3

*Note: Groups are not mutually exclusive.*

*Percentage of babies given HFOV and NO are given as a percentage of babies given ventilation via endotracheal tube (IPPV and/or HFOV)*

## Ventilation in babies born at less than 32 weeks gestation

The major indication for assisted ventilation in babies born at less than 32 weeks gestation was hyaline membrane disease. Among the 3,501 babies born before 32 weeks gestation, 92.8% were given assisted ventilation in the form of IPPV or CPAP. For registrants in this age group CPAP was the only form of ventilation for 39.1% and IPPV was the only form of ventilation for 5.8% of registrants. Both IPPV and CPAP were given to 47.9% of registrants.

The total duration of IPPV for these very preterm babies was 373,720 hours (15,572 days), and the duration of CPAP was 1,214,469 hours (50,603 days).

Of the babies born before 32 weeks gestational age and given IPPV in 2013, 22.1% were given high frequency ventilation while 9.4% of these babies were given NO (Table 16).

Among 2013 ANZNN registrants born at less than 32 weeks gestation, 3,327 (95.0%) survived to day 28. Of these 46.7% of registrants received respiratory support (airway support or supplemental oxygen therapy) at 28 days of age, with 16.7% of them discharged on home oxygen (Table 17).

## Ventilation in babies born at 32 to 36 weeks gestation

Among the babies born at 32–36 weeks gestation, 91.0% received assisted ventilation. Non-specific respiratory distress was the main reason for ventilation. Total duration of CPAP use by registrants in this gestational age group was 135,224 hours (5,634 days) and IPPV use was 92,431 hours (3,852 days).

Of the babies born at 32–36 weeks gestation and given IPPV in 2013, 8.0% were given high frequency ventilation while 6.7% of these babies were given NO (Table 16).

## Ventilation in babies born at term

The main indication for respiratory support in term babies was non-specific respiratory distress (41.2%). This group required 117,405 hours of IPPV (4,892 days) and 92,393 hours (3,850 days) of CPAP.

Of the babies born at term and given IPPV in 2013, 10.4% were given high frequency ventilation while 17.7% of these babies were given NO. There were 15 babies born at term who received extracorporeal membrane oxygenation (ECMO) (Table 16).

## Respiratory support

Respiratory support is critical for the survival of some babies especially those with respiratory problems and those born prematurely. Babies requiring treatment in a level III unit commonly require long-term respiratory support as part of their specialised care. The duration of respiratory support may vary between babies, from as little as a few hours to several weeks or months. For the ANZNN audit, four consecutive hours in any single 24-hour period of CPAP, nasal high flow, IPPV, HFOV or supplemental oxygen therapy constitutes the use of respiratory support on that day. The continued use of respiratory support at 28 days of age is a predictor of postneonatal morbidity and the need for continued oxygen therapy after discharge.

Among 2013 ANZNN registrants, 9,385 babies survived to day 28 and of these, 19.3% were reported as having received respiratory support on day 28. Of the registrants who received respiratory support on day 28 and survived to discharge to home, 17.4% were discharged on home oxygen (Table 17).

**TABLE 17: Respiratory support (airway support or supplemental oxygen therapy) for level III registrants who survived to day 28 by gestational age group, 2013**

	Gestational age group								
Respiratory support (airway support or oxygen)	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
No respiratory support on day 28	0	<5	45	406	1,316	1,397	n.p.	2,747	7,554
Respiratory support on day 28	26	n.p.	540	472	180	60	n.p.	136	1,828
▪ survived to discharge home	n.p.	310	525	461	174	52	n.p.	117	1,721
▪ died before discharge	<5	n.p.	15	11	6	8	15	19	107
Not stated	0	0	0	0	0	1	1	1	3
Total	26	342	585	878	1,496	1,458	1,716	2,884	9,385
Number									
Respiratory support on day 28 and given home oxygen	n.p.	103	98	37	13	7	n.p.	28	299
Per cent									
No respiratory support on day 28	0.0	n.p.	7.7	46.2	88.0	95.9	n.p.	95.3	80.5
Respiratory support on day 28	100.0	n.p.	92.3	53.8	12.0	4.1	n.p.	4.7	19.5
▪ survived to discharge home	n.p.	91.4	97.2	97.7	96.7	86.7	n.p.	86.0	94.1
▪ died before discharge	n.p.	n.p.	2.8	2.3	3.3	13.3	20.0	14.0	5.9
Per cent									
Respiratory support on day 28 and given home oxygen <sup>(a)</sup>	36.4	33.2	18.7	8.0	7.5	13.5	8.3	23.9	17.4

*n.p.* Data not published to maintain confidentiality of small numbers.

*(a)* Denominator is babies who received respiratory support on day 28 and survived to discharge to home.

**Note:** Not stated data are excluded from per cent calculations.

## Nasal high flow therapy

Nasal high flow therapy (NHFT) as a form of non-invasive respiratory support for premature babies, is an emerging trend within neonatal units. Humidified blended air and oxygen mix is administered through a high flow device via high flow nasal cannula (HFNC). NHFT may deliver a positive end-expiratory pressure and for this reason can be preferred to nasal CPAP for use in premature infants (Wilkinson et al. 2011).

In 2013 nasal high flow therapy was reported for 2,332 babies (24.0%) of all level III registrants (Table 18), compared with 8.1% in 2009. The overall increase of 5.9% from 2012 was observed predominantly in the babies born at less than 30 weeks gestation. In this gestational age group, 60.2% of babies received NHFT. Overall, the minimum flow recorded was 0.5 litres/min and the maximum 15 litres/min. Of the babies receiving NHFT 69.4% were reported to have received a minimum rate of 2–4 litres/min while 65.3% received a maximum of 6–8 litres /min.

**TABLE 18: Nasal high flow respiratory support for level III registrants by gestational age group, 2013**

	Gestational age group								
Nasal high flow	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
High flow	16	264	432	481	339	165	217	418	2,332
No high flow	35	147	196	412	1,179	1,310	1,544	2,566	7,389
Total	51	411	628	893	1,518	1,475	1,761	2,984	9,721
Per cent									
High flow	31.4	64.2	68.8	53.9	22.3	11.2	12.3	14.0	24.0
No high flow	68.6	35.8	31.2	46.1	77.7	88.8	87.7	86.0	76.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

## Parenteral nutrition

Intravenous total parenteral nutrition (TPN) is common in very preterm babies because of the need for optimal nutrition from day one when enteral nutrition is difficult, whilst recovery from acute illness or from an intervention occurs, or due to poor weight gain. Of the ANZNN registrants born at less than 32 weeks gestation and/or less than 1,500g at birth, 2,685 (72.0%) received TPN during admission (Table 19). The median duration of TPN reported was 236 hours.

Some babies are discharged home with a nasogastric tube in place to allow gavage or infusion feeding at home and this practice is increasing. Of those who received TPN, 3.4% of babies were discharged home on gavage feeds. Care should be taken in interpretation of the TPN and home gavage feed data as this is the only the second year of collection for the ANZNN.

**TABLE 19: Total parenteral nutrition for level III registrants by gestational age, 2013**

Parenteral nutrition	Gestational age										Total
	<24	24	25	26	27	28	29	30	31	≥32	
Number											
Parenteral nutrition	41	161	206	279	294	352	406	432	369	145	2,685
No parenteral nutrition	8	13	12	16	14	25	68	229	430	231	1,046
Not stated	2	7	12	17	8	23	19	23	35	23	169
<b>Total</b>	<b>51</b>	<b>181</b>	<b>230</b>	<b>312</b>	<b>316</b>	<b>400</b>	<b>493</b>	<b>684</b>	<b>834</b>	<b>399</b>	<b>3,900</b>
Number											
Home gavage feeding	<5	12	9	12	10	13	14	10	8	<5	91
Per cent											
Parenteral nutrition	83.7	92.5	94.5	94.6	95.5	93.4	85.7	65.4	46.2	38.6	72.0
No parenteral nutrition	16.3	7.5	5.5	5.4	4.5	6.6	14.3	34.6	53.8	61.4	28.0
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
Per cent											
Home gavage feeding <sup>(a)</sup>	n.p.	7.5	4.4	4.3	3.4	3.7	3.4	2.3	2.2	n.p.	3.4

n.p. Data not published to maintain confidentiality of small numbers.

(a) Denominator is babies who received parenteral nutrition.

**Note:** Not stated data are excluded from per cent calculations.

## Chronic lung disease

Chronic lung disease (CLD) is currently defined by the ANZNN as a continued need for any form of respiratory support (supplemental oxygen and/or assisted ventilation) at 36 weeks post menstrual age (PMA) (post menstrual age is calculated by adding the baby's age in weeks to the gestational age at birth in weeks). For ANZNN registrants 8.1% of babies in 2013 were reported to have had respiratory support at 36 weeks PMA. CLD is a complication of premature lung development and the trauma of early respiratory support (supplemental oxygen and/or assisted ventilation). The prevalence of chronic lung disease continues to be highest in babies born less than 27 weeks gestation. The highest percentage was in those babies born at 25 weeks gestation (61.3%) (Table 20). Not all the babies born at earlier gestations survived to 36 weeks PMA. CLD by gestational age is represented by Figure 22 in Appendix 1.

**TABLE 20: Chronic lung disease for level III registrants by gestational age, 2013**

Chronic lung disease (CLD)	Gestational age										Total
	<24	24	25	26	27	28	29	30	31	≥32	
Number											
No CLD	30	79	89	151	205	308	420	621	806	6,220	8,929
CLD	21	102	141	161	111	92	73	63	28	0	792
▪ CLD and survived	n.p.	96	n.p.	156	n.p.	84	73	n.p.	n.p.	0	763
▪ CLD and died	<5	6	<5	5	<5	8	0	<5	<5	0	29
<b>Total</b>	<b>51</b>	<b>181</b>	<b>230</b>	<b>312</b>	<b>316</b>	<b>400</b>	<b>493</b>	<b>684</b>	<b>834</b>	<b>6,220</b>	<b>9,721</b>
Per cent											
No CLD	58.8	43.6	38.7	48.4	64.9	77.0	85.2	90.8	96.6	100.0	91.9
CLD	41.2	56.4	61.3	51.6	35.1	23.0	14.8	9.2	3.4	0.0	8.1
▪ CLD and survived	n.p.	94.1	n.p.	96.9	n.p.	91.3	100.0	n.p.	n.p.	0.0	96.3
▪ CLD and died	n.p.	5.9	n.p.	3.1	n.p.	8.7	0.0	n.p.	n.p.	0.0	3.7

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Survival is assessed to discharge from hospital.

There is evidence that postnatal treatment with corticosteroids of high risk infants can facilitate weaning from ventilator and lead to increased survival without CLD at 36 weeks post menstrual age (Halliday et al 2003). While there are associated increased short and long term risks according to the severity of CLD (Doyle et al 2005), early postnatal systemic corticosteroids are commonly administered to high risk infants for evolving CLD. Of the ANZNN registrants born at less than 32 weeks, 215 (6.1%) babies were treated with systemic corticosteroids. Of these, 180 were reported to have had respiratory support at 36 weeks, while the remaining 35 (16.3%) reported no CLD. Care should be taken in interpretation of these data as this is the first year of collection for the ANZNN.

## Pulmonary air leak

A pulmonary air leak is a collection of air in the space around the lungs which can cause difficulty in breathing. There are several types of pulmonary air leak and while some produce only minor symptoms a number of them require treatment by the insertion of a drainage tube. For the purposes of this report the presence of any form of air leak that required drainage (either transient or continuous drainage) is reported for ANZNN registrants (Table 21).

**TABLE 21: Pulmonary air leak for level III registrants by gestational age group, 2013**

	Gestational age group								
Air leak	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
Air leak	7	24	28	34	42	32	77	138	382
No air leak	44	387	600	859	1,476	1,443	1,684	2,846	9,339
Not stated	0	0	0	0	0	0	0	0	0
<b>Total</b>	<b>51</b>	<b>411</b>	<b>628</b>	<b>893</b>	<b>1,518</b>	<b>1,475</b>	<b>1,761</b>	<b>2,984</b>	<b>9,721</b>
Per cent									
Air leak	13.7	5.8	4.5	3.8	2.8	2.2	4.4	4.6	3.9
No air leak	86.3	94.2	95.5	96.2	97.2	97.8	95.6	95.4	96.1
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*Note:* Not stated data are excluded from per cent calculations.

## Neonatal sepsis

Each episode of sepsis is recorded as either early or late onset. Early onset sepsis is defined as the presence of at least one episode of systemic sepsis where the initial symptoms occurred within the first 48 hours after birth that is, in babies aged from 0 to 47 hours. Late onset sepsis is the presence of at least one episode of systemic sepsis with the initial symptoms occurring among babies aged 48 or more hours. Episodes of sepsis involving the same organism separated by at least 14 days are considered to be new episodes of infection. Symptomatic, blood culture positive septicaemia was reported in 5.7% of ANZNN registrants in 2013. Of these babies, 49.2% were born at less than 28 weeks gestation, 73.4% were born at less than 32 weeks gestation and 98.4% of registrants survived up to 2 days of life (Table 22). Episodes of both early and late sepsis were reported in four babies. The 5-year trends (2009–2013) for early and late sepsis are represented by Figure 25 and Figure 26 respectively in Appendix 1.

**TABLE 22: Neonatal sepsis for level III registrants by gestational age group, 2013**

	Gestational age group								
Sepsis	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
No sepsis	37	275	518	811	1,468	1,448	1,714	2,913	9,184
Sepsis at <48 hrs <sup>(a)</sup>	<5	11	12	n.p.	9	6	11	32	92
Sepsis at ≥48 hrs <sup>(a)</sup>	n.p.	134	104	n.p.	44	23	36	40	469
Babies alive on day 2	44	397	608	n.p.	1,513	1,467	1,753	2,959	9,631
Babies who did not survive to day 2	7	14	20	<5	5	8	8	25	90
<b>Total in each age group</b>	<b>51</b>	<b>411</b>	<b>628</b>	<b>893</b>	<b>1,518</b>	<b>1,475</b>	<b>1,761</b>	<b>2,984</b>	<b>9,721</b>
Per cent									
No sepsis <sup>(b)</sup>	72.5	66.9	82.5	90.8	96.7	98.2	97.3	97.6	94.5
Sepsis at <48 hrs <sup>(b)</sup>	n.p.	2.7	1.9	n.p.	0.6	0.4	0.6	1.1	0.9
Sepsis at ≥48 hrs <sup>(c)</sup>	n.p.	33.8	17.1	n.p.	2.9	1.6	2.1	1.4	4.9

*n.p.* Data not published to maintain confidentiality of small numbers.

*(a)* Groups are not mutually exclusive.

*(b)* Denominator is all registrants.

*(c)* Denominator is registrants alive at 48 hours.

Viral infection for the purposes of this audit is defined as the presence of at least one episode of viral infection with initial symptoms occurring following 48 hours after birth. Symptomatic viral infection was reported in 127 (1.3%) of ANZNN registrants in 2013, as identified by isolation or identification of an organism by PCR, immunofluorescence or similar technology from an appropriate body fluid. Care should be taken in interpretation of these data as this is only the second year of collection for the ANZNN.

## Retinopathy of prematurity

The classification of retinopathy of prematurity (ROP) for ANZNN registrants are those recommended by the Committee for the Classification of Retinopathy of Prematurity (1984). The examination criteria for ROP vary between units within ANZNN. As in previous reports, the prevalence of ROP screening in 2013 was assessed among registrants with a gestational age of less than 31 weeks and/or a birthweight of less than 1,250 grams. Among the 2013 registrants, 29.4% were eligible for ROP examination and of these eligible registrants, 81.5% were examined and had the results of their eye examination recorded.

Of those ANZNN registrants who were eligible for an eye examination, 177 died before their ROP status could be determined. Of those examined, 6.4% had stage 3 or 4 eye disease (Table 23, Figure 6) and of these babies 42.3% received surgical treatment. The 9-year trend (2005–2013) for stages 3 and 4 ROP and treatment are represented by Figure 23 in Appendix 1.

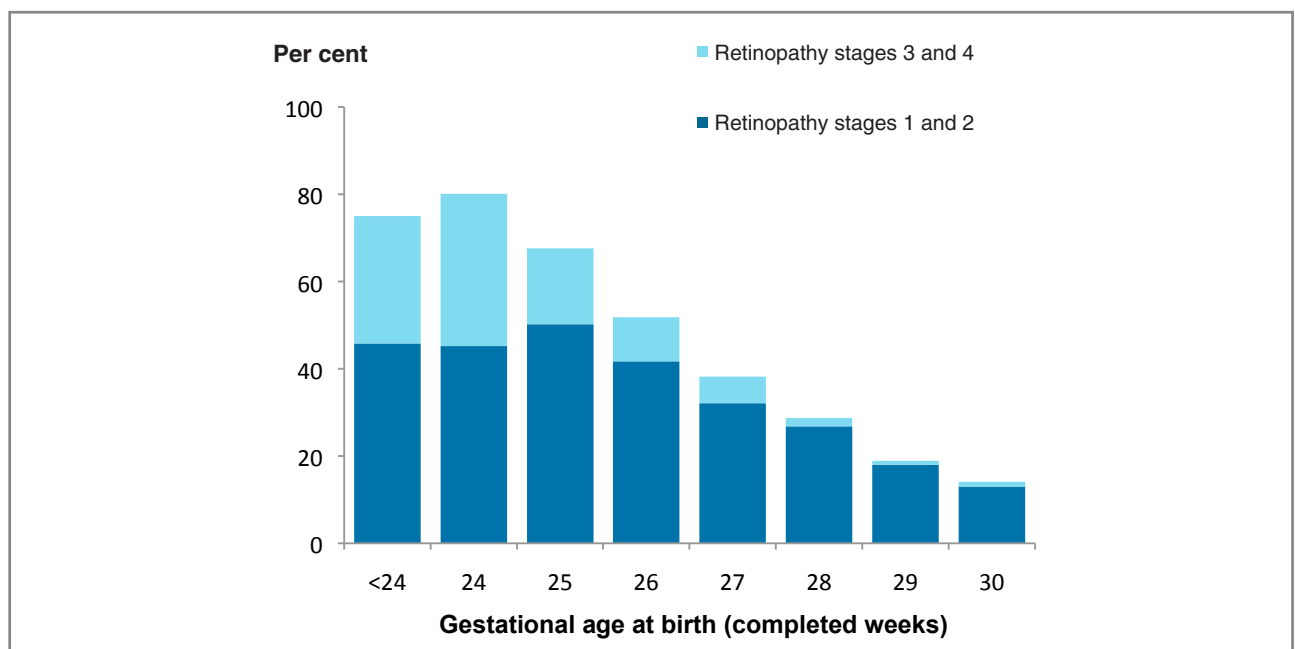
**TABLE 23: Retinopathy of prematurity for level III registrants by gestational age, 2013**

Retinopathy of prematurity (ROP)	Gestational age									Total
	<24	24	25	26	27	28	29	30	>30	
Number										
No ROP	n.p.	n.p.	65	133	183	269	375	378	n.p.	1,544
Stage 1	<5	20	34	50	44	57	n.p.	26	10	n.p.
Stage 2	8	37	67	65	51	44	39	31	5	347
Stage 3	7	43	35	28	18	7	<5	5	<5	148
Stage 4	0	<5	0	0	0	0	0	0	0	<5
Not examined	26	51	27	32	17	23	30	231	60	497
Not stated	1	4	2	4	3	0	1	13	5	33
<b>Total</b>	<b>51</b>	<b>181</b>	<b>230</b>	<b>312</b>	<b>316</b>	<b>400</b>	<b>493</b>	<b>684</b>	<b>191</b>	<b>2,858</b>
Per cent										
No ROP	n.p.	n.p.	32.3	48.2	61.8	71.4	81.2	85.9	n.p.	66.3
Stage 1	n.p.	15.9	16.9	18.1	14.9	15.1	n.p.	5.9	7.9	n.p.
Stage 2	33.3	29.4	33.3	23.6	17.2	11.7	8.4	7.0	4.0	14.9
Stage 3	29.2	34.1	17.4	10.1	6.1	1.9	n.p.	1.1	n.p.	6.4
Stage 4	0.0	n.p.	0.0	0.0	0.0	0.0	0.0	0.0	0.0	n.p.
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not stated and not examined data are excluded from per cent calculations.

**FIGURE 6: Retinopathy of prematurity for level III registrants by gestational age, 2013**



## Intraventricular haemorrhage

An initial head ultrasound is generally performed during the first week of life to detect signs of intraventricular haemorrhage (IVH) which is graded according to an internationally recognised method in which severity increases with higher grade (Papile et al. 1978).

There were 3,501 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, 3,424 survived to day 3 and 91.6% had an examination recorded. A normal report was recorded for 79.4% of these 2013 ANZNN registrants.

There were 123 babies reported to have grade 3 or 4 IVH representing 3.6% of the babies born before 32 weeks gestation. The incidence of IVH, particularly of severe grades, is clearly shown to be inversely related to gestation. The highest percentage of babies who had severe IVH (grade 4) were born before 27 weeks gestational age, with the majority (55.0%) of the babies born before 26 weeks gestation (Table 24, Figure 7). The 10-year trend (2004–2013) for registrants with grades 3 and 4 IVH who survived to day 3 is represented in Figure 24 in Appendix 1.

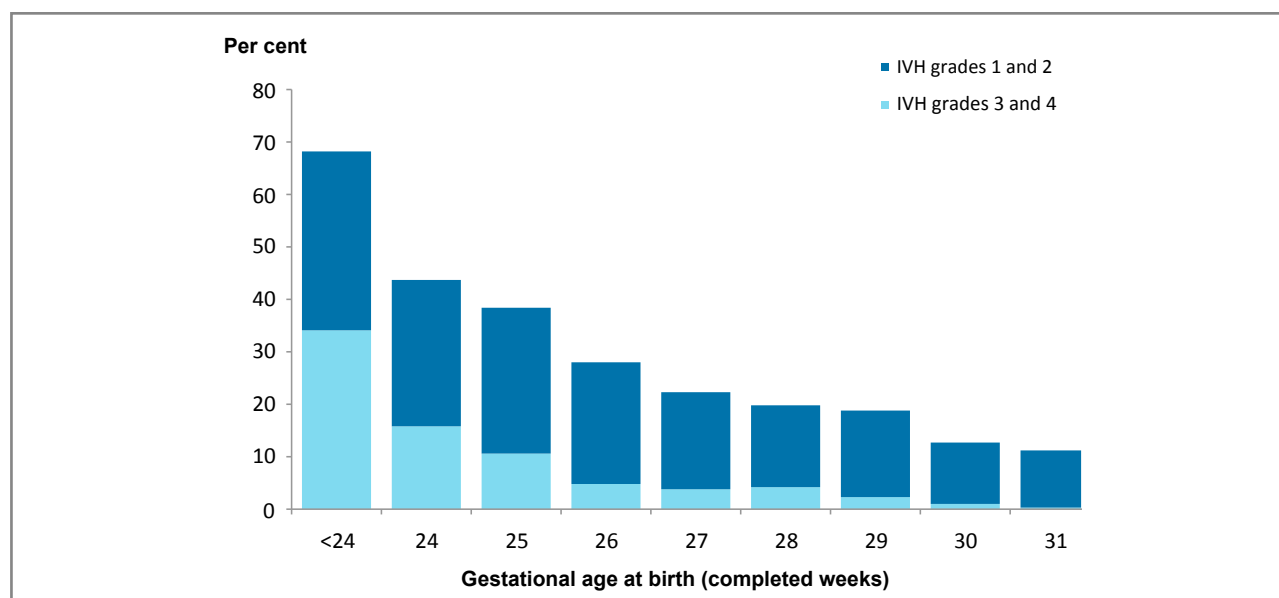
**TABLE 24: Intraventricular haemorrhage for level III registrants born before 32 weeks and survived to day 3 by gestational age, 2013**

Intraventricular haemorrhage	Gestational age									Total
	<24	24	25	26	27	28	29	30	31	
	Number									
None	13	93	133	n.p.	n.p.	309	385	538	584	2,491
Grade 1	<5	28	33	44	32	46	n.p.	60	61	366
Grade 2	11	18	27	24	22	14	19	12	11	158
Grade 3	<5	7	9	<5	7	7	<5	<5	<5	43
Grade 4	11	19	14	11	<5	9	7	<5	<5	80
Not examined	0	1	2	5	13	13	16	64	172	286
<b>Total</b>	<b>41</b>	<b>166</b>	<b>218</b>	<b>297</b>	<b>304</b>	<b>398</b>	<b>490</b>	<b>680</b>	<b>830</b>	<b>3,424</b>
Per cent										
None	31.7	56.4	61.6	n.p.	n.p.	80.3	81.2	87.3	88.8	79.4
Grade 1	n.p.	17.0	15.3	15.1	11.0	11.9	n.p.	9.7	9.3	11.7
Grade 2	26.8	10.9	12.5	8.2	7.6	3.6	4.0	1.9	1.7	5.0
Grade 3	n.p.	4.2	4.2	n.p.	2.4	1.8	n.p.	n.p.	n.p.	1.4
Grade 4	26.8	11.5	6.5	3.8	n.p.	2.3	1.5	n.p.	n.p.	2.5
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not examined data are excluded from per cent calculations.

**FIGURE 7: Intraventricular haemorrhage in level III registrants born at less than 32 weeks gestation and survived to day 3, by gestational age, 2013**





## Late cerebral ultrasound

Late cerebral ultrasound data are based on changes seen in brain tissue at the cerebral ultrasound scan nearest to six weeks of age. As noted above there were 3,501 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, 3,424 survived until day 3 and late ultrasound results were available for 2,412 (70.4%) of these babies. A normal report of no cysts was recorded for 97.0% of these registrants, 0.9% reported porencephalic cysts, 2.0% reported periventricular leukomalacia (PVL) and there were two reports of encephaloclastic porencephaly (Table 25). Hydrocephalus was reported for 27 (1.1%) of these registrants in 2013.

**TABLE 25: Late cerebral ultrasound results for level III registrants born before 32 weeks by gestational age, 2013**

Cerebral ultrasound results	Gestational age									Total
	<24	24	25	26	27	28	29	30	31	
	Number									
No cysts	25	128	185	257	264	333	379	402	360	2,333
Porencephalic cysts	<5	5	<5	<5	<5	<5	<5	<5	<5	22
Periventricular leukomalacia	0	<5	10	5	<5	10	7	6	5	47
Encephaloclastic porencephaly	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	2
Not stated	25	46	30	46	49	55	105	273	468	1,097
<b>Total</b>	<b>51</b>	<b>181</b>	<b>230</b>	<b>312</b>	<b>316</b>	<b>400</b>	<b>493</b>	<b>684</b>	<b>834</b>	<b>3,501</b>
	Per cent									
No cysts	96.2	94.8	92.5	96.6	98.9	96.5	97.7	97.8	98.4	97.0
Porencephalic cysts	n.p.	3.7	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	0.9
Periventricular leukomalacia	0.0	n.p.	5.0	1.9	n.p.	2.9	1.8	1.5	1.4	2.0
Encephaloclastic porencephaly	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	0.1
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

## Therapeutic hypothermia

Therapeutic hypothermia is the intentional cooling of an infant to a core temperature of less than 35°C (generally 33–34°C). The evidence in support for controlled hypothermia, initiated before 6 hours of age, as a means of limiting the reperfusion injury that follows perinatal asphyxia in term infants has been evolving over the last 10 years. Several multi centre randomised controlled trials have provided evidence which supports this approach, especially in moderately asphyxiated term infants. Hypothermia has potential for harm and its use should be carefully monitored.

Hypothermia begins at the onset of cooling and ends at the onset of warming. Cooling is normally for 72 hours with a period of up to 6 hours of rewarming. In 2013, 317 (7.8%) of the ANZNN registrants born at more than 34 weeks gestation received therapeutic hypothermia, and of these, 67.5% were cooled for at least 72 hours. Of those babies who did not receive cooling for a full 72 hours, information on the principal reason for non-completion of the full 72 hours of therapeutic hypothermia was available for 94.4% of babies. The main reason for cessation of cooling before 72 hours was that the baby was recognised as not fulfilling the standard criteria for cooling (27.5%), followed by palliation (25.5%).

## Necrotising enterocolitis

Necrotising enterocolitis (NEC) is a gastrointestinal disease affecting premature infants that can be life threatening and is a leading cause of mortality and morbidity among infants in NICUs. There is no definitive cause identified for NEC although infection, empirical use of antibiotics for more than five days and enteral artificial formula feeding are thought to be involved. With an early diagnosis, NEC can be treated medically through cessation of feeds, use of parenteral nutrition and antibiotic treatment. If medical treatment is unsuccessful surgery may be required to remove the affected bowel.

For ANZNN registrants in 2013 the percentage of babies with confirmed NEC was 1.3%. Of these babies, 63.8% were born before 28 weeks gestation with 49.4% of them undergoing surgery, and 36.2% were born after 27 weeks gestation; surgery was required for 50.0% of them. In total 34 registrants died from NEC. The number of registrants with confirmed NEC is less than in 2012 (Table 26).

**TABLE 26: Necrotising enterocolitis in level III registrants by year of birth, 2004–2013**

Necrotising enterocolitis	Year of birth									
	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Number										
NEC at <28 weeks										
▪ NEC	85	87	95	77	118	97	111	71	86	81
▪ No NEC at <28 weeks	941	952	945	1,034	1,050	1,031	952	1,026	983	1,009
▪ Not stated	0	0	20	30	14	2	4	5	2	0
NEC at ≥28 weeks										
▪ NEC	63	49	72	40	74	50	68	51	51	46
▪ No NEC at ≥28 weeks	6,316	6,561	6,420	6,918	7,339	7,801	7,093	8,027	8,191	8,584
▪ Not stated	0	0	32	59	27	3	8	1	5	1
<b>Total in each birth year</b>	<b>7,405</b>	<b>7,649</b>	<b>7,584</b>	<b>8,158</b>	<b>8,622</b>	<b>8,984</b>	<b>8,236</b>	<b>9,181</b>	<b>9,318</b>	<b>9,721</b>
Per cent										
NEC <28 weeks <sup>(a)</sup>	8.3	8.4	9.1	6.9	10.1	8.6	10.4	6.5	8.0	7.4
NEC ≥28 weeks <sup>(b)</sup>	1.0	0.7	1.1	0.6	1.0	0.6	0.9	0.6	0.6	0.5

(a) Denominator is babies born at <28 weeks.

(b) Denominator is babies born at ≥28 weeks.

**Note:** Not stated data are excluded from per cent calculations.

## Spontaneous intestinal perforation

Spontaneous intestinal perforation is distinct from NEC and usually involves a single perforation of the intestine. In 2013, 59 (0.6%) of all ANZNN registrants had a confirmed diagnosis of spontaneous intestinal perforation. Of these, 10 babies were also reported to have a confirmed NEC diagnosis. Care should be taken in interpretation of these data as this is the first year of collection for the ANZNN.

## Neonatal surgery

The information given in this report includes the registrant's first admission to an NICU before their first discharge home after birth. Babies who were discharged home and re-admitted for surgery during the neonatal period are not included in this audit.

In 2013, there were 972 ANZNN registrants who had major surgery, of whom over half (53.1%) were born at term. Of registrants born in a hospital, 73.6% were born in a hospital with tertiary care facilities. Of registrants who had major surgery, 78.3% also had a congenital anomaly present with 56.5% of these diagnosed during the antenatal period. 6.5% had surgery for proven NEC. The median length of stay (LOS) for survivors was 32 days (Table 27).

**TABLE 27: Characteristics of level III registrants who underwent surgery by gestational age group, 2013**

	Gestational age group								
Characteristics	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
Male	<5	40	32	21	n.p.	30	117	310	571
Female	n.p.	39	17	14	n.p.	20	73	206	401
Congenital anomaly present	<5	n.p.	11	16	28	42	171	476	761
Congenital anomaly diagnosed antenatally	0	<5	<5	<5	7	24	126	268	430
Proven NEC	<5	23	13	9	<5	<5	<5	6	63
Hospital of birth:									
▪ Tertiary	6	69	41	29	n.p.	n.p.	155	328	709
▪ Non-tertiary	5	10	7	6	<5	n.p.	35	180	254
Median LOS for survivors (days)	137	129.5	106.5	91	67	55.5	30	20	32
Died before discharge home	<5	8	5	6	<5	<5	13	7	46
Total in each age group	11	79	49	35	42	50	190	516	972
Per cent									
Male	n.p.	50.6	65.3	60.0	n.p.	60.0	61.6	60.1	58.7
Female	n.p.	49.4	34.7	40.0	n.p.	40.0	38.4	39.9	41.3
Congenital anomaly present	n.p.	n.p.	22.4	45.7	66.7	84.0	90.0	92.2	78.3
Congenital anomaly diagnosed antenatally	0.0	n.p.	n.p.	n.p.	16.7	48.0	66.3	51.9	44.2
Proven NEC	n.p.	29.1	26.5	25.7	n.p.	n.p.	n.p.	1.2	6.5
Hospital of birth:									
▪ Tertiary	54.5	87.3	83.7	82.9	n.p.	n.p.	81.6	63.6	72.9
▪ Non-tertiary	45.5	12.7	14.3	17.1	n.p.	n.p.	18.4	34.9	26.1
Died before discharge home	n.p.	10.1	10.2	17.1	n.p.	n.p.	6.8	1.4	4.7

*n.p.* Data not published to maintain confidentiality of small numbers.

## Congenital anomalies

In 2013, 1,409 ANZNN registrants (14.5%) had one or more major congenital anomalies. For registrants who had a congenital anomaly, 16.3% were born before 32 weeks gestation, 28.2% were born between 32 and 36 weeks gestation and more than half of registrants (55.4%) were born at term.

Nearly half of ANZNN registrants (48.2%) with congenital anomalies were diagnosed during the antenatal period with 10.1% of babies recorded as having a fatal congenital anomaly. A higher percentage of babies with congenital anomalies were male (58.8%).

## Transfer from level III NICUs to other units

Once intensive care is no longer required babies are often ‘down’ transferred to a level II unit, sometimes referred to as a ‘special care baby unit’, either within the same hospital or to another hospital for convalescence before discharge home. In 2013, nearly two in five of ANZNN registrants (37.4%) were transferred from a level III unit to a level II unit before discharge home. The ability to down transfer for any level III unit will depend on the availability of receiving level II hospitals and this is a limiting factor in some regions (eg. South Australia). Almost half of the registrants (46.5%) transferred from level III to level II units were born at less than 32 weeks gestation compared to 14.7% born at term.

Some level III registrants required transfer to a specialist children’s hospital and in 2013 these accounted for 3.8% of transfers from level III units. Overall 54.8% of level III registrants were not transferred after registration (Table 28).

**TABLE 28: Transfer after registration of level III registrants by level of destination hospital and gestational age group, 2013**

	Gestational age group								
Transfer status	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	Total
Number									
Not transferred	32	230	304	366	564	614	1,028	2,184	5,322
Level III hospital	n.p.	32	55	47	65	n.p.	49	84	388
Level II hospital	11	113	243	455	868	789	625	533	3,637
Children's hospital	<5	36	26	25	21	n.p.	58	183	373
Not stated	0	0	0	0	0	0	1	0	1
Total	51	411	628	893	1,518	1,475	1,761	2,984	9,721
Per cent									
Not transferred	62.7	56.0	48.4	41.0	37.2	41.6	58.4	73.2	54.8
Level III hospital	n.p.	7.8	8.8	5.3	4.3	n.p.	2.8	2.8	4.0
Level II hospital	21.6	27.5	38.7	51.0	57.2	53.5	35.5	17.9	37.4
Children's hospital	n.p.	8.8	4.1	2.8	1.4	n.p.	3.3	6.1	3.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

## Length of stay until discharge home

Factors that influence a baby’s length of stay (LOS) in hospital are gestational age, birthweight and plurality. Preterm and low birthweight babies require more intensive care, lengthening their hospital stay. Extremely preterm babies are usually discharged home by the time they reach 40 weeks corrected age.

In ANZNN the LOS includes all the time the baby spends in hospital from the first day of their first admission up until and including the day of their discharge home. The LOS has added together the time spent in all hospitals, which includes level III and subsequent level II or I hospitals or children’s hospitals. It does not include the time spent in hospital in any subsequent admissions from home, nor does it include periods spent in ‘Hospital in the Home’ programs. Discharge information was available for 95.8% of ANZNN registrants in 2013. The median length of stay was 27 days with an interquartile range of 11–51 days (Table 29). LOS is inversely related to gestational age with the very preterm and extremely preterm babies having a longer stay in hospital than those babies born at or near term.

Babies born at less than 32 weeks gestation spent approximately 213,278 days in hospital, babies born between 32 and 36 weeks spent 77,507 days and babies born at term spent 41,806 days in hospital.

**TABLE 29: Median length of stay for level III registrants who survived until discharge home by gestational age, 2013**

Gestational age (completed weeks)	Number of babies	Median LOS (in days)	Interquartile range (in days)
<24	22	137	120–162
24	120	122	111–145
25	193	108	96–124
26	273	93.5	83–110
27	295	78	71–95.5
28	383	69	61–80
29	484	59	51–70
30	666	48	41–56
31	824	38	33–47
32	755	33	27–40
33	693	25	20–32
34	656	19	15–26
35	536	14	9–21
36	508	11	7–19
37	540	9	5–19
38	640	8	5–17
39	672	7	4–15
40	608	7	4–15
41	374	6	4–14
≥42	29	5.5	4–8
<b>Total</b>	<b>9,271</b>	<b>27</b>	<b>11–51</b>

*Note:* Death status was not provided for four babies.

Gestational ages ≥42 weeks have been combined to maintain confidentiality of small numbers.

## Survival of the ANZNN registrants

In 2013, 95.4% of ANZNN registrants survived to go home. These data include babies who were transferred to level I or level II units, those transferred to another level III unit and those babies transferred to a children's hospital. The survival rate to discharge home as shown in Table 28 does not encompass the following: fetal deaths; neonatal deaths that occurred on a labour ward; babies born in level II hospitals; and babies not transferred to an NICU or children's hospital.

During 2013, there were 446 neonatal deaths, of which 213 occurred in the early neonatal period that is within seven days of birth (Table 30). Mortality was highest among babies born before 28 weeks gestation with a survival rate at discharge increasing week on week from 43.1% for babies born before 24 weeks to 95.8% for babies born at 28 weeks (Table 30, Figure 8). A similar pattern of increasing survival with increasing birthweight is seen in Figure 9.

Lethal congenital anomaly was the cause of death for 1.5% of registrants, with most occurring in babies born between 34–39 weeks gestation (Table 30).

TABLE 30: Survival to discharge home for level III registrants by gestational age at birth, 2013

Gestational age (completed weeks)	Number of babies	Lethal congenital anomalies	Babies alive on day 7	Babies alive on day 28	Survived to go home	Per cent survival at discharge to home
<24	51	0	33	26	22	43.1
24	181	<5	155	137	120	66.3
25	230	<5	214	205	193	83.9
26	312	<5	291	285	273	87.5
27	316	5	303	300	295	93.4
28	400	<5	395	393	383	95.8
29	493	<5	489	485	484	98.2
30	684	7	674	671	666	97.4
31	834	5	830	825	824	98.8
32	766	<5	763	760	755	98.6
33	709	5	700	698	693	97.7
34	672	13	668	661	656	97.6
35	560	16	551	543	536	95.7
36	529	11	523	512	508	96.0
37	567	19	551	544	540	95.2
38	676	22	659	643	640	94.7
39	700	14	684	680	672	96.0
40	629	8	616	612	608	96.7
41	383	<5	380	376	374	97.7
≥42	29	0	29	29	29	100.0
<b>Total</b>	<b>9,721</b>	<b>143</b>	<b>9,508</b>	<b>9,385</b>	<b>9,271</b>	<b>95.4</b>

*Note:* Death status was not provided for four babies.

Gestational ages ≥42 weeks have been combined to maintain confidentiality of small numbers.

FIGURE 8: Survival of level III registrants to discharge home (with 95% CI) by gestational age, 2013

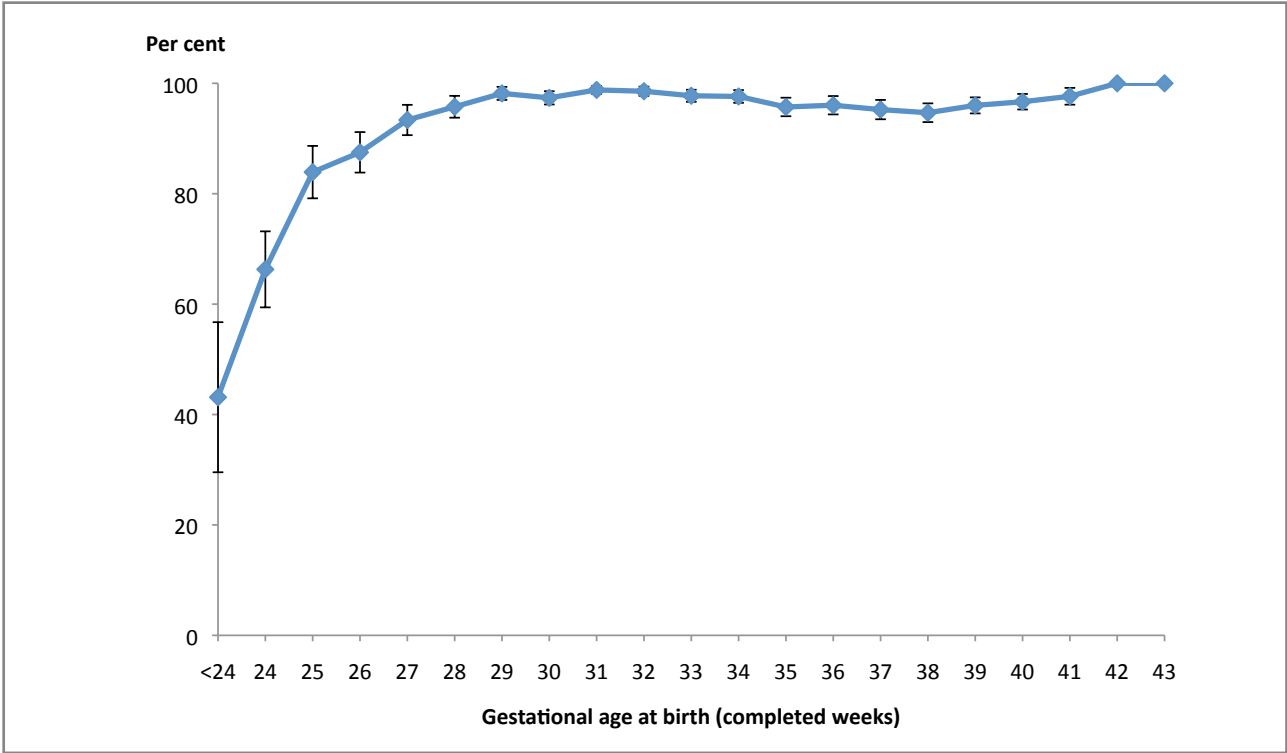
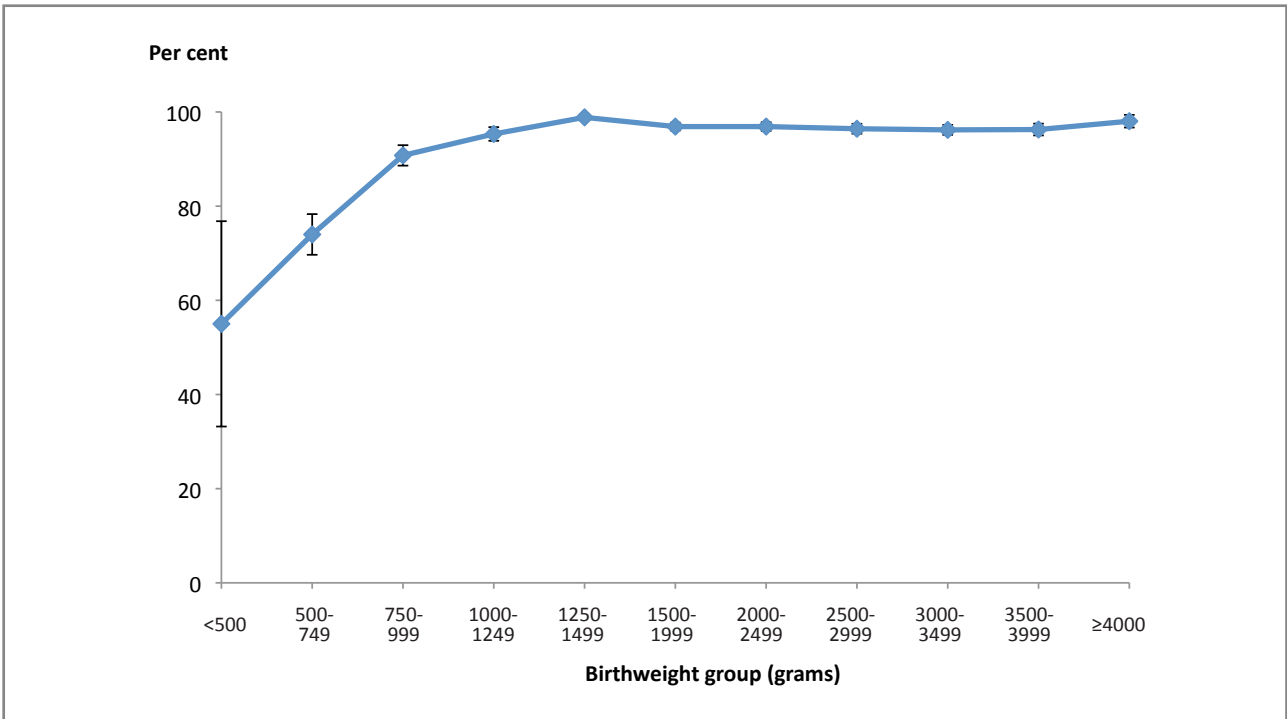


FIGURE 9: Survival of level III registrants to discharge home (with 95% CI) by birthweight group, 2013



## 5. Babies registered to level II units

### Overview

Neonatal units with facilities to manage mild or moderately ill babies are known as ‘level II units’ or ‘special care baby units’. The classification of the level for care for perinatal hospitals is changing and the new classifications for ‘level II’ are now often ‘level IV and V’. For the purpose of this report at this time, the term “level II” has been retained. Individual units may have varying levels of resources for giving special care. The ANZNN registration criteria for level II and level III units are the same. Babies born in a level II unit and transferred to a level III unit within 28 days of birth are registered to that level III unit. Babies are registered to a level II unit if their hospital stay was entirely within non-tertiary centre units, or if they were transferred to a level III NICU after 28 days, or they were transferred to a level II neonatal unit from a children’s hospital without first having been admitted to a level III unit.

There are 16 level II units in New Zealand and ten in Australia that are members of the ANZNN. Altogether, 24 level II units contributed data for this 2013 report.

In 2013, 1,090 babies fulfilled the ANZNN criteria for registration to a level II unit. Of those babies, 11.6% were born at less than 32 weeks gestation and 8.1% weighed less than 1,500 grams at birth (Table 31 and Table 32). The highest number of babies registered to a level II unit in 2013 was just over 150.

**TABLE 31: Level II registrants by gestational age group, 2013**

Gestational age group	Number of babies	Per cent	Cumulative per cent
<30	26	2.4	2.4
30–31	100	9.2	11.6
<b>All babies &lt;32 weeks gestation</b>	<b>126</b>	<b>11.6</b>	
32–33	164	15.1	26.6
34–36	307	28.2	54.8
37–43	492	45.2	100.0
<b>Total</b>	<b>1,090</b>	<b>100.0</b>	

*Note:* Gestational age groups below 30 weeks have been combined to maintain confidentiality of small numbers. Gestational age was not provided for one baby.

**TABLE 32: Level II registrants by birthweight group, 2013**

Birthweight group (grams)	Number of babies	Per cent	Cumulative per cent
<1,100	9	0.8	0.8
1,100–1,199	10	0.9	1.7
1,200–1,299	13	1.2	2.9
1,300–1,399	27	2.5	5.4
1,400–1,499	29	2.7	8.1
<b>All babies &lt;1,500g birthweight</b>	<b>88</b>	<b>8.1</b>	
1,500–1,999	174	16.0	24.0
2,000–2,499	196	18.0	42.0
2,500–2,999	184	16.9	58.9
3,000–3,499	209	19.2	78.1
3,500–3,999	144	13.2	91.3
≥4,000	95	8.7	100.0
<b>Total</b>	<b>1,090</b>	<b>100.0</b>	

*Note:* Birthweight groups below 1,100g have been combined to maintain confidentiality of small numbers.



More than half of the level II registrants, 570 babies (52.3%), were born to Caucasian mothers, 56.7% of whom were born preterm. The number of registrants born to Maori mothers was 130 (11.9%), and 64 (49.2%) were born preterm. There were 28 babies (2.6%) born to Pacific Islander mothers.

There were 660 male (60.6%) and 425 female (39.0%) registrants in the audit. No gender was recorded for five registrants (0.5%). Non-specific respiratory distress was the major reason for assisted ventilation for level II registrants.

## Maternal, pregnancy and birth characteristics

Of the mothers of level II registrants, 26.2% did not present with any maternal complications. Among babies born before 37 weeks, 44.1% of mothers had presented with preterm labour (Table 33).

**TABLE 33: Mothers of level II registrants presenting antenatal problem by gestational age group, 2013**

Presenting antenatal problem	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
	Number					
No antenatal problems	0	0	<5	n.p.	275	284
Preterm pre-labour rupture of membranes	6	27	26	50	<5	n.p.
Preterm labour	15	42	70	n.p.	<5	263
Hypertension in pregnancy	<5	11	n.p.	32	24	89
Antepartum haemorrhage	<5	n.p.	16	23	6	60
Intrauterine growth restriction	0	<5	16	23	n.p.	58
Fetal distress	0	5	7	10	93	115
Other problem	0	0	9	24	70	103
Congenital anomalies	0	0	0	0	<5	<5
Not stated	0	0	0	3	1	4
<b>Total</b>	<b>26</b>	<b>100</b>	<b>164</b>	<b>307</b>	<b>492</b>	<b>1,090</b>
Per cent						
No antenatal problems	0.0	0.0	n.p.	n.p.	56.0	26.2
Preterm pre-labour rupture of membranes	23.1	27.0	15.9	16.4	n.p.	n.p.
Preterm labour	57.7	42.0	42.7	n.p.	n.p.	24.2
Hypertension in pregnancy	n.p.	11.0	n.p.	10.5	4.9	8.2
Antepartum haemorrhage	n.p.	n.p.	9.8	7.6	1.2	5.5
Intrauterine growth restriction	0.0	n.p.	9.8	7.6	n.p.	5.3
Fetal distress	0.0	5.0	4.3	3.3	18.9	10.6
Other problem	0.0	0.0	5.5	7.9	14.3	9.5
Congenital anomalies	0.0	0.0	0.0	0.0	n.p.	n.p.
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

Gestational age was not provided for one baby.

Previous preterm births were reported by 107 (9.8%) of the mothers of level II registrants and 28 mothers (2.6%) had had a previous perinatal death(s).

Most mothers (88.4%) of level II registrants had booked into a level II hospital for delivery. Of the level II registrants born before 34 weeks gestation, 71.7% of the mothers were given antenatal corticosteroids within seven days of the birth (Table 34).

**TABLE 34: Antenatal corticosteroid use by mothers of level II registrants by gestational age group, 2013**

	Gestational age group					
Antenatal corticosteroids	<30	30–31	32–33	34–36	37–43	Total
Number						
None	5	9	38	201	476	729
Incomplete course	n.p.	32	56	30	<5	132
Complete course	8	43	58	45	7	161
Completed >7 days	<5	11	10	21	<5	47
Not stated	0	5	2	10	3	20
<b>Total</b>	<b>26</b>	<b>100</b>	<b>164</b>	<b>307</b>	<b>492</b>	<b>1,090</b>
Per cent						
None	19.2	9.5	23.5	67.7	97.3	68.2
Incomplete course	n.p.	33.7	34.6	10.1	n.p.	12.3
Complete course	30.8	45.3	35.8	15.2	1.4	15.1
Completed >7 days	n.p.	11.6	6.2	7.1	n.p.	4.4
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

Gestational age was not provided for one baby.

Caesarean section was the most common method of birth for 50.4% of level II registrants, with just over half (51.5%) of these occurring before the onset of labour (Table 35).

**TABLE 35: Method of delivery for level II registrants by gestational age group, 2013**

	Gestational age group					
Method of delivery	<30	30–31	32–33	34–36	37–43	Total
Number						
Vaginal <sup>(a)</sup>	16	44	60	121	296	537
Caesarean <sup>(b)</sup>	10	56	104	185	190	545
Not stated	0	0	0	1	6	7
<b>Total</b>	<b>26</b>	<b>100</b>	<b>164</b>	<b>307</b>	<b>492</b>	<b>1,090</b>
Per cent						
Vaginal	61.5	44.0	36.6	39.5	60.9	49.6
Caesarean	38.5	56.0	63.4	60.5	39.1	50.4
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

<sup>(a)</sup> Vaginal and assisted births have been combined to maintain confidentiality of small numbers.

<sup>(b)</sup> Caesarean section deliveries in labour and no labour have been combined to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

Gestational age was not provided for one baby.

## Characteristics of level II babies

Among the 1,090 babies registered to level II units, 132 were from multiple births (12.1%). There were 660 male births and five babies whose gender was not recorded.

A low Apgar score of less than 4 at one minute of age was recorded for 17.3% of babies and 15.0% of them required endotracheal intubation in the labour ward to assist in their adaptation to extrauterine life.

Non-specific respiratory distress (59.1%) was the major reason for assisted ventilation for level II registrants, followed by hyaline membrane disease (21.1%) (Table 36).

For level II registrants, the median duration of assisted ventilation by IPPV was 29 hours and 17 hours by CPAP (Table 37).

**TABLE 36: Indication for respiratory support for level II registrants by gestational age group, 2013**

Indication for respiratory support	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
	Number					
No respiratory support	0	20	n.p.	11	<5	47
Non-specific respiratory distress	n.p.	31	n.p.	203	320	640
Hyaline membrane disease	18	46	66	69	30	229
Meconium aspiration syndrome	0	0	0	<5	n.p.	70
Pneumonia	0	<5	0	10	29	n.p.
Persistent pulmonary hypertension	0	0	0	<5	6	n.p.
Apnoea	0	<5	<5	6	5	15
Congenital anomaly	0	0	0	0	<5	<5
Other	<5	<5	<5	<5	14	22
Peri-surgery	0	0	0	0	0	0
Newborn encephalopathy	0	0	0	0	8	8
Not stated	0	0	0	0	6	6
<b>Total</b>	<b>26</b>	<b>100</b>	<b>164</b>	<b>307</b>	<b>492</b>	<b>1,090</b>
	Per cent					
No respiratory support	0.0	20.0	n.p.	3.6	n.p.	4.3
Non-specific respiratory distress	n.p.	31.0	n.p.	66.1	65.8	59.1
Hyaline membrane disease	69.2	46.0	40.2	22.5	6.2	21.1
Meconium aspiration syndrome	0.0	0.0	0.0	n.p.	n.p.	6.5
Pneumonia	0.0	n.p.	0.0	3.3	6.0	n.p.
Persistent pulmonary hypertension	0.0	0.0	0.0	n.p.	1.2	n.p.
Apnoea	0.0	n.p.	n.p.	2.0	1.0	1.4
Congenital anomaly	0.0	0.0	0.0	0.0	n.p.	n.p.
Other	n.p.	n.p.	n.p.	n.p.	2.9	2.0
Peri-surgery	0.0	0.0	0.0	0.0	0.0	0.0
Newborn encephalopathy	0.0	0.0	0.0	0.0	1.6	0.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

Gestational age was not provided for one baby.

**TABLE 37: Duration of assisted ventilation use by level II registrants by gestational age group, 2013**

Median & Interquartile range	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
IPPV (hours)						
Median	49.5	18.5	32.5	41	22	29
IQR	5–72.5	8–41	4.5–81	26–72	6–52	7–57
CPAP (hours)						
Median	106	42.5	23	17	12	17
IQR	47–336	22–83	10–50	10–45	7–22	9–38

*Note: IQR = Interquartile range.*

## Eye examination

Screening for retinopathy of prematurity (ROP) was reported for only 55 of the 73 eligible babies born at less than 31 weeks gestational age and/or weighing less than 1,250 grams at birth (75.3% compared to 81.5% of eligible level III registrants). Most were reported as normal except for four babies who had stage 1 and one baby who had stage 2 ROP.

## Cerebral ultrasound

Of the 126 babies born at less than 32 weeks, 103 (81.7%) had a cerebral ultrasound in the first week after birth. 92 of them were reported as normal, that is no intraventricular haemorrhage (IVH), eight reported a grade 1 IVH, two reported a grade 2 IVH and one reported a grade 3 IVH. Most babies who did not have an early cerebral ultrasound reported at this time were born at 30 or 31 weeks gestation. A late cerebral ultrasound was reported for 60 babies, all of whom had normal reports.

## Other morbidities

Septicaemia was proven in 28 babies, including 21 before day two, that is less than 48 hours. There was one case of necrotising enterocolitis. Major congenital anomalies were reported for 25 babies, three required major surgery, and five registrants died due to congenital anomalies.

## Level II transfers

In total 96 level II registrants were transferred to other units, 69 were transferred to a level I or another level II unit, 24 were transferred to a level III unit and the remaining three to a children's hospital.

## Survival

There were 1,064 level II registrants who survived to discharge home (97.6%). Ten babies died within the first seven days of birth and a further five babies died before discharge home (Table 38). Five babies were reported to have had a lethal congenital anomaly.

**TABLE 38: Survival to discharge home for level II registrants by gestational age group, 2013**

<b>Gestational age group</b>	<b>All babies</b>	<b>Babies alive on day 7</b>	<b>Babies alive on day 28</b>	<b>Survived to go home</b>	<b>Per cent survival at discharge to home</b>
<30	26	23	23	23	88.5
30-31	100	100	100	98	98.0
32-33	164	164	164	160	97.6
34-36	307	307	305	304	99.0
37-43	492	485	484	478	97.2
<b>All babies</b>	<b>1,090</b>	<b>1,079</b>	<b>1,076</b>	<b>1,063</b>	<b>97.6</b>

*Note:* Gestational age was not provided for one baby.  
Death status was not provided for 11 babies.

## 6. Extremely preterm follow-up, 2009–2010 births

### Introduction

Neurological and developmental problems are common among surviving extremely preterm and/or extremely low birthweight babies (Doyle et al. 2010, Doyle et al. 2011). Impairments can include cerebral palsy, blindness, deafness and developmental delay.

This chapter includes 2–3 year outcome data on extremely preterm and/or extremely low birthweight ANZNN registrants from 2009 and 2010. All infants less than 28 weeks gestation or less than 1,000 grams at birth admitted to one of the 28 level III NICUs in Australia and New Zealand in 2009 and 2010, who survived to discharge to home were eligible for follow-up at 2–3 years of age, corrected for prematurity. There were 2,333 infants who fulfilled the criteria for 2–3 year follow-up.

Care should be taken with interpretation of these data as this is only the second year of collection for the ANZNN and post-discharge data were not retrieved from the NICU for 346 (14.8%) of the eligible ANZNN registrants born in 2009 and 2010.

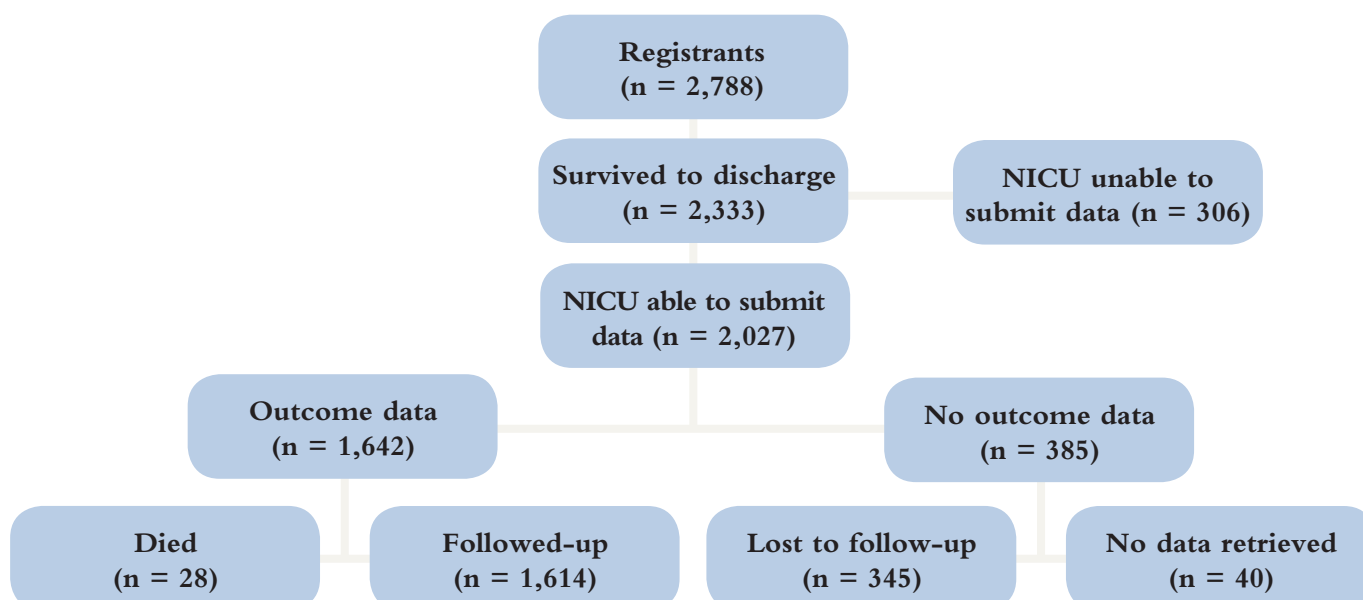
### Follow-up rate

In 2009 and 2010, 2,788 extremely preterm and/or extremely low birthweight babies were registered to the ANZNN, with 2,333 (83.7%) surviving to hospital discharge. For the babies who survived to discharge, not all NICUs were able to submit post-discharge data. It should be noted that two NICUs were unable to submit post-discharge data for 2009 and 2010 births and one was unable to submit post-discharge data for 2009 births before the publication of this Report. The 306 eligible survivors registered to these NICUs were excluded from further outcome analysis.

Of the 2,027 eligible survivors registered to NICUs who were able to submit their data, 1,642 (81.0%) had outcome data available. There were 28 infants who died after discharge and 1,614 who had a follow-up assessment. Outcome data were not available for 385 (19.0%) infants, with 345 (17.0%) recorded by the NICU as lost to follow-up and the remainder with no post-discharge data being retrieved from the NICU (Figure 10). Overall, the rate of follow-up among these surviving eligible infants was 80.7% (1,614 of 1,999). The follow-up rate was seen to decrease with increasing gestational age and increasing birthweight (Table 39 & Table 40).

Of the 1,614 infants who were followed-up, 1,422 (88.1%) had a formal developmental assessment. For the remaining 192 (11.9%) infants, some follow-up information was obtained but a formal developmental assessment was not completed.

**FIGURE 10: Flowchart of 2009–2010 follow-up cohort**



**TABLE 39: Births, survival and 2–3 year follow-up of extremely preterm and/or extremely low birthweight infants by gestational age, 2009–2010 births**

	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28 <sup>(a)</sup>	
Number							
Registrants	123	353	497	633	663	519	2,788
Survived to discharge	68	227	387	554	601	496	2,333
Per cent							
Survived to discharge <sup>(b)</sup>	55.3	64.3	77.9	87.5	90.6	95.6	83.7
Number							
NICU not included	11	35	50	78	63	69	306
Follow-up cohort <sup>(c)</sup>	57	192	337	476	538	427	2,027
▪ Died post-discharge	<5	<5	8	5	9	<5	28
▪ Follow-up assessment <sup>(d)</sup>	53	171	273	385	419	313	1,614
▪ No outcome data	<5	n.p.	56	86	110	n.p.	385
Per cent							
Follow-up rate <sup>(e)</sup>	94.6	90.0	83.0	81.7	79.2	73.8	80.7

*n.p.* Data not published to maintain confidentiality of small numbers.

(a) These infants were <1,000 grams at birth.

(b) Denominator is all registrants.

(c) Registrants who survived to discharge from NICUs able to submit data.

(d) Includes 63 infants assessed at <18 months corrected age and 10 infants with unknown corrected age at assessment.

(e) Denominator is registrants who survived to discharge from NICUs able to submit data minus registrants who died post-discharge.

**TABLE 40: Births, survival and 2–3 year follow-up of extremely preterm and/or extremely low birthweight infants by birthweight, 2009–2010 births**

	Birthweight group (grams)							Total
	<500	500–599	600–699	700–799	800–899	900–999	≥1000 <sup>(a)</sup>	
Number								
Registrants	70	186	400	467	555	617	493	2,788
Survived to discharge	27	124	289	381	487	576	449	2,333
Per cent								
Survived to discharge <sup>(b)</sup>	38.6	66.7	72.3	81.6	87.7	93.4	91.1	83.7
Number								
NICU not included	1	10	40	52	73	77	53	306
Follow-up cohort <sup>(c)</sup>	26	114	249	329	414	499	396	2,027
▪ Died post-discharge	<5	<5	<5	<5	5	11	<5	28
▪ Follow-up assessment <sup>(d)</sup>	22	97	210	276	333	375	301	1,614
▪ No outcome data	<5	n.p.	n.p.	n.p.	76	113	n.p.	385
Per cent								
Follow-up rate <sup>(e)</sup>	91.7	87.4	85.0	84.7	81.4	76.8	76.4	80.7

*n.p.* Data not published to maintain confidentiality of small numbers.

(a) These infants were <28 weeks at birth.

(b) Denominator is all registrants.

(c) Registrants who survived to discharge from NICUs able to submit data.

(d) Includes 63 infants assessed at <18 months corrected age and 10 infants with unknown corrected age at assessment.

(e) Denominator is registrants who survived to discharge from NICUs able to submit data minus registrants who died post-discharge.

## Assessment and tools

Children were assessed by the developmental assessment team at the level III hospital in which they received their neonatal care or the closest level III hospital to their current place of residence. If the parents were unable to travel to a level III hospital then a local paediatrician or general practitioner may have examined the child. The median age of assessment was 24.8 months with an interquartile range of 23.8–29.0 months, corrected for prematurity.

A formal developmental assessment comprised of neurological examination by a developmental paediatrician or physiotherapist, vision by an ophthalmologist or optometrist, hearing by an audiologist, and a developmental test using the Bayley Scales of Infant Development-III, Griffiths Mental Developmental Scales or another developmental test performed by a psychologist, developmental paediatrician, physiotherapist, or other qualified person.

## Neurological outcome

Cerebral palsy is characterised by abnormal muscle tone and impaired motor function and control. It is a well-recognised neurological outcome among extremely preterm and/or extremely low birthweight babies (Oskoui et al. 2013). Cerebral palsy outcomes were only included for infants assessed at 18 months corrected age or older as mild cerebral palsy may be difficult to diagnose prior to this age.

Information about cerebral palsy was available for 97.5% of infants with a follow-up assessment at 18 months corrected age or older, and of these, 117 (7.8%) had a diagnosis of cerebral palsy. The movement ability of 114 (97.4%) infants with cerebral palsy was graded by the Gross Motor Function Classification System (GMFCS), from level 1 for minimal impairment to level 5 for severe impairment. Of the infants with a GMFCS classification, 47 (41.2%) infants were graded as level 1, 30 (26.3%) as level 2, 14 (12.3%) as level 3, eight (7.0%) as level 4 and 15 (13.2%) as level 5. Although cerebral palsy was most prevalent and most severe among infants less than 24 weeks gestational age, these infants accounted for only 5% of the total infants with cerebral palsy (Table 41).

Of the 73 infants who were assessed at less than 18 months corrected age, there was one case of mild cerebral palsy, three cases of moderate cerebral palsy and one case of severe cerebral palsy.



**TABLE 41: Cerebral Palsy at 2–3 year follow-up by gestational age, 2009–2010 births**

	Gestational age (completed weeks)						
Cerebral Palsy (CP)	<24	24	25	26	27	≥28	Total
Number							
No CP	44	138	241	322	365	275	1,385
CP	6	16	19	39	19	18	117
▪ Mild Level 1	<5	8	n.p.	n.p.	n.p.	n.p.	47
▪ Moderate Level 2–3	<5	<5	9	13	7	8	44
▪ Severe Level 4–5	<5	<5	<5	7	5	<5	23
▪ Level unknown	0	0	0	<5	<5	0	3
Not stated	2	8	4	9	10	6	39
<b>Total<sup>(a)</sup></b>	<b>52</b>	<b>162</b>	<b>264</b>	<b>370</b>	<b>394</b>	<b>299</b>	<b>1,541</b>
Per cent							
No CP	88.0	89.6	92.7	89.2	95.1	93.9	92.2
CP	12.0	10.4	7.3	10.8	4.9	6.1	7.8
▪ Mild Level 1	n.p.	5.2	n.p.	n.p.	n.p.	n.p.	3.1
▪ Moderate Level 2–3	n.p.	n.p.	3.5	3.6	1.8	2.7	2.9
▪ Severe Level 4–5	n.p.	n.p.	n.p.	1.9	1.3	n.p.	1.5
▪ Level unknown	0.0	0.0	0.0	n.p.	n.p.	0.0	0.2

*n.p.* Data not published to maintain confidentiality of small numbers.

*(a)* Excludes 63 infants assessed at <18 months corrected age and 10 infants with unknown corrected age at assessment.

**Note:** Not stated data are excluded from per cent calculations.

## Vision and Hearing

Extremely preterm and/or extremely low birthweight babies are at significant risk of retinopathy of prematurity which has, in some cases, substantial long term retinal morbidity plus a risk of amblyopia and strabismus. Data on blindness were available for 96.7% of infants with a follow-up assessment and of these, only nine (0.6%) were recorded as being blind (< 6/60 in the better eye). Close to half of the infants with blindness were born at 24 weeks gestational age or younger.

Permanent congenital, delayed-onset, or progressive hearing loss is a significant adverse outcome of extreme prematurity. Risk factors include prolonged oxygen supplementation and hyperbilirubinemia (Robertson et al. 2009). Data on the use of devices for hearing amplification were only included for the 1,598 infants assessed at nine months corrected age or older as hearing devices would only likely be fitted from this age.

Information about the use of hearing devices was available for 97.4% of infants with a follow-up assessment at nine months corrected age or older. Of these, three (0.2%) infants were fitted with a unilateral hearing aid, 17 (1.1%) infants with bilateral hearing aids, six (0.4%) infants with a cochlear implant and six (0.4%) infants with a cochlear implant and hearing aids. The proportion of infants with hearing devices was more than double among those 24 weeks gestational age or younger (5.6%) compared with any other gestational age group (0.7%–2.2%).

## Congenital anomalies

Congenital anomalies reported for infants with a follow-up assessment were reviewed by the Follow-up Subcommittee to identify central nervous system malformations and chromosomal anomalies known to directly cause central nervous system dysfunction and hence delayed cognitive, language and motor development.

The congenital anomalies identified included: congenital hypothyroidism, cerebral cysts, hydrocephalus, absent septum pellucidum, Trisomy 21, ventriculomegaly, visual cortical impairment, auditory neuropathy, microcephaly, bilateral optic nerve hypoplasia, Cornelia De Lange syndrome, malformation of posterior segment of eye, Triple X syndrome (karyotype 47, XXX), agenesis of corpus callosum, holoprosencephaly, septo-optic dysplasia, duplication of chromosome 6, small selection long arm chromosome 2, lissencephaly, and other specified congenital malformation of the brain.

There were 28 infants who had one or more of these congenital anomalies and these infants were subsequently excluded from cognitive, language and motor delay analyses and functional impairment analyses (Table 42 to Table 46).

## Developmental testing

Cognitive and language delay is the most prevalent impairment in extremely preterm and/or extremely low birthweight babies (Doyle et al. 2010, Doyle et al. 2011). As mild delays are unlikely to be reliably diagnosed prior to 18 months corrected age or without formal developmental assessment, cognitive, language and motor delay was graded only for those infants formally assessed at 18 months corrected age or older.

Results were included for 1,245 infants assessed by the Bayley Scales of Development-III, 78 infants assessed by the Griffiths Mental Developmental Scales and 17 infants assessed by the Wechsler Preschool and Primary Scale of Intelligence (WPPSI). It should be noted that motor and language subscale scores were not available for the few infants who were assessed by WPPSI alone.

Those with results from other formal developmental assessments including screening assessments such as the Bayley Screening Test or Ages and Stages Questionnaires or based on clinical assessments by healthcare professionals were not included.

Cognitive, language and motor delay were graded as mild, moderate or severe, whereby severe delay was defined as scores  $<-3$  standard deviations (SD), moderate delay as scores  $-3$  SD to  $<-2$  SD, and mild delay as scores  $-2$  SD to  $<-1$  SD relative to the mean. For a typical scale with mean 100 (SD 15), these cut-points are as follows: severe  $<55$ , moderate 55–69, and mild 70–84. As 55 is the lowest composite score that can be assigned on the Bayley cognitive scale, cut-points for severe and moderate cognitive delay were adjusted to  $\leq 55$  and 56–69 respectively for infants assessed on this scale.

Additionally, there were 15 infants who were reported as unable to be assessed due to severe developmental delay and were therefore included in the severe category for cognitive, language and motor delay. While an additional nine infants without formal developmental assessment had a severe impairment recorded (one with severe cerebral palsy and blindness, three with severe cerebral palsy, three with blindness and two with a clinical assessment of severe impairment), severe cognitive, language or motor delay could not be reliably assigned to these infants.

Overall, there were 197 (14.6%) infants with mild to severe cognitive delay, 332 (26.2%) with mild to severe language delay and 216 (16.7%) with mild to severe motor delay. Cognitive, language and motor delay was most prevalent and most severe among infants who were less than 24 weeks gestational age (Table 42 to Table 44).

**TABLE 42: Cognitive delay at 2–3 year follow-up by gestational age for Bayley, Griffiths and WPPSI assessments, 2009–2010 births**

	Gestational age (completed weeks)						
Cognitive delay	<24	24	25	26	27	≥28	Total
Number							
None	28	116	206	291	308	203	1,152
Mild	12	n.p.	n.p.	24	30	n.p.	136
Moderate	<5	<5	<5	9	7	6	30
Severe	<5	5	6	9	5	<5	31
Not stated <sup>(a)</sup>	0	0	0	1	3	2	6
<b>Total<sup>(b)</sup></b>	<b>47</b>	<b>140</b>	<b>241</b>	<b>334</b>	<b>353</b>	<b>240</b>	<b>1,355</b>
Per cent							
None	59.6	82.9	85.5	87.4	88.0	85.3	85.4
Mild	25.5	n.p.	n.p.	7.2	8.6	n.p.	10.1
Moderate	n.p.	n.p.	n.p.	2.7	2.0	2.5	2.2
Severe	n.p.	3.6	2.5	2.7	1.4	n.p.	2.3
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

(a) Infants assessed by Bayley, Griffiths or WPPSI but with no Bayley cognitive subscale composite score, Griffiths performance subscale quotient or WPPSI full scale intelligence quotient recorded.

(b) Infants assessed by Bayley, Griffiths or WPPSI at ≥18 months corrected age or older or unable to be assessed due to severe delay. Excludes 28 infants with a congenital anomaly known to impair development.

**Note:** Assessments with no cognitive subscale score are excluded from per cent calculations.

**TABLE 43: Language delay at 2–3 year follow-up by gestational age for Bayley and Griffiths assessments, 2009–2010 births**

	Gestational age (completed weeks)						
Language delay	<24	24	25	26	27	≥28	Total
Number							
None	23	88	175	238	248	164	936
Mild	11	29	31	58	n.p.	n.p.	217
Moderate	5	12	17	20	19	14	87
Severe	5	6	6	5	n.p.	<5	28
Not stated <sup>(a)</sup>	3	5	11	12	20	19	70
<b>Total<sup>(b)</sup></b>	<b>47</b>	<b>140</b>	<b>240</b>	<b>333</b>	<b>348</b>	<b>230</b>	<b>1,338</b>
Per cent							
None	52.3	65.2	76.4	74.1	75.6	77.7	73.8
Mild	25.0	21.5	13.5	18.1	n.p.	n.p.	17.1
Moderate	11.4	8.9	7.4	6.2	5.8	6.6	6.9
Severe	11.4	4.4	2.6	1.6	n.p.	n.p.	2.2
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

(a) Infants assessed by Bayley or Griffiths but with no Bayley language subscale composite score or Griffiths language subscale quotient recorded.

(b) Infants assessed by Bayley or Griffiths at ≥18 months corrected age or older or unable to be assessed due to severe delay. Excludes 28 infants with a congenital anomaly known to impair development.

**Note:** Assessments with no language subscale score are excluded from per cent calculations.

**TABLE 44: Motor delay at 2–3 year follow-up by gestational age for Bayley and Griffiths assessments, 2009–2010 births**

	Gestational age (completed weeks)						
Motor delay	<24	24	25	26	27	≥28	Total
Number							
None	32	110	196	271	280	187	1,076
Mild	n.p.	n.p.	n.p.	32	n.p.	27	153
Moderate	<5	<5	<5	9	6	<5	26
Severe	5	5	7	11	n.p.	<5	37
Not stated <sup>(a)</sup>	1	2	8	10	15	10	46
<b>Total<sup>(b)</sup></b>	<b>47</b>	<b>140</b>	<b>240</b>	<b>333</b>	<b>348</b>	<b>230</b>	<b>1,338</b>
Per cent							
None	69.6	79.7	84.5	83.9	84.1	85.0	83.3
Mild	n.p.	n.p.	n.p.	9.9	n.p.	12.3	11.8
Moderate	n.p.	n.p.	n.p.	2.8	1.8	n.p.	2.0
Severe	10.9	3.6	3.0	3.4	n.p.	n.p.	2.9
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

(a) Infants assessed by Bayley or Griffiths but with no Bayley motor subscale composite score or Griffiths locomotor subscale quotient recorded.

(b) Infants assessed by Bayley or Griffiths at ≥18 months corrected age or older or unable to be assessed due to severe delay. Excludes 28 infants with a congenital anomaly known to impair development.

**Note:** Assessments with no motor subscale score are excluded from per cent calculations.

## Functional impairment

Functional impairment was analysed for 1,177 infants assessed at 18 months corrected age or older, with cognitive, language and motor subscale scores from Bayley or Griffiths assessments, and with data on blindness, hearing device use, and cerebral palsy. Functional impairment was graded as mild (GMFCS level 1 cerebral palsy, mild language, cognitive or motor delay), moderate (GMFCS level 2 to 3 cerebral palsy, deafness requiring amplification, moderate language, cognitive or motor delay) or severe (GMFCS level 4 to 5 cerebral palsy, blindness or severe language, cognitive or motor delay).

Additionally, 12 infants who met at least one of the criteria for severe impairment, but had missing data for one of more outcome, and 15 infants who were unable to be assessed due to severe developmental delay were included in the severe category for functional impairment. Of these infants, three were less than 24 weeks, three were 24 weeks, five were 25 weeks, seven were 26 weeks, seven were 27 weeks and two were 28 weeks gestational age or older.

Of the 1,204 infants where functional impairment could be graded, there were 429 (35.6%) infants with any degree of functional impairment, including 277 (23.0%) with a mild impairment, 97 (8.1%) with a moderate impairment and 55 (4.6%) with a severe impairment. Functional impairment was most prevalent and most severe among infants who were less than 24 weeks gestational age, with over half (61.9%) having some degree of functional impairment (Table 45).

**TABLE 45: Severity of functional impairment at 2–3 year follow-up by gestational age, 2009–2010 births**

	Gestational age (completed weeks)						
Functional Impairment	<24	24	25	26	27	≥28	Total
Number							
None	16	68	143	202	206	140	775
Mild	13	40	48	66	n.p.	n.p.	277
Moderate	7	13	18	20	26	13	97
Severe	6	8	12	17	n.p.	<5	55
Incomplete formal assessment <sup>(a)</sup>	5	12	20	32	43	31	143
Other formal assessment	2	1	2	6	13	12	36
No formal assessment	1	18	18	23	26	45	131
<b>Total<sup>(b)</sup></b>	<b>50</b>	<b>160</b>	<b>261</b>	<b>366</b>	<b>389</b>	<b>288</b>	<b>1,514</b>
Per cent							
None	38.1	52.7	64.7	66.2	67.1	70.0	64.4
Mild	31.0	31.0	21.7	21.6	n.p.	n.p.	23.0
Moderate	16.7	10.1	8.1	6.6	8.5	6.5	8.1
Severe	14.3	6.2	5.4	5.6	n.p.	n.p.	4.6
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*n.p.* Data not published to maintain confidentiality of small numbers.

*(a)* Infants with Bayley or Griffiths assessments but with missing data for one or more outcome.

*(b)* Excludes 63 infants assessed at <18 months corrected age and 10 infants with unknown corrected age at assessment. Also excludes 28 infants with a congenital anomaly known to impair development.

**Note:** Infants with incomplete, other or no formal developmental assessment are excluded from per cent calculations.

## Moderate to severe functional impairment

In addition to the above infants where functional impairment could be graded, infants assessed by Bayley or Griffiths but with missing data for one or more outcome, infants assessed by other formal developmental assessments, and infants without formal developmental assessments, were reviewed by a member of the Follow-up Subcommittee to determine if there was sufficient information to be classified as with or without moderate to severe functional impairment. In some cases, further information was requested from the NICU for clarification of outcomes.

A classification of ‘without moderate to severe impairment’ was assigned to infants where moderate to severe impairment could be reasonably excluded based on the following criteria:

- Infants who did not have moderate or severe functional impairment based on formal developmental assessment conducted at 18 months corrected age or older.
- Infants who did not have moderate or severe functional impairment based on assessment by a health care professional at 18 months corrected age or older. Where a clinical assessment of normal development or only mild developmental delay was not specifically recorded by the NICU, it was presumed likely for infants where speech and motor function were recorded as normal.

Functional impairment was classified as ‘not stated’ for infants with no moderate or severe impairment reported who did not meet the above criteria. Moderate or severe impairment may be present among these infants, but for the purposes of this Report they are excluded from the calculation of moderate to severe impairment, on the basis of lack of sufficient information.

Upon review, 242 infants with incomplete or other formal developmental assessments, or without formal developmental assessments had sufficient information to be classified as with or without moderate to severe functional impairment. Of these 242 infants, together with the 1,204 infants graded in Table 45, there were 186 (12.9%) infants with moderate to severe functional impairment. Moderate to severe functional impairment was seen to decrease with increasing gestational age (Table 46).

**TABLE 46: Infants with or without moderate to severe functional impairment at 2–3 year follow-up by gestational age, 2009–2010 births**

	Gestational age (completed weeks)						
Functional Impairment	<24	24	25	26	27	≥28	Total
Number							
Moderate–severe impairment	15	30	35	43	40	23	186
Without moderate–severe impairment	34	122	221	307	334	242	1,260
Not stated <sup>(a)</sup>	1	8	5	16	15	23	68
<b>Total<sup>(b)</sup></b>	<b>50</b>	<b>160</b>	<b>261</b>	<b>366</b>	<b>389</b>	<b>288</b>	<b>1,514</b>
Per cent							
Moderate–severe impairment	30.6	19.7	13.7	12.3	10.7	8.7	12.9
Without moderate–severe impairment	69.4	80.3	86.3	87.7	89.3	91.3	87.1
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

(a) Infants where moderate to severe functional impairment could not be excluded based on the available data.

(b) Excludes 63 infants assessed at <18 months corrected age and 10 infants with unknown corrected age at assessment. Also excludes 28 infants with a congenital anomaly known to impair development.

**Note:** Not stated data are excluded from per cent calculations.

## Growth – weight, height and head circumference

Growth charts published by the United States National Center for Health Statistics (Centers for Disease Control and Prevention) were used to determine weight, height and head circumference for age percentiles and weight for height percentiles.

Growth measurements were only included for the 1,541 infants assessed at 18 months corrected age or older. Of these infants with computable percentiles, 19.1% fell below the 3rd percentile for weight for age, 11.3% for height for age, 7.5% for head circumference for age and 13.5% for weight for height at 2–3 year follow-up. For weight and height for age and weight for height, the proportion of infants below the 3rd percentile was highest among those 28 weeks gestational age or older who weighed less than 1,000 grams at birth (Table 47 to Table 50). These infants were highly likely to have been intrauterine growth restricted (IUGR) and may continue to show a pattern of slower growth (Hediger et al. 1998).

A more consistent trend with birthweight over gestational age was seen for weight, height and head circumference for age percentiles and weight for height percentiles at 2–3 year follow-up, whereby the number of infants in the bottom 3rd percentile decreased with increasing birthweight.

**TABLE 47: Weight for age at 2–3 year follow-up by gestational age, 2009–2010 births**

	Gestational age (completed weeks)						
Weight for age centile	<24	24	25	26	27	≥28	Total
Number							
<3	11	33	37	47	46	93	267
3–9	n.p.	21	31	38	n.p.	31	164
10–90	28	83	170	231	234	140	886
>90	<5	9	6	19	n.p.	5	78
Not stated	2	16	20	35	43	30	146
<b>Total<sup>(a)</sup></b>	<b>52</b>	<b>162</b>	<b>264</b>	<b>370</b>	<b>394</b>	<b>299</b>	<b>1,541</b>
Per cent							
<3	22.0	22.6	15.2	14.0	13.1	34.6	19.1
3–9	n.p.	14.4	12.7	11.3	n.p.	11.5	11.8
10–90	56.0	56.8	69.7	69.0	66.7	52.0	63.5
>90	n.p.	6.2	2.5	5.7	n.p.	1.9	5.6
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

n.p. Data not published to maintain confidentiality of small numbers.

(a) Excludes 63 infants assessed at <18 months corrected age and 10 infants with unknown corrected age at assessment.

Note: Not stated data are excluded from per cent calculations.

**TABLE 48: Height for age at 2–3 year follow-up by gestational age, 2009–2010 births**

	Gestational age (completed weeks)						
Height for age centile	<24	24	25	26	27	≥28	Total
Number							
<3	6	15	23	33	22	51	150
3–9	<5	19	20	32	32	n.p.	149
10–90	35	96	178	232	229	157	927
>90	<5	12	14	24	48	<5	105
Not stated	4	20	29	49	63	45	210
<b>Total<sup>(a)</sup></b>	<b>52</b>	<b>162</b>	<b>264</b>	<b>370</b>	<b>394</b>	<b>299</b>	<b>1,541</b>
Per cent							
<3	12.5	10.6	9.8	10.3	6.6	20.1	11.3
3–9	n.p.	13.4	8.5	10.0	9.7	n.p.	11.2
10–90	72.9	67.6	75.7	72.3	69.2	61.8	69.6
>90	n.p.	8.5	6.0	7.5	14.5	n.p.	7.9
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

n.p. Data not published to maintain confidentiality of small numbers.

(a) Excludes 63 infants assessed at <18 months corrected age and 10 infants with unknown corrected age at assessment.

Note: Not stated data are excluded from per cent calculations.

TABLE 49: Head circumference for age at 2–3 year follow-up by gestational age, 2009–2010 births

Head circumference for age centile	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
Number							
<3	8	18	11	13	10	24	84
3–9	n.p.	20	25	26	n.p.	39	132
10–90	25	70	159	198	216	128	796
>90	<5	7	15	27	n.p.	7	106
Not stated	2	30	29	60	65	56	242
<b>Total<sup>(a)</sup></b>	<b>42</b>	<b>145</b>	<b>239</b>	<b>324</b>	<b>356</b>	<b>254</b>	<b>1,360</b>
Per cent							
<3	20.0	15.7	5.2	4.9	3.4	12.1	7.5
3–9	n.p.	17.4	11.9	9.8	n.p.	19.7	11.8
10–90	62.5	60.9	75.7	75.0	74.2	64.6	71.2
>90	n.p.	6.1	7.1	10.2	n.p.	3.5	9.5
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

n.p. Data not published to maintain confidentiality of small numbers.

(a) Head circumference percentiles calculated for infants ≤36 months corrected age only. Excludes 63 infants assessed at <18 months corrected age and 10 infants with unknown corrected age at assessment.

**Note:** Not stated data are excluded from per cent calculations.

TABLE 50: Weight for height at 2–3 year follow-up by gestational age, 2009–2010 births

	Gestational age (completed weeks)						
Weight for height centile	<24	24	25	26	27	≥28	Total
Number							
<3	<5	20	20	34	n.p.	71	180
3–9	n.p.	17	28	35	n.p.	32	154
10–90	30	91	173	224	227	143	888
>90	5	14	13	28	40	8	108
Not stated	4	20	30	49	63	45	211
<b>Total<sup>(a)</sup></b>	<b>52</b>	<b>162</b>	<b>264</b>	<b>370</b>	<b>394</b>	<b>299</b>	<b>1,541</b>
Per cent							
<3	n.p.	14.1	8.5	10.6	n.p.	28.0	13.5
3–9	n.p.	12.0	12.0	10.9	n.p.	12.6	11.6
10–90	62.5	64.1	73.9	69.8	68.6	56.3	66.8
>90	10.4	9.9	5.6	8.7	12.1	3.1	8.1
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

n.p. Data not published to maintain confidentiality of small numbers.

(a) Excludes 63 infants assessed at <18 months corrected age and 10 infants with unknown corrected age at assessment.

**Note:** Not stated data are excluded from per cent calculations.



## Respiratory and gastrointestinal tract

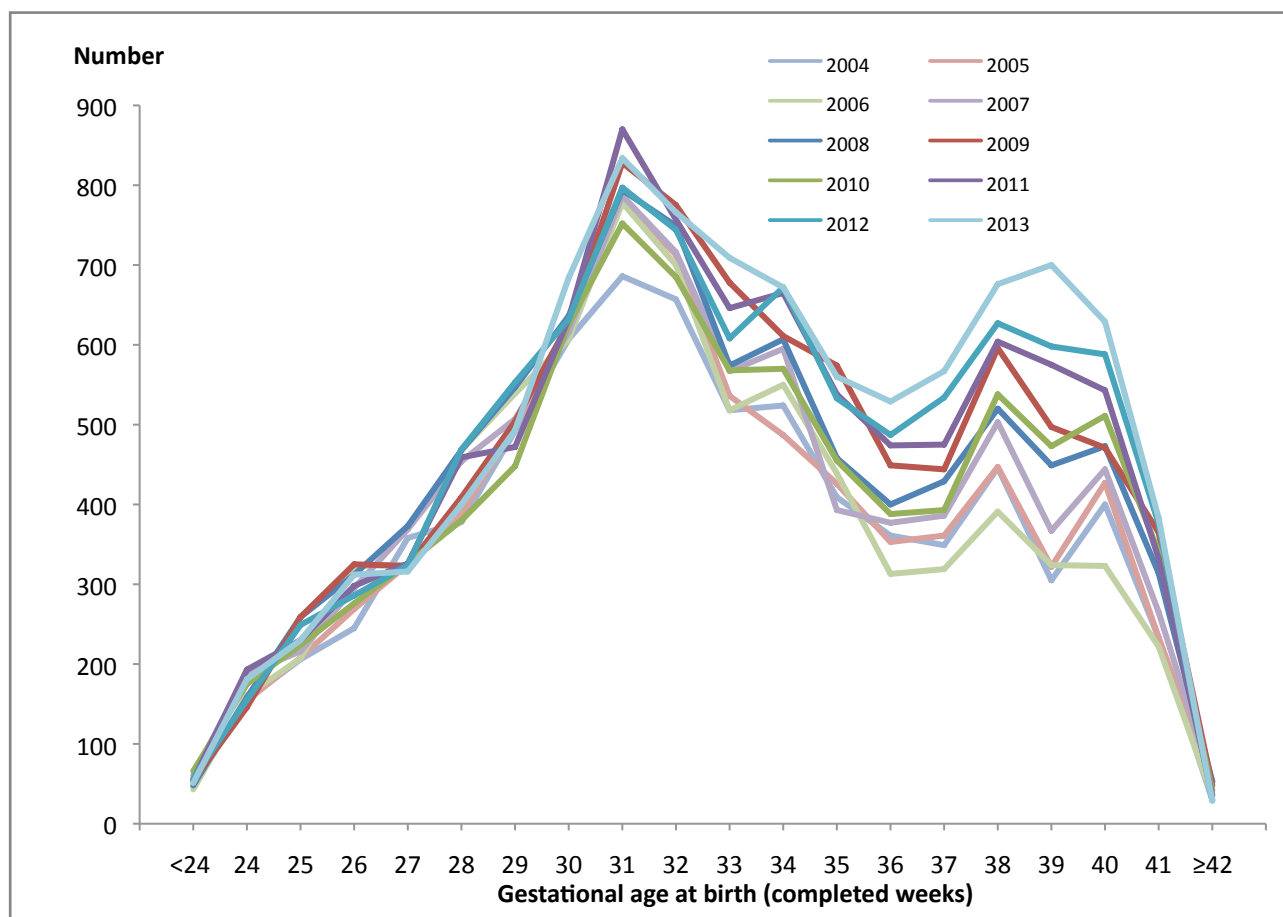
Respiratory and gastrointestinal tract (GIT) complications such as respiratory distress syndrome and necrotising enterocolitis commonly affect extremely premature babies and can lead to ongoing disease. Of the 1,494 infants with data available on the use of respiratory support, seven (0.5%) were supported by tracheostomy and 17 (1.1%) were supported by supplemental oxygen at the time of 2–3 year follow-up. Over one-third of infants receiving respiratory support were less than 25 weeks gestational age.

While no infants were reported as receiving parenteral nutrition for nutritional support, intragastric tube feeding via a percutaneous endoscopic gastronomy tube or nasogastric tube was reported for 33 (2.2%) of the 1,501 infants with nutritional support data at the time of 2–3 year follow-up. It should be noted that two of the 33 infants receiving nutritional support at follow-up were assessed at younger than 18 months corrected age and therefore support may have ceased by two years corrected age. Nutritional support was most prevalent among infants less than 25 weeks gestational age (4.7%) and infants 28 weeks gestational age or older who weighed less than 1,000 grams at birth (3.8%).

# APPENDICES

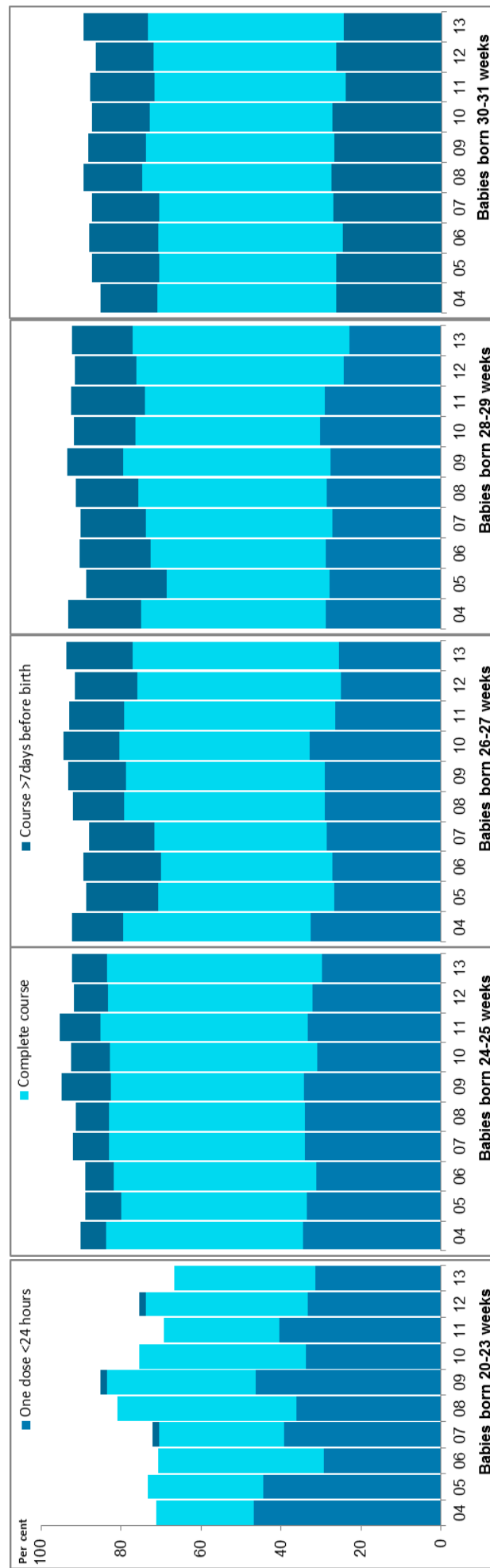
## Appendix 1: Trends

FIGURE 11: Trends in gestational age at birth of level III registrants, 2004–2013



*Note:* Data on the ANZNN registrants from two level III NICUs were not included in 2010.

**FIGURE 12: Trends in the use of corticosteroids for mothers of babies less than 32 weeks gestation, 2004–2013**



**Note:** Corticosteroid treatment to enhance fetal lung maturation is considered 'complete' when two doses are given, the first dose more than 24 hours and less than 8 days before the baby's birth. Stacked bars represent annual cumulative percentages.

FIGURE 13: Trends in multiple births of level III registrants by gestational age group, 2004–2013

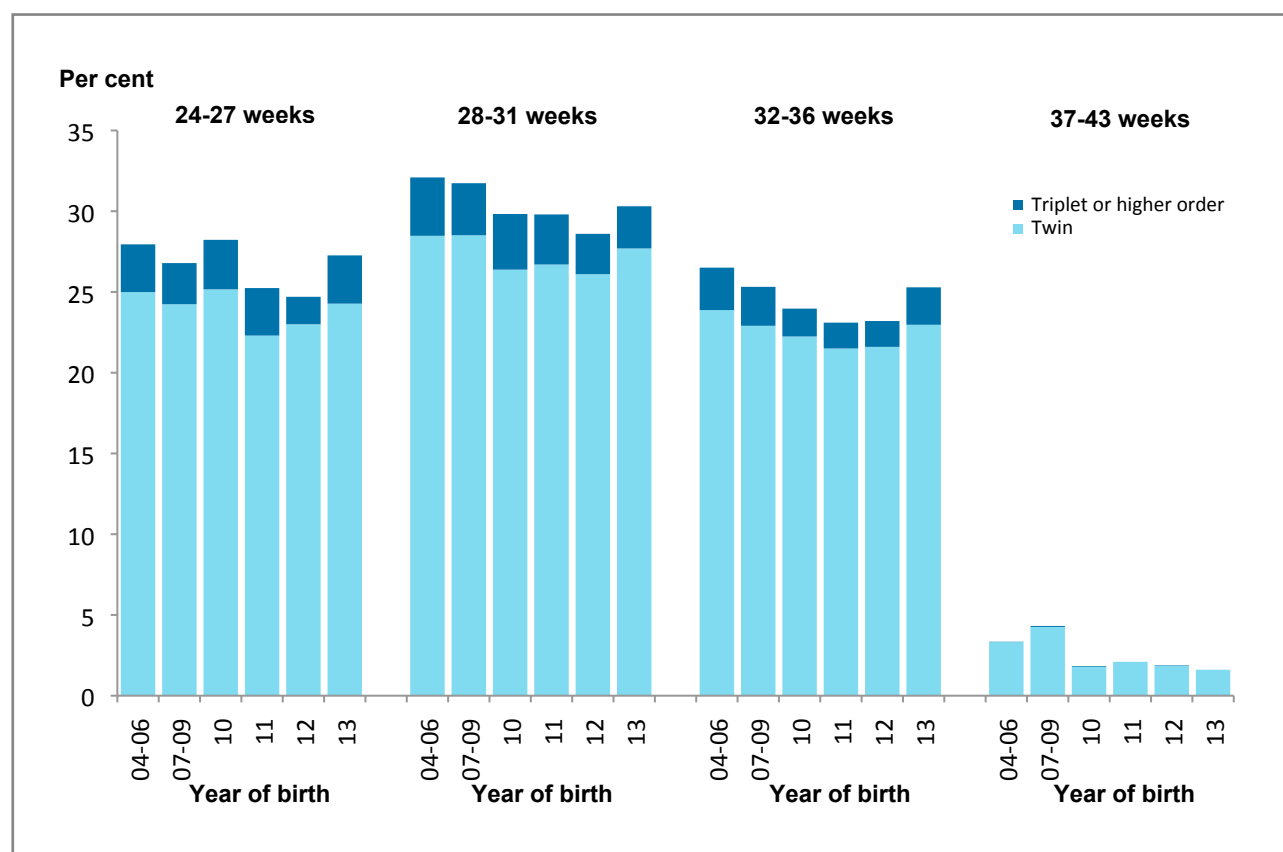
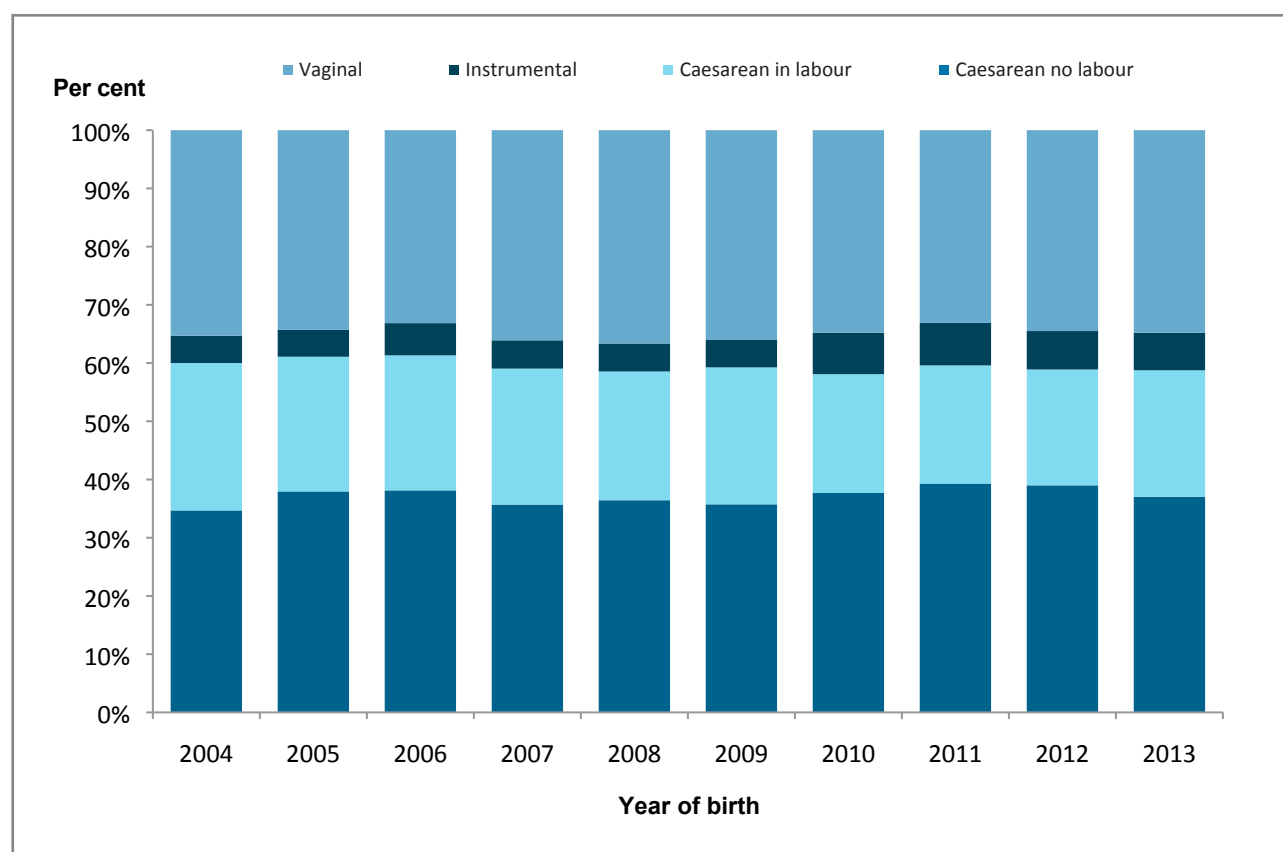
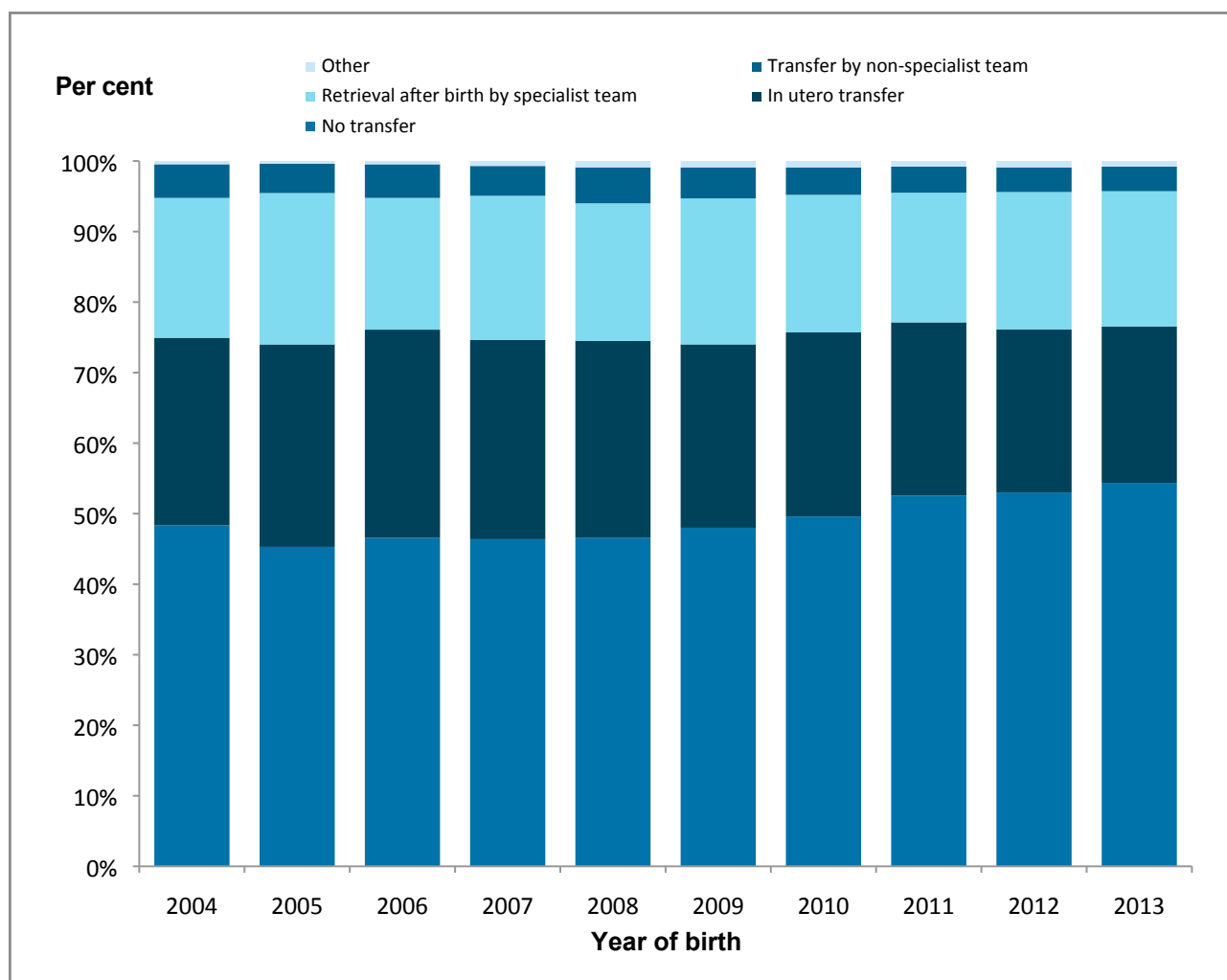


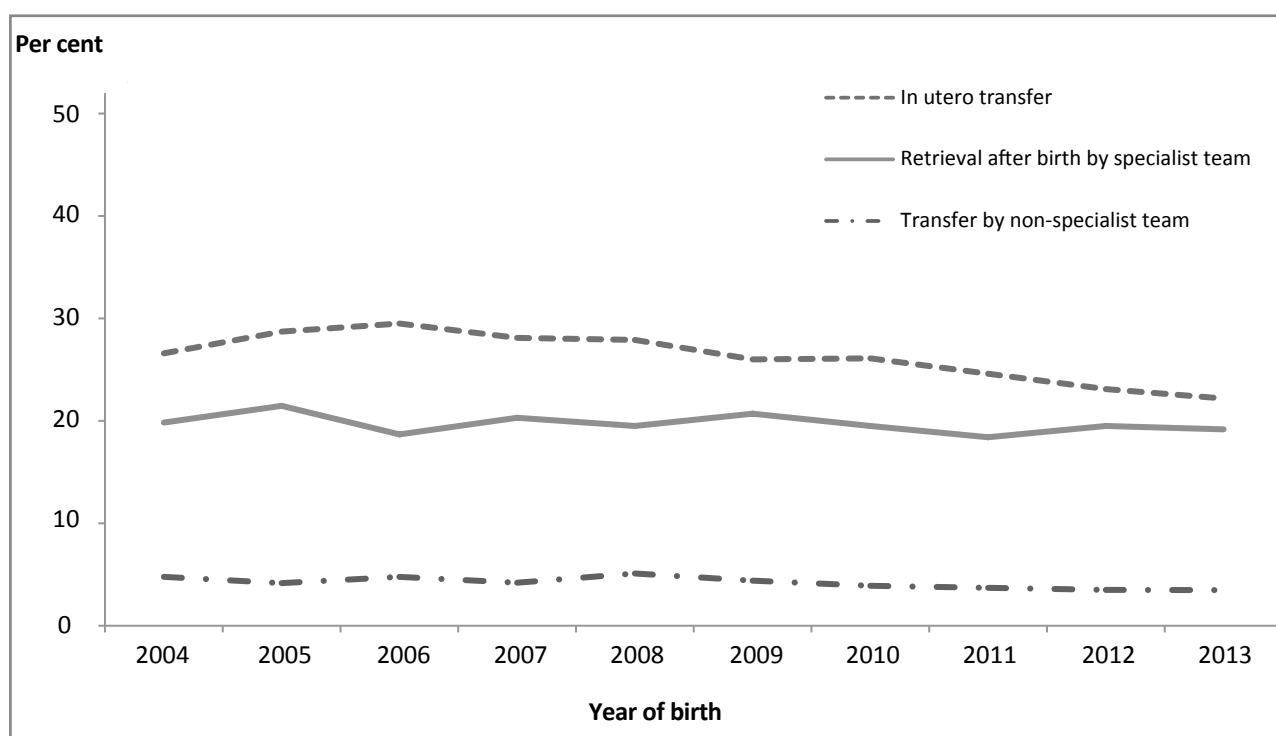
FIGURE 14: Trends in method of birth for level III registrants by year of birth, 2004–2013



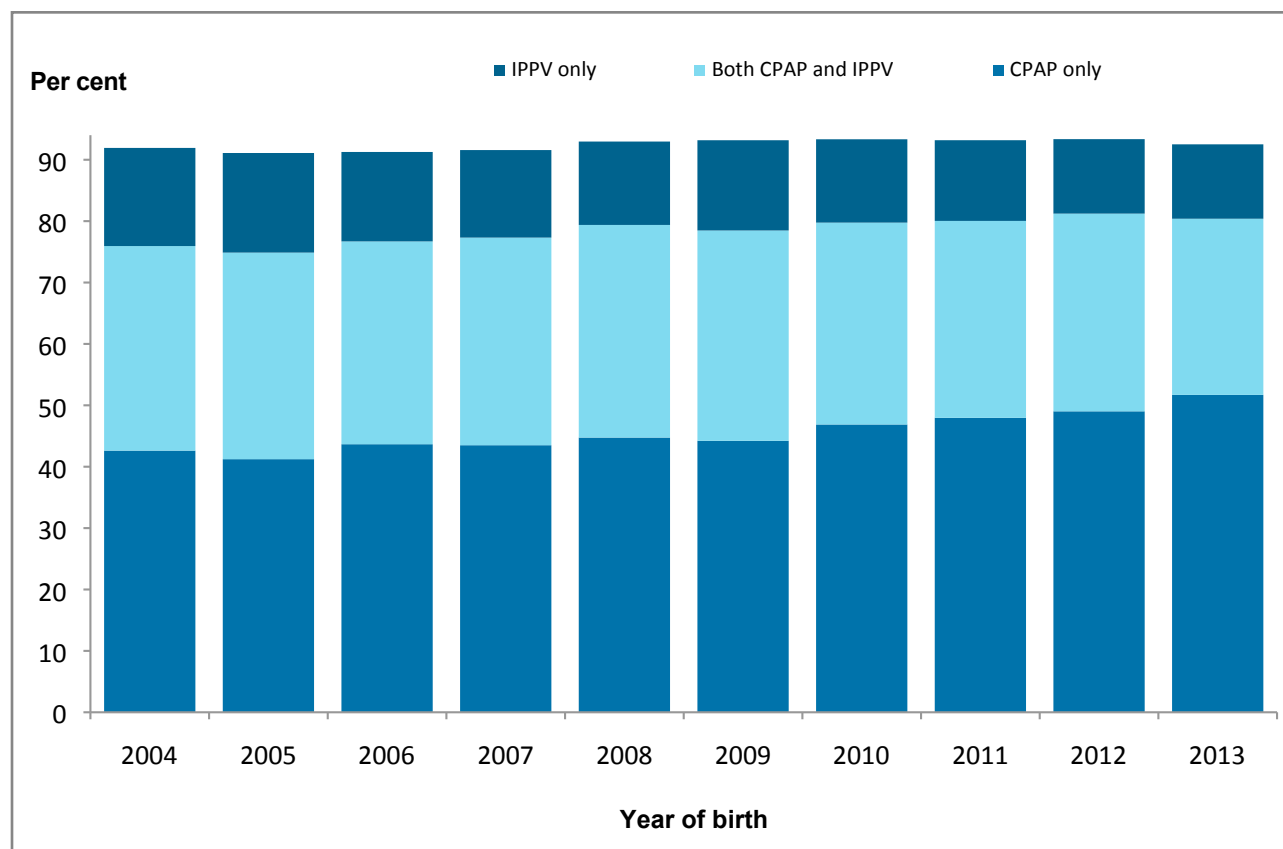
**FIGURE 15: Trends in referral source to level III NICU by year of birth, 2004–2013**



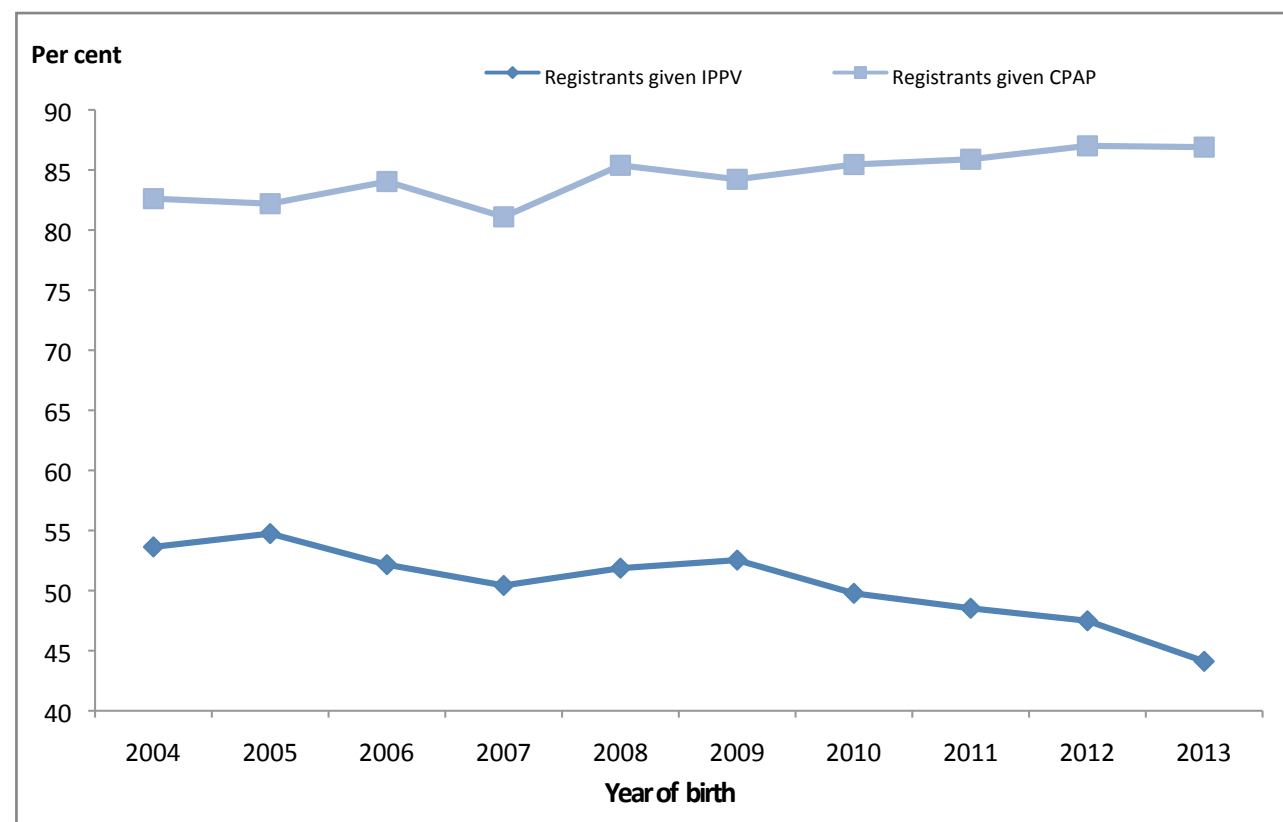
**FIGURE 16: Trends in mode of transport to level III NICU, 2004-2013**



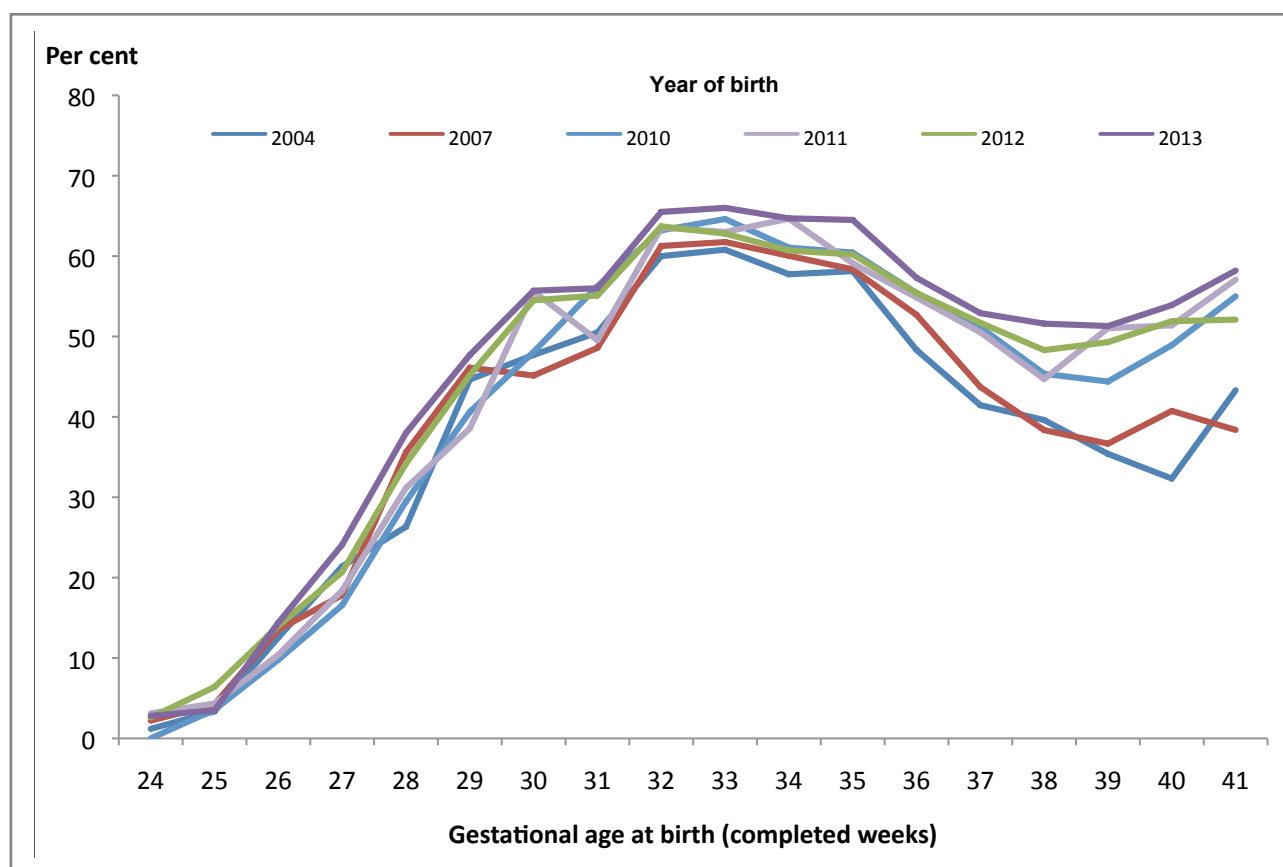
**FIGURE 17: Trends in mode of assisted ventilation for level III registrants, 2004–2013**



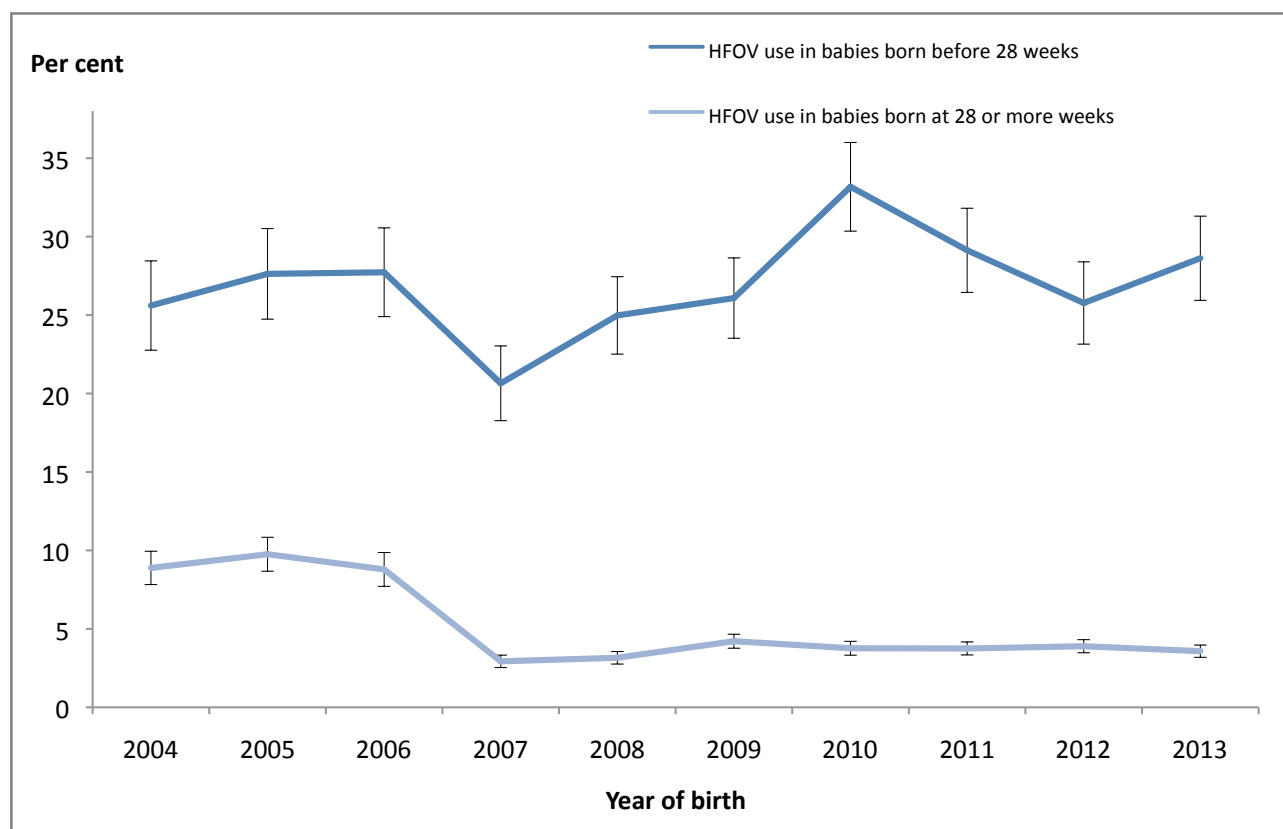
**FIGURE 18: Trends in provision of intermittent positive pressure ventilation and continuous positive pressure ventilation by year of birth for level III registrants ventilated, 2004–2013**



**FIGURE 19: Trends in the use of CPAP as the only form of ventilation by gestational age for level III registrants, 2004, 2007, 2010–2013**

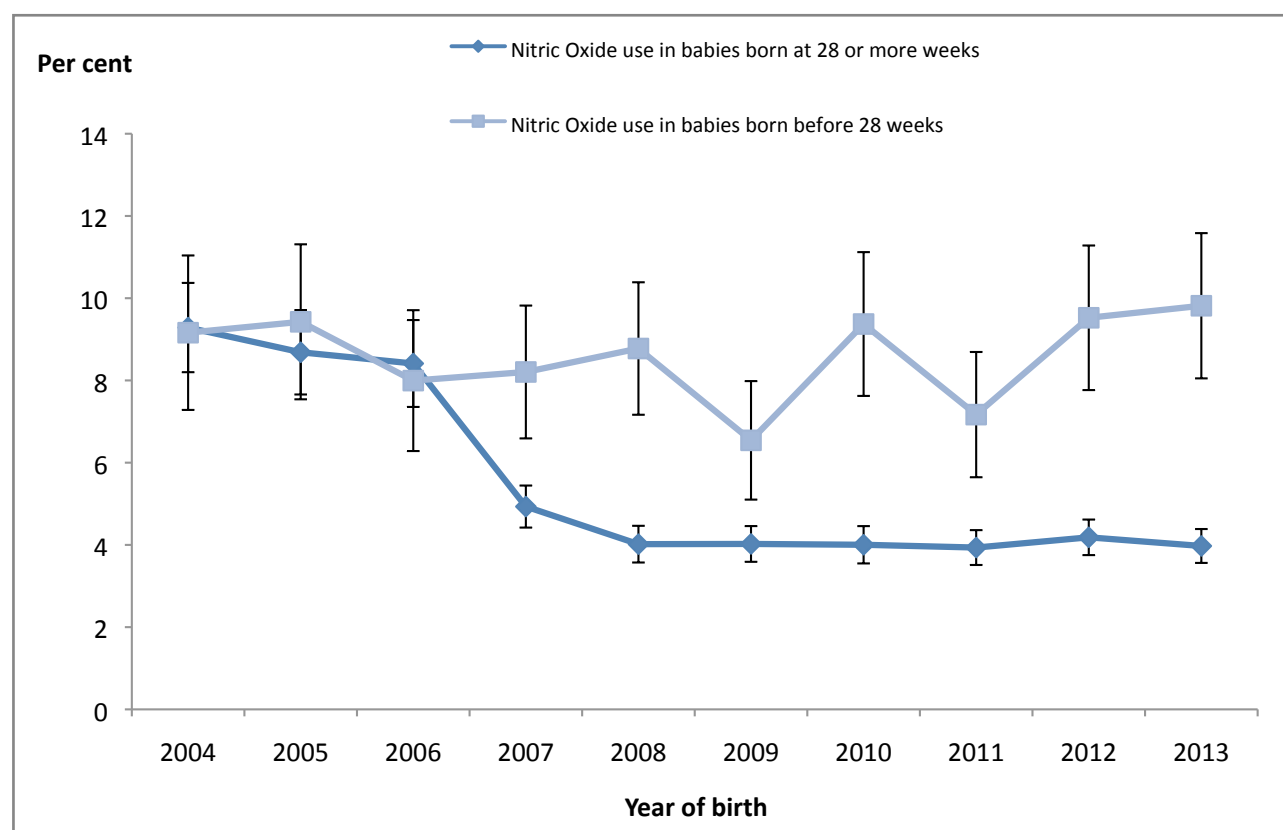


**FIGURE 20: Trends in provision of high frequency oscillatory ventilation (with 95% CI) for level III registrants born before 28 weeks and at 28 or more weeks gestation, 2004–2013**



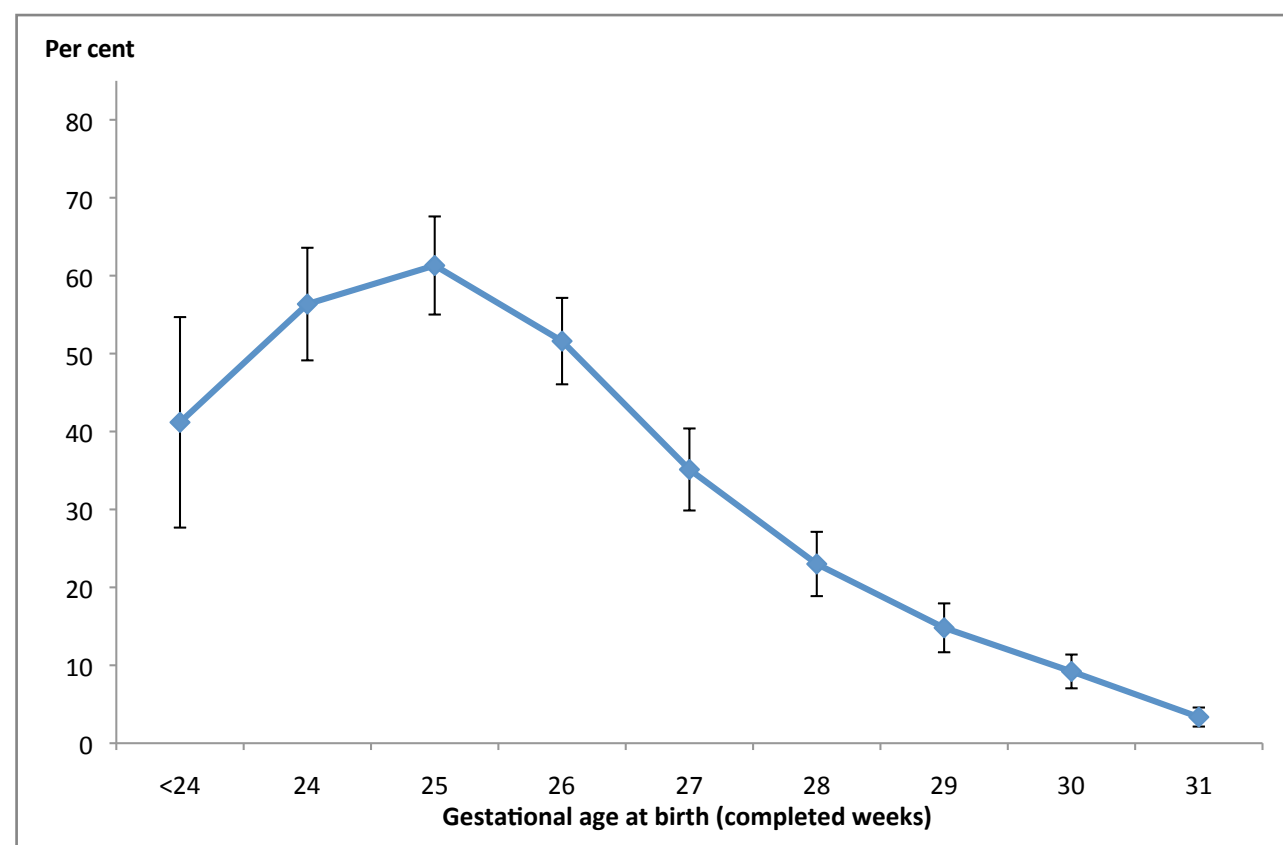
*Note: The results are given as the percentage of babies given IPPV.*

**FIGURE 21: Trends in nitric oxide (with 95% CI) provision for level III registrants born before 28 weeks and 28 or more weeks gestation, 2004–2013**



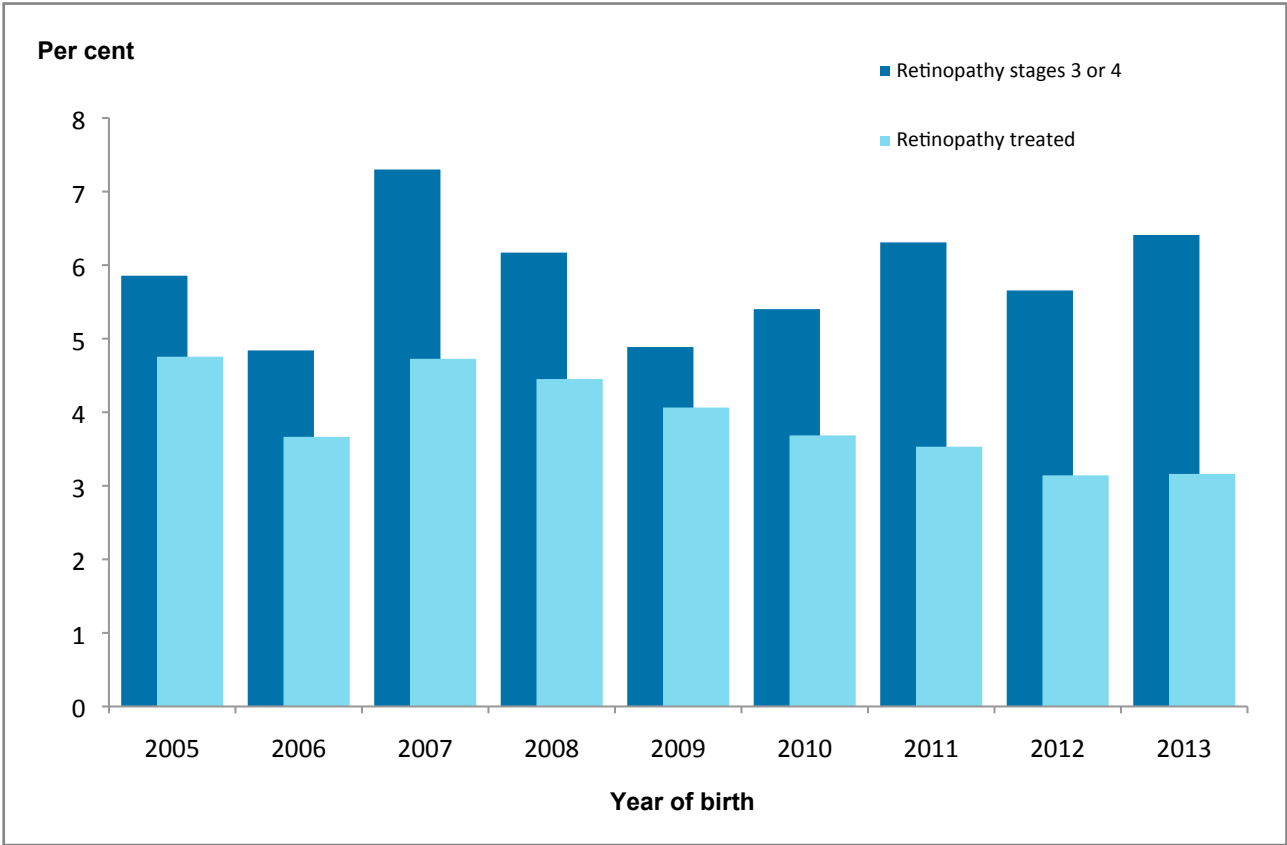
*Note: Results are given as the percentage of babies given IPPV.*

**FIGURE 22: Incidence of chronic lung disease (with 95% CI) for level III registrants by gestational age, 2013**





**FIGURE 23: Stage 3 or 4 retinopathy of prematurity and treated retinopathy among babies born before 31 weeks gestation and/or birthweight of less than 1,250 grams who survived to 36 weeks corrected age for level III registrants, 2005–2013**



**FIGURE 24: Trends in grade 3 or 4 intraventricular haemorrhage (with 95% CI) in babies born at less than 32 weeks gestation who survived to day 3 for level III registrants, 2004–2013**

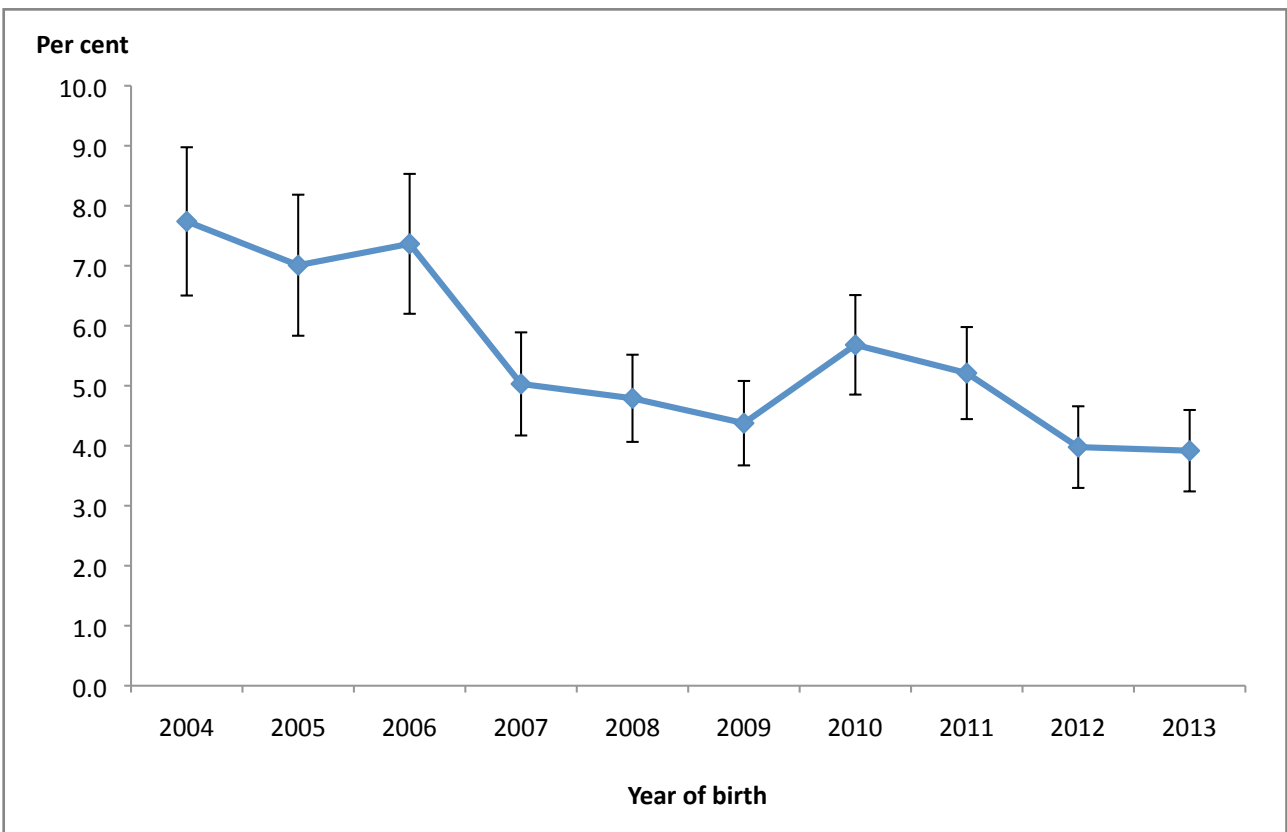


FIGURE 25: Incidence of early sepsis for level III registrants by gestational age group, 2009–2013

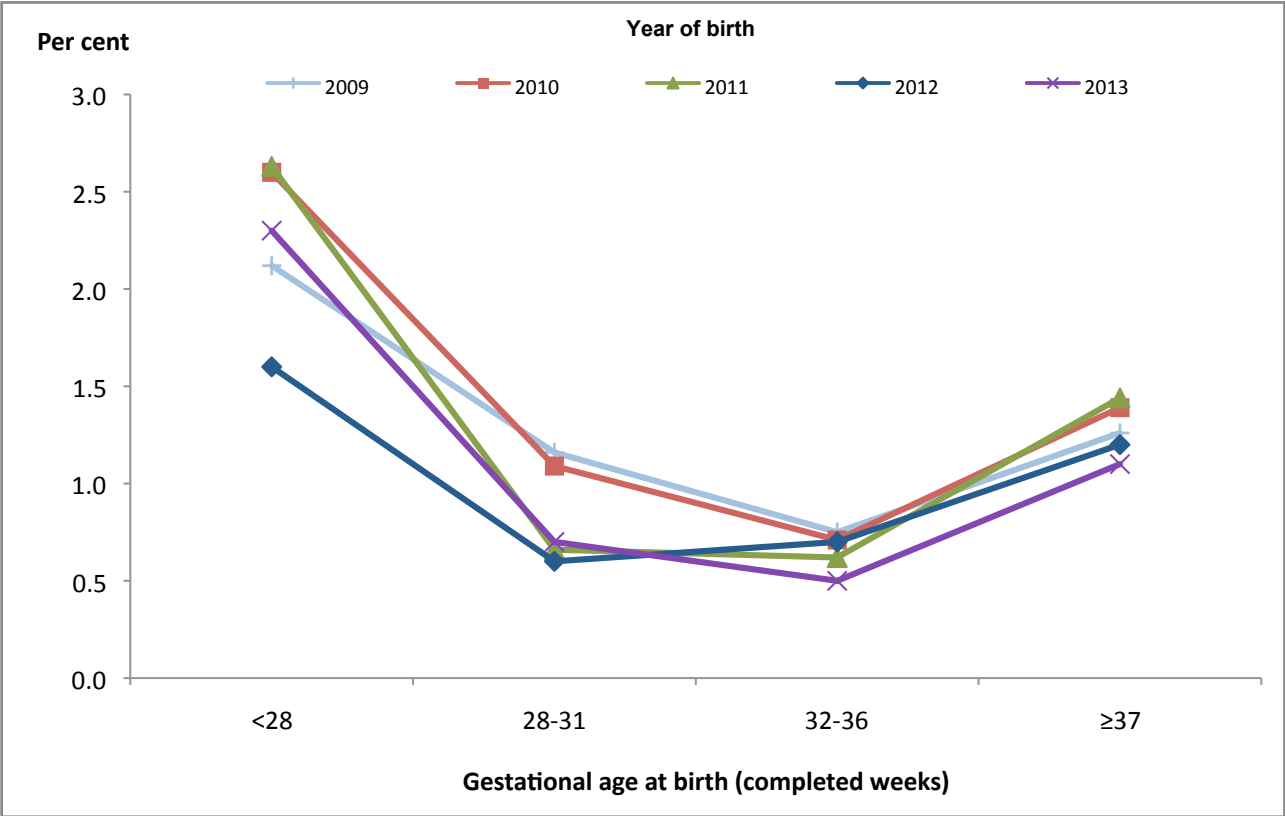
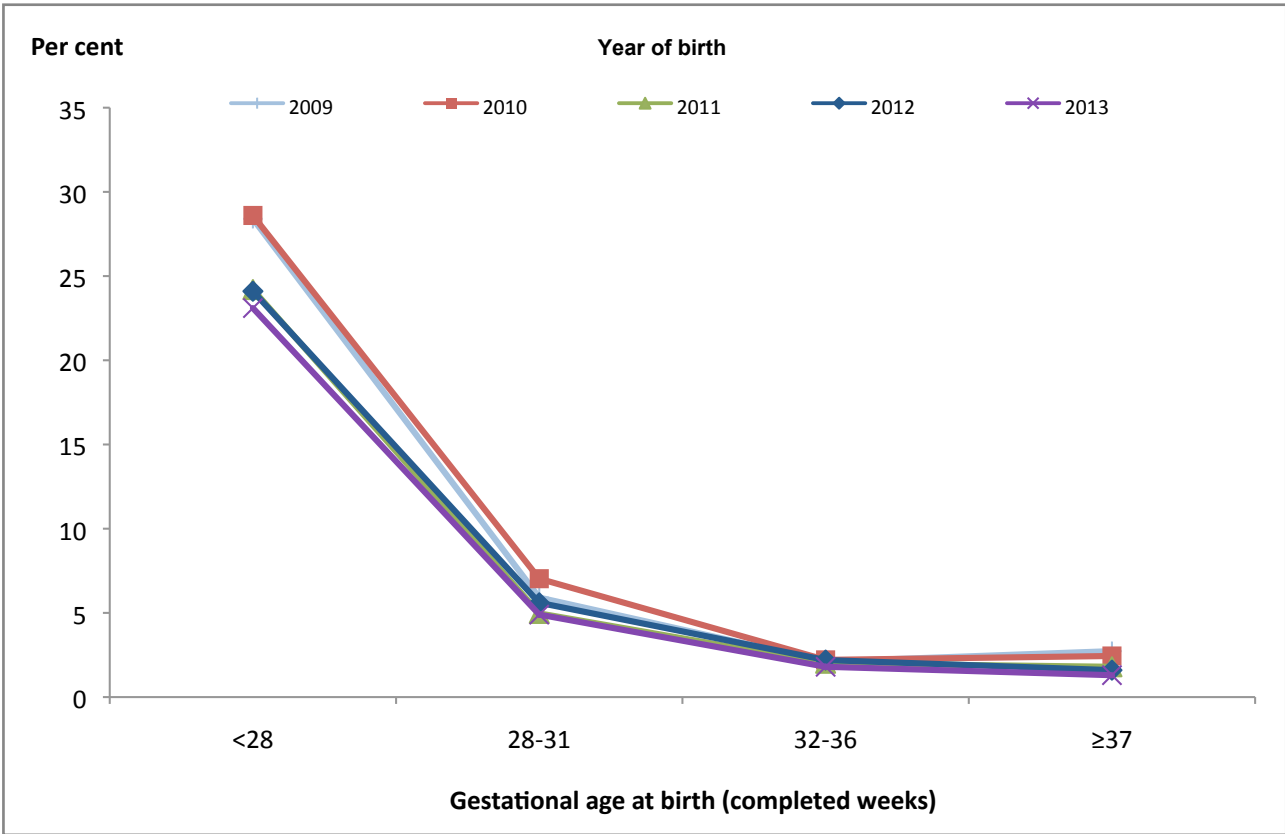


FIGURE 26: Incidence of late sepsis for level III registrants by gestational age group, 2009–2013



## Appendix 2: Data tables by birthweight

TABLE 51: Antenatal corticosteroid use for level III registrants by birthweight group, 2013

Antenatal corticosteroids	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
	Number											
None	0	36	53	87	114	285	533	808	944	697	317	3,874
Incomplete course	5	87	153	191	228	396	239	66	22	n.p.	<5	1,399
Course completed	15	223	374	405	520	707	339	129	38	19	8	2,777
Completed > 7 days	0	45	96	119	170	250	143	67	40	n.p.	n.p.	949
Not stated	0	5	7	11	18	37	68	137	218	151	70	722
<b>Total</b>	<b>20</b>	<b>396</b>	<b>683</b>	<b>813</b>	<b>1,050</b>	<b>1,675</b>	<b>1,322</b>	<b>1,207</b>	<b>1,262</b>	<b>885</b>	<b>408</b>	<b>9,721</b>
Per cent												
None	0.0	9.2	7.8	10.8	11.0	17.4	42.5	75.5	90.4	95.0	93.8	43.0
Incomplete course	25.0	22.3	22.6	23.8	22.1	24.2	19.1	6.2	2.1	n.p.	n.p.	15.5
Course completed	75.0	57.0	55.3	50.5	50.4	43.2	27.0	12.1	3.6	2.6	2.4	30.9
Completed > 7 days	0.0	11.5	14.2	14.8	16.5	15.3	11.4	6.3	3.8	n.p.	n.p.	10.5
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

n.p. Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

TABLE 52: Plurality of level III registrants by birthweight group, 2013

Plurality	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
	Number											
Singleton	15	305	485	551	700	1,135	1,015	n.p.	1,237	n.p.	408	7,829
Twins	<5	83	173	242	310	477	292	109	25	<5	0	1,718
Triplets and higher orders	<5	8	25	19	39	61	15	<5	0	0	0	169
Not stated	0	0	0	1	1	2	0	1	0	0	0	5
<b>Total</b>	<b>20</b>	<b>396</b>	<b>683</b>	<b>812</b>	<b>1,049</b>	<b>1,673</b>	<b>1,322</b>	<b>1,206</b>	<b>1,262</b>	<b>885</b>	<b>408</b>	<b>9,721</b>
Per cent												
Singleton	75.0	77.0	71.0	67.9	66.8	67.9	76.8	n.p.	98.0	n.p.	100.0	80.6
Twins	n.p.	21.0	25.3	29.8	29.6	28.5	22.1	9.0	2.0	n.p.	0.0	17.7
Triplets and higher orders	n.p.	2.0	3.7	2.3	3.7	3.7	1.1	n.p.	0.0	0.0	0.0	1.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.1</b>	<b>100.1</b>	<b>100.1</b>	<b>100.0</b>	<b>100.1</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

n.p. Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

**TABLE 53: Method of birth for level III registrants by birthweight group, 2013**

Method of birth	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
Number												
Vaginal	0	162	201	234	293	537	445	482	492	350	166	3,362
Vaginal instrumental birth	0	<5	10	10	24	77	82	112	157	115	n.p.	623
Caesarean in labour	<5	n.p.	151	181	217	372	283	239	273	216	110	2,102
Caesarean no labour	n.p.	171	318	385	513	684	507	366	326	194	n.p.	3,578
Not stated	0	1	3	3	3	5	5	8	14	10	4	56
Total	20	396	683	813	1,050	1,675	1,322	1,207	1,262	885	408	9,721
Per cent												
Vaginal	0.0	41.0	29.6	28.9	28.0	32.2	33.8	40.2	39.4	40.0	41.1	34.8
Vaginal instrumental birth	0.0	n.p.	1.5	1.2	2.3	4.6	6.2	9.3	12.6	13.1	n.p.	6.4
Caesarean in labour	n.p.	n.p.	22.2	22.3	20.7	22.3	21.5	19.9	21.9	24.7	27.2	21.7
Caesarean no labour	n.p.	43.3	46.8	47.5	49.0	41.0	38.5	30.5	26.1	22.2	n.p.	37.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

n.p. Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

**TABLE 54: Level of hospital of birth for level III registrants by birthweight group, 2013**

Level of birth hospital	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
Number												
Tertiary	20	355	618	705	933	1,430	1009	854	868	597	283	7,672
Non-tertiary	0	41	60	98	110	235	307	345	385	n.p.	n.p.	1,979
Not born in a hospital <sup>(a)</sup>	0	0	5	9	7	8	6	7	8	n.p.	<5	64
Not stated	0	0	0	1	0	2	0	1	1	0	1	6
<b>Total</b>	<b>20</b>	<b>396</b>	<b>683</b>	<b>813</b>	<b>1,050</b>	<b>1,675</b>	<b>1,322</b>	<b>1,207</b>	<b>1,262</b>	<b>885</b>	<b>408</b>	<b>9,721</b>
Per cent												
Tertiary	100.0	89.6	90.5	86.8	88.9	85.5	76.3	70.8	68.8	67.5	69.5	79.0
Non-tertiary	0.0	10.4	8.8	12.1	10.5	14.0	23.2	28.6	30.5	n.p.	n.p.	20.4
Not born in a hospital <sup>(a)</sup>	0.0	0.0	0.7	1.1	0.7	0.5	0.5	0.6	0.6	n.p.	n.p.	0.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

n.p. Data not published to maintain confidentiality of small numbers.

(a) These babies were either born before arrival to hospital or born at home.

**Note:** Not stated data are excluded from per cent calculations.

Table 55: Mode of transport for level III registrants to level III unit after birth by birthweight group, 2013

Mode of transport	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
Number												
Not transported	20	348	613	693	923	1,398	972	803	803	571	275	7,419
Specialist retrieval team	0	34	50	92	105	218	300	334	367	250	108	1,858
Non-specialist team	0	8	11	19	14	38	40	51	73	60	23	337
Other	0	6	9	8	6	16	8	10	11	3	1	78
Not stated	0	0	0	1	2	5	2	9	8	1	1	29
Total	20	396	683	813	1,050	1,675	1,322	1,207	1,262	885	408	9,721
Per cent												
Not transported	100.0	87.9	89.8	85.3	88.1	83.7	73.6	67.0	64.0	64.6	67.6	76.5
Specialist retrieval team	0.0	8.6	7.3	11.3	10.0	13.1	22.7	27.9	29.3	28.3	26.5	19.2
Non-specialist team	0.0	2.0	1.6	2.3	1.3	2.3	3.0	4.3	5.8	6.8	5.7	3.5
Other	0.0	1.5	1.3	1.0	0.6	1.0	0.6	0.8	0.9	0.3	0.2	0.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Note: Not stated data are excluded from per cent calculations.

Table 56: Exogenous surfactant use by level III registrants by birthweight group, 2013

	Birthweight group (grams)											
Exogenous surfactant	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	Total
Number												
None	<5	31	n.p.	375	719	1,216	1046	1021	n.p.	805	378	6,867
Curosurf	18	308	432	341	240	348	208	135	95	58	20	2,203
Survanta	<5	51	101	94	84	n.p.	63	47	31	17	9	607
Curosurf and Survanta	0	<5	<5	<5	<5	<5	<5	<5	<5	0	0	17
Other or unknown surfactant	0	n.p.	0	n.p.	n.p.	0	n.p.	n.p.	0	2	1	12
Not stated	0	1	1	1	1	1	2	1	4	3	0	15
Total	20	396	683	813	1,050	1,675	1,322	1,207	1,262	885	408	9,721
Per cent												
None	n.p.	7.8	n.p.	46.2	68.5	72.6	79.2	84.7	n.p.	91.3	92.6	70.8
Curosurf	90.0	78.0	63.3	42.0	22.9	20.8	15.8	11.2	7.6	6.6	4.9	22.7
Survanta	n.p.	12.9	14.8	11.6	8.0	n.p.	4.8	3.9	2.5	1.9	2.2	6.3
Curosurf and Survanta	0.0	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	0.0	0.0	0.2
Other or unknown surfactant	0.0	n.p.	0.0	n.p.	n.p.	0.0	n.p.	n.p.	0.0	0.2	0.2	0.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

n.p. Data not published to maintain confidentiality of small numbers.

Note: Not stated data are excluded from per cent calculations.

**Table 57: Assisted ventilation for level III registrants by birthweight group, 2013**

Ventilation type	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
Number												
CPAP given	14	320	626	716	791	1,426	1,118	935	893	655	321	7,815
Invasive ventilation	20	371	516	409	281	507	438	459	529	324	122	3,976
▪ IPPV given	20	370	514	409	281	505	438	457	527	324	122	3,967
▪ HFOV given	12	165	130	57	22	47	35	40	62	40	11	621
NO given	<5	62	43	26	17	42	22	49	91	72	n.p.	450
<b>Total in each birthweight group</b>	<b>20</b>	<b>396</b>	<b>683</b>	<b>813</b>	<b>1,050</b>	<b>1,675</b>	<b>1,322</b>	<b>1,207</b>	<b>1,262</b>	<b>885</b>	<b>408</b>	<b>9,721</b>
Per cent												
CPAP given	70.0	80.8	91.7	88.1	75.3	85.1	84.6	77.5	70.8	74.0	78.7	80.4
IPPV given	100.0	93.4	75.3	50.3	26.8	30.1	33.1	37.9	41.8	36.6	29.9	40.8
Per cent of babies given invasive ventilation												
HFOV given	60.0	44.5	25.2	13.9	7.8	9.3	8.0	8.7	11.7	12.3	9.0	15.6
NO given	n.p.	16.7	8.3	6.4	6.0	8.3	5.0	10.7	17.2	22.2	n.p.	11.3

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Groups are not mutually exclusive.

Percentage of babies given HFOV and NO are given as a percentage of babies given ventilation via endotracheal tube (IPPV and/or HFOV).

**Table 58: Medians and interquartile ranges of assisted ventilation for level III registrants by birthweight group, 2013**

Median & interquartile range	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
IPPV (hours)												
Median	375	318	95	26.5	23	23.5	33	46	52	54	45	45
IQR	139–819	73–740	20–314.5	11–102	10–57	10–56	15–85	21–109	21–112	22–108	21–89	17–132
CPAP (hours)												
Median	1,432.5	976.5	707	228	74	39	25	21	19	17	18	40
IQR	277–1,753	519–1,336	297–1,038	68–675	26–179	17–92	12–58	9–50	9–45	8–38	9–35	14–128

**Note:** IQR = Interquartile range

**TABLE 59: Chronic lung disease for level III registrants by birthweight group, 2013**

Chronic lung disease (CLD)	Birthweight group (grams)							Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	≥2000	
Number								
No CLD	11	151	391	657	996	1,641	5,082	8,929
CLD	9	245	292	156	54	n.p.	<5	792
▪ CLD and survived	9	234	283	150	54	n.p.	<5	763
▪ CLD and died	0	11	9	6	0	<5	<5	29
<b>Total</b>	<b>20</b>	<b>396</b>	<b>683</b>	<b>813</b>	<b>1,050</b>	<b>1,675</b>	<b>5,084</b>	<b>9,721</b>
Per cent								
No CLD	55.0	38.1	57.2	80.8	94.9	98.0	100.0	91.9
CLD	45.0	61.9	42.8	19.2	5.1	n.p.	n.p.	8.1
▪ CLD and survived	100.0	95.5	96.9	96.2	100.0	n.p.	n.p.	96.3
▪ CLD and died	0.0	4.5	3.1	3.8	0.0	n.p.	n.p.	3.7

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Survival is assessed to discharge from hospital.

**Table 60: Respiratory support (airway support or supplemental oxygen therapy) for level III registrants who survived to day 28 by birthweight group, 2013**

Respiratory support (airway support or oxygen)	Birthweight group (grams)											Total
	<500	500- 749	750- 999	1000- 1249	1250- 1499	1500- 1999	2000- 2499	2500- 2999	3000- 3499	3500- 3999	≥4000	
Number												
No respiratory support on day 28	0	5	102	366	843	1,498	1,242	1,115	1,170	821	392	7,554
Respiratory support on day 28	13	314	538	426	195	140	50	60	47	36	9	1,828
▪ survived to discharge home	n.p.	288	518	411	195	126	40	49	n.p.	31	n.p	1,721
▪ died before discharge	<5	26	20	15	0	14	10	11	<5	5	<5	107
Not stated	0	0	0	0	0	1	1	0	1	0	0	3
<b>Total</b>	<b>13</b>	<b>319</b>	<b>640</b>	<b>792</b>	<b>1,038</b>	<b>1,639</b>	<b>1,293</b>	<b>1,175</b>	<b>1,218</b>	<b>857</b>	<b>401</b>	<b>9,385</b>
Number												
Respiratory support on day 28 and given home oxygen	<5	97	100	42	11	10	<5	8	13	9	<5	299
Per cent												
No respiratory support on day 28	0.0	1.6	15.9	46.2	81.2	91.5	96.1	94.9	96.1	95.8	97.8	80.5
Respiratory support on day 28	100.0	98.4	84.1	53.8	18.8	8.5	3.9	5.1	3.9	4.2	2.2	19.5
▪ survived to discharge home	n.p.	91.7	96.3	96.5	100.0	90.0	80.0	81.7	n.p.	86.1	n.p.	94.1
▪ died before discharge	n.p.	8.3	3.7	3.5	0.0	10.0	20.0	18.3	n.p.	13.9	n.p.	5.9
Per cent												
Respiratory support on day 28 and given home oxygen <sup>(a)</sup>	n.p.	33.7	19.3	10.2	5.6	7.9	n.p.	16.3	n.p.	29.0	n.p.	17.4

*n.p.* Data not published to maintain confidentiality of small numbers.

*(a)* Denominator is babies who received respiratory support on day 28 and survived to discharge to home.

**Note:** Not stated data are excluded from per cent calculations.

**Table 61: Transfer after registration of level III registrants by level of destination hospital by birthweight group, 2013**

Transfer status	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
	Number											
Not transferred	14	220	342	337	379	701	681	783	907	661	297	5,322
Level III hospital	<5	31	52	52	49	60	47	32	31	15	n.p.	388
Level II hospital	<5	115	250	399	605	889	558	330	241	168	n.p.	3,637
Children's hospital	<5	30	39	25	17	25	35	62	83	41	n.p.	373
Not stated	0	0	0	0	0	0	1	0	0	0	0	1
Total	20	396	683	813	1,050	1,675	1,322	1,207	1,262	885	408	9,721
Per cent												
Not transferred	70.0	55.6	50.1	41.5	36.1	41.9	51.6	64.9	71.9	74.7	72.8	54.8
Level III hospital	n.p.	7.8	7.6	6.4	4.7	3.6	3.6	2.7	2.5	1.7	n.p.	4.0
Level II hospital	n.p.	29.0	36.6	49.1	57.6	53.1	42.2	27.3	19.1	19.0	n.p.	37.4
Children's hospital	n.p.	7.6	5.7	3.1	1.6	1.5	2.6	5.1	6.6	4.6	n.p.	3.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Not stated data are excluded from per cent calculations.

**Table 62: Retinopathy of prematurity for level III registrants by birthweight group, 2013**

Retinopathy of prematurity (ROP)	Birthweight group (grams)						Total
	<500	500-749	750-999	1000-1249	1250-1499	≥1500	
Number							
No ROP	<5	105	n.p.	522	546	670	2,163
Stage 1 ROP	0	43	111	83	n.p.	21	n.p.
Stage 2 ROP	<5	88	132	78	29	n.p.	352
Stage 3 ROP	5	67	60	13	<5	<5	148
Stage 4 ROP	0	0	<5	0	0	0	<5
Not examined	9	86	56	110	380	5,127	5,768
Not stated	0	7	5	7	55	919	993
Total	20	396	683	813	1,050	6,759	9,721
Per cent							
No ROP	n.p.	34.7	n.p.	75.0	88.8	94.0	73.1
Stage 1 ROP	0.0	14.2	17.8	11.9	n.p.	2.9	n.p.
Stage 2 ROP	n.p.	29.0	21.2	11.2	4.7	n.p.	11.9
Stage 3 ROP	45.5	22.1	9.6	1.9	n.p.	n.p.	5.0
Stage 4 ROP	0.0	0.0	n.p.	0.0	0.0	0.0	n.p.
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

*n.p.* Data not published to maintain confidentiality of small numbers.

**Note:** Weight criterion less than 1,250 grams for ANZNN but 1,500 grams for some individual units.

Not stated and not examined data are excluded from per cent calculations.



**Table 63: Intraventricular haemorrhage for level III registrants survived to day 3 by birthweight group, 2013<sup>(a)</sup>**

Intraventricular haemorrhage	Birthweight group (grams)						Total
	<500	500-749	750-999	1000-1249	1250-1499	≥1500	
Number							
None	14	236	496	604	744	2,084	4,178
Grade 1	0	51	74	81	96	165	467
Grade 2	<5	35	40	44	n.p.	39	177
Grade 3	<5	10	12	10	n.p.	17	55
Grade 4	0	32	20	13	12	12	89
Not examined	1	3	20	52	169	4,379	4,624
<b>Total</b>	<b>17</b>	<b>367</b>	<b>662</b>	<b>804</b>	<b>1,044</b>	<b>6,696</b>	<b>9,590</b>
Per cent							
None	87.5	64.8	77.3	80.3	85.0	89.9	84.1
Grade 1	0.0	14.0	11.5	10.8	11.0	7.1	9.4
Grade 2	n.p.	9.6	6.2	5.9	n.p.	1.7	3.6
Grade 3	n.p.	2.7	1.9	1.3	n.p.	0.7	1.1
Grade 4	0.0	8.8	3.1	1.7	1.4	0.5	1.8
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

n.p. Data not published to maintain confidentiality of small numbers.

(a) Weight criterion for IVH is a birthweight of less than 1,500 grams.

**Note:** Not examined data are excluded from per cent calculations.

**Table 64: Neonatal sepsis for level III registrants by birthweight group, 2013**

Sepsis	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
	Number											
No sepsis	17	286	549	731	1,013	1,622	1,291	1,179	1,230	869	397	9,184
Sepsis at <48 hrs <sup>(a)</sup>	<5	<5	14	11	<5	12	9	7	11	10	9	92
Sepsis at ≥48 hrs <sup>(a)</sup>	<5	113	128	75	35	42	23	22	21	6	<5	469
Babies alive on day 2	n.p.	376	670	807	n.p.	1,662	1,316	1,199	1,254	876	n.p.	9,631
Babies who did not survive to day 2	<5	20	13	6	<5	13	6	8	8	9	<5	90
<b>Total in each birthweight group</b>	<b>20</b>	<b>396</b>	<b>683</b>	<b>813</b>	<b>1,050</b>	<b>1,675</b>	<b>1,322</b>	<b>1,207</b>	<b>1,262</b>	<b>885</b>	<b>408</b>	<b>9,721</b>
Per cent												
No sepsis <sup>(b)</sup>	85.0	72.2	80.4	89.9	96.5	96.8	97.7	97.7	97.5	98.2	97.3	94.5
Sepsis at <48 hrs <sup>(b)</sup>	n.p.	n.p.	2.0	1.4	n.p.	0.7	0.7	0.6	0.9	1.1	2.2	0.9
Sepsis at ≥48 hrs <sup>(c)</sup>	n.p.	30.1	19.1	9.3	n.p.	2.5	1.7	1.8	1.7	0.7	n.p.	4.9

n.p. Data not published to maintain confidentiality of small numbers.

(a) Groups are not mutually exclusive.

(b) Denominator is all registrants.

(c) Denominator is registrants alive at 48 hours.

**Table 65: Median length of stay for level III registrants who survived until discharge home by birthweight group, 2013**

Birthweight group (grams)	Number of babies	Median LOS (days)	Interquartile range (days)
<500	11	140	124–165
500-749	293	117	99–135
750-999	620	90	73–107
1,000-1,249	775	64	52–77
1,250-1,499	1,038	47	37–59
1,500-1,999	1,623	36	28–45
2,000-2,499	1,281	21	14–28
2,500-2,999	1,164	12	7–21
3,000-3,499	1,214	8	5–16
3,500-3,999	852	7	4–15
≥4,000	400	6	4–13
<b>Total</b>	<b>9,271</b>	<b>27</b>	<b>11–51</b>

*Note: Death status was not provided for four babies.*

**Table 66: Survival to discharge home for level III registrants by birthweight group, 2013**

Birthweight group (grams)	Number of babies	Lethal congenital anomalies	Babies alive on day 7	Babies alive on day 28	Survived to go home	Percent survival at discharge home
<500	20	0	16	13	11	55.0
500-749	396	<5	347	319	293	74.0
750-999	683	11	653	640	620	90.8
1,000-1,249	813	10	799	792	775	95.3
1,250-1,499	1,050	<5	1,043	1,038	1,038	98.9
1,500-1,999	1,675	28	1,649	1,639	1,623	96.9
2,000-2,499	1,322	22	1,308	1,293	1,281	96.9
2,500-2,999	1,207	27	1,189	1,175	1,164	96.4
3,000-3,499	1,262	26	1,235	1,218	1,214	96.2
3,500-3,999	885	10	866	857	852	96.3
≥4,000	408	<5	403	401	400	98.0
<b>Total</b>	<b>9,721</b>	<b>143</b>	<b>9,508</b>	<b>9,385</b>	<b>9,271</b>	<b>95.4</b>

*Note: Death status was not provided for four babies.*

## Appendix 3: Methods used in this report

The ANZNN data collection was moved to the then-named Perinatal & Reproductive Epidemiology Research Unit, School of Women's & Children's Health, University of New South Wales in June 2008.

The historical ANZNN data were received as a Microsoft Access database and archived as a Microsoft SQL Server database. Updated data for the ANZNN audit of babies born in 2013 who qualified as high-risk neonates were requested from each participating unit in June 2014 with a deadline of August 2014. The data was submitted to the ANZNN by each participating unit through a newly developed online Data Capture System (DCS), which uses a series of queries to ensure quality, consistency and completeness of data. Units are unable to submit data if mandatory data items are missing or contain non-compliant data values. For all other data items, outliers flagged by the program may only be submitted by designated supervisors at each unit.

An extract from the database was made in February 2015. Apart from grouping, the data presented in the report reflect the database at that time with one exception: a series of derived data items were generated. These are listed below.

### Derived data items:

<b>Survival to day n</b>	The number of days between the date of birth and the date of death was calculated and records flagged if this was less than n days.
<b>Survival to 36 weeks post menstrual age</b>	This item is for babies born at less than 36 weeks gestation only. The day the baby reaches 36 weeks post menstrual age is considered to be the infant's gestational age (completed weeks) plus chronological age in days. For example, a baby born at '28 weeks and four days' gestation on 1 January is 36 weeks post menstrual age on 26 February.
<b>Chronic lung disease (CLD)</b>	This item is for babies born at less than 32 weeks gestation only. The baby received any respiratory support (supplemental oxygen or intermittent positive pressure ventilation (IPPV) or continuous positive airways pressure (CPAP) for a chronic pulmonary disorder on the day the baby reached 36 weeks post menstrual age. Date of final added respiratory support must be: > Date of birth or $\{[(\text{Hours of IPPV} + \text{Hours of CPAP})/168] + \text{Gestational age}\} > 35.9$ weeks
<b>Length of stay</b>	The total number of days a baby spent in hospital during their first admission from birth. The total may include stays in more than one hospital.

All data manipulations and analysis for the 2013 report were carried out using Microsoft SQL Server software, and tabulations and figures were produced using Microsoft Excel.

## Appendix 4: Confidentiality guidelines

Confidentiality guidelines provide an unambiguous framework for the handling of data that met the strict criteria of governing bodies. Confidentiality guidelines for the collection, processing and analysis of data from the minimum data collection of ANZNN were devised and agreed to by the Advisory Committee at the ANZNN Advisory Committee Meeting, Auckland, New Zealand on 2 April 1995. The summary below incorporates modifications agreed in the Memorandum of Understanding (MOU) between ANZNN and the National Perinatal Epidemiology and Statistics Unit, School of Women's and Children's Health, the University of New South Wales.

The purpose of these guidelines is to set out the principles under which the National Minimum Data Collection (NMDC) for neonatal intensive care units (NICUs) is formulated and the conditions that apply to the use of these data and release to parties internal and external to the ANZNN.

The essential purpose of the NMDC is to provide national unit record tabulations on babies meeting specified criteria who have been admitted to NICUs or affiliated nurseries in Australia and New Zealand. In general, this will be achieved through distribution of an annual report containing summary tables without identifying characteristics, either of a personal, institutional or state, territory or national nature. In certain other instances, data may be provided internally in the following manner:

- as de-identified summary tables not provided in the annual report, but available upon request
- as de-identified unit record data for analytical purposes as approved by the ANZNN
- as NICU identifiable summary and/or unit record data for clinical audit purposes by the respective NICU providing the data. These guidelines will cover the collection and provision of data retrospectively from 1 January 1994.

### Principles of ownership and maintenance of data

- The National Perinatal Epidemiology and Statistics Unit (NPESU) agrees to house and maintain the ANZNN Data Collection through electronic data submission from neonatal intensive care units and special care nurseries during the period 1 January 2008 to 31 December 2012. A renewed agreement extends this period from 1 January 2013 to 31 December 2017.
- The ANZNN Data Collection will be housed at NPESU. It will be managed according to existing data security procedures as for other data collections at NPESU. The Data Custodian is the Director of NPESU.

The ANZNN Data Collection Operation Committee ("ANZNN DCOC") was established in June 2008 to make decisions concerning the management, operation, data provision and reporting of the ANZNN Data Collection. The ANZNN DCOC is comprised of: three members appointed by the ANZNN Executive Committee and the ANZNN Advisory Council; two members appointed by the NPESU; and the Chairperson appointed by the ANZNN Executive Committee. The operations and progress of ANZNN Data Collection will be reported quarterly by ANZNN DCOC to the ANZNN Executive Committee.

NPESU will ensure that the data structure of the ANZNN Data Collection will remain the same as the existing data collection. Any modification to the data structure will be a joint decision between ANZNN Executive Committee and NPESU. Issues such as data entry, collation, retrieval and analysis will be considered.

The ANZNN will be responsible for collection and maintenance of the data set and decision-making with respect to its use.

All queries related to the NMDC should be referred to the Data Custodian at NPESU who will address them personally or refer them to the appropriate source person.

### Conditions for data collection

It is expected that all participating NICUs will collect the agreed-upon minimum set of data in a standardised format for eligible babies registered to the ANZNN audit in their unit. Data will be transferred securely to the ANZNN coordinator.

## Conditions for data security

The electronic version of these data is maintained in a secure partition at the University of New South Wales. Access to the server is limited to authorised named staff and further protected by the use of a high-level password. Attempted security breaches are monitored and investigated. Hard copy patient identifiable data and electronic backup files are kept in secured and locked safe cabinets. Master lists of code material and source record identifiers are kept away from the database in a separate locked area. All rooms and offices used by the ANZNN are locked when not in use. Filing cabinets containing data are locked when not in use. Computerised data on the server are protected by high-level passwords known only to each person who has access to computerised data. Potentially identifiable data will not leave the site of the ANZNN. Security disposal of data is available through use of designated bags or a shredding machine and must be witnessed by at least two staff members. A destruction certificate stating the name of the data and the date on which they are destroyed is to be issued and retained in the records.

## Small numbers

Cell values of less than five in tables have not been published, in accordance with ethical guidelines for protecting the privacy of individuals. Exceptions to this are small numbers in 'Other' and 'Not stated' categories. The cell with small numbers and at least one other cell in the same row and column are suppressed to prevent back calculation. Where n.p. (not published) has been used to protect confidentiality, the suppressed numbers are included in the totals.

## Appendix 5: Minimum Data Set variables

### Neonatal Minimum Data Set

#### Registration hospital

Definition: The hospital of registration is the first level III NICU that the baby remained in for four or more hours during the first 28 days of life. Babies who received their entire care in a level II hospital, or who were not transferred to a level III NICU during the first 28 days are registered to the first level II centre that they remain in for four or more hours.

Coding: Numeric code representing registration hospital

Guide for use: If a baby dies within four hours, they are registered to the unit where they died.

#### Maternal age

Definition: Age in completed years of the woman giving birth on the date of the baby's birth.

Coding: 2-digit number representing maternal age in completed years

#### Previous preterm birth

Definition: This mother has had a previous birth that was at less than 37 weeks gestation and more than 20 completed weeks, regardless of outcome.

Coding:

99: unknown.

0: no previous preterm birth.

-1: yes, there was a previous preterm birth.

#### Previous perinatal death

Definition: Mother has had a previous perinatal loss.

Coding:

99: unknown.

0: no previous perinatal death.

-1: yes, has had a previous perinatal death.

Guide for use: A perinatal loss is when a baby with a birthweight of more than 400 grams or a gestational age of more than 20 completed weeks died during the first 28 days of life.

#### Assisted conception in this pregnancy

Definition: The type of infertility treatment used during conception or used to conceive this pregnancy.

Coding:

0: unknown.

1: none – no infertility treatment used for this pregnancy.

2: hyperovulation – any hormone therapy used to stimulate ovulation.

3: IVF / GIFT etc. – any method of in vitro fertilisation. Including in vitro fertilisation, gamete intrafallopian transfer, zygote intrafallopian transfer and IC sperm injection.

4: other – infertility treatment used that is not mentioned above, including artificial insemination.

Guide for use: Disregard any treatment for any previous pregnancies.

## Ethnicity of mother

Definition: Ethnic origin of the mother of baby, as identified by the mother.

Coding:

- 0: unknown.
- 1: Aboriginal or Torres Strait Islander – is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community with which she is associated.
- 2: Asian – all whose ethnic background originates from countries of Asia, South East Asia and Indian subcontinent (eg. Fijian Indian).
- 3: Caucasian – all of Caucasoid heritage, including, European, Russian, Middle Eastern and Arabic.
- 4: Other – includes African Negroes, Inuit, American Blacks and Indians, Melanesian.
- 5: Pacific Islander – all from Pacific Islander background, including Samoan, Cook Islands Maori, Niuean, Tokelauan, and other Pacific Islands groups (eg. Hawaiian, Tahitian). Excludes Maori.
- 6: Maori – a person of New Zealand Maori descent who identifies as Maori.

## Source of referral

Definition: Source of referral to registration unit.

Coding:

- 0: unknown.
- 1: booked at tertiary obstetric hospital – mother booked into a hospital with a NICU and was not transferred during the most recent admission.
- 2: in utero transfer from obstetric hospital – mother transferred during most recent admission, baby in utero.
- 3: ex utero retrieval – baby transferred from any hospital by a specialist retrieval team.
- 4: ex utero transfer – baby transferred from any hospital by non-specialist team, includes transport by ambulance.
- 5: other – born in transit or not booked.
- 6: booked at this level II unit – mother booked into this hospital, no NICU.
- 7: in utero transfer to this level II unit – mother transferred, baby in utero.
- 8: ex utero retrieval to this level II unit – baby ‘retrieved’ from any other hospital.
- 9: ex utero transfer to this level II unit.

Guide for use: Use most recent referral.

## Presenting antenatal problem

Definition: The antenatal complication that the mother presented with in this pregnancy.

Coding:

- 0: unknown.
- 1: preterm pre-labour rupture of membranes – confirmed spontaneous rupture of membranes occurring prior to the onset of labour and before 37 weeks gestation.
- 2: preterm labour.
- 3: hypertension in pregnancy.

- 4: antepartum haemorrhage.
- 5: suspected intrauterine growth restriction.
- 6: fetal distress.
- 7: other.
- 8: none – no presenting problem. Born at term.
- 9: antenatal diagnosis of fetal malformation.

## Other antenatal complications

Definition: Any other antenatal complication.

Coding:

- 99: unknown.
- 0: no other antenatal complication present.
- 1: yes, other antenatal complication present.

## Prolonged rupture of membranes (ROM)

Definition: Confirmed spontaneous ROM.

An obvious gush of clear amniotic fluid from vagina or if fluid available, by differentiation with urine or vaginal secretions, for more than 24 hours before birth.

Coding:

- 99: unknown.
- 0: no, membranes intact/ruptured for < 24 hrs.
- 1: yes, membranes ruptured for  $\geq$  24 hours.

## Preterm labour

Definition: Regular painful contractions, leading to progressive effacement and dilatation of the cervix, eventually leading to the birth of the baby, and commencing before 37 weeks gestation.

Coding:

- 99: unknown.
- 0: no, labour did not commence before term.
- 1: yes, labour commenced in preterm period.

## Hypertension in pregnancy

Definition: A systolic blood pressure (BP) > 140 mmHg and/or diastolic BP > 90 mmHg, or a rise in systolic BP > 25 mmHg and/or a rise in diastolic BP > 15 mmHg from a reading before conception or in 1st trimester; confirmed by 2 readings 6 hours apart

Coding:

- 99: unknown.
- 0: no hypertension in pregnancy detected.
- 1: yes, hypertension in pregnancy diagnosed.



## Antepartum haemorrhage

Definition: Significant haemorrhage in the time from 20 weeks gestation to the end of second stage of labour (excludes a 'show').

Coding:

- 99: unknown.
- 0: no antepartum haemorrhage noted.
- 1: yes, antepartum haemorrhage.

## Suspected intrauterine growth restriction

Definition: A condition of the fetus in which it fails to reach its genetically predetermined full growth potential due to intrinsic or extrinsic factors based on more than one obstetric ultrasound.

Coding:

- 99: unknown.
- 0: no intrauterine growth restriction.
- 1: yes, intrauterine growth restriction suspected.

## Fetal distress

Definition: Any 'distress' of this fetus leading to intervention by the obstetric team.

Coding:

- 99: unknown.
- 0: no intervention necessary.
- 1: yes, obstetric intervention required.

## Antenatal diagnosis of fetal malformation

Definition: A fetal malformation is diagnosed prior to the baby's birth, by any method.

Coding:

- 99: unknown.
- 0: no.
- 1: yes, malformation detected prior to birth.

Guide for use: The diagnosis of the malformation may or may not be confirmed after birth.

## Other antenatal complication

Definition: Complication, not specified.

Coding:

- 99: unknown.
- 0: no other significant antenatal complication.
- 1: yes, other antenatal complication present.

## Sex

Definition: The sex of the patient.

Coding:

- 0: unknown.
- 1: male.
- 2: female.
- 3: ambiguous or indeterminate.

## Infant weight

Definition: The first weight of the baby after birth.

Coding: A 4-digit number representing birthweight in grams.

Guide for use: The weight is usually measured to the nearest five grams and is obtained within one hour of birth, or shortly after the infant has been admitted.

## Gestational age

Definition: The estimated gestational age of the baby in completed weeks.

Coding: A 2-digit number representing the number of completed weeks of gestation.

Guide for use: Derived from a clinical assessment of the baby when accurate information is not stated.

## Place of birth

Definition: Place of baby's birth.

Coding:

- 0: unknown.
- 1: non-tertiary hospital – born in a hospital with no level III NICU.
- 2: tertiary hospital – born in a hospital with a level III NICU.
- 3: homebirth – planned.
- 4: born before arrival – unplanned birth at home, or in an ambulance, a car etc.

## Presentation at birth

Definition: Presenting part of the fetus (at lower segment of the uterus) at birth.

Coding:

- 0: unknown.
- 1: cephalic – including face and brow.
- 2: breech – legs or feet were facing the cervix.
- 3: other – includes transverse.

## Mode of birth

Definition: The method of complete expulsion or extraction from its mother of a product of conception.

Coding:

- 0: unknown.
- 1: vaginal – vaginal birth, includes breech.
- 2: instrument – vaginal birth using an instrument – forceps, rotations, vacuum extraction.

- 3: Caesarean section in labour – caesarean performed after the commencement of labour.
- 4: Caesarean section, no labour – caesarean section performed prior to labour commencing.

## Antenatal corticosteroids

Definition: Corticosteroids given during the antenatal period via any route to the mother at a time likely to enhance fetal lung maturation.

Coding:

- 0: unknown.
- 1: none – steroids not given.
- 2: less than 24 hours – first dose given less than 24 hours prior to this baby's birth.
- 3: complete – more than 1 dose of steroids given, and 1st dose at more than 24 hours and less than 8 days before birth.
- 4: given at more than 7 days before baby's birth.

Guide for use: If two courses given, and one fulfils the 'complete' criteria, use 'complete'. If the time of doses given is not available, but two doses are known to have been given appropriately, also use 'complete'.

## Magnesium sulphate

Definition: Magnesium sulphate ( $\text{MgSO}_4$ ) provided to the mother during the 6 hours immediately before birth, either because of maternal preeclampsia or specifically for fetal neuro-protection.

Coding:

- 0:  $\text{MgSO}_4$  not given at all.
- 1:  $\text{MgSO}_4$  course finished > 6 hours before birth (likely to be ineffective).
- 2:  $\text{MgSO}_4$  given as intramuscular injection within 6 hours of birth.
- 3:  $\text{MgSO}_4$  given for < 4 hours within 6 hour time slot (incomplete course).
- 4:  $\text{MgSO}_4$  given by infusion over 4 hours or more within 6 hours of birth (complete course).
- 5:  $\text{MgSO}_4$  given but details not known.
- 6: unknown – information not available.

Guide for use: The minimum dose is 4G infused IV over 20 minutes but a complete course of treatment is 4 hours. A short IV infusion or an intramuscular injection given within the 6 hour window is likely to be effective but less so than a 4 hour infusion.

## Plurality

Definition: The total number of births resulting from this pregnancy.

Coding:

- 0: singleton – only one baby born.
- 1: twins – two babies.
- 2: triplets – three babies.
- 3: quads – four babies.
- 4: more – quintuplets, sextuplets etc.

Guide for use: Determined by the number of live births or by the number of fetuses that remain in utero at 20 weeks gestation. If gestational age is unknown, only live births of any birthweight or gestation, or fetuses weighing  $\geq 400$  grams are taken into account. Fetuses aborted at < 20 weeks or fetuses compressed in the placenta at or more than 20 weeks are excluded.

## Birth order

Definition: Order of each baby of a multiple birth.

Coding: Single-digit number representing birth order.

- 0: singleton.
- 1: first of a multiple birth.
- 2: second of a multiple birth.
- 3: third of a multiple birth etc.
- 4: other.

## Date of birth

Definition: Date of birth of the patient.

Coding: DD / MM / YYYY

## Admission date

Definition: The date on which an inpatient or same-day patient commences an episode of care.

Coding: DD / MM / YYYY

## Apgar score (1 minute)

Definition: Numerical score to evaluate the baby's condition at one minute after birth.

Coding: 2-digit number representing Apgar score.

Guide for use: The score is based on the five characteristics of heart rate, respiratory condition, muscle tone, reflexes and colour.

## Apgar score (5 minute)

Definition: Numerical score to evaluate the baby's condition at five minutes after birth.

Coding: 2 digit number.

Guide for use: As for Apgar score (1 minute).

## Intubated at resuscitation

Definition: An active measure taken shortly after birth to establish independent respiration and heart rate, or to treat depressed respiratory effort by endotracheal intubation.

Coding:

- 99: unknown.
- 0: no, intubation was not necessary in labour ward.
- 1: yes, intubation necessary in labour ward.

Guide for use: Does not include intubation for tracheal aspiration or intubation in the NICU after resuscitation is complete.

## **Congenital anomalies**

Definition: Structural abnormalities (including deformations) present at birth and diagnosed prior to separation from care (discharge home).

Coding:

- 99: unknown.
- 0: no major congenital malformations noted.
- 1: yes, major congenital malformation noted.

## **Specified congenital anomalies**

Definition: Detail of the major congenital malformation.

Coding: Free text field representing congenital malformation coded by ICD-10-AM.

## **Temperature on admission**

Definition: Temperature on admission to the NICU or closest to admission to registration unit. Use rectal temperature or, if not available, per axilla.

Coding: A 4-digit number representing temperature measured in degrees Celsius to 1 decimal place.

Guide for use: If the baby is transported by a specialist neonatal retrieval team, admission is considered to commence when the team arrive at the baby's bedside. If the baby is more than 12 hours of age when NICU care started, or if an admission temperature is not recorded, use '0' to denote missing.

## **Worst base excess**

Definition: Worst base deficit recorded between admission to NICU and 12 hours after birth.

Coding: 3 digit numbered field representing base excess measured in mmol/l. May be negative.

Guide for use: Use '99' to denote missing.

## **Main respiratory diagnosis**

Definition: Main indication for respiratory support.

Coding:

- 0: unknown.
- 1: normal – no respiratory support.
- 2: non-specific – any non-specific respiratory distress (RD) in an infant requiring respiratory support (combines previous items transient tachypnoea of newborn and immature lung).
- 3: hyaline membrane disease – increasing RD or oxygen (O<sub>2</sub>) requirements, or the need for ventilator support from the first six hours of life with a chest x-ray showing generalised reticulogranular pattern, plus or minus air bronchogram.
- 4: meconium aspiration – RD presenting from immediately after birth to 12 hours of age. Hypoxia, tachypnoea and gasping respirations are often signs of underlying asphyxia. Chest x-ray shows over-expansion of lungs with wide spread coarse, fluffy infiltrates.
- 5: pneumonia – RD with proven or suspected infection (toxic blood count), and chest x-ray showing persisting opacities.
- 6: persistent pulmonary hypertension – echocardiatic (shunting) or clinical evidence – O<sub>2</sub> need unexplained by chest x-ray or loud P<sub>2</sub>, or differential pre /post ductal TCPO<sub>2</sub>.
- 8: apnoea – recurrent pauses in breathing for more than 20 seconds, or for less than 20 seconds associated with bradycardia or any desaturation requiring intervention.

- 9: congenital malformation – malformation is the primary reason for RD, e.g. diaphragmatic hernia (list malformation in appropriate field).
- 10: other – unspecified other RD.
- 11: peri surgical – no RD, support given for surgical intervention.
- 12: newborn encephalopathy – a syndrome of disturbed neurological function in an infant with difficulties initiating or maintaining respiration, depression of tone reflexes or consciousness and often with seizures.

Guide for use: For a diagnosis other than ‘normal’ the baby must receive respiratory support. If more than one diagnosis is possible, use the most serious condition.

## Exogenous surfactant

Definition: Any treatment with exogenous surfactant.

Coding:

- 0: unknown.
- 1: none – no exogenous surfactant ever given.
- 2: Exosurf – any treatment using ‘Exosurf’.
- 3: Survanta – any treatment using ‘Survanta’.
- 4: any combination – any combination of surfactant.
- 5. Curosurf– any treatment using ‘Curosurf’.
- 6. Curosurf and Survanta.

Guide for use: Includes incomplete use.

## Air leak requiring drainage

Definition: Any form of pulmonary air leak requiring drainage (transient or continuous).

Coding:

- 99: unknown.
- 0: no air leak requiring drainage present.
- 1: yes, air leak requiring drainage.

## Hours of intermittent positive pressure ventilation (IPPV)

Definition: Total number of hours of IPPV given via an endotracheal tube, at any rate.

Coding: 4- digit number – IPPV hours.

Guide for use: The hours of all forms of assisted ventilation via an endotracheal tube are summed. The usual rounding up applies.

## Hours of continuous positive airways pressure (CPAP)

Definition: Total number of hours of CPAP via any route, and nasopharyngeal ventilation.

Coding: 4-digit number – CPAP hours

Guide for use: As for hours of IPPV.

## High frequency oscillatory ventilation (HFOV)

Definition: Mechanical ventilation presented at high frequencies (small tidal volumes with frequencies > 4Hz) initiated for this baby.

Coding:

- 99: unknown.
- 0: no high frequency oscillatory ventilation initiated.
- 1: yes, high frequency oscillatory ventilation was initiated.

## Nitric oxide

Definition: Nitric oxide was used in any form or dose for respiratory support of the baby.

Coding:

- 99: unknown.
- 0: no, nitric oxide therapy never used.
- 1: yes, nitric oxide therapy used.

## Extracorporeal membrane oxygenation

Definition: An extracorporeal circuit was established to divert baby's blood to a membrane lung for oxygenation, was initiated for this baby.

Coding:

- 99: unknown.
- 0: no ECMO initiated.
- 1: yes, ECMO initiated.

## Date of final added respiratory support

Definition: Date supplemental oxygen (O<sub>2</sub>), high flow, CPAP or mechanical ventilation ceased appropriately.

Coding: DD / MM / YYYY

Guide for use: Four consecutive hours in any 24-hour period constitutes a 'day'.

## Nasal high flow therapy

Definition: Blended air and oxygen mix with a delivery flow of greater than 1 litre/min through any high flow device with humidification.

Coding:

- 99: unknown.
- 0: nasal high flow was never initiated.
- 1: yes, nasal high flow was used for more than four hours.

## Chronic lung disease (CLD)

Definition: The baby received respiratory support (supplemental O<sub>2</sub> or any form of assisted ventilation) for a chronic pulmonary disorder at 36 weeks post menstrual age.

Coding:

- 99: unknown.
- 0: no chronic lung disease.
- 1: yes, chronic lung disease.

Guide for use: Four consecutive hours in any one 24-hour period constitutes respiratory support on that day.

## Post-natal steroids for chronic lung disease

Definition: The infant was treated with systemic corticosteroids by any route for chronic lung disease.

Coding:

99: unknown.

0: no systemic post-natal steroids for chronic lung disease.

-1: yes, the baby did have post-natal steroids for chronic lung disease.

Guide for use: Record if corticosteroids used with the objective of treating evolving CLD at any stage or to prevent development of CLD. It must not include corticosteroid use for the treatment of conditions such as post-extubation subglottic oedema or in the use for hypotension or any forms of corticosteroid deficiency.

## Home oxygen therapy

Definition: Supplemental oxygen therapy was used at home after discharge from hospital.

Coding:

99: unknown.

0: no supplemental oxygen used at home.

-1: yes, home oxygen therapy given.

Guide for use: Must have required supplemental oxygen in hospital.

## Neonatal surgery

Definition: Did this baby have major surgery that involved opening a body cavity?

Coding:

99: unknown.

0: no.

-1: yes.

## Parenteral nutrition

Definition: Intravenous infusion of a nutria solution consisting of a minimum of dextrose and protein but generally providing a complete nutrient infusion including electrolytes, calcium, phosphorus, zinc, trace elements, vitamins and fat.

Coding:

99: unknown.

0: parenteral nutrition never initiated.

-1: yes, parenteral nutrition initiated.

## Home gavage feeding

Definition: The baby was discharged home with a nasogastric tube in place to allow gavage / infusion feeding at home.

Coding:

99: unknown.

0: no, not discharged with gavage tube.

-1: yes, discharged to home with a gavage tube.

Guide for use: Must have required gavage feeding in hospital.



## Proven necrotising enterocolitis (NEC)

Definition: Diagnosis of proven necrotising enterocolitis (NEC) is definite.

Coding:

- 99: unknown.
- 0: no necrotising enterocolitis proven.
- 1: yes, necrotising enterocolitis proven.

Guide for use: Has at least four of the following symptoms:

1. At least one systemic sign: temperature instability, apnoea, bradycardia or lethargy; and one intestinal sign: a residual of more than 25% of the previous feed on 2 consecutive occasions, abdominal distension, vomiting or faecal blood.
2. Has profile consistent with definite NEC including at least one of the following: abdominal wall cellulitis and palpable abdominal mass, or pneumatosis intestinalis, or portal vein gas, or a persistent dilated loop on serial x-rays, or a surgical or post mortem diagnosis.
3. Plus the baby warranted treatment for NEC, which included nil by mouth and antibiotics.

## Spontaneous intestinal perforation (SIP)

Definition: Intestinal perforation not associated with NEC nor with any bowel obstruction/atresia, nor with any mechanical trauma.

Coding:

- 99: unknown.
- 0: no, the baby did not have spontaneous intestinal perforation
- 1: yes, the baby did have spontaneous intestinal perforation

Guide for use: Record if SIP has occurred, without any radiological signs of NEC and/or without surgical diagnosis of NEC.

## Therapeutic hypothermia

Definition: Intentional cooling of an infant of any gestational age to a core temperature  $<35.0^{\circ}\text{C}$  (generally  $33\text{--}34^{\circ}\text{C}$ ).

Coding:

- 99: unknown.
- 0: no.
- 1: yes.

Guide for use: Record if therapeutic hypothermia has occurred.

## Principal reason for non-completion of full 72 hours of hypothermia

Definition: The principal reason why therapeutic hypothermia was terminated early / before 72 hours of treatment had been completed.

Coding:

- 0: not ceased before 72 hours
- 1: palliation.
- 2: recognised as not fulfilling standard criteria for cooling.
- 3: fulfilled standard criteria for cooling but clinical improvement suggests no need.

- 4: qualification equivocal with change of clinical decision making.
- 5: severe coagulopathy not responding to blood products.
- 6: hypotension not responding to inotrope.
- 7: severe PPHN refractory to iNO.
- 8: arrhythmia.
- 9: reason for early cessation not known.

Guide for use: Hypothermia begins at the onset of cooling and ends at the onset of warming.

## Early infection

Definition: An episode of systemic sepsis with initial symptoms occurring before 48 hours after birth.

Coding:

- 99: unknown.
- 0: no early infection noted.
- 1: yes, early infection noted.

Guide for use: These conditions must apply:

Isolation of an organism from at least one blood culture and, after consideration of the clinical and laboratory evidence, a decision is made to give antibiotics with therapeutic intent against this organism. Mixed coagulase negative staphylococci or other skin flora – contaminant are not included.

## Episodes of late-onset sepsis

Definition: At least one episode of systemic sepsis with initial symptoms from 48 hours after birth.

Coding: 2-digit field representing total episodes of late onset sepsis.

Guide for use: Isolation of organisms from one blood culture and, after considering clinical / laboratory evidence, decision made to give antibiotics with therapeutic intent against this organism. The following must not apply: mixed coagulase negative staphylococci or other skin flora contaminant. Same blood organism isolated from blood during previous 14 days – repeat isolate.

## Maximum grade of intraventricular haemorrhage

Definition: Worst level of IVH seen on either side by ultrasound or post mortem examination.

Coding:

- 0: none – ultrasound / post mortem shows no haemorrhage.
- 1: Grade 1 – subependymal germinal matrix haemorrhage.
- 2: Grade 2 – intraventricular haemorrhage with no ventricular distension.
- 3: Grade 3 – intraventricular haemorrhage with ventricle distended with blood.
- 4: Grade 4 – intraparenchymal haemorrhage.
- 5: Not examined- by ultrasound or by post mortem examination.

## Date of late head ultrasound

Definition: Date of the cerebral ultrasound scan nearest to six weeks of age.

Coding: DD / MM / YYYY

## Ventricle size

Definition: Size of ventricle at the ultrasound closest to six weeks of age (date above). Ventricular index (VI) is measured as the furthest lateral extent of each ventricle from the midline measured at the level of Foramen of Monro.

Coding:

- 0: unknown.
- 1: no dilatation – VI less than 97th centile.
- 2: dilatation – VI equal to 97th centile / 97th centile + 4mm.
- 3: hydrocephalus – VI greater than 97th centile + 4mm or hydrocephalus present requiring a shunt or drainage (permanent or transient).

## Ventricular Index (VI)

Definition: Size of ventricle at the ultrasound closest to six weeks of age (date above).

Coding: 4-digit number representing VI in mm correct to one decimal place.

Guide for use: Record if ventricular dilatation is present, i.e. 'dilatation' or 'hydrocephalus'.

## Cerebral cystic formations

Definition: Changes in brain parenchyma seen at the scan closest to six weeks of age.

Coding:

- 0: unknown.
- 1: no cysts – none seen on ultrasound.
- 2: porencephalic cyst(s) – parenchymal lesions corresponding to grade 4 IVH.
- 3: periventricular leukomalacia (PVL) – ischaemic brain injury affecting periventricular white matter in the boundary zones supplied by terminal branches of both centripetal and centrifugal arteries.
- 4: encephaloclastic porencephaly – relatively late development on cerebral scan of extensive dense, cystic lesions involving the periphery of the brain (ANZNN 2009).

## Baby meets local criteria for ROP exam

Definition: The baby meets the criteria for eye examination for ROP.

Coding:

- 99: unknown.
- 0: no.
- 1: yes, did meet local criteria.

## Retinopathy of prematurity (ROP)

Definition: Worst stage of ROP in either eye prior to going home.

Coding:

- 0: none seen – no changes seen.
- 1: stage I – demarcation line.
- 2: stage II – ridge.
- 3: stage III – ridge with extraretinal fibro-vascular proliferation.
- 4: stage IV – retinal detachment.
- 5: not examined – no eye examination.

## Therapy for retinopathy of prematurity

Definition: Any therapy used to treat retinopathy of prematurity (ROP), i.e. laser or cryotherapy.

Coding:

- 99: unknown.
- 0: no therapy for ROP received.
- 1: yes, therapy given for ROP.

## Died

Definition: The death of this baby occurred prior to discharge from hospital.

Coding:

- 99: unknown.
- 0: no, survived to discharge to home.
- 1: yes, died.

## Date of death

Definition: Date of death of the baby.

Coding: DD / MM / YYYY

Guide for use: If baby is known to have died after discharge, record date here and 'no' to died.

## Post mortem

Definition: Post mortem examination performed.

Coding:

- 99: unknown.
- 0: no post mortem performed.
- 1: yes, a post mortem was performed.

## Immediate cause of death

Definition: The cause of death as stated on the death certificate.

Coding: unspecified free text field

Guide for use: To be described in morbid anatomical terms.

## Death due to congenital anomaly

Definition: The death of the infant directly attributed to the congenital anomaly.

Coding:

- 99: unknown.
- 0: no.
- 1: yes.

Guide for use: Must be coded as 'yes' for major congenital anomaly and 'yes' for died.

## Transferred to another hospital

Definition: The baby was transferred to another hospital nursery before going home.

Coding:

99: unknown.

0: no, never transferred.

-1: yes, transferred.

## Date of transfer

Definition: Date on which a baby completes an episode of care after birth in the hospital of registration.

Coding: DD / MM / YYYY

Guide for use: Use the most significant date.

## Discharge date

Definition: Date on which a patient completes an episode of care.

Coding: DD / MM / YYYY

Comment: All data collection ceases on this date.

# Extremely Preterm Follow-up Minimum Data Set

## Estimated date of confinement

Definition: The estimated calendar date of when the baby will be born in completed weeks as determined by documentation of the date of last menstrual period and early antenatal ultrasound.

Coding: DD / MM / YYYY

Guide for use: The estimated date of confinement is generally defined by the date of the last menstrual period. If the date of the last menstrual period is not known, early ultrasound prior to 10 weeks is accurate  $\pm 3$  days. If dates are uncertain an ultrasound performed prior to 20 weeks has an accuracy of  $\pm 2$  weeks.

## Date assessed

Definition: Date on which the two to three year follow-up developmental assessment was performed.

Coding: DD / MM / YYYY

## Outcome for children at two to three years

Definition: Survival of the child at two to three years corrected age.

Coding:

- 99: unknown.
- 0: no, child died after discharge from hospital to home and prior to the two to three year follow-up.
- 1: yes, survived to the two to three year follow-up.

## Outcome for follow-up at two to three years

Definition: Outcome of the child for follow-up at two to three years of age.

Coding:

- 1: formal developmental assessment (e.g. Bayley III or Griffiths).
- 2: information obtained but formal assessment not done.
- 3: child is unable to be assessed due to severe developmental delay.
- 4: child is unable to be assessed due to behavioural disorder.
- 5: child is unable to be assessed due to non-compliance.
- 6: lost- the child is lost to follow-up.

Guide for use: If the child attended assessment but was uncooperative, child is recorded as “Child is unable to be assessed due to non-compliance (5)”. If no contact with the child’s parent(s)/guardian(s) could be made or if the child’s parent(s)/guardian(s) were unwilling or unable to bring the child in for assessment, child is recorded as “Lost- the child has been lost to follow-up (6)”.

## Weight

Definition: The weight (body mass) of a child measured in kilograms.

Coding: A 2-4 digit number representing weight in kilograms.

Guide for use: If the weight of the child was measured either side of one month of the date of assessment then an extrapolated value should be provided as determined by the z-score.

## Type of Stature Measurement

Definition: The type of stature measurement used at the two to three year follow-up assessment.

Coding:

99: unknown.

1: standing height.

2: recumbent length.

## Stature

Definition: The stature of a child measured in centimetres.

Coding: A 2-4 digit number representing stature in centimetres.

Guide for use: If the stature of the child was measured either side of one month of the date of assessment then an extrapolated value should be provided as determined by the z-score.

## Head Circumference

Definition: The head circumference of a child aged between two and three years measured in centimetres.

Coding: A 2-4 digit number representing head circumference in centimetres.

Guide for use: If the head circumference of the child was measured either side of one month of the date of assessment then an extrapolated value should be provided as determined by the z-score.

## Hearing Aid

Definition: Hearing aid has been prescribed or not. Information as provided by parent or carer at the two to three year follow-up assessment.

Coding:

99: unknown.

0: no hearing aid prescribed.

1: unilateral hearing aid prescribed.

2: bilateral hearing aid prescribed.

## Cochlear Implant

Definition: Cochlear Implant has been inserted or not. Information as provided by parent or carer at the two to three year follow-up assessment.

Coding:

99: unknown.

0: no cochlear implant.

-1: yes, cochlear implant.

## Blind

Definition: Ophthalmologist assessment has demonstrated that the child has blindness (<6/60 in better eye). This information may be provided by the parent or carer at the two to three year follow-up assessment.

Coding:

99: unknown.

0: no blindness.

-1: yes, blindness (<6/60 in better eye).

## Respiratory support

Definition: At the time of the two to three year follow-up assessment, the type of therapy the child is receiving for respiratory disease.

Coding:

- 99: unknown.
- 0: no respiratory support.
- 1: continued ventilator support.
- 2: oxygen.
- 3: tracheostomy.

## Gastrointestinal feeding

Definition: At the time of the two to three year follow-up assessment, the therapy the child requires for gastrointestinal disease, represented by a code.

Coding:

- 99: unknown.
- 0: no therapy.
- 1: nasogastric tube (NGT).
- 2: parenteral nutrition (PN).
- 3: percutaneous endoscopic gastrostomy (PEG) feeding.

## Cerebral Palsy

Definition: Cerebral palsy diagnosed.

Coding:

- 99: unknown.
- 0: no cerebral palsy.
- 1: yes, cerebral palsy.

## Gross motor function classification system for cerebral palsy (GMFCS) (2-4 years)

Definition: The Gross Motor Function Classification System (GMFCS) classifies the movement ability of children with cerebral palsy. The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility, as represented by a code.

Coding:

- 1: Level I – Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.
- 2: Level II – Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.
- 3: Level III – Children maintain floor sitting often by “W-sitting” (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.



- 4: Level IV – Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.
- 5: Level V – Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

## Bayley scales of infant and toddler development – third edition

Definition: The Bayley-III assesses infant and toddler development across five domains: Cognitive, Language, Motor, Social-Emotional, and Adaptive.

Coding:

- 99: unknown.
- 0: no Bayley-III assessment performed.
- 1: yes, Bayley-III assessment performed.

## Cognitive composite score

Definition: The cognitive scale of the Bayley-III assesses the sensory motor development, exploration and manipulation, object relatedness, concept formation, memory and other aspects of cognitive processing.

Coding: A 2-3 digit number representing the composite score from the cognitive scale.

## Receptive communication scaled score

Definition: The receptive communication scale of the Bayley-III includes items that assess preverbal behaviours, vocabulary development, such as being able to identify objects and pictures that are referenced; vocabulary related to morphological development, such as pronouns and prepositions; and understanding of morphological markers, such as plural -s, tense markings (-ing, -ed) and the possessive -'s.

Coding: A 1-2 digit number representing the scaled score from the receptive communication scale.

## Expressive communication scaled score

Definition: The expressive communication scale of the Bayley-III includes items that assess preverbal communication, such as babbling, gesturing, joint referencing, and turn taking, vocabulary development such as naming objects, pictures and attributes (e.g. colour and size); and morpho-syntactic development, such as using two-word utterances, plurals and verb tense.

Coding: A 1-2 digit number representing the scaled score from the expressive communication scale.

## Language composite score

Definition: The language scale of the Bayley-III is the sum of the receptive communication score and the expressive communication score. This sum is then used to calculate the composite score for the language scale.

Coding: A 2-3 digit number representing the composite score from the language scale.

## Fine motor scaled score

Definition: The fine motor scale of the Bayley-III includes skills associated with prehension, perceptual-motor integration, motor planning, and motor speed. Items measure young children's skills related to visual tracking, reaching, object manipulation and grasping. Children's functional hand skills and responses to tactile information are also measured.

Coding: A 1-2 digit number representing the scaled score from the fine motor scale.

## Gross motor scaled score

Definition: The gross motor scale of the Bayley-III primarily measures the movement of the limbs and torso. Items assess static positioning (e.g., sitting, standing); dynamic movement, including locomotion and coordination; balance; and motor planning.

Coding: A 1–2 digit number representing the scaled score from the gross motor scale.

## Motor composite score

Definition: The motor scale of the Bayley-III is the sum of the fine motor score and the gross motor score. This sum is then used to calculate the composite score for the motor scale.

Coding: A 2–3 digit number representing the composite score from the motor scale.

## Griffiths Mental Development Scales (GMDS)

Definition: The GMDS assesses the mental development of young children. The GMDS consists of six subscales – Locomotor, Personal-Social, Language, Eye and Hand Co-ordination, Performance and Practical Reasoning.

Coding:

99: unknown.

0: no GMDS assessment performed.

–1: yes, GMDS assessment performed.

## Locomotor subscale quotient

Definition: The locomotor subscale of the GMDS examines the child's gross motor skills including the child's ability to balance, and to co-ordinate and control movements. Test items include age appropriate activities such as walking up and down stairs, kicking a ball, riding a bike, jumping and skipping.

Coding: A 2–3 digit number representing the quotient from locomotor subscale.

## Personal/social subscale quotient

Definition: The personal/social subscale of the GMDS examines the child's proficiency in the activities of daily living, level of independence and ability to interact with other children. Test items include age appropriate activities such as dressing and undressing, competency using cutlery and knowledge of information such as date of birth or address.

Coding: A 2–3 digit number representing the quotient from personal/social subscale.

## Language subscale quotient

Definition: The language subscale of the GMDS examines the child's receptive and expressive language. The test includes age appropriate items such as naming objects and colours, repeating sentences, describing a picture and answering a series of questions about comprehension/similarities/ differences.

Coding: A 2–3 digit number representing the quotient from language subscale.

## Eye and hand co-ordination subscale quotient

Definition: The eye and hand co-ordination subscale of the GMDS examines the child's fine motor skills, manual dexterity and visual perception skills. The test items include age appropriate items such as threading beads, cutting with scissors, copying shapes and writing letters and numbers.

Coding: A 2–3 digit number representing the quotient from eye and hand co-ordination subscale.

## Performance subscale quotient

Definition: The performance subscale of the GMDS examines the child's manipulation skills including their speed of working and precision. The test items include age appropriate activities such as building bridges or stairs, completion of foam boards and pattern making.

Coding: A 2-3 digit number representing the quotient from performance subscale.

## Practical reasoning subscale quotient

Definition: The practical reasoning subscale of the GMDS examines the child's ability to solve practical problems and understand basic mathematical concepts and questions about moral and sequential issues. The test items include age appropriate activities such as counting and comparison of size, length and height. This subscale also assesses the child's knowledge of the days of the week, ability to tell the time and understanding of right and wrong.

Coding: A 2-3 digit number representing the quotient from practical reasoning subscale.

## General quotient

Definition: The general quotient of the GMDS shows how the child's total score varies around the total mean, with a mean of 100 and a standard deviation of 15.

Coding: A 2-3 digit number representing the general quotient.

## Other developmental tests administered

Definition: Other developmental tests administered, including clinical developmental assessments.

Coding:

99: unknown.

0: no other developmental tests administered.

-1: yes, other developmental tests administered.

## Date of test

Definition: Date on which the other development tests were administered.

Coding: DD / MM / YYYY

## Name of test administered

Definition: The name of the other development tests administered.

Coding: Free text field representing developmental test name.

## Subscales of other developmental tests

Definition: Total number of the subscales for other developmental tests administered.

Coding: Number representing the total subscales of other developmental tests administered.

## Score of other developmental tests

Definition: Score of other developmental tests administered.

Coding: Number representing the score of other developmental tests administered.

## Level of development (months)

Definition: Level of development in months determined by other developmental tests administered.

Coding: Number representing level of development in months from the other developmental tests administered.

# Glossary

**Antepartum fetal death:** fetal death occurring before the onset of labour.

**Apgar score:** numerical score used to indicate the baby's condition at 1 minute and 5 minutes after birth. Between 0 and 2 points are given for each of five characteristics: heart rate, breathing, colour, muscle tone and reflex irritability, and the total score is between 0 and 10.

**Baby's length of stay:** number of days between date of birth and date of separation from the hospital of birth (calculated by subtracting the date of birth from the date of separation).

**Bayley Scales of Infant and Toddler**

**Development- third edition:** Assesses the motor (fine and gross), language (receptive and expressive), and cognitive development of infants and toddlers.

**Birth status:** status of the baby immediately after birth.

**Birthweight:** the first weight of the baby (stillborn or liveborn) obtained after birth (usually measured to the nearest 5 grams and obtained within one hour of birth).

**Caesarean section:** operative birth by surgical incision through the abdominal wall and uterus.

**Cerebral palsy:** a developmental disability that results from damage to or dysfunction of the developing brain.

**Corrected age:** the age a preterm baby would be if they had been born on their due date.

**Early neonatal death:** death of a liveborn baby within seven days of birth.

**Extremely low birthweight:** birthweight of less than 1,000 grams.

**Extremely preterm birth:** birth before 28 weeks of gestation

**Fetal death (stillbirth):** death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400 grams or more birthweight. The death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles.

**Forceps:** assisted birth using a metallic obstetric instrument.

**Gestational age:** the duration of pregnancy in completed weeks calculated from the date of the first day of a woman's last menstrual period and her baby's date of birth, or via ultrasound, or derived from clinical assessment during pregnancy or from examination of the baby after birth.

**Griffiths Mental Development Scales:** Assesses the mental development of young children across five subscales; locomotor, personal-social, language, eye and hand co-ordination, performance and practical reasoning

**Gross Motor Function Classification System (GMFCS):** Classifies the movement ability of children with cerebral palsy

**Hyaline membrane disease:** a disorder of the respiratory system.

**Instrumental delivery:** vaginal delivery using forceps or vacuum extraction.

**Intrapartum fetal death:** fetal death occurring during labour.

**Intrauterine growth restriction:** a fetus whose estimated weight is below the 10th percentile for its gestational age.

**Late neonatal death:** death of a liveborn baby after seven completed days and before 28 completed days.

**Live birth:** the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached; each product of such a birth is considered liveborn (WHO definition).

**Low birthweight:** birthweight of less than 2,500 grams.

**Maternal age:** mother's age in completed years at the birth of her baby.

**Mode of separation:** status at separation of patient (discharge/transfer/death) and place to which patient is released (where applicable).

**Neonatal care levels:** Level I care is for normal healthy term babies, some of whom may need short-term observation during the first few hours of life.

Level II refers to a nursery that generally has babies born at 32–36 weeks gestation weighing around 1,500 to 2,500 grams at birth. It includes care for

babies who require intravenous therapy or antibiotics, and/or those who are convalescing after intensive care, and/or those who need their heart rate or breathing monitored, and/or those who need short-term oxygen therapy.

Level III or intensive care refers to the care of newborn infants who require more specialised care and treatment. It includes most babies born at less than 32 weeks gestation or less than 1,500 grams birthweight, and others who may require such interventions as intravenous feeding, and/or surgery, and/or cardiorespiratory monitoring for management of apnoea or seizures, and/or require assisted ventilation, and/or supplemental oxygen over 40% or long-term oxygen.

**Neonatal death:** death of a liveborn baby within 28 days of birth.

**Neonatal morbidity:** any condition or disease of the baby diagnosed after birth and before separation from care.

**Perinatal death:** a fetal or neonatal death of at least 20 weeks gestation or at least 400 grams birthweight.

**Plurality:** the number of births resulting from a pregnancy.

**Post menstrual age (completed weeks)** is calculated by taking the gestational age plus postnatal age – e.g. when a baby born at 25 weeks gestation is 15 weeks old, they are 40 weeks PMA (also known as term equivalent age).

**Post neonatal death:** death of a liveborn baby after 28 days and within one year of birth.

**Post term birth:** birth at 42 or more weeks of gestation.

**Presentation at birth:** presenting part of the fetus at birth.

**Preterm birth:** birth before 37 weeks of gestation.

**Resuscitation of baby:** active measures taken shortly after birth to assist the baby's ventilation and heartbeat, or to treat depressed respiratory effort and to correct metabolic disturbances.

**Retinopathy of prematurity (ROP):** a disorder of the developing eye.

**Sex ratio:** number of male liveborn babies per 100 female liveborn babies.

**Spontaneous vaginal:** birth without intervention in which the baby's head is the presenting part.

**Stillbirth:** see Fetal death (stillbirth).

**Teenage mother:** mother aged less than 20 years at the birth of her baby.

**Vacuum extraction:** assisted birth using a suction cap applied to the baby's head.

**Vaginal breech:** vaginal birth in which the baby's buttocks is the presenting part.

**Very low birthweight:** birthweight of less than 1,500 grams.

**Very preterm birth:** birth before 32 weeks of gestation.

## References

- Australian Bureau of Statistics 2013. *Births, Australia, 2013*. Cat. no. 3301.0. Canberra: ABS.
- Centers for Disease Control and Prevention, National Center for Health Statistics. *Growth Charts 2000*. Atlanta: CDC < <http://www.cdc.gov/growthcharts/> >.
- Chow SSW 2014. *Report of the Australian and New Zealand Neonatal Network 2012*. Sydney: ANZNN < <http://www.anznn.net> >.
- Conde-Agudelo A & Romero R 2009. Antenatal magnesium sulfate for the prevention of cerebral palsy in preterm infants less than 34 weeks' gestation: a systematic review and metaanalysis. *American Journal of Obstetrics & Gynecology* 200(6):595–609.
- Crowley PA 1995. Antenatal corticosteroid therapy: a meta-analysis of the randomized trials, 1972 to 1994. *American Journal of Obstetrics & Gynecology* 173(1):322–335.
- Crowther CA, Hiller JE, Doyle LW, Haslam RR for the Australasian Collaborative Trial of Magnesium Sulphate (ACTO MgSO<sub>4</sub>) Collaborative Group 2003. Effect of magnesium sulphate given for neuroprotection before preterm birth: a randomised controlled trial. *JAMA: The Journal of the American Medical Association* 290(20):2669–2676.
- Doyle LW, Halliday HL, Ehrenkranz RA, Davis PG, & Sinclair JC 2005. Impact of postnatal systemic corticosteroids on mortality and cerebral palsy in preterm infants: effect modification by risk for chronic lung disease. *Pediatrics* 115(3):655–661.
- Doyle LW, Roberts G, Anderson PJ & the Victorian Infant Collaborative Group 2010. Outcomes at age 2 years of infants < 28 weeks' gestational age born in Victoria 2005. *Journal of Paediatrics* 156(1):49–53.
- Doyle LW, Roberts G, Anderson PJ & the Victorian Infant Collaborative Group 2011. Changing long-term outcomes for infants 500–999 g birth weight in Victoria, 1997–2005. *Archives of Disease in Childhood – Fetal and Neonatal edition* 96(6):F443–447.
- Finer NN & Barrington KJ 2006. Nitric oxide for respiratory failure in infants born at or near term. *Cochrane Database of Systematic Reviews* 18(4):CD000399.
- Halliday HL, Ehrenkranz RA & Doyle LW 2003. Early postnatal (<96 hours) corticosteroids for preventing chronic lung disease in preterm infants. *Cochrane Database Systematic Reviews* (1):CD001146.
- Hediger ML, Overpeck MD, Maurer KR, Kuczmarski RJ, McGlynn A & Davis WW 1998. Growth of infants and young children born small or large for gestational age: findings from the Third National Health and Nutrition Examination Survey. *Archives of Pediatrics & Adolescent Medicine* 152(12):1225–1231.
- Oskoui M, Coutinho F, Dykeman J, Jette N & Pringsheim T 2013. An update on the prevalence of cerebral palsy: a systematic review and meta-analysis. *Developmental Medicine & Child Neurology* 55(6):509–519.
- Papile LA, Burstein J, Burstein R & Hoffer H 1978. Incidence and evolution of subependymal and intraventricular hemorrhage: a study of infants with birth weights less than 1500gm. *Journal of Paediatrics* 92(4):529–34.
- Robertson CMT, Howarth TM, Bork DLR & Dinu IA 2009. Permanent bilateral sensory and neural hearing loss of children after neonatal intensive care because of extreme prematurity: a thirty-year study. *Pediatrics* 123(5):e797–807.
- Rouse DJ 2009. Magnesium sulfate for the prevention of cerebral palsy. *American Journal of Obstetrics & Gynecology*. 200(6):610–612.
- Statistics New Zealand 2013. Demographic tables 2013. Wellington: Statistics New Zealand < [www.stats.govt.nz](http://www.stats.govt.nz) >.
- Wilkinson D, Andersen C, O'Donnell CP & De Paoli AG 2011. High flow nasal cannula for respiratory support in preterm infants. *Cochrane Database of Systematic Reviews* 11(5): CD006405.



# List of Tables

<b>Table 1:</b> Level III registrants born at each completed week of gestation, 2013.....	7	<b>Table 25:</b> Late cerebral ultrasound results for level III registrants born before 32 weeks by gestational age, 2013.....	28
<b>Table 2:</b> Level III registrants in each birthweight group, 2013.....	8	<b>Table 26:</b> Necrotising enterocolitis in level III registrants by year of birth, 2004–2013.....	29
<b>Table 3:</b> Age group of mothers of level III registrants by gestational age group, 2013.....	9	<b>Table 27:</b> Characteristics of level III registrants who underwent surgery by gestational age group, 2013.....	30
<b>Table 4:</b> Mother's presenting antenatal problem for level III registrants by gestational age group, 2013.....	10	<b>Table 28:</b> Transfer after registration of level III registrants by level of destination hospital and gestational age group, 2013.....	31
<b>Table 5:</b> Antenatal corticosteroid use for mothers of level III registrants by gestational age group, 2013.....	12	<b>Table 29:</b> Median length of stay for level III registrants who survived until discharge home by gestational age, 2013.....	32
<b>Table 6:</b> Magnesium sulphate use for mothers of level III registrants by gestational age, 2013.....	12	<b>Table 30:</b> Survival to discharge home for level III registrants by gestational age at birth, 2013.....	33
<b>Table 7:</b> Plurality of level III registrants by gestational age group, 2013.....	13	<b>Table 31:</b> Level II registrants by gestational age group, 2013.....	35
<b>Table 8:</b> Method of birth for level III registrants by gestational age group, 2013.....	14	<b>Table 32:</b> Level II registrants by birthweight group, 2013.....	35
<b>Table 9:</b> Level of hospital of birth for level III registrants by gestational age group, 2013.....	14	<b>Table 33:</b> Mothers of level II registrants presenting antenatal problem by gestational age group, 2013.....	36
<b>Table 10:</b> Mode of transport to level III NICU after birth for level III registrants by gestational age group, 2013.....	15	<b>Table 34:</b> Antenatal corticosteroid use by mothers of level II registrants by gestational age group, 2013.....	37
<b>Table 11:</b> Apgar scores at birth for level III registrants by gestational age group, 2013.....	16	<b>Table 35:</b> Method of delivery for level II registrants by gestational age group, 2013.....	37
<b>Table 12:</b> Median admission temperature and interquartile ranges for level III registrants by gestational age group, 2013.....	17	<b>Table 36:</b> Indication for respiratory support for level II registrants by gestational age group, 2013.....	38
<b>Table 13:</b> Indication for respiratory support for level III registrants by gestational age, 2013.....	18	<b>Table 37:</b> Duration of assisted ventilation use by level II registrants by gestational age group, 2013.....	39
<b>Table 14:</b> Exogenous surfactant use for level III registrants by gestational age group, 2013.....	19	<b>Table 38:</b> Survival to discharge home for level II registrants by gestational age group, 2013.....	40
<b>Table 15:</b> Duration of assisted ventilation use by level III registrants by gestational age group, 2013.....	20	<b>Table 39:</b> Births, survival and 2–3 year follow-up of extremely preterm and/or extremely low birthweight infants by gestational age, 2009–2010 births.....	42
<b>Table 16:</b> Assisted ventilation for level III registrants by gestational age group, 2013.....	20	<b>Table 40:</b> Births, survival and 2–3 year follow-up of extremely preterm and/or extremely low birthweight infants by birthweight, 2009–2010 births.....	42
<b>Table 17:</b> Respiratory support (airway support or supplemental oxygen therapy) for level III registrants who survived to day 28 by gestational age group, 2013.....	22	<b>Table 41:</b> Cerebral Palsy at 2–3 year follow-up by gestational age, 2009–2010 births.....	44
<b>Table 18:</b> Nasal high flow respiratory support for level III registrants by gestational age group, 2013.....	23	<b>Table 42:</b> Cognitive delay at 2–3 year follow-up by gestational age for Bayley, Griffiths and WPPSI assessments, 2009–2010 births.....	46
<b>Table 19:</b> Total parenteral nutrition for level III registrants by gestational age, 2013.....	23	<b>Table 43:</b> Language delay at 2–3 year follow-up by gestational age for Bayley and Griffiths assessments, 2009–2010 births.....	46
<b>Table 20:</b> Chronic lung disease for level III registrants by gestational age, 2013.....	24	<b>Table 44:</b> Motor delay at 2–3 year follow-up by gestational age for Bayley and Griffiths assessments, 2009–2010 births.....	47
<b>Table 21:</b> Pulmonary air leak for level III registrants by gestational age group, 2013.....	25	<b>Table 45:</b> Severity of functional impairment at 2–3 year follow-up by gestational age, 2009–2010 births.....	48
<b>Table 22:</b> Neonatal sepsis for level III registrants by gestational age group, 2013.....	25	<b>Table 46:</b> Infants with or without moderate to severe functional impairment at 2–3 year follow-up by gestational age, 2009–2010 births.....	49
<b>Table 23:</b> Retinopathy of prematurity for level III registrants by gestational age, 2013.....	26	<b>Table 47:</b> Weight for age at 2–3 year follow-up by gestational age, 2009–2010 births.....	50
<b>Table 24:</b> Intraventricular haemorrhage for level III registrants born before 32 weeks and survived to day 3 by gestational age, 2013.....	27		

<b>Table 48:</b> Height for age at 2–3 year follow-up by gestational age, 2009–2010 births.....	50
<b>Table 49:</b> Head circumference for age at 2–3 year follow-up by gestational age, 2009–2010 births .....	51
<b>Table 50:</b> Weight for height at 2–3 year follow-up by gestational age, 2009–2010 births.....	51
<b>Table 51:</b> Antenatal corticosteroid use for level III registrants by birthweight group, 2013 .....	62
<b>Table 52:</b> Plurality of level III registrants by birthweight group, 2013.....	62
<b>Table 53:</b> Method of birth for level III registrants by birthweight group, 2013 .....	63
<b>Table 54:</b> Level of hospital of birth for level III registrants by birthweight group, 2013 .....	63
<b>Table 55:</b> Mode of transport for level III registrants to level III unit after birth by birthweight group, 2013 .....	64
<b>Table 56:</b> Exogenous surfactant use by level III registrants by birthweight group, 2013 .....	64
<b>Table 57:</b> Assisted ventilation for level III registrants by birthweight group, 2013 .....	65

<b>Table 58:</b> Medians and interquartile ranges of assisted ventilation for level III registrants by birthweight group, 2013 .....	65
<b>Table 59:</b> Chronic lung disease for level III registrants by birthweight group, 2013 .....	66
<b>Table 60:</b> Respiratory support (airway support or supplemental oxygen therapy) for level III registrants who survived to day 28 by birthweight group, 2013 .....	66
<b>Table 61:</b> Transfer after registration of level III registrants by level of destination hospital by birthweight group, 2013.....	67
<b>Table 62:</b> Retinopathy of prematurity for level III registrants by birthweight group, 2013 .....	67
<b>Table 63:</b> Intraventricular haemorrhage for level III registrants survived to day 3 by birthweight group, 2013 <sup>(a)</sup> .....	68
<b>Table 64:</b> Neonatal sepsis for level III registrants by birthweight group, 2013 .....	68
<b>Table 65:</b> Median length of stay for level III registrants who survived until discharge home by birthweight group, 2013 ....	69
<b>Table 66:</b> Survival to discharge home for level III registrants by birthweight group, 2013 .....	69



# List of Figures

<b>Figure 1:</b> Schematic flow chart of ANZNN .....	2	<b>Figure 17:</b> Trends in mode of assisted ventilation for level III registrants, 2004–2013 .....	57
<b>Figure 2:</b> Babies registered to ANZNN audit of level III units each year as a percentage of liveborn babies in Australia and New Zealand 2004–2013 .....	6	<b>Figure 18:</b> Trends in provision of intermittent positive pressure ventilation and continuous positive pressure ventilation by year of birth for level III registrants ventilated, 2004–2013.....	57
<b>Figure 3:</b> Number of level III registrants born at each neonatal intensive care unit, 2013 .....	7	<b>Figure 19:</b> Trends in the use of CPAP as the only form of ventilation by gestational age for level III registrants, 2004, 2007, 2010–2013 .....	58
<b>Figure 4:</b> Level III registrants by registration criteria, 2009–2013 .....	8	<b>Figure 20:</b> Trends in provision of high frequency oscillatory ventilation (with 95% CI) for level III registrants born before 28 weeks and at 28 or more weeks gestation, 2004–2013 ....	58
<b>Figure 5:</b> Presenting antenatal problem for mothers of level III registrants by gestational age group, 2013.....	11	<b>Figure 21:</b> Trends in nitric oxide (with 95% CI) provision for level III registrants born before 28 weeks and 28 or more weeks gestation, 2004–2013.....	59
<b>Figure 6:</b> Retinopathy of prematurity for level III registrants by gestational age, 2013 .....	26	<b>Figure 22:</b> Incidence of chronic lung disease (with 95% CI) for level III registrants by gestational age, 2013.....	59
<b>Figure 7:</b> Intraventricular haemorrhage in level III registrants born at less than 32 weeks gestation and survived to day 3, by gestational age, 2013 .....	27	<b>Figure 23:</b> Stage 3 or 4 retinopathy of prematurity and treated retinopathy among babies born before 31 weeks gestation and/or birthweight of less than 1,250 grams who survived to 36 weeks corrected age for level III registrants, 2005–2013.....	60
<b>Figure 8:</b> Survival of level III registrants to discharge home (with 95% CI) by gestational age, 2013 .....	34	<b>Figure 24:</b> Trends in grade 3 or 4 intraventricular haemorrhage (with 95% CI) in babies born at less than 32 weeks gestation who survived to day 3 for level III registrants, 2004–2013.....	60
<b>Figure 9:</b> Survival of level III registrants to discharge home (with 95% CI) by birthweight group, 2013 .....	34	<b>Figure 25:</b> Incidence of early sepsis for level III registrants by gestational age group, 2009–2013 .....	61
<b>Figure 10:</b> Flowchart of 2009–2010 follow-up cohort .....	41	<b>Figure 26:</b> Incidence of late sepsis for level III registrants by gestational age group, 2009–2013 .....	61
<b>Figure 11:</b> Trends in gestational age at birth of level III registrants, 2004–2013 .....	53		
<b>Figure 12:</b> Trends in the use of corticosteroids for mothers of babies less than 32 weeks gestation, 2004–2013.....	54		
<b>Figure 13:</b> Trends in multiple births of level III registrants by gestational age group, 2004–2013 .....	55		
<b>Figure 14:</b> Trends in method of birth for level III registrants by year of birth, 2004–2013 .....	55		
<b>Figure 15:</b> Trends in referral source to level III NICU by year of birth, 2004–2013.....	56		
<b>Figure 16:</b> Trends in mode of transport to level III NICU, 2004–2013 .....	56		