

# 2012

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



**UNSW**  
AUSTRALIA

**ANZNN**

# 2012

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## REPORT OF THE AUSTRALIAN AND NEW ZEALAND NEONATAL NETWORK

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# Acknowledgements

This is the seventeenth report of the Australian and New Zealand Neonatal Network (ANZNN), the fifth report in the new format and the first to include a report on 2-3 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 nine 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, Brian Darlow, Koert de Waal, Guan Koh, Kei Lui, Shelley Reid, Karen Simmer, Elizabeth Sullivan, Kenneth Tan, William Tarnow-Mordi 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), Ian Callander, David Cartwright, Deborah Donoghue, Lex Doyle, Lisa Hilder, Jim Holberton, Timothy Hong, Caroline Karskens, Peter Marshall and Elizabeth Sullivan. The newly formed Follow-up Subcommittee of Kei Lui (Chairperson), Lex Doyle, Liza Edmonds, Peter Gray, Noel French, Ross Haslam and Crista Wocadlo were instrumental in the ability to include for the first time a 2-3 year follow-up component. Particular acknowledgement goes to Renate Le Marsney for leading the data analysis and writing the inaugural 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 QHealth (Australia) and Douglas Pharmaceuticals (New Zealand) for their ongoing support and for helping us to achieve our aims. We also thank the Australian National Data Service (ANDS) for funding the development of the Data Capture System which now is a valuable tool as a portal for data submission and validation. We also thank the Leslie Stevens Fund for Newborn Care, Sydney Children's Hospital Foundation for infrastructure support (2008 to 2010), as well as the Royal Hospital for Women Foundation for funding development of the previous data validation program. We acknowledge our colleagues from the National Perinatal Epidemiology and Statistics Unit (formerly Perinatal & Reproductive Epidemiology Research Unit) for their continued technical 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 2012.
- Chapter 2:** ‘Babies registered to level III units’ provides information and characteristics on the ANZNN registrants in 2012 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 2012.
- Chapter 4:** ‘Characteristics of level III registrants’ provides information about the babies admitted to a level III neonatal unit during 2012.
- Chapter 5:** ‘Babies registered to level II units’ provides information about babies registered to the level II special care baby units during 2012.
- Chapter 6:** ‘Extremely preterm follow-up, 2009 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.
- Appendices:** Appendix 1 presents 10-year trends  
Appendix 2 presents data tables by birthweight for 2012  
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	IVH	intraventricular haemorrhage
ANZNN	Australian and New Zealand Neonatal Network	LOS	length of stay
APH	antepartum haemorrhage	MgSO <sub>4</sub>	magnesium sulphate
CI	confidence interval	NEC	necrotising enterocolitis
CLD	chronic lung disease	NHFT	nasal high flow therapy
CP	cerebral palsy	NHMRC	National Health and Medical Research Council
CPAP	continuous positive airways pressure	NICU	neonatal intensive care unit
CRIB	Clinical Risk Index for Babies	NPESU	National Perinatal Epidemiology and Statistics Unit
ECMO	extracorporeal membrane oxygenation	NO	nitric oxide
g	gram	O <sub>2</sub>	oxygen – normal air is 21% oxygen
GIFT	gamete intra-fallopian transfer	PMA	post menstrual age (completed weeks)
GIT	gastrointestinal tract	PPROM	preterm pre-labour rupture of membranes
GMFCS	gross motor function classification system	PRERU	Perinatal & Reproductive Epidemiology Research Unit
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
IVF	<i>in vitro</i> fertilisation	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

*(Nursery beds: 25)*

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

##### John Hunter Hospital

*(Nursery beds: 42)*

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

##### Liverpool Health Service

*(Nursery beds: 31)*

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

##### Nepean Hospital

*(Nursery beds: 35)*

Vijay Shingde (Director), Basiliki Lampropoulos,  
Jacqueline Furey, Mee Fong Chin

##### Royal Hospital for Women

*(Nursery beds: 44)*

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

##### Royal North Shore Hospital

*(Nursery beds: 25)*

Mary Paradisis (Director), Jennifer Bowen, Martin  
Kluckow, Linda Hayes-Cameron, Claire Jacobs

##### RPA Women and Babies

*(Nursery beds: 34)*

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

##### Sydney Children's Hospital

*(Nursery beds: 4)*

Andrew Numa (Director), Janelle Young

##### Westmead Hospital

*(Nursery beds: 41)*

Mark Tracy (Director), Melissa Luig, 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, Lynne  
Cruden

### Australian Capital Territory

#### The Canberra Hospital

*(Nursery beds: 25)*

Zsuzsoka Kecskes (Director), Alison Kent, Hazel  
Carlisle, Alana Carter, Lyn Barnes

### Victoria

#### Mercy Hospital for Women

*(Nursery beds: 56)*

Andrew Watkins (Director), Jim Holberton, Julie  
Keng

#### Monash Medical Centre

*(Nursery beds: 54)*

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

#### Royal Children's Hospital

*(Nursery beds: 28)*

Rod Hunt (Director), Jo Brooks

#### Royal Women's Hospital

*(Nursery beds: 57)*

Carl Kuschel (Director), Caroline Collis, Lex Doyle  
(Professor of Neonatology), Sheryle Rogerson,  
Esther Wong

### Tasmania

#### Royal Hobart Hospital

*(Nursery beds: 26)*

Peter Dargaville (Director), Karen Butterley

### Queensland

#### Mater Mothers' Hospital

*(Nursery beds: 79)*

David Knight (Director), Peter Gray, Elizabeth  
Hurrian, Chrissy Harbridge

## **Royal Brisbane and Women's Hospital**

*(Nursery beds: 71)*

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

## **The Townsville Hospital**

*(Nursery beds: 44)*

Guan Koh (Director), Gary Alcock, Jenny Binney, Louise McIlldowie, Cherie Boniface

## **South Australia**

### **Flinders Medical Centre**

*(Nursery beds: 35)*

Peter Marshall (Director), Rebecca Davis

### **Women's and Children's Hospital**

*(Nursery beds: 49)*

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

## **Western Australia**

### **King Edward Memorial and Princess Margaret Hospitals**

*(Nursery 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**

*(Nursery beds: 18)*

Charles Kilburn (Director), Alan Ruben, Gurmeet Singh, Margaret Stewart, Ajit Aiyappan, Manbir Chauhan, Sarah Thomas, Julie Furlan, 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

## **New Zealand**

### **Christchurch Women's Hospital**

*(Nursery beds: 38)*

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

### **Dunedin Hospital**

*(Nursery beds: 16)*

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

### **Middlemore Hospital**

*(Nursery beds: 30)*

Lindsay Mildenhall (Director), Maisie Wong, David Hou

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

*(Nursery beds: 46)*

Malcolm Battin (Director), Coila Bevan

### **Waikato Hospital**

*(Nursery beds: 41)*

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

### **Wellington Women's Hospital**

*(Nursery beds: 40)*

Vaughan Richardson (Director), Dawn Elder, Keith Fisher, Helen Miller, Michael Hewson

## Level II nurseries:

### Australia

#### New South Wales

##### Blacktown Hospital

*(Nursery beds: 24)*

Kavita Bhola (Co-director), Anjali Dhawan (Co-director), Therese Freeman

##### Campbelltown Hospital

*(Nursery beds: 15)*

Raymond Chin (Director), Melissa Cooke

##### Gosford District Hospital

*(Nursery beds: 25)*

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

##### St George Hospital

*(Nursery beds: 8)*

Bob Fonseca (Director), Helen Giles

##### Wollongong Hospital

*(Nursery beds: 20)*

Susie Piper (Director), Sylvia Lees

### Queensland

#### Cairns Base Hospital

*(Nursery beds: 22)*

Ross Messer (Director), Sue McMahon

#### Gold Coast Hospital

*(Nursery beds: 22)*

Peter Schmidt (Director), Timothy Hong, John Hyland

#### Mackay Base Hospital

*(Nursery beds: 4)*

Michael Williams (Director), Kerry Topping

### Tasmania

#### Launceston General Hospital

*(Nursery beds: 12)*

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

### Northern Territory

#### Alice Springs Hospital

*(Nursery beds: 8)*

Rose Fahy, Marion Bates

### New Zealand

#### Gisborne Hospital

*(Nursery beds: 6)*

Heinrich Stander (Director), Graeme Lear, Barbara Reid

#### Hawkes Bay Hospital

*(Nursery beds: 12)*

Jenny Corban (Director), Kay Hodson, Mercy Jensen

#### Lower Hutt Hospital

*(Nursery beds: 12)*

Robyn Shaw (Director), Debbie Bashaw, Anne Mitchell

#### Nelson Hospital

*(Nursery beds: 10)*

Peter McIlroy (Director), Nathalie Robinson, Maureen Higgs

#### North Shore Hospital

*(Nursery beds: 12)*

Jutta van den Boom (Director), Diane Chesney

#### Palmerston North Hospital

*(Nursery beds: 17)*

Jeff Brown (Director), Amy Hinder

#### Rotorua Hospital

*(Nursery beds: 10)*

Stephen Bradley (Director), Jacquie Koberstein, Gaye France

#### Southland Hospital

*(Nursery beds: 6)*

Ian Shaw (Director), Paul Tomlinson

#### Taranaki Base Hospital

*(Nursery beds: 8)*

John Doran (Director), Jane Bock

#### Tauranga Hospital

*(Nursery beds: 10)*

Hugh Lees (Director), Heather McAlley

#### Timaru Hospital

*(Nursery beds: 3)*

Philip Morrison (Director), Bid Esler, Mark Liddy

#### Wairau Hospital

*(Nursery beds: 4)*

David Bond (Director)

**Wanganui Hospital**

*(Nursery beds: 4)*

David Montgomery (Director), Barbara Hammond

**Whakatane Hospital**

*(Nursery beds: 5)*

Chris Moyes (Director), Margret Norris, Lee Willetts

**Whangarei Area Hospital**

*(Nursery beds: 8)*

Ransford Addo (Director), Janine Whale,  
Lynne Clarke

**Waitakere Hospital**

*(Nursery beds: 12)*

Jutta van den Boom (Director), Janis Stockman

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

Elizabeth Sullivan (Director), Sharon Chow, Sadia  
Hossain, Renate Le Marsney, Lisa Hilder

# 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 nine units contributing data in 2012.

## 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, formerly Perinatal & Reproductive Epidemiology Research Unit (PRERU)) 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.

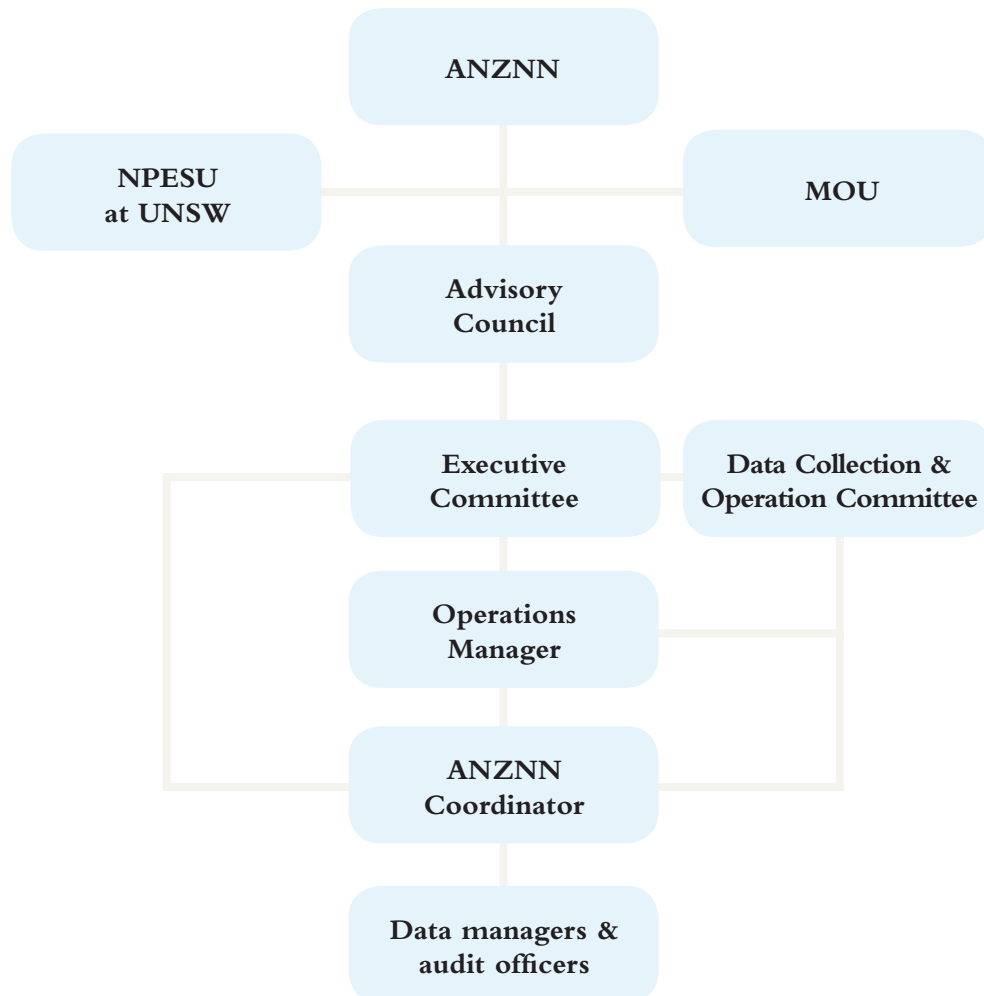
The Executive Committee is an elected committee that has regional representation from directors, a data manager group representative and neonatal nurse representatives from across the network. It is concerned with the general functioning of the network, finance and decision-making, as reported by the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

QHealth (Australia) and Douglas Pharmaceuticals (New Zealand) make an annual contribution and the ANZNN thanks them for their generosity and support. The ANZNN also thanks the Australian National Data Service (ANDS) for funding the development of the Data Capture System which now is a valuable tool as a portal for data submission and validation. The ANZNN also thanks the Leslie Stevens Fund for Newborn Care, Sydney Children's Hospital Foundation for infrastructure support (2008 to 2010), as well as the Royal Hospital for Women Foundation for funding development of the previous data validation program.

## **Data set variables**

The variables used for the 2012 audit are listed in Appendix 5 and are also available on the website <http://www.npesu.unsw.edu.au/data-collection/australian-new-zealand-neonatal-network-anznn>.



# 2012

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REPORT OF THE  
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NEONATAL NETWORK**

## Babies born in Australia

There were 7,452 babies registered to the ANZNN from 21 level III NICUs in Australia, representing 2.4% of notified live births in 2012 (Australian Bureau of Statistics 2012). Of these registrants, 75.4% were born in a hospital with tertiary care facilities. There were 2,899 babies born before 32 weeks gestation representing 38.9% of Australian registrants.

Maternal ethnicity was provided for 96.9% of mothers: 76.8% of the mothers of these babies identified as Caucasian and 12.2% as Asian. Over one in twenty mothers (5.5%) identified as Aboriginal or Torres Strait Islander compared to 5.9% of all births in Australia in 2012 (Australian Bureau of Statistics 2012).

Among Australian NICU admissions registered to the ANZNN, 1,420 were from multiple births representing 19.1% of ANZNN admissions in Australia in 2012.

Male babies were over-represented among NICU admissions – 59.2% of the Australian ANZNN registrants, compared with 51.4% among live births in Australia (Australian Bureau of Statistics 2012).

Assisted ventilation was provided for 6,899 babies (2.2% of live births) and continuous positive airways pressure (CPAP) was the only form of respiratory assistance for 3,422 babies.

## Babies born in New Zealand

There were 1,864 babies who met ANZNN registration criteria from six level III NICUs in New Zealand representing 3.0% of the 61,178 live births registered in New Zealand in 2012 (Statistics New Zealand 2012). Of these registrants, 88.4% were born in a hospital with tertiary care facilities. There were 621 babies born before 32 weeks gestation representing 33.3% of New Zealand registrants.

Maternal ethnicity was reported for 99.5% of the New Zealand registrants. The percentage of Caucasian mothers was 52.5%. A higher proportion of mothers identified themselves as Maori (20.2%) compared to 12.1% of mothers identified as Pacific Islander and 11.5% as Asian.

Among New Zealand NICU admissions registered to the ANZNN, 304 were from multiple births representing 16.3% of ANZNN admissions in New Zealand in 2012.

Male babies were also over-represented among NICU admissions in New Zealand – 56.4% of the New Zealand registrants compared to 51.1% of total live births in New Zealand (Statistics New Zealand 2012).

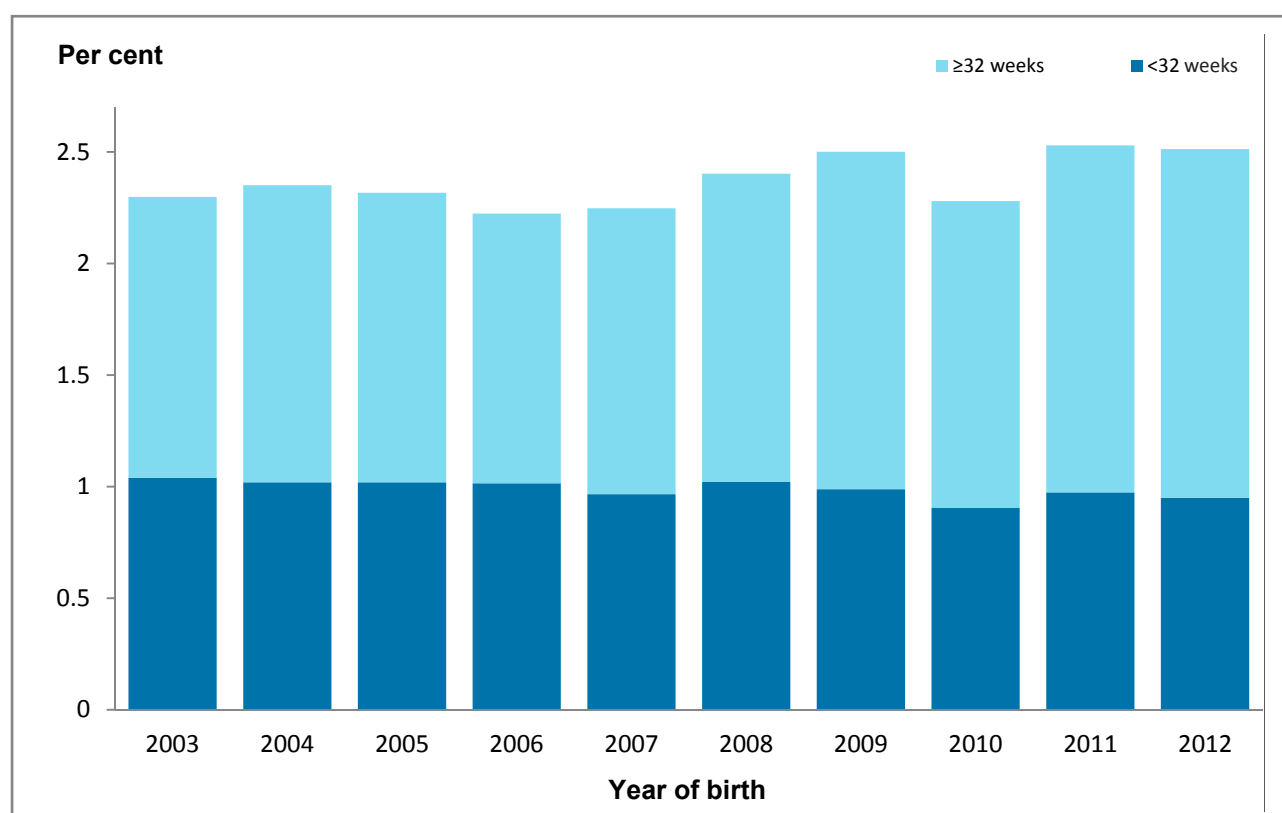
Assisted ventilation was given to 1,798 babies representing 2.4% of all live births with 1,145 babies receiving CPAP as the only form of respiratory assistance (1.9% of all live births).

## 2. Babies registered to level III units

This section includes data on the ANZNN registrants from 27 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 2012, 9,316 fulfilled the registration criteria for inclusion in the ANZNN audit. The population represents 2.5% of the 370,760 live births in the two countries in 2012 (Australian Bureau of Statistics 2012; Statistics New Zealand 2012) (Figure 2) illustrating an increase of 134 registrants from 2011 (2.5% of all live births). It should be noted that data on the ANZNN registrants from one level III NICU was unable to be included before the publication of this report. When available, these data will be included into the data collection for future trend analyses.

**FIGURE 2: Babies registered to ANZNN audit of level III units each year as a percentage of liveborn babies in Australia and New Zealand 2003-2012**



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

There were 3,520 (37.8 %) babies born before 32 weeks gestation and 5,796 babies born at 32 weeks or more (62.2%). Of the registrants born before 32 weeks gestation 94.1% 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 over 1,000 babies in 2012, the smallest just over 50 (Figure 3). The median number of babies registered to an ANZNN unit was 315.

The gestational age group at birth and birthweight for babies qualifying for inclusion in the ANZNN 2012 level III audit is set out in Tables 1 and 2 respectively. The 10-year trend (2003–2012) in gestational age at birth is presented in Figure 10 in Appendix 1.

FIGURE 3: Number of level III registrants born at each neonatal intensive care unit, 2012

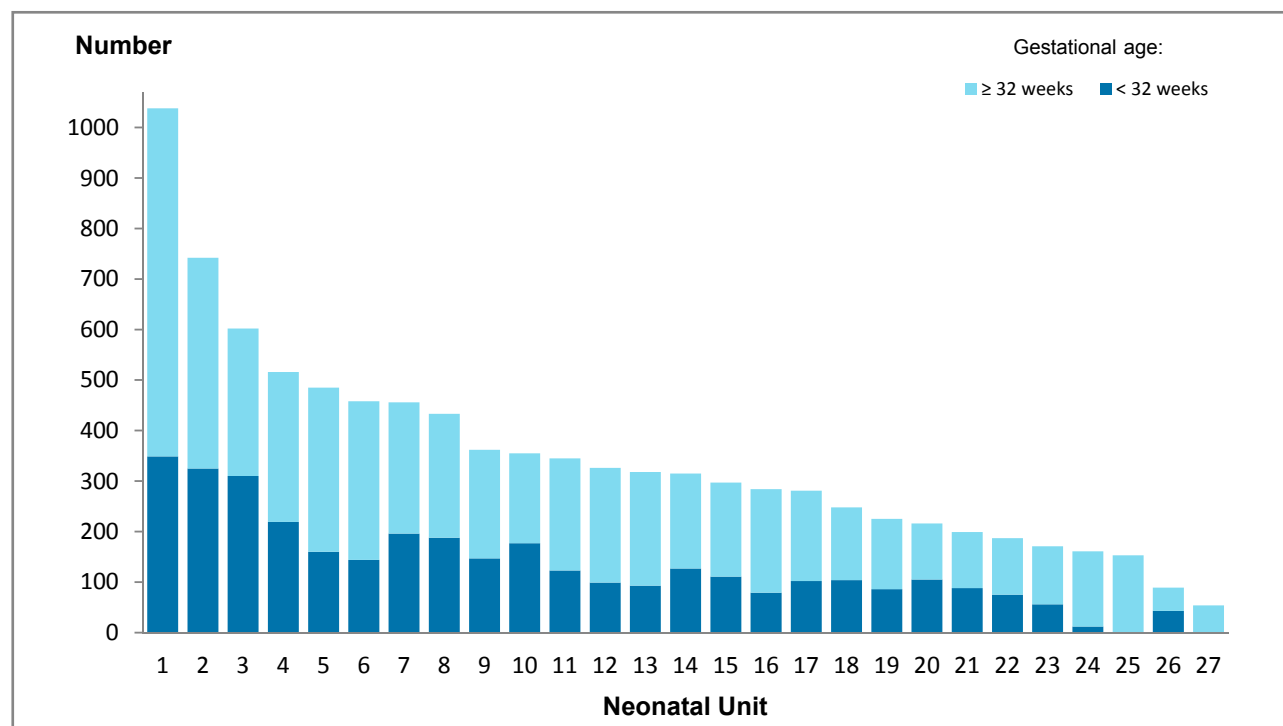


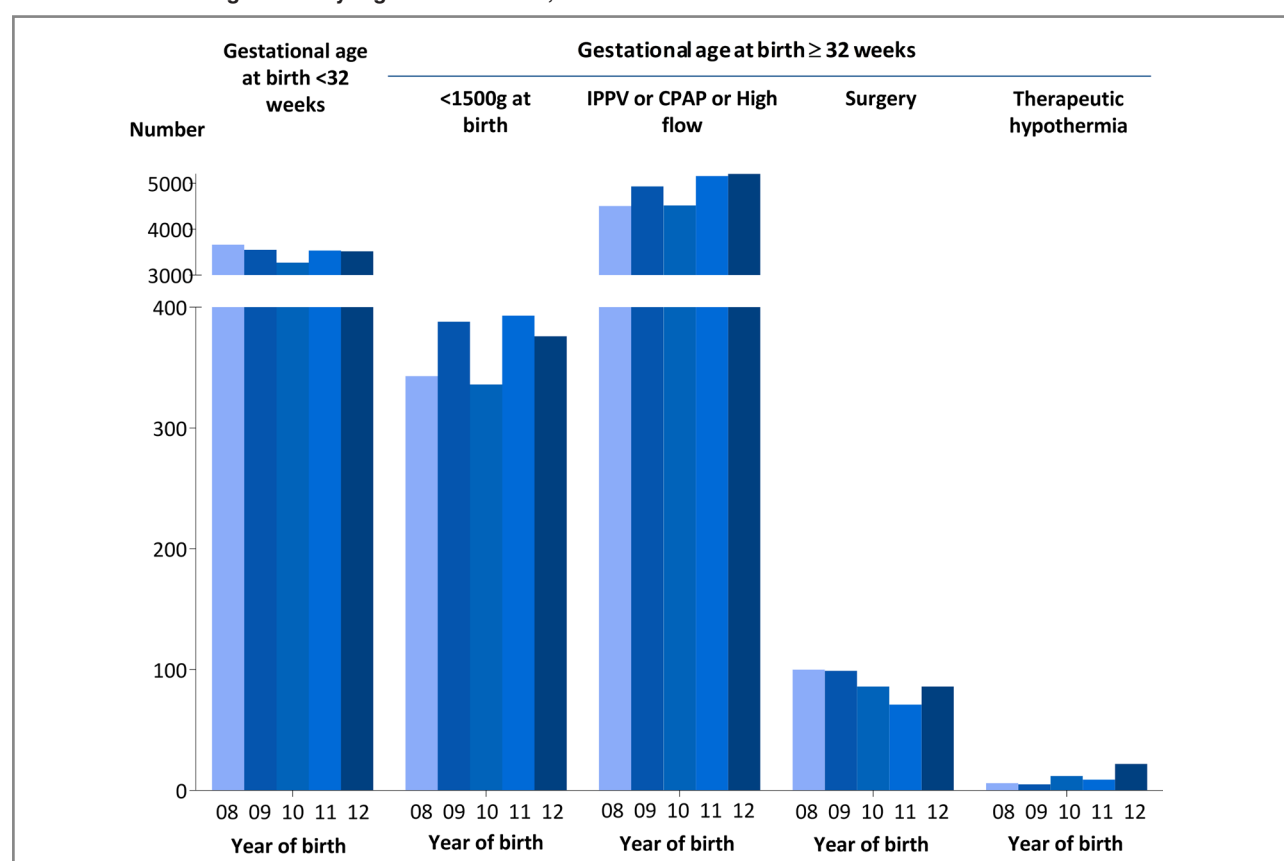
TABLE 1: Level III registrants born at each completed week of gestation, 2012

Gestational age (completed weeks)	Number of babies	Percent	Cumulative percent
<24	58	0.6	0.6
24	155	1.7	2.3
25	249	2.7	5.0
26	286	3.1	8.0
27	323	3.5	11.5
28	468	5.0	16.5
29	553	5.9	22.5
30	631	6.8	29.2
31	797	8.6	37.8
<b>All babies &lt;32 weeks</b>	<b>3,520</b>	<b>37.8</b>	
32	744	8.0	45.8
33	608	6.5	52.3
34	672	7.2	59.5
35	533	5.7	65.2
36	487	5.2	70.5
37	534	5.7	76.2
38	627	6.7	82.9
39	598	6.4	89.3
40	588	6.3	95.7
41	376	4.0	99.7
42	24	0.3	99.9
≥43	5	0.1	100.0
<b>Total</b>	<b>9,316</b>	<b>100.0</b>	

**TABLE 2: Level III registrants in each birthweight group, 2012**

Birth weight (grams)	Number of babies	Percent	Cumulative percent
<500	38	0.4	0.4
500–599	82	0.9	1.3
600–699	188	2.0	3.3
700–799	210	2.3	5.6
800–899	275	3.0	8.5
900–999	290	3.1	11.6
1,000–1,099	322	3.5	15.1
1,100–1,199	321	3.4	18.5
1,200–1,299	394	4.2	22.8
1,300–1,399	412	4.4	27.2
1,400–1,499	449	4.8	32.0
<b>All babies &lt;1,500g birthweight</b>	<b>2,981</b>	<b>32.0</b>	
1,500–1,999	1,598	17.2	49.2
2,000–2,499	1,237	13.3	62.4
2,500–2,999	1,076	11.6	74.0
3,000–3,499	1,191	12.8	86.8
3,500–3,999	818	8.8	95.5
≥4,000	415	4.5	100.0
<b>Total</b>	<b>9,316</b>	<b>100.0</b>	

**FIGURE 4: Level III registrants by registration criteria, 2008–2012**



*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 2012, the age of mothers of neonates registered as high-risk ranged from less than 15 years to just over 55 years. The highest proportion of registrant mothers was aged 30–34 years (28.8%) followed by mothers aged 25–29 years (25.8%). Together they accounted for more than half of the mothers (54.6%) of ANZNN registrants in 2012 (Table 3). In 2012, the proportion of babies born to teenage mothers decreased slightly (0.1%) from 2011, while those born to mothers in the 35–39 age group decreased by 0.5%, from 19.4% in 2011 to 18.9%.

Two in five of the babies born to teenage mothers (41.0%) were born at less than 32 weeks completed gestation, while 37.4% 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, 2012**

Maternal age (years)	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
Number									
Less than 20	n.p.	n.p.	34	57	59	56	76	133	449
20–24	11	74	96	158	209	184	254	428	1,414
25–29	14	92	174	272	353	324	436	704	2,369
30–34	19	111	163	276	419	395	451	809	2,643
35–39	5	76	89	177	294	289	323	480	1,733
40 and over	<5	n.p.	50	80	83	82	113	141	572
Not stated	0	3	3	1	11	22	39	57	136
Total	58	404	609	1,021	1,428	1,352	1,692	2,752	9,316
Per cent									
Less than 20	n.p.	n.p.	5.6	5.6	4.2	4.2	4.6	4.9	4.9
20–24	19.0	18.5	15.8	15.5	14.7	13.8	15.4	15.9	15.4
25–29	24.1	22.9	28.7	26.7	24.9	24.4	26.4	26.1	25.8
30–34	32.8	27.7	26.9	27.1	29.6	29.7	27.3	30.0	28.8
35–39	8.6	19.0	14.7	17.4	20.7	21.7	19.5	17.8	18.9
40 and over	n.p.	n.p.	8.3	7.8	5.9	6.2	6.8	5.2	6.2
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.

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

### Previous antenatal history

In 2012, a previous preterm delivery was reported by 1,056 mothers (11.3%) of babies registered to ANZNN while 334 mothers (3.6%) 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 750 (8.1%) pregnancies resulting from assisted conception in the ANZNN 2012 cohort with most (80.5%) the result of IVF treatment. Of the pregnancies resulting from assisted conception, 52.4% of the mothers were more than 34 years of age at the time of giving birth, compared with 44.4% in 2011.

## 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 99.2% of 2012 ANZNN registrants. The mothers of one-quarter of registrants (23.6%) presented with preterm labour while fetal distress was the second highest (13.2%) 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 (37.0% and 31.1% respectively) followed by preterm pre-labour rupture of membranes (19.1% and 14.0% respectively).

Overall 88.6% of mothers of registrants had a pregnancy complication recorded. Among women who gave birth at term, nearly two in five (38.0%) were recorded as having no maternal presenting antenatal problem.

**TABLE 4: Mother's presenting antenatal problem for level III registrants by gestational age group, 2012**

	Gestational age group								
Presenting antenatal problem	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
	Number								
No antenatal problems	0	0	0	0	0	0	9	1,046	1,055
Preterm pre-labour rupture of membranes (PROM)	9	85	130	191	257	217	235	38	1,162
Preterm labour	37	217	243	351	451	350	523	11 <sup>(a)</sup>	2,183
Hypertension in pregnancy	0	28	64	130	212	225	179	100	938
Antepartum haemorrhage (APH)	7	34	85	121	160	137	144	73	761
Intrauterine growth restriction (IUGR)	n.p.	<5	23	53	89	128	115	69	480
Fetal distress	<5	n.p.	42	104	137	124	167	616	1,217
Other problem	2	12	21	65	114	154	206	483	1,057
Congenital anomalies	0	0	0	5	6	13	104	263	391
Not stated	0	1	1	1	2	4	10	53	72
<b>Total</b>	<b>58</b>	<b>404</b>	<b>609</b>	<b>1,021</b>	<b>1,428</b>	<b>1,352</b>	<b>1,692</b>	<b>2,752</b>	<b>9,316</b>
	Per cent								
No antenatal problems	0.0	0.0	0.0	0.0	0.0	0.0	0.5	38.8	11.4
Preterm pre-labour rupture of membranes (PROM)	15.5	21.1	21.4	18.7	18.0	16.1	14.0	1.4	12.6
Preterm labour	63.8	53.8	40.0	34.4	31.6	26.0	31.1	0.4	23.6
Hypertension in pregnancy	0.0	6.9	10.5	12.7	14.9	16.7	10.6	3.7	10.1
Antepartum haemorrhage (APH)	12.1	8.4	14.0	11.9	11.2	10.2	8.6	2.7	8.2
Intrauterine growth restriction (IUGR)	n.p.	n.p.	3.8	5.2	6.2	9.5	6.8	2.6	5.2
Fetal distress	n.p.	n.p.	6.9	10.2	9.6	9.2	9.9	22.8	13.2
Other problem	3.4	3.0	3.5	6.4	8.0	11.4	12.2	17.9	11.4
Congenital anomalies	0.0	0.0	0.0	0.5	0.4	1.0	6.2	9.7	4.2
<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>	<b>100.0</b>	<b>100.0</b>

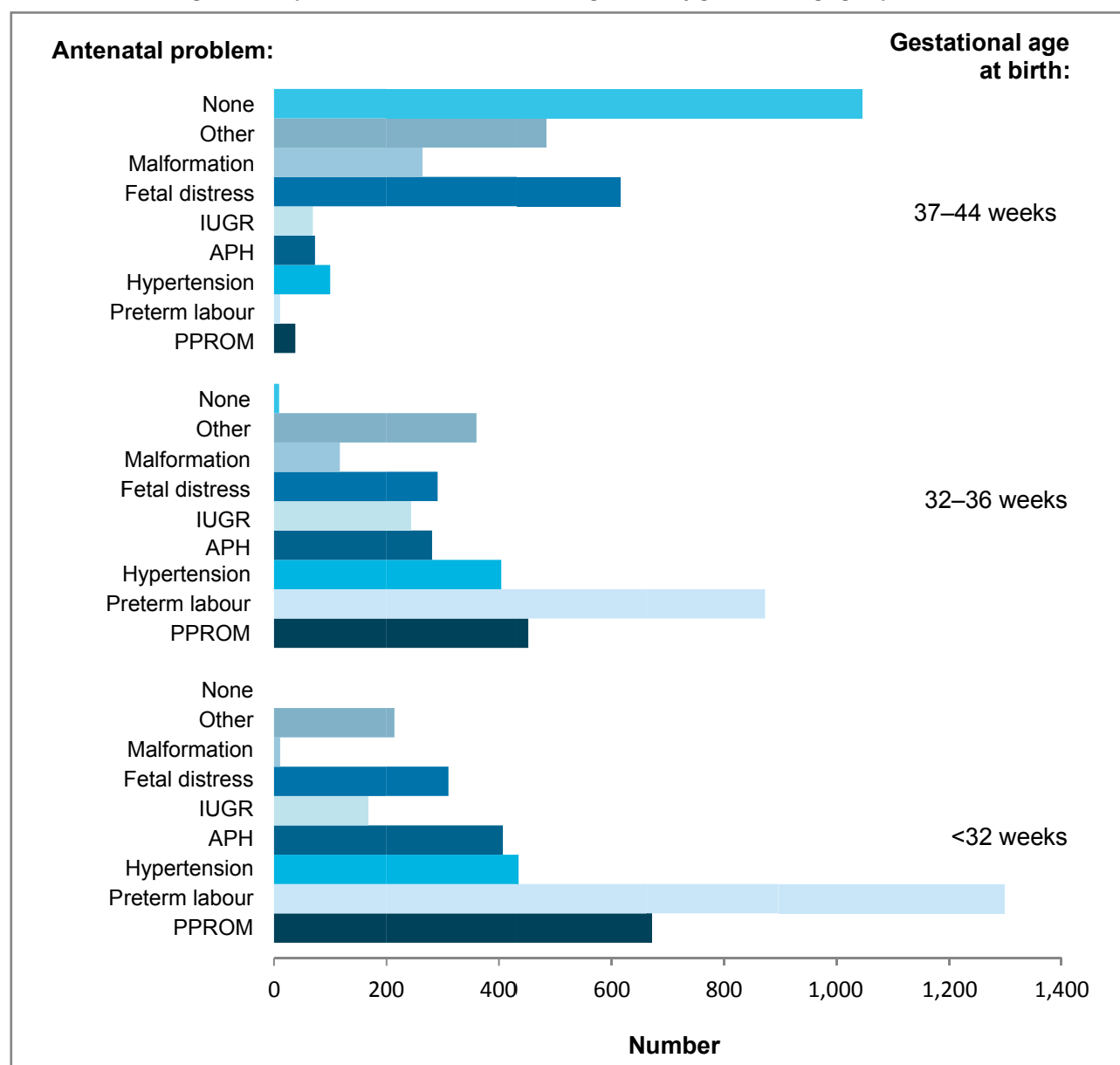
*n.p.* Data not published to maintain confidentiality of small numbers.

*(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, 2012**



## 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 2012, 85.6% of mothers of ANZNN registrants born before 34 weeks of gestation received one or more doses of antenatal corticosteroids leaving 14.4% of mothers of registrants in this group who did not report receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 17.0% received them more than seven days prior to giving birth.

For mothers of ANZNN registrants born before 32 weeks of gestation, 87.0% received one or more doses of antenatal corticosteroids and 13.0% of mothers of registrants in this group did not report receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 15.7% received them more than seven days prior to giving birth (Table 5). The 10-year trend (2003–2012) for maternal corticosteroids is represented by Figure 11 in Appendix 1.



**TABLE 5: Antenatal corticosteroid use for mothers of level III registrants by gestational age group, 2012**

	Gestational age group								
Antenatal corticosteroids	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
	Number								
None	n.p.	n.p.	64	107	177	215	966	2,232	3,817
Incomplete course	19	125	146	239	373	330	157	16	1,405
Course completed	23	199	298	508	652	549	317	37	2,583
Completed >7 days prior to birth	<5	n.p.	90	152	205	227	176	40	924
Not stated	1	5	11	15	21	31	76	427	587
<b>Total</b>	<b>58</b>	<b>404</b>	<b>609</b>	<b>1,021</b>	<b>1,428</b>	<b>1,352</b>	<b>1,692</b>	<b>2,752</b>	<b>9,316</b>
	Per cent								
None	n.p.	n.p.	10.7	10.6	12.6	16.3	59.8	96.0	43.7
Incomplete course	33.3	31.3	24.4	23.8	26.5	25.0	9.7	0.7	16.1
Course completed	40.4	49.9	49.8	50.5	46.3	41.6	19.6	1.6	29.6
Completed >7 days prior to birth	n.p.	n.p.	15.1	15.1	14.6	17.2	10.9	1.7	10.6
<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>	<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.

## 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, 34.9% were given antenatal MgSO<sub>4</sub> (Table 6). Of these, 20.4% 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 the first year of collection for ANZNN.

**TABLE 6: Magnesium sulphate use for mothers of level III registrants by gestational age, 2012**

	Gestational age									
Magnesium sulphate	<24	24	25	26	27	28	29	30	31	Total
Number										
None	23	57	98	113	128	190	237	348	463	1,657
Complete course	<5	n.p.	22	31	39	54	54	33	38	288
Incomplete course or intramuscular injection	6	10	21	12	31	43	41	37	32	233
Given but details unknown	<5	n.p.	36	46	44	57	74	38	36	368
Not stated	21	42	72	84	81	124	147	175	228	974
Total	58	155	249	286	323	468	553	631	797	3,520
Per cent										
None	62.2	50.4	55.4	55.9	52.9	55.2	58.4	76.3	81.4	65.1
Complete course	n.p.	n.p.	12.4	15.3	16.1	15.7	13.3	7.2	6.7	11.3
Incomplete course or intramuscular injection	16.2	8.8	11.9	5.9	12.8	12.5	10.1	8.1	5.6	9.2
Given but details unknown	n.p.	n.p.	20.3	22.8	18.2	16.6	18.2	8.3	6.3	14.5
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.

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

## 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 2012, 18.5% of ANZNN registrants were reported as being from a multiple pregnancy, and of these, the greatest percentage were twins (92.6%). Of the 2012 ANZNN registrants from multiple births, 56.2% were born before 32 weeks gestation and 97.0% were born before 37 weeks gestation (Table 7). The 10-year trend (2003–2012) for multiple births is represented by Figure 12 in Appendix 1.

**TABLE 7: Plurality of level III registrants by gestational age group, 2012**

Plurality	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
	Number								
Singletons	39	314	449	731	1,018	956	1,384	2,701	7,592
Twins	n.p.	n.p.	147	270	368	357	299	51	1,597
Triplets and higher orders	n.p.	<5	13	20	42	39	9	0	127
<b>Total</b>	<b>58</b>	<b>404</b>	<b>609</b>	<b>1,021</b>	<b>1,428</b>	<b>1,352</b>	<b>1,692</b>	<b>2,752</b>	<b>9,316</b>
	Per cent								
Singletons	67.2	77.7	73.7	71.6	71.3	70.7	81.8	98.1	81.5
Twins	n.p.	n.p.	24.1	26.4	25.8	26.4	17.7	1.9	17.1
Triplets and higher orders	n.p.	n.p.	2.1	2.0	2.9	2.9	0.5	0.0	1.4
<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>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

## 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 2012 registrants (58.8%) the method of birth was caesarean section with 66.2% of caesarean sections occurring before the onset of labour. One-third of registrants (34.5%) 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 59.6% in 2011. The 2012 data show a decrease of 0.8% from 2011.

The most common method of birth for registrants born before 24 weeks gestation was vaginal birth (82.8%) (Table 8). The 10-year trend (2003–2012) for method of birth is represented by Figure 13 in Appendix 1.

**TABLE 8: Method of birth for level III registrants by gestational age group, 2012**

	Gestational age group								
Method of birth	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
Vaginal	48	221	198	307	435	344	535	1,113	3,201
Vaginal instrumental birth	n.p.	<5	12	18	50	54	107	372	615
Caesarean section in labour	<5	n.p.	178	216	260	212	322	567	1,840
Caesarean section no labour	6	98	221	478	678	740	719	671	3,611
Not stated	0	2	0	2	5	2	9	29	49
Total	58	404	609	1,021	1,428	1,352	1,692	2,752	9,316
Per cent									
Vaginal	82.8	55.0	32.5	30.1	30.6	25.5	31.8	40.9	34.5
Vaginal instrumental birth	n.p.	n.p.	2.0	1.8	3.5	4.0	6.4	13.7	6.6
Caesarean section in labour	n.p.	n.p.	29.2	21.2	18.3	15.7	19.1	20.8	19.9
Caesarean section no labour	10.3	24.4	36.3	46.9	47.6	54.8	42.7	24.6	39.0
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.

## 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 2012, 78.0% of all babies and 87.4% of babies less than 32 weeks gestation at birth were born in a tertiary centre equipped with an NICU; 21.4% of all ANZNN registrants were born in a non-tertiary hospital; while 0.6% 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, 2012**

	Gestational age group								
Level of birth hospital	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
Tertiary hospital	52	349	524	887	1,263	1,115	1,273	1,802	7,265
Non-tertiary hospital	6	n.p.	n.p.	125	154	229	413	929	1,991
Not born in a hospital <sup>(a)</sup>	0	<5	<5	9	11	8	5	20	58
Not stated	0	0	0	0	0	0	1	1	2
<b>Total</b>	<b>58</b>	<b>404</b>	<b>609</b>	<b>1,021</b>	<b>1,428</b>	<b>1,352</b>	<b>1,692</b>	<b>2,752</b>	<b>9,316</b>
Per cent									
Tertiary hospital	89.7	86.4	86.0	86.9	88.4	82.5	75.3	65.5	78.0
Non-tertiary hospital	10.3	n.p.	n.p.	12.2	10.8	16.9	24.4	33.8	21.4
Not born in a hospital <sup>(a)</sup>	0.0	n.p.	n.p.	0.9	0.8	0.6	0.3	0.7	0.6
<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>	<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.

## 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 2012, 23.9% of ANZNN registrants were transferred to an NICU after birth. Of these the greatest percentage (81.5%) were transported by a specialist team with 14.8% transported by a non-specialist team (Table 10). The 10-year trend (2003–2012) for mode of transport to level III unit is represented by Figure 15 in Appendix 1.

**TABLE 10: Mode of transport to level III NICU after birth for level III registrants by gestational age group, 2012**

	Gestational age group								
Mode of Transport	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
Not transported	49	344	522	885	1,249	1,101	1,234	1,687	7,071
Specialist retrieval team	7	43	79	101	151	204	396	830	1,811
Non-specialist team	0	8	6	28	16	32	50	189	329
Other	2	7	2	6	10	11	9	34	81
Not stated	0	2	0	1	2	4	3	12	24
Total	58	404	609	1,021	1,428	1,352	1,692	2,752	9,316
Per cent									
Not transported	84.5	85.6	85.7	86.8	87.6	81.7	73.1	61.6	76.1
Specialist retrieval team	12.1	10.7	13.0	9.9	10.6	15.1	23.4	30.3	19.5
Non-specialist team	0.0	2.0	1.0	2.7	1.1	2.4	3.0	6.9	3.5
Other	3.4	1.7	0.3	0.6	0.7	0.8	0.5	1.2	0.9
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 99.3% 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, 72.9% were breastfed at discharge. The rate of breastfeeding at discharge of surviving extremely preterm babies (born at less than 28 weeks gestation) was 63.3% compared to 75.2% 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 51.3% of combined live births in both countries in 2012 (Australian Bureau of Statistics 2012; Statistics New Zealand 2012). The percentage was higher among ANZNN registrants with male births representing 58.6%. Gender was not available for five babies. For births at less than 32 weeks gestation, 55.4% were male; of births at term, 61.2% 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; 22.8% of registrants were intubated in the delivery suite to establish independent respiration and heart rate. For babies born before 32 weeks the percentage was 40.1% and for babies born at term the percentage was 14.6%.

### 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 17.4% of ANZNN registrants, with 3.8% 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, 40.2% of babies were born at less than 32 weeks and 36.7% were born at term (Table 11).

**TABLE 11: Apgar scores at birth for level III registrants by gestational age group, 2012**

Table 1. Apgar scores at birth for term infants by gestational age group, 2012									
Apgar score	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
Number									
Apgar at 1 minute									
Apgar < 4	31	152	144	167	154	148	224	591	1,611
Apgar 4–7	n.p.	n.p.	363	565	713	620	630	958	4,078
Apgar ≥ 8	<5	n.p.	99	278	551	578	827	1,183	3,554
Not Stated	2	10	3	11	10	6	11	20	73
Total	58	404	609	1,021	1,428	1,352	1,692	2,752	9,316
Number									
Apgar at 5 minutes									
Apgar < 4	10	32	28	27	25	19	44	167	352
Apgar 4–7	34	214	253	293	302	303	387	828	2,614
Apgar ≥ 8	12	148	326	690	1,091	1,025	1,253	1,741	6,286
Not Stated	2	10	2	11	10	5	8	16	64
Total	58	404	609	1,021	1,428	1,352	1,692	2,752	9,316

*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 all ANZNN registrants in 2012. 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 35.8°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, 2012**

Gestational age group	Number of babies	Temperature	
		Median	Inter quartile range
<24	58	35.8	34.9–36.2
24–25	404	36.2	35.5–36.6
26–27	609	36.4	35.9–36.8
28–29	1,021	36.5	36.0–36.9
30–31	1,428	36.4	36.0–36.8
32–33	1,352	36.4	36.0–36.7
34–36	1,692	36.5	36.1–36.8
37–44	2,752	36.6	36.2–37.0
<b>Total</b>	<b>9,316</b>	<b>36.5</b>	<b>36.0–36.8</b>

## Indication for respiratory support

In 2012, only 5.1% 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 43.6%. Non-specific respiratory distress accounted for 31.7% of babies, surgery for 4.1%, while meconium aspiration syndrome accounted for 3.5% (Table 13).

For babies born before 37 weeks gestation, HMD (57.3%) remained the most common indication for respiratory support. For babies born at term, non-specific respiratory distress (40.0%) was the most common indication followed by meconium aspiration (11.6%) and surgery (9.3%) (Table 13). The 10-year trend (2003–2012) for mode of assisted ventilation is represented by Figure 16 in Appendix 1.

**TABLE 13: Indication for respiratory support for level III registrants by gestational age, 2012**

Indication for respiratory support	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
	Number								
No respiratory support	0	<5	<5	20	156	103	78	106	468
Non-specific respiratory distress	0	15	36	134	365	538	756	1,064	2,908
Hyaline membrane disease	55	359	544	828	824	609	542	236	3,997
Meconium aspiration syndrome	0	0	0	0	<5	n.p.	7	310	323
Pneumonia	0	0	<5	0	<5	<5	15	64	85
Persistent pulmonary hypertension	<5	0	<5	<5	<5	6	11	105	129
Apnoea	<5	n.p.	20	26	42	26	31	44	216
Congenital anomaly	0	0	0	5	9	17	51	191	273
Other	0	0	1	3	7	16	30	97	154
Peri-surgery	<5	0	0	<5	6	16	104	248	376
Newborn encephalopathy	0	0	0	<5	<5	<5	40	198	246
Not stated	0	3	0	1	11	10	27	89	141
<b>Total</b>	<b>58</b>	<b>404</b>	<b>609</b>	<b>1,021</b>	<b>1,428</b>	<b>1,352</b>	<b>1,692</b>	<b>2,752</b>	<b>9,316</b>
	Per cent								
No respiratory support	0.0	n.p.	n.p.	2.0	10.9	7.6	4.6	3.9	5.1
Non-specific respiratory distress	0.0	3.7	5.9	13.1	25.8	40.1	45.4	40.0	31.7
Hyaline membrane disease	94.8	89.5	89.3	81.2	58.2	45.4	32.6	8.9	43.6
Meconium aspiration syndrome	0.0	0.0	0.0	0.0	n.p.	n.p.	0.4	11.6	3.5
Pneumonia	0.0	0.0	n.p.	0.0	n.p.	n.p.	0.9	2.4	0.9
Persistent pulmonary hypertension	n.p.	0.0	n.p.	n.p.	n.p.	0.4	0.7	3.9	1.4
Apnoea	n.p.	n.p.	3.3	2.5	3.0	1.9	1.9	1.7	2.4
Congenital anomaly	0.0	0.0	0.0	0.5	0.6	1.3	3.1	7.2	3.0
Other	0.0	0.0	0.2	0.3	0.5	1.2	1.8	3.6	1.7
Peri-surgery	n.p.	0.0	0.0	n.p.	0.4	1.2	6.2	9.3	4.1
Newborn encephalopathy	0.0	0.0	0.0	n.p.	n.p.	n.p.	2.4	7.4	2.7
<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.

## 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 2012, one-third of ANZNN registrants (32.1%) were administered exogenous surfactant (Table 14). There were 2,400 babies who received IPPV for HMD in 2012. Exogenous surfactant was given to 2,251 of these babies (93.8%). There were 149 babies diagnosed with HMD who were not given exogenous surfactant.

**TABLE 14: Exogenous surfactant use for level III registrants by gestational age group, 2012**

Exogenous surfactant	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
	Number								
None	<5	n.p.	85	391	929	1,031	1,354	2,481	6,293
Curosurf	49	331	437	497	396	239	245	181	2,375
Survanta	n.p.	41	80	121	93	n.p.	82	71	568
Curosurf and Survanta	0	6	<5	<5	<5	5	<5	6	32
Other or unknown surfactant	0	<5	<5	n.p.	n.p.	<5	<5	6	30
Not stated	0	2	0	3	0	1	5	7	18
Total	58	404	609	1,021	1,428	1,352	1,692	2,752	9,316
Per cent									
None	n.p.	n.p.	14.0	38.4	65.1	76.3	80.3	90.4	67.7
Curosurf	84.5	82.3	71.8	48.8	27.7	17.7	14.5	6.6	25.5
Survanta	n.p.	10.2	13.1	11.9	6.5	n.p.	4.9	2.6	6.1
Curosurf and Survanta	0.0	1.5	n.p.	n.p.	n.p.	0.4	n.p.	0.2	0.3
Other or unknown surfactant	0.0	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	0.2	0.3
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.

## 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 2012, 93.4% 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 (2003–2012) for assisted ventilation is represented in Figures 16 to 18 in Appendix 1.

In 2012, IPPV was given for a total of 543,622 hours to ANZNN registrants and CPAP was given for 1,605,095 hours. The total number of hours of ventilation equates to each baby receiving 9.6 days of assisted ventilation. The median number of days 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 2012 remains CPAP with 49.0% of registrants receiving CPAP only, 12.1% receiving IPPV only and 32.2% 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 2012, 13.8% of registrants who received IPPV also received HFOV. However, 29 babies received HFOV without at least four hours of IPPV. The use of HFOV among individual units varied between 0.7% and 14.9% with the highest percentage of babies receiving HFOV born at less than 24 weeks (55.2%) followed by babies born at 24–25 weeks gestation (41.9%) (Table 16). The 10-year trend (2003–2012) for HFOV is represented in Figure 19 in Appendix 1.

**TABLE 15: Duration of assisted ventilation use by level III registrants by gestational age group, 2012**

Median & Interquartile range	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
IPPV (hours)									
Median	290	293	54	23	19	25	39	47	40
IQR	80–860	73–622	16–184	10–68	9–45	12–69	17–88	21–100	15–113
CPAP (hours)									
Median	767.5	1067	822	236	59	31	21	16	41
IQR	405.5–1,281	671–1,354.5	48–1,101	73.5–592.5	21.5–134	13–71	10–49	8–39	13–146

*Note: IQR = Interquartile range*

In 2012, 14 registrants received ECMO of whom the majority were born at term. The percentage of ANZNN registrants who received nitric oxide (NO) was 4.8%. The use of NO continues to have a U-shaped distribution with the highest percentage of babies to receive NO born at term (19.0%) (Table 16). The 10-year trend (2003–2012) for NO is represented in Figure 20 in Appendix 1.

**TABLE 16: Assisted ventilation for level III registrants by gestational age group, 2012**

	Gestational age group								
Ventilation type	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
CPAP given	36	348	572	959	1,207	1,139	1,352	1,954	7,567
Invasive ventilation	58	382	501	594	472	369	580	1,203	4,159
▪ IPPV given	58	378	498	589	471	366	580	1,190	4,130
▪ HFOV given	32	160	84	66	30	32	47	146	597
NO given	6	59	37	33	18	27	39	228	447
Total in each age group	58	404	609	1,021	1,428	1,352	1,692	2,752	9,316
Per cent									
CPAP given	62.1	86.1	93.9	93.9	84.5	84.2	79.9	71.0	81.2
IPPV given	100.0	93.6	81.8	57.7	33.0	27.1	34.3	43.2	44.3
Per cent of babies given invasive ventilation									
HFOV given	55.2	41.9	16.8	11.1	6.4	8.7	8.1	12.1	14.4
NO given	10.3	15.4	7.4	5.6	3.8	7.3	6.7	19.0	10.7

*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 3,520 babies born before 32 weeks gestation, 94.1% 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 37.5% and IPPV was the only form of ventilation for 5.5% of registrants. Both IPPV and CPAP were given to 51.2% of registrants.

The total duration of IPPV for these very preterm babies was 349,023 hours (14,543 days), and the duration of CPAP was 1,384,783 hours (57,699 days).

Of the babies born before 32 weeks gestational age and given IPPV in 2012, 18.0% were given high frequency ventilation while 7.7% of these babies were given NO (Table 16).

Among 2012 ANZNN registrants born at less than 32 weeks gestation, 3,348 (95.1%) 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 14.9% 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, 92.0% 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 128,446 hours (5,352 days) and IPPV use was 82,388 hours (3,433 days).

Of the babies born at 32–36 weeks gestation and given IPPV in 2012, 8.0% were given high frequency ventilation while 7.0% 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 (39.2%). This group required 112,211 hours of IPPV (4,676 days) and 91,866 hours (3,828 days) of CPAP.

Of the babies born at term and given IPPV in 2012, 11.2% were given high frequency ventilation while 19.2% of these babies were given NO. There were 13 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 2012 ANZNN registrants, 9,000 babies survived to day 28 and of these, 19.6% 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, 15.8% 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, 2012**

	Gestational age group								
Respiratory support (airway support or oxygen)	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
	Number								
No respiratory support on day 28	0	5	47	487	1,242	1,276	1,599	2,569	7,225
Respiratory support on day 28	33	333	530	500	171	48	59	96	1,770
▪ survived to discharge home	n.p.	n.p.	517	486	162	48	49	79	1,673
▪ died before discharge	<5	n.p.	13	14	9	0	10	17	97
Not stated	0	0	0	0	0	2	1	2	5
<b>Total</b>	<b>33</b>	<b>338</b>	<b>577</b>	<b>987</b>	<b>1,413</b>	<b>1,326</b>	<b>1,659</b>	<b>2,667</b>	<b>9,000</b>
	Number								
Respiratory support on day 28 and given home oxygen	n.p.	n.p.	67	47	12	6	12	14	265
	Per cent								
No respiratory support on day 28	0.0	1.5	8.1	49.3	87.9	96.4	96.4	96.4	80.3
Respiratory support on day 28	100.0	98.5	91.9	50.7	12.1	3.6	3.6	3.6	19.7
▪ survived to discharge home	n.p.	n.p.	97.5	97.2	94.7	100.0	83.1	82.3	94.5
▪ died before discharge	n.p.	n.p.	2.5	2.8	5.3	0.0	16.9	17.7	5.5
	Per cent								
Respiratory support on day 28 and given home oxygen <sup>(a)</sup>	27.6	32.7	13.0	9.7	7.4	12.5	24.5	17.7	15.8

*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 2012 nasal high flow therapy was reported for 1,686 babies (18.1%) of all level III registrants (Table 18), compared with 8.1% in 2009. The overall increase of 2.5% from 2011 was observed predominantly in the babies born at less than 28 weeks gestation. In this gestational age group, 50.4% of babies received NHFT. Overall, the minimum flow recorded was 1 litre/min and the maximum 15 litres/min. Of the babies receiving NHFT 71.5% were reported to have received a minimum rate of 2–4 litres/min while 58.4% received a maximum of 6–8 litres /min.

Care should be taken in interpretation of these data as this is only the fourth year of collection for ANZNN and NHFT is an emerging trend amongst member units.

**TABLE 18: Nasal high flow respiratory support for level III registrants by gestational age group, 2012**

	Gestational age group								
Nasal high flow	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
High flow	22	197	321	383	208	121	151	283	1,686
No high flow	36	207	288	638	1,220	1,231	1,541	2,469	7,630
Total	58	404	609	1,021	1,428	1,352	1,692	2,752	9,316
Per cent									
High flow	37.9	48.8	52.7	37.5	14.6	8.9	8.9	10.3	18.1
No high flow	62.1	51.2	47.3	62.5	85.4	91.1	91.1	89.7	81.9
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, 2,745 (73.9%) received TPN during admission (Table 19). The median duration of TPN reported was 249.5 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 first year of collection for the ANZNN.

**TABLE 19: Total parenteral nutrition for level III registrants by gestational age, 2012**

Parenteral nutrition	Gestational age										Total
	<24	24	25	26	27	28	29	30	31	≥32	
Number											
Parenteral nutrition	n.p.	n.p.	218	270	288	414	438	409	373	149	2,745
No parenteral nutrition	<5	n.p.	16	9	18	33	81	191	393	210	969
Not stated	0	9	15	7	17	21	34	31	31	17	182
Total	58	155	249	286	323	468	553	631	797	376	3,896
Number											
Home gavage feeding	12	<5	<5	12	8	13	17	10	12	<5	93
Per cent											
Parenteral nutrition	n.p.	n.p.	93.2	96.8	94.1	92.6	84.4	68.2	48.7	41.5	73.9
No parenteral nutrition	n.p.	n.p.	6.8	3.2	5.9	7.4	15.6	31.8	51.3	58.5	26.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Per cent											
Home gavage feeding	21.8	n.p.	n.p.	4.4	2.8	3.1	3.9	2.4	3.2	n.p.	3.4

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

**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 8.4% of babies in 2012 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 24 weeks gestation (63.2%) (Table 20). Not all the babies born at earlier gestations survived to 36 weeks PMA. CLD by gestational age is represented by Figure 21 in Appendix 1.

**TABLE 20: Chronic lung disease for level III registrants by gestational age, 2012**

Chronic lung disease (CLD)	Gestational age										Total
	<24	24	25	26	27	28	29	30	31	≥32	
Number											
No CLD	31	57	102	158	205	351	487	590	757	5,796	8,534
CLD	27	98	147	128	118	117	66	41	40	0	782
▪ CLD and survived	n.p.	91	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	35	0	753
▪ CLD and died	<5	7	<5	<5	<5	<5	<5	<5	5	0	29
Total	58	155	249	286	323	468	553	631	797	5,796	9,316
Per cent											
No CLD	53.4	36.8	41.0	55.2	63.5	75.0	88.1	93.5	95.0	100.0	91.6
CLD	46.6	63.2	59.0	44.8	36.5	25.0	11.9	6.5	5.0	0.0	8.4
▪ CLD and survived	n.p.	92.9	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	87.5	0.0	96.3
▪ CLD and died	n.p.	7.1	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	12.5	0.0	3.7

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

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

## 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, 2012**

	Gestational age group								
Air leak	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
Air leak	5	27	33	32	35	42	64	122	360
No air leak	53	375	574	988	1,391	1,309	1,623	2,623	8,936
Not stated	0	2	2	1	2	1	5	7	20
<b>Total</b>	<b>58</b>	<b>404</b>	<b>609</b>	<b>1,021</b>	<b>1,428</b>	<b>1,352</b>	<b>1,692</b>	<b>2,752</b>	<b>9,316</b>
Per cent									
Air leak	8.6	6.7	5.4	3.1	2.5	3.1	3.8	4.4	3.9
No air leak	91.4	93.3	94.6	96.9	97.5	96.9	96.2	95.6	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 6.3% of ANZNN registrants in 2012. Of these babies, 46.3% were born at less than 28 weeks gestation, 72.2% were born at less than 32 weeks gestation and 99.3% of registrants survived up to 2 days of life (Table 22). Episodes of both early and late sepsis were reported in three babies. The 5-year trends (2008–2012) for early and late sepsis are represented by Figure 24 and Figure 25 respectively in Appendix 1.

**TABLE 22: Neonatal sepsis for level III registrants by gestational age group, 2012**

	Gestational age group								
Sepsis	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
No sepsis	39	279	480	921	1,376	1,313	1,645	2,674	8,727
Sepsis at <48 hrs <sup>(a)</sup>	<5	n.p.	9	9	n.p.	n.p.	10	34	86
Sepsis at ≥48 hrs <sup>(a)</sup>	n.p.	n.p.	121	91	n.p.	n.p.	37	44	506
Babies alive on day 2	51	381	603	1,011	n.p.	n.p.	1,684	2,734	9,237
Babies who did not survive to day 2	7	23	6	10	<5	<5	8	18	79
<b>Total in each age group</b>	<b>58</b>	<b>404</b>	<b>609</b>	<b>1,021</b>	<b>1,428</b>	<b>1,352</b>	<b>1,692</b>	<b>2,752</b>	<b>9,316</b>
Per cent									
No sepsis <sup>(b)</sup>	67.2	69.1	78.8	90.2	96.4	97.1	97.2	97.2	93.7
Sepsis at <48 hrs <sup>(b)</sup>	n.p.	n.p.	1.5	0.9	0.4	0.7	0.6	1.2	0.9
Sepsis at ≥48 hrs <sup>(c)</sup>	n.p.	n.p.	20.1	9.0	3.2	2.2	2.2	1.6	5.5

**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 146 (1.6%) of ANZNN registrants in 2012, 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 the first year of collection for 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 2010 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 2012 registrants, 31.2% were eligible for ROP examination and of these eligible registrants, 83.1% were examined and had the results of their eye examination recorded.

Of those ANZNN registrants who were eligible for an eye examination, 170 died before their ROP status could be determined. Of those examined, 5.6% had stage 3 or 4 eye disease (Table 23, Figure 6) and of these babies 50.0% received treatment. The 8-year trend (2005–2012) for stages 3 and 4 ROP and treatment are represented by Figure 22 in Appendix 1.

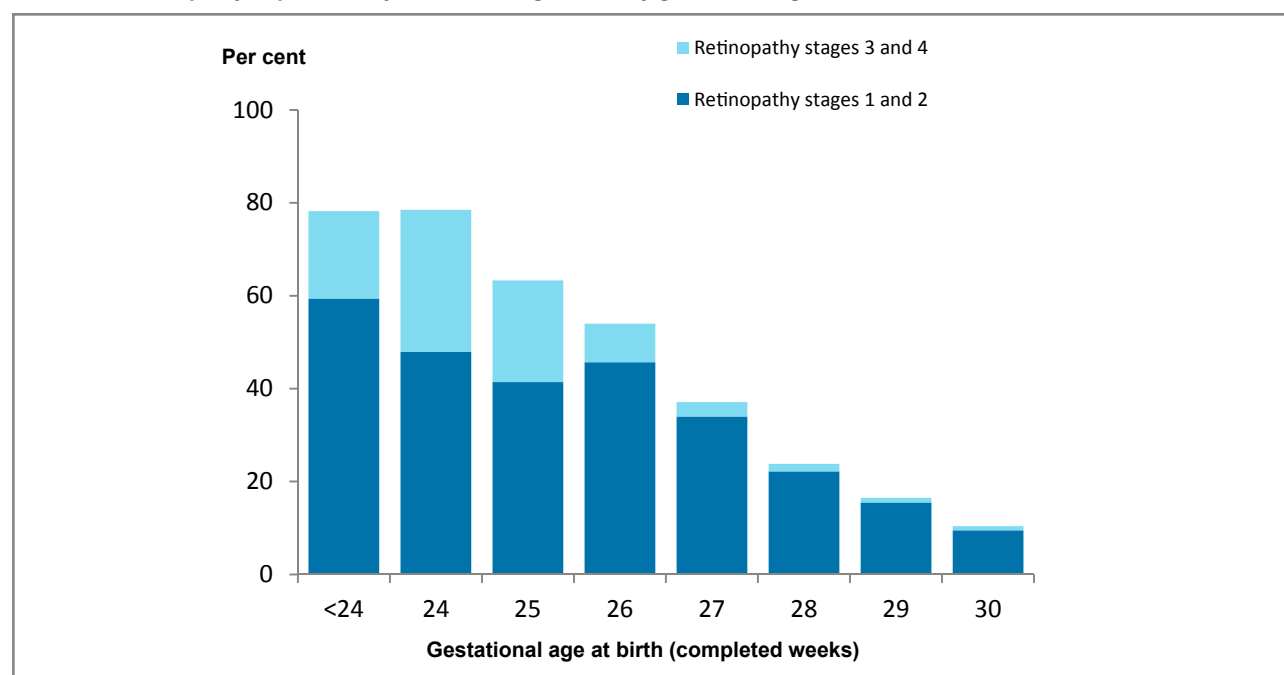
**TABLE 23: Retinopathy of prematurity for level III registrants by gestational age, 2012**

Retinopathy of prematurity (ROP)	Gestational age									Total
	<24	24	25	26	27	28	29	30	>30	
	Number									
No ROP	7	26	77	122	185	325	414	395	119	1,670
Stage 1	7	24	n.p.	57	64	62	40	n.p.	8	320
Stage 2	12	34	55	64	36	33	37	16	6	293
Stage 3	6	37	45	22	9	7	5	<5	0	n.p.
Stage 4	0	0	<5	0	0	0	0	0	0	<5
Not examined	26	34	38	21	26	41	57	188	52	483
Not stated	0	0	1	0	3	0	0	2	2	8
<b>Total</b>	<b>58</b>	<b>155</b>	<b>249</b>	<b>286</b>	<b>323</b>	<b>468</b>	<b>553</b>	<b>631</b>	<b>187</b>	<b>2,910</b>
Per cent										
No ROP	21.9	21.5	36.7	46.0	62.9	76.1	83.5	89.6	89.5	69.0
Stage 1	21.9	19.8	n.p.	21.5	21.8	14.5	8.1	n.p.	6.0	13.2
Stage 2	37.5	28.1	26.2	24.2	12.2	7.7	7.5	3.6	4.5	12.1
Stage 3	18.8	30.6	21.4	8.3	3.1	1.6	1.0	n.p.	0.0	n.p.
Stage 4	0.0	0.0	n.p.	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, 2012**



## 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 3,520 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, 3,453 survived to day 3 and 91.7% had an examination recorded. A normal report was recorded for 80.9% of these 2012 ANZNN registrants.

There were 126 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 (57.0%) of the babies born before 26 weeks gestation (Table 24, Figure 7). The 10-year trend (2003–2012) for registrants with grades 3 and 4 IVH who survived to day 3 is represented in Figure 23 in Appendix 1.

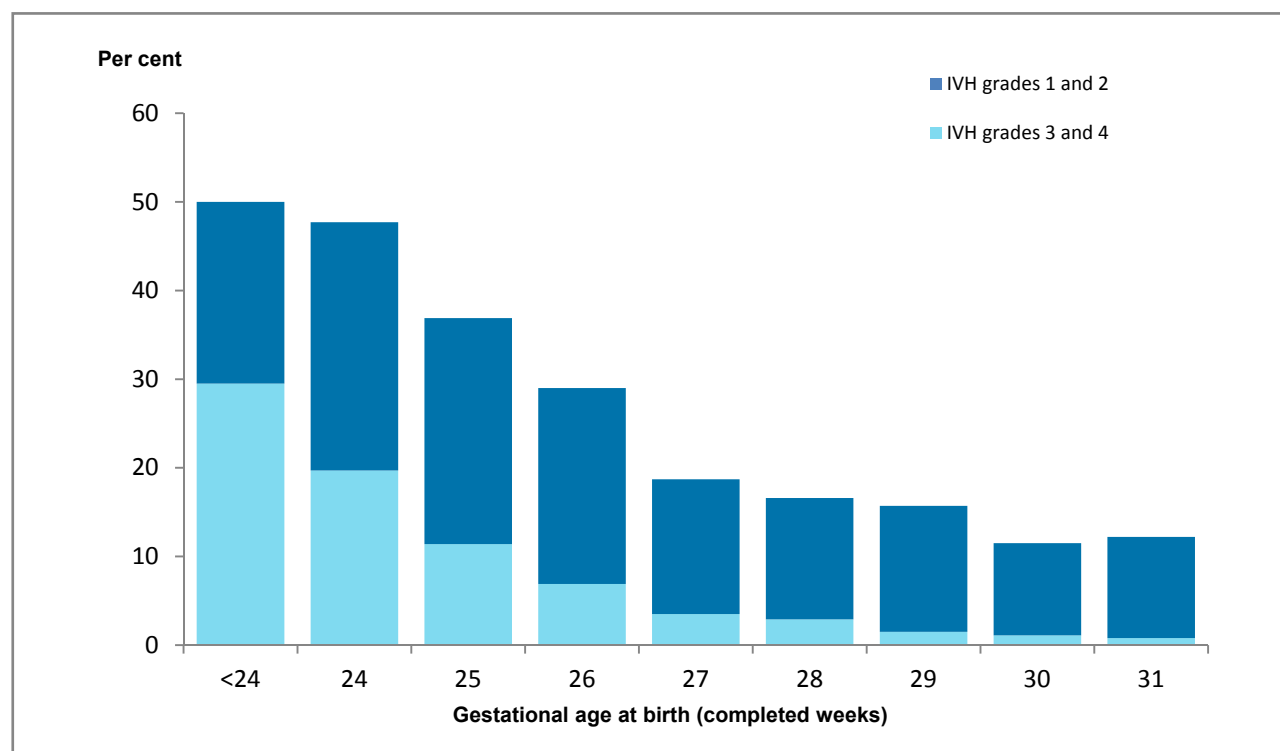
**TABLE 24: Intraventricular haemorrhage for level III registrants born before 32 weeks and survived to day 3 by gestational age, 2012**

Intraventricular haemorrhage	Gestational age									Total
	<24	24	25	26	27	28	29	30	31	
	Number									
None	22	69	139	196	252	377	446	501	561	2,563
Grade 1	6	17	40	36	32	50	64	50	64	359
Grade 2	<5	20	16	25	15	n.p.	11	9	9	120
Grade 3	<5	9	8	6	5	n.p.	<5	<5	<5	47
Grade 4	11	17	17	13	6	5	n.p.	<5	<5	79
Not examined	5	8	14	5	8	10	18	61	156	285
<b>Total</b>	<b>49</b>	<b>140</b>	<b>234</b>	<b>281</b>	<b>318</b>	<b>462</b>	<b>547</b>	<b>627</b>	<b>795</b>	<b>3,453</b>
Per cent										
None	50.0	52.3	63.2	71.0	81.3	83.4	84.3	88.5	87.8	80.9
Grade 1	13.6	12.9	18.2	13.0	10.3	11.1	12.1	8.8	10.0	11.3
Grade 2	n.p.	15.2	7.3	9.1	4.8	n.p.	2.1	1.6	1.4	3.8
Grade 3	n.p.	6.8	3.6	2.2	1.6	n.p.	n.p.	n.p.	n.p.	1.5
Grade 4	25.0	12.9	7.7	4.7	1.9	1.1	n.p.	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, 2012**





## 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 3,520 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, 3,453 survived until day 3 and late ultrasound results were available for 2,583 (74.8%) of these babies. A normal report of no cysts was recorded for 97.2% of these registrants, 1.3% reported porencephalic cysts, 1.3% reported periventricular leukomalacia (PVL) (Table 25) and there were four reports of encephaloclastic porencephaly. Hydrocephalus was reported for 19 (0.7%) of these registrants in 2012.

**TABLE 25: Late cerebral ultrasound results for level III registrants born before 32 weeks by gestational age, 2012**

Cerebral ultrasound results	Gestational age									Total
	<24	24	25	26	27	28	29	30	31	
	Number									
No cysts	n.p.	111	n.p.	246	280	397	441	416	383	2,514
Porencephalic cysts	0	<5	5	n.p.	n.p.	5	<5	<5	<5	34
Periventricular leukomalacia	<5	<5	<5	<5	<5	5	n.p.	<5	<5	34
Not stated	21	37	39	30	36	61	96	207	407	934
<b>Total</b>	<b>58</b>	<b>155</b>	<b>249</b>	<b>286</b>	<b>323</b>	<b>468</b>	<b>553</b>	<b>631</b>	<b>797</b>	<b>3,520</b>
	Per cent									
No cysts	n.p.	94.1	n.p.	96.1	97.6	97.5	96.5	98.1	98.2	97.2
Porencephalic cysts	0.0	n.p.	2.4	n.p.	n.p.	1.2	n.p.	n.p.	n.p.	1.3
Periventricular leukomalacia	n.p.	n.p.	n.p.	n.p.	n.p.	1.2	n.p.	n.p.	n.p.	1.3
<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>	<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 2012, 283 (7.5%) of the ANZNN registrants born at more than 34 weeks gestation received therapeutic hypothermia, and of these, 50.5% 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 82.0% 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 (41.5%).

## 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 2012 the percentage of babies with confirmed NEC was 1.5%. Of these babies, 62.8% were born before 28 weeks gestation with 60.5% of them undergoing surgery, and 37.2% were born after 27 weeks gestation; surgery was required for 39.2% of them. In total 43 registrants died from NEC. The number of registrants with confirmed NEC is more than in 2011 (Table 26).

**TABLE 26: Necrotising enterocolitis in level III registrants by year of birth, 2003–2012**

Necrotising enterocolitis	Year of birth									
	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012
Number										
NEC at <28 weeks	78	85	85	95	80	118	97	111	71	86
▪ No NEC at <28 weeks	943	941	951	944	1,005	1,052	1,032	952	1,026	983
▪ Not stated	2	0	0	20	24	15	2	4	5	2
NEC at ≥28 weeks	77	63	50	72	50	74	50	68	51	51
▪ No NEC at ≥28 weeks	6,091	6,316	6,560	6,428	6,773	7,339	7,801	7,093	8,028	8,189
▪ Not stated	4	2	0	32	70	27	3	8	1	5
<b>Total</b>	<b>7,195</b>	<b>7,407</b>	<b>7,646</b>	<b>7,591</b>	<b>8,002</b>	<b>8,628</b>	<b>8,986</b>	<b>8,236</b>	<b>9,182</b>	<b>9,316</b>
Per cent										
NEC <28 weeks	7.6	8.3	8.2	9.1	7.4	10.1	8.6	10.4	6.5	8.0
NEC ≥28 weeks	1.2	1.0	0.8	1.1	0.7	1.0	0.6	0.9	0.6	0.6

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

## 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 2012, there were 961 ANZNN registrants who had major surgery, of whom over half (52.7%) were born at term. Of registrants born in a hospital, 71.2% were born in a hospital with tertiary care facilities. Of registrants who had major surgery, 74.8% also had a congenital anomaly present with 51.6% of these diagnosed during the antenatal period. 7.5% had surgery for proven NEC. The median length of stay (LOS) for survivors was 31 days (Table 27).

**TABLE 27: Characteristics of level III registrants who underwent surgery by gestational age group, 2012**

	Gestational age group								
Characteristics	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
Male	n.p.	50	28	27	n.p.	27	102	290	545
Female	<5	32	21	12	n.p.	23	92	216	416
Congenital anomaly present	0	12	6	15	21	36	167	460	717
Congenital anomaly diagnosed antenatally	0	<5	0	n.p.	9	18	126	226	387
Proven NEC	5	28	19	10	<5	<5	<5	<5	72
Hospital of birth:									
▪ Tertiary	8	70	47	35	29	31	153	308	681
▪ Non-tertiary	<5	10	<5	<5	<5	19	41	196	275
Median LOS for survivors (days)	174	125	118	94	74	56.5	34	22	31
Died before discharge home	6	18	11	8	n.p.	5	<5	15	71
Total in each age group	10	82	49	39	31	50	194	506	961
Per cent									
Male	n.p.	61.0	57.1	69.2	n.p.	54.0	52.6	57.3	56.7
Female	n.p.	39.0	42.9	30.8	n.p.	46.0	47.4	42.7	43.3
Congenital anomaly present	0.0	14.6	12.2	38.5	67.7	72.0	86.1	90.9	74.6
Congenital anomaly diagnosed antenatally	0.0	n.p.	0.0	n.p.	29.0	36.0	64.9	44.7	40.3
Proven NEC	50.0	34.1	38.8	25.6	n.p.	n.p.	n.p.	n.p.	7.5
Hospital of birth:									
▪ Tertiary	80.0	85.4	95.9	89.7	93.5	62.0	78.9	60.9	70.9
▪ Non-tertiary	n.p.	12.2	n.p.	n.p.	n.p.	38.0	21.1	38.7	28.6
Died before discharge home	60.0	22.0	22.4	20.5	n.p.	10.0	n.p.	3.0	7.4
Total in each age group	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.

## Congenital anomalies

In 2012, 1,198 ANZNN registrants (12.9%) had one or more major congenital anomalies. For registrants who had a congenital anomaly, 14.6% were born before 32 weeks gestation, 30.3% were born between 32 and 36 weeks gestation and more than half of registrants (55.1%) were born at term.

Over half of ANZNN registrants (46.2%) with congenital anomalies were diagnosed during the antenatal period with 9.1% of babies recorded as having a fatal congenital anomaly. A higher percentage of babies with congenital anomalies were male (55.0%).

## 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 2012, two in five of ANZNN registrants (39.0%) 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 (47.3%) transferred from level III to level II units were born at less than 32 weeks gestation compared to 15.5% born at term.

Some level III registrants required transfer to a specialist children’s hospital and in 2012 these accounted for 3.6% of transfers from level III units. Overall 54.4% 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, 2012**

	Gestational age group								
Transfer status	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
Not transferred	44	229	265	403	569	576	986	1,987	5,059
Level III hospital	n.p.	n.p.	48	55	58	20	33	48	288
Level II hospital	5	108	275	550	778	728	623	561	3,628
Children's hospital	<5	n.p.	20	12	23	26	47	154	331
Not stated	0	1	1	1	0	2	3	2	10
Total	58	404	609	1,021	1,428	1,352	1,692	2,752	9,316
Per cent									
Not transferred	75.9	56.8	43.6	39.5	39.8	42.7	58.4	72.3	54.4
Level III hospital	n.p.	n.p.	7.9	5.4	4.1	1.5	2.0	1.7	3.1
Level II hospital	8.6	26.8	45.2	53.9	54.5	53.9	36.9	20.4	39.0
Children's hospital	n.p.	n.p.	3.3	1.2	1.6	1.9	2.8	5.6	3.6
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 94.7% of ANZNN registrants in 2012. The median length of stay was 29 days with an interquartile range of 11–54 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 212,071 days in hospital, babies born between 32 and 36 weeks spent 74,191 days and babies born at term spent 36,937 days in hospital.

**TABLE 29: Median length of stay for level III registrants who survived until discharge home by gestational age, 2012**

Gestational age (completed weeks)	Number of babies	Median LOS (in days)	Interquartile range (in days)
<24	29	132	116–146
24	109	119	109–132
25	199	110	97.5–128.5
26	264	91	82–108
27	300	81	70–94
28	443	70	60–81
29	530	58	50–70
30	623	48	41–57
31	781	39	33–46
32	733	33	27–40
33	591	25	21–33
34	656	20	15–27
35	513	14	9–20
36	478	10.5	7–18.5
37	510	9	6–20
38	598	9	5–18
39	577	7	5–18
40	570	7	4–14
41	364	7	4–15
42	24	7	5–15
≥43	5	3.5	3–7
<b>Total</b>	<b>8,897</b>	<b>29</b>	<b>11–54</b>

*Note: Death status was not provided for one baby.*

## Survival of the ANZNN registrants

In 2012, 95.5% 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 30 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 2012, there were 418 neonatal deaths, of which 209 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 50.0% for babies born before 24 weeks to 95.8% for babies born at 29 weeks (Table 30, Figure 8). A similar pattern of increasing survival with increasing birthweight is seen in Figure 9.

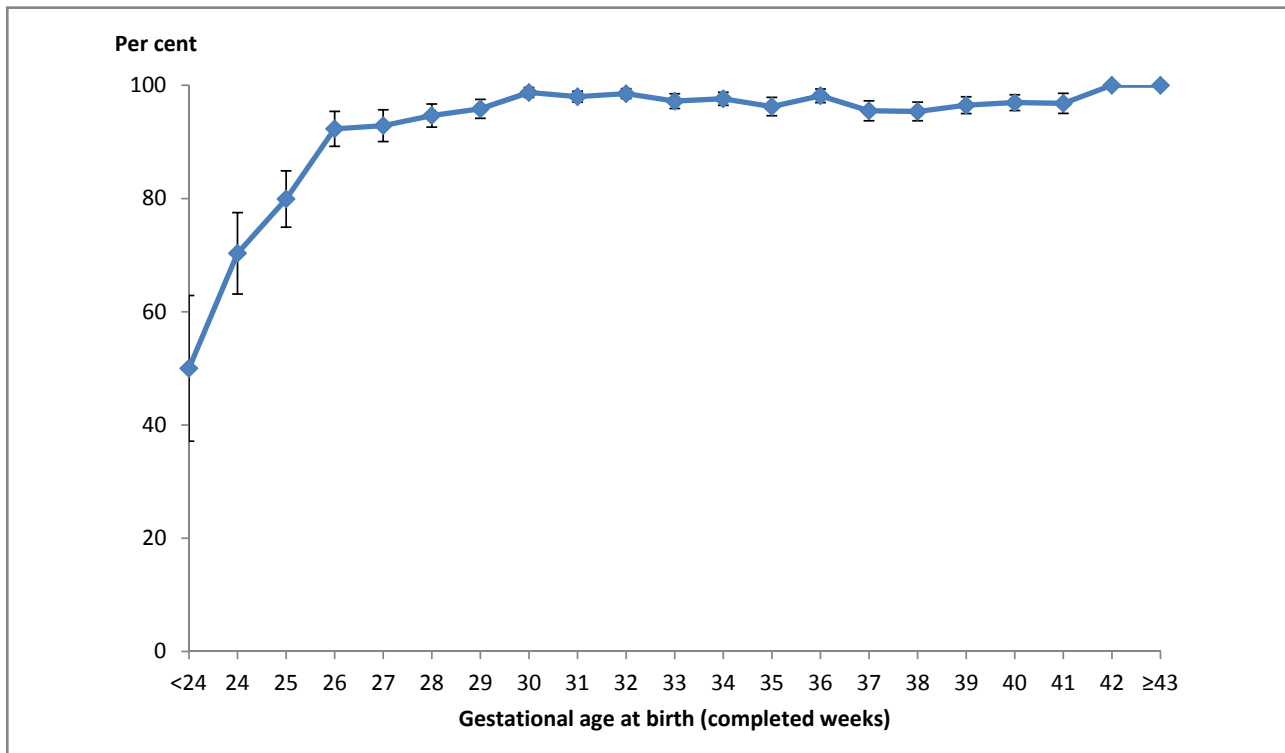
Lethal congenital anomaly was the cause of death for 1.2% of registrants, with most occurring in babies born between 33–38 weeks gestation (Table 30).

TABLE 30: Survival to discharge home for level III registrants by gestational age at birth, 2012

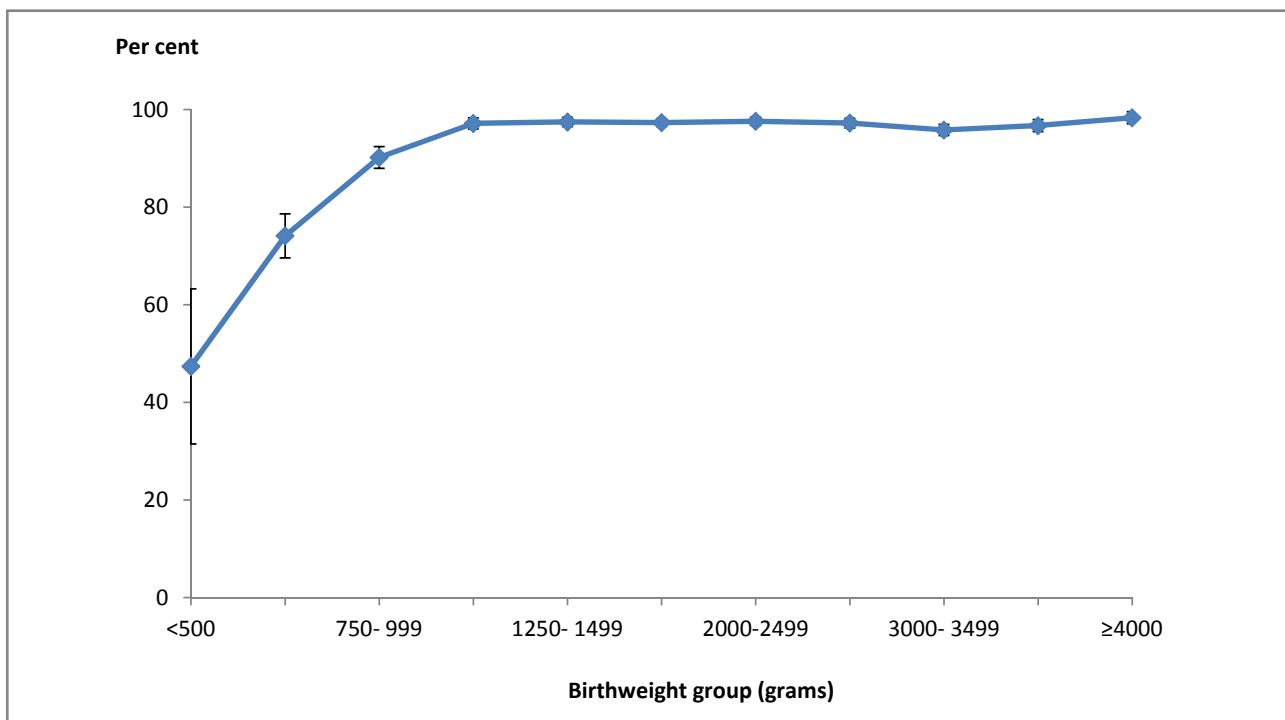
Gestational age (completed weeks)	Number of babies	Lethal congenital anomalies	Babies alive on day 7	Babies alive on day 28	Survived to go home	Per cent survival at discharge to home
<24	58	0	42	33	29	50.0
24	155	0	127	123	109	70.3
25	249	0	229	215	199	79.9
26	286	<5	275	269	264	92.3
27	323	<5	315	308	300	92.9
28	468	<5	456	450	443	94.7
29	553	6	540	537	530	95.8
30	631	<5	626	624	623	98.7
31	797	8	793	789	781	98.0
32	744	<5	740	733	733	98.5
33	608	11	601	594	591	97.2
34	672	8	665	662	656	97.6
35	533	12	522	518	513	96.2
36	487	6	485	479	478	98.2
37	534	17	520	516	510	95.5
38	627	11	614	605	598	95.4
39	598	8	585	581	577	96.5
40	588	6	575	571	570	96.9
41	376	5	368	366	364	96.8
42	24	0	24	24	24	100.0
≥43	5	0	5	5	5	100.0
<b>Total</b>	<b>9,316</b>	<b>109</b>	<b>9,107</b>	<b>9,002</b>	<b>8,897</b>	<b>95.5</b>

*Note: Death status was not provided for one baby.*

**FIGURE 8: Survival of level III registrants to discharge home (with 95% CI) by gestational age, 2012**



**FIGURE 9: Survival of level III registrants to discharge home (with 95% CI) by birthweight group, 2012**



## 5. Babies registered to level II units

### Overview

Nurseries 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 nurseries 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 nurseries, or if they were transferred to a level III NICU after 28 days, or they were transferred to a level II nursery 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, 23 level II units contributed data for this 2012 report.

In 2012, 969 babies fulfilled the ANZNN criteria for registration to a level II unit. Of those babies, 15.5% were born at less than 32 weeks gestation and 11.0% 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 2012 was 115.

**TABLE 31: Level II registrants by gestational age group, 2012**

Gestational age group	Number of babies	Per cent	Cumulative per cent
<28	10	1.0	1.0
28–29	30	3.1	4.1
30–31	110	11.4	15.5
<b>All babies &lt;32 weeks gestation</b>	<b>150</b>	<b>15.5</b>	
32–33	159	16.4	31.9
34–36	275	28.4	60.3
37–43	384	39.6	100.0
<b>Total</b>	<b>969</b>	<b>100.0</b>	

*Note: Gestational age groups below 28 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, 2012**

Birthweight group (grams)	Number of babies	Per cent	Cumulative per cent
<1,000	11	1.1	1.1
1,000–1,099	6	0.6	1.8
1,100–1,199	8	0.8	2.6
1,200–1,299	23	2.4	5.0
1,300–1,399	28	2.9	7.8
1,400–1,499	31	3.2	11.0
<b>All babies &lt;1,500g birthweight</b>	<b>107</b>	<b>11.0</b>	
1,500–1,999	163	16.8	27.9
2,000–2,499	168	17.3	45.2
2,500–2,999	164	16.9	62.1
3,000–3,499	162	16.7	78.8
3,500–3,999	131	13.5	92.4
≥4,000	73	7.5	100.0
<b>Total</b>	<b>969</b>	<b>100.0</b>	

*Note: Birthweight groups below 1,000g have been combined to maintain confidentiality of small numbers. Birthweight was not provided for one baby.*



More than half of the level II registrants, 529 babies (54.6%), were born to Caucasian mothers, 59.9% of whom were born preterm. The number of registrants born to Maori mothers was 150 (15.5%), and 82 (54.7%) were born preterm. There were 26 babies (2.7%) born to Pacific Islander mothers.

There were 572 male (59.0%) and 393 female (40.6%) registrants in the audit. No gender was recorded for four registrants (0.4%). 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, 20.5% did not present with any maternal complications. Among babies born before 37 weeks, 41.4% of mothers had presented with preterm labour (Table 33).

**TABLE 33: Mothers of level II registrants presenting antenatal problem by gestational age group, 2012**

Presenting antenatal problem	Gestational age group						Total
	<28	28–29	30–31	32–33	34–36	37–43	
	Number						
No antenatal problems	0	0	0	0	<5	n.p.	196
Preterm pre-labour rupture of membranes	<5	5	23	35	40	n.p.	110
Preterm labour	n.p.	14	52	62	103	<5	242
Hypertension in pregnancy	0	<5	n.p.	17	33	16	73
Antepartum haemorrhage	0	<5	22	19	33	n.p.	87
Intrauterine growth restriction	0	<5	<5	14	16	16	51
Fetal distress	0	<5	<5	<5	10	91	108
Other problem	0	2	1	5	33	41	82
Congenital anomalies	0	0	0	<5	<5	6	9
Not stated	0	0	2	1	5	3	11
<b>Total</b>	<b>10</b>	<b>30</b>	<b>110</b>	<b>159</b>	<b>275</b>	<b>384</b>	<b>969</b>
Per cent							
No antenatal problems	0.0	0.0	0.0	0.0	n.p.	n.p.	20.5
Preterm pre-labour rupture of membranes	n.p.	16.7	21.3	22.2	14.8	n.p.	11.5
Preterm labour	n.p.	46.7	48.1	39.2	38.1	n.p.	25.3
Hypertension in pregnancy	0.0	n.p.	n.p.	10.8	12.2	4.2	7.6
Antepartum haemorrhage	0.0	n.p.	20.4	12.0	12.2	n.p.	9.1
Intrauterine growth restriction	0.0	n.p.	n.p.	8.9	5.9	4.2	5.3
Fetal distress	0.0	n.p.	n.p.	n.p.	3.7	23.9	11.3
Other problem	0.0	6.7	0.9	3.2	12.2	10.8	8.6
Congenital anomalies	0.0	0.0	0.0	n.p.	n.p.	1.6	0.9
<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.

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

Gestational age was not provided for one baby.

Previous preterm births were reported by 105 (10.8%) of the mothers of level II registrants and 29 mothers (3.0%) had had a previous perinatal death(s).

Most mothers (83.2%) of level II registrants had booked into a level II hospital for delivery. Of the level II registrants born before 34 weeks gestation, 68.9% 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, 2012**

Antenatal corticosteroids	Gestational age group						Total
	<28	28–29	30–31	32–33	34–36	37–43	
Number							
None	<5	<5	21	43	192	371	635
Incomplete course	n.p.	11	45	45	24	<5	131
Complete course	<5	14	34	58	34	<5	143
Completed >7 days	0	<5	9	9	13	<5	34
Not stated	0	0	1	4	12	9	26
<b>Total</b>	<b>10</b>	<b>30</b>	<b>110</b>	<b>159</b>	<b>275</b>	<b>384</b>	<b>969</b>
Per cent							
None	n.p.	n.p.	19.3	27.7	73.0	98.9	67.3
Incomplete course	n.p.	36.7	41.3	29.0	9.1	n.p.	13.9
Complete course	n.p.	46.7	31.2	37.4	12.9	n.p.	15.2
Completed >7 days	0.0	n.p.	8.3	5.8	4.9	n.p.	3.6
<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.

**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 51.1% of level II registrants, with just over half (52.6%) of these occurring before the onset of labour (Table 35).

**TABLE 35: Method of delivery for level II registrants by gestational age group, 2012**

	Gestational age group						
Method of delivery	<28	28–29	30–31	32–33	34–36	37–43	Total
Number							
Vaginal <sup>(a)</sup>	n.p.	n.p.	48	59	98	232	457
Caesarean <sup>(b)</sup>	<5	n.p.	60	93	161	142	477
Not stated	0	0	2	7	16	10	35
<b>Total</b>	<b>10</b>	<b>30</b>	<b>110</b>	<b>159</b>	<b>275</b>	<b>384</b>	<b>969</b>
Per cent							
Vaginal	n.p.	n.p.	44.4	38.8	37.8	62.0	48.9
Caesarean	n.p.	n.p.	55.6	61.2	62.2	38.0	51.1
<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)** Vaginal and assisted births have been combined to maintain confidentiality of small numbers.

**(b)** 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 969 babies registered to level II units, 110 were from multiple births (11.4%). There were 572 male births and four babies whose gender was not recorded.

A low Apgar score of less than 4 at one minute of age was recorded for 19.0% of babies and 19.2% of them required endotracheal intubation in the labour ward to assist in their adaptation to extrauterine life.

Non-specific respiratory distress (52.8%) was the major reason for assisted ventilation for level II registrants, followed by hyaline membrane disease (26.9%) (Table 36).

For level II registrants, the median duration of assisted ventilation by IPPV was 23.5 hours and 19 hours by CPAP (Table 37).

**TABLE 36: Indication for respiratory support for level II registrants by gestational age group, 2012**

Indication for respiratory support	Gestational age group						Total
	<28	28–29	30–31	32–33	34–36	37–43	
	Number						
No support	0	<5	21	13	<5	<5	45
Non-specific distress	<5	<5	27	71	175	228	504
Hyaline membrane disease	n.p.	23	60	68	75	n.p.	257
Meconium aspiration syndrome	0	0	n.p.	0	<5	64	65
Pneumonia	0	n.p.	0	<5	8	15	24
Persistent pulmonary hypertension	0	<5	0	0	0	n.p.	12
Apnoea	0	0	<5	<5	<5	9	16
Congenital anomaly	0	0	0	<5	<5	<5	6
Other	n.p.	0	0	1	n.p.	9	14
Peri-surgery	0	0	0	0	0	0	0
Newborn encephalopathy	0	0	0	0	<5	n.p.	11
Not stated	0	0	1	0	4	9	14
<b>Total</b>	<b>10</b>	<b>30</b>	<b>110</b>	<b>159</b>	<b>275</b>	<b>384</b>	<b>969</b>
Per cent							
No support	0.0	n.p.	19.3	8.2	n.p.	n.p.	4.7
Non-specific distress	n.p.	n.p.	24.8	44.7	64.6	60.8	52.8
Hyaline membrane disease	n.p.	76.7	55.0	42.8	27.7	n.p.	26.9
Meconium aspiration syndrome	0.0	0.0	n.p.	0.0	n.p.	17.1	6.8
Pneumonia	0.0	n.p.	0.0	n.p.	3.0	4.0	2.5
Persistent pulmonary hypertension	0.0	n.p.	0.0	0.0	0.0	n.p.	1.3
Apnoea	0.0	0.0	n.p.	n.p.	n.p.	2.4	1.7
Congenital anomaly	0.0	0.0	0.0	n.p.	n.p.	n.p.	0.6
Other	n.p.	0.0	0.0	0.6	n.p.	2.4	1.5
Peri-surgery	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Newborn encephalopathy	0.0	0.0	0.0	0.0	n.p.	n.p.	1.2
<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.

**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, 2012**

Median & Interquartile range	Gestational age group						Total
	<28	28–29	30–31	32–33	34–36	37–43	
IPPV (hours)							
Median	4.5	40	37	17.5	40	17	23.5
IQR	3–18	4–94	24–49	8–23	6–53	6–48	6–49
CPAP (hours)							
Median	38	93	58	27	19	13	19
IQR	11–120	56.5–212	19–95	15–63	9–42	7–26	9–44

*Note: IQR = Interquartile range.*

## Eye examination

Screening for retinopathy of prematurity (ROP) was reported for only 63 of the 86 eligible babies born at less than 31 weeks gestational age and/or weighing less than 1,250 grams at birth (73.3% compared to 83.1% of eligible level III registrants). Most were reported as normal except for five babies who had stage 1, one baby who had stage 2 and one baby who had stage 3 ROP.

## Cerebral ultrasound

Of the 150 babies born at less than 32 weeks, 127 (84.7%) had a cerebral ultrasound in the first week after birth. 113 of them were reported as normal, that is no intraventricular haemorrhage (IVH), ten reported a grade 1 IVH, two reported a grade 2 IVH and two reported a grade 4 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 46 babies, all of whom had normal reports except for one baby with reported periventricular leukomalacia.

## Other morbidities

Septicaemia was proven in 19 babies, including 17 before day two, that is less than 48 hours. There were no cases of necrotising enterocolitis. Major congenital anomalies were reported for 16 babies, three required major surgery, and two registrants died due to congenital anomalies.

## Level II transfers

In total 115 level II registrants were transferred to other units, 76 were transferred to a level I or another level II unit, 38 were transferred to a level III unit and the remaining one to a children's hospital.

## Survival

There were 955 level II registrants who survived to discharge home (98.6%). Seven babies died within the first seven days of birth and a further two babies died before discharge home (Table 38). Two babies were reported to have had a lethal congenital anomaly.

**TABLE 38: Survival to discharge home for level II registrants by gestational age group, 2012**

<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>
<28	10	7	6	<5	n.p.
28-29	30	30	30	n.p.	n.p.
30-31	110	109	109	109	99.1
32-33	159	159	159	159	100.0
34-36	275	274	274	273	99.3
37-43	384	382	382	379	98.7
<b>Total</b>	<b>969</b>	<b>961</b>	<b>960</b>	<b>954</b>	<b>98.5</b>

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

**Note:** Gestational age groups below 28 weeks have been combined to maintain confidentiality of small numbers.

Gestational age was not provided for one baby.

Death status was not provided for five babies.

## 6. Extremely preterm follow-up, 2009 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. 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, who survived to discharge to home were eligible for follow-up at 2–3 years of age, corrected for prematurity. There were 1,166 infants who fulfilled the criteria for 2–3 year follow-up, and of these, outcome data were obtained on 799 (68.5%) infants.

Care should be taken with interpretation of these data as this is only the first year of collection for the ANZNN and post-discharge data were not retrieved for 183 (15.7%) of the eligible ANZNN registrants born in 2009.

### Follow-up rate

In 2009, 1,383 extremely preterm and/or extremely low birthweight babies were registered to the ANZNN, with 1,166 (84.3%) surviving to hospital discharge. Of the babies who survived to discharge, 799 (68.5%) had outcome data available. There were 13 infants who had died after discharge and 786 who were followed-up at 2–3 years of age, corrected for prematurity. Overall, the rate of follow-up among surviving eligible infants was 68.2% (786 of 1,153). The follow-up rate was seen to decrease with increasing gestational age and increasing birthweight (Table 39 & Table 40).

Outcome data were not available for 367 (31.5%) infants, with 184 (15.8%) being lost to follow-up and the remainder with no post-discharge data being retrieved from the NICU. It should be noted that of the NICUs with eligible infants, three were unable to provide post-discharge data before the publication of this report, accounting for the majority of those infants with no post-discharge data. Among the surviving eligible infants registered to NICUs who were able to submit their data, the follow-up rate was 79.8% (786 of 985).

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

	Gestational age group					Total
	<25	25	26	27	≥28 <sup>(a)</sup>	
	Number					
Registrants	218	260	336	316	253	1,383
Survived to discharge	134	205	286	299	242	1,166
▪ Died post-discharge	<5	<5	<5	5	<5	13
▪ Follow-up assessment <sup>(b)</sup>	101	146	194	201	144	786
▪ No outcome data	n.p.	n.p.	n.p.	93	n.p.	367
	Per cent					
Survived to discharge <sup>(c)</sup>	61.5	78.8	85.1	94.6	95.7	84.3
Follow-up rate <sup>(d)</sup>	76.5	72.6	68.1	68.4	59.8	68.2

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

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

**(b)** Includes 236 infants assessed at <24 months corrected age (68 assessed at 6–22 months corrected age, 168 assessed at 23 months corrected age) and 20 infants with unknown corrected age at assessment.

**(c)** Denominator is all registrants.

**(d)** Denominator is registrants who survived to discharge to home minus registrants who died post-discharge.

**Note:** Gestational age groups below 25 weeks have been combined to maintain confidentiality of small numbers.

Of the 786 infants who were followed-up, 687 (87.4 %) had a formal developmental assessment. For the remaining 99 (12.6%) infants, some follow-up information was obtained but a formal developmental assessment was not completed.

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

	Birthweight group (grams)							Total
	<500	500–599	600–699	700–799	800–899	900–999	≥1000 <sup>(a)</sup>	
	Number							
Registrants	30	85	201	239	273	305	250	1,383
Survived to discharge	12	57	147	196	236	284	234	1,166
▪ Died post-discharge	<5	<5	<5	<5	<5	5	<5	13
▪ Follow-up assessment <sup>(b)</sup>	9	46	105	139	156	180	151	786
▪ No outcome data	n.p.	n.p.	n.p.	n.p.	n.p.	99	n.p.	367
	Per cent							
Survived to discharge <sup>(c)</sup>	40.0	67.1	73.1	82.0	86.4	93.1	93.6	84.3
Follow-up rate <sup>(d)</sup>	81.8	83.6	71.9	71.3	66.7	64.5	64.8	68.2

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

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

**(b)** Includes 236 infants assessed at <24 months corrected age (68 assessed at 6–22 months corrected age, 168 assessed at 23 months corrected age) and 20 infants with unknown corrected age at assessment.

**(c)** Denominator is all registrants.

**(d)** Denominator is registrants who survived to discharge to home 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 the local paediatrician or general practitioner examined the child. The median age of assessment was 24.6 months with an interquartile range of 23.8–27.0 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 or Griffiths Mental Developmental Scales performed by a psychologist or a developmental paediatrician.

## 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). Information about cerebral palsy was available for 91.1% of infants with a follow-up assessment at 2–3 years of age, corrected for prematurity and of these, 65 (9.1%) had a diagnosis of cerebral palsy. The movement ability of 63 (96.9%) 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, 27 (42.9%) infants were graded as level 1, 17 (27.0%) as level 2, six (9.5%) as level 3, five (7.9%) as level 4 and eight (12.7%) as level 5. Cerebral palsy was most prevalent and most severe among infants less than 25 weeks gestational age (Table 41).

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

	Gestational age (completed weeks)					
Cerebral Palsy (CP)	<25	25	26	27	≥28	Total
Number						
No CP	75	119	158	177	122	651
CP	14	11	18	13	9	65
Not stated	12	16	18	11	13	70
Total	101	146	194	201	144	786
Per cent						
No CP	84.3	91.5	89.8	93.2	93.1	90.9
CP	15.7	8.5	10.2	6.8	6.9	9.1
Total	100.0	100.0	100.0	100.0	100.0	100.0

*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 97.2% of infants with a follow-up assessment at 2–3 years of age, corrected for prematurity and of these, only three (0.4%) were recorded as being blind (< 6/60 in the better eye).

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). Information on the use of devices for hearing amplification was available for 97.1% of infants with a follow-up assessment at 2–3 years of age, corrected for prematurity. A total of nine infants were fitted with hearing aids, including four (0.5%) infants with a unilateral hearing aid and five (0.7%) with bilateral hearing aids. A further four (0.5%) infants were fitted with a cochlear implant. The proportion of infants with hearing devices was more than double among those less than 25 weeks gestational age (3.1%) compared to any other gestational age group (0.7%–1.5%).

## Developmental testing

Developmental delay is often the most prevalent impairment in extremely preterm and/or extremely low birthweight babies (Doyle et al. 2010, Doyle et al. 2011). Of the infants with a follow-up assessment at 2–3 years of age, corrected for prematurity, 687 (87.4%) had a standardised developmental test, including 644 who were assessed using the Bayley Scales of Development-III, 27 using the Griffiths Mental Developmental Scales and 16 using other developmental tests.

Developmental delay was graded as mild, moderate or severe, whereby severe delay was defined as greater than 3 standard deviations (SD), moderate delay as between 2 and 3 SD and mild delay as between 1 and 2 SD below the mean on either of the cognitive or language scales (mean = 100, SD = 15). There were an additional 15 infants whose developmental delay was determined by clinical assessment and four infants who were unable to be assessed due to severe developmental delay and were therefore included in the severe developmental delay category. Overall, there were 192 (27.5%) infants with any degree of developmental delay, including 127 (18.2%) with a mild delay, 50 (7.2%) with a moderate delay and 15 (2.1%) with a severe delay. Development delay was greatest among infants less than 25 weeks gestational age (42.9%) (Table 42).



**TABLE 42: Developmental delay at 2–3 year follow-up by gestational age, 2009 births**

	Gestational age (completed weeks)					
Developmental delay	<25	25	26	27	≥28	Total
Number						
Normal	52	102	127	138	88	507
Mild	28	21	27	29	22	127
Moderate or severe <sup>(a)</sup>	11	9	21	14	10	65
Incomplete/no scores	0	2	1	3	1	7
Not stated	10	12	18	17	23	80
<b>Total</b>	<b>101</b>	<b>146</b>	<b>194</b>	<b>201</b>	<b>144</b>	<b>786</b>
Per cent						
Normal	57.1	77.3	72.6	76.2	73.3	72.5
Mild	30.8	15.9	15.4	16.0	18.3	18.2
Moderate or severe	12.1	6.8	12.0	7.8	8.4	9.3
<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>

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

*(a)* Moderate and severe developmental delay have been combined to maintain confidentiality of small numbers.

**Note:** Not stated data and assessments with incomplete/no scores are excluded from per cent calculations.

## Functional disability

Functional disability was graded as mild (GMFCS level 1 cerebral palsy or mild developmental delay), moderate (GMFCS level 2 to 3 cerebral palsy, deafness requiring amplification or moderate developmental delay) or severe (GMFCS level 4 to 5 cerebral palsy, blindness or severe developmental delay). Functional disability could be ascertained for 664 (84.5%) infants with a follow-up assessment at 2–3 years of age, corrected for prematurity. There were 230 (34.6%) infants with any degree of functional disability, including 140 (21.1%) with a mild disability, 67 (10.1%) with a moderate disability and 23 (3.5%) with a severe disability. Functional disability was most prevalent and most severe among infants less than 25 weeks gestational age, with over half (51.7%) having some degree of functional disability (Table 43).

**TABLE 43: Severity of functional disability at 2–3 year follow-up by gestational age, 2009 births**

Severity of functional disability	Gestational age (completed weeks)					Total
	<25	25	26	27	≥28	
Number						
None	43	81	105	123	82	434
Mild	30	n.p.	32	n.p.	n.p.	140
Moderate	11	10	20	16	10	67
Severe	5	<5	7	<5	<5	23
Not stated	12	27	30	29	24	122
<b>Total</b>	<b>101</b>	<b>146</b>	<b>194</b>	<b>201</b>	<b>144</b>	<b>786</b>
Per cent						
None	48.3	68.1	64.0	71.5	68.3	65.4
Mild	33.7	n.p.	19.5	n.p.	n.p.	21.1
Moderate	12.4	8.4	12.2	9.3	8.3	10.1
Severe	5.6	n.p.	4.3	n.p.	n.p.	3.5
<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>

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

**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.

Of the infants with computable percentiles, 19.1% fell below the third percentile for weight for age, 11.8% for height for age, 8.2% for head circumference for age and 12.2% 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 (Tables 44 to 47). 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 follow-up, whereby the number of infants in the bottom 3rd percentile decreased with increasing birthweight.

**TABLE 44: Weight for age at 2–3 year follow-up by gestational age, 2009 births**

	Gestational age (completed weeks)					
Weight for age centile	<25	25	26	27	≥28	Total
Number						
<3	17	22	27	25	43	134
3–9	18	n.p.	19	20	n.p.	88
10–90	47	96	120	116	61	440
>90	6	<5	8	21	<5	41
Not stated	13	10	20	19	21	83
Total	101	146	194	201	144	786
Per cent						
<3	19.3	16.2	15.5	13.7	35.0	19.1
3–9	20.5	n.p.	10.9	11.0	n.p.	12.5
10–90	53.4	70.6	69.0	63.7	49.6	62.6
>90	6.8	n.p.	4.6	11.5	n.p.	5.8
Total	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 45: Height for age at 2–3 year follow-up by gestational age, 2009 births**

	Gestational age (completed weeks)					
Height for age centile	<25	25	26	27	≥28	Total
Number						
<3	11	12	19	11	27	80
3–9	n.p.	n.p.	18	20	20	85
10–90	57	103	120	122	73	475
>90	<5	<5	8	23	0	38
Not stated	16	14	29	25	24	108
<b>Total</b>	<b>101</b>	<b>146</b>	<b>194</b>	<b>201</b>	<b>144</b>	<b>786</b>
Per cent						
<3	12.9	9.1	11.5	6.3	22.5	11.8
3–9	n.p.	n.p.	10.9	11.4	16.7	12.5
10–90	67.1	78.0	72.7	69.3	60.8	70.1
>90	n.p.	n.p.	4.8	13.1	0.0	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>

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

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

**TABLE 46: Head circumference for age at 2–3 year follow-up by gestational age, 2009 births**

Head circumference for age centile	Gestational age (completed weeks)					Total
	<25	25	26	27	≥28	
Number						
<3	13	8	8	6	14	49
3–9	n.p.	14	14	9	n.p.	65
10–90	42	93	110	120	65	430
>90	<5	8	16	23	<5	54
Not stated	15	12	17	21	20	85
<b>Total<sup>(a)</sup></b>	<b>86</b>	<b>135</b>	<b>165</b>	<b>179</b>	<b>118</b>	<b>683</b>
Per cent						
<3	18.3	6.5	5.4	3.8	14.3	8.2
3–9	n.p.	11.4	9.5	5.7	n.p.	10.9
10–90	59.2	75.6	74.3	75.9	66.3	71.9
>90	n.p.	6.5	10.8	14.6	n.p.	9.0
<b>Total<sup>(a)</sup></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.

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

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

	Gestational age (completed weeks)					
Weight for height centile	<25	25	26	27	≥28	Total
Number						
<3	8	11	17	15	32	83
3–9	13	n.p.	15	13	n.p.	70
10–90	56	99	115	125	67	462
>90	8	n.p.	18	23	<5	63
Not stated	16	14	29	25	24	108
<b>Total</b>	<b>101</b>	<b>146</b>	<b>194</b>	<b>201</b>	<b>144</b>	<b>786</b>
Per cent						
<3	9.4	8.3	10.3	8.5	26.7	12.2
3–9	15.3	n.p.	9.1	7.4	n.p.	10.3
10–90	65.9	75.0	69.7	71.0	55.8	68.1
>90	9.4	n.p.	10.9	13.1	n.p.	9.3
<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>

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

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

## Respiratory and gastrointestinal tract

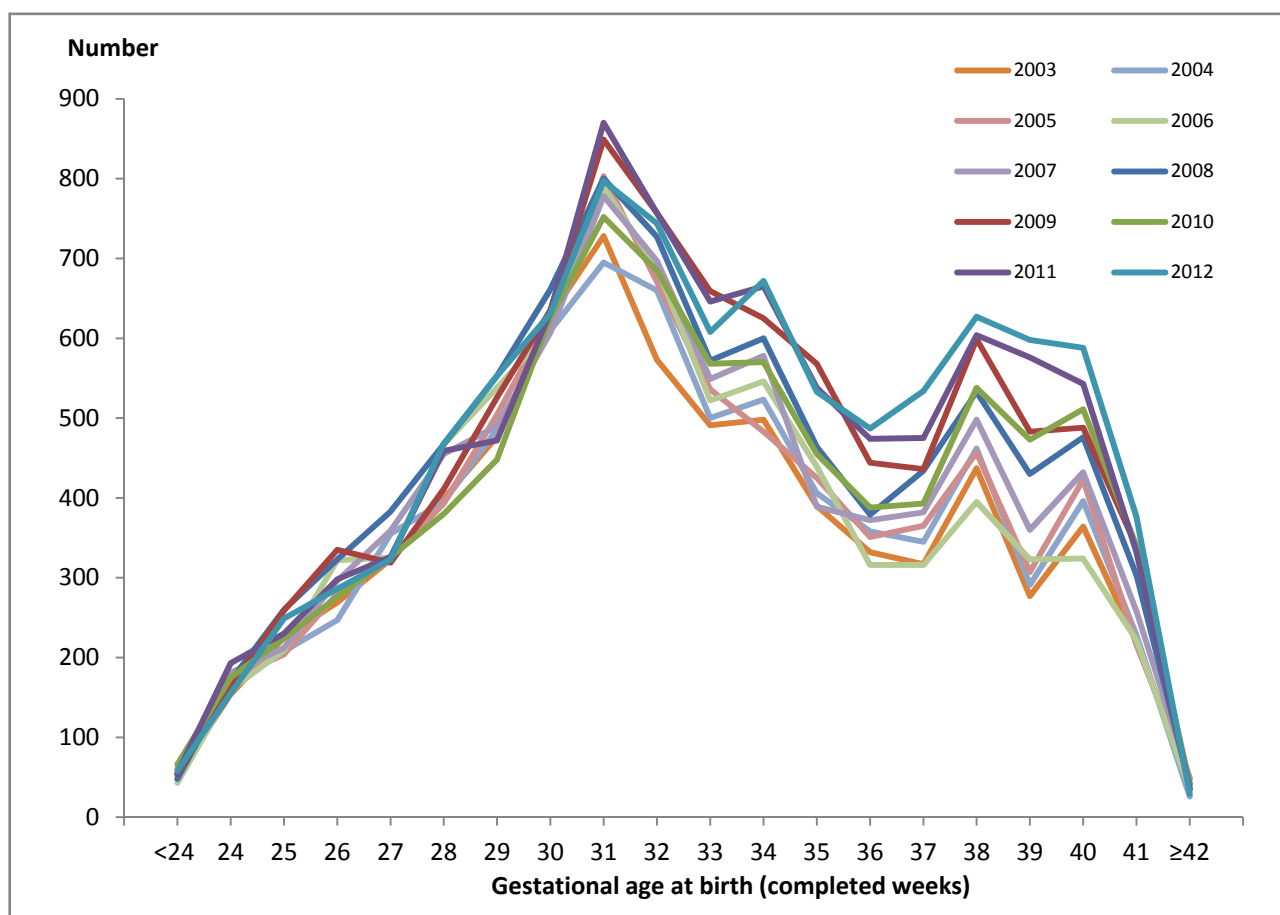
Respiratory and gastrointestinal tract (GIT) complications such as respiratory distress syndrome and necrotising enterocolitis commonly affect extremely premature babies and can lead to ongoing disease. Of the 683 infants with data available on the use of respiratory support, five (0.7%) were supported by supplemental oxygen at the time of 2–3 year follow-up. Two-thirds 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 14 (2.0%) of the 692 infants with nutritional support data at the time of 2–3 year follow-up. Nutritional support was most prevalent among infants less than 25 weeks gestational age (4.3%) and infants 28 weeks gestational age or older who weighed less than 1,000 grams at birth (4.0%).

# APPENDICES

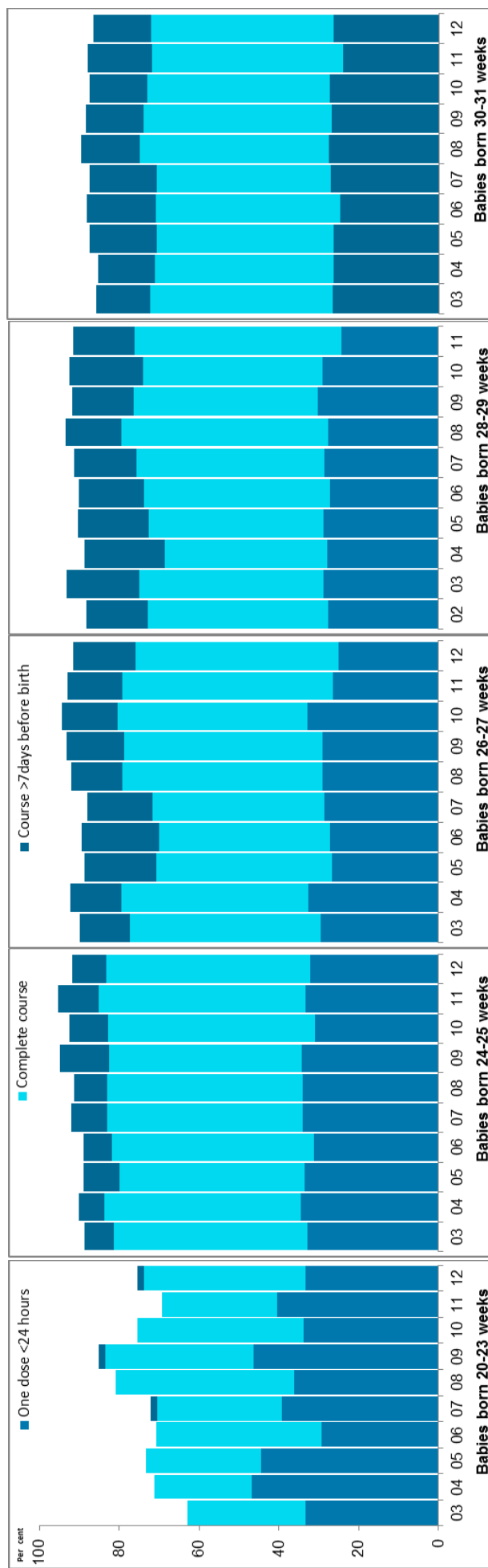
## Appendix 1: Trends

FIGURE 10: Trends in gestational age at birth of level III registrants, 2003–2012



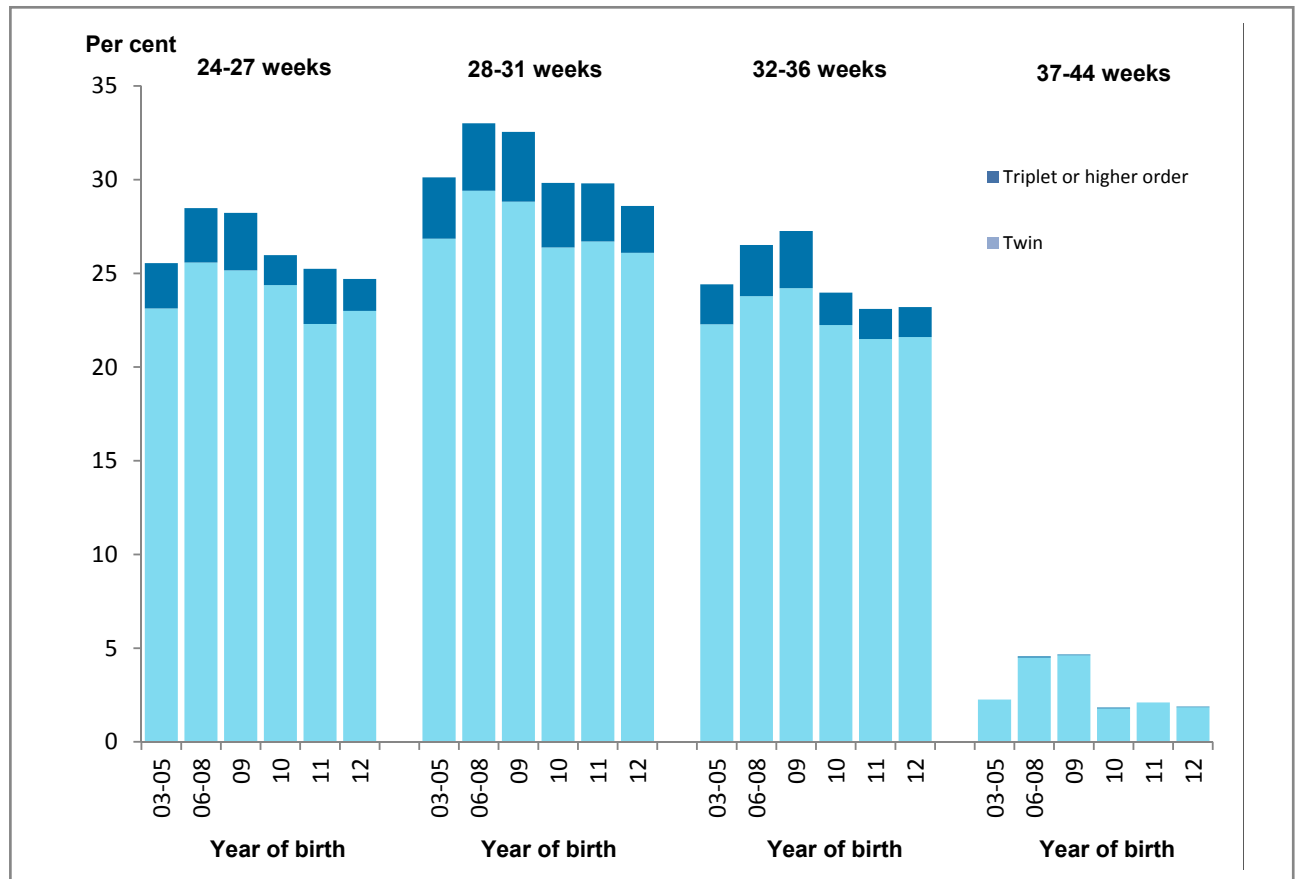
*Note: Data on the ANZNN registrants from two level III NICUs were not included in 2010.*

**FIGURE 11: Trends in the use of corticosteroids for mothers of babies less than 32 weeks gestation, 2003–2012**



**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 12: Trends in multiple births of level III registrants by gestational age group, 2003–2012**



**FIGURE 13: Trends in method of birth for level III registrants by year of birth, 2003–2012**

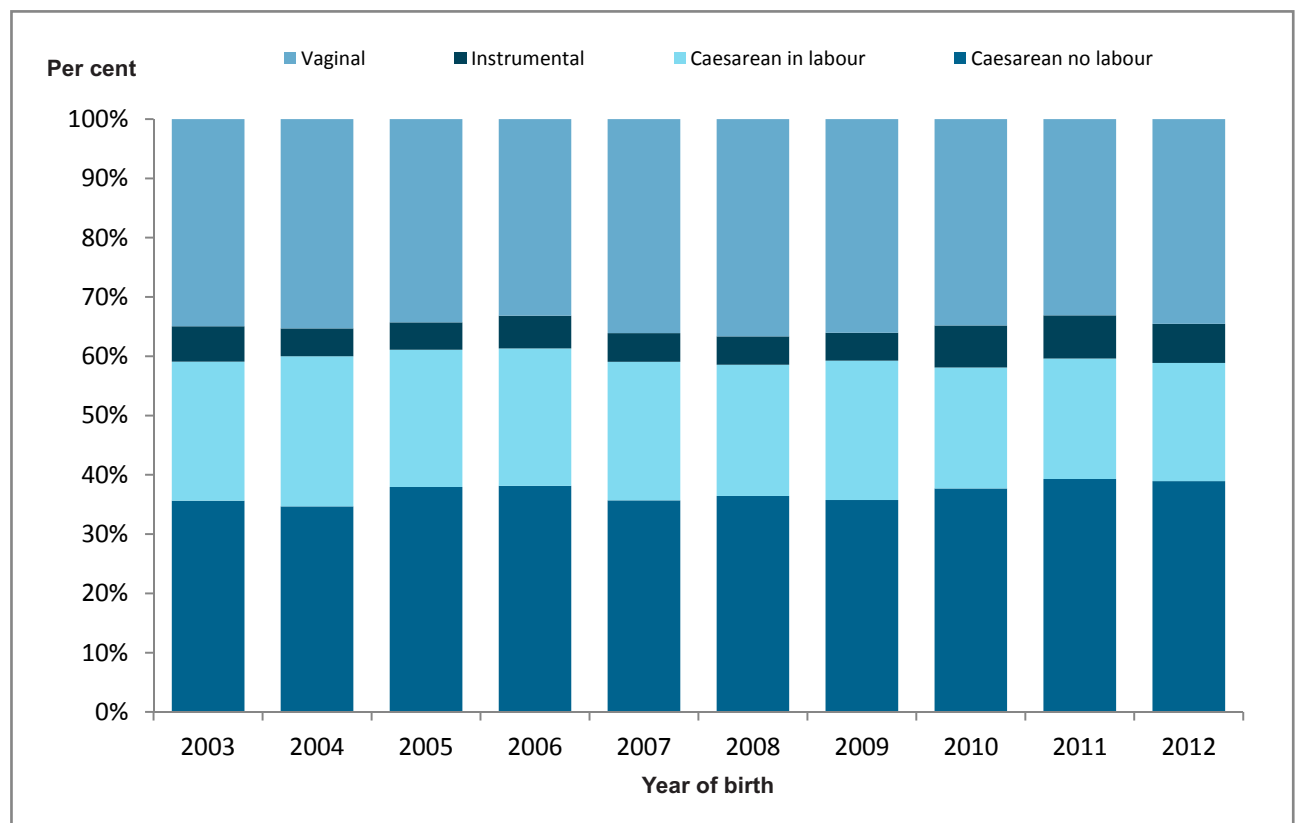


FIGURE 14: Trends in referral source to level III NICU by year of birth, 2003–2012

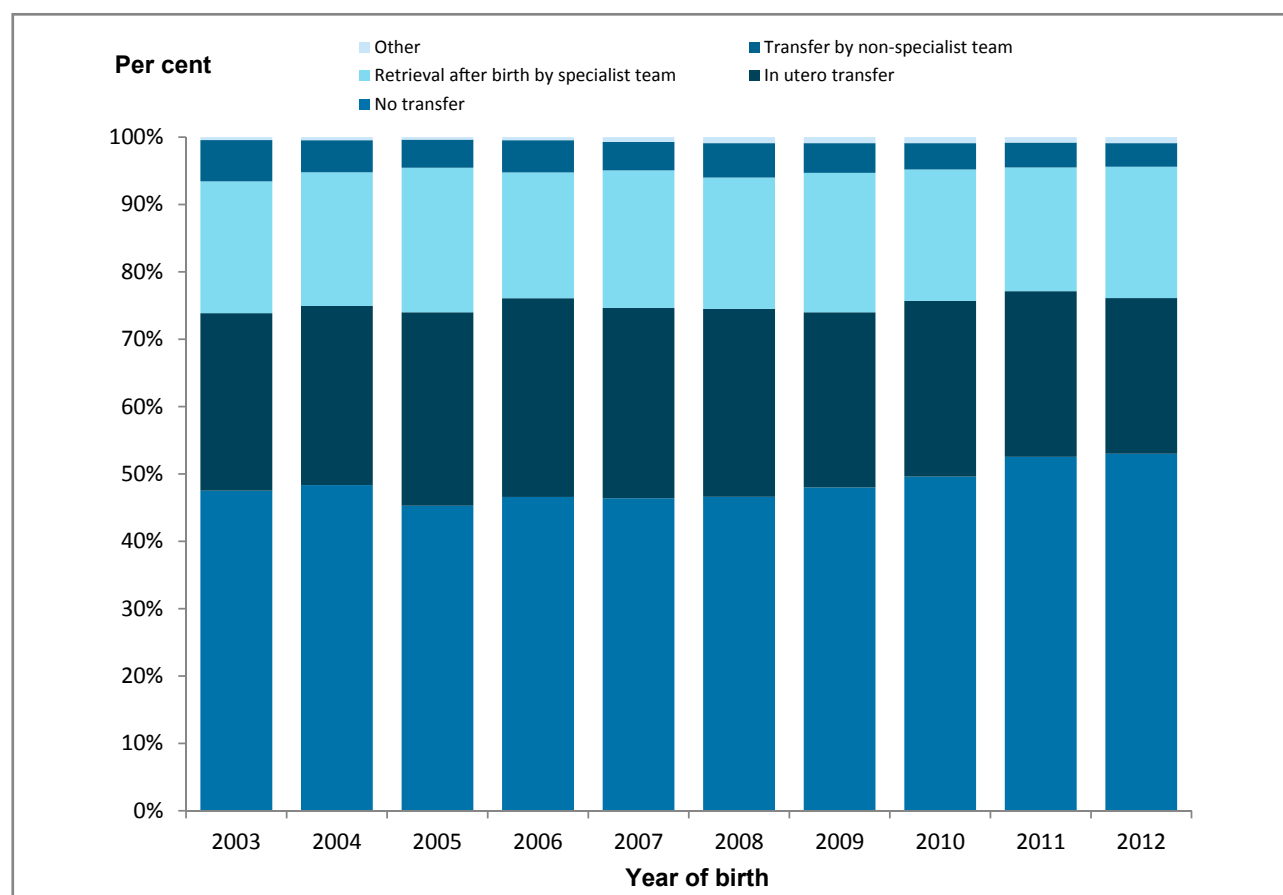
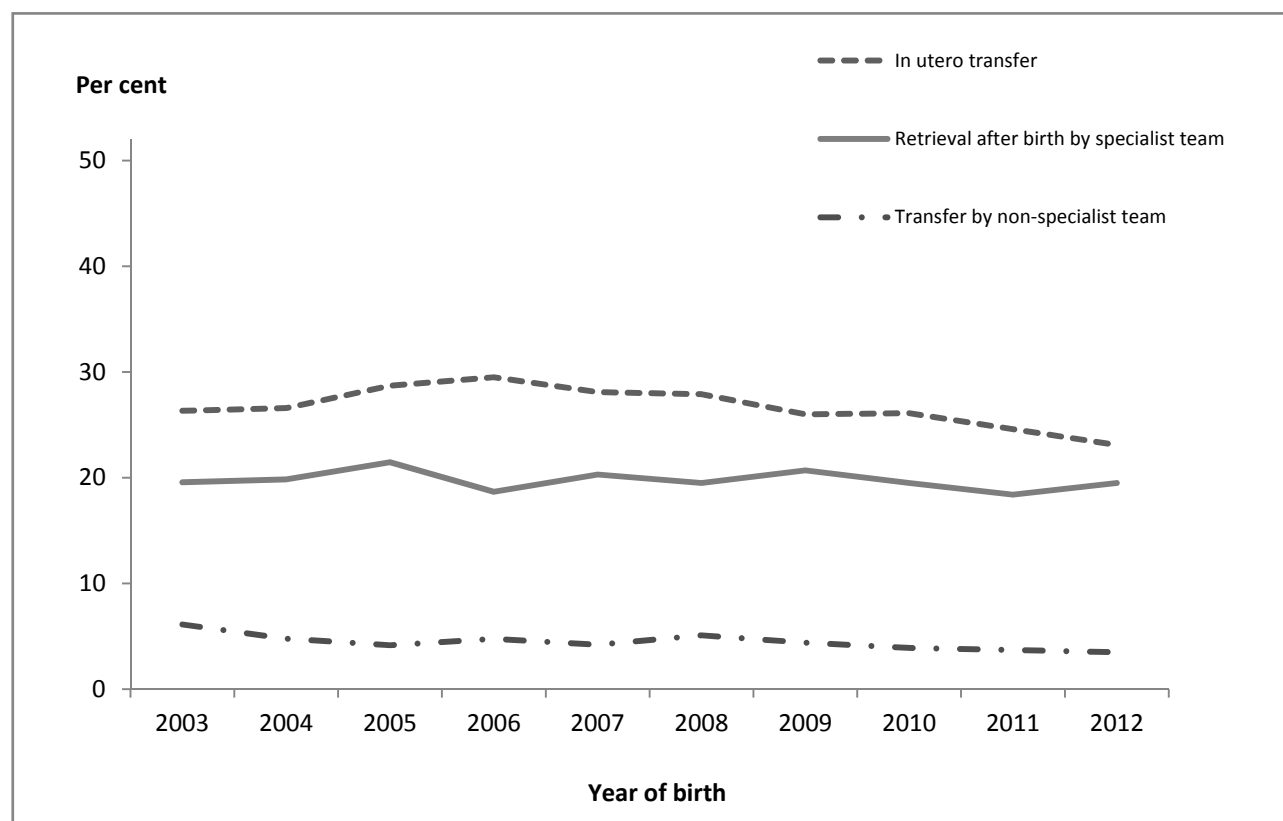
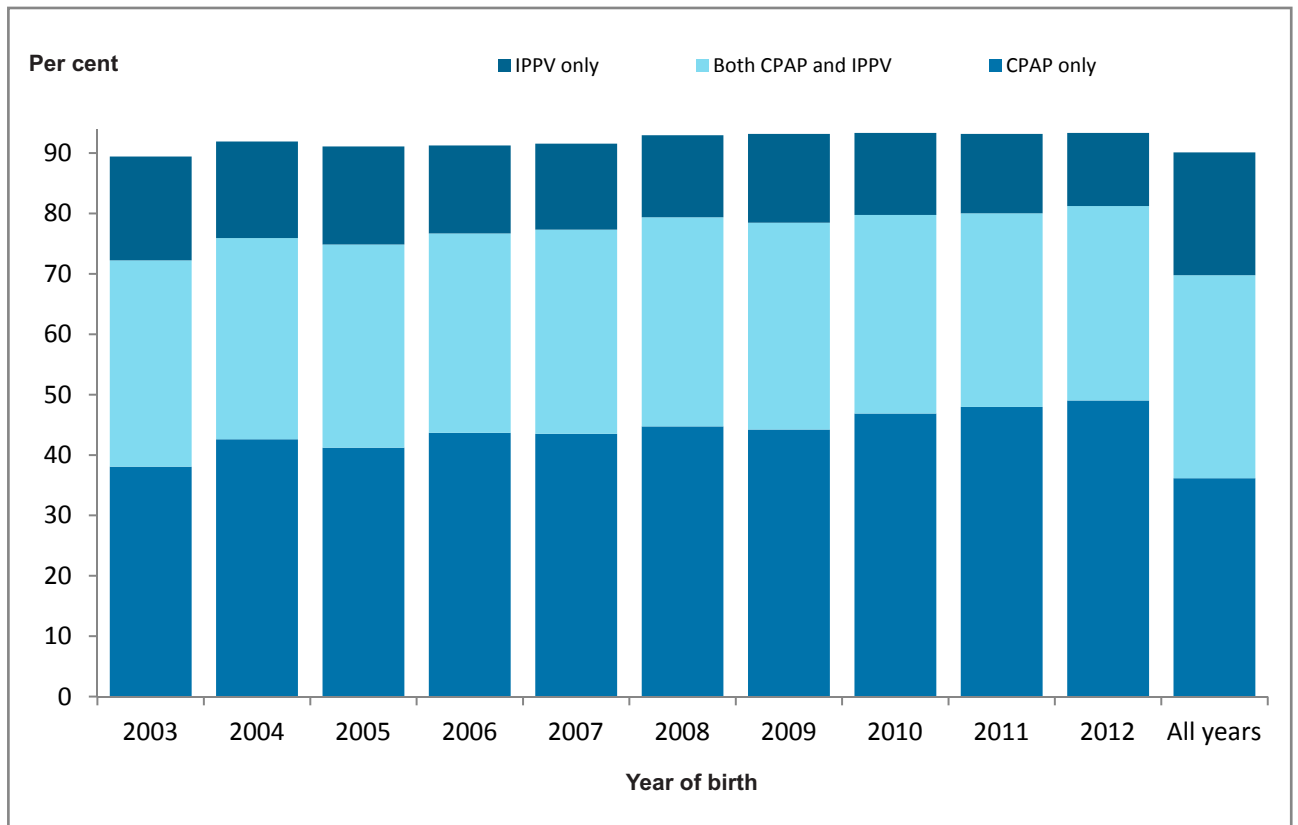


FIGURE 15: Trends in mode of transport to level III NICU, 2003-2012

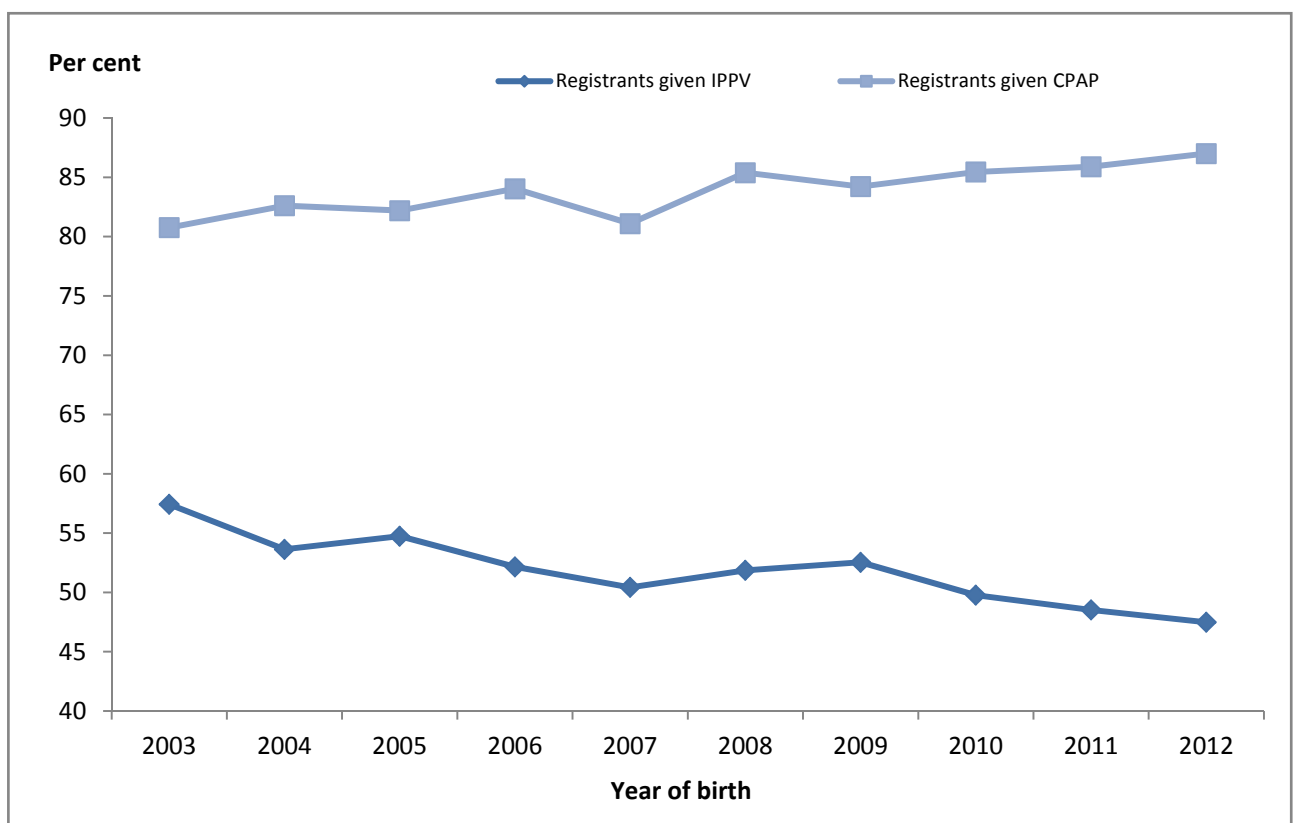




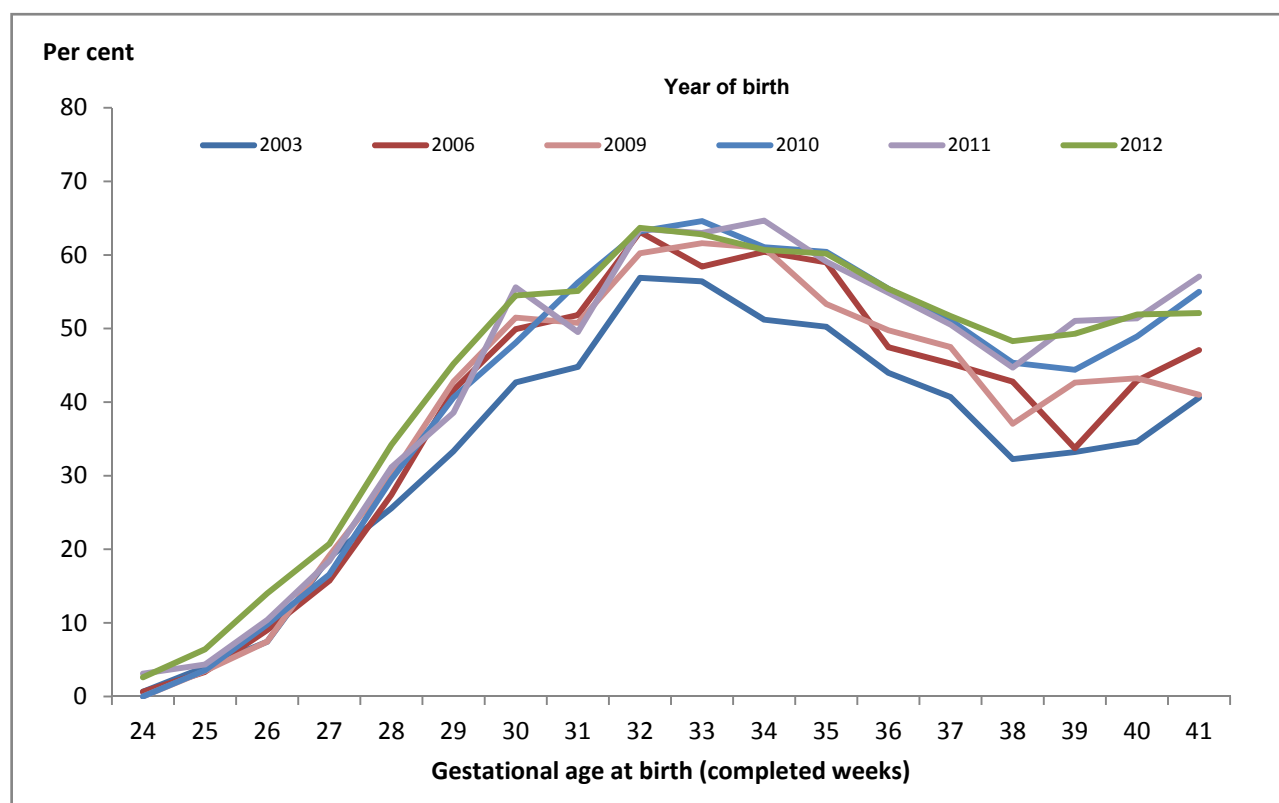
**FIGURE 16: Trends in mode of assisted ventilation for level III registrants, 2003–2012**



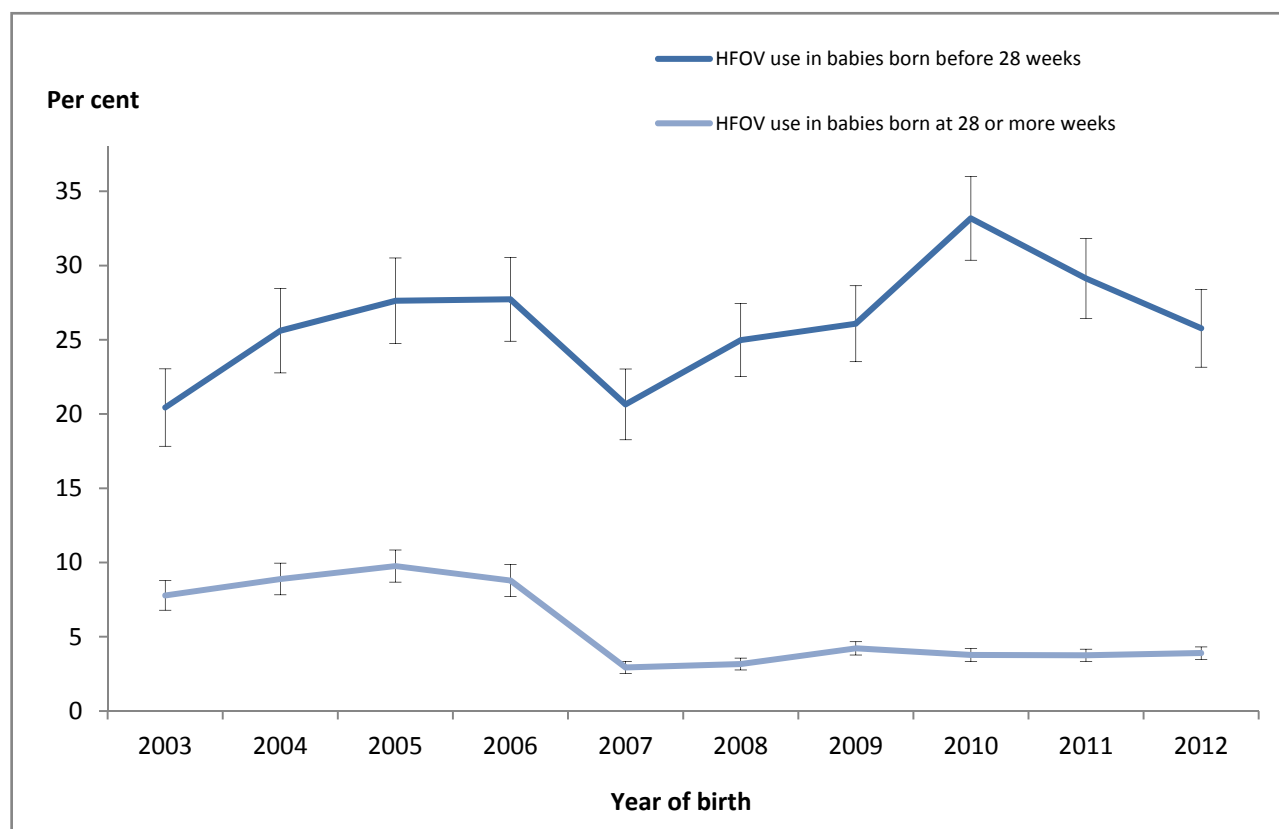
**FIGURE 17: Trends in provision of intermittent positive pressure ventilation and continuous positive pressure ventilation by year of birth for level III registrants ventilated, 2003–2012**



**FIGURE 18: Trends in the use of CPAP as the only form of ventilation by gestational age for level III registrants, 2003, 2006, 2009–2012**

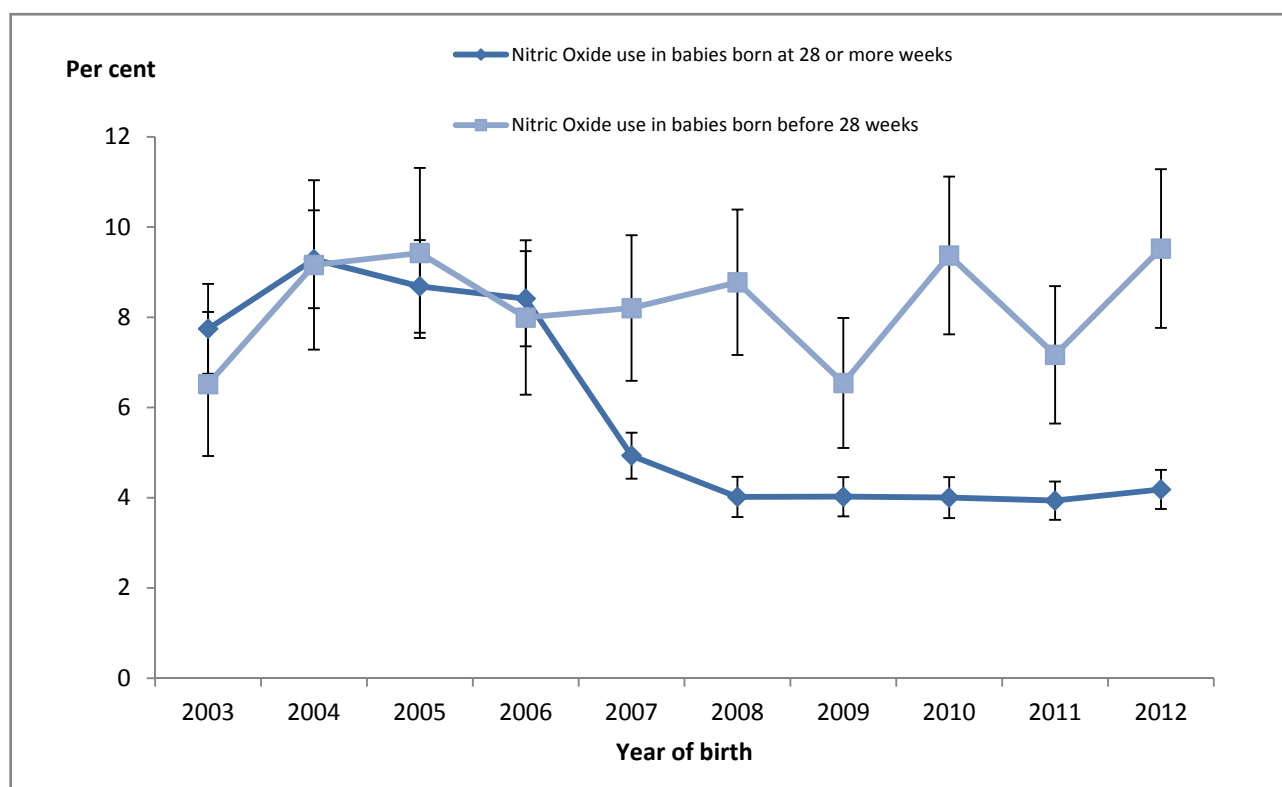


**FIGURE 19: Trends in provision of high frequency oscillatory ventilation (with 95% CI) for level III registrants born before 28 weeks and at 28 or more weeks gestation, 2003–2012**



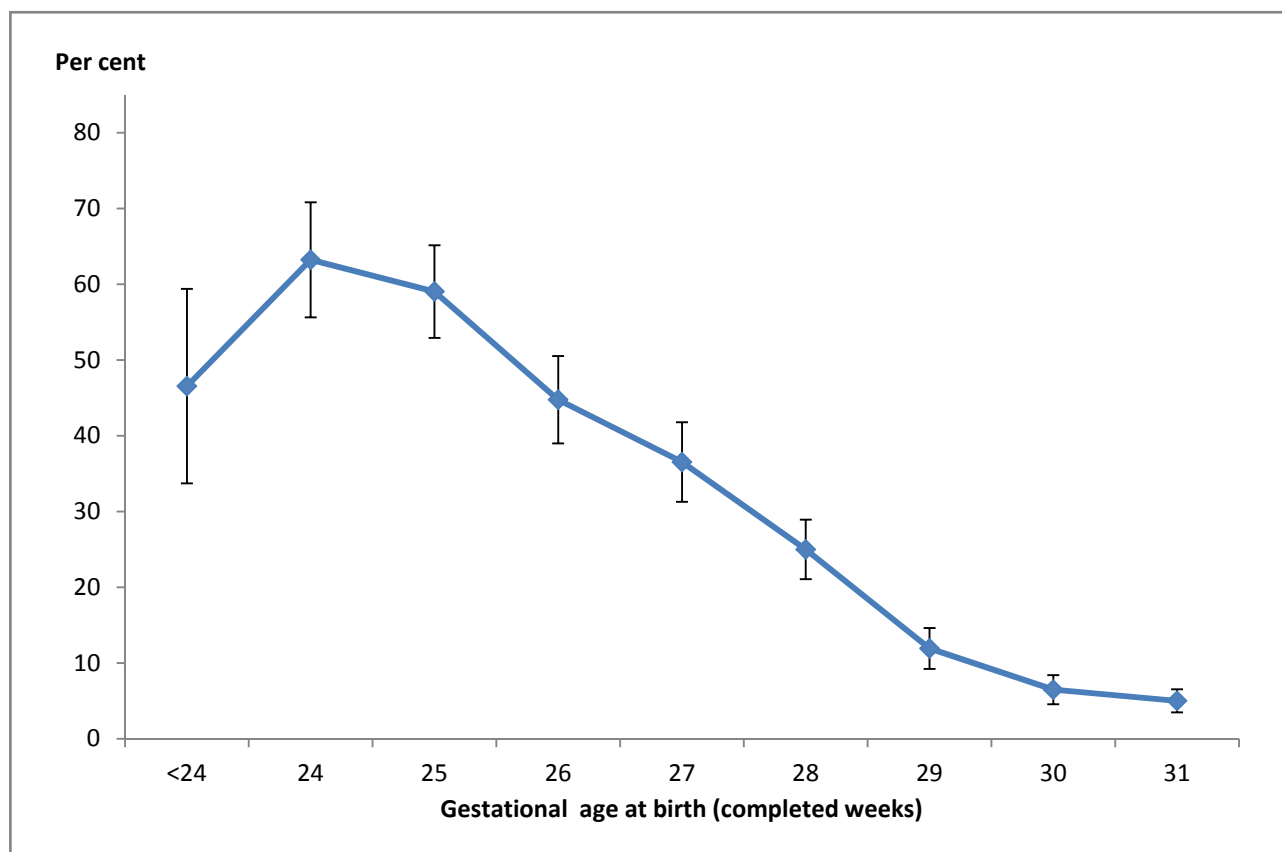
*Note: The results are given as the percentage of babies given IPPV.*

**FIGURE 20: Trends in nitric oxide (with 95% CI) provision for level III registrants born before 28 weeks and 28 or more weeks gestation, 2003–2012**

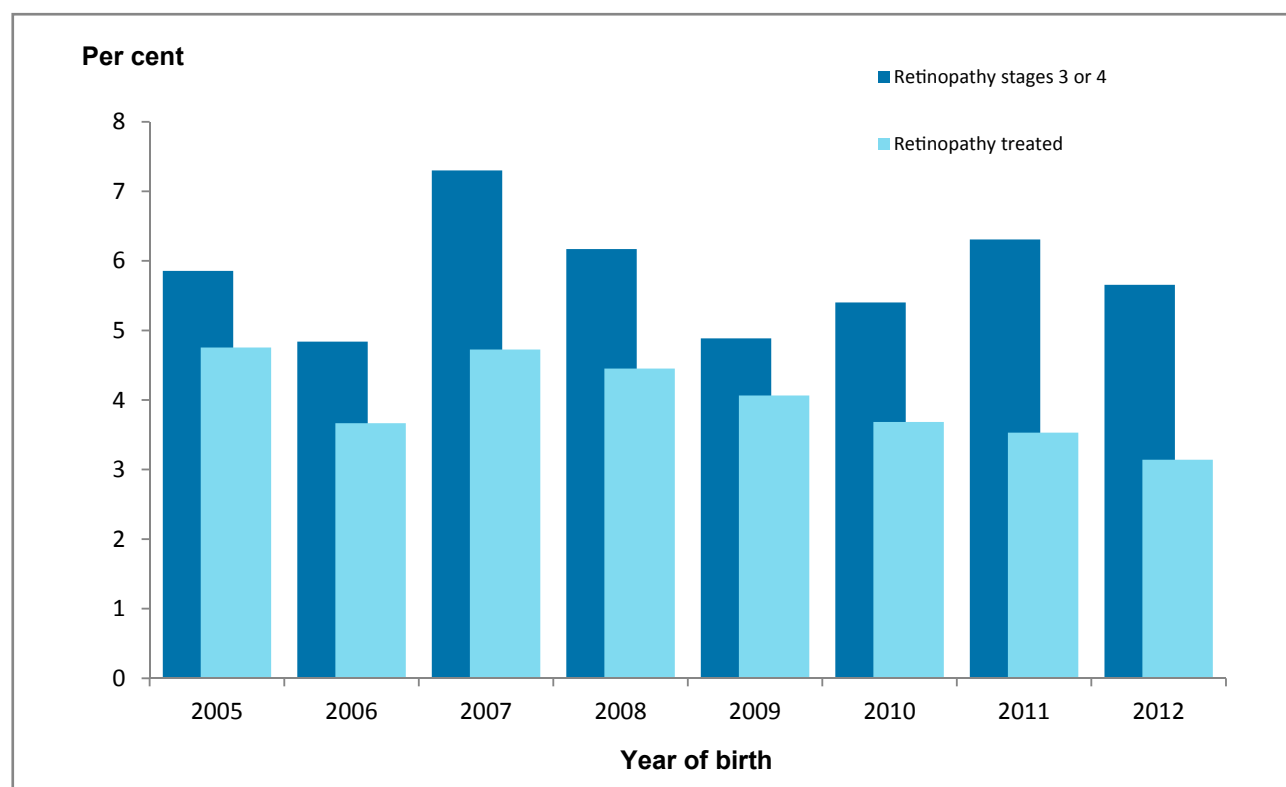


*Note: Results are given as the percentage of babies given IPPV.*

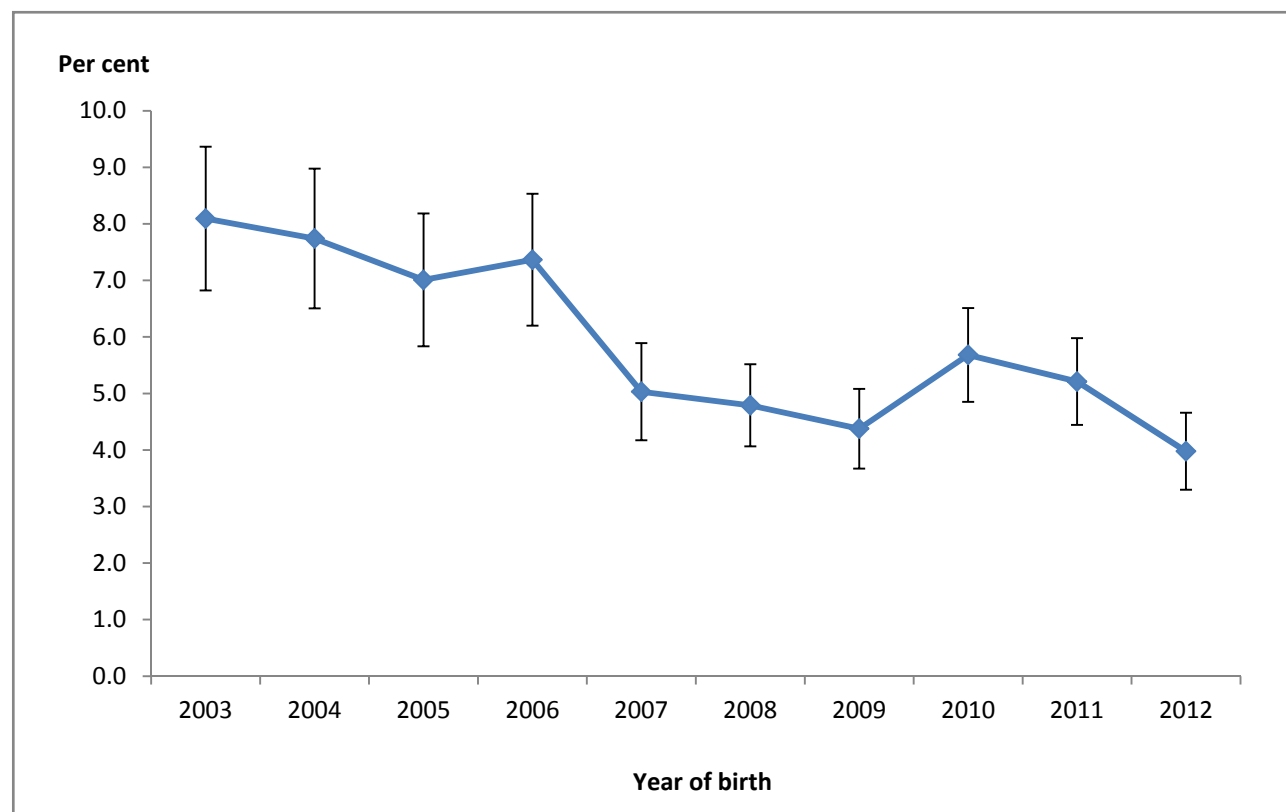
**FIGURE 21: Incidence of chronic lung disease (with 95% CI) for level III registrants by gestational age, 2012**



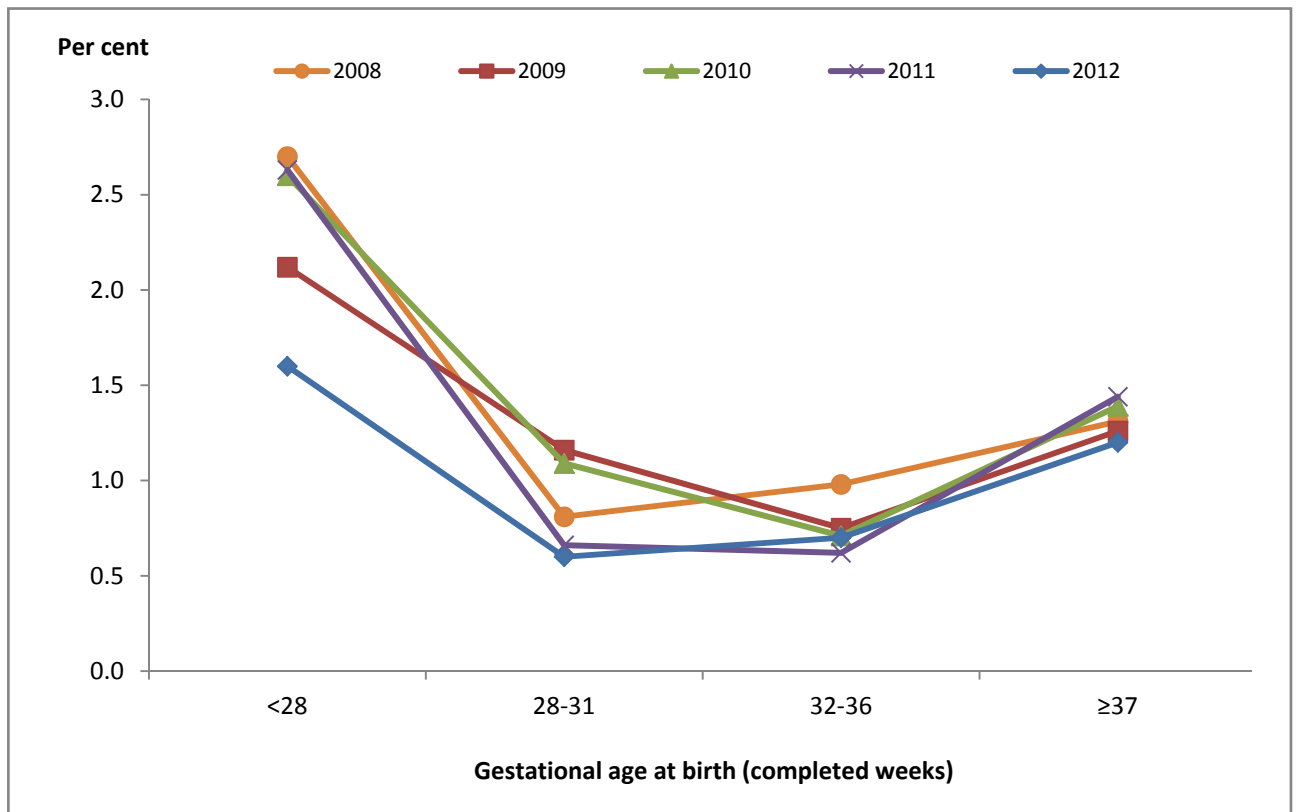
**FIGURE 22: Stage 3 or 4 retinopathy of prematurity and treated retinopathy among babies born before 31 weeks gestation and/or birthweight of less than 1,250 grams who survived to 36 weeks corrected age for level III registrants, 2005–2012**



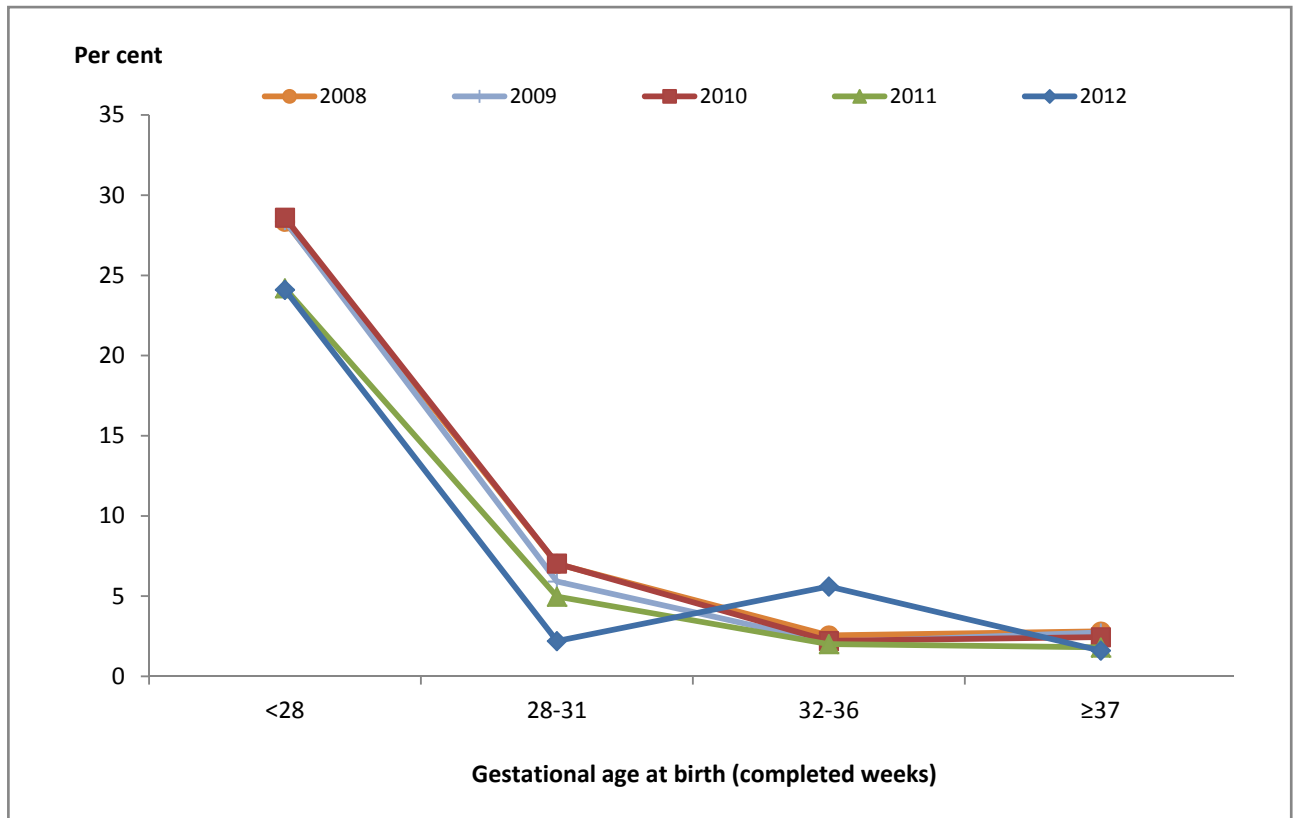
**FIGURE 23: Trends in grade 3 or 4 intraventricular haemorrhage (with 95% CI) in babies born at less than 32 weeks gestation who survived to day 3 for level III registrants, 2003–2012**



**FIGURE 24: Incidence of early sepsis for level III registrants by gestational age group, 2008–2012**



**FIGURE 25: Incidence of late sepsis for level III registrants by gestational age group, 2008–2012**



## APPENDIX 2: Data tables by birthweight

TABLE 48: Antenatal corticosteroid use for level III registrants by birthweight group, 2012

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	<5	41	64	98	137	277	543	696	947	673	n.p.	3,817
Incomplete course	n.p.	97	155	189	221	428	208	66	25	6	<5	1,405
Course completed	26	183	358	409	505	623	303	120	34	14	8	2,583
Completed > 7 days	<5	39	96	123	178	241	127	76	25	8	n.p.	924
Not stated	0	3	9	22	16	29	56	118	160	117	57	587
Total	38	363	682	841	1,057	1,598	1,237	1,076	1,191	818	415	9,316
Per cent												
None	n.p.	11.4	9.5	12.0	13.2	17.7	46.0	72.7	91.9	96.0	n.p.	43.7
Incomplete course	n.p.	26.9	23.0	23.1	21.2	27.3	17.6	6.9	2.4	0.9	n.p.	16.1
Course completed	68.4	50.8	53.2	49.9	48.5	39.7	25.7	12.5	3.3	2.0	2.2	29.6
Completed > 7 days	n.p.	10.8	14.3	15.0	17.1	15.4	10.8	7.9	2.4	1.1	n.p.	10.6
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 49: Plurality of level III registrants by birthweight group, 2012

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	25	275	498	599	724	1,130	974	970	1,168	814	415	7,592
Twins	13	82	168	222	298	430	254	n.p.	23	<5	0	1,597
Triplets and higher orders	0	6	16	20	35	38	9	<5	0	n.p.	0	127
Total	38	363	682	841	1,057	1,598	1,237	1,076	1,191	818	415	9,316
Per cent												
Singleton	65.8	75.8	73.0	71.2	68.5	70.7	78.7	90.1	98.1	99.5	100.0	81.5
Twins	34.2	22.6	24.6	26.4	28.2	26.9	20.5	n.p.	1.9	n.p.	0.0	17.1
Triplets and higher orders	0.0	1.7	2.3	2.4	3.3	2.4	0.7	n.p.	0.0	n.p.	0.0	1.4
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.

**TABLE 50: Method of delivery for level III registrants by birthweight group, 2012**

Method of Delivery	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	8	139	228	202	306	528	424	402	463	349	152	3,201
Vaginal instrumental birth	n.p.	<5	n.p.	13	25	70	78	86	170	108	56	615
Caesarean in labour	<5	n.p.	n.p.	181	190	307	249	203	220	177	109	1,840
Caesarean no labour	26	164	302	442	536	687	479	379	327	176	93	3,611
Not stated	0	2	1	3	0	6	7	6	11	8	5	49
Total	38	363	682	841	1,057	1,598	1,237	1,076	1,191	818	415	9,316
Per cent												
Vaginal	21.1	38.5	33.5	24.1	28.9	33.2	34.5	37.6	39.2	43.1	37.1	34.5
Vaginal instrumental birth	n.p.	n.p.	n.p.	1.6	2.4	4.4	6.3	8.0	14.4	13.3	13.7	6.6
Caesarean in labour	n.p.	n.p.	n.p.	21.6	18.0	19.3	20.2	19.0	18.6	21.9	26.6	19.9
Caesarean no labour	68.4	45.4	44.3	52.7	50.7	43.2	38.9	35.4	27.7	21.7	22.7	39.0
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 51: Level of hospital of birth for level III registrants by birthweight group, 2012**

Level of 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	n.p.	337	596	728	929	1,347	955	765	773	n.p.	270	7,265
Non-tertiary	<5	26	n.p.	n.p.	120	237	272	n.p.	409	286	138	1,991
Not born in a hospital <sup>(a)</sup>	0	0	<5	<5	8	14	10	<5	7	<5	7	58
Not stated	0	0	0	0	0	0	0	0	2	0	0	2
<b>Total</b>	<b>38</b>	<b>363</b>	<b>682</b>	<b>841</b>	<b>1,057</b>	<b>1,598</b>	<b>1,237</b>	<b>1,076</b>	<b>1,191</b>	<b>818</b>	<b>415</b>	<b>9,316</b>
Per cent												
Tertiary	n.p.	92.8	87.4	86.6	87.9	84.3	77.2	71.1	65.0	n.p.	65.1	78.0
Non-tertiary	n.p.	7.2	n.p.	n.p.	11.4	14.8	22.0	n.p.	34.4	35.0	33.3	21.4
Not born in a hospital <sup>(a)</sup>	0.0	0.0	n.p.	n.p.	0.8	0.9	0.8	n.p.	0.6	n.p.	1.7	0.6
<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>	<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 52: Mode of transport for level III registrants to level III unit after birth by birthweight group, 2012**

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	n.p.	n.p.	592	718	921	1,339	917	718	721	513	265	7,071
Specialist retrieval team	<5	n.p.	72	97	109	218	261	292	378	242	118	1,811
Non-specialist team	n.p.	<5	11	19	20	27	46	55	76	52	19	329
Other	0	4	7	6	6	12	9	8	11	7	11	81
Not stated	1	1	0	1	1	2	4	3	5	4	2	24
Total	38	363	682	841	1,057	1,598	1,237	1,076	1,191	818	415	9,316
Per cent												
Not transported	n.p.	n.p.	86.8	85.5	87.2	83.9	74.4	66.9	60.8	63.0	64.2	76.1
Specialist retrieval team	n.p.	n.p.	10.6	11.5	10.3	13.7	21.2	27.2	31.9	29.7	28.6	19.5
Non-specialist team	n.p.	n.p.	1.6	2.3	1.9	1.7	3.7	5.1	6.4	6.4	4.6	3.5
Other	0.0	1.1	1.0	0.7	0.6	0.8	0.7	0.7	0.9	0.9	2.7	0.9
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 53: Exogenous surfactant use by level III registrants by birthweight group, 2012**

	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	3	32	135	378	646	1,122	948	898	1,033	724	374	6,293
Curosurf	31	284	459	366	328	367	208	125	109	67	31	2,375
Survanta	<5	42	77	87	76	98	76	43	34	23	n.p.	568
Curosurf and Survanta	<5	<5	<5	<5	<5	5	<5	<5	n.p.	<5	<5	32
Other or unknown surfactant	0	<5	<5	n.p.	<5	6	<5	<5	<5	<5	0	30
Not stated	0	0	5	1	0	0	1	4	7	0	0	18
Total	38	363	682	841	1,057	1,598	1,237	1,076	1,191	818	415	9,316
Per cent												
None	7.9	8.8	19.9	45.0	61.1	70.2	76.7	83.8	87.2	88.5	90.1	67.7
Curosurf	81.6	78.2	67.8	43.6	31.0	23.0	16.8	11.7	9.2	8.2	7.5	25.5
Survanta	n.p.	11.6	11.4	10.4	7.2	6.1	6.1	4.0	2.9	2.8	n.p.	6.1
Curosurf and Survanta	n.p.	n.p.	n.p.	n.p.	n.p.	0.3	n.p.	n.p.	n.p.	n.p.	n.p.	0.3
Other or unknown surfactant	0.0	n.p.	n.p.	n.p.	n.p.	0.4	n.p.	n.p.	n.p.	n.p.	0.0	0.3
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: Assisted ventilation for level III registrants by birthweight group, 2012**

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	25	304	631	753	836	1,383	1,038	821	872	593	311	7,567
Invasive ventilation	37	332	527	445	407	523	442	427	518	353	148	4,159
▪ IPPV given	37	329	525	442	405	520	442	421	512	349	148	4,130
▪ HFOV given	23	134	114	48	32	44	36	44	61	39	22	597
NO given	14	45	37	21	21	33	32	45	92	75	32	447
ECMO given	0	0	0	0	0	1	1	3	7	2	0	14
<b>Total in each birthweight group</b>	<b>38</b>	<b>363</b>	<b>682</b>	<b>841</b>	<b>1,057</b>	<b>1,598</b>	<b>1,237</b>	<b>1,076</b>	<b>1,191</b>	<b>818</b>	<b>415</b>	<b>9,316</b>
Per cent												
CPAP given	65.8	83.7	92.5	89.5	79.1	86.5	83.9	76.3	73.2	72.5	74.9	81.2
IPPV given	97.4	90.6	77.0	52.6	38.3	32.5	35.7	39.1	43.0	42.7	35.7	44.3
Per cent of babies given invasive ventilation												
HFOV given	62.2	40.4	21.6	10.8	7.9	8.4	8.1	10.3	11.8	11.0	14.9	14.4
NO given	37.8	13.6	7.0	4.7	5.2	6.3	7.2	10.5	17.8	21.2	21.6	10.7

*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 55: Medians and interquartile ranges of assisted ventilation for level III registrants by birthweight group, 2012**

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	441.5	264.5	75	24.5	22	23	33	48	45	45	38.5	40
IQR	75.5–936.5	59–658	18–283	11–73	11–56	10–60	16–78	22–98	20–96	20–98	16.5–88.5	15–113
CPAP (hours)												
Median	674	986	824	254	90	40	23	22	18	17	16	41
IQR	356–1,460	506–1,304	333–1,160	65–701	29.5–252	15–97	10–53	10–51	8–44	8–36	7–37	13–146

*Note: IQR = Interquartile range*

**TABLE 56: Chronic lung disease for level III registrants by birthweight group, 2012**

Chronic lung disease (CLD)	Birthweight group (grams)							Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	≥2000	
Number								
No CLD	19	143	387	706	983	n.p.	n.p.	8,534
CLD	19	220	295	135	74	n.p.	<5	782
▪ CLD and survived	n.p.	206	289	n.p.	n.p.	n.p.	<5	753
▪ CLD and died	<5	14	6	<5	<5	<5	n.p.	29
Total	38	363	682	841	1,057	1,598	4,737	9,316
Per cent								
No CLD	50.0	39.4	56.7	83.9	93.0	n.p.	n.p.	91.6
CLD	50.0	60.6	43.3	16.1	7.0	n.p.	n.p.	8.4
▪ CLD and survived	n.p.	93.6	98.0	n.p.	n.p.	n.p.	n.p.	96.3
▪ CLD and died	n.p.	6.4	2.0	n.p.	n.p.	n.p.	n.p.	3.7

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

**TABLE 57: Respiratory support (airway support or supplemental oxygen therapy) for level III registrants who survived to day 28 by birthweight group, 2012**

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	<5	6	95	413	806	1,439	1,167	1,011	1,111	775	n.p.	7,225
Respiratory support on day 28	n.p.	294	538	409	232	124	44	42	40	18	n.p.	1,770
▪ survived to discharge home	17	263	520	404	224	116	n.p.	35	30	n.p.	n.p.	1,673
▪ died before discharge	<5	31	18	5	8	8	<5	7	10	<5	<5	97
Not stated	0	0	0	0	0	0	2	0	1	2	0	5
Total	22	300	633	822	1,038	1,563	1,213	1,053	1,152	795	409	9,000
Number												
Respiratory support on day 28 and given home oxygen	6	78	94	36	16	11	n.p.	6	8	<5	<5	265
Per cent												
No respiratory support on day 28	n.p.	2.0	15.0	50.2	77.6	92.1	96.4	96.0	96.5	97.7	n.p.	80.3
Respiratory support on day 28	n.p.	98.0	85.0	49.8	22.4	7.9	3.6	4.0	3.5	2.3	n.p.	19.7
▪ survived to discharge home	81.0	89.5	96.7	98.8	96.6	93.5	n.p.	83.3	75.0	n.p.	n.p.	94.5
▪ died before discharge	n.p.	10.5	3.3	1.2	3.4	6.5	n.p.	16.7	25.0	n.p.	n.p.	5.5
Per cent												
Respiratory support on day 28 and given home oxygen <sup>(a)</sup>	35.3	29.7	18.1	8.9	7.1	9.5	12.2	17.1	26.7	18.8	28.6	15.8

*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 58: Transfer after registration of level III registrants by level of destination hospital by birthweight group, 2012**

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	32	202	307	322	436	648	668	709	839	592	304	5,059
Level III hospital	<5	33	46	39	40	45	28	16	17	18	<5	288
Level II hospital	<5	94	289	466	562	871	517	294	269	174	n.p.	3,628
Children's hospital	<5	33	39	14	19	30	22	55	66	34	n.p.	331
Not stated	0	1	1	0	0	4	2	2	0	0	0	10
Total	38	363	682	841	1,057	1,598	1,237	1,076	1,191	818	415	9,316
Per cent												
Not transferred	84.2	55.8	45.1	38.3	41.2	40.7	54.1	66.0	70.4	72.4	73.3	54.4
Level III hospital	n.p.	9.1	6.8	4.6	3.8	2.8	2.3	1.5	1.4	2.2	n.p.	3.1
Level II hospital	n.p.	26.0	42.4	55.4	53.2	54.6	41.9	27.4	22.6	21.3	n.p.	39.0
Children's hospital	n.p.	9.1	5.7	1.7	1.8	1.9	1.8	5.1	5.5	4.2	n.p.	3.6
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 59: Retinopathy of prematurity for level III registrants by birthweight group, 2012**

Retinopathy of prematurity (ROP)	Birthweight group (grams)						Total
	<500	500-749	750-999	1000-1249	1250-1499	≥1500	
Number							
No ROP	<5	91	n.p.	565	590	626	2,214
Stage 1 ROP	<5	62	114	92	n.p.	14	326
Stage 2 ROP	<5	79	112	61	32	n.p.	296
Stage 3 ROP	10	60	49	15	<5	0	n.p.
Stage 4 ROP	0	0	<5	0	0	<5	<5
Not examined	17	71	67	107	383	5,415	6,060
Not stated	1	0	0	1	9	271	282
Total	38	363	682	841	1,057	6,335	9,316
Per cent							
No ROP	n.p.	31.2	n.p.	77.1	88.7	96.5	74.4
Stage 1 ROP	n.p.	21.2	18.5	12.6	n.p.	2.2	11.0
Stage 2 ROP	n.p.	27.1	18.2	8.3	4.8	n.p.	10.0
Stage 3 ROP	50.0	20.5	8.0	2.0	n.p.	0.0	n.p.
Stage 4 ROP	0.0	0.0	n.p.	0.0	0.0	n.p.	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 60: Intraventricular haemorrhage for level III registrants survived to day 3 by birthweight group, 2012<sup>(a)</sup>**

Intraventricular haemorrhage	Birthweight group (grams)						Total
	<500	500-749	750-999	1000-1249	1250-1499	≥1500	
Number							
None	21	213	484	664	807	2,290	4,479
Grade 1 IVH	5	33	81	86	80	160	445
Grade 2 IVH	0	21	43	28	15	20	127
Grade 3 IVH	<5	15	12	8	7	n.p.	56
Grade 4 IVH	<5	31	25	11	8	n.p.	91
Not examined	5	23	18	37	132	3,781	3,996
Not stated	0	0	0	1	0	4	5
<b>Total</b>	<b>33</b>	<b>336</b>	<b>663</b>	<b>835</b>	<b>1,049</b>	<b>6,283</b>	<b>9,199</b>
Per cent							
None	75.0	68.1	75.0	83.3	88.0	91.7	86.2
Grade 1 IVH	17.9	10.5	12.6	10.8	8.7	6.4	8.6
Grade 2 IVH	0.0	6.7	6.7	3.5	1.6	0.8	2.4
Grade 3 IVH	n.p.	4.8	1.9	1.0	0.8	n.p.	1.1
Grade 4 IVH	n.p.	9.9	3.9	1.4	0.9	n.p.	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 stated and not examined data are excluded from per cent calculations.

**TABLE 61: Neonatal sepsis for level III registrants by birthweight group, 2012**

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	27	249	549	753	1,009	1,536	1,206	1,042	1,161	792	403	8,727
Sepsis at <48 hrs <sup>(a)</sup>	0	6	6	7	6	15	7	10	10	13	6	86
Sepsis at ≥48 hrs <sup>(a)</sup>	11	109	127	82	42	48	24	24	20	13	6	506
Babies alive on day 2	n.p.	341	671	835	n.p.	1,592	n.p.	1,071	1,181	813	n.p.	9,237
Babies who did not survive to day 2	<5	22	11	6	<5	6	<5	5	10	5	<5	79
Total in each birthweight group	38	363	682	841	1,057	1,598	1,237	1,076	1,191	818	415	9,316
Per cent												
No sepsis <sup>(b)</sup>	71.1	68.6	80.5	89.5	95.5	96.1	97.5	96.8	97.5	96.8	97.1	93.7
Sepsis at <48 hrs <sup>(b)</sup>	0.0	1.7	0.9	0.8	0.6	0.9	0.6	0.9	0.8	1.6	1.4	0.9
Sepsis at ≥48 hrs <sup>(c)</sup>	n.p.	32.0	18.9	9.8	n.p.	3.0	n.p.	2.2	1.7	1.6	n.p.	5.5

*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 62: Median length of stay for level III registrants who survived until discharge home by birthweight group, 2012**

Birthweight group (grams)	Number of babies	Median LOS (days)	Interquartile range (days)
<500	18	128	127–153
500-749	269	113	97–132
750-999	615	88	72–108
1000-1249	817	65	54–77
1250-1499	1,030	49	38–60
1500-1999	1,555	35	28–45
2000-2499	1,207	21	14–28
2500-2999	1,046	13	7–21
3000-3499	1,141	8	5–17
3500-3999	791	7	4–14
≥4000	408	7	4–16
<b>Total</b>	<b>8,897</b>	<b>29</b>	<b>11–54</b>

**TABLE 63: Survival to discharge home for level III registrants by birthweight group, 2012**

	Birthweight group (grams)											
Survival until discharge home	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	Total
Number												
Lethal congenital anomalies	0	<5	<5	8	7	22	16	16	22	10	<5	109
Babies alive on day 7	27	317	654	828	1,043	1,578	1,224	1,061	1,162	803	410	9,107
Babies alive on day 28	22	300	633	822	1,038	1,564	1,213	1,053	1,153	795	409	9,002
Survived to go home	18	269	615	817	1,030	1,555	1,207	1,046	1,141	791	408	8,897
Total in each birthweight group	38	363	682	841	1,057	1,598	1,237	1,076	1,191	818	415	9,316
Per cent												
Survived to go home	47.4	74.1	90.2	97.1	97.4	97.3	97.6	97.2	95.8	96.7	98.3	95.5

## 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 2012 who qualified as high-risk neonates were requested from each participating unit in June 2013 with a deadline of August 2013. 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 2014. 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 2012 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 (formerly Perinatal & Reproductive Epidemiology Research Unit (PRERU)), 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 (MgSO<sub>4</sub>) provided to the mother during the 6 hours immediately before birth, either because of maternal preeclampsia or specifically for fetal neuro-protection.

Coding:

- 0: MgSO<sub>4</sub> not given at all.
- 1: MgSO<sub>4</sub> course finished > 6 hours before birth (likely to be ineffective).
- 2: MgSO<sub>4</sub> given as intramuscular injection within 6 hours of birth.
- 3: MgSO<sub>4</sub> given for < 4 hours within 6 hour time slot (incomplete course).
- 4: MgSO<sub>4</sub> given by infusion over 4 hours or more within 6 hours of birth (complete course).
- 5: MgSO<sub>4</sub> 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 ≥ 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

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.

## 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.

## 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 5 severe PPHN refractory to iNO.

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 (GMFCS) for cerebral palsy (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 six 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.



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