

2014

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



UNSW
AUSTRALIA

ANZNN

2014

REPORT OF THE AUSTRALIAN AND NEW ZEALAND NEONATAL NETWORK

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Acknowledgements

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

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

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

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

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

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

Structure of this report

- Chapter 1: This chapter presents the structure and organisation of the ANZNN together with some historical information related to its establishment. Also included is information on funding, selection criteria as well as a brief synopsis of level III registrants in Australia and New Zealand for 2014.
- Chapter 2: ‘Babies registered to level III units’ provides information and characteristics on the ANZNN registrants in 2014 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 2014.
- Chapter 4: ‘Characteristics of level III registrants’ provides information about the babies admitted to a level III neonatal unit during 2014.
- Chapter 5: ‘Babies registered to level II units’ provides information about babies registered to the level II special care baby units during 2014.
- Chapter 6: ‘Extremely preterm follow-up, 2009–2011 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 to 2011.
- Appendices:
- Appendix 1 presents 10-year trends
 - Appendix 2 presents data tables by birthweight for 2014
 - Appendix 3 presents the methods employed for this report
 - Appendix 4 contains confidentiality guidelines, and conditions for data collection, use and security
 - Appendix 5 presents the Minimum Data Sets for the ANZNN.

Abbreviations

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

Participating units and supporting staff

Level III nurseries:

Australia

New South Wales

Children's Hospital at Westmead

(NICU & special care beds: 22)

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

John Hunter Hospital

(NICU & special care beds: 42)

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

Liverpool Health Service

(NICU & special care beds: 31)

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

Nepean Hospital

(NICU & special care beds: 37)

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

Royal Hospital for Women

(NICU & special care beds: 44)

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

Royal North Shore Hospital

(NICU & special care beds: 26)

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

RPA Women and Babies

(NICU & special care beds: 34)

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

Sydney Children's Hospital

(NICU & special care beds: 4)

Andrew Numa (Director), Janelle Young

Westmead Hospital

(NICU & special care beds: 42)

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

Neonatal Intensive Care Units' (NICUS) Data Collection

(New South Wales and Australian Capital Territory)

Barbara Bajuk, Sara Sedgley, Mark Leckie

Australian Capital Territory

The Canberra Hospital

(NICU & special care beds: 25)

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

Victoria

Mercy Hospital for Women

(NICU & special care beds: 56)

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

Monash Medical Centre

(NICU & special care beds: 56)

Charles Barfield (Director), Elizabeth Carse, Andrew Ramsden, Kenneth Tan, Rose Li, Marie Hayes

Royal Children's Hospital

(NICU & special care beds: 32)

Rod Hunt (Director), Jo Brooks

Royal Women's Hospital

(NICU & special care beds: 59)

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

Tasmania

Royal Hobart Hospital

(NICU & special care beds: 26)

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

Queensland

Gold Coast University Hospital

(NICU & special care beds: 28)

Peter Schmidt (Director), Timothy Hong, John Hyland, Kobi Best

Mater Mothers' Hospital

(NICU & special care beds: 79)

Lucy Cooke (Director), David Knight, Peter Gray, Elizabeth Hurrion, Dion Hattersley, Karen Nothdurft, Kate Taylor, Leith Poulsen

Royal Brisbane and Women's Hospital

(NICU & special care beds: 71)

David Cartwright (Director), Pieter Koorts (Acting Director), Anja Lipponer

The Townsville Hospital

(NICU & special care beds: 44)

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

South Australia

Flinders Medical Centre

(NICU & special care beds: 35)

Peter Marshall (Director), Rebecca Davis

Women's and Children's Hospital

(NICU & special care beds: 49)

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

Western Australia

King Edward Memorial and Princess Margaret Hospitals

(NICU & special care beds: 125)

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

Northern Territory

Royal Darwin Hospital

(NICU & special care beds: 25)

Charles Kilburn (Director of Perinatal Services), Rakesh Seth, Deborah Ribbon, Sarah Thomas, Connie Yii, Kobi Schutz

Newborn emergency transport services

NETS NSW (Newborn & Paediatric Emergency Transport Service)

Andrew Berry (Director)

Newborn Emergency Transport Service (Victoria)

Michael Stewart (Director)

Western Australia Neonatal Transport Service

Steven Resnick (Director)

New Zealand

Christchurch Women's Hospital

(NICU & special care beds: 41)

Nicola Austin (Director), Adrienne Lynn, Brian Darlow (Professor of Paediatrics), Trish Graham

Dunedin Hospital

(NICU & special care beds: 16)

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

Middlemore Hospital

(NICU & special care beds: 38)

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National Women's Health (at Auckland City Hospital)

(NICU & special care beds: 46)

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Waikato Hospital

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(NICU & special care beds: 40)

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

Level II nurseries:

Australia

New South Wales

Blacktown Hospital

(Special care beds: 24)

Anjali Dhawan (Director), Therese Freeman

Campbelltown Hospital

(Special care beds: 15)

Raymond Chin (Director), Kellie Gear

Gosford District Hospital

(Special care beds: 25)

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

St George Hospital

(Special care beds: 8)

Bob Fonseca (Director), Anne Hurst

Wollongong Hospital

(Special care beds: 20)

Susie Piper (Director), Ian Wright, Sylvia Lees

Victoria

Sunshine Hospital

(Special care beds: 21)

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

Queensland

Cairns Base Hospital

(Special care beds: 22)

Ross Messer (Director), Sue McMahon

Mackay Base Hospital

(Special care beds: 8)

Michael Williams (Director), Kerry Topping

Nambour General Hospital

(Special care beds: 10)

Tom Hurley (Director), Tonya Gibbs

Tasmania

Launceston General Hospital

(Special care beds: 12)

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

Northern Territory

Alice Springs Hospital

(Special care beds: 8)

Deborah Fearon (Director), Marion Bates

New Zealand

Gisborne Hospital

(Special care beds: 6)

Heinrich Stander (Director), Graeme Lear, Barbara Reid

Hawkes Bay Hospital

(Special care beds: 12)

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

Lower Hutt Hospital

(Special care beds: 12)

Robyn Shaw (Director), Debbie Bashaw, Anne Mitchell

Nelson Hospital

(Special care beds: 10)

Peter McIlroy (Director), Nathalie Robinson, Maureen Higgs

North Shore Hospital

(Special care beds: 12)

Jutta van den Boom (Director), Karen Boyle, Susan Law

Palmerston North Hospital

(Special care beds: 17)

Jeff Brown (Director), Amy Hinder

Rotorua Hospital

(Special care beds: 10)

Stephen Bradley (Director), Jacquie Koberstein, Gaye France

Southland Hospital

(Special care beds: 6)

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

Taranaki Base Hospital

(Special care beds: 8)

John Doran (Director), Jane Bocock

Tauranga Hospital

(Special care beds: 10)

Hugh Lees (Director), Heather McAlley, Anna Moore

Timaru Hospital

(Special care beds: 3)

Philip Morrison (Director), Bid Esler, Mark Liddy

Wairau Hospital

(Special care beds: 4)

David Bond (Director)

Wanganui Hospital

(Special care beds: 4)

David Montgomery (Director), Barbara Hammond

Whakatane Hospital

(Special care beds: 5)

Chris Moyes (Director), Margret Norris, Lee Willetts

Whangarei Area Hospital

(Special care beds: 8)

Ransford Addo (Director), Janine Whale, Merophy Brown, Ellen Parker

Waitakere Hospital

(Special care beds: 12)

Jutta van den Boom (Director), Debbie Daniel, Susan Law

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

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

1. Organisation of the ANZNN

History

A prospective audit commenced in 1994 with all level III neonatal intensive care units (NICUs) in Australia and New Zealand contributing data on babies from 1 January 1995. One of the member level II units became a level III unit in 2014, bringing the total of NICU members to 29.

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 eleven units contributing data in 2014.

Purpose of this report

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

This is achieved through:

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

Structure of the ANZNN

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

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

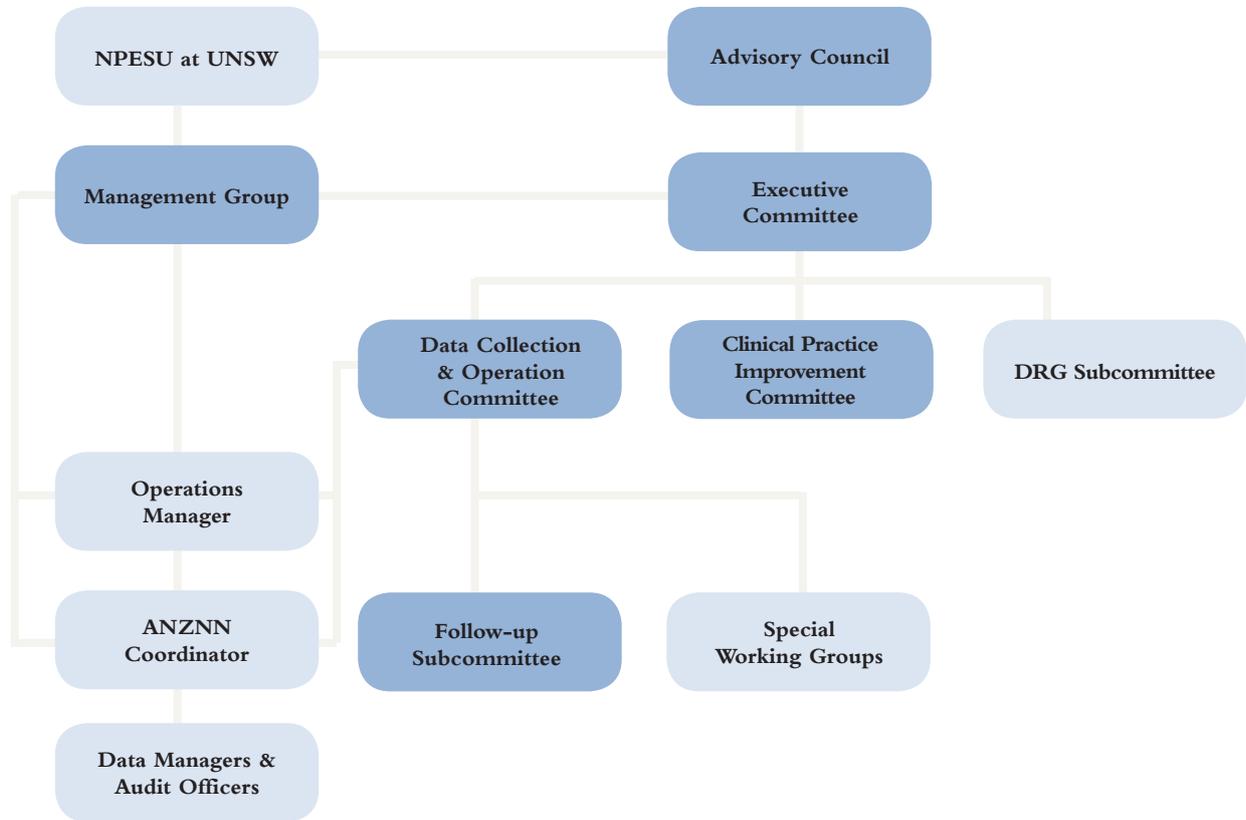
The Executive Committee is an elected committee that has regional representation from directors, a data manager group representative and neonatal nurse representatives from across the network. It is concerned with the general functioning of the network, finance and decision-making, as reported by the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

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

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

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

FIGURE 1: Schematic flow chart of ANZNN



Registration criteria

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

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

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

Funding support

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

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

Data set variables

The variables used for the 2014 audit are listed in Appendix 5 and are also available on the website <<http://www.anznn.net>>.

2014

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Babies born in Australia

There were 8,288 babies registered to the ANZNN from 23 level III NICUs in Australia, representing 2.8% of notified live births in 2014 (Australian Bureau of Statistics 2014). Of these registrants, 77.9% were born in a hospital with tertiary care facilities. There were 3,071 babies born before 32 weeks gestation representing 37.1% of Australian registrants.

Maternal ethnicity was provided for 93.1% of mothers: 74.7% of the mothers of these babies identified as Caucasian and 13.8% as Asian. Over one in fifteen mothers (6.7%) identified as Aboriginal or Torres Strait Islander, which was more than the proportion reported in all births in Australia in 2014 (4.3%) (Australian Bureau of Statistics 2014).

Among Australian NICU admissions registered to the ANZNN, 1,663 were from multiple births representing 20.1% of ANZNN admissions in Australia in 2014.

Male babies were over-represented among NICU admissions – 58.2% of the Australian ANZNN registrants, compared with 51.2% among live births in Australia (Australian Bureau of Statistics 2014).

Assisted ventilation was provided for 7,630 babies (2.5% of live births) and continuous positive airways pressure (CPAP) was the only form of respiratory assistance for 4,099 babies

Babies born in New Zealand

There were 1,873 babies who met ANZNN registration criteria from six level III NICUs in New Zealand representing 3.3% of the 57,242 live births registered in New Zealand in 2014 (Statistics New Zealand 2014). Of these registrants, 88.8% were born in a hospital with tertiary care facilities. There were 544 babies born before 32 weeks gestation representing 29.0% of New Zealand registrants.

Maternal ethnicity was reported for 99.3% of the New Zealand registrants. The percentage of Caucasian mothers was 54.4%. A higher proportion of mothers identified themselves as Maori (19.7%) compared to 11.0% of mothers identified as Pacific Islander and 11.8% as Asian.

Among New Zealand NICU admissions registered to the ANZNN, 267 were from multiple births representing 14.3% of ANZNN admissions in New Zealand in 2014.

Male babies were also over-represented among NICU admissions in New Zealand – 58.1% of the New Zealand registrants compared to 51.7% of total live births in New Zealand (Statistics New Zealand 2014).

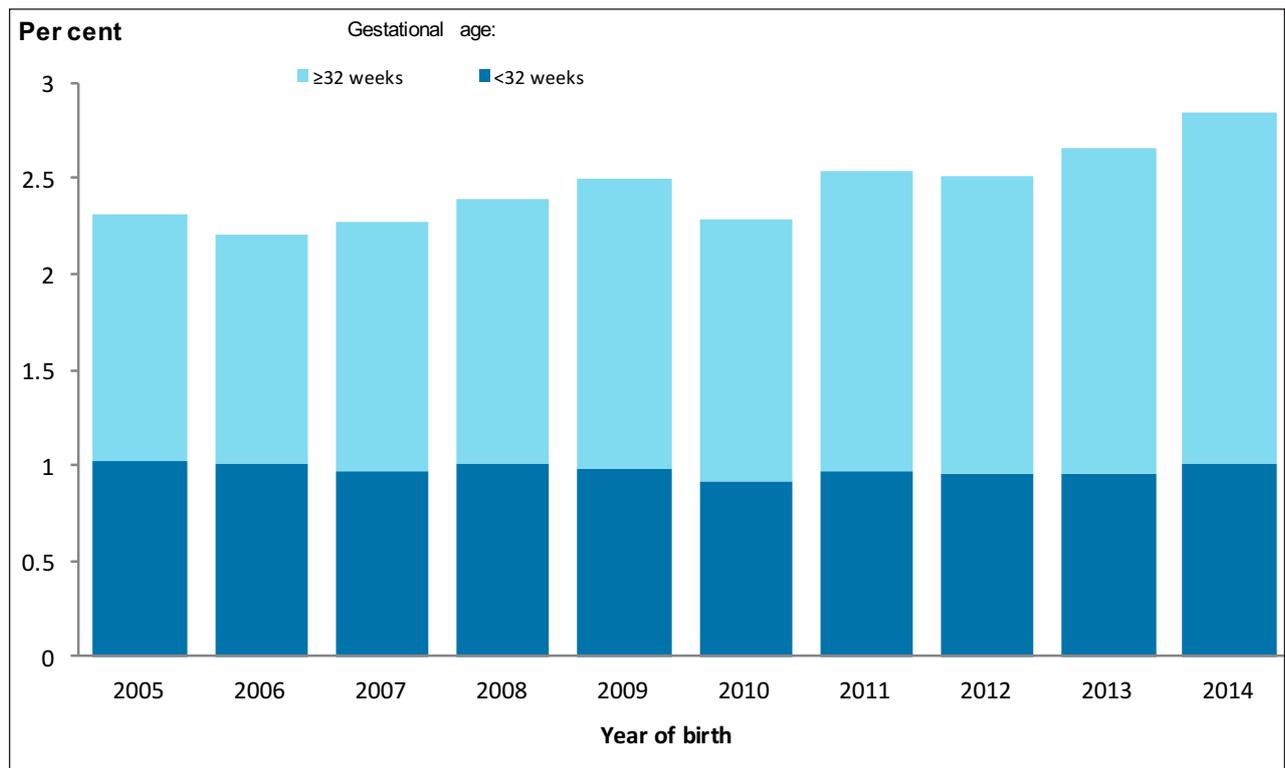
Assisted ventilation was given to 1,628 babies representing 2.8% of all live births with 1,019 babies receiving CPAP as the only form of respiratory assistance (1.8% of all live births).

2. Babies registered to level III units

This section includes data on the ANZNN registrants from 29 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 2014, 10,161 fulfilled the registration criteria for inclusion in the ANZNN audit. The population represents 2.8% of the 356,939 live births in the two countries in 2014 (Australian Bureau of Statistics 2014; Statistics New Zealand 2014) (Figure 2) illustrating an increase of 440 registrants from 2013 (2.7% of all live births).

FIGURE 2: Babies registered to ANZNN audit of level III units each year as a percentage of liveborn babies in Australia and New Zealand 2005-2014



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

There were 3,615 (35.6%) babies born before 32 weeks gestation and 6,546 babies born at 32 weeks or more (64.4%). Of the registrants born before 32 weeks gestation 93.1% 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 under 1,150 babies in 2014, the smallest just over 30 (Figure 3). The median number of babies registered to an ANZNN unit was 318.

The gestational age group at birth and birthweight for babies qualifying for inclusion in the ANZNN 2014 level III audit is set out in Tables 1 and 2 respectively. The 10-year trend (2005–2014) in gestational age at birth is presented in Figure 11 in Appendix 1.

FIGURE 3: Number of level III registrants born at each neonatal intensive care unit, 2014

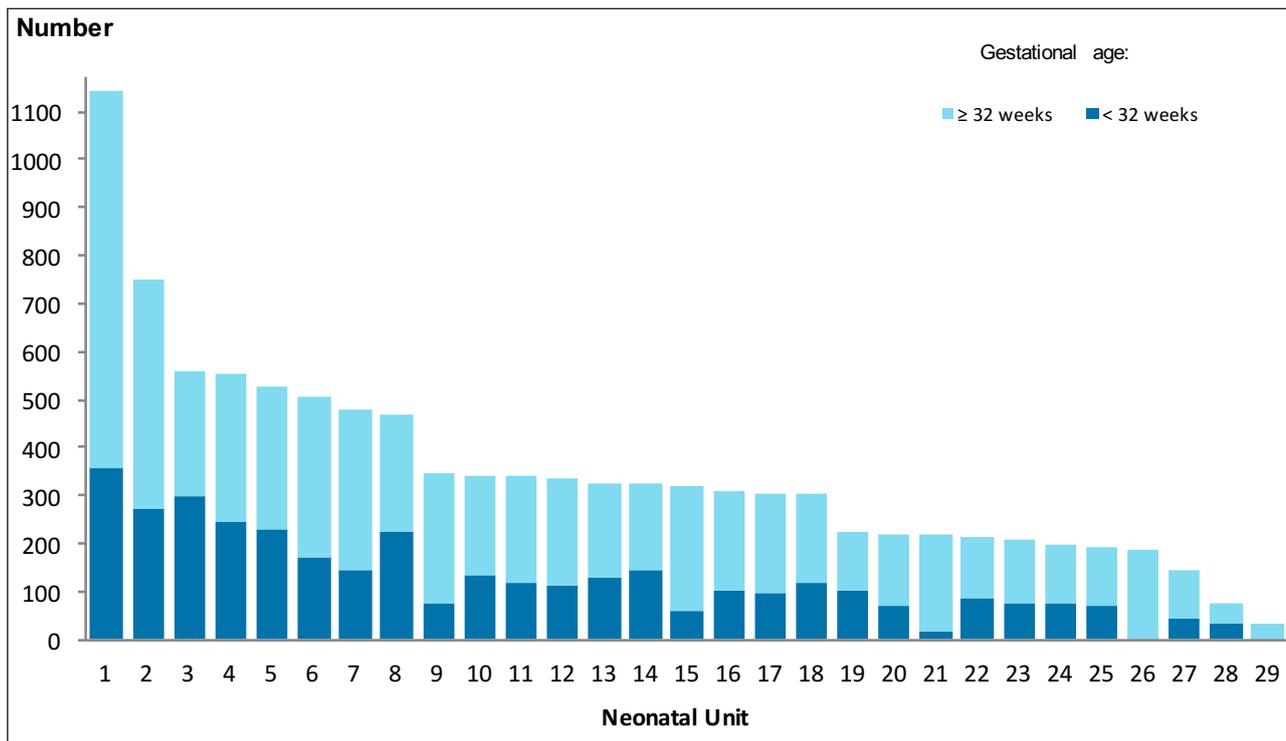


TABLE 1: Level III registrants born at each completed week of gestation, 2014

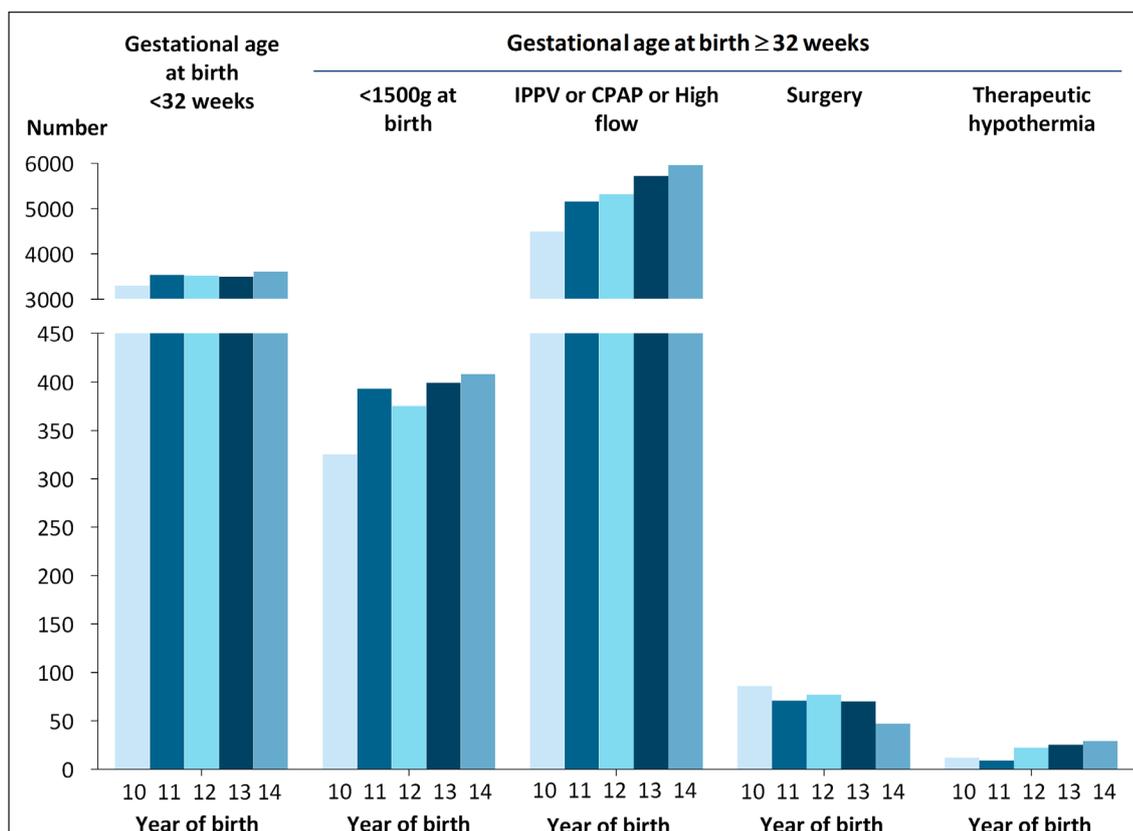
Gestational age (completed weeks)	Number of babies	Percent	Cumulative percent
<24	67	0.7	0.7
24	187	1.8	2.5
25	251	2.5	5.0
26	287	2.8	7.8
27	315	3.1	10.9
28	461	4.5	15.4
29	484	4.8	20.2
30	707	7.0	27.2
31	856	8.4	35.6
All babies <32 weeks	3,615	35.6	
32	796	7.8	43.4
33	696	6.9	50.3
34	704	6.9	57.2
35	596	5.9	63.1
36	551	5.4	68.5
37	593	5.8	74.3
38	780	7.7	82.0
39	755	7.4	89.4
40	648	6.4	95.8
41	397	3.9	99.7
≥42	30	0.3	100.0
Total	10,161	100.0	

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

TABLE 2: Level III registrants in each birthweight group, 2014

Birth weight (grams)	Number of babies	Percent	Cumulative percent
<500	33	0.3	0.3
500–599	95	0.9	1.3
600–699	186	1.8	3.1
700–799	277	2.7	5.8
800–899	272	2.7	8.5
900–999	317	3.1	11.6
1,000–1,099	293	2.9	14.5
1,100–1,199	342	3.4	17.9
1,200–1,299	345	3.4	21.3
1,300–1,399	413	4.1	25.3
1,400–1,499	474	4.7	30.0
All babies <1,500g birthweight	3,047	30.0	
1,500–1,999	1,751	17.2	47.2
2,000–2,499	1,319	13.0	60.2
2,500–2,999	1,246	12.3	72.5
3,000–3,499	1,341	13.2	85.7
3,500–3,999	969	9.5	95.2
≥4,000	488	4.8	100.0
Total	10,161	100.0	

FIGURE 4: Level III registrants by registration criteria, 2010–2014



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 2014, the age of mothers of neonates registered as high-risk ranged from less than 15 years to over 50 years. The highest proportion of registrant mothers was aged 30–34 years (30.8%) followed by mothers aged 25–29 years (25.8%). Together they accounted for more than half of the mothers (56.6%) of ANZNN registrants in 2014 (Table 3). In 2014, the proportion of babies born to teenage mothers decreased slightly (0.1%) from 2013, and those born to mothers in the 35–39 age group decreased by 0.7%, from 19.3% in 2013 to 18.6%.

Two in five of the babies born to teenage mothers (41.3%) were born at less than 32 weeks completed gestation, while 34.2% 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, 2014

Maternal age (years)	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Less than 20	n.p.	n.p.	34	57	65	39	91	127	438
20–24	13	76	89	149	198	203	259	449	1,436
25–29	23	138	155	231	393	379	449	832	2,600
30–34	10	119	163	278	491	468	553	1,018	3,100
35–39	10	69	129	176	308	267	350	562	1,871
40 and over	<5	n.p.	31	51	99	121	133	163	619
Not stated	0	1	1	3	9	15	16	52	97
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
	Per cent								
Less than 20	n.p.	n.p.	5.7	6.1	4.2	2.6	5.0	4.0	4.4
20–24	19.4	17.4	14.8	15.8	12.7	13.7	14.1	14.2	14.3
25–29	34.3	31.6	25.8	24.5	25.3	25.7	24.5	26.4	25.8
30–34	14.9	27.2	27.1	29.5	31.6	31.7	30.1	32.3	30.8
35–39	14.9	15.8	21.5	18.7	19.8	18.1	19.1	17.8	18.6
40 and over	n.p.	n.p.	5.2	5.4	6.4	8.2	7.2	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 2014, a previous preterm delivery was reported by 1,005 mothers (9.9%) of babies registered to ANZNN while 345 mothers (3.4%) 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 830 (8.2%) pregnancies resulting from assisted conception in the ANZNN 2014 cohort with most (81.3%) the result of IVF treatment. Of the pregnancies resulting from assisted conception, 47.2% of the mothers were more than 34 years of age at the time of giving birth, compared with 50.7% in 2013.

Presenting antenatal problem

Many mothers of ANZNN registrants were admitted to hospital with complications prior to the baby's birth. The presenting antenatal problem refers to the antenatal complication that led to the baby's birth and subsequent admission to an NICU. There may be other complications related to this pregnancy but they are not reported here. Information about the presenting antenatal problem was available for 98.8% of 2014 ANZNN registrants. The mothers of nearly one-quarter of registrants (22.7%) 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 37–43 weeks, 32–36 weeks and less than 32 weeks gestational age are set out in Figure 5. For women who gave birth before 32 weeks gestation and women who gave birth at 34–36 weeks gestation, the most common presenting antenatal problem was preterm labour (36.9% and 29.4% respectively) followed by preterm pre-labour rupture of membranes (21.3% and 13.0% respectively).

Overall 83.3% of mothers of registrants had a pregnancy complication recorded. Among women who gave birth at term, half (49.0%) were recorded as having no maternal presenting antenatal problem.

TABLE 4: Mother's presenting antenatal problem for level III registrants by gestational age group, 2014

Presenting antenatal problem	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
No antenatal problems	0	0	0	0	0	5	9	1,568	1,582
Preterm pre-labour rupture of membranes (PROM)	16	109	138	184	320	241	239	30	1,277
Preterm labour	39	229	236	307	520	404	539	8 ^(a)	2,282
Hypertension in pregnancy	<5	20	n.p.	128	206	228	178	99	928
Antepartum haemorrhage (APH)	7	41	65	83	158	143	148	76	721
Intrauterine growth restriction (IUGR)	0	<5	n.p.	64	75	120	143	76	505
Fetal distress	<5	19	47	n.p.	180	170	202	611	1,328
Other problem	1	13	26	70	87	154	273	333	957
Congenital anomalies	0	<5	0	n.p.	11	23	105	311	464
Not stated	0	1	0	0	6	4	15	91	117
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
	Per cent								
No antenatal problems	0.0	0.0	0.0	0.0	0.0	0.3	0.5	50.4	15.8
Preterm pre-labour rupture of membranes (PROM)	23.9	24.9	22.9	19.5	20.6	16.2	13.0	1.0	12.7
Preterm labour	58.2	52.4	39.2	32.5	33.4	27.2	29.4	0.3	22.7
Hypertension in pregnancy	n.p.	4.6	n.p.	13.5	13.2	15.3	9.7	3.2	9.2
Antepartum haemorrhage (APH)	10.4	9.4	10.8	8.8	10.1	9.6	8.1	2.4	7.2
Intrauterine growth restriction (IUGR)	0.0	n.p.	n.p.	6.8	4.8	8.1	7.8	2.4	5.0
Fetal distress	n.p.	4.3	7.8	n.p.	11.6	11.4	11.0	19.6	13.2
Other problem	1.5	3.0	4.3	7.4	5.6	10.3	14.9	10.7	9.5
Congenital anomalies	0.0	n.p.	0.0	n.p.	0.7	1.5	5.7	10.0	4.6
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

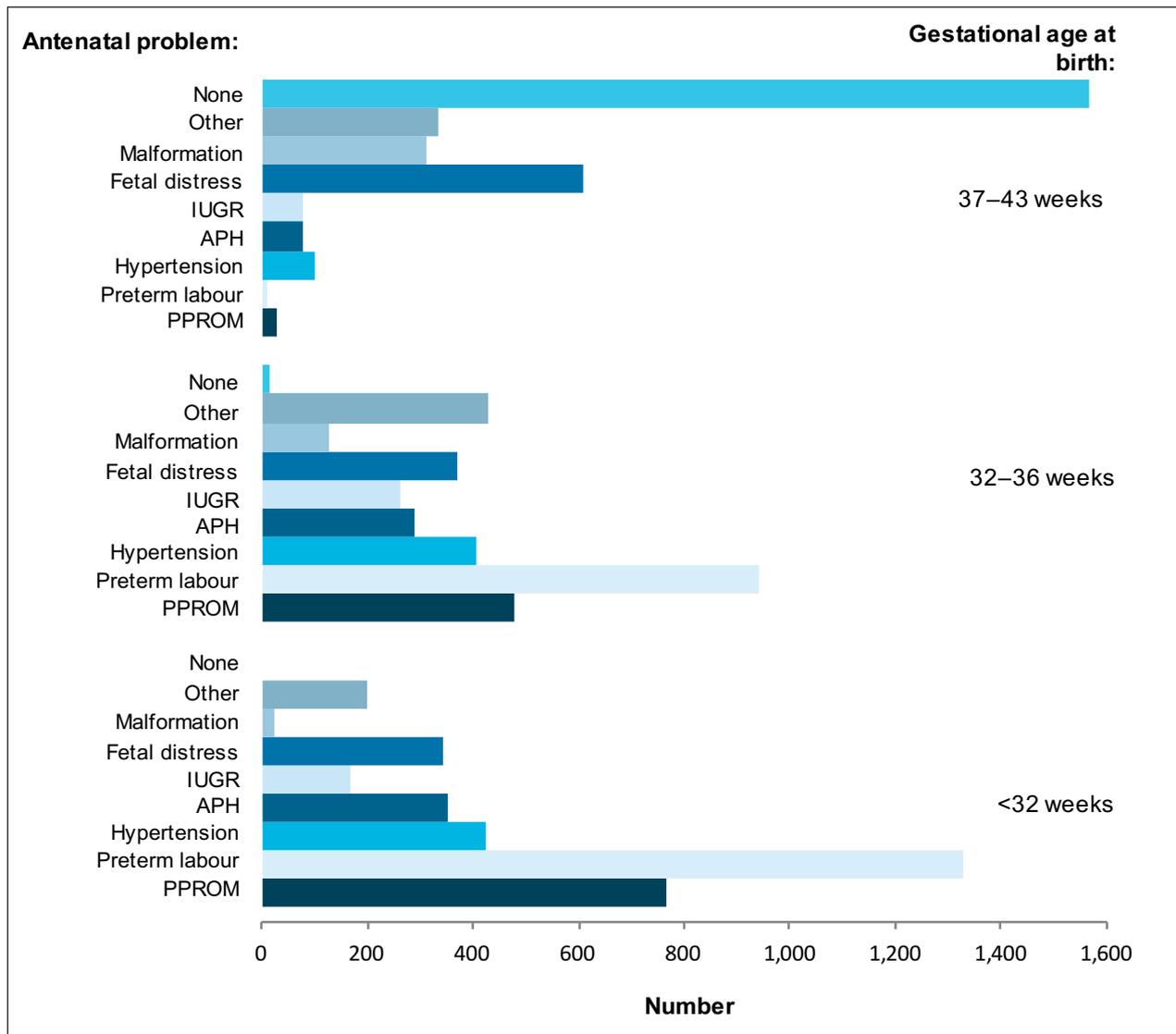
n.p. Data not published to maintain confidentiality of small numbers.

(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, 2014



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 2014, 87.8% of mothers of ANZNN registrants born before 34 weeks of gestation received one or more doses of antenatal corticosteroids leaving 12.2% of mothers of registrants in this group who did not report receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 15.3% received them more than seven days prior to giving birth.

For mothers of ANZNN registrants born before 32 weeks of gestation, 89.5% received one or more doses of antenatal corticosteroids and 10.5% of mothers of registrants in this group did not report receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 14.7% received them more than seven days prior to giving birth (Table 5). The 10-year trend (2005–2014) for maternal corticosteroids is represented by Figure 12 in Appendix 1.

TABLE 5: Antenatal corticosteroid use for mothers of level III registrants by gestational age group, 2014

Antenatal corticosteroids	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
Number									
None	n.p.	n.p.	54	66	171	220	983	2,620	4,156
Incomplete course	26	125	144	246	419	375	201	24	1,560
Course completed	23	240	306	484	748	660	365	53	2,879
Completed >7 days prior to birth	<5	n.p.	90	138	210	212	201	39	928
Not stated	2	9	8	11	15	25	101	467	638
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
Per cent									
None	n.p.	n.p.	9.1	7.1	11.0	15.0	56.2	95.8	43.6
Incomplete course	40.0	29.1	24.2	26.3	27.1	25.6	11.5	0.9	16.4
Course completed	35.4	55.9	51.5	51.8	48.3	45.0	20.9	1.9	30.2
Completed >7 days prior to birth	n.p.	n.p.	15.2	14.8	13.6	14.5	11.5	1.4	9.7
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.

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 (MgSO₄) 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, 53.2% were given antenatal MgSO₄ (Table 6). Of these, 27.4% received a complete course by infusion over 4 hours or more within 6 hours of birth. MgSO₄ administration is an emerging trend among the member units. Care should be taken in interpretation of these data as this is only the third year of collection for the ANZNN.

TABLE 6: Magnesium sulphate use for mothers of level III registrants by gestational age, 2014

Magnesium sulphate	Gestational age								Total	
	<24	24	25	26	27	28	29	30		31
Number										
None	n.p.	n.p.	59	73	80	132	138	326	423	1,305
Complete course	15	44	63	70	72	100	107	81	72	624
Incomplete course or intramuscular injection	<5	n.p.	46	58	70	81	91	69	62	508
Given but details unknown	13	23	33	25	39	69	60	46	43	351
Not stated	13	41	50	61	54	79	88	185	256	827
Total	67	187	251	287	315	461	484	707	856	3,615
Per cent										
None	n.p.	n.p.	29.4	32.3	30.7	34.6	34.8	62.5	70.5	46.8
Complete course	27.8	30.1	31.3	31.0	27.6	26.2	27.0	15.5	12.0	22.4
Incomplete course or intramuscular injection	n.p.	n.p.	22.9	25.7	26.8	21.2	23.0	13.2	10.3	18.2
Given but details unknown	24.1	15.8	16.4	11.1	14.9	18.1	15.2	8.8	7.2	12.6
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 2014, 19.0% of ANZNN registrants were reported as being from a multiple pregnancy, and of these, the greatest percentage were twins (93.2%). Of the 2014 ANZNN registrants from multiple births, 52.9% were born before 32 weeks gestation and 97.2% were born before 37 weeks gestation (Table 7). The 10-year trend (2005–2014) for multiple births is represented by Figure 13 in Appendix 1.

TABLE 7: Plurality of level III registrants by gestational age group, 2014

Plurality	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Singletons	49	322	478	678	1,067	1,005	1,484	3,148	8,231
Twins	13	108	112	252	462	443	353	55	1,798
Triplets and higher orders	5	8	12	15	34	44	14	0	132
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
	Per cent								
Singletons	73.1	73.5	79.4	71.7	68.3	67.4	80.2	98.3	81.0
Twins	19.4	24.7	18.6	26.7	29.6	29.7	19.1	1.7	17.7
Triplets and higher orders	7.5	1.8	2.0	1.6	2.2	2.9	0.8	0.0	1.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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 2014 registrants (58.5%) the method of birth was caesarean section with 64.9% of caesarean sections occurring before the onset of labour. One-third of registrants (34.3%) were non-instrumental vaginal births (Table 8). The rate of birth by caesarean section has gradually increased from 49.8%, since the first data collection in 1995, to 58.8% in 2013. The 2014 data shows a slight decrease of 0.3% from 2013.

The most common method of birth for registrants born before 24 weeks gestation was non-instrumental vaginal birth (88.1%) (Table 8). The 10-year trend (2005–2014) for method of birth is represented by Figure 14 in Appendix 1.

TABLE 8: Method of birth for level III registrants by gestational age group, 2014

Method of birth	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
Number									
Vaginal	59	246	227	274	464	391	555	1,241	3,457
Vaginal instrumental birth	<5	n.p.	11	29	45	53	115	470	731
Caesarean section in labour	<5	n.p.	143	191	328	258	342	710	2,072
Caesarean section no labour	5	86	221	448	721	781	824	741	3,827
Not stated	0	1	0	3	5	9	15	41	74
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
Per cent									
Vaginal	88.1	56.3	37.7	29.1	29.8	26.4	30.2	39.2	34.3
Vaginal instrumental birth	n.p.	n.p.	1.8	3.1	2.9	3.6	6.3	14.9	7.2
Caesarean section in labour	n.p.	n.p.	23.8	20.3	21.1	17.4	18.6	22.5	20.5
Caesarean section no labour	7.5	19.7	36.7	47.6	46.3	52.7	44.9	23.4	37.9
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 2014, 80.1% of all babies and 88.8% of babies less than 32 weeks gestation at birth were born in a tertiary centre equipped with an NICU; 19.2% of all ANZNN registrants were born in a non-tertiary hospital; while 0.7% of registrants were not born in a hospital (Table 9).

TABLE 9: Level of hospital of birth for level III registrants by gestational age group, 2014

Level of birth hospital	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
Number									
Tertiary hospital	59	387	524	848	1,391	1,273	1,436	2,203	8,121
Non-tertiary hospital	n.p.	42	73	90	n.p.	n.p.	408	954	1,951
Not born in a hospital ^(a)	<5	8	5	6	<5	<5	6	33	69
Not stated	0	1	0	1	1	3	1	13	20
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
Per cent									
Tertiary hospital	88.1	88.6	87.0	89.8	89.1	85.5	77.6	69.1	80.1
Non-tertiary hospital	n.p.	9.6	12.1	9.5	n.p.	n.p.	22.1	29.9	19.2
Not born in a hospital ^(a)	n.p.	1.8	0.8	0.6	n.p.	n.p.	0.3	1.0	0.7
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.

(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 2014, 22.4% of ANZNN registrants were transferred to an NICU after birth. Of these the greatest percentage (79.3%) were transported by a specialist team with 16.6% transported by a non-specialist team (Table 10). The 10-year trend (2005–2014) for mode of transport to a level III NICU is represented by Figure 16 in Appendix 1.

Table 10: Mode of transport to level III NICU after birth for level III registrants by gestational age group, 2014

Mode of Transport	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Not transported	59	385	515	837	1,366	1,257	1,377	2,059	7,855
Specialist retrieval team	n.p.	38	64	79	148	188	381	n.p.	1,798
Non-specialist team	<5	7	15	13	32	31	68	n.p.	376
Other	0	8	8	14	12	11	15	24	92
Not stated	0	0	0	2	5	5	10	18	40
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
	Per cent								
Not transported	88.1	87.9	85.5	88.8	87.7	84.5	74.8	64.6	77.6
Specialist retrieval team	n.p.	8.7	10.6	8.4	9.5	12.6	20.7	n.p.	17.8
Non-specialist team	n.p.	1.6	2.5	1.4	2.1	2.1	3.7	n.p.	3.7
Other	0.0	1.8	1.3	1.5	0.8	0.7	0.8	0.8	0.9
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.

Breastfeeding at discharge

Data on breastfeeding at discharge were available for 95.5% 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, 72.5% were breastfed at discharge. The rate of breastfeeding at discharge of surviving extremely preterm babies (born at less than 28 weeks gestation) was 64.9% compared to 75.1% 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 51.2% of combined live births in both countries in 2014 (Australian Bureau of Statistics 2014; Statistics New Zealand 2014). The percentage was higher among ANZNN registrants with male births representing 58.1%. Gender was not available for one baby. For births at less than 32 weeks gestation, 54.7% were male; of births at term, 61.0% were male.

Resuscitation in delivery suite

The type of resuscitation given to babies immediately after birth ranges from the least severe, suction to the most severe, external cardiac massage and ventilator support. For the purpose of this audit ANZNN only collected data on babies on whom endotracheal intubation was performed; 21.1% of registrants were intubated in the delivery suite to establish independent respiration and heart rate. For babies born before 32 weeks the percentage was 37.8% and for babies born at term the percentage was 14.2%.

Apgar score at birth

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

An Apgar score of less than 4 at one minute of age was recorded for 17.9% of ANZNN registrants, with 4.0% 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, 39.2% of babies were born at less than 32 weeks and 38.6% were born at term (Table 11).

TABLE 11: Apgar scores at birth for level III registrants by gestational age group, 2014

Apgar score	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
Number									
Apgar at 1 minute									
Apgar < 4	36	175	153	148	196	166	233	697	1,804
Apgar 4-7	n.p.	n.p.	348	518	790	664	679	1,082	4,327
Apgar ≥ 8	<5	n.p.	98	272	573	655	930	1,404	3,971
Not stated	2	7	3	7	4	7	9	20	59
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
Number									
Apgar at 5 minutes									
Apgar < 4	15	40	28	16	31	22	41	210	403
Apgar 4-7	38	227	257	293	366	326	439	964	2,910
Apgar ≥ 8	13	164	314	629	1,161	1,138	1,364	2,010	6,793
Not stated	1	7	3	7	5	6	7	19	55
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161

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 91.7% of ANZNN registrants in 2014. 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, 2014

Gestational age group	Number of babies in each age group	Temperature	
		Median	Inter quartile range
<24	67	35.8	35.0–36.5
24–25	438	36.1	35.5–36.7
26–27	602	36.4	35.8–36.9
28–29	945	36.4	35.9–36.8
30–31	1,563	36.3	35.9–36.7
32–33	1,492	36.4	36.0–36.7
34–36	1,851	36.5	36.1–36.8
37–43	3,203	36.6	36.2–37.0
Total	10,161	36.5	36.0–36.8

Indication for respiratory support

In 2014, only 4.1% 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 43.9%. Non-specific respiratory distress accounted for 32.2% of babies, surgery for 4.3%, while meconium aspiration syndrome accounted for 3.4% (Table 13).

For babies born before 37 weeks gestation, HMD (59.3%) remained the most common indication for respiratory support. For babies born at term, non-specific respiratory distress (43.2%) was the most common indication followed by meconium aspiration (10.4%) and surgery (9.0%) (Table 13). The 10-year trend (2005–2014) for mode of assisted ventilation is represented by Figure 17 in Appendix 1.

TABLE 13: Indication for respiratory support for level III registrants by gestational age, 2014

Indication for respiratory support	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
No respiratory support	0	<5	0	5	146	102	n.p.	87	414
Non-specific respiratory distress	0	7	23	100	377	553	814	1,348	3,222
Hyaline membrane disease	64	425	560	799	952	727	598	268	4,393
Meconium aspiration syndrome	0	0	0	0	<5	0	n.p.	325	338
Pneumonia	0	0	<5	0	<5	6	9	85	106
Persistent pulmonary hypertension	<5	0	<5	<5	<5	<5	23	112	148
Apnoea	0	<5	6	n.p.	36	23	38	44	165
Congenital anomaly	0	0	0	8	12	16	58	211	305
Other	<5	<5	5	6	7	15	45	161	242
Peri-surgery	0	0	<5	0	7	n.p.	122	282	432
Newborn encephalopathy	0	<5	0	<5	6	6	35	198	248
Not stated	0	1	3	5	13	20	24	82	148
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
	Per cent								
No respiratory support	0.0	n.p.	0.0	0.5	9.3	6.8	n.p.	2.7	4.1
Non-specific respiratory distress	0.0	1.6	3.8	10.6	24.3	37.6	44.6	43.2	32.2
Hyaline membrane disease	95.5	97.3	93.5	85.0	61.4	49.4	32.7	8.6	43.9
Meconium aspiration syndrome	0.0	0.0	0.0	0.0	n.p.	0.0	n.p.	10.4	3.4
Pneumonia	0.0	0.0	n.p.	0.0	n.p.	0.4	0.5	2.7	1.1
Persistent pulmonary hypertension	n.p.	0.0	n.p.	n.p.	n.p.	n.p.	1.3	3.6	1.5
Apnoea	0.0	n.p.	1.0	n.p.	2.3	1.6	2.1	1.4	1.6
Congenital anomaly	0.0	0.0	0.0	0.9	0.8	1.1	3.2	6.8	3.0
Other	n.p.	n.p.	0.8	0.6	0.5	1.0	2.5	5.2	2.4
Peri-surgery	0.0	0.0	n.p.	0.0	0.5	n.p.	6.7	9.0	4.3
Newborn encephalopathy	0.0	n.p.	0.0	n.p.	0.4	0.4	1.9	6.3	2.5
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.

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 2014, over a quarter of ANZNN registrants (28.7%) were administered exogenous surfactant (Table 14). There were 2,446 babies who received intermittent positive pressure ventilation for HMD in 2014. Exogenous surfactant was given to 2,243 of these babies (91.7%). There were 203 babies diagnosed with HMD who were not given exogenous surfactant.

TABLE 14: Exogenous surfactant use for level III registrants by gestational age group, 2014

Exogenous surfactant	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
None	<5	34	120	391	1,079	1,143	1,534	n.p.	7,223
Curosurf	53	350	383	432	355	251	213	194	2,231
Survanta	11	50	90	113	121	91	97	79	652
SurvCuro	0	<5	<5	<5	<5	<5	<5	<5	16
Other or unknown surfactant	<5	<5	<5	<5	<5	<5	<5	5	18
Not stated	0	0	6	4	5	2	3	1	21
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
	Per cent								
None	n.p.	7.8	20.1	41.6	69.3	76.7	83.0	n.p.	71.2
Curosurf	79.1	79.9	64.3	45.9	22.8	16.8	11.5	6.1	22.0
Survanta	16.4	11.4	15.1	12.0	7.8	6.1	5.2	2.5	6.4
SurvCuro	0.0	n.p.	0.2						
Other or unknown surfactant	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	0.2	0.2
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.

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 2014, 91.1% 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 (2005–2014) for assisted ventilation is represented in Figures 17 to 19 in Appendix 1.

In 2014, IPPV was given for a total of 534,997 hours to ANZNN registrants and CPAP was given for 1,513,176 hours. The total number of hours of ventilation equates to each baby receiving 8.4 days of assisted ventilation. The median number of hours of assisted ventilation is inversely related to the gestational age at birth in babies born preterm (Table 15).

The most common form of ventilation given to ANZNN registrants in 2014 remains CPAP with 50.4% of registrants receiving CPAP only, 12.9% receiving IPPV only and 27.8% 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 2014, 15.5% of registrants who received IPPV also received HFOV. However, nine babies received HFOV without at least four hours of IPPV. The use of HFOV among individual units varied between 1.1% and 14.3% with the highest percentage of babies receiving HFOV born at less than 24 weeks (58.2%) followed by babies born at 24–25 weeks gestation (44.5%) (Table 16). The 10-year trend (2005–2014) for HFOV is represented in Figure 20 in Appendix 1.

TABLE 15: Duration of assisted ventilation use by level III registrants by gestational age group, 2014

Median & Interquartile range	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
IPPV (hours)									
Median	392	274.5	64	22	22	24	37	50	44
IQR	120–730	97.5–611.5	17–199	10–71	10–51	10–60	16–79	23–100	16–120
CPAP (hours)									
Median	1,101	935	794	178	58	29	22	15	38
IQR	567–1,389	541–1,242	360–1,116	72–493	23–121.5	13–68	10–49.5	7–34	13–127

Note: IQR = Interquartile range

In 2014, 31 registrants received ECMO of whom the majority were born at term. The percentage of ANZNN registrants who received nitric oxide (NO) was 4.7%. The use of NO continues to have a U-shaped distribution with the highest percentage of babies to receive NO born at less than 24 weeks (19.4%) (Table 16). The 10-year trend (2005–2014) for NO is represented in Figure 21 in Appendix 1.

TABLE 16: Assisted ventilation for level III registrants by gestational age group, 2014

Ventilation type	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
Number									
CPAP given	38	355	549	882	1,284	1,240	1,424	2,172	7,944
Invasive ventilation	67	420	486	494	482	358	571	1,271	4,149
▪ IPPV given	66	420	486	494	480	358	570	1,266	4,140
▪ HFOV given	39	187	115	63	42	25	32	149	652
NO given	13	52	49	30	32	20	40	243	479
Total in each age group	67	438	602	945	1,563	1,492	1,851	3,203	10,161
Per cent									
CPAP given	56.7	81.1	91.2	93.3	82.1	83.1	76.9	67.8	78.2
IPPV given	98.5	95.9	80.7	52.3	30.7	24.0	30.8	39.5	40.7
Per cent of babies given invasive ventilation									
HFOV given	58.2	44.5	23.7	12.8	8.7	7.0	5.6	11.7	15.7
NO given	19.4	12.4	10.1	6.1	6.6	5.6	7.0	19.1	11.5

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 3,615 babies born before 32 weeks gestation, 93.1% 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 39.2% and IPPV was the only form of ventilation for 7.1% of registrants. Both IPPV and CPAP were given to 46.7% of registrants.

The total duration of IPPV for these very preterm babies was 345,514 hours (14,396 days), and the duration of CPAP was 1,269,859 hours (52,911 days).

Of the babies born before 32 weeks gestational age and given IPPV in 2014, 22.8% were given high frequency ventilation while 9.0% of these babies were given NO (Table 16).

Among 2014 ANZNN registrants born at less than 32 weeks gestation, 3,416 (94.5%) survived to day 28. Of these, 47.2% of registrants received respiratory support (airway support or supplemental oxygen therapy) at 28 days of age, with 15.9% 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, 89.2% 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 137,994 hours (5,750 days) and IPPV use was 69,240 hours (2,885 days).

Of the babies born at 32–36 weeks gestation and given IPPV in 2014, 6.0% were given high frequency ventilation while 6.5% 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 (42.1%). This group required 120,243 hours of IPPV (5,010 days) and 105,323 hours (4,389 days) of CPAP.

Of the babies born at term and given IPPV in 2014, 11.4% were given high frequency ventilation while 19.2% of these babies were given NO (Table 16). There were 28 babies born at term who received extracorporeal membrane oxygenation (ECMO).

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 2014 ANZNN registrants, 9,814 babies survived to day 28 and of these, 19.5% were reported as having received respiratory support on day 28 or later. Of the registrants who received respiratory support on day 28 and survived to discharge to home, 17.5% 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, 2014

Respiratory support (airway support or oxygen)	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
Number									
No respiratory support on day 28	0	<5	41	430	1,326	1,392	1,743	n.p.	7,888
Respiratory support on day 28	37	n.p.	524	489	211	81	75	n.p.	1,923
▪ survived to discharge home	n.p.	332	504	480	205	n.p.	65	133	1,830
▪ died before discharge	<5	n.p.	20	9	6	<5	10	n.p.	93
Not stated	0	2	0	0	0	1	0	0	3
Total	37	358	565	919	1,537	1,474	1,818	3,106	9,814
Number									
Respiratory support on day 28 and given home oxygen	n.p.	86	86	47	24	n.p.	15	34	320
Per cent									
No respiratory support on day 28	0.0	n.p.	7.3	46.8	86.3	94.5	95.9	n.p.	80.4
Respiratory support on day 28	100.0	n.p.	92.7	53.2	13.7	5.5	4.1	n.p.	19.6
▪ survived to discharge home	n.p.	93.5	96.2	98.2	97.2	n.p.	86.7	88.1	95.2
▪ died before discharge	n.p.	n.p.	3.8	1.8	2.8	n.p.	13.3	n.p.	4.8
Per cent									
Respiratory support on day 28 and given home oxygen ^(a)	42.4	25.9	17.1	9.8	11.7	17.9	23.1	25.6	17.5

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 2014 nasal high flow therapy was reported for 2,773 babies (27.3%) of all level III registrants (Table 18), compared with 8.1% in 2009. The overall increase of 3.3% from 2013 was observed predominantly in the babies born at less than 28 weeks gestation. In this gestational age group, 69.0% of babies received NHFT. Overall, the minimum flow recorded was 1 litre/min and the maximum 15 litres/min. Of the babies receiving NHFT 74.3% were reported to have received a minimum rate of 2–4 litres/min while 72.7% received a maximum of 6–8 litres/min.

TABLE 18: Nasal high flow respiratory support for level III registrants by gestational age group, 2014

Nasal high flow	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
Number									
High flow	25	290	449	572	468	252	243	474	2,773
No high flow	42	148	153	373	1,095	1,240	1,608	2,729	7,388
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
Per cent									
High flow	37.3	66.2	74.6	60.5	29.9	16.9	13.1	14.8	27.3
No high flow	62.7	33.8	25.4	39.5	70.1	83.1	86.9	85.2	72.7
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, 2,898 (75.2%) received TPN during admission (Table 19). The median duration of TPN reported was 233 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, 4.7% of babies were discharged home on gavage feeds. Care should be taken in interpretation of the TPN and home gavage feed data as this is the only the third year of collection for the ANZNN.

TABLE 19: Total parenteral nutrition for level III registrants by gestational age, 2014

Parenteral nutrition	Gestational age										Total
	<24	24	25	26	27	28	29	30	31	≥32 ^(a)	
	Number										
Parenteral nutrition	n.p.	163	236	n.p.	296	426	408	477	405	n.p.	2,898
No parenteral nutrition	n.p.	12	7	<5	6	23	59	190	422	n.p.	958
Not stated	0	12	8	15	13	12	17	40	29	21	167
Total	67	187	251	287	315	461	484	707	856	408	4,023
	Number										
Home gavage feeding	<5	8	11	n.p.	17	22	21	15	15	<5	135
	Per cent										
Parenteral nutrition	n.p.	93.1	97.1	n.p.	98.0	94.9	87.4	71.5	49.0	n.p.	75.2
No parenteral nutrition	n.p.	6.9	2.9	n.p.	2.0	5.1	12.6	28.5	51.0	n.p.	24.8
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 ^(b)	6.5	4.9	4.7	6.7	5.7	5.2	5.1	3.1	3.7	2.6	4.7

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

(a) These babies were less than 1,500g at birth.

(b) Denominator is babies who received parenteral nutrition.

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

Chronic lung disease

Chronic lung disease (CLD) is currently defined by the ANZNN as a continued need for any form of respiratory support (supplemental oxygen and/or assisted ventilation) at 36 weeks post menstrual age (PMA) (post menstrual age is calculated by adding the baby's age in weeks to the gestational age at birth in weeks). For ANZNN registrants, 8.6% of babies in 2014 were reported to have had respiratory support at 36 weeks PMA, and of these, 26 (3.0%) died prior to discharge to home. 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 (61.5%) (Table 20). Not all the babies born at earlier gestations survived to 36 weeks PMA. The 10-year trend (2005–2014) for CLD is represented by Figure 22 in Appendix 1.

TABLE 20: Chronic lung disease for level III registrants by gestational age, 2014

Chronic lung disease (CLD)	Gestational age									Total
	<24	24	25	26	27	28	29	30	31	
	Number									
No CLD	43	72	118	138	173	351	398	639	812	2,744
CLD	24	115	133	149	142	110	86	68	44	871
Total	67	187	251	287	315	461	484	707	856	3,615
	Per cent									
No CLD	64.2	38.5	47.0	48.1	54.9	76.1	82.2	90.4	94.9	75.9
CLD	35.8	61.5	53.0	51.9	45.1	23.9	17.8	9.6	5.1	24.1

There is evidence that postnatal treatment with corticosteroids of high risk infants can facilitate weaning from ventilator and lead to increased survival without CLD at 36 weeks post menstrual age (Halliday et al 2003). While there are associated increased short and long term risks according to the severity of CLD (Doyle et al 2005), early postnatal systemic corticosteroids are commonly administered to high risk infants for evolving CLD. Of the ANZNN registrants born at less than 32 weeks, 259 (7.2%) babies were treated with systemic corticosteroids. Of these, 218 were reported to have had respiratory support at 36 weeks, while 40 (15.4%) reported no CLD. Care should be taken in interpretation of these data as this is only the second year of collection for the ANZNN.

Pulmonary air leak

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

TABLE 21: Pulmonary air leak for level III registrants by gestational age group, 2014

Air leak	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Air leak	8	22	24	36	38	48	69	160	405
No air leak	59	416	577	909	1,525	1,444	1,782	3,043	9,755
Not stated	0	0	1	0	0	0	0	0	1
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
	Per cent								
Air leak	11.9	5.0	4.0	3.8	2.4	3.2	3.7	5.0	4.0
No air leak	88.1	95.0	96.0	96.2	97.6	96.8	96.3	95.0	96.0
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.

Neonatal sepsis

Each episode of sepsis is recorded as either early or late onset. Early onset sepsis is defined as the presence of at least one episode of systemic sepsis where the initial symptoms occurred within the first 48 hours after birth that is, in babies aged from 0 to 47 hours. Late onset sepsis is the presence of at least one episode of systemic sepsis with the initial symptoms occurring among babies aged 48 or more hours. Episodes of sepsis involving the same organism separated by at least 14 days are considered to be new episodes of infection. Symptomatic, blood culture positive septicaemia was reported in 5.2% of ANZNN registrants in 2014. Of these babies, 45.4% were born at less than 28 weeks gestation, 70.4% were born at less than 32 weeks gestation and 99.4%

of registrants survived up to 2 days of life (Table 22). Episodes of both early and late sepsis were reported in eight babies. The 5-year trends (2010–2014) for early and late sepsis are represented by Figure 25 and Figure 26 respectively in Appendix 1.

TABLE 22: Neonatal sepsis for level III registrants by gestational age group, 2014

Sepsis	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
No sepsis	45	302	517	874	1,501	1,458	1,818	3,112	9,627
Sepsis at <48 hrs ^(a)	<5	14	9	8	10	8	5	n.p.	92
Sepsis at ≥48 hrs ^(a)	20	126	77	63	52	26	28	57	449
Babies alive on day 2	59	411	593	937	1,558	1,487	1,839	3,168	10,052
Babies who did not survive to day 2	8	27	9	8	5	5	12	35	109
Total in each age group	67	438	602	945	1,563	1,492	1,851	3,203	10,161
	Per cent								
No sepsis ^(b)	67.2	68.9	85.9	92.5	96.0	97.7	98.2	97.2	94.7
Sepsis at <48 hrs ^(b)	n.p.	3.2	1.5	0.8	0.6	0.5	0.3	n.p.	0.9
Sepsis at ≥48 hrs ^(c)	33.9	30.7	13.0	6.7	3.3	1.7	1.5	1.8	4.5

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 123 (1.2%) of ANZNN registrants in 2014, as identified by isolation or identification of an organism by PCR, immunofluorescence or similar technology from an appropriate body fluid. Care should be taken in interpretation of these data as this is only the third year of collection for the ANZNN.

Retinopathy of prematurity

The classification of retinopathy of prematurity (ROP) for ANZNN registrants are those recommended by the Committee for the Classification of Retinopathy of Prematurity (1984). The examination criteria for ROP vary between units within ANZNN. As in previous reports, the prevalence of ROP screening in 2014 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 2014 registrants, 29.1% were eligible for ROP examination and of these eligible registrants, 81.7% were examined and had the results of their eye examination recorded.

Of those ANZNN registrants who were eligible for an eye examination, 206 died before their ROP status could be determined. Of those examined, 6.3% had stage 3 or 4 eye disease (Table 23, Figure 6) and of these babies 49.7% received surgical treatment. The 10-year trend (2005–2014) for stages 3 and 4 ROP and treatment are represented by Figure 23 in Appendix 1.

TABLE 23: Retinopathy of prematurity for level III registrants by gestational age, 2014

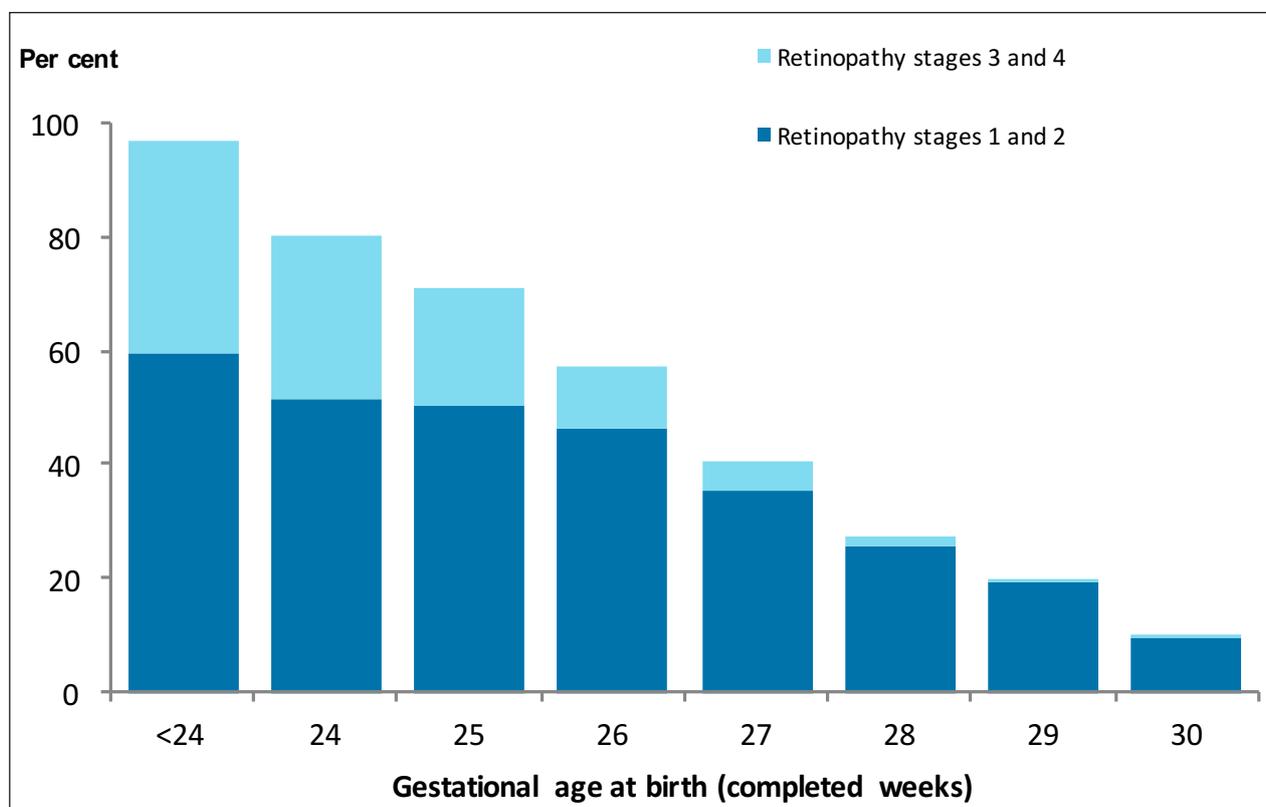
Retinopathy of prematurity (ROP)	Gestational age									Total
	<24	24	25	26	27	28	29	30	≥31 ^(a)	
Number										
No ROP	<5	26	n.p.	111	172	315	n.p.	437	119	1,594
Stage 1	6	24	40	55	61	76	45	n.p.	9	n.p.
Stage 2	13	43	66	n.p.	41	34	39	16	<5	321
Stage 3	11	37	43	27	16	8	<5	<5	<5	150
Stage 4	<5	0	<5	<5	0	0	0	0	0	<5
Not examined	33	56	39	28	25	28	44	209	57	519
Not stated	2	1	0	0	0	0	2	11	7	23
Total	67	187	251	287	315	461	484	707	197	2,956
Per cent										
No ROP	n.p.	20.0	n.p.	42.9	59.3	72.7	n.p.	89.7	89.5	66.0
Stage 1	18.8	18.5	18.9	21.2	21.0	17.6	10.3	n.p.	6.8	n.p.
Stage 2	40.6	33.1	31.1	n.p.	14.1	7.9	8.9	3.3	n.p.	13.3
Stage 3	34.4	28.5	20.3	10.4	5.5	1.8	n.p.	n.p.	n.p.	6.2
Stage 4	n.p.	0.0	n.p.	n.p.	0.0	0.0	0.0	0.0	0.0	n.p.
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.

(a) These babies were less than 1,250g at birth.

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, 2014



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 3,615 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, 3,535 survived to day 3 and 90.0% had an examination recorded. A normal report was recorded for 81.4% of these 2014 ANZNN registrants.

There were 128 babies reported to have grade 3 or 4 IVH representing 3.6% of the babies born before 32 weeks gestation. Of the babies who had a grade 3 IVH, 28.8% were unilateral, while 78.5% of grade IV IVH cases were unilateral. 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 26 weeks gestational age, with the majority (55.3%) of the babies born before 25 weeks gestation (Table 24, Figure 7). The 10-year trend (2005–2014) for registrants with grades 3 and 4 IVH who survived to day 3 is represented in Figure 24 in Appendix 1.

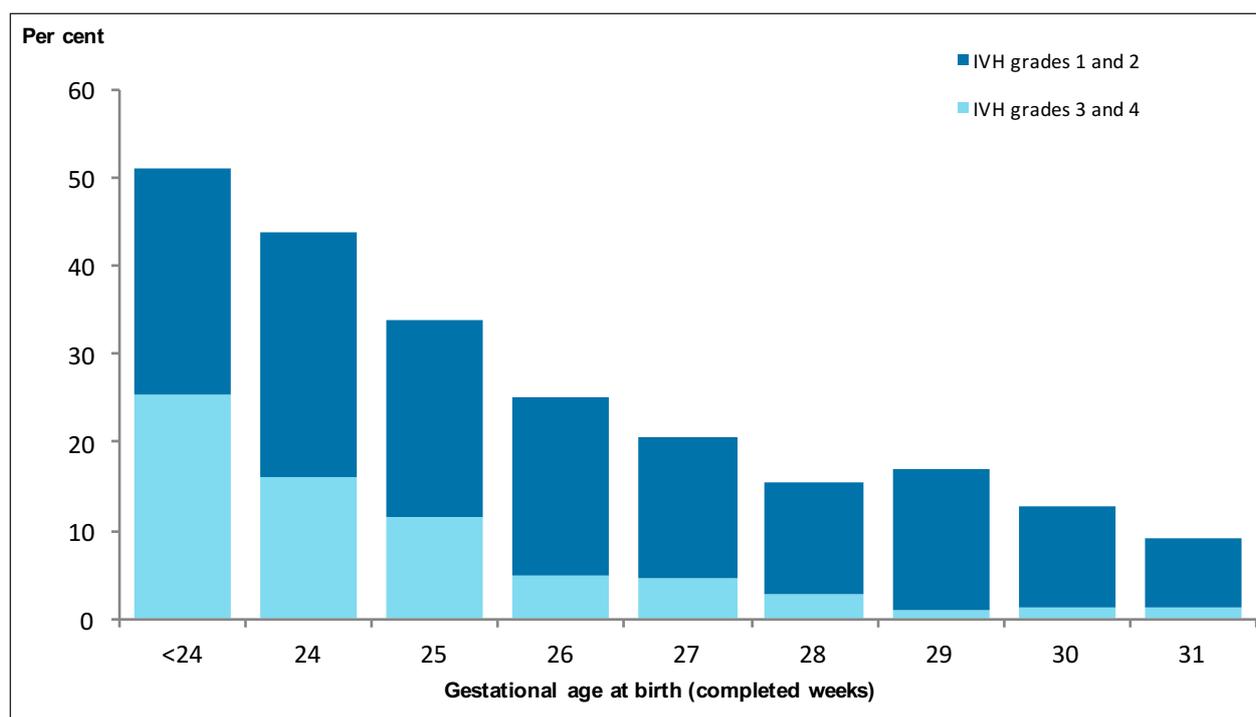
TABLE 24: Intraventricular haemorrhage for level III registrants born before 32 weeks and survived to day 3 by gestational age, 2014

Intraventricular haemorrhage	Gestational age									Total
	<24	24	25	26	27	28	29	30	31	
	Number									
None	27	91	155	204	242	372	374	512	613	2,590
Grade 1	8	24	29	40	38	45	54	60	51	349
Grade 2	n.p.	21	23	15	11	11	18	n.p.	<5	116
Grade 3	<5	11	6	5	5	7	<5	6	<5	49
Grade 4	11	15	21	9	9	6	<5	<5	<5	79
Not examined	1	4	4	6	5	15	26	116	175	352
Total	56	166	238	279	310	456	477	704	849	3,535
	Per cent									
None	49.1	56.2	66.2	74.7	79.3	84.4	82.9	87.1	90.9	81.4
Grade 1	14.5	14.8	12.4	14.7	12.5	10.2	12.0	10.2	7.6	11.0
Grade 2	n.p.	13.0	9.8	5.5	3.6	2.5	4.0	n.p.	n.p.	3.6
Grade 3	n.p.	6.8	2.6	1.8	1.6	1.6	n.p.	1.0	n.p.	1.5
Grade 4	20.0	9.3	9.0	3.3	3.0	1.4	n.p.	n.p.	n.p.	2.5
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 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, 2014



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 3,615 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, 3,535 survived until day 3 and late ultrasound results were available for 2,105 (59.5%) of these babies. A normal report of no cysts was recorded for 97.2% of these registrants, 1.0% reported porencephalic cysts and 1.8% reported periventricular leukomalacia (PVL) (Table 25). Of the 38 babies who were reported with PVL, nine had extensive leukomalacia involving two or more of the anterior frontal, posterior frontal, parietal, temporal or occipital regions.

TABLE 25: Late cerebral ultrasound results for level III registrants born before 32 weeks by gestational age, 2014

Cerebral ultrasound results	Gestational age									
	<24	24	25	26	27	28	29	30	31	Total
	Number									
No cysts	n.p.	116	176	215	249	340	317	n.p.	n.p.	2,045
Porencephalic cysts	0	<5	6	<5	<5	<5	<5	<5	<5	22
Periventricular leukomalacia	<5	<5	5	<5	<5	<5	<5	6	6	38
Not stated	39	63	64	64	59	115	162	371	573	1,510
Total	67	187	251	287	315	461	484	707	856	3,615
	Per cent									
No cysts	n.p.	93.5	94.1	96.4	97.3	98.3	98.4	n.p.	n.p.	97.1
Porencephalic cysts	0.0	n.p.	3.2	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	1.0
Periventricular leukomalacia	n.p.	n.p.	2.7	n.p.	n.p.	n.p.	n.p.	1.8	2.1	1.8
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.

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 2014, 326 (7.5%) of the ANZNN registrants born at more than 34 weeks gestation received therapeutic hypothermia, and of these, 66.9% 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 93.1% of babies. The main reason for cessation of cooling before 72 hours was that the baby was palliation (35.8%), followed by recognised as not fulfilling the standard criteria for cooling (22.4%).

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 2014 the percentage of babies with confirmed NEC was 1.3%. Of these babies, 58.5% were born before 28 weeks gestation with 49.4% of them undergoing surgery, and 41.5% were born after 27 weeks gestation; surgery was required for 42.9% of them. In total 34 registrants died from NEC. The number of registrants with confirmed NEC is slightly less than in 2013 (Table 26).

TABLE 26: Necrotising enterocolitis in level III registrants by year of birth, 2005–2014

Necrotising enterocolitis	Year of birth									
	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
	Number									
Babies born at <28 weeks										
▪ NEC	83	90	76	116	96	113	73	86	81	79
▪ No NEC	948	934	1,014	1,042	1,029	963	1,029	981	1,009	1,025
▪ Not stated	0	19	27	9	2	4	5	2	0	3
Babies born at ≥28 weeks										
▪ NEC	49	73	40	72	50	66	50	51	46	56
▪ No NEC	6,557	6,390	6,886	7,303	7,797	7,081	8,028	8,193	8,584	8,991
▪ Not stated	0	30	58	25	3	8	1	5	1	7
Total in each birth year	7,637	7,536	8,101	8,567	8,977	8,235	9,186	9,318	9,721	10,161
	Per cent									
NEC <28 weeks ^(a)	8.1	8.8	7.0	10.0	8.5	10.5	6.6	8.1	7.4	7.2
NEC ≥28 weeks ^(b)	0.7	1.1	0.6	1.0	0.6	0.9	0.6	0.6	0.5	0.6

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

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

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

Spontaneous intestinal perforation

Spontaneous intestinal perforation is distinct from NEC and usually involves a single perforation of the intestine. In 2014, 41 (0.4%) of all ANZNN registrants had a confirmed diagnosis of spontaneous intestinal perforation without necrotising enterocolitis. Care should be taken in interpretation of these data as this is only the second year of collection for the ANZNN.

Neonatal surgery

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

In 2014, there were 1,029 ANZNN registrants who had major surgery, of whom over half (53.6%) were born at term. Of registrants born in a hospital, 74.6% were born in a hospital with tertiary care facilities. Of registrants who had major surgery, 77.0% also had a congenital anomaly present with 56.6% of these diagnosed during the antenatal period. 6.1% had surgery for proven NEC. The median length of stay (LOS) for survivors was 34 days (Table 27).

Table 27: Characteristics of level III registrants who underwent surgery by gestational age group, 2014

Characteristics	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Male	n.p.	43	24	19	n.p.	36	105	316	588
Female	<5	40	17	19	n.p.	21	91	236	441
Congenital anomaly present	0	15	8	18	35	45	175	496	792
Congenital anomaly diagnosed antenatally	0	<5	<5	7	15	27	117	279	448
Proven NEC	<5	25	10	6	<5	<5	6	5	63
Hospital of birth:									
▪ Tertiary	n.p.	76	n.p.	n.p.	45	41	155	367	763
▪ Non-tertiary	<5	5	<5	<5	9	15	40	183	260
Median LOS for survivors (days)	155	128	108	82	69	54	31.5	23	34
Died before discharge home	<5	16	5	<5	7	<5	<5	13	53
Total in each age group	8	83	41	38	54	57	196	552	1,029
	Per cent								
Male	n.p.	51.8	58.5	50.0	n.p.	63.2	53.6	57.2	57.1
Female	n.p.	48.2	41.5	50.0	n.p.	36.8	46.4	42.8	42.9
Congenital anomaly present	0.0	18.1	19.5	47.4	64.8	78.9	89.3	89.9	77.0
Congenital anomaly diagnosed antenatally	0.0	n.p.	n.p.	18.4	27.8	47.4	59.7	50.5	43.5
Proven NEC	n.p.	30.1	24.4	15.8	n.p.	n.p.	3.1	0.9	6.1
Hospital of birth:									
▪ Tertiary	n.p.	91.6	n.p.	n.p.	83.3	71.9	79.1	66.5	74.1
▪ Non-tertiary	n.p.	6.0	n.p.	n.p.	16.7	26.3	20.4	33.2	25.3
Died before discharge home	n.p.	19.3	12.2	n.p.	13.0	n.p.	n.p.	2.4	5.2

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

Congenital anomalies

In 2014, 1,378 ANZNN registrants (13.6%) had one or more major congenital anomalies. For registrants who had a congenital anomaly, 19.1% were born before 32 weeks gestation, 28.7% were born between 32 and 36 weeks gestation and more than half of registrants (52.2%) were born at term.

Nearly half of ANZNN registrants (47.2%) with congenital anomalies were diagnosed during the antenatal period with 8.2% of babies recorded as having a fatal congenital anomaly. A higher percentage of babies with congenital anomalies were male (59.1%).

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 2014, nearly two in five of ANZNN registrants (37.5%) were transferred from a level III NICU to a level II unit in another hospital 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 (45.4%) transferred from level III to level II units were born at less than 32 weeks gestation compared to 15.1% born at term.

Some level III registrants required transfer to a specialist children’s hospital and in 2014 these accounted for 3.5% of registrants. Overall 54.5% 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, 2014

Transfer status	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Not transferred	48	236	291	399	562	605	1,058	2,339	5,538
Level III hospital	n.p.	40	52	62	79	n.p.	58	123	456
Level II hospital	9	131	231	463	895	825	681	574	3,809
Children’s hospital	<5	31	28	20	27	n.p.	54	167	357
Not stated	0	0	0	1	0	0	0	0	1
Total	67	438	602	945	1,563	1,492	1,851	3,203	10,161
	Per cent								
Not transferred	71.6	53.9	48.3	42.3	36.0	40.5	57.2	73.0	54.5
Level III hospital	n.p.	9.1	8.6	6.6	5.1	n.p.	3.1	3.8	4.5
Level II hospital	13.4	29.9	38.4	49.0	57.3	55.3	36.8	17.9	37.5
Children’s hospital	n.p.	7.1	4.7	2.1	1.7	n.p.	2.9	5.2	3.5
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 the 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 96.4% of ANZNN registrants in 2014 who survived to discharge to home. The median length of stay was 27 days with an interquartile range of 10–51 days (Table 29). LOS is inversely related to gestational age with the very preterm and extremely preterm babies having a longer stay in hospital than those babies born at or near term.

Babies born at less than 32 weeks gestation spent approximately 229,199 days in hospital, babies born between 32 and 36 weeks spent 81,941 days and babies born at term spent 43,024 days in hospital.

TABLE 29: Median length of stay for level III registrants who survived until discharge home by gestational age, 2014

Gestational age (completed weeks)	Number of babies	Median LOS (in days)	Interquartile range (in days)
<24	33	137	120–157
24	128	121	109–139
25	205	107	94–127
26	256	94	83–109
27	289	83	73–97
28	442	66.5	59–79
29	468	58	50–69
30	691	49	42–58
31	838	40	34–47
32	786	33	28–41
33	684	25	20–32
34	692	20	15–26
35	579	14	10–21
36	537	10.5	6–18
37	565	9	5–18
38	748	8	5–17
39	731	7	4–16
40	627	6	4–11
41	388	6	4–11
≥42	29	8	5–13
Total	9,716	27	10–51

Note: Death status was not provided for two babies.

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

Survival of the ANZNN registrants

In 2014, 95.6% 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 2014, there were 443 neonatal deaths, of which 232 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 49.3% for babies born before 24 weeks to 95.9% for babies born at 28 weeks (Table 30, Figure 8). A similar pattern of increasing survival with increasing birthweight is seen in Figure 9.

Lethal congenital anomaly was the cause of death for 1.1% of registrants, with most occurring in babies born between 37–39 weeks gestation (Table 30).

TABLE 30: Survival to discharge home for level III registrants by gestational age at birth, 2014

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	67	0	52	37	33	49.3
24	187	<5	155	139	128	68.4
25	251	<5	231	219	205	81.7
26	287	0	271	266	256	89.2
27	315	<5	305	299	289	91.7
28	461	<5	453	447	442	95.9
29	484	7	474	472	468	96.7
30	707	<5	703	695	691	97.7
31	856	6	846	842	838	97.9
32	796	5	789	787	786	98.7
33	696	7	688	687	684	98.3
34	704	9	695	695	692	98.3
35	596	9	588	582	579	97.1
36	551	6	546	541	537	97.5
37	593	18	581	574	565	95.3
38	780	16	761	752	748	95.9
39	755	10	738	734	731	96.8
40	648	5	634	628	627	96.8
41	397	<5	390	389	388	97.7
≥42	30	0	29	29	29	96.7
Total	10,161	113	9,929	9,814	9,716	95.6

Note: Death status was not provided for two babies.

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

FIGURE 8: Survival of level III registrants to discharge home (with 95% CI) by gestational age, 2014

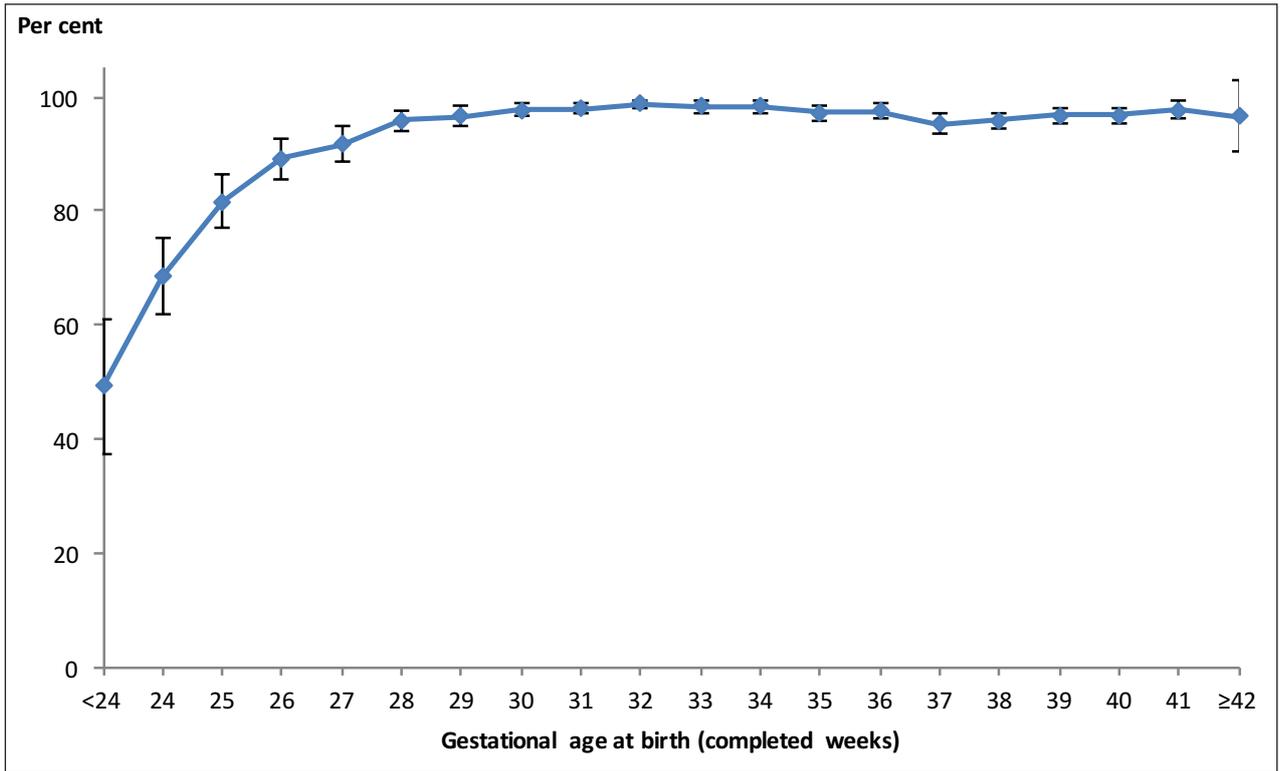
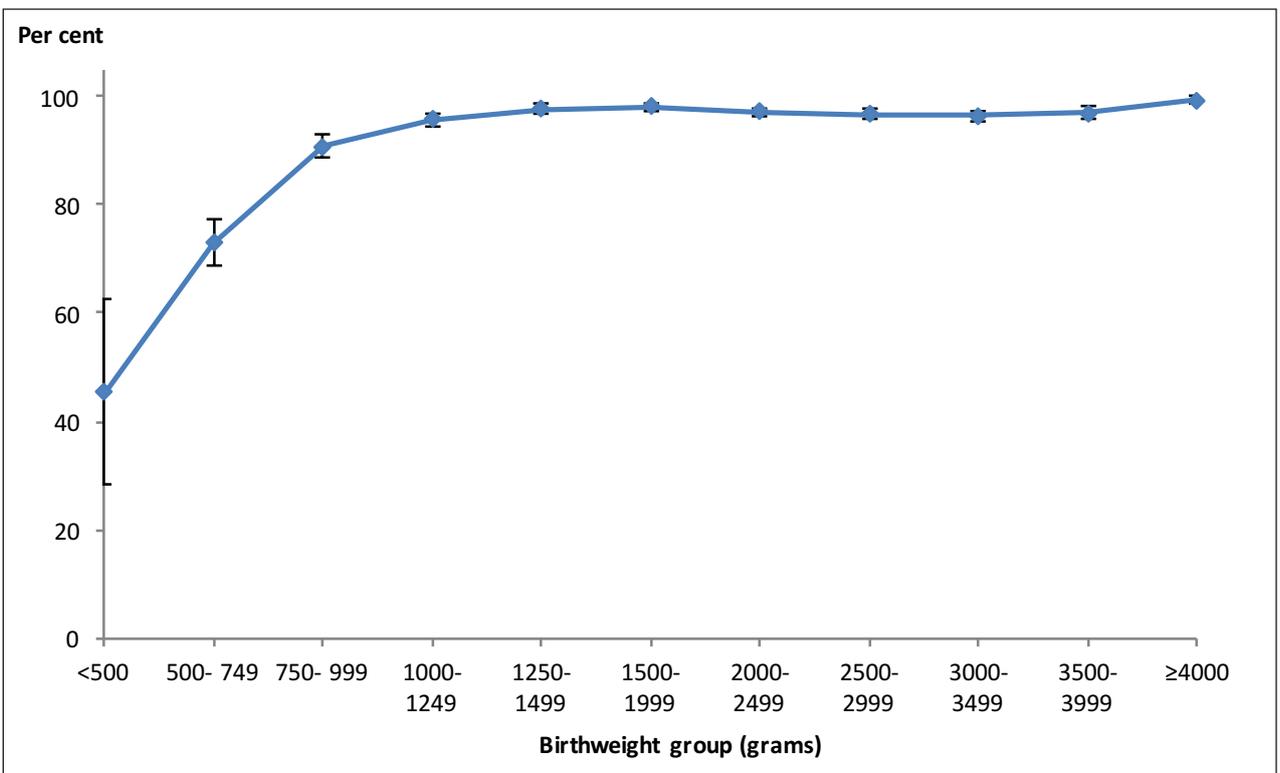


FIGURE 9: Survival of level III registrants to discharge home (with 95% CI) by birthweight group, 2014



5. Babies registered to level II units

Overview

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

There are 16 level II units in New Zealand and eleven in Australia that are members of the ANZNN. Altogether, 25 level II units contributed data for this 2014 report.

In 2014, 1,170 babies fulfilled the ANZNN criteria for registration to a level II unit. Of those babies, 7.9% were born at less than 32 weeks gestation and 6.2% 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 2014 was just over 100.

TABLE 31: Level II registrants by gestational age group, 2014

Gestational age group	Number of babies	Per cent	Cumulative per cent
<30	18	1.5	1.5
30–31	75	6.4	8.0
All babies <32 weeks gestation	93	8.0	
32–33	203	17.4	25.3
34–36	319	27.3	52.7
37–43	553	47.3	100.0
Total	1,168	100.0	

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

TABLE 32: Level II registrants by birthweight group, 2014

Birthweight group (grams)	Number of babies	Per cent	Cumulative per cent
<1,100	7	0.6	0.6
1,100–1,199	9	0.8	1.4
1,200–1,299	11	0.9	2.3
1,300–1,399	17	1.5	3.8
1,400–1,499	29	2.5	6.2
All babies <1,500g birthweight	73	6.2	
1,500–1,999	158	13.5	19.8
2,000–2,499	230	19.7	39.4
2,500–2,999	208	17.8	57.2
3,000–3,499	236	20.2	77.4
3,500–3,999	163	13.9	91.4
≥4,000	101	8.6	100.0
Total	1,169	100.0	

Note: Birthweight groups below 1,100g have been combined to maintain confidentiality of small numbers. Birthweight was not provided for one baby.

Three in five of the level II registrants, 707 babies (60.4%), were born to Caucasian mothers, 54.2% of whom were born preterm. The number of registrants born to Maori mothers was 168 (14.4%), and 88 (52.4%) were born preterm. There were 42 babies (3.6%) born to Pacific Islander mothers.

There were 716 male (61.2%) and 450 female (38.5%) registrants in the audit. No gender was recorded for four registrants (0.3%). 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, 28.2% did not present with any maternal complications. Among babies born before 37 weeks, 39.0% of mothers had presented with preterm labour (Table 33).

TABLE 33: Mothers of level II registrants presenting antenatal problem by gestational age group, 2014

Presenting antenatal problem	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
	Number					
No antenatal problems	0	0	0	<5	n.p.	328
Preterm pre-labour rupture of membranes	6	20	39	66	11	142
Preterm labour	7	n.p.	78	124	<5	240
Hypertension in pregnancy	<5	11	22	n.p.	24	90
Antepartum haemorrhage	<5	9	22	n.p.	9	59
Intrauterine growth restriction	0	<5	n.p.	27	15	63
Fetal distress	0	<5	n.p.	25	108	152
Other problem	0	1	9	27	50	87
Congenital anomalies	0	0	0	0	0	0
Not stated	0	0	0	2	5	7
Total	18	75	203	319	553	1,168
	Per cent					
No antenatal problems	0.0	0.0	0.0	n.p.	n.p.	28.3
Preterm pre-labour rupture of membranes	33.3	26.7	19.2	20.8	2.0	12.2
Preterm labour	38.9	n.p.	38.4	39.1	n.p.	20.7
Hypertension in pregnancy	n.p.	14.7	10.8	n.p.	4.4	7.8
Antepartum haemorrhage	n.p.	12.0	10.8	n.p.	1.6	5.1
Intrauterine growth restriction	0.0	n.p.	n.p.	8.5	2.7	5.4
Fetal distress	0.0	n.p.	n.p.	7.9	19.7	13.1
Other problem	0.0	1.3	4.4	8.5	9.1	7.5
Congenital anomalies	0.0	0.0	0.0	0.0	0.0	0.0
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.

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

Gestational age was not provided for two babies.

Previous preterm births were reported by 110 (9.4%) of the mothers of level II registrants and 33 mothers (2.8%) had had a previous perinatal death(s).

Most mothers (87.9%) of level II registrants had booked into a level II hospital for delivery. Of the level II registrants born before 34 weeks gestation, 76.4% 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, 2014

Antenatal corticosteroids	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
Number						
None	<5	n.p.	38	213	534	801
Incomplete course	n.p.	28	74	31	<5	140
Complete course	9	29	80	57	8	183
Completed >7 days prior to birth	0	<5	10	11	<5	26
Not stated	0	1	1	7	9	18
Total	18	75	203	319	553	1,168
Per cent						
None	n.p.	n.p.	18.8	68.3	98.2	69.7
Incomplete course	n.p.	37.8	36.6	9.9	n.p.	12.2
Complete course	50.0	39.2	39.6	18.3	1.5	15.9
Completed >7 days prior to birth	0.0	n.p.	5.0	3.5	n.p.	2.3
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.

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

Gestational age was not provided for two babies.

Vaginal and assisted delivery was the most common method of birth for 51.2% of level II registrants (Table 35). Of those who were delivered by caesarean section, just over half (54.4%) of these occurred before the onset of labour.

TABLE 35: Method of delivery for level II registrants by gestational age group, 2014

Method of delivery	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
Number						
Vaginal ^(a)	7	32	79	140	335	593
Caesarean ^(b)	11	43	123	177	211	565
Not stated	0	0	1	2	7	10
Total	18	75	203	319	553	1,168
Per cent						
Vaginal	38.9	42.7	39.1	44.2	61.4	51.2
Caesarean	61.1	57.3	60.9	55.8	38.6	48.8
Total	100.0	100.0	100.0	100.0	100.0	100.0

(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 two babies.

Characteristics of level II babies

Among the 1,170 babies registered to level II units, 120 were from multiple births (10.3%). There were 716 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 17.9% of babies and 16.4% of them required endotracheal intubation in the labour ward to assist in their adaptation to extrauterine life.

Non-specific respiratory distress (64.6%) was the major reason for assisted ventilation for level II registrants, followed by hyaline membrane disease (18.2%) (Table 36).

For level II registrants, the median duration of assisted ventilation by IPPV was 19 hours and 18 hours by CPAP (Table 37).

TABLE 36: Indication for respiratory support for level II registrants by gestational age group, 2014

Indication for respiratory support	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
	Number					
No respiratory support	0	n.p.	14	11	<5	35
Non-specific respiratory distress	8	31	120	205	387	751
Hyaline membrane disease	10	33	60	87	22	212
Meconium aspiration syndrome	0	0	0	<5	n.p.	68
Pneumonia	0	<5	<5	6	28	38
Persistent pulmonary hypertension	0	0	0	<5	n.p.	9
Apnoea	0	0	<5	<5	9	15
Congenital anomaly	0	0	0	<5	<5	<5
Other	0	<5	<5	5	17	25
Peri-surgery	0	0	0	0	<5	<5
Newborn encephalopathy	0	0	0	0	6	6
Not stated	0	0	0	0	5	5
Total	18	75	203	319	553	1,168
	Per cent					
No respiratory support	0.0	n.p.	6.9	3.4	n.p.	3.0
Non-specific respiratory distress	44.4	41.3	59.1	64.3	70.6	64.6
Hyaline membrane disease	55.6	44.0	29.6	27.3	4.0	18.2
Meconium aspiration syndrome	0.0	0.0	0.0	n.p.	n.p.	5.8
Pneumonia	0.0	n.p.	n.p.	1.9	5.1	3.3
Persistent pulmonary hypertension	0.0	0.0	0.0	n.p.	n.p.	0.8
Apnoea	0.0	0.0	n.p.	n.p.	1.6	1.3
Congenital anomaly	0.0	0.0	0.0	n.p.	n.p.	n.p.
Other	0.0	n.p.	n.p.	1.6	3.1	2.1
Peri-surgery	0.0	0.0	0.0	0.0	n.p.	n.p.
Newborn encephalopathy	0.0	0.0	0.0	0.0	1.1	0.5
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.

Gestational age was not provided for two babies.

TABLE 37: Duration of assisted ventilation use by level II registrants by gestational age group, 2014

Median & Interquartile range	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
IPPV (hours)						
Median	13	22	53	13.5	8	19
IQR	5–19	13–46	27.5–64	3–24.5	5–21	6–45
CPAP (hours)						
Median	78	40	27.5	19	15	18
IQR	23–106	19–81	14–52	11–39	7–26	10–37

Note: IQR = Interquartile range.

Eye examination

Screening for retinopathy of prematurity (ROP) was reported for only 43 of the 58 eligible babies born at less than 31 weeks gestational age and/or weighing less than 1,250 grams at birth (74.1% compared to 81.7% of eligible level III registrants). Most were reported as normal except for four babies who had stage 1 ROP.

Cerebral ultrasound

Of the 93 babies born at less than 32 weeks, 80 (86.0%) had a cerebral ultrasound in the first week after birth. 72 of them were reported as normal, that is no intraventricular haemorrhage (IVH), six reported a grade 1 IVH, one reported a grade 2 IVH and one 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 44 babies, all of whom had normal reports except for one baby with reported porencephalic cysts.

Other morbidities

Septicaemia was proven in 12 babies, including eleven before day two, that is less than 48 hours. There were no cases of necrotising enterocolitis. Major congenital anomalies were reported for 29 babies, two required major surgery, and four registrants died due to congenital anomalies.

Level II transfers

In total 102 level II registrants were transferred to other units, 69 were transferred to a level I or another level II unit, 28 were transferred to a level III unit and the remaining five to a children's hospital.

Survival

There were 1,158 level II registrants who survived to discharge home (99.0%). Seven babies died within the first seven days of birth and a further one baby died before discharge home (Table 38). Four babies were reported to have had a lethal congenital anomaly.

Table 38: Survival to discharge home for level II registrants by gestational age group, 2014

Gestational age group	All babies	Babies alive on day 7	Babies alive on day 28	Survived to go home	Per cent survival at discharge to home
<30	18	18	18	18	100.0
30-31	75	75	75	75	100.0
32-33	203	203	203	202	99.5
34-36	319	317	317	314	98.4
37-43	553	548	547	547	98.9
All babies	1,168	1,161	1,160	1,156	99.0

Note: Gestational age was not provided for two babies.
 Death status was not provided for four babies.

6. Extremely preterm follow-up, 2009–2011 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 for 2009 to 2011 births. All infants born from 2009 to 2011 at less than 28 weeks gestation or less than 1,000 grams at birth and admitted to one of the 28 level III NICUs in Australia and New Zealand, who survived to discharge to home were eligible for follow-up at 2–3 years of age, corrected for prematurity. There were 3,489 infants who fulfilled the criteria for 2–3 year follow-up.

Care should be taken with interpretation of these data as post-discharge data were not retrieved from the NICU for 211 (6.0%) of the eligible ANZNN registrants born from 2009 to 2011.

Follow-up rate

From 2009 to 2011, 4,175 extremely preterm and/or extremely low birthweight babies were registered to the ANZNN, with 3,489 (83.6%) surviving to discharge to home. For the babies who survived to discharge, not all NICUs were able to submit post-discharge data. It should be noted that two NICUs were unable to submit post-discharge data for 2009 births and one was unable to submit post-discharge data for 2010 or 2011 births before the publication of this Report. The 149 eligible survivors registered to these NICUs were excluded from further outcome analysis.

Of the 3,340 eligible survivors registered to NICUs that were able to submit data, 2,628 (78.7%) had outcome data available. There were 39 infants who died after discharge and 2,589 who had a follow-up assessment. Outcome data were not available for 712 (21.3%) infants, with 650 (19.5%) recorded by the NICU as lost to follow-up and the remainder with no post-discharge data being retrieved from the NICU (Figure 10). Overall, the rate of follow-up among these surviving eligible infants was 78.4% (2,589 of 3,301). The follow-up rate was seen to decrease with increasing gestational age and increasing birthweight (Table 39 & Table 40).

Of the 2,589 infants who were followed-up, 2,278 (88.0%) had a formal developmental assessment. For the remaining 311 (12.0%) infants, some follow-up information was obtained but a formal developmental assessment was not completed.

FIGURE 10: Flowchart of 2009–2011 follow-up cohort

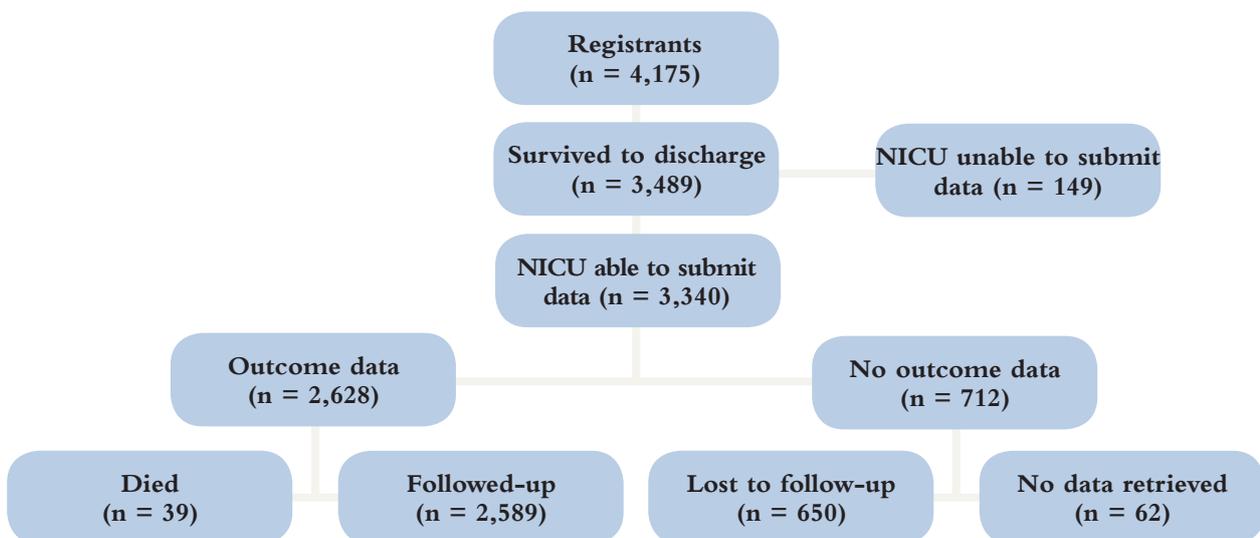


TABLE 39: Births, survival and 2–3 year follow-up of extremely preterm and/or extremely low birthweight infants by gestational age, 2009–2011 births

	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28 ^(a)	
Number							
Registrants	179	554	727	931	995	789	4,175
Survived to discharge	98	356	571	804	910	750	3,489
Per cent							
Survived to discharge ^(b)	54.7	64.3	78.5	86.4	91.5	95.1	83.6
Number							
NICU not included	5	19	24	42	33	26	149
Follow-up cohort ^(c)	93	337	547	762	877	724	3,340
▪ Died post-discharge	<5	<5	10	5	15	<5	39
▪ Follow-up assessment ^(d)	n.p.	n.p.	428	601	659	n.p.	2,589
▪ No outcome data	5	49	109	156	203	190	712
Per cent							
Follow-up rate ^(e)	94.6	85.3	79.7	79.4	76.5	73.6	78.4

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

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

(b) Denominator is all registrants.

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

(d) Includes 102 infants assessed at <18 months corrected age and 15 infants with unknown corrected age at assessment.

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

TABLE 40: Births, survival and 2–3 year follow-up of extremely preterm and/or extremely low birthweight infants by birthweight, 2009–2011 births

	Birthweight group (grams)							Total
	<500	500–599	600–699	700–799	800–899	900–999	≥1000 ^(a)	
Number								
Registrants	107	276	601	701	818	909	763	4,175
Survived to discharge	48	182	433	568	711	851	696	3,489
Per cent								
Survived to discharge ^(b)	44.9	65.9	72.0	81.0	86.9	93.6	91.2	83.6
Number								
NICU not included	0	5	17	24	28	39	36	149
Follow-up cohort ^(c)	48	177	416	544	683	812	660	3,340
▪ Died post-discharge	<5	<5	<5	6	5	12	8	39
▪ Follow-up assessment ^(d)	n.p.	n.p.	n.p.	432	527	609	489	2,589
▪ No outcome data	5	22	74	106	151	191	163	712
Per cent								
Follow-up rate ^(e)	89.1	87.4	82.1	80.3	77.7	76.1	75.0	78.4

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

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

(b) Denominator is all registrants.

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

(d) Includes 102 infants assessed at <18 months corrected age and 15 infants with unknown corrected age at assessment.

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

Assessment and tools

Children were assessed by the developmental assessment team at the level III hospital in which they received their neonatal care or the closest level III hospital to their current place of residence. If the parents were unable to travel to a level III hospital then a local paediatrician or general practitioner may have examined the child. The median age of assessment was 24.8 months with an interquartile range of 23.9–29.0 months, corrected for prematurity.

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

Neurological outcome

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

Information about cerebral palsy was available for 96.1% of infants with a follow-up assessment at 18 months corrected age or older, and of these, 175 (7.4%) had a diagnosis of cerebral palsy. The movement ability of 169 (96.6%) 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, 73 (43.2%) infants were graded as level 1, 44 (26.0%) as level 2, 23 (13.6%) as level 3, 12 (7.1%) as level 4 and 17 (10.1%) as level 5. Cerebral palsy was most prevalent and most severe among infants 24 weeks gestational age or younger (Table 41).

Of the 117 infants who were assessed at less than 18 months corrected age, there was one case of mild cerebral palsy, four cases of moderate cerebral palsy, one case of severe cerebral palsy and two cases of cerebral palsy where the severity was unknown.

TABLE 41: Cerebral Palsy at 2–3 year follow-up by gestational age, 2009–2011 births

Cerebral Palsy (CP)	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
No CP	69	222	369	504	574	462	2,200
CP	10	34	30	49	25	27	175
▪ Mild Level 1	<5	14	n.p.	n.p.	n.p.	n.p.	73
▪ Moderate Level 2–3	5	14	14	15	9	10	67
▪ Severe Level 4–5	<5	<5	<5	9	7	<5	29
▪ Level unknown	<5	<5	0	<5	<5	0	6
Not stated	5	15	15	25	23	14	97
Total in each age group^(a)	84	271	414	578	622	503	2,472
	Per cent						
No CP	87.3	86.7	92.5	91.1	95.8	94.5	92.6
CP	12.7	13.3	7.5	8.9	4.2	5.5	7.4
▪ Mild Level 1	n.p.	5.5	n.p.	n.p.	n.p.	n.p.	3.1
▪ Moderate Level 2–3	6.3	5.5	3.5	2.7	1.5	2.0	2.8
▪ Severe Level 4–5	n.p.	n.p.	n.p.	1.6	1.2	n.p.	1.2
▪ Level unknown	n.p.	n.p.	0.0	n.p.	n.p.	0.0	0.3

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

(a) Excludes 102 infants assessed at <18 months corrected age and 15 infants with unknown corrected age at assessment.

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

Vision and Hearing

Extremely preterm and/or extremely low birthweight babies are at significant risk of retinopathy of prematurity which has, in some cases, substantial long term retinal morbidity plus a risk of amblyopia and strabismus. Data on blindness were available for 96.8% of infants with a follow-up assessment and of these, only 13 (0.5%) were recorded as being blind (< 6/60 in the better eye). Half of the infants with blindness were born at 24 weeks gestational age or younger.

Permanent congenital, delayed-onset, or progressive hearing loss is a significant adverse outcome of extreme prematurity. Risk factors include prolonged oxygen supplementation and hyperbilirubinemia (Robertson et al. 2009). Data on the use of devices for hearing amplification were only included for the 2,568 infants assessed at nine months corrected age or older as hearing devices would only likely be fitted from this age.

Information about the use of hearing devices was available for 97.3% of infants with a follow-up assessment at nine months corrected age or older. Of these, seven (0.3%) infants were fitted with a unilateral hearing aid, 28 (1.1%) infants with bilateral hearing aids, eight (0.3%) infants with a cochlear implant and eight (0.3%) infants with a cochlear implant and hearing aids. The proportion of infants with hearing devices was more than double among those 24 weeks gestational age or younger (4.8%) compared with any other gestational age group (1.3–1.7%).

Congenital anomalies

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

The congenital anomalies identified included: congenital hypothyroidism, cerebral cysts, hydrocephalus, absent septum pellucidum, Trisomy 21, ventriculomegaly, visual cortical impairment, auditory neuropathy, microcephaly, bilateral optic nerve hypoplasia, Cornelia De Lange syndrome, malformation of posterior segment of eye, Triple X syndrome (karyotype 47, XXX), agenesis of corpus callosum, holoprosencephaly, septo-optic dysplasia, duplication of chromosome 6, small selection long arm chromosome 2, lissencephaly, fetal alcohol syndrome, tuberous sclerosis, deletion of terminal 10q, encephalomalacia, and other specified congenital malformation of the brain.

There were 39 infants who had one or more of these congenital anomalies and these infants were subsequently excluded from cognitive, language and motor delay analyses and functional impairment analyses (Table 42 to Table 46).

Developmental testing

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

Results were included for 2,037 infants assessed by the Bayley Scales of Development-III, 90 infants assessed by the Griffiths Mental Developmental Scales and 31 infants assessed by the Wechsler Preschool and Primary Scale of Intelligence (WPPSI). It should be noted that motor and language subscale scores were not available for the few infants who were assessed by WPPSI alone.

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

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

Additionally, there were 19 infants who were reported as unable to be assessed due to severe developmental delay and were therefore included in the severe category for cognitive, language and motor delay. While an additional 11 infants without formal developmental assessment had a severe impairment recorded (two with severe cerebral palsy and blindness, four with severe cerebral palsy, three with blindness and two with a clinical assessment of severe impairment), severe cognitive, language or motor delay could not be reliably assigned to these infants.

Overall, there were 328 (15.1%) infants with mild to severe cognitive delay, 551 (27.0%) with mild to severe language delay and 359 (17.5%) with mild to severe motor delay. Cognitive, language and motor delay was most prevalent and most severe among infants who were less than 24 weeks gestational age (Table 42 to Table 44).

TABLE 42: Cognitive delay at 2–3 year follow-up by gestational age for Bayley, Griffiths and WPPSI assessments, 2009–2011 births

Cognitive delay	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
Number							
None	48	187	324	437	485	360	1,841
Mild	n.p.	33	n.p.	48	48	42	231
Moderate	6	7	<5	14	12	n.p.	50
Severe	<5	9	9	13	7	<5	47
Not stated ^(a)	0	0	0	1	3	4	8
Total^(b)	76	236	380	513	555	417	2,177
Per cent							
None	63.2	79.2	85.3	85.4	87.9	87.2	84.9
Mild	n.p.	14.0	n.p.	9.4	8.7	10.2	10.7
Moderate	7.9	3.0	n.p.	2.7	2.2	n.p.	2.3
Severe	n.p.	3.8	2.4	2.5	1.3	n.p.	2.2
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.

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

(b) Infants assessed by Bayley, Griffiths or WPPSI at ≥18 months corrected age or older or unable to be assessed due to severe delay. Excludes 39 infants with a congenital anomaly known to impair development.

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

TABLE 43: Language delay at 2–3 year follow-up by gestational age for Bayley and Griffiths assessments, 2009–2011 births

Language delay	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
Number							
None	42	142	265	358	393	286	1,486
Mild	15	46	54	83	n.p.	n.p.	351
Moderate	6	30	25	37	26	26	150
Severe	7	9	11	9	n.p.	<5	50
Not stated ^(a)	6	7	22	18	31	25	109
Total^(b)	76	234	377	505	548	406	2,146
Per cent							
None	60.0	62.6	74.6	73.5	76.0	75.1	73.0
Mild	21.4	20.3	15.2	17.0	n.p.	n.p.	17.2
Moderate	8.6	13.2	7.0	7.6	5.0	6.8	7.4
Severe	10.0	4.0	3.1	1.8	n.p.	n.p.	2.5
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.

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

(b) Infants assessed by Bayley or Griffiths at ≥18 months corrected age or older or unable to be assessed due to severe delay. Excludes 39 infants with a congenital anomaly known to impair development.

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

TABLE 44: Motor delay at 2–3 year follow-up by gestational age for Bayley and Griffiths assessments, 2009–2011 births

Motor delay	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
None	49	170	303	405	438	327	1,692
Mild	13	38	45	51	58	45	250
Moderate	5	10	7	17	13	7	59
Severe	6	8	9	14	8	5	50
Not stated ^(a)	3	8	13	18	31	22	95
Total^(b)	76	234	377	505	548	406	2,146
	Per cent						
None	67.1	75.2	83.2	83.2	84.7	85.2	82.5
Mild	17.8	16.8	12.4	10.5	11.2	11.7	12.2
Moderate	6.8	4.4	1.9	3.5	2.5	1.8	2.9
Severe	8.2	3.5	2.5	2.9	1.5	1.3	2.4
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

(b) Infants assessed by Bayley or Griffiths at ≥18 months corrected age or older or unable to be assessed due to severe delay. Excludes 39 infants with a congenital anomaly known to impair development.

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

Functional impairment

Functional impairment was analysed for 1,843 infants assessed at 18 months corrected age or older, with cognitive, language and motor subscale scores from Bayley or Griffiths assessments, and with data on blindness, hearing device use, and cerebral palsy. Functional impairment was graded as mild (GMFCS level 1 cerebral palsy, mild language, cognitive or motor delay), moderate (GMFCS level 2 to 3 cerebral palsy, deafness requiring amplification, moderate language, cognitive or motor delay) or severe (GMFCS level 4 to 5 cerebral palsy, blindness or severe language, cognitive or motor delay).

Additionally, 18 infants who met at least one of the criteria for severe impairment, but had missing data for one of more outcome, and 19 infants who were unable to be assessed due to severe developmental delay were included in the severe category for functional impairment. Of these infants, four were less than 24 weeks, four were 24 weeks, seven were 25 weeks, 11 were 26 weeks, nine were 27 weeks and two were 28 weeks gestational age or older.

Of the 1,880 infants where functional impairment could be graded, there were 672 (35.7%) infants with any degree of functional impairment, including 410 (21.8%) with a mild impairment, 176 (9.4%) with a moderate impairment and 86 (4.6%) with a severe impairment. Functional impairment was most prevalent and most severe among infants who were less than 24 weeks gestational age, with over half (58.5%) having some degree of functional impairment (Table 45).

TABLE 45: Severity of functional impairment at 2–3 year follow-up by gestational age, 2009–2011 births

Functional Impairment	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
None	27	104	217	299	320	241	1,208
Mild	20	57	71	87	99	76	410
Moderate	10	35	30	39	36	26	176
Severe	8	13	17	25	16	7	86
Incomplete formal assessment ^(a)	11	26	43	60	80	57	277
Other formal assessment	1	2	3	15	15	16	52
No formal assessment	5	30	29	47	49	65	225
Total^(b)	82	267	410	572	615	488	2,434
	Per cent						
None	41.5	49.8	64.8	66.4	67.9	68.9	64.3
Mild	30.8	27.3	21.2	19.3	21.0	21.7	21.8
Moderate	15.4	16.7	9.0	8.7	7.6	7.4	9.4
Severe	12.3	6.2	5.1	5.6	3.4	2.0	4.6
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

(b) Excludes 102 infants assessed at <18 months corrected age and 15 infants with unknown corrected age at assessment. Also excludes 39 infants with a congenital anomaly known to impair development.

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

Moderate to severe functional impairment

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

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

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

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

Upon review, 449 infants with incomplete or other formal developmental assessments, or without formal developmental assessments had sufficient information to be classified as with or without moderate to severe functional impairment. Of these 449 infants, together with the 1,880 infants graded in Table 45, there were 326 (14.0%) infants with moderate to severe functional impairment. Moderate to severe functional impairment was seen to decrease with increasing gestational age (Table 46).

TABLE 46: Infants with or without moderate to severe functional impairment at 2–3 year follow-up by gestational age, 2009–2011 births

Functional Impairment	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
Moderate–severe impairment	22	65	56	75	65	43	326
Without moderate–severe impairment	59	190	345	472	528	409	2,003
Not stated ^(a)	1	12	9	25	22	36	105
Total^(b)	82	267	410	572	615	488	2,434
	Per cent						
Moderate–severe impairment	27.2	25.5	14.0	13.7	11.0	9.5	14.0
Without moderate–severe impairment	72.8	74.5	86.0	86.3	89.0	90.5	86.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

(b) Excludes 102 infants assessed at <18 months corrected age and 15 infants with unknown corrected age at assessment. Also excludes 39 infants with a congenital anomaly known to impair development.

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

Growth – weight, height and head circumference

Growth standards published by the World Health Organization, 2006, were used to determine weight, height and head circumference for age percentiles and weight for height percentiles.

Growth measurements were only included for the 2,472 infants assessed at 18 months corrected age or older. Of these infants with computable percentiles, 9.7% fell below the 3rd percentile for weight for age, 16.8% for length/height for age, 7.1% for head circumference for age and 5.2% for weight for length/height at 2–3 year follow-up. For weight and length/height for age and weight for length/height, the proportion of infants below the 3rd percentile was highest among those 28 weeks gestational age or older who weighed less than 1,000 grams at birth (Table 47 to Table 50). These infants were highly likely to have been intrauterine growth restricted (IUGR) and may continue to show a pattern of slower growth (Hediger et al. 1998).

TABLE 47: Weight for age at 2–3 year follow-up by gestational age, 2009–2011 births

Weight for age centile	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
Number							
<3	7	18	30	46	31	85	217
3–9	10	35	42	40	38	67	232
10–90	58	171	289	374	426	284	1,602
>90	6	18	20	56	64	17	181
Not stated	3	29	33	62	63	50	240
Total^(a)	84	271	414	578	622	503	2,472
Per cent							
<3	8.6	7.4	7.9	8.9	5.5	18.8	9.7
3–9	12.3	14.5	11.0	7.8	6.8	14.8	10.4
10–90	71.6	70.7	75.9	72.5	76.2	62.7	71.8
>90	7.4	7.4	5.2	10.9	11.4	3.8	8.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(a) Excludes 102 infants assessed at <18 months corrected age and 15 infants with unknown corrected age at assessment.

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

TABLE 48: Length/height for age at 2–3 year follow-up by gestational age, 2009–2011 births

Length/height for age centile	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
Number							
<3	14	36	62	74	64	109	359
3–9	14	38	52	70	58	73	305
10–90	42	144	236	316	351	238	1,327
>90	7	16	17	37	55	16	148
Not stated	7	37	47	81	94	67	333
Total^(a)	84	271	414	578	622	503	2,472
Per cent							
<3	18.2	15.4	16.9	14.9	12.1	25.0	16.8
3–9	18.2	16.2	14.2	14.1	11.0	16.7	14.3
10–90	54.5	61.5	64.3	63.6	66.5	54.6	62.0
>90	9.1	6.8	4.6	7.4	10.4	3.7	6.9
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(a) Excludes 102 infants assessed at <18 months corrected age and 15 infants with unknown corrected age at assessment.

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

TABLE 49: Head circumference for age at 2–3 year follow-up by gestational age, 2009–2011 births

Head circumference for age centile	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
<3	8	24	20	22	20	42	136
3–9	8	24	29	40	19	40	160
10–90	49	131	254	321	346	257	1,358
>90	8	20	37	69	91	34	259
Not stated	11	72	74	126	146	130	559
Total^(a)	84	271	414	578	622	503	2,472
	Per cent						
<3	11.0	12.1	5.9	4.9	4.2	11.3	7.1
3–9	11.0	12.1	8.5	8.8	4.0	10.7	8.4
10–90	67.1	65.8	74.7	71.0	72.7	68.9	71.0
>90	11.0	10.1	10.9	15.3	19.1	9.1	13.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(a) Excludes 102 infants assessed at <18 months corrected age and 15 infants with unknown corrected age at assessment.

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

TABLE 50: Weight for Length/height at 2–3 year follow-up by gestational age, 2009–2011 births

Weight for Length/height centile	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
<3	<5	11	18	22	n.p.	43	112
3–9	7	19	23	37	37	57	180
10–90	n.p.	178	293	358	n.p.	306	1,577
>90	9	26	32	80	92	30	269
Not stated	7	37	48	81	94	67	334
Total^(a)	84	271	414	578	622	503	2,472
	Per cent						
<3	n.p.	4.7	4.9	4.4	n.p.	9.9	5.2
3–9	9.1	8.1	6.3	7.4	7.0	13.1	8.4
10–90	n.p.	76.1	80.1	72.0	n.p.	70.2	73.8
>90	11.7	11.1	8.7	16.1	17.4	6.9	12.6
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.

(a) Excludes 102 infants assessed at <18 months corrected age and 15 infants with unknown corrected age at assessment.

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

Respiratory and gastrointestinal tract

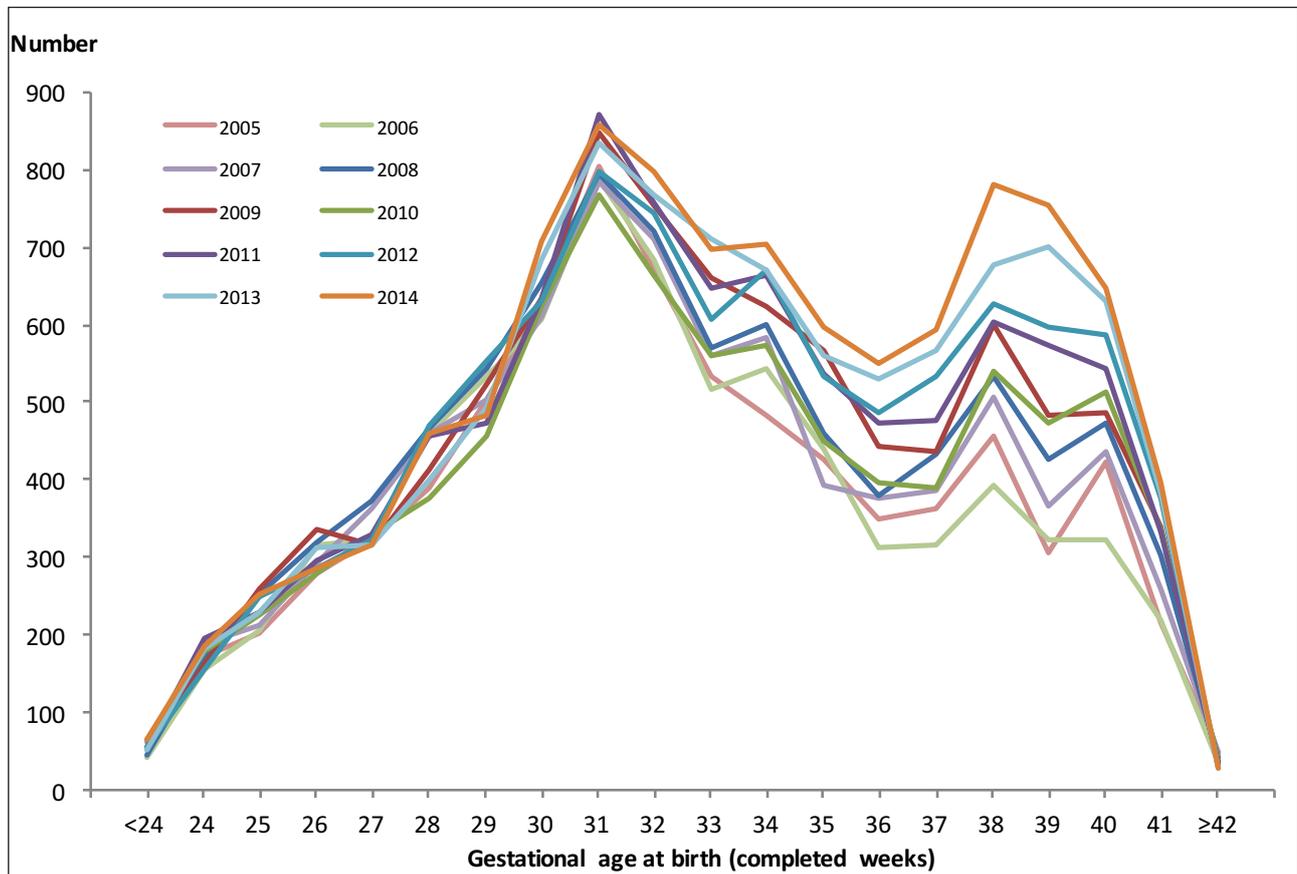
Respiratory and gastrointestinal tract (GIT) complications such as respiratory distress syndrome and necrotising enterocolitis commonly affect extremely premature babies and can lead to ongoing disease. Of the 2,297 infants with data available on the use of respiratory support, nine (0.4%) were supported by tracheostomy and 19 (0.8%) were supported by supplemental oxygen at the time of 2–3 year follow-up. Over one-third of infants receiving respiratory support were less than 25 weeks gestational age.

While no infants were reported as receiving parenteral nutrition for nutritional support, intragastric tube feeding via a percutaneous endoscopic gastrostomy tube or nasogastric tube was reported for 51 (2.2%) of the 2,302 infants with nutritional support data at the time of 2–3 year follow-up. It should be noted that seven of the 51 infants receiving nutritional support at follow-up were assessed at younger than 18 months corrected age and therefore support may have ceased by two years corrected age. Nutritional support was most prevalent among infants less than 25 weeks gestational age (4.6%) and infants 28 weeks gestational age or older who weighed less than 1,000 grams at birth (3.4%).

APPENDICES

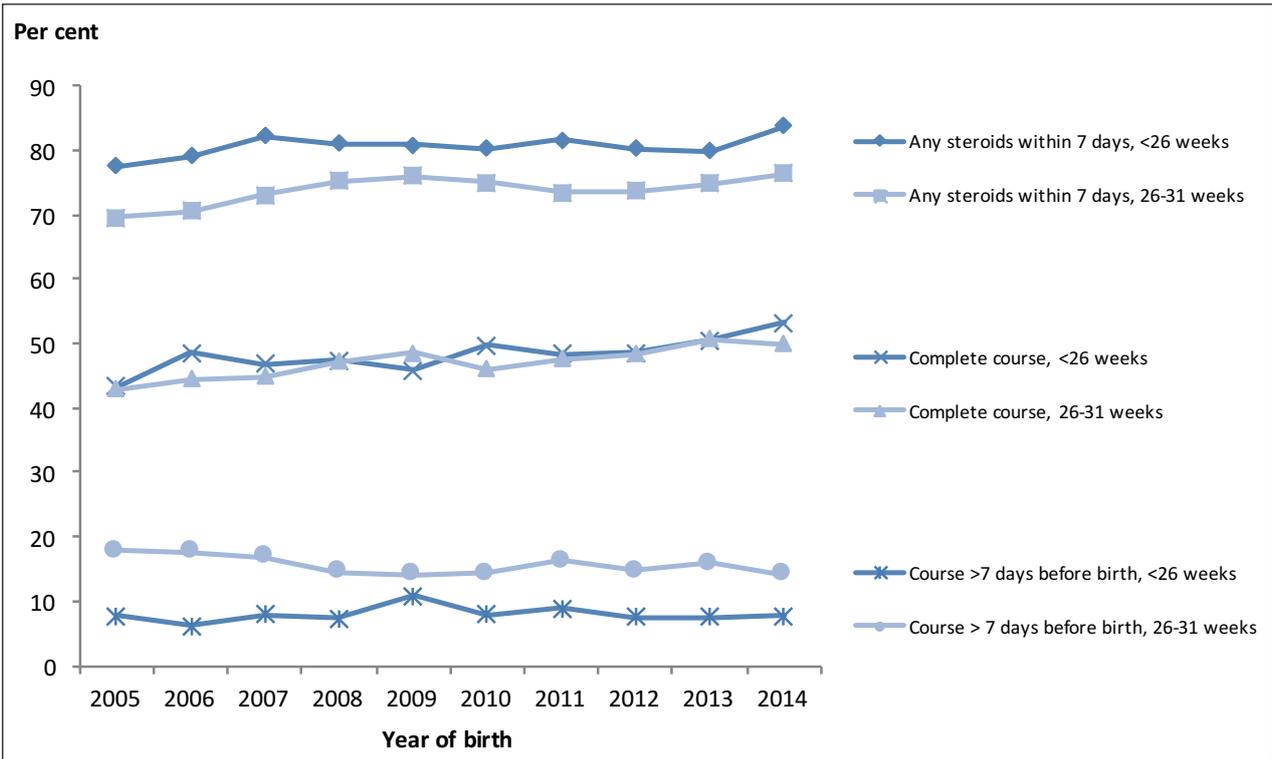
Appendix 1: Trends

FIGURE 11: Trends in gestational age at birth of level III registrants, 2005–2014



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

FIGURE 12: Trends in the use of corticosteroids for mothers of babies less than 32 weeks gestation, 2005–2014



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. ‘Any steroids within 7 days’ includes babies who received a ‘complete course’ as well as babies who received their first dose of corticosteroids at less than 24 hours prior to birth.

FIGURE 13: Trends in multiple births of level III registrants by gestational age group, 2005–2014

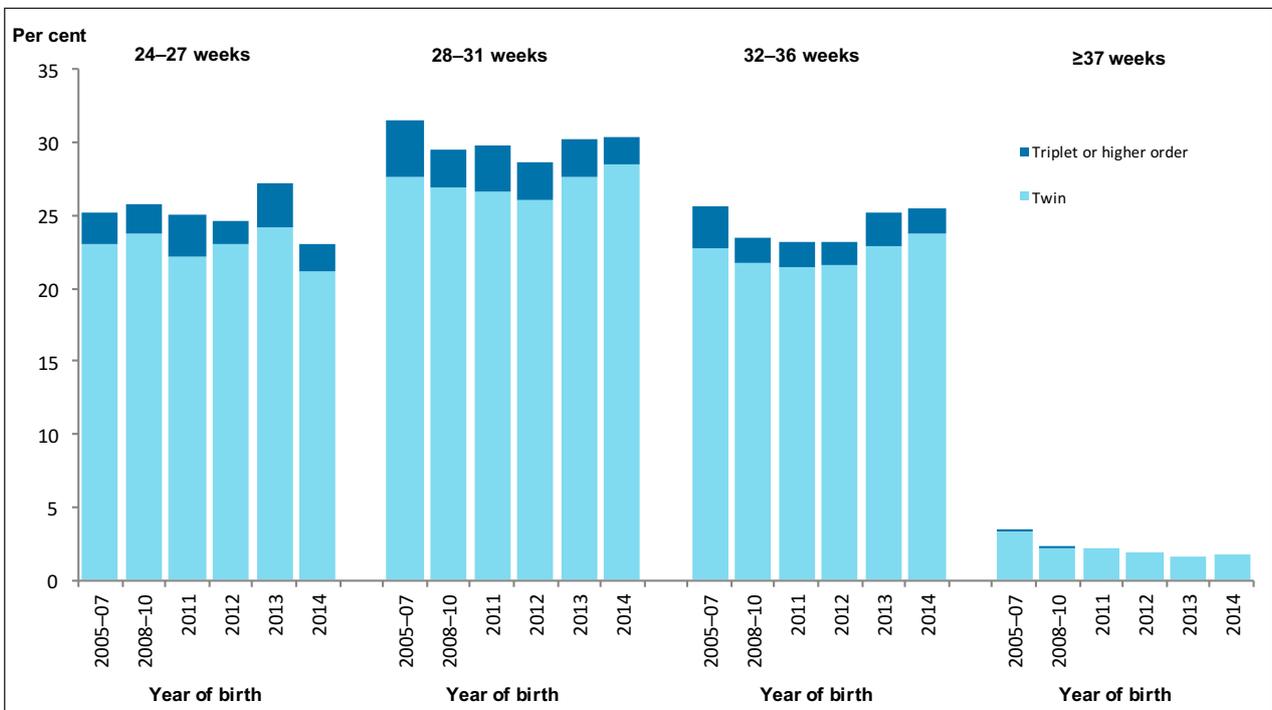


FIGURE 14: Trends in method of birth for level III registrants by year of birth, 2005–2014

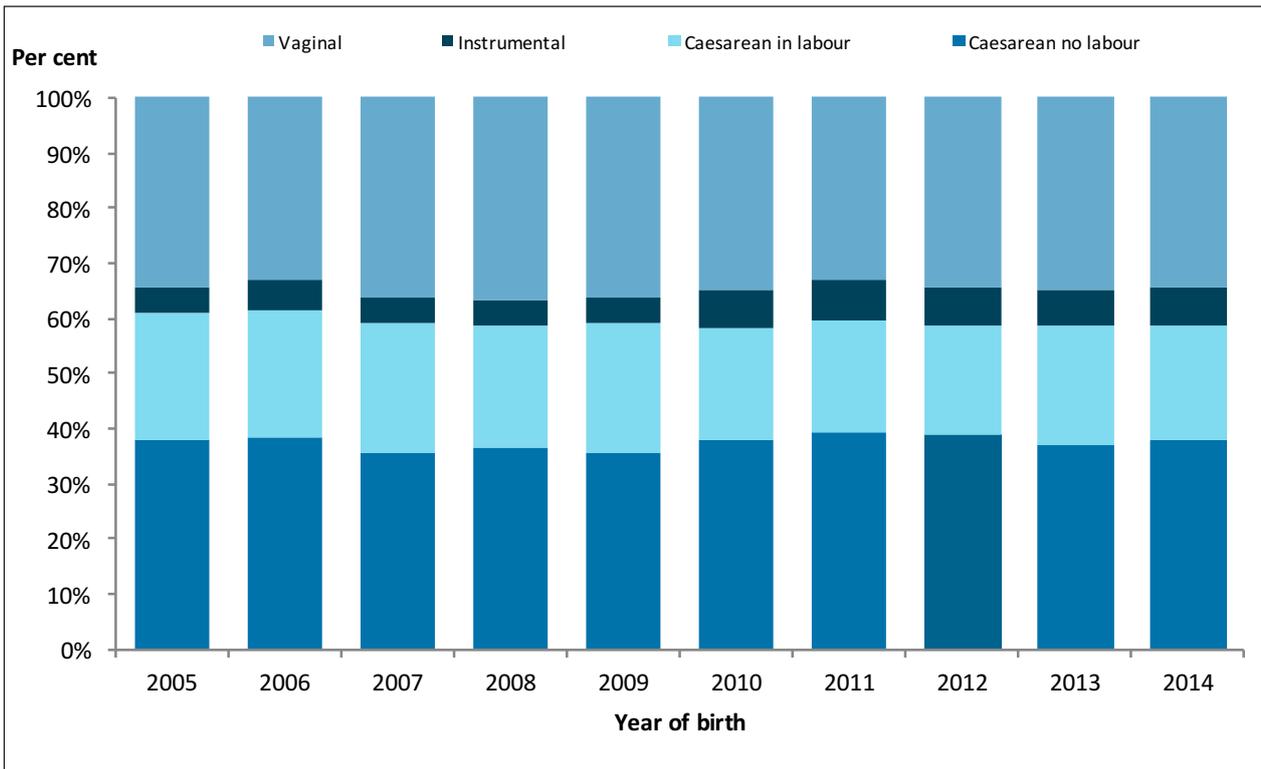


FIGURE 15: Trends in referral source to level III NICU by year of birth, 2005–2014

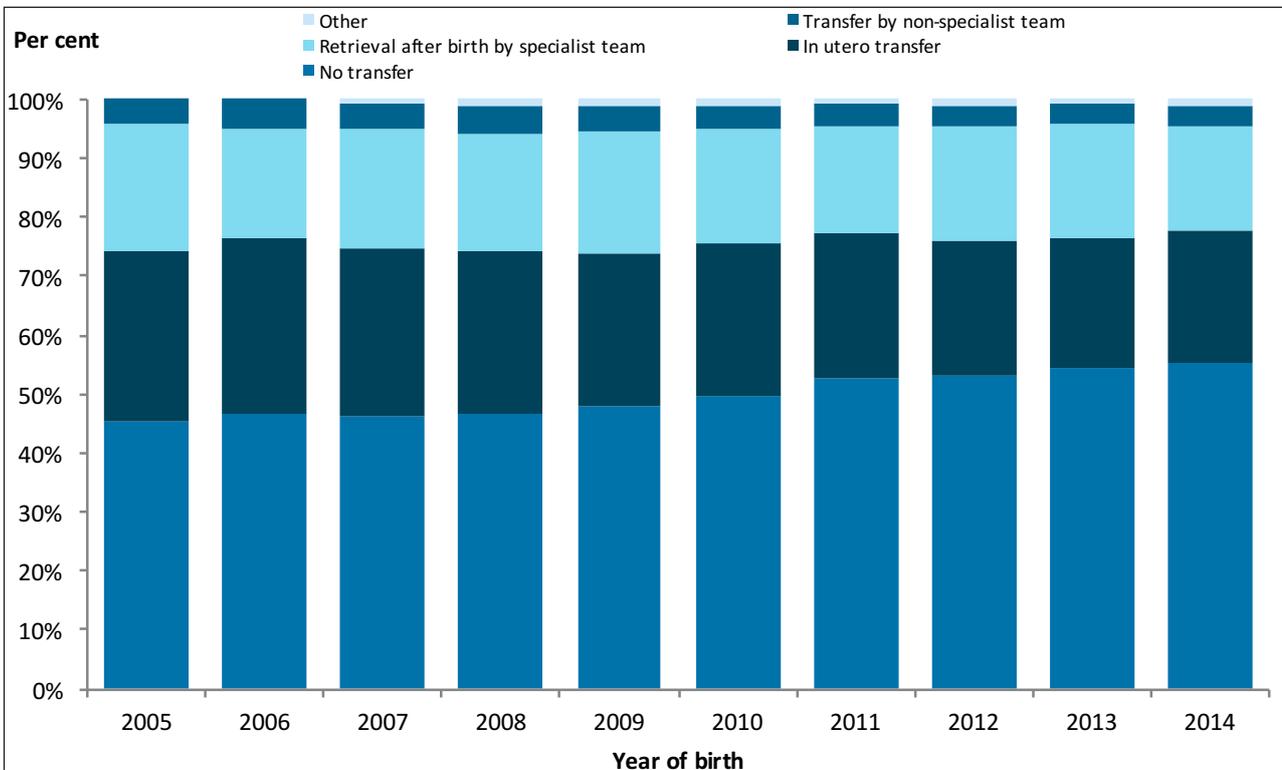


FIGURE 16: Trends in mode of transport to level III NICU, 2005-2014

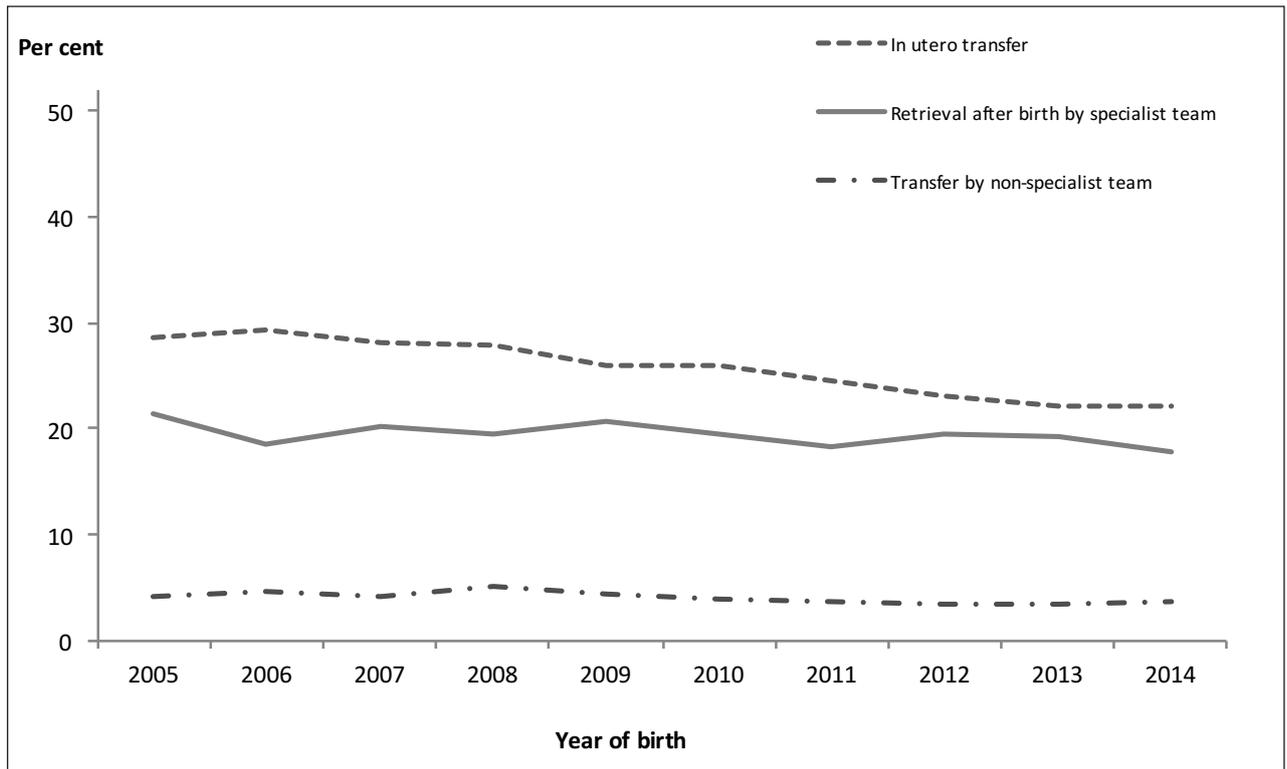


FIGURE 17: Trends in mode of assisted ventilation for level III registrants, 2005-2014

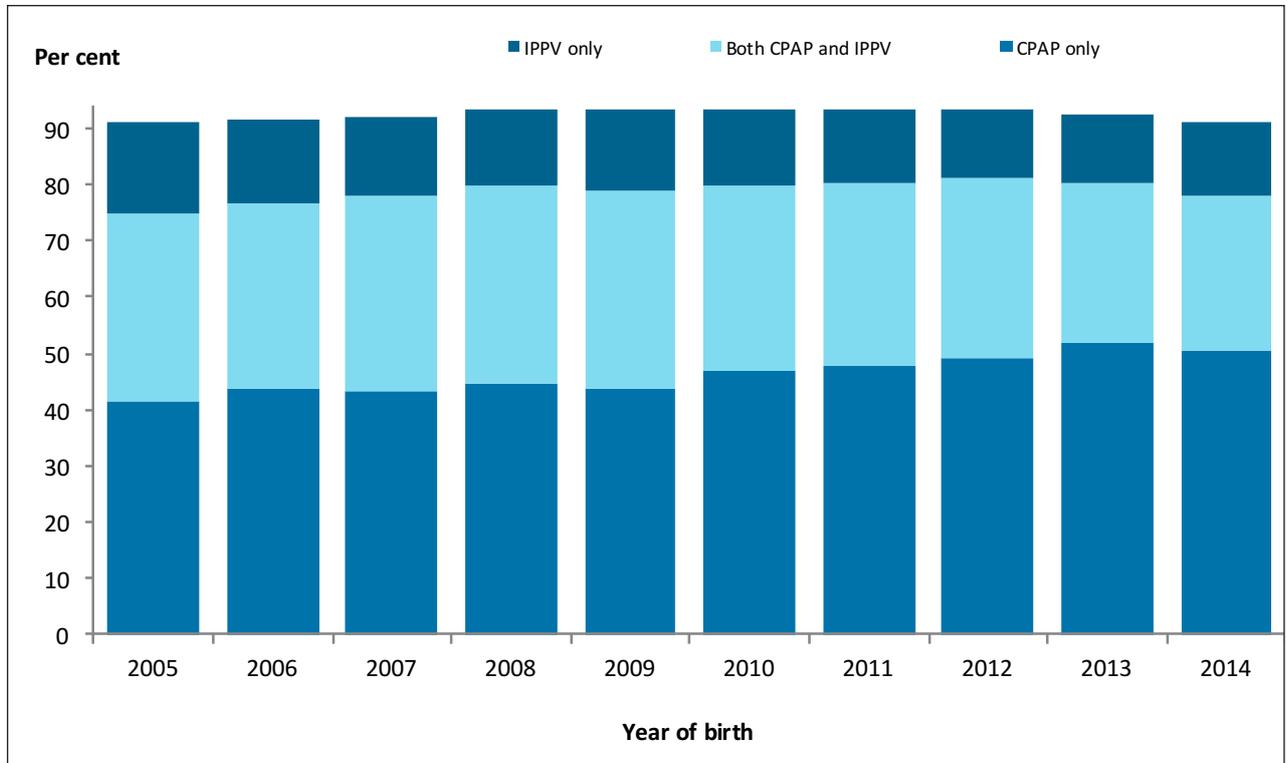


FIGURE 18: Trends in provision of intermittent positive pressure ventilation and continuous positive pressure ventilation by year of birth for level III registrants ventilated, 2005–2014

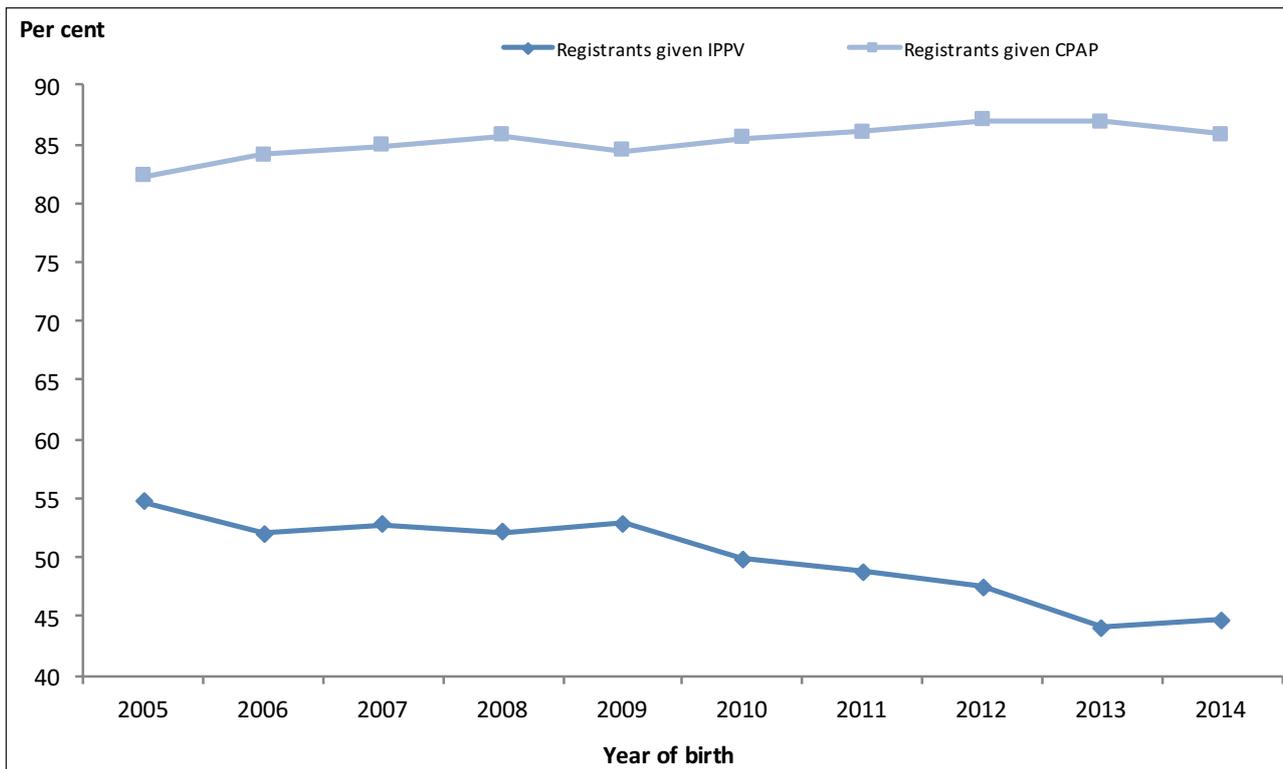


FIGURE 19: Trends in the use of CPAP as the only form of ventilation by gestational age for level III registrants, 2005, 2008, 2011–2014

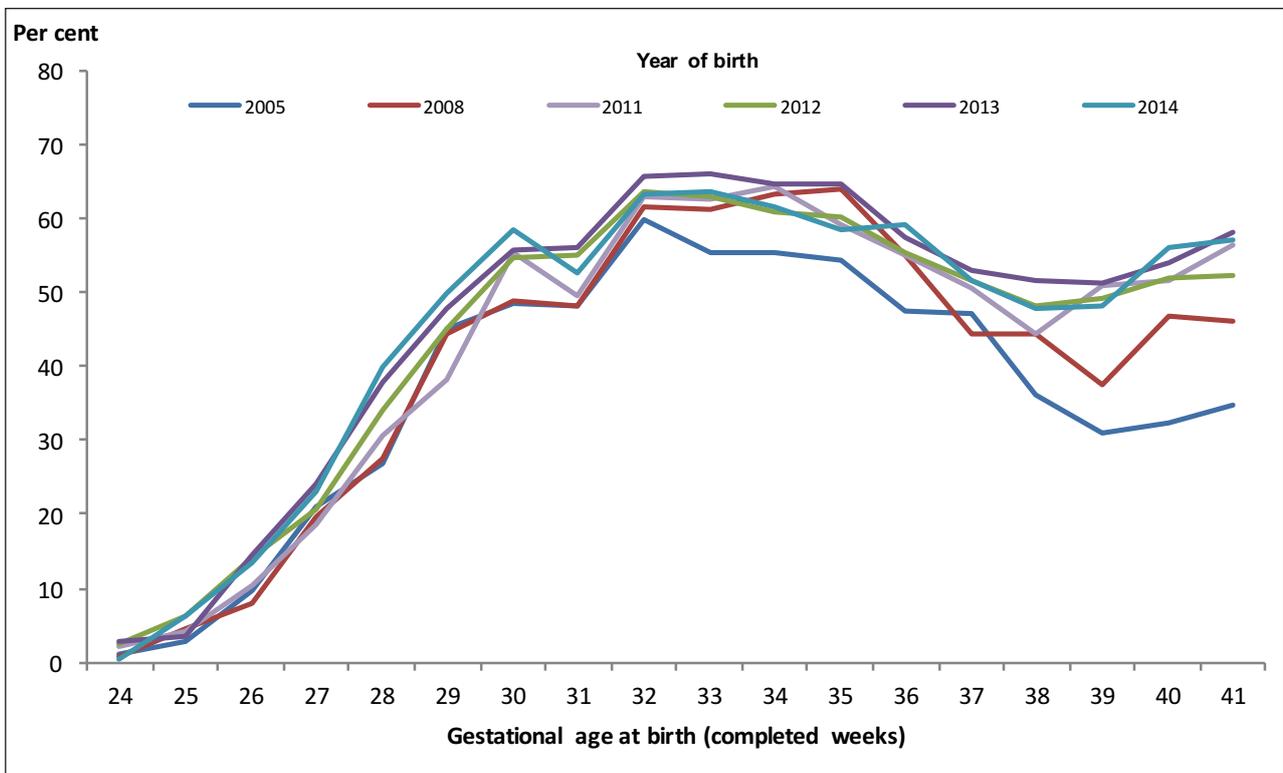
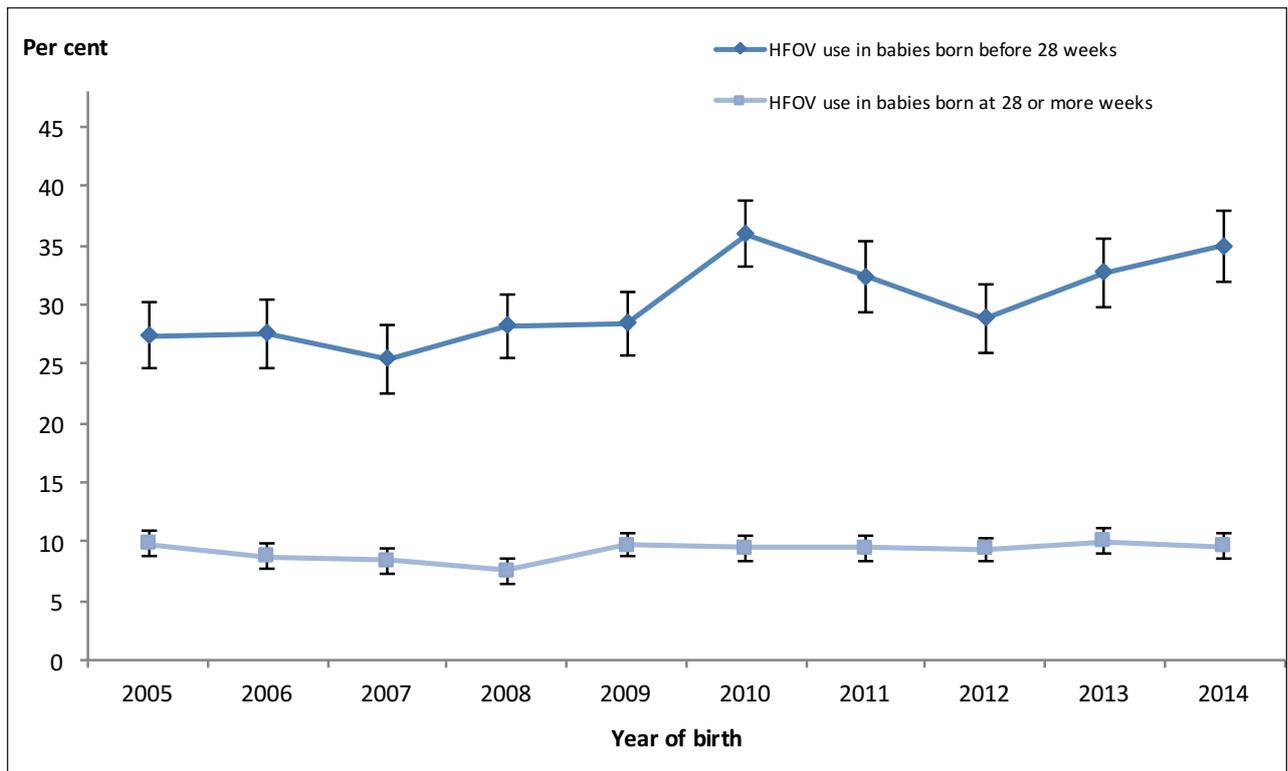
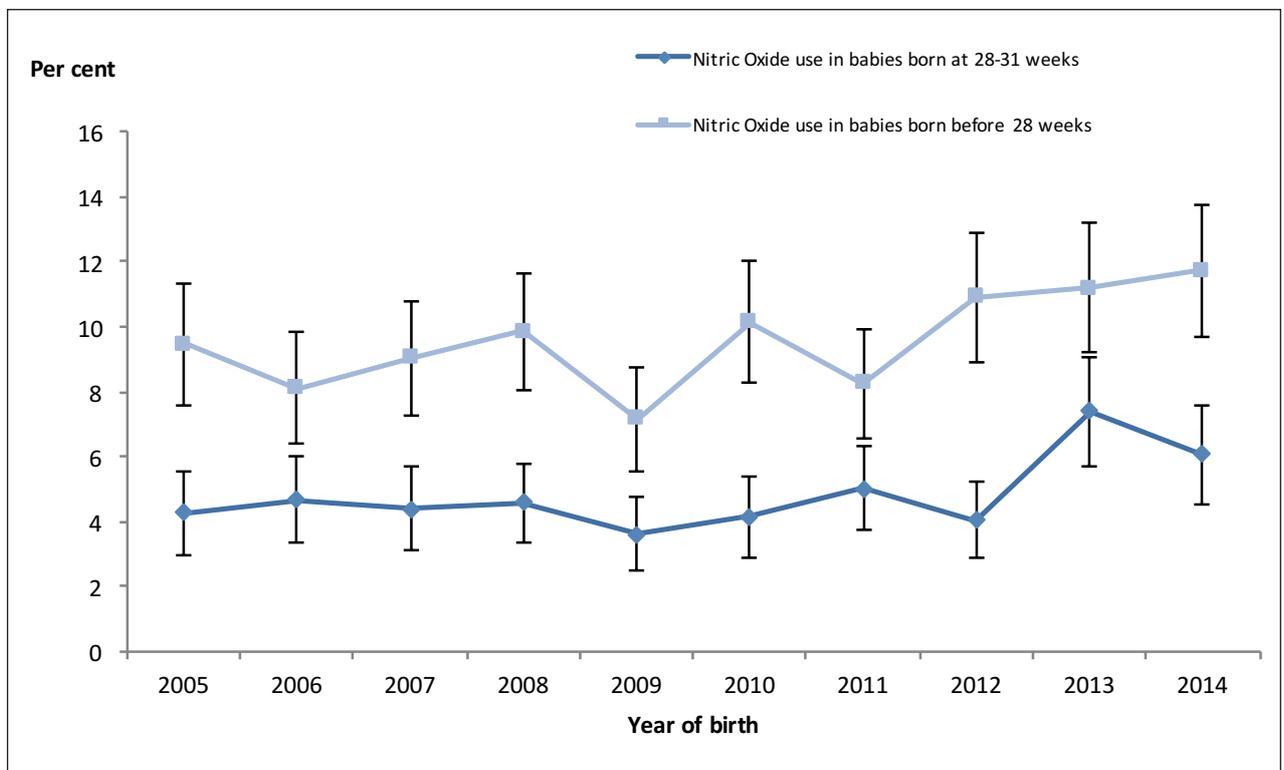


FIGURE 20: Trends in provision of high frequency oscillatory ventilation (with 95% CI) for level III registrants born before 28 weeks and at 28 or more weeks gestation, 2005–2014



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

FIGURE 21: Trends in nitric oxide (with 95% CI) provision for level III registrants born before 28 weeks and 28-31 weeks gestation, 2005–2014



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

FIGURE 22: Trends in chronic lung disease (with 95% CI) for level III registrants who survived to 36 weeks corrected age, 2005–2014

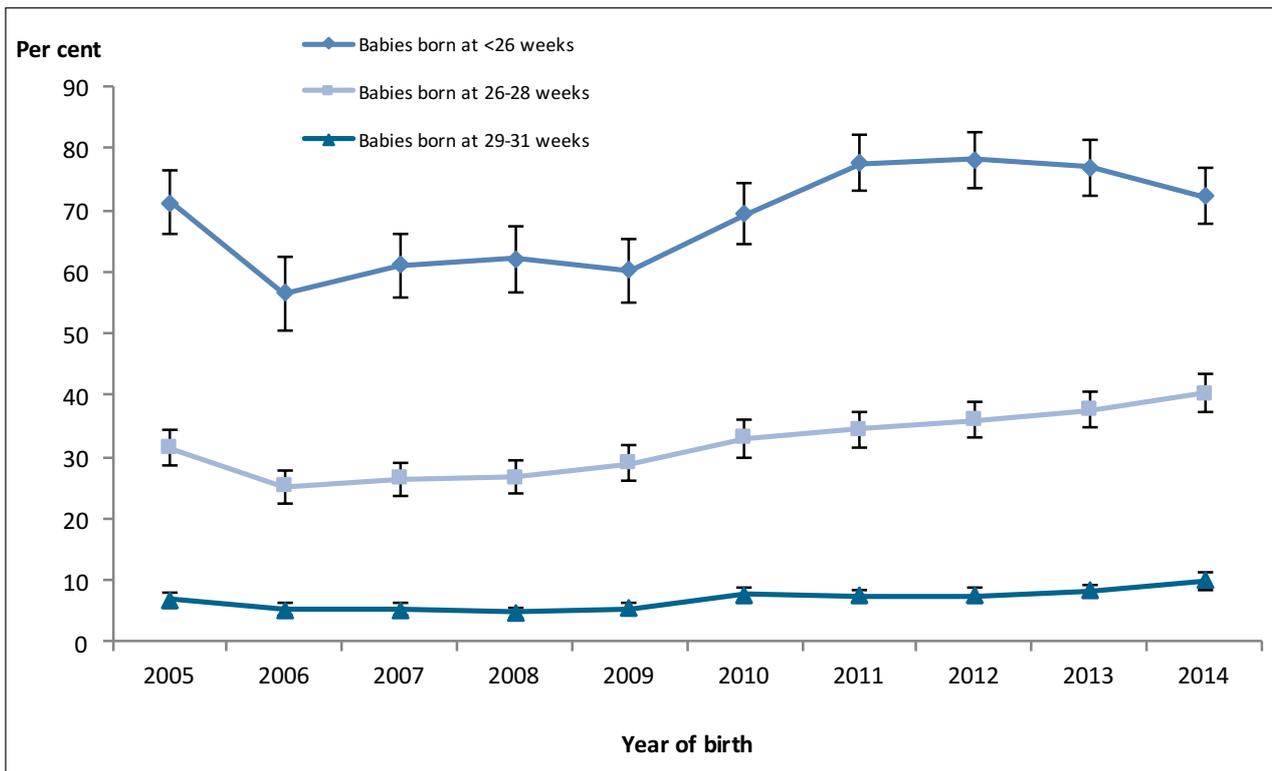


FIGURE 23: Stage 3 or 4 retinopathy of prematurity and treated retinopathy among babies born before 31 weeks gestation and/or birthweight of less than 1,250 grams who survived to 36 weeks corrected age for level III registrants, 2005–2014

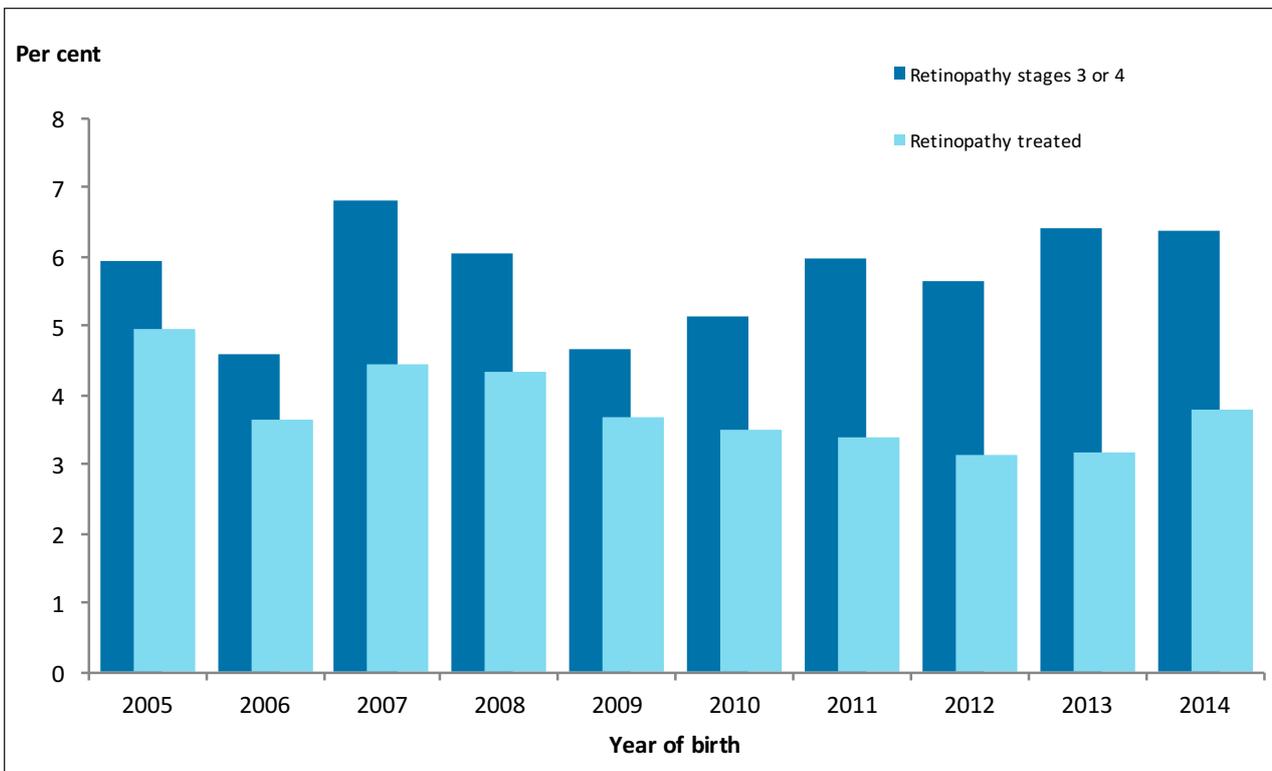


FIGURE 24: Trends in grade 3 or 4 intraventricular haemorrhage (with 95% CI) in babies born at less than 32 weeks gestation who survived to day 3 for level III registrants, 2005–2014

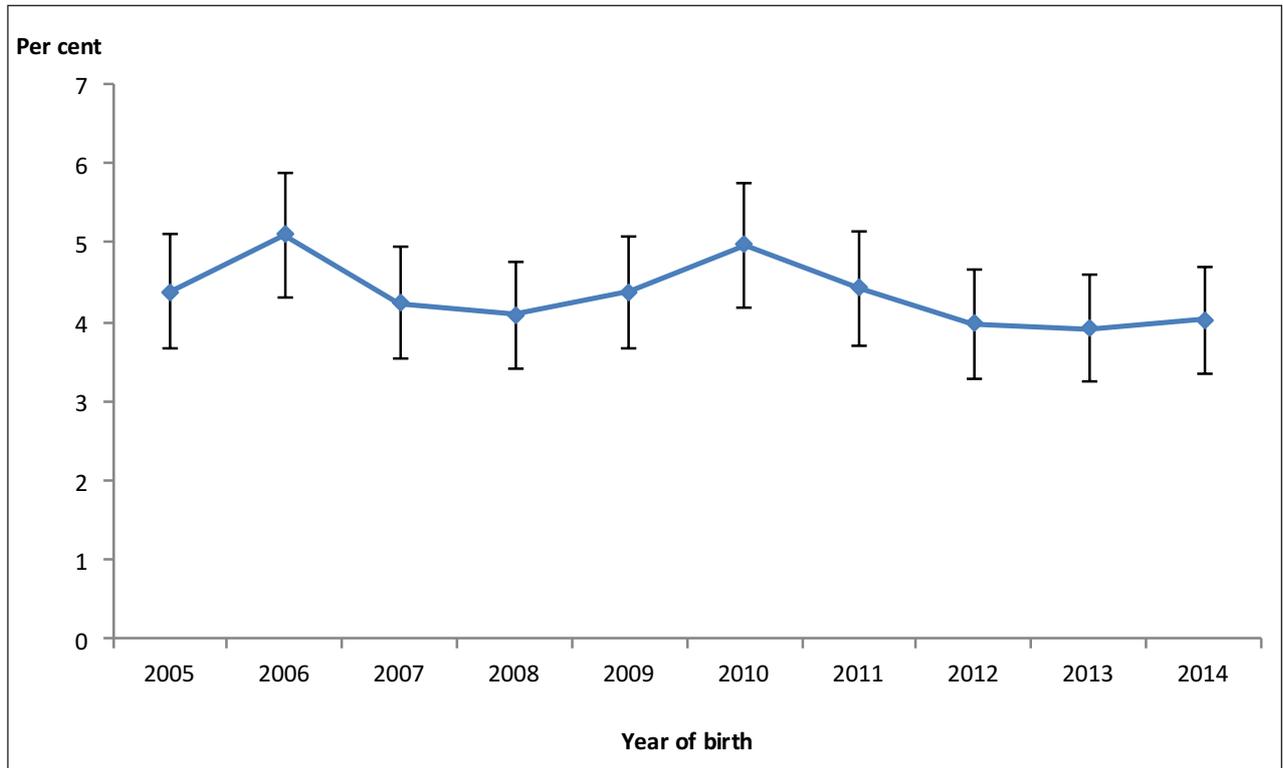


FIGURE 25: Incidence of early sepsis for level III registrants by gestational age group, 2010–2014

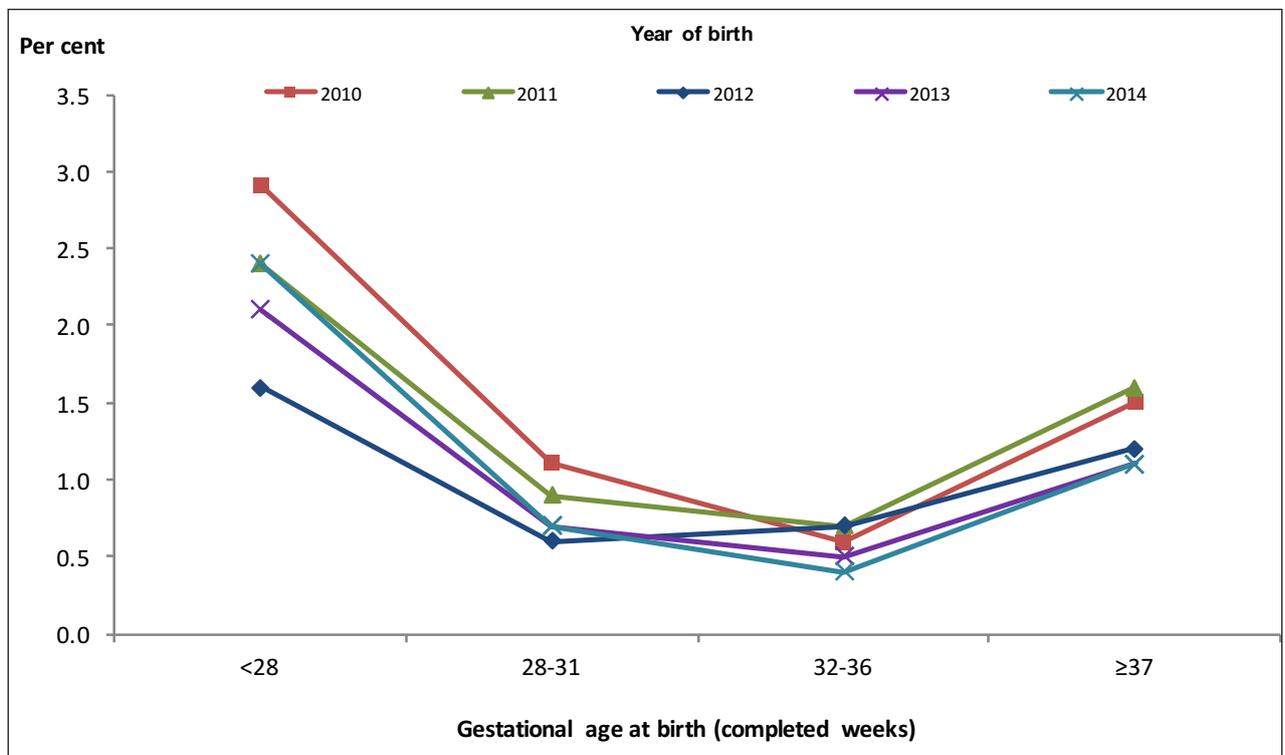
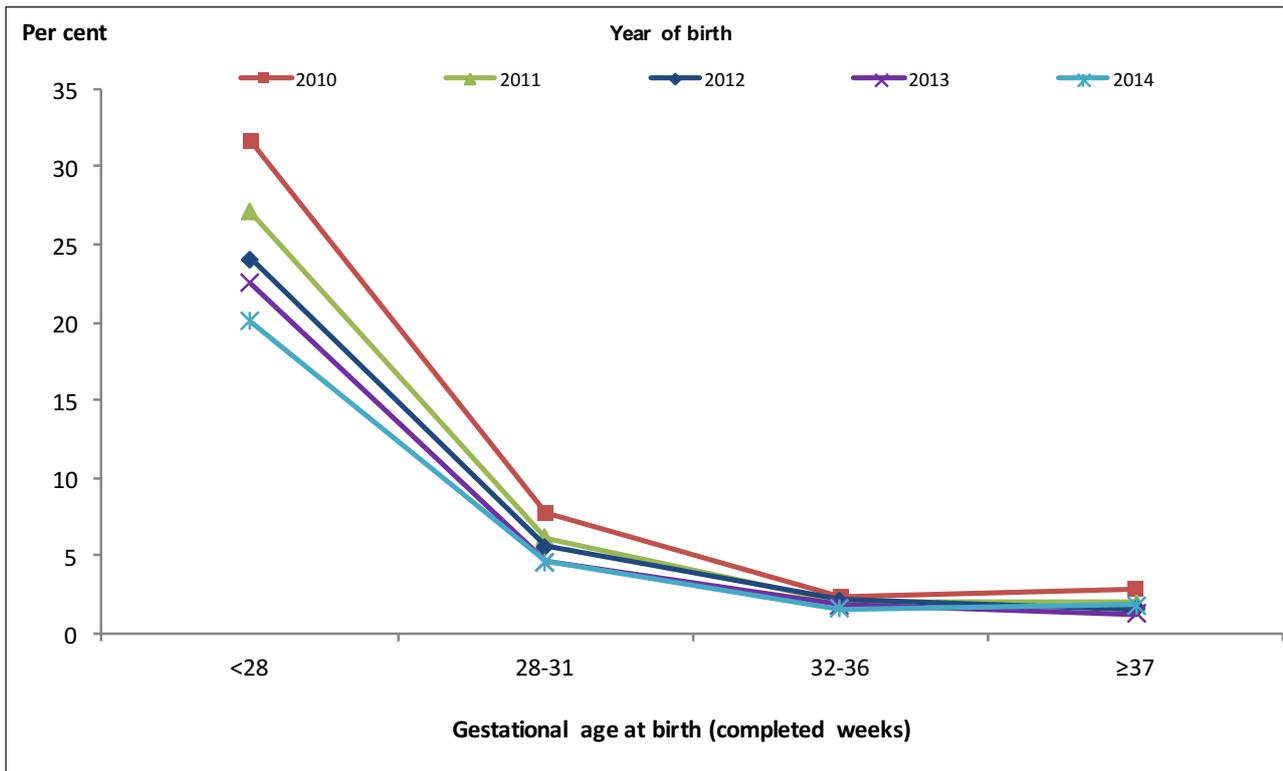


FIGURE 26: Incidence of late sepsis for level III registrants by gestational age group, 2010–2014



Appendix 2: Data tables by birthweight

TABLE 51: Antenatal corticosteroid use for level III registrants by birthweight group, 2014

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	31	52	75	110	287	532	833	1,028	799	n.p.	4,156
Incomplete course	7	112	184	175	241	469	235	89	32	9	7	1,560
Course completed	22	224	386	434	530	728	344	136	45	20	10	2,879
Completed > 7 days	<5	40	99	116	163	237	147	70	43	8	<5	928
Not stated	0	5	14	12	11	30	61	118	193	133	61	638
Total	33	412	735	812	1,055	1,751	1,319	1,246	1,341	969	488	10,161
Per cent												
None	n.p.	7.6	7.2	9.4	10.5	16.7	42.3	73.8	89.5	95.6	n.p.	43.6
Incomplete course	21.2	27.5	25.5	21.9	23.1	27.3	18.7	7.9	2.8	1.1	1.6	16.4
Course completed	66.7	55.0	53.5	54.3	50.8	42.3	27.3	12.1	3.9	2.4	2.3	30.2
Completed > 7 days	n.p.	9.8	13.7	14.5	15.6	13.8	11.7	6.2	3.7	1.0	n.p.	9.7
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 52: Plurality of level III registrants by birthweight group, 2014

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	26	307	561	585	711	1158	n.p.	1,123	1,313	n.p.	n.p.	8,231
Twins	n.p.	96	159	209	322	551	301	123	28	<5	<5	1,798
Triplets and higher orders	<5	9	15	18	22	42	n.p.	0	0	0	0	132
Total	33	412	735	812	1,055	1,751	1,319	1,246	1,341	969	488	10,161
Per cent												
Singleton	78.8	74.5	76.3	72.0	67.4	66.1	n.p.	90.1	97.9	n.p.	n.p.	81.0
Twins	n.p.	23.3	21.6	25.7	30.5	31.5	22.8	9.9	2.1	n.p.	n.p.	17.7
Triplets and higher orders	n.p.	2.2	2.0	2.2	2.1	2.4	n.p.	0.0	0.0	0.0	0.0	1.3
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.

Table 53: Method of birth for level III registrants by birthweight group, 2014

Method of birth	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
Number												
Vaginal	6	181	239	237	283	542	453	446	511	374	185	3,457
Vaginal instrumental birth	0	<5	15	13	30	76	76	115	190	157	n.p.	731
Caesarean in labour	<5	n.p.	157	151	188	389	260	258	275	218	118	2,072
Caesarean no labour	n.p.	170	323	409	552	732	520	409	352	209	n.p.	3,827
Not stated	0	1	1	2	2	12	10	18	13	11	4	74
Total	33	412	735	812	1,055	1,751	1,319	1,246	1,341	969	488	10,161
Per cent												
Vaginal	18.2	44.0	32.6	29.3	26.9	31.2	34.6	36.3	38.5	39.0	38.2	34.3
Vaginal instrumental birth	0.0	n.p.	2.0	1.6	2.8	4.4	5.8	9.4	14.3	16.4	n.p.	7.2
Caesarean in labour	n.p.	n.p.	21.4	18.6	17.9	22.4	19.9	21.0	20.7	22.8	24.4	20.5
Caesarean no labour	n.p.	41.4	44.0	50.5	52.4	42.1	39.7	33.3	26.5	21.8	n.p.	37.9
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 54: Method of birth for level III registrants by birthweight group, 2014

Level of birth hospital	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
Number												
Tertiary	n.p.	377	661	718	943	1,524	1053	906	918	632	n.p.	8,121
Non-tertiary	<5	29	67	87	105	219	260	326	406	326	n.p.	1,951
Not born in a hospital ^(a)	0	6	7	5	5	6	5	10	12	7	6	69
Not stated	0	0	0	2	2	2	1	4	5	4	0	20
Total	33	412	735	812	1,055	1,751	1,319	1,246	1,341	969	488	10,161
Per cent												
Tertiary	n.p.	91.5	89.9	88.6	89.6	87.1	79.9	72.9	68.7	65.5	n.p.	80.1
Non-tertiary	n.p.	7.0	9.1	10.7	10.0	12.5	19.7	26.2	30.4	33.8	n.p.	19.2
Not born in a hospital ^(a)	0.0	1.5	1.0	0.6	0.5	0.3	0.4	0.8	0.9	0.7	1.2	0.7
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.

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

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

Table 55: Mode of transport for level III registrants to level III unit after birth by birthweight group, 2014

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	30	374	652	706	926	1,489	1,015	856	849	601	357	7,855
Specialist retrieval team	<5	24	62	78	104	187	236	311	397	294	n.p.	1,798
Non-specialist team	<5	8	14	14	13	46	50	65	81	64	n.p.	376
Other	0	6	7	12	9	22	11	4	6	7	8	92
Not stated	0	0	0	2	3	7	7	10	8	3	0	40
Total	33	412	735	812	1,055	1,751	1,319	1,246	1,341	969	488	10,161
	Per cent											
Not transported	90.9	90.8	88.7	87.2	88.0	85.4	77.4	69.3	63.7	62.2	73.2	77.6
Specialist retrieval team	n.p.	5.8	8.4	9.6	9.9	10.7	18.0	25.2	29.8	30.4	n.p.	17.8
Non-specialist team	n.p.	1.9	1.9	1.7	1.2	2.6	3.8	5.3	6.1	6.6	n.p.	3.7
Other	0.0	1.5	1.0	1.5	0.9	1.3	0.8	0.3	0.5	0.7	1.6	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 56: Exogenous surfactant use by level III registrants by birthweight group, 2014

Exogenous surfactant	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	n.p.	199	418	703	1,252	1,046	1,069	1,183	861	450	7,223
Curosurf	27	321	436	293	265	370	188	125	102	72	32	2,231
Survanta	<5	47	92	88	n.p.	123	79	46	52	31	6	652
Curosurf and Survanta	0	0	<5	<5	0	<5	<5	<5	<5	<5	<5	16
Other or unknown surfactant	0	<5	n.p.	n.p.	<5	<5	<5	<5	<5	<5	0	18
Not stated	0	1	5	7	2	1	1	2	1	1	0	21
Total	33	412	735	812	1,055	1,751	1,319	1,246	1,341	969	488	10,161
	Per cent											
None	n.p.	n.p.	27.3	51.9	66.8	71.5	79.4	85.9	88.3	88.9	92.2	71.2
Curosurf	81.8	78.1	59.7	36.4	25.2	21.1	14.3	10.0	7.6	7.4	6.6	22.0
Survanta	n.p.	11.4	12.6	10.9	n.p.	7.0	6.0	3.7	3.9	3.2	1.2	6.4
Curosurf and Survanta	0.0	0.0	n.p.	n.p.	0.0	n.p.	n.p.	n.p.	n.p.	n.p.	0.0	0.2
Other or unknown surfactant	0.0	n.p.	0.0	0.2								
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

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

Table 57: Assisted ventilation for level III registrants by birthweight group, 2014

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	20	322	666	699	800	1,478	1,075	918	937	686	343	7,944
Invasive ventilation	33	384	546	385	331	517	435	485	535	367	131	4,149
• IPPV given	33	383	546	385	330	515	435	484	534	365	130	4,140
• HFOV given	23	186	130	62	26	26	37	50	57	39	16	652
NO given	7	58	45	33	18	25	30	59	96	71	37	479
Total in each birthweight group	33	412	735	812	1,055	1,751	1,319	1,246	1,341	969	488	10,161
Per cent												
CPAP given	60.6	78.2	90.6	86.1	75.8	84.4	81.5	73.7	69.9	70.8	70.3	78.2
IPPV given	100.0	93.0	74.3	47.4	31.3	29.4	33.0	38.8	39.8	37.7	26.6	40.7
Per cent of babies given invasive ventilation												
HFOV given	69.7	48.4	23.8	16.1	7.9	5.0	8.5	10.3	10.7	10.6	12.2	15.7
NO given	21.2	15.1	8.2	8.6	5.4	4.8	6.9	12.2	17.9	19.3	28.2	11.5

Note: Groups are not mutually exclusive.

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

Table 58: Medians and interquartile ranges of assisted ventilation for level III registrants by birthweight group, 2014

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	357	262	88	28	21	23	28.5	44	48	48	52.5	44
IQR	136-550	97-640	19-279	11-85	10-50	10-58	13-71	20-89	23-94	20-96	23-96	176-120
CPAP (hours)												
Median	889	952.5	673.5	166	79.5	38	24	21	16	15	14	38
IQR	260.5-1,321	538-1,266	230-1,076	54-558	28.5-191.5	15-89	11-59	9-51	7-40	7-34	7-30	13-127

Note: IQR = Interquartile range

TABLE 59: Chronic lung disease for level III registrants by birthweight group, 2014

Chronic lung disease (CLD)	Birthweight group (grams)							Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	≥2000	
	Number							
No CLD	19	165	409	658	976	1,708	5,355	9,290
CLD	14	247	326	154	79	43	8	871
Total	33	412	735	812	1,055	1,751	5,363	10,161
	Per cent							
No CLD	57.6	40.0	55.6	81.0	92.5	97.5	99.9	91.4
CLD	42.4	60.0	44.4	19.0	7.5	2.5	0.1	8.6

Table 60: Respiratory support (airway support or supplemental oxygen therapy) for level III registrants who survived to day 28 by birthweight group, 2014

Respiratory support (airway support or oxygen)	Birthweight group (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
	Number											
No respiratory support on day 28	0	10	88	406	807	1,585	1,220	1,141	1,254	905	472	7,888
Respiratory support on day 28	19	319	599	378	228	141	70	73	45	38	13	1,923
▪ survived to discharge home	n.p.	291	579	371	n.p.	135	62	64	n.p.	n.p.	13	1,830
▪ died before discharge	<5	28	20	7	<5	6	8	9	<5	<5	0	93
Not stated	0	2	0	0	0	1	0	0	0	0	0	3
Total in each birthweight group	19	331	687	784	1,035	1,727	1,290	1,214	1,299	943	485	9,814
	Number											
Respiratory support on day 28 and given home oxygen	<5	99	82	42	n.p.	19	14	15	n.p.	n.p.	<5	320
	Per cent											
No respiratory support on day 28	0.0	3.0	12.8	51.8	78.0	91.8	94.6	94.0	96.5	96.0	97.3	80.4
Respiratory support on day 28	100.0	97.0	87.2	48.2	22.0	8.2	5.4	6.0	3.5	4.0	2.7	19.6
▪ survived to discharge home	n.p.	91.2	96.7	98.1	n.p.	95.7	88.6	87.7	n.p.	n.p.	100.0	95.2
▪ died before discharge	n.p.	8.8	3.3	1.9	n.p.	4.3	11.4	12.3	n.p.	n.p.	0.0	4.8
	Per cent											
Respiratory support on day 28 and given home oxygen ^(a)	26.7	34.0	14.2	11.3	10.7	14.1	22.6	23.4	34.1	14.3	15.4	17.5

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

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

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

Table 61: Transfer after registration of level III registrants by level of destination hospital by birthweight group, 2014

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	26	235	341	347	386	681	690	803	931	715	383	5,538
Level III hospital	<5	38	68	50	46	59	50	48	n.p.	25	15	456
Level II hospital	5	107	285	401	603	974	540	346	291	182	75	3,809
Children's hospital	<5	32	41	13	20	37	39	49	n.p.	47	15	357
Not stated	0	0	0	1	0	0	0	0	0	0	0	1
Total	33	412	735	812	1,055	1,751	1,319	1,246	1,341	969	488	10,161
Per cent												
Not transferred	78.8	57.0	46.4	42.8	36.6	38.9	52.3	64.4	69.4	73.8	78.5	54.5
Level III hospital	n.p.	9.2	9.3	6.2	4.4	3.4	3.8	3.9	n.p.	2.6	3.1	4.5
Level II hospital	15.2	26.0	38.8	49.4	57.2	55.6	40.9	27.8	21.7	18.8	15.4	37.5
Children's hospital	n.p.	7.8	5.6	1.6	1.9	2.1	3.0	3.9	n.p.	4.9	3.1	3.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

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

Table 62: Retinopathy of prematurity for level III registrants by birthweight group, 2014

Retinopathy of prematurity (ROP)	Birthweight group (grams)						Total
	<500	500-749	750-999	1000-1249	1250-1499	≥1500	
Number							
No ROP	<5	87	341	522	n.p.	n.p.	2,061
Stage 1 ROP	<5	55	129	96	49	24	n.p.
Stage 2 ROP	6	n.p.	n.p.	57	14	18	327
Stage 3 ROP	5	72	49	20	<5	<5	150
Stage 4 ROP	0	<5	<5	0	0	0	<5
Not examined	17	94	79	113	372	5,248	5,923
Not stated	0	2	4	4	61	1,272	1,343
Total	33	412	735	812	1,055	7,114	10,161
Per cent							
No ROP	n.p.	27.5	52.3	75.1	n.p.	n.p.	71.2
Stage 1 ROP	n.p.	17.4	19.8	13.8	7.9	4.0	n.p.
Stage 2 ROP	37.5	n.p.	n.p.	8.2	2.3	3.0	11.3
Stage 3 ROP	31.3	22.8	7.5	2.9	n.p.	n.p.	5.2
Stage 4 ROP	0.0	n.p.	n.p.	0.0	0.0	0.0	n.p.
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

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

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

Table 63: Intraventricular haemorrhage for level III registrants survived to day 3 by birthweight group, 2014^(a)

Intraventricular haemorrhage	Birthweight group (grams)						Total
	<500	500-749	750-999	1000-1249	1250-1499	≥1500	
	Number						
None	17	250	543	607	738	2,052	4,207
Grade 1	6	44	71	82	81	114	398
Grade 2	<5	34	35	16	19	n.p.	127
Grade 3	0	12	14	13	6	12	57
Grade 4	<5	30	27	12	7	<5	81
Not examined	2	7	26	72	196	4,835	5,138
Total	29	377	716	802	1,047	7,037	10,008
	Per cent						
None	63.0	67.6	78.7	83.2	86.7	93.2	86.4
Grade 1	22.2	11.9	10.3	11.2	9.5	5.2	8.2
Grade 2	n.p.	9.2	5.1	2.2	2.2	n.p.	2.6
Grade 3	0.0	3.2	2.0	1.8	0.7	0.5	1.2
Grade 4	n.p.	8.1	3.9	1.6	0.8	n.p.	1.7
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.

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

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

Table 64: Neonatal sepsis for level III registrants by birthweight group, 2014

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	n.p.	290	614	761	1,007	1,697	1,285	1,219	1,309	943	n.p.	9,627
Sepsis at <48 hrs ^(a)	0	12	11	10	<5	13	8	<5	16	10	7	92
Sepsis at ≥48 hrs ^(a)	n.p.	114	112	42	n.p.	41	26	26	16	16	n.p.	449
Babies alive on day 2	n.p.	385	721	806	n.p.	1,743	1,313	1,237	1,324	955	n.p.	10,052
Babies who did not survive to day 2	<5	27	14	6	<5	8	6	9	17	14	<5	109
Total in each birthweight group	33	412	735	812	1,055	1,751	1,319	1,246	1,341	969	488	10,161
	Per cent											
No sepsis ^(b)	n.p.	70.4	83.5	93.7	95.5	96.9	97.4	97.8	97.6	97.3	n.p.	94.7
Sepsis at <48 hrs ^(b)	0.0	2.9	1.5	1.2	n.p.	0.7	0.6	n.p.	1.2	1.0	1.4	0.9
Sepsis at ≥48 hrs ^(c)	20.0	29.6	15.5	5.2	4.2	2.4	2.0	2.1	1.2	1.7	1.2	4.5

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 65: Median length of stay for level III registrants who survived until discharge home by birthweight group, 2014

Birthweight group (grams)	Number of babies	Median LOS (days)	Interquartile range (days)
<500	15	128	99–170
500-749	301	114	97–137
750-999	667	86	71–106
1,000-1,249	777	63	51–79
1,250-1,499	1,031	47	38–58
1,500-1,999	1,719	36	28–45
2,000-2,499	1,281	21	14–29
2,500-2,999	1,205	12	7–20
3,000-3,499	1,295	8	4–15
3,500-3,999	940	6	4–13
≥4,000	485	6	4–11
Total	9,716	27	10–51

Note: Death status was not provided for two babies.

Table 66: Survival to discharge home for level III registrants by birthweight group, 2014

Birthweight group (grams)	Number of babies	Lethal congenital anomalies	Babies alive on day 7	Babies alive on day 28	Survived to go home	Percent survival at discharge home
<500	33	0	25	19	15	45.5
500-749	412	5	360	331	301	73.1
750-999	735	7	704	687	667	90.7
1,000-1,249	812	7	794	784	777	95.7
1,250-1,499	1,055	9	1,043	1,035	1,031	97.7
1,500-1,999	1,751	18	1,736	1,727	1,719	98.2
2,000-2,499	1,319	17	1,301	1,290	1,281	97.1
2,500-2,999	1,246	20	1,230	1,214	1,205	96.7
3,000-3,499	1,341	25	1,306	1,299	1,295	96.6
3,500-3,999	969	<5	945	943	940	97.0
≥4,000	488	<5	485	485	485	99.4
Total	10,161	113	9,929	9,814	9,716	95.6

Note: Death status was not provided for two babies.

Appendix 3: Methods used in this report

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

The historical ANZNN data were received as a Microsoft Access database and archived as a Microsoft SQL Server database. Updated data for the ANZNN audit of babies born in 2014 who qualified as high-risk neonates were requested from each participating unit in June 2015 with a deadline of August 2015. 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 March 2016. 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:

Survival to day n	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.
Survival to 36 weeks post menstrual age	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.
Chronic lung disease (CLD)	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
Length of stay	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 2014 report were carried out using Microsoft SQL Server software, and tabulations and figures were produced using Microsoft Excel.

Appendix 4: Confidentiality guidelines

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

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

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

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

Principles of ownership and maintenance of data

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

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

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

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

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

Conditions for data collection

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

Conditions for data security

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

Small numbers

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

Appendix 5: Minimum Data Set variables

Neonatal Minimum Data Set

Registration hospital

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

Coding: Numeric code representing registration hospital

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

Maternal age

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

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

Previous preterm birth

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

Coding:

99: unknown.

0: no previous preterm birth.

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

Previous perinatal death

Definition: Mother has had a previous perinatal loss.

Coding:

99: unknown.

0: no previous perinatal death.

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

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

Assisted conception in this pregnancy

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

Coding:

0: unknown.

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

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

3: IVF / GIFT etc. – any method of in vitro fertilisation. Including in vitro fertilisation, gamete intra-fallopian transfer, zygote intra-fallopian 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 Indigenous Africans, Inuit, African Americans, Native Americans, 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.

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 two 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 compromise

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 for fetal compromise.

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_4) provided to the mother during the 6 hours immediately before birth, either because of maternal preeclampsia or specifically for fetal neuro-protection.

Coding:

- 1: MgSO₄ not given at all.
- 2: MgSO₄ course finished > 6 hours before birth (likely to be ineffective).
- 3: MgSO₄ given as intramuscular injection within 6 hours of birth.
- 4: MgSO₄ given for < 4 hours within 6 hour time slot (incomplete course).
- 5: MgSO₄ given by infusion over 4 hours or more within 6 hours of birth (complete course).
- 6: MgSO₄ given but details not known.
- 7: 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 the baby was admitted to the tertiary hospital responsible for documentation 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 in an infant requiring respiratory support (combines previous items transient tachypnoea of newborn and immature lung).
- 3: hyaline membrane disease – increasing respiratory distress or oxygen (O₂) 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 – respiratory distress 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 – respiratory distress with proven or suspected infection (toxic blood count), and chest x-ray showing persisting opacities.
- 6: persistent pulmonary hypertension – echocardiatic (shunting) or clinical evidence – O₂ need unexplained by chest x-ray or loud P₂, or differential pre /post ductal TCPO₂.
- 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 respiratory distress, e.g. diaphragmatic hernia (list malformation in appropriate field).
- 10: other – unspecified other respiratory distress.
- 11: peri surgical – no respiratory distress, 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: other – use of other surfactant.
- 6: Curosurf – any treatment using ‘Curosurf’.
- 7: 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 (O₂), 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.

Minimum nasal high flow

Definition: Minimum flow rate (greater than 1L/min) with air and oxygen mix delivered through a high flow device during the entire treatment period.

Coding: Number correct to one decimal place.

Guide for use: Device specifically designed to deliver high intranasal flow which has been shown to be associated with some air pressure.

Maximum nasal high flow

Definition: Maximum flow rate (in L/min) with air and oxygen mix delivered through a high flow device during the entire treatment period.

Coding: Number correct to one decimal place.

Guide for use: Device specifically designed to deliver high intranasal flow which has been shown to be associated with some air pressure.

Chronic lung disease (CLD)

Definition: The baby received respiratory support (supplemental O₂ or any form of assisted ventilation) for a chronic pulmonary disorder at 36 weeks post menstrual age.

Coding:

99: unknown.

0: no chronic lung disease.

-1: yes, chronic lung disease.

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

Post-natal steroids for chronic lung disease

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

Coding:

99: unknown.

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

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

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

Home oxygen therapy

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

Coding:

99: unknown.

0: no supplemental oxygen used at home.

-1: yes, home oxygen therapy given.

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

Neonatal surgery

Definition: This baby had surgery which involved opening a body cavity during this admission.

Coding:

99: unknown.

0: no major neonatal surgery.

-1: yes, major surgery took place during this admission.

Parenteral nutrition

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

Coding:

99: unknown.

0: parenteral nutrition never initiated.

-1: yes, parenteral nutrition initiated.

Home gavage feeding

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

Coding:

99: unknown.

0: no, not discharged with gavage tube.

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

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

Proven necrotising enterocolitis (NEC)

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

Coding:

99: unknown.

0: no necrotising enterocolitis proven.

-1: yes, necrotising enterocolitis proven.

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

1. At least one systemic sign: temperature instability, apnoea, bradycardia or lethargy; and one intestinal sign: a residual of more than 25% of the previous feed on 2 consecutive occasions, abdominal distension, vomiting or faecal blood.

2. Has profile consistent with definite NEC including at least one of the following: abdominal wall cellulitis and palpable abdominal mass, or pneumatosis intestinalis, or portal vein gas, or a persistent dilated loop on serial x-rays, or a surgical or post mortem diagnosis.
3. Plus the baby warranted treatment for NEC, which included nil by mouth and antibiotics.

Spontaneous intestinal perforation (SIP)

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

Coding:

99: unknown.

0: no, the baby did not have spontaneous intestinal perforation.

-1: yes, the baby did have spontaneous intestinal perforation.

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

Therapeutic hypothermia

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

Coding:

99: unknown.

0: no.

-1: yes.

Guide for use: Record if therapeutic hypothermia has occurred.

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

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

Coding:

0: not ceased before 72 hours

1: palliation.

2: recognised as not fulfilling standard criteria for cooling.

3: fulfilled standard criteria for cooling but clinical improvement suggests no need.

4: qualification equivocal with change of clinical decision making.

5: severe coagulopathy not responding to blood products.

6: hypotension not responding to inotrope.

7: severe PPHN refractory to iNO.

8: arrhythmia.

9: reason for early cessation not known.

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

Bacterial, fungal or viral infection present

Definition: The presence of proven systemic bacterial or fungal sepsis or late onset nosocomial viral infection for this baby.

Coding:

99: unknown.

0: no, the baby did not have a proven bacterial, fungal or viral infection noted.

-1: yes, the baby did have a proven bacterial, fungal or viral infection noted.

Guide for use: Systemic sepsis is defined as a clinical picture consistent with sepsis, and either a positive bacterial or fungal culture of blood and/or cerebrospinal fluid. For each episode of sepsis, the following conditions must apply:

- Isolation of an organism from at least one blood or CSF culture or identification via polymerase chain reaction in CSF and,
- After consideration of clinical and laboratory evidence, a decision is made to give the patient antibiotics with therapeutic intent against this organism.

For each episode of infection, the following conditions must not apply:

- Mixed coagulase negative staphylococcus or other skin flora contaminant episode.

Viral infection should only be considered if initial symptoms occurred after 48 hours of birth.

- Clinical features consistent with viral infection
- Isolation or identification of an organism by PCR, immunofluorescence or similar technology from an appropriate body fluid eg mouth swab/saliva, rectal swab/faeces, nasopharyngeal aspirate, endotracheal aspirate, CSF, or other relevant tissues eg skin lesion
- Asymptomatic colonisation with rotavirus should be excluded.

Type of infection

Definition: The type of the proven systemic bacterial or fungal infection or nosocomial viral infection present.

Coding:

-1: early infection (bacterial or fungal infection) – the presence of systemic bacterial or fungal sepsis with initial symptoms occurring prior to 48 hours after birth.

0: late infection (bacterial or fungal infection) – the presence of blood or CSF infection with initial symptoms occurring from 48 hours after birth.

2: viral infection – the presence of at least one episode of viral infection with initial symptoms occurring following 48 hours after birth.

Guide for use: As for Bacterial, fungal or viral infection present. The same organism isolated from blood or CSF during previous 14 days-repeat isolate should not be included.

Date of collection of positive blood or CSF culture for systemic sepsis or date of onset of nosocomial viral infection occurring after 48 hours of birth

Definition: The date of the collection of blood or CSF culture for each episode of systemic sepsis, or the date of the onset of clinical illness caused by each episode of viral infection, with initial symptoms occurring after 48 hours of birth.

Coding: DD / MM / YYYY

Guide for use: Must be coded as “yes” for ‘Bacterial, fungal or viral infection present’. The same organism isolated from blood or CSF during previous 14 days-repeat isolate should not be included. Leave blank when corresponding ‘Type of infection’ is coded as “Early infection”.

Maximum grade of left sided periventricular haemorrhage

Definition: Worst level of periventricular haemorrhage seen on the left side of the head by imaging or post mortem examination during the first 14 days of life.

Coding:

- 0: none – ultrasound / post mortem shows no haemorrhage.
- 1: grade 1 – subependymal germinal matrix haemorrhage.
- 2: grade 2 – intraventricular haemorrhage.
- 3: grade 3 – intraventricular haemorrhage with ventricle distended with blood.
- 4: grade 4 – localised intraparenchymal haemorrhage.
- 5: grade 4 – extensive intraparenchymal haemorrhage.
- 9: not examined- by ultrasound or by post mortem examination.

Guide for use: Early ventricular dilatation may occur with or without haemorrhages. Mild ventricular dilatation without intraventricular blood distension is excluded (not grade 3). Localised intraparenchymal haemorrhage/haemorrhagic infarction is defined as being solitary and mainly confined to one of the following territories: anterior frontal, posterior frontal, parietal, occipital, temporal, thalamus. Extensive intraparenchymal haemorrhage/haemorrhagic infarction is defined as involving two or more of the territories. Note: exclude echodensity which resolves within 10 days.

Maximum grade of right sided periventricular haemorrhage

Definition: Worst level of periventricular haemorrhage seen on the right side of the head by imaging or post mortem examination during the first 14 days of life.

Coding:

- 0: none – ultrasound / post mortem shows no haemorrhage.
- 1: grade 1 – subependymal germinal matrix haemorrhage.
- 2: grade 2 – intraventricular haemorrhage.
- 3: grade 3 – intraventricular haemorrhage with ventricle distended with blood.
- 4: grade 4 – localised intraparenchymal haemorrhage.
- 5: grade 4 – extensive intraparenchymal haemorrhage.
- 9: not examined- by ultrasound or by post mortem examination.

Guide for use: As for Maximum grade of left sided periventricular haemorrhage.

Cerebellar haemorrhage

Definition: Most extensive cerebellar haemorrhage noted by imaging or post mortem examination during the first 14 days of life.

Coding:

- 0: no cerebellar haemorrhage – mastoid ultrasound views undertaken and no cerebellar haemorrhage / post mortem shows no cerebellar haemorrhage.
- 1: left hemisphere haemorrhage only.
- 2: right hemisphere haemorrhage only.
- 3: haemorrhage in vermis only.
- 4: bilateral hemisphere haemorrhage.
- 5: haemorrhage in either or both hemispheres AND vermis.
- 9: not examined- by ultrasound or by post mortem examination.

Guide for use: Mastoid view is required for this detection.

Date of late head ultrasound

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

Coding: DD / MM / YYYY

Guide for use: Data is confined to ultrasounds performed between four and eight weeks of age. Accept finding if transferred to Level II units between three and four weeks of age.

Ventricle size

Definition: Ventricular size measured by the ultrasound scan closest to six weeks (four to eight weeks) of age, as the largest measurement from either ventricle.

Coding: 4-digit number correct to one decimal place.

Guide for use: Record if the measurement for the largest ventricle. The lateral ventricle measurement is taken at the mid body in the coronal view at the foramen of Munroe.

Cerebral cysts (left)

Definition: Cystic change in left cerebral hemisphere measured by the ultrasound scan closest to six weeks of age. Record worst cystic periventricular leukomalacia severity (extensive or localised) if more cystic changes seen in four to eight week scans.

Coding:

- 0: no cysts – no cystic lesions seen on ultrasound.
- 1: porencephalic cyst(s).
- 2: periventricular leukomalacia primarily confined to one of the regions: anterior frontal, posterior frontal, parietal, temporal or occipital region (same as defined for periventricular haemorrhage).
- 3: extensive leukomalacia involving two or more of the above regions.
- 4: unknown – information not available, includes not scanned.

Guide for use: Ependymal cysts, cysts of the choroid plexus and conatal cysts are considered normal variants and are excluded. If any of these are present score as no cysts.

Cerebral cysts (right)

Definition: Cystic change in right cerebral hemisphere measured by the ultrasound scan closest to six weeks of age. Record worst cystic periventricular leukomalacia severity (extensive or localised) if more cystic changes seen in four to eight week scans.

Coding:

- 0: no cysts – no cystic lesions seen on ultrasound.
- 1: porencephalic cyst(s).
- 2: periventricular leukomalacia primarily confined to one of the regions: anterior frontal, posterior frontal, parietal, temporal or occipital region (same as defined for periventricular haemorrhage).
- 3: extensive leukomalacia involving two or more of the above regions.
- 4: unknown – information not available, includes not scanned.

Guide for use: As for Cerebral cysts (left)

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 +/- 3 days. If dates are uncertain an ultrasound performed prior to 20 weeks has an accuracy of +/- 2 weeks.

Date assessed

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

Coding: DD / MM / YYYY

Outcome for children at two to three years

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

Coding:

99: unknown.

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

-1: yes, survived to the two to three year follow-up.

Outcome for follow-up at two to three years

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

Coding:

1: formal developmental assessment (e.g. Bayley III or Griffiths).

2: information obtained but formal assessment not done.

3: child is unable to be assessed due to severe developmental delay.

4: child is unable to be assessed due to behavioural disorder.

5: child is unable to be assessed due to non-compliance.

6: lost- the child is lost to follow-up.

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

Weight

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

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

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

Type of Stature Measurement

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

Coding:

- 99: unknown.
- 1: standing height.
- 2: recumbent length.

Stature

Definition: The stature of a child measured in centimetres.

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

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

Head Circumference

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

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

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

Hearing Aid

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

Coding:

- 99: unknown.
- 0: no hearing aid prescribed.
- 1: unilateral hearing aid prescribed.
- 2: bilateral hearing aid prescribed.

Cochlear Implant

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

Coding:

- 99: unknown.
- 0: no cochlear implant.
- 1: yes, cochlear implant.

Blind

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

Coding:

- 99: unknown.
- 0: no blindness.
- 1: yes, blindness (<6/60 in better eye).

Respiratory support

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

Coding:

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

Gastrointestinal feeding

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

Coding:

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

Cerebral Palsy

Definition: Cerebral palsy diagnosed.

Coding:

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

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

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

Coding:

- 1: Level I – Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.
- 2: Level II – Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

- 3: Level III – Children maintain floor sitting often by “W-sitting” (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.
- 4: Level IV – Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.
- 5: Level V – Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

Bayley scales of infant and toddler development – third edition

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

Coding:

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

Cognitive composite score

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

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

Receptive communication scaled score

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

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

Expressive communication scaled score

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

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

Language composite score

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

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

Fine motor scaled score

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

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

Gross motor scaled score

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

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

Motor composite score

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

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

Griffiths Mental Development Scales (GMDS)

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

Coding:

99: unknown.

0: no GMDS assessment performed.

-1: yes, GMDS assessment performed.

Locomotor subscale quotient

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

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

Personal/social subscale quotient

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

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

Language subscale quotient

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

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

Eye and hand co-ordination subscale quotient

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

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

Performance subscale quotient

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

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

Practical reasoning subscale quotient

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

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

General quotient

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

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

Other developmental tests administered

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

Coding:

99: unknown.

0: no other developmental tests administered.

-1: yes, other developmental tests administered.

Date of test

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

Coding: DD / MM / YYYY

Name of test administered

Definition: The name of the other development tests administered.

Coding: Free text field representing developmental test name.

Subscales of other developmental tests

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

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

Score of other developmental tests

Definition: Score of other developmental tests administered.

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

Level of development (months)

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

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

Glossary

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

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

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

Bayley Scales of Infant and Toddler

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

Birth status: status of the baby immediately after birth.

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

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

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

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

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

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

Extremely preterm birth: birth before 28 weeks of gestation

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

Forceps: assisted birth using a metallic obstetric instrument.

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

from clinical assessment during pregnancy or from examination of the baby after birth.

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

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

Hyaline membrane disease: a disorder of the respiratory system.

Instrumental delivery: vaginal delivery using forceps or vacuum extraction.

Intrapartum fetal death: fetal death occurring during labour.

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

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

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

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

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

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

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

Level II refers to a nursery that generally has babies born at 32–36 weeks gestation weighing around 1,500 to 2,500 grams at birth. It includes care for babies who require intravenous therapy or antibiotics, and/or those who are convalescing after intensive care, and/or those who need their heart rate or breathing monitored, and/or those who need short-term oxygen therapy.

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

Neonatal death: death of a liveborn baby within 28 days of birth.

Neonatal morbidity: any condition or disease of the baby diagnosed after birth and before separation from care.

Perinatal death: a fetal or neonatal death of at least 20 weeks gestation or at least 400 grams birthweight.

Plurality: the number of births resulting from a pregnancy.

Post menstrual age (completed weeks) is calculated by taking the gestational age plus postnatal age – e.g. when a baby born at 25 weeks gestation is 15 weeks old, they are 40 weeks PMA (also known as term equivalent age).

Post neonatal death: death of a liveborn baby after 28 days and within one year of birth.

Post term birth: birth at 42 or more weeks of gestation.

Presentation at birth: presenting part of the fetus at birth.

Preterm birth: birth before 37 weeks of gestation.

Resuscitation of baby: active measures taken shortly after birth to assist the baby's ventilation and heartbeat, or to treat depressed respiratory effort and to correct metabolic disturbances.

Retinopathy of prematurity (ROP): a disorder of the developing eye.

Sex ratio: number of male liveborn babies per 100 female liveborn babies.

Spontaneous vaginal: birth without intervention in which the baby's head is the presenting part.

Stillbirth: see Fetal death (stillbirth).

Teenage mother: mother aged less than 20 years at the birth of her baby.

Vacuum extraction: assisted birth using a suction cap applied to the baby's head.

Vaginal breech: vaginal birth in which the baby's buttocks is the presenting part.

Very low birthweight: birthweight of less than 1,500 grams.

Very preterm birth: birth before 32 weeks of gestation.

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