

2016

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



UNSW
SYDNEY

ANZNN

2016

REPORT OF THE AUSTRALIAN AND NEW ZEALAND NEONATAL NETWORK

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

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Acknowledgements

This is the twenty-first report of the Australian and New Zealand Neonatal Network (ANZNN), the ninth report in the new format and the fifth 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 fourteen 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 Committee: Kei Lui (Chairperson), Ross Haslam (Immediate Past Chairperson), Chad Andersen, Barbara Bajuk, Malcolm Battin, Georgina Chambers, Lucy Cooke, Koert de Waal, Fiona Dineen, Andy Gill, Jim Holberton, Christine Jorgensen, Natalie Merida, Jane Pillow, Victor Samuel Rajadurai, and Jutta van den Boom as well as immediate past member Roland Broadbent for their commitment and guidance for all the activities of the ANZNN. Particular thanks to the ANZNN Data Collection Operation Committee, namely Jim Holberton (Chairperson), Georgina Chambers, Liza Edmonds, Andy Gill, Jim Holberton, Timothy Hong, Rod Hunt, Caroline Karskens, Kei Lui, Peter Marshall, Karen Nothdurft and Victor Samuel Rajadurai. The Follow-up Subcommittee of Liza Edmonds (Chairperson), Peter Anderson, Kei Lui, Lex Doyle, Vanessa Ellison, Elizabeth Hurrion, Mary Sharp, Rachel Taufer and Crista Wocadlo were instrumental in advising the data collection and analysis for the 2-3-year follow-up chapter. We would also like to acknowledge Vinosan Kander and Evelyn Karantonis for running the data validation queries for the neonatal data and populating the tables and figures for this report.

We thank Emerge Health (Australia) and Douglas Pharmaceuticals (New Zealand) for their ongoing support and for helping us to achieve our aims. We acknowledge our colleagues from the National Perinatal Epidemiology and Statistics Unit and the Centre for Big Data Research in Health 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 2016.
- Chapter 2:** ‘Babies registered to level III units’ provides information and characteristics on the ANZNN registrants in 2016 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 2016.
- Chapter 4:** ‘Characteristics of level III registrants’ provides information about the babies admitted to a level III neonatal unit during 2016.
- Chapter 5:** ‘Babies registered to level II units’ provides information about babies registered to the level II special care baby units during 2016.
- Chapter 6:** ‘Extremely preterm follow-up, 2010–2013 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 2010 to 2013.
- Appendices:**
- Appendix 1 presents 10-year trends
 - Appendix 2 presents data tables by birthweight for 2016
 - 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	in vitro fertilisation
ANZNN	Australian and New Zealand Neonatal Network	IVH	intraventricular haemorrhage
APH	ante partum 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 airway 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 cannula	PVL	periventricular leukomalacia
HFOV	high frequency oscillatory ventilation	RDS	respiratory distress syndrome
HMD	hyaline membrane disease	ROM	rupture of membranes
ICD-10-AM	The International Statistics Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification	ROP	retinopathy of prematurity
IPPV	intermittent positive pressure ventilation	SD	standard deviation
IQR	interquartile range	TPN	total parenteral nutrition
IUGR	intrauterine growth restriction	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, Christine Jorgensen

John Hunter Hospital

(NICU & special care beds: 42)

Paul Craven (Director), Koert de Waal, Javeed Travadi, Rebecca Glover, Lynne Cruden, Larissa Korostenski, Susanne Wooderson, Alissa Argomand

Liverpool Health Service

(NICU & special care beds: 31)

Jacqueline Stack (Director), Ian Callander, Kathryn Medlin, Amanda Beasley

Nepean Hospital

(NICU & special care beds: 37)

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

Royal Hospital for Women

(NICU & special care beds: 44)

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

Royal North Shore Hospital

(NICU & special care beds: 26)

Mary Paradisis (Director), Jennifer Bowen, Martin Kluckow, Amy Sparks, Lyn Barnes

RPA Women and Babies

(NICU & special care beds: 34)

Ingrid Rieger (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)

Alice Stewart (Director), Charles Barfield, Elizabeth Carse, 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), 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 Hospital

(NICU & special care beds: 28)
Peter Schmidt (Director), Timothy Hong,
John Hyland

Mater Mothers' Hospital

(NICU & special care beds: 79)
Pita Birch (Director), Lucy Cooke, Peter Gray,
Elizabeth Hurriion, Karen Nothdurft, Leith
Poulsen

Royal Brisbane and Women's Hospital

(NICU & special care beds: 71)
Pieter Koorts (Director), David Cartwright,
Anja Lipponer

The Townsville Hospital

(NICU & special care beds: 44)
Guan Koh (Director), Gary Alcock,
Jenny Binney, Louise McIldowie

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, Cindy Golding, Ros Lontis

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, Steven Resnick,
Mary Sharp, Corrado Minutillo, Shripada Rao,
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, Rachael Alford,
Connie Yii

Newborn emergency transport services

NETS NSW (Newborn & Paediatric Emergency Transport Service)

Andrew Berry (Director)

Newborn Emergency Transport Service (Victoria)

Michael Stewart (Director)

Western Australia Neonatal Transport Service

Jonathan Davis (Director)

New Zealand

Christchurch Women's Hospital

(NICU & special care beds: 41)
Adrienne Lynn (Director), Nicola Austin, Brian
Darlow (Professor of Paediatrics), Trish Graham

Dunedin Hospital

(NICU & special care beds: 16)
Liza Edmonds (Director), Roland Broadbent,
Carole Chettleburgh, Frances McCaffrey

Middlemore Hospital

(NICU & special care beds: 38)
Lindsay Mildenhall (Director), Maisie Wong,
David Hou

National Women's Health (at Auckland City Hospital)

(NICU & special care beds: 46)
Mariam Buksh (Director), Malcolm Battin,
David Knight, Coila Bevan, Sabine Huth

Waikato Hospital

(NICU & special care beds: 41)
David Bouchier (Director), Phil Weston,
Deborah Harris, Arun Nair, Claire West

Wellington Regional Hospital

(NICU & special care beds: 40)
Vaughan Richardson (Director), Keith Fisher,
Helen Miller, Michael Hewson, Harshad Patel,
Bronwyn Cook, Jackie Chin-Poy

Singapore*

KK Women's and Children's Hospital*

(NICU & special care beds: 32)
Victor Samuel Rajadurai (Director),
Kee Thai Yeo, Rowena Dela Puerta

*data not included in this report

Level II nurseries:

Australia

New South Wales

Blacktown Hospital

(Special care beds: 24)

Anjali Dhawan (Director), Therese Freeman,
Jessica Lagos

Campbelltown Hospital

(Special care beds: 15)

Raymond Chin (Director), Lauren Rodgers,
Catherine Allgood, Fiona Kite

Gosford District Hospital

(Special care beds: 25)

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

St George Hospital

(Special care beds: 8)

Bob Fonseca (Director), Anne Hurst, Beverley
Lewis

The Maitland Hospital

(Special care beds: 8)

David Rogers (Director), Jessica Crombie

Wagga Wagga Rural Referral Hospital

(Special care beds: 7)

John Preddy (Director), Dianne Webb

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 Hospital

(Special care beds: 22)

Neil Archer (Director), Sue McMahon

Logan Hospital

(Special care beds: 16)

Jan Cullen (Director), Pamela McErlean

Mackay Base Hospital

(Special care beds: 8)

Jacinta Tobin (Director), Kerry Topping

Nambour General Hospital

(Special care beds: 10)

Lizelle Weber (Director), Tom Hurley,
Tonya Gibbs

Redland Hospital

(Special care beds: 8)

Dougie Thomas (Director), Greg Pallas,
Pamela McErlean

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)

Shaun Grant (Director), Heinrich Stander,
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)

Sarah Mills (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, Misty Curry

Rotorua Hospital

(Special care beds: 10)

Stephen Bradley (Director), Jacquie Koberstein,
Gaye France, Leanne Turvey

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 Boccock

Tauranga Hospital

(Special care beds: 10)

Hugh Lees (Director), Heather McAlley,
Anna Hayns

Timaru Hospital

(Special care beds: 3)

Mick Goodwin (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)

John Malcolm (Director), Chris Moyes,
Margret Norris, Lee Willetts, Katherine Dumauual

Whangarei Area Hospital

(Special care beds: 8)

David Barker (Director), Ransford Addo, Janine
Whale, Merophy Brown, Wendy Hines, Ellen
Parker

Waitakere Hospital

(Special care beds: 12)

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

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

Georgina Chambers (Director), Sharon Chow,
Prudence Creighton, Vinosan Kander,
Evelyn Karantonis

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 and an NICU in Singapore joined in 2016, bringing the total of NICU members to 30. For the purposes of this report, data submitted by the Singaporean NICU member has not been included.

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 fourteen units contributing data in 2016.

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 the ANZNN and UNSW.

The governance structure of the ANZNN (Figure 1) consists of the Advisory Council, the Executive 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 the NPESU, who is the data custodian for the ANZNN, is also a member of the Advisory Council. The purpose of the Advisory Council is to monitor the progress of the 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.

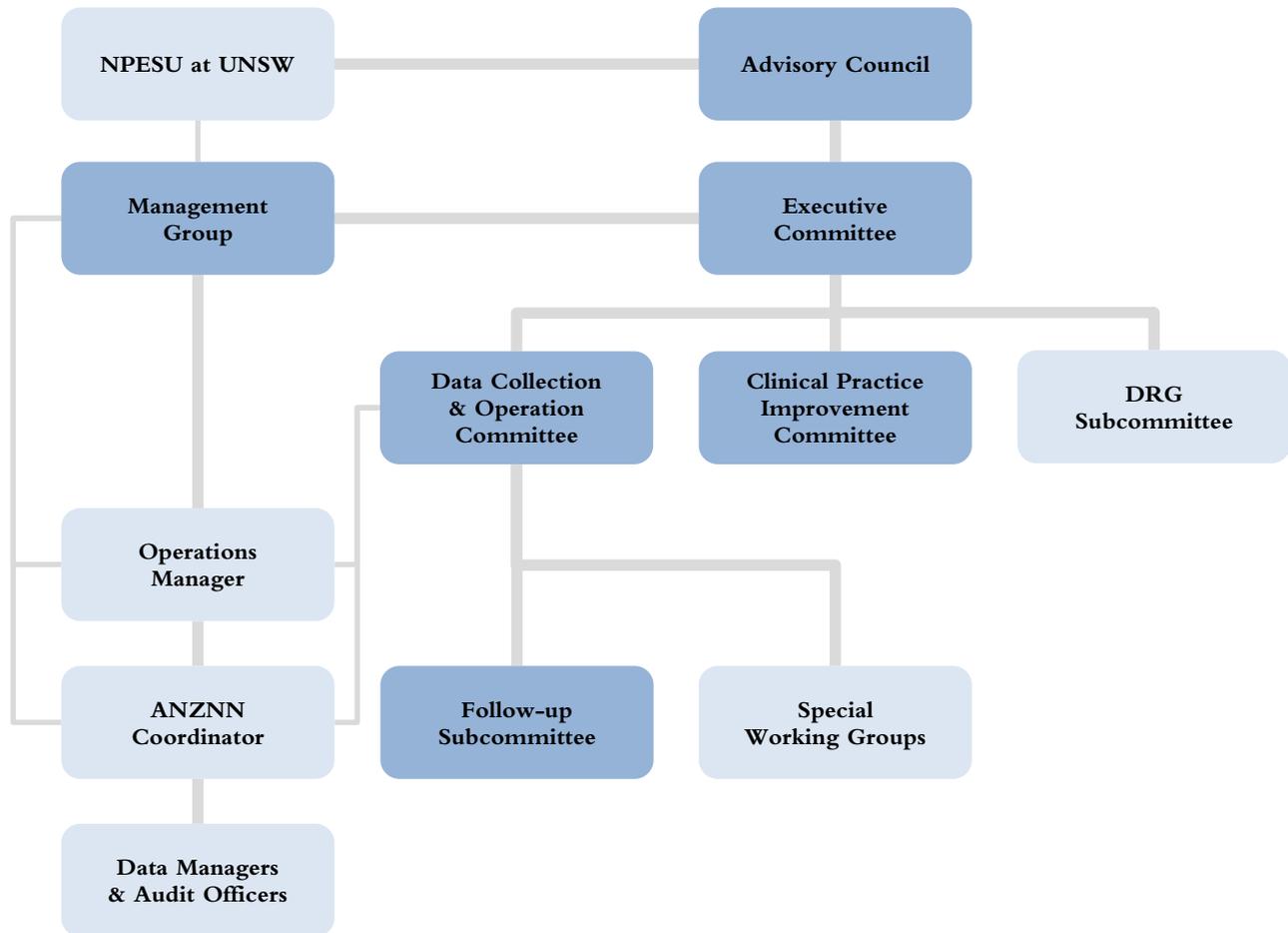
The Executive Committee is an elected committee that has regional representation from directors, a data manager group representative and neonatal nurse representatives from across the network. It is concerned with the general functioning of the network, finance and decision-making, as reported by the 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 the 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 airway 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) and Douglas Pharmaceuticals (New Zealand) make an annual contribution and the ANZNN thanks them for their generosity and support.

Data set variables

The variables used for the 2016 audit are listed in Appendix 5 and are also available on the website <<http://www.anznn.net>>.

2016

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Babies born in Australia

There were 8,610 babies registered to the ANZNN from 23 level III NICUs in Australia, representing 2.8% of notified live births in 2016 (Australian Bureau of Statistics 2016). Of these registrants, 77.7% were born in a hospital with tertiary care facilities. There were 3,025 babies born before 32 weeks gestation representing 35.1% of Australian registrants.

Maternal ethnicity was provided for 93.6% of mothers: 72.1% of the mothers of these babies identified as Caucasian and 15.7% as Asian. Over one in fourteen mothers (7.2%) identified as Aboriginal or Torres Strait Islander, which was more than the proportion reported in all births in Australia in 2016 (4.2%) (Australian Bureau of Statistics 2016).

Among Australian NICU admissions registered to the ANZNN, 1,641 were from multiple births representing 19.1% of ANZNN admissions in Australia in 2016.

Male babies were over-represented among NICU admissions – 57.8% of the Australian ANZNN registrants, compared with 51.3% among live births in Australia (Australian Bureau of Statistics 2016).

Assisted ventilation was provided for 7,930 babies (2.5% of live births) and continuous positive airway pressure (CPAP) was the only form of respiratory assistance for 4,492 babies.

Babies born in New Zealand

There were 1,863 babies who met ANZNN registration criteria from six level III NICUs in New Zealand representing 3.1% of the 59,430 live births registered in New Zealand in 2016 (Statistics New Zealand 2016). Of these registrants, 87.4% were born in a hospital with tertiary care facilities. There were 585 babies born before 32 weeks gestation representing 31.4% of New Zealand registrants.

Maternal ethnicity was reported for 99.1% of the New Zealand registrants. The percentage of Caucasian mothers was 51.3%. A higher proportion of mothers identified themselves as Maori (20.2%) compared to 11.2% of mothers identified as Pacific Islander and 14.7% as Asian.

Among New Zealand NICU admissions registered to the ANZNN, 273 were from multiple births representing 14.7% of ANZNN admissions in New Zealand in 2016.

Male babies were also over-represented among NICU admissions in New Zealand – 59.5% of the New Zealand registrants compared to 51.4% of total live births in New Zealand (Statistics New Zealand 2016).

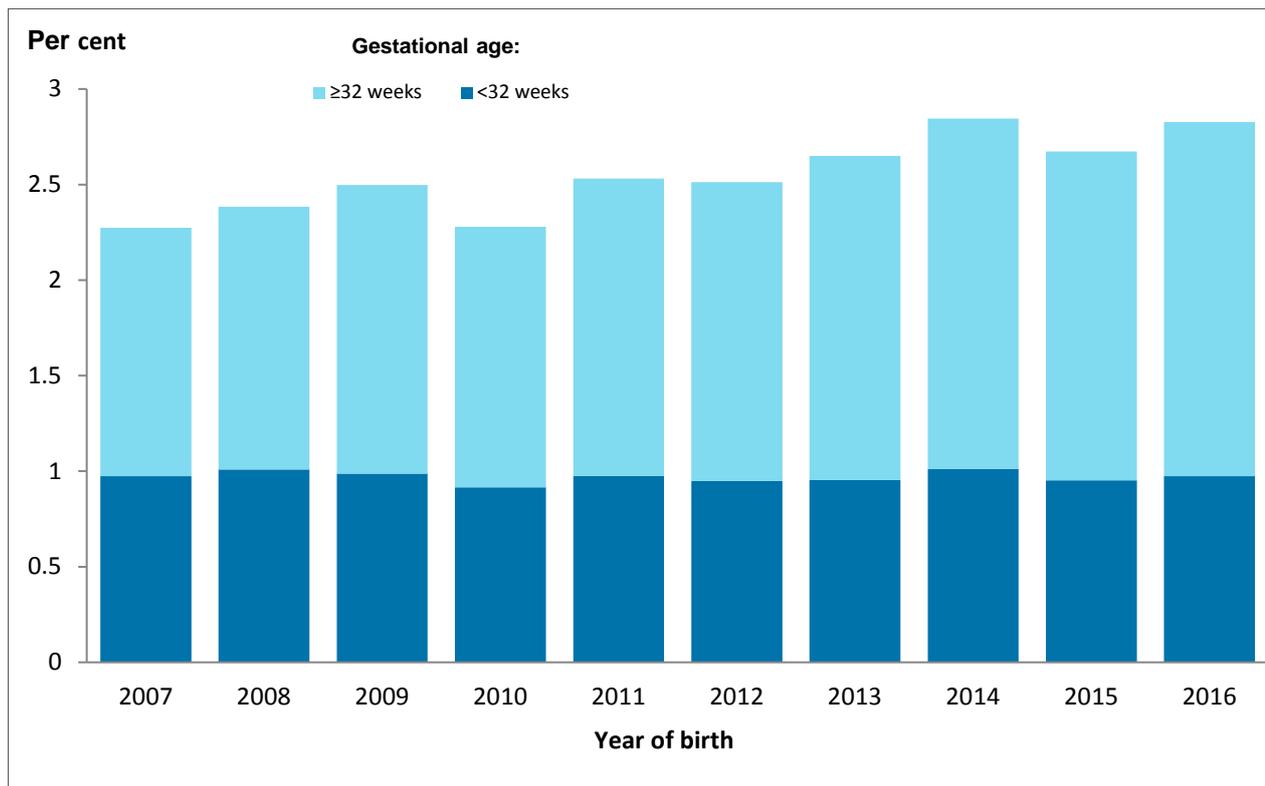
Assisted ventilation was given to 1,580 babies representing 2.7% of all live births with 1,008 babies receiving CPAP as the only form of respiratory assistance (1.7% of all live births).

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 2016, 10,473 fulfilled the registration criteria for inclusion in the ANZNN audit. The population represents 2.8% of the 370,534 live births in the two countries in 2016 (Australian Bureau of Statistics 2016; Statistics New Zealand 2016) (Figure 2) illustrating an increase of 801 registrants from 2015 (2.6% 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 2007–2016



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

There were 3,610 (34.5%) babies born before 32 weeks gestation and 6,863 babies born at 32 weeks or more (65.5%). Of the registrants born before 32 weeks gestation 92.9% received assisted ventilation. The major indication for assisted ventilation in this age group was hyaline membrane disease.

The largest level III NICU in Australia and New Zealand registered just over 1,000 babies in 2016, the smallest just under 50 (Figure 3). The median number of babies registered to an ANZNN unit was 320.

The gestational age group at birth and birthweight for babies qualifying for inclusion in the ANZNN 2016 level III audit is set out in Tables 1 and 2 respectively. The 10-year trend (2007–2016) 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, 2016

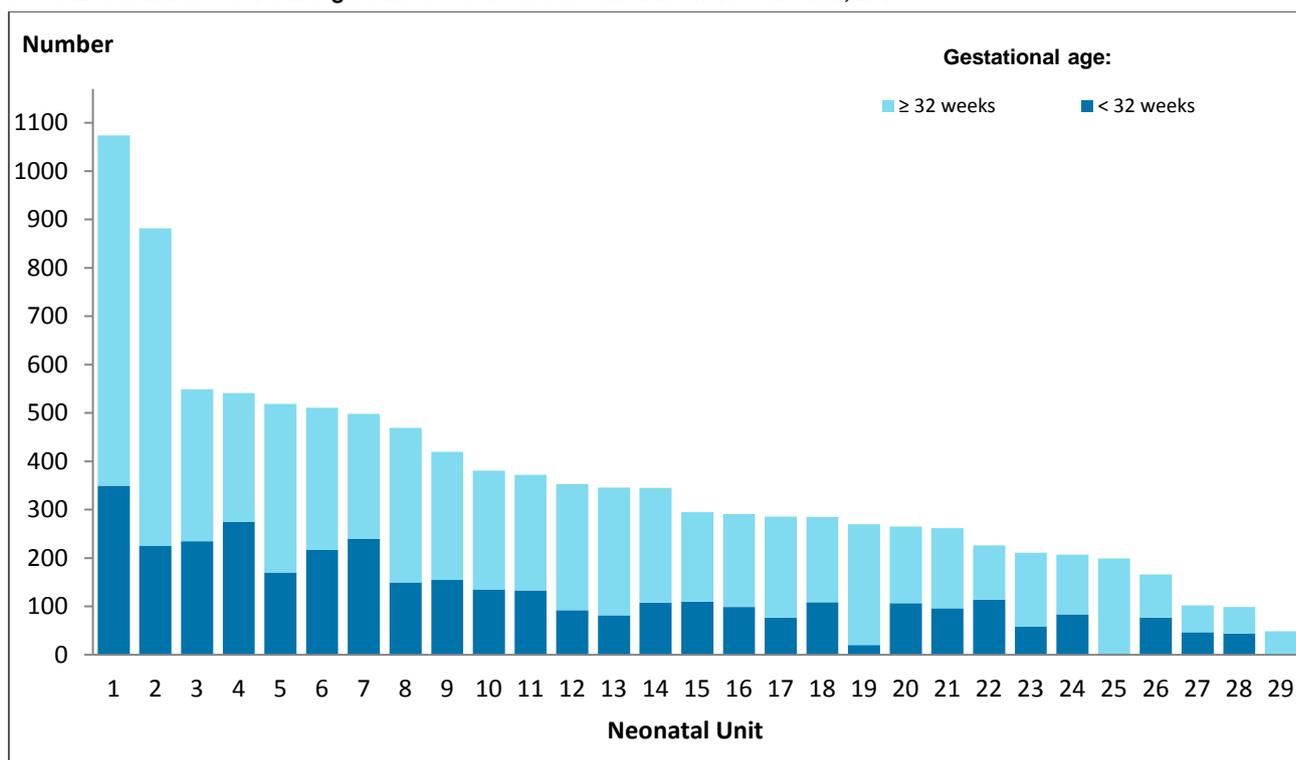


TABLE 1: Level III registrants born at each completed week of gestation, 2016

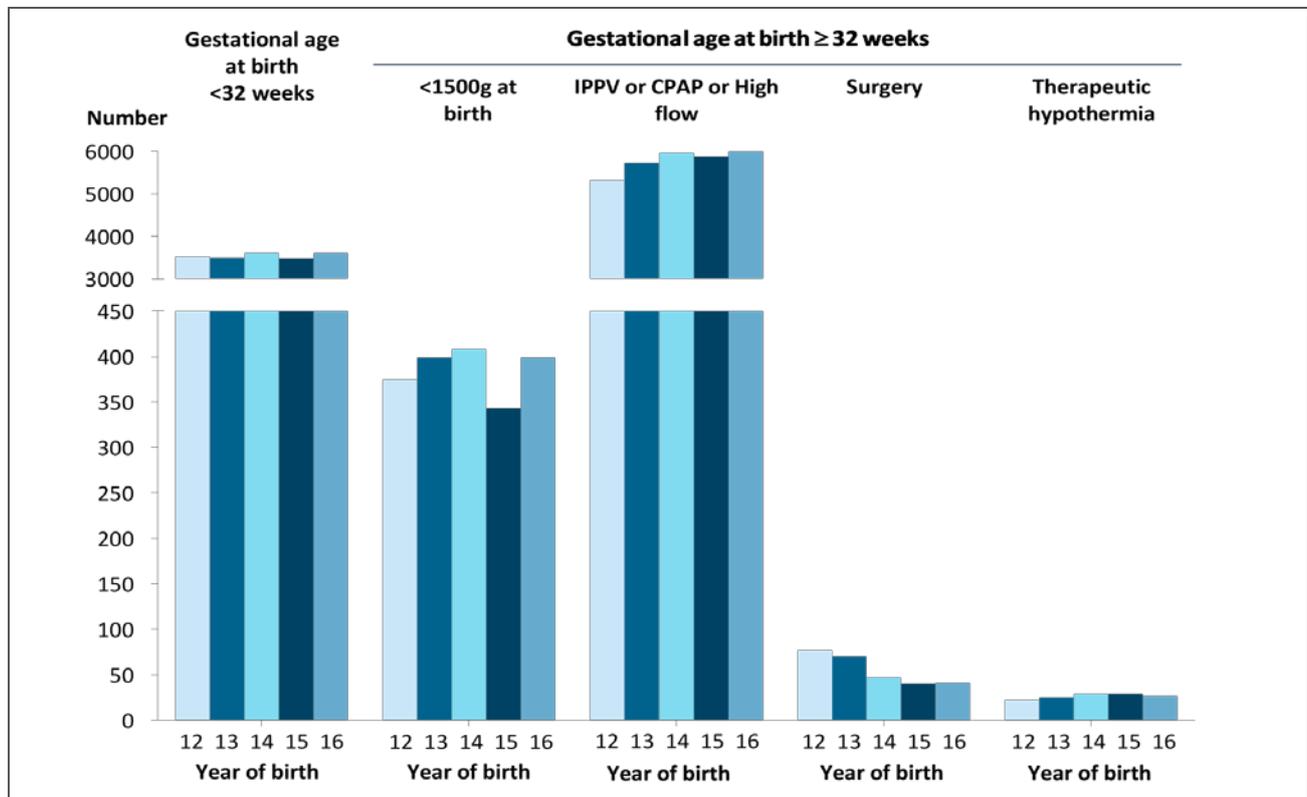
Gestational age (completed weeks)	Number of babies	Percent	Cumulative percent
<24	95	0.9	0.9
24	215	2.1	3.0
25	229	2.2	5.1
26	286	2.7	7.9
27	394	3.8	11.6
28	393	3.8	15.4
29	516	4.9	20.3
30	711	6.8	27.1
31	771	7.4	34.5
All babies <32 weeks	3,610	34.5	
32	828	7.9	42.4
33	656	6.3	48.6
34	713	6.8	55.4
35	588	5.6	61.1
36	601	5.7	66.8
37	716	6.8	73.6
38	798	7.6	81.3
39	776	7.4	88.7
40	726	6.9	95.6
41	432	4.1	99.7
≥42	29	0.3	100.0
Total	10,473	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, 2016

Birth weight (grams)	Number of babies	Percent	Cumulative percent
<500	28	0.3	0.3
500–599	87	0.8	1.1
600–699	226	2.2	3.3
700–799	224	2.1	5.4
800–899	287	2.7	8.1
900–999	340	3.2	11.4
1,000–1,099	311	3.0	14.4
1,100–1,199	341	3.3	17.6
1,200–1,299	365	3.5	21.1
1,300–1,399	406	3.9	25.0
1,400–1,499	449	4.3	29.3
All babies <1,500g birthweight	3,064	29.3	
1,500–1,999	1,761	16.8	46.1
2,000–2,499	1,343	12.8	58.9
2,500–2,999	1,315	12.6	71.5
3,000–3,499	1,448	13.8	85.3
3,500–3,999	1,037	9.9	95.2
≥4,000	505	4.8	100.0
Total	10,473	100.0	

FIGURE 4: Level III registrants by registration criteria, 2012–2016



3. Mothers of level III registrants

Maternal age

While there are many determinants of perinatal outcome, an important one is maternal age. In 2016, 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 (32.9%) followed by mothers aged 25–29 years (25.6%). Together they accounted for more than half of the mothers (57.8%) of ANZNN registrants in 2016 (Table 3). In 2016, the proportion of babies born to teenage mothers decreased slightly (0.1%) from 2015, and those born to mothers in the 35–39 age group decreased by 0.2%, from 19.2% in 2015 to 19.0%.

Over two in five of the babies born to teenage mothers (43.8%) were born at less than 32 weeks completed gestation, while 32.8% of babies born to mothers 30–34 years were less than 32 weeks gestation at birth (Table 3).

TABLE 3: Age group of mothers of level III registrants by gestational age group, 2016

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	7	28	26	34	54	47	55	89	340
20–24	13	61	104	139	159	173	226	450	1,325
25–29	22	106	171	231	384	369	448	925	2,656
30–34	33	145	195	279	467	468	634	1,191	3,412
35–39	12	73	130	163	306	309	358	622	1,973
40 and over	8	31	50	54	104	110	150	168	675
Not stated	0	0	4	9	8	8	31	32	92
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
Per cent									
Less than 20	7.4	6.3	3.8	3.8	3.7	3.2	2.9	2.6	3.3
20–24	13.7	13.7	15.4	15.4	10.8	11.7	12.1	13.1	12.8
25–29	23.2	23.9	25.3	25.7	26.1	25.0	23.9	26.9	25.6
30–34	34.7	32.7	28.8	31.0	31.7	31.7	33.9	34.6	32.9
35–39	12.6	16.4	19.2	18.1	20.8	20.9	19.1	18.1	19.0
40 and over	8.4	7.0	7.4	6.0	7.1	7.5	8.0	4.9	6.5
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.

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

Previous antenatal history

In 2016, a previous preterm delivery was reported by 1,115 mothers (10.6%) of babies registered to ANZNN while 380 mothers (3.6%) reported a previous perinatal loss.

Assisted conception

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

There were 959 (9.2%) pregnancies resulting from assisted conception in the ANZNN 2016 cohort with most (84.4%) the result of IVF treatment. Of the pregnancies resulting from assisted conception, 55.2% of the mothers were more than 34 years of age at the time of giving birth, compared with 49.3% in 2015.

Presenting antenatal problem

Many mothers of ANZNN registrants were admitted to hospital with complications prior to the baby's birth. The presenting antenatal problem refers to the antenatal complication that led to the baby's birth and subsequent admission to an NICU. There may be other complications related to this pregnancy, but they are not reported here. Information about the presenting antenatal problem was available for 99.2% of 2016 ANZNN registrants. The mothers of over one-fifth of registrants (22.0%) presented with preterm labour while fetal distress (15.9%) was the second highest 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 (37.2% and 29.6% respectively) followed by preterm pre-labour rupture of membranes (20.7% and 14.2% respectively).

Overall 85.5% of mothers of registrants had a pregnancy complication recorded. Among women who gave birth at term, two in five (40.3%) were recorded as having no maternal presenting antenatal problem.

TABLE 4: Mother's presenting antenatal problem for level III registrants by gestational age group, 2016

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	n.p.	1,400	1,418
Preterm pre-labour rupture of membranes (PPROM)	21	88	152	187	299	236	269	29	1,281
Preterm labour	52	244	271	313	463	376	561	10 ^(a)	2,290
Hypertension in pregnancy	<5	n.p.	56	108	216	219	190	102	913
Antepartum haemorrhage (APH)	10	53	76	91	148	159	150	69	756
Intrauterine growth restriction (IUGR)	0	5	n.p.	51	86	n.p.	148	88	545
Fetal distress	8	18	65	107	175	193	251	837	1,654
Other problem	<5	15	32	n.p.	81	127	n.p.	535	1,072
Congenital anomalies	0	<5	<5	<5	11	27	83	336	463
Not stated	0	0	0	0	3	3	4	71	81
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
No antenatal problems	0.0	0.0	0.0	0.0	0.0	n.p.	n.p.	41.1	13.6
Preterm pre-labour rupture of membranes (PPROM)	22.1	19.8	22.4	20.6	20.2	15.9	14.2	0.9	12.3
Preterm labour	54.7	55.0	39.9	34.4	31.3	25.4	29.6	0.3	22.0
Hypertension in pregnancy	n.p.	n.p.	8.2	11.9	14.6	14.8	10.0	3.0	8.8
Antepartum haemorrhage (APH)	10.5	11.9	11.2	10.0	10.0	10.7	7.9	2.0	7.3
Intrauterine growth restriction (IUGR)	0.0	1.1	n.p.	5.6	5.8	n.p.	7.8	2.6	5.2
Fetal distress	8.4	4.1	9.6	11.8	11.8	13.0	13.2	24.6	15.9
Other problem	n.p.	3.4	4.7	n.p.	5.5	8.6	n.p.	15.7	10.3
Congenital anomalies	0.0	n.p.	n.p.	n.p.	0.7	1.8	4.4	9.9	4.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

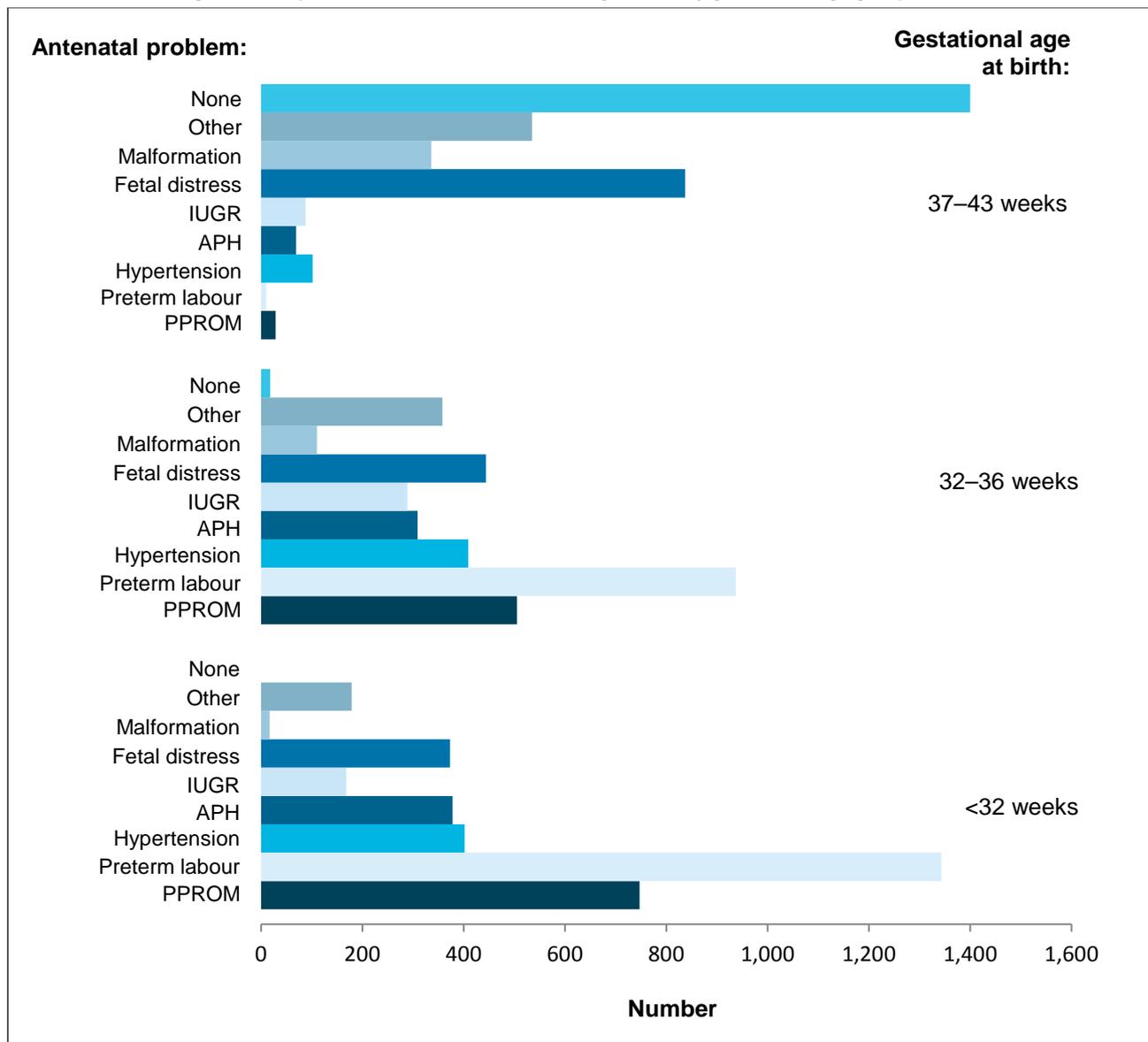
n.p. Data not published to maintain confidentiality of small numbers.

(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, 2016



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 2016, 88.5% of mothers of ANZNN registrants born before 34 weeks of gestation received one or more doses of antenatal corticosteroids leaving 11.5% of mothers of registrants in this group who did not report receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 15.4% received them more than seven days prior to giving birth.

For mothers of ANZNN registrants born before 32 weeks of gestation, 90.4% received one or more doses of antenatal corticosteroids and 9.6% mothers of registrants in this group did not report receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 15.1% received them more than seven days prior to giving birth (Table 5). The 10-year trend (2007–2016) 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, 2016

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.	34	42	70	145	196	n.p.	2,820	4,216
Incomplete course	47	136	176	236	395	389	253	23	1,655
Course completed	34	223	357	459	708	657	461	84	2,983
Completed >7 days prior to birth	<5	47	95	138	211	201	n.p.	56	949
Not stated	1	4	10	6	23	41	91	494	670
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
None	n.p.	7.7	6.3	7.8	9.9	13.6	n.p.	94.5	43.0
Incomplete course	50.0	30.9	26.3	26.1	27.1	27.0	14.0	0.8	16.9
Course completed	36.2	50.7	53.3	50.8	48.5	45.5	25.5	2.8	30.4
Completed >7 days prior to birth	n.p.	10.7	14.2	15.3	14.5	13.9	n.p.	1.9	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).

For mothers of ANZNN registrants born at less than 32 weeks of gestation, 51.6% were given antenatal MgSO₄ (Table 6). MgSO₄ administration is an emerging trend among the member units.

TABLE 6: Magnesium sulphate use for mothers of level III registrants by gestational age, 2016

Magnesium sulphate	Gestational age									Total
	<24	24	25	26	27	28	29	30	31	
	Number									
None	35	60	70	100	125	119	180	396	526	1,611
Complete course	17	62	51	59	91	101	114	76	56	627
Incomplete course	18	43	51	63	88	84	98	99	64	608
Given but details unknown	21	37	49	50	74	72	93	59	26	481
Not stated or clinical trial	4	13	8	14	16	17	31	81	99	283
Total	95	215	229	286	394	393	516	711	771	3,610
	Per cent									
None	38.5	29.7	31.7	36.8	33.1	31.6	37.1	62.9	78.3	48.4
Complete course	18.7	30.7	23.1	21.7	24.1	26.9	23.5	12.1	8.3	18.8
Incomplete course	19.8	21.3	23.1	23.2	23.3	22.3	20.2	15.7	9.5	18.3
Given but details unknown	23.1	18.3	22.2	18.4	19.6	19.1	19.2	9.4	3.9	14.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Note: Not stated and clinical trial 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 2016, 18.3% of ANZNN registrants were reported as being from a multiple pregnancy, and of these, the greatest percentage were twins (93.3%). Of the 2016 ANZNN registrants from multiple births, 52.0% were born before 32 weeks gestation and 96.9% were born before 37 weeks gestation (Table 7). The 10-year trend (2007–2016) for multiple births is represented by Figure 13 in Appendix 1.

TABLE 7: Plurality of level III registrants by gestational age group, 2016

Plurality	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Singletons	n.p.	347	493	666	1,039	1,001	n.p.	3,417	8,558
Twins	22	89	170	226	413	439	367	60	1,786
Triplets and higher orders	<5	8	17	17	30	43	n.p.	0	128
Not stated	0	0	0	0	0	1	0	0	1
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
Singletons	n.p.	78.2	72.5	73.3	70.1	67.5	n.p.	98.3	81.7
Twins	23.2	20.0	25.0	24.9	27.9	29.6	19.3	1.7	17.1
Triplets and higher orders	n.p.	1.8	2.5	1.9	2.0	2.9	n.p.	0.0	1.2
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.

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 2016 registrants (57.9%) the method of birth was caesarean section with 64.6% of caesarean sections occurring before the onset of labour. One-third of registrants (34.4%) 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 57.7% in 2015. The 2016 data shows a slight decrease of 0.2% from 2015.

The most common method of birth for registrants born before 24 weeks gestation was non-instrumental vaginal birth (64.2%) (Table 8). The 10-year trend (2007–2016) 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, 2016

Method of birth	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Vaginal	n.p.	209	223	290	437	n.p.	620	1,386	3,596
Vaginal instrumental birth	<5	8	14	27	49	n.p.	105	542	799
Caesarean section in labour	21	122	179	190	291	266	345	731	2,145
Caesarean section no labour	12	103	262	401	703	791	828	810	3,910
Not stated	0	2	2	1	2	4	4	8	23
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
Vaginal	n.p.	47.3	32.9	31.9	29.5	n.p.	32.7	40.0	34.4
Vaginal instrumental birth	n.p.	1.8	2.1	3.0	3.3	n.p.	5.5	15.6	7.6
Caesarean section in labour	22.1	27.6	26.4	20.9	19.7	18.0	18.2	21.1	20.5
Caesarean section no labour	12.6	23.3	38.6	44.2	47.5	53.4	43.6	23.3	37.4
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 2016, 79.6% of all babies and 87.1% of babies less than 32 weeks gestation at birth were born in a tertiary centre equipped with an NICU; 19.6% of all ANZNN registrants were born in a non-tertiary hospital; while 0.8% 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, 2016

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	86	394	590	789	1,279	1,270	1,466	2,448	8,322
Non-tertiary hospital	n.p.	40	n.p.	110	196	202	418	988	2,045
Not born in a hospital ^(a)	<5	9	<5	9	7	10	11	34	83
Not stated	0	1	5	1	0	2	7	7	23
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
Tertiary hospital	90.5	88.9	87.4	86.9	86.3	85.7	77.4	70.5	79.6
Non-tertiary hospital	n.p.	9.0	n.p.	12.1	13.2	13.6	22.1	28.5	19.6
Not born in a hospital ^(a)	n.p.	2.0	n.p.	1.0	0.5	0.7	0.6	1.0	0.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

(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 2016, 23.1% of ANZNN registrants were transferred to an NICU after birth. Of these the greatest percentage (81.4%) were transported by a specialist team with 13.8% transported by a non-specialist team (Table 10). The 10-year trend (2007–2016) 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, 2016

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	86	386	585	786	1,265	1,246	1,403	2,289	8,046
Specialist retrieval team	8	37	76	100	183	207	427	934	1,972
Non-specialist team	0	6	9	10	18	15	56	220	334
Other	1	15	10	11	16	16	16	31	116
Not stated	0	0	0	2	0	0	0	3	5
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
Not transported	90.5	86.9	86.0	86.7	85.4	84.0	73.8	65.9	76.9
Specialist retrieval team	8.4	8.3	11.2	11.0	12.3	13.9	22.5	26.9	18.8
Non-specialist team	0.0	1.4	1.3	1.1	1.2	1.0	2.9	6.3	3.2
Other	1.1	3.4	1.5	1.2	1.1	1.1	0.8	0.9	1.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

Breastfeeding at discharge

Data on breastfeeding at discharge were available for 99.7% 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, 75.1% were breastfed at discharge. The rate of breastfeeding at discharge of surviving extremely preterm babies (born at less than 28 weeks gestation) was 65.9% compared to 78.5% 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 Australia and New Zealand and accounted for 51.3% of combined live births in both countries in 2016 (Australian Bureau of Statistics 2016; Statistics New Zealand 2016). The percentage was higher among ANZNN registrants with male births representing 58.1%. For births at less than 32 weeks gestation, 56.0% were male; of births at term, 61.3% 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; 18.6% of registrants were intubated in the delivery suite to establish independent respiration and heart rate. For babies born before 32 weeks the percentage was 34.3% and for babies born at term the percentage was 12.7%.

Apgar score at birth

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

An Apgar score of less than 4 at one minute of age was recorded for 16.9% 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, 40.4% of babies were born at less than 32 weeks and 37.8% were born at term (Table 11).

TABLE 11: Apgar scores at birth for level III registrants by gestational age group, 2016

Median & interquartile range	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
Apgar score at 1 minute									
Median	3	4	5	6	7	7	7	7	7
IQR	2–5	2–6	4–7	4–8	5–8	5–9	5–9	4–9	5–9
Apgar score at 5 minutes									
Median	6	7	8	8	9	9	9	8	8
IQR	5–8	5–8	7–9	7–9	8–9	8–9	7–9	7–9	7–9

Note: IQR = Interquartile range

Admission temperature

The temperature at admission to the NICU, or temperature nearest to admission to the registration unit, was reported for 93.4% of ANZNN registrants in 2016. 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 36.0°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, 2016

Gestational age group	Number of babies	Temperature	
		Median	Interquartile range
<24	95	36.0	35.1–36.5
24–25	444	36.2	35.5–36.8
26–27	680	36.5	36.0–37.0
28–29	909	36.5	36.1–36.9
30–31	1,482	36.4	36.0–36.8
32–33	1,484	36.4	36.0–36.8
34–36	1,902	36.6	36.2–36.9
37–43	3,477	36.7	36.3–37.0
Total	10,473	36.5	36.1–36.9

Indication for respiratory support

In 2016, only 3.2% 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 44.2%. Non-specific respiratory distress accounted for 31.3% of babies, surgery for 4.0%, while congenital anomaly accounted for 3.4% (Table 13).

For babies born before 37 weeks gestation, HMD (61.1%) 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 hyaline membrane disease (9.5%) and meconium aspiration syndrome (8.8%) (Table 13). The 10-year trend (2007–2016) 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, 2016

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	6	125	93	n.p.	59	337
Non-specific respiratory distress	<5	11	24	66	n.p.	514	817	1,491	3,256
Hyaline membrane disease	93	424	640	817	944	730	629	328	4,605
Meconium aspiration syndrome	0	0	0	0	0	<5	<5	303	307
Pneumonia	0	<5	0	<5	0	<5	7	97	107
Persistent pulmonary hypertension	<5	<5	<5	<5	5	<5	17	124	157
Apnoea	0	0	<5	7	26	28	n.p.	53	165
Congenital anomaly	0	<5	<5	<5	5	13	68	258	349
Other	0	2	5	3	31	60	98	208	407
Peri-surgery	0	0	<5	<5	<5	19	110	279	415
Newborn encephalopathy	0	<5	<5	<5	<5	7	44	249	310
Not stated	0	0	0	1	6	14	9	28	58
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
No respiratory support	0.0	n.p.	0.0	0.7	8.4	6.3	n.p.	1.7	3.2
Non-specific respiratory distress	n.p.	2.5	3.5	7.3	n.p.	35.0	43.2	43.2	31.3
Hyaline membrane disease	97.9	95.5	94.1	90.0	64.0	49.7	33.2	9.5	44.2
Meconium aspiration syndrome	0.0	0.0	0.0	0.0	0.0	n.p.	n.p.	8.8	2.9
Pneumonia	0.0	n.p.	0.0	n.p.	0.0	n.p.	0.4	2.8	1.0
Persistent pulmonary hypertension	n.p.	n.p.	n.p.	n.p.	0.3	n.p.	0.9	3.6	1.5
Apnoea	0.0	0.0	n.p.	0.8	1.8	1.9	n.p.	1.5	1.6
Congenital anomaly	0.0	n.p.	n.p.	n.p.	0.3	0.9	3.6	7.5	3.4
Other	0.0	0.5	0.7	0.3	2.1	4.1	5.2	6.0	3.9
Peri-surgery	0.0	0.0	n.p.	n.p.	n.p.	1.3	5.8	8.1	4.0
Newborn encephalopathy	0.0	n.p.	n.p.	n.p.	n.p.	0.5	2.3	7.2	3.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

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

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 2016, over a quarter of ANZNN registrants (27.3%) were administered exogenous surfactant (Table 14). There were 2,325 babies who received intermittent positive pressure ventilation for HMD in 2016. Exogenous surfactant was given to 2,133 of these babies (91.7%). There were 192 babies diagnosed with HMD who were not given exogenous surfactant.

TABLE 14: Exogenous surfactant use for level III registrants by gestational age group, 2016

Exogenous surfactant	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
None	<5	29	152	414	1,032	n.p.	1,614	3,181	7,611
Curosurf	93	405	493	423	376	246	241	246	2,523
Survanta	<5	n.p.	31	67	72	48	45	44	314
Curosurf and Survanta	0	<5	0	<5	<5	<5	0	<5	11
Other or unknown surfactant	0	0	1	n.p.	n.p.	0	2	n.p.	7
Not stated	0	1	3	1	0	1	0	1	7
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
None	n.p.	6.5	22.5	45.6	69.6	n.p.	84.9	91.5	72.7
Curosurf	97.9	91.4	72.8	46.6	25.4	16.6	12.7	7.1	24.1
Survanta	n.p.	n.p.	4.6	7.4	4.9	3.2	2.4	1.3	3.0
Curosurf and Survanta	0.0	n.p.	0.0	n.p.	n.p.	n.p.	0.0	n.p.	0.1
Other or unknown surfactant	0.0	0.0	0.1	n.p.	n.p.	0.0	0.1	n.p.	0.1
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 2016, 90.8% 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 airway 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 (2007–2016) for assisted ventilation is represented in Figures 17 to 19 in Appendix 1.

In 2016, IPPV was given for a total of 555,482 hours to ANZNN registrants and CPAP was given for 1,606,201 hours. The total number of hours of ventilation equates to each baby receiving 8.6 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 2016 remains CPAP with 52.5% of registrants receiving CPAP only, 11.2% receiving IPPV only and 27.1% 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. In 2016, 18.3% of registrants who received IPPV also received HFOV. However, seven babies received HFOV without at least four hours of IPPV. The use of HFOV among individual units varied between 1.1% and 13.3% with the highest percentage of babies receiving HFOV born at less than 24 weeks (62.4%) followed by babies born at 24–25 weeks gestation (52.2%) (Table 16). The 10-year trend (2007–2016) 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, 2016

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	313	45.5	24	20	23	44	53	47
IQR	117–826	93–587	15–168.5	10–74	10–46	11–61	18–91	21–102	16–125
CPAP (hours)									
Median	937	1,078	799	190	54	28	22	14	36
IQR	519–1,258	698–1,374	375–1,090	90–479	23–115	14–67.5	10–48	7–33	13–123

Note: IQR = Interquartile range

In 2016, 32 registrants received ECMO of whom the majority were born at term. The percentage of ANZNN registrants who received nitric oxide (NO) was 5.1%. 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 (20.2%) (Table 16). The 10-year trend (2007–2016) for NO is represented in Figure 21 in Appendix 1.

TABLE 16: Assisted ventilation for level III registrants by gestational age group, 2016

Ventilation type	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
Number									
CPAP given	65	376	638	850	1,222	1,232	1,499	2,453	8,335
Invasive ventilation	93	423	501	451	433	319	523	1,273	4,016
▪ IPPV given	93	423	500	450	433	318	523	1,270	4,010
▪ HFOV given	58	221	121	58	47	25	41	167	738
NO given	19	75	46	33	25	16	46	275	535
Total in each age group	95	444	680	909	1,482	1,484	1,902	3,477	10,473
Per cent									
CPAP given	68.4	84.7	93.8	93.5	82.5	83.0	78.8	70.5	79.6
IPPV given	97.9	95.3	73.5	49.5	29.2	21.4	27.5	36.5	38.3
Per cent of babies given invasive ventilation									
HFOV given	62.4	52.2	24.2	12.9	10.9	7.8	7.8	13.1	18.4
NO given	20.4	17.7	9.2	7.3	5.8	5.0	8.8	21.6	13.3

Note: Groups are not mutually exclusive.

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

Ventilation in babies born at less than 32 weeks gestation

The major indication for assisted ventilation in babies born at less than 32 weeks gestation was hyaline membrane disease. Among the 3,610 babies born before 32 weeks gestation, 92.9% 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 40.2% and IPPV was the only form of ventilation for 5.6% of registrants. Both IPPV and CPAP were given to 47.0% of registrants.

The total duration of IPPV for these very preterm babies was 359,871 hours (14,995 days), and the duration of CPAP was 1,371,099 hours (57,129 days).

Of the babies born before 32 weeks gestational age and given IPPV in 2016, 26.5% were given high frequency ventilation while 10.4% of these babies were given NO (Table 16).

Among 2016 ANZNN registrants born at less than 32 weeks gestation, 3,443 (95.4%) survived to day 28. Of these, 50.6% of registrants received respiratory support (airway support or supplemental oxygen therapy) at 28 days of age, with 17.2% 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, 88.9% received assisted ventilation. Hyaline membrane disease was the main reason for ventilation. Total duration of CPAP use by registrants in this gestational age group was 132,770 hours (5,532 days) and IPPV use was 68,086 hours (2,837 days).

Of the babies born at 32–36 weeks gestation and given IPPV in 2016, 7.7% were given high frequency ventilation while 7.4% 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 (42.9%). This group required 127,525 hours of IPPV (5,314 days) and 102,332 hours (4,264 days) of CPAP.

Of the babies born at term and given IPPV in 2016, 12.9% were given high frequency ventilation while 21.7% 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 2016 ANZNN registrants, 10,161 babies survived to day 28 and of these, 19.3% 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, 17.2% 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, 2016

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	<5	9	53	383	1,239	1,399	1,803	n.p.	8,141
Respiratory support on day 28	n.p.	369	593	507	229	66	67	n.p.	2,014
▪ survived to discharge home	50	350	582	499	n.p.	n.p.	59	102	1,930
▪ died before discharge	n.p.	19	11	8	<5	<5	8	n.p.	84
Not stated	0	3	0	0	0	0	0	3	6
Total in each age group	58	381	646	890	1,468	1,465	1,870	3,383	10,161
	Number								
Respiratory support on day 28 and given home oxygen	23	118	106	40	n.p.	<5	8	17	336
	Per cent								
No respiratory support on day 28	n.p.	2.4	8.2	43.0	84.4	95.5	96.4	n.p.	80.2
Respiratory support on day 28	n.p.	97.6	91.8	57.0	15.6	4.5	3.6	n.p.	19.8
▪ survived to discharge home	87.7	94.9	98.1	98.4	n.p.	n.p.	88.1	81.0	95.8
▪ died before discharge	n.p.	5.1	1.9	1.6	n.p.	n.p.	11.9	n.p.	4.2
	Per cent								
Respiratory support on day 28 and given home oxygen ^(a)	46.0	33.7	18.2	8.0	8.8	6.5	13.6	16.7	17.4

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

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

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

Nasal high flow therapy

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

In 2016 nasal high flow therapy was reported for 3,232 babies (30.9%) of all level III registrants (Table 18), compared with 8.1% in 2009. Overall, the minimum flow recorded was 1.5 litres/min and the maximum 15 litres/min. Of the babies receiving NHFT 70.2% were reported to have received a minimum rate of 2–4 litres/min while 71.5% received a maximum of 6–8 litres/min.

TABLE 18: Nasal high flow respiratory support for level III registrants by gestational age group, 2016

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	50	311	530	573	480	282	311	695	3,232
No high flow	45	133	150	336	1,002	1,202	1,591	2,782	7,241
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
High flow	52.6	70.0	77.9	63.0	32.4	19.0	16.4	20.0	30.9
No high flow	47.4	30.0	22.1	37.0	67.6	81.0	83.6	80.0	69.1
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, 3,009 (75.1%) received TPN during admission (Table 19). The median duration of TPN reported was 231 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, 5.9% of babies were discharged home on gavage feeds.

TABLE 19: Total parenteral nutrition for level III registrants by gestational age, 2016

Parenteral nutrition	Gestational age										Total
	<24	24	25	26	27	28	29	30	31	≥32 ^(a)	
	Number										
Parenteral nutrition	89	209	n.p.	275	381	370	n.p.	461	388	154	3,009
No parenteral nutrition	6	6	<5	11	13	23	n.p.	250	383	241	996
Not stated	0	0	0	0	0	0	0	0	0	3	5
Total	95	215	229	286	394	393	516	711	771	398	4,008
	Number										
Home gavage feeding	4	20	n.p.	18	23	26	n.p.	24	12	3	179
	Per cent										
Parenteral nutrition	93.7	97.2	n.p.	96.2	96.7	94.1	n.p.	64.8	50.3	39.0	75.2
No parenteral nutrition	6.3	2.8	n.p.	3.8	3.3	5.9	n.p.	35.2	49.7	61.0	24.9
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)	4.5	9.6	9.7	6.5	6.0	7.0	5.9	5.2	3.1	1.9	5.9

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, 9.8% of babies in 2016 were reported to have had respiratory support at 36 weeks PMA, and of these, 27 (2.6%) 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 25 weeks gestation (69.9%) (Table 20). Not all the babies born at earlier gestations survived to 36 weeks PMA. The 10-year trend (2007–2016) for CLD is represented by Figure 22 in Appendix 1.

TABLE 20: Chronic lung disease for level III registrants by gestational age, 2016

Chronic lung disease (CLD)	Gestational age									Total
	<24	24	25	26	27	28	29	30	31	
	Number									
No CLD	44	81	69	139	217	266	410	619	737	2,582
CLD	51	134	160	147	177	127	106	92	34	1,028
Total	95	215	229	286	394	393	516	711	771	3,610
	Per cent									
No CLD	46.3	37.7	30.1	48.6	55.1	67.7	79.5	87.1	95.6	71.5
CLD	53.7	62.3	69.9	51.4	44.9	32.3	20.5	12.9	4.4	28.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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, 275 (7.6%) babies were treated with systemic corticosteroids. Of these, 239 were reported to have had respiratory support at 36 weeks, while 36 (13.1%) reported no CLD.

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, 2016

Air leak	Gestational age group							Total	
	<24	24–25	26–27	28–29	30–31	32–33	34–36		37–43
	Number								
Air leak	10	27	21	31	32	47	73	167	408
No air leak	85	417	659	878	1,450	1,437	1,829	3,310	10,065
Not stated	0	0	0	0	0	0	0	0	0
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
Air leak	10.5	6.1	3.1	3.4	2.2	3.2	3.8	4.8	3.9
No air leak	89.5	93.9	96.9	96.6	97.8	96.8	96.2	95.2	96.1
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 5.1% of ANZNN registrants in 2016. Of these babies, 55.1% were born at less than 28 weeks gestation, 74.7% were born at less than 32 weeks gestation and 98.9% of registrants survived up to 2 days of life (Table 22). Episodes of both early and late sepsis were reported in fourteen babies. The 5-year trends (2012–2016) 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, 2016

Sepsis	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
No sepsis	58	287	578	848	1,438	1,465	1,863	3,399	9,936
Sepsis at <48 hrs ^(a)	9	19	10	16	17	7	15	44	137
Sepsis at ≥48 hrs ^(a)	32	142	95	45	27	13	26	34	414
Babies alive on day 2	90	431	674	n.p.	n.p.	1,479	1,890	3,453	10,401
Babies who did not survive to day 2	5	13	6	<5	<5	5	12	24	72
Total in each age group	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
No sepsis ^(b)	61.1	64.6	85.0	93.3	97.0	98.7	97.9	97.8	94.9
Sepsis at <48 hrs ^(b)	9.5	4.3	1.5	1.8	1.1	0.5	0.8	1.3	1.3
Sepsis at ≥48 hrs ^(c)	35.6	32.9	14.1	5.0	1.8	0.9	1.4	1.0	4.0

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 177 (1.7%) of ANZNN registrants in 2016, as identified by isolation or identification of an organism by PCR, immunofluorescence or similar technology from an appropriate body fluid.

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 2016 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 2016 registrants, 28.8% were eligible for ROP examination and of these eligible registrants, 83.7% were examined and had the results of their eye examination recorded.

Of those ANZNN registrants who were eligible for an eye examination, 179 died before their ROP status could be determined. Of those examined, 7.7% had stage 3 or 4 eye disease (Table 23, Figure 6) and of these babies 42.6% received surgical treatment. The 10-year trend (2007–2016) 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, 2016

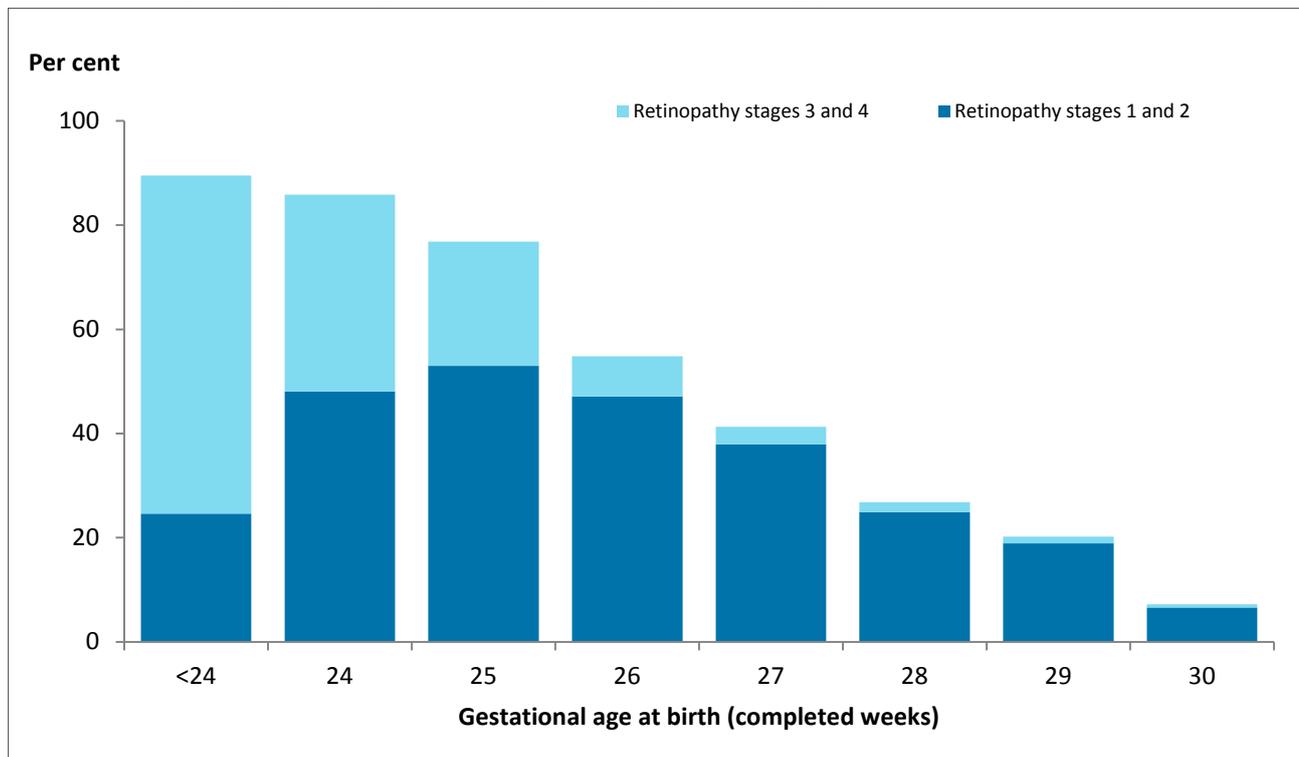
Retinopathy of prematurity (ROP)	Gestational age									Total
	<24	24	25	26	27	28	29	30	≥31 ^(a)	
Number										
No ROP	n.p.	23	47	117	221	271	379	n.p.	128	1,641
Stage 1	5	n.p.	n.p.	57	77	60	64	20	10	358
Stage 2	9	50	70	65	66	32	26	12	5	335
Stage 3	35	60	47	20	13	7	6	<5	0	n.p.
Stage 4	<5	<5	<5	0	0	0	0	0	0	<5
Not examined	38	53	27	27	17	22	39	202	31	456
Not stated	0	0	0	0	0	1	2	25	7	35
Total	95	215	229	286	394	393	516	711	181	3,020
Per cent										
No ROP	n.p.	14.2	23.3	45.2	58.6	73.2	79.8	n.p.	89.5	64.9
Stage 1	8.8	n.p.	n.p.	22.0	20.4	16.2	13.5	4.1	7.0	14.2
Stage 2	15.8	30.9	34.7	25.1	17.5	8.6	5.5	2.5	3.5	13.2
Stage 3	61.4	37.0	23.3	7.7	3.4	1.9	1.3	n.p.	0.0	n.p.
Stage 4	n.p.	n.p.	n.p.	0.0	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, 2016



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 3,610 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, 3,561 survived to day 3 and 91.4% had an examination recorded. A normal report was recorded for 79.5% of these 2016 ANZNN registrants.

There were 144 babies reported to have grade 3 or 4 IVH representing 4.0% of the babies born before 32 weeks gestation. Of the babies who had a grade 3 IVH, 23.2% were unilateral, while 78.8% 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 (67.9%) of these babies born before 25 weeks gestation (Table 24, Figure 7). The 10-year trend (2007–2016) for registrants with grades 3 and 4 IVH who survived to day 3 is represented in Figure 24 in Appendix 1.

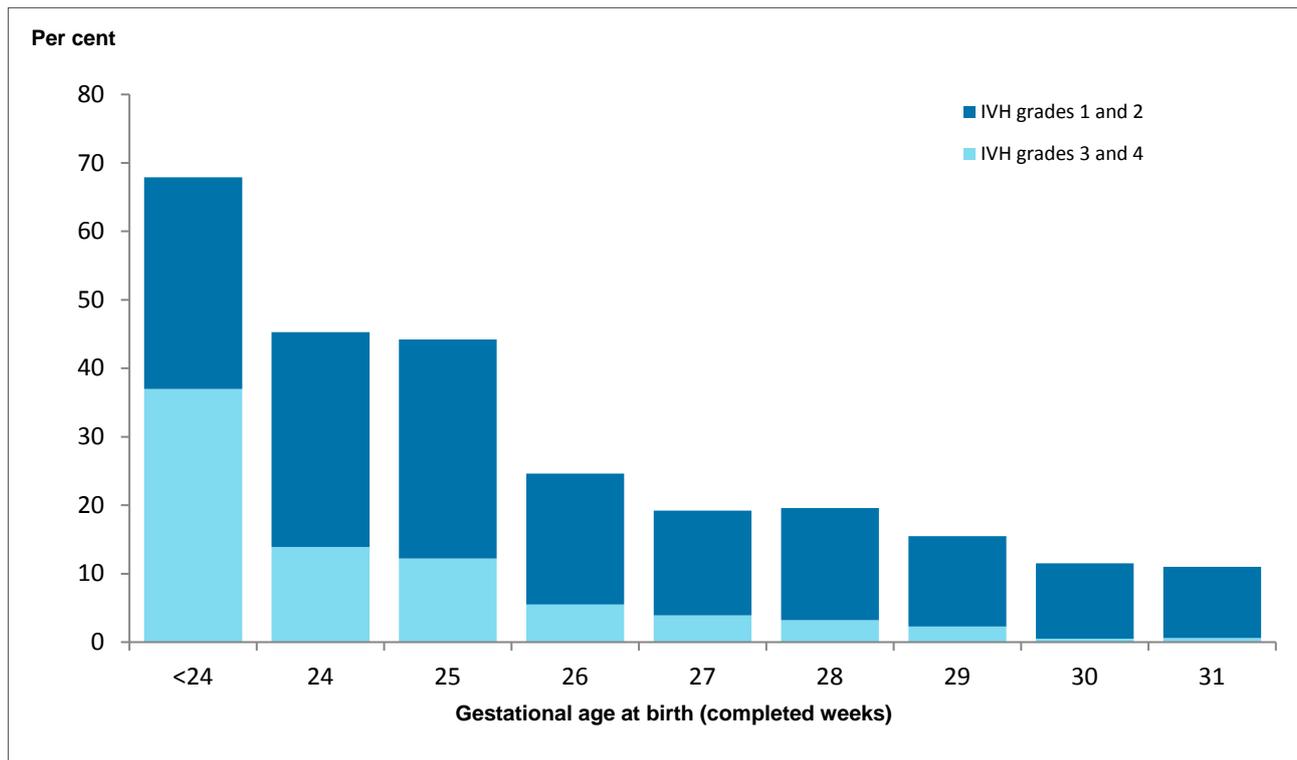
TABLE 24: Intraventricular haemorrhage for level III registrants born before 32 weeks and survived to day 3 by gestational age, 2016

Intraventricular haemorrhage	Gestational age									Total
	<24	24	25	26	27	28	29	30	31	
	Number									
None	26	106	124	205	307	303	411	553	550	2,585
Grade 1	11	27	41	34	41	41	54	62	56	367
Grade 2	14	34	30	18	17	21	10	7	8	159
Grade 3	11	8	9	10	7	6	5	<5	<5	59
Grade 4	19	19	18	5	8	6	6	<5	<5	85
Not examined	5	5	3	6	14	13	27	82	151	306
Total	86	199	225	278	394	390	513	707	769	3,561
	Per cent									
None	32.1	54.6	55.9	75.4	80.8	80.4	84.6	88.5	89.0	79.4
Grade 1	13.6	13.9	18.5	12.5	10.8	10.9	11.1	9.9	9.1	11.3
Grade 2	17.3	17.5	13.5	6.6	4.5	5.6	2.1	1.1	1.3	4.9
Grade 3	13.6	4.1	4.1	3.7	1.8	1.6	1.0	n.p.	n.p.	1.8
Grade 4	23.5	9.8	8.1	1.8	2.1	1.6	1.2	n.p.	n.p.	2.6
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 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, 2016



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 3,610 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, 3,561 survived until day 3 and late ultrasound results were available for 2,321 (65.2%) of these babies. A normal report of no cysts was recorded for 97.7% of these registrants, 0.9% reported porencephalic cysts and 1.5% reported periventricular leukomalacia (PVL) (Table 25). Of the 34 babies who were reported with PVL, six 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, 2016

Cerebral ultrasound results	Gestational age									
	<24	24	25	26	27	28	29	30	31	Total
	Number									
No cysts	49	n.p.	180	n.p.	322	n.p.	374	n.p.	277	2,267
Porencephalic cysts	<5	0	<5	5	<5	<5	<5	<5	<5	20
Periventricular leukomalacia	<5	<5	<5	<5	<5	9	<5	9	<5	34
Not stated	42	58	44	53	68	78	135	321	490	1,289
Total	95	215	229	286	394	393	516	711	771	3,610
	Per cent									
No cysts	92.5	n.p.	97.3	n.p.	98.8	n.p.	98.2	n.p.	98.6	97.7
Porencephalic cysts	n.p.	0.0	n.p.	2.1	n.p.	n.p.	n.p.	n.p.	n.p.	0.9
Periventricular leukomalacia	n.p.	n.p.	n.p.	n.p.	n.p.	2.9	n.p.	2.3	n.p.	1.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

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

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 2016, 336 (7.2%) of the ANZNN registrants born at more than 34 weeks gestation received therapeutic hypothermia, and of these, 66.1% 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 85.2% of babies.

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 2016 the percentage of babies with confirmed NEC was 1.5%. Of these babies, 57.6% were born before 28 weeks gestation with 47.3% of them undergoing surgery, and 23.4% were born between 28–31 weeks gestation; surgery was required for 51.4% of them. In total 35 registrants died from NEC. The number of registrants with confirmed NEC is slightly more than in 2015 (Table 26).

TABLE 26: Necrotising enterocolitis in level III registrants by year of birth, 2007–2016

Necrotising enterocolitis	Year of birth									
	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
	Number									
Babies born at <28 weeks										
▪ NEC	73	114	94	112	78	87	75	64	81	91
▪ No NEC	1,015	1,039	1,031	964	1,024	980	1,015	1,039	977	1,126
▪ Not stated	27	9	2	4	5	2	0	3	4	2
Babies born at 28-31 weeks										
▪ NEC	21	49	34	41	36	35	27	21	40	37
▪ No NEC	2,302	2,395	2,385	2,180	2,398	2,415	2,384	2,484	2,384	2,353
▪ Not stated	31	15	0	4	0	2	0	2	6	1
Babies born at ≥32 weeks										
▪ NEC	16	23	19	21	14	14	19	26	27	30
▪ No NEC	4,585	4,907	5,410	4,905	5,630	5,780	6,200	6,515	6,268	6,832
▪ Not stated	26	10	2	4	1	3	1	4	9	1
Total in each birth year	8,096	8,561	8,977	8,235	9,186	9,318	9,721	10,158	9,796	10,473
	Per cent									
NEC <28 weeks ^(a)	6.7	9.9	8.4	10.4	7.1	8.2	6.9	5.8	7.7	7.5
NEC 28-31 weeks ^(b)	0.9	2.0	1.4	1.8	1.5	1.4	1.1	0.8	1.7	1.5
NEC ≥32 weeks ^(c)	0.3	0.5	0.3	0.4	0.2	0.2	0.3	0.4	0.4	0.4

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

(b) Denominator is babies born at 28-31 weeks.

(c) Denominator is babies born at ≥32 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 2016, 58 (0.6%) of all ANZNN registrants had a confirmed diagnosis of spontaneous intestinal perforation. Of these, four babies were also reported to have a confirmed NEC diagnosis. Of babies born before 28 weeks gestation, 34 (2.8%) had a confirmed diagnosis of spontaneous intestinal perforation.

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 2016, there were 929 ANZNN registrants who had major surgery, of whom over half (55.7%) were born at term. Of registrants born in a hospital, 72.7% were born in a hospital with tertiary care facilities. Of registrants who had major surgery, 75.7% also had a congenital anomaly present with 60.7% of these diagnosed during the antenatal period. 8.5% had surgery for proven NEC. The median length of stay (LOS) for survivors was 29 days (Table 27).

TABLE 27: Characteristics of level III registrants who underwent surgery by gestational age group, 2016

Characteristics	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Male	14	21	27	21	18	22	111	305	539
Female	5	21	22	14	16	22	78	212	390
Congenital anomaly present	0	<5	9	10	n.p.	32	170	462	703
Congenital anomaly diagnosed antenatally	0	0	<5	n.p.	12	21	117	271	427
Proven NEC	6	24	13	10	9	<5	n.p.	8	79
Hospital of birth:									
▪ Tertiary	n.p.	n.p.	41	29	n.p.	37	147	330	667
▪ Non-tertiary	<5	<5	8	6	<5	7	41	180	251
Median LOS for survivors (days)	142.5	123.5	126.5	92	72	54	29	21	29
Died before discharge home	<5	7	7	6	<5	<5	6	15	47
Total in each age group	19	42	49	35	34	44	189	517	929
	Per cent								
Male	73.7	50.0	55.1	60.0	52.9	50.0	58.7	59.0	58.0
Female	26.3	50.0	44.9	40.0	47.1	50.0	41.3	41.0	42.0
Congenital anomaly present	0.0	n.p.	18.4	28.6	n.p.	72.7	89.9	89.4	75.7
Congenital anomaly diagnosed antenatally	0.0	0.0	n.p.	n.p.	35.3	47.7	61.9	52.4	46.0
Proven NEC	31.6	57.1	26.5	28.6	26.5	n.p.	n.p.	1.5	8.5
Hospital of birth:									
▪ Tertiary	n.p.	n.p.	83.7	82.9	n.p.	84.1	77.8	63.8	71.8
▪ Non-tertiary	n.p.	n.p.	16.3	17.1	n.p.	15.9	21.7	34.8	27.0
Died before discharge home	n.p.	16.7	14.3	17.1	n.p.	n.p.	3.2	2.9	5.1

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

The median age of mothers of neonates who received major surgery was 30 years. Within the 2016 surgical cohort, 6.2% of pregnancies resulted from assisted conception, compared with 9.2% in the whole cohort. Of the 2016 ANZNN registrants who received major surgery, gastrointestinal procedures were the most commonly performed (62.5%) followed by cardiac procedures (27.9%).

There were 96 (0.9%) babies born in 2016 who received surgery to repair a gastroschisis before discharge to home. The majority of these babies were male (52.1%) and were born at more than 35 weeks gestation (59.4%). In 2016, 56 babies received surgery to repair a congenital diaphragmatic hernia, of which 55% were male. 55.4% of these babies were born at more than 38 weeks gestation.

Congenital anomalies

In 2016, 1,253 ANZNN registrants (12.0%) had one or more major congenital anomalies. For registrants who had a congenital anomaly, 13.6% were born before 32 weeks gestation, 30.2% were born between 32 and 36 weeks gestation and more than half of registrants (56.3%) were born at term.

Over half of ANZNN registrants (50.5%) with congenital anomalies were diagnosed during the antenatal period with 8.0% of babies recorded as having a fatal congenital anomaly. A higher percentage of babies with congenital anomalies were male (57.7%).

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 2016, more than one third of ANZNN registrants (35.7%) 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 (e.g. South Australia). Almost half of the registrants (46.8%) transferred from level III to level II units were born at less than 32 weeks gestation compared to 14.7% born at term.

Some level III registrants required transfer to a specialist children’s hospital and in 2016 these accounted for 3.9% of registrants. Overall 56.2% 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, 2016

Transfer status	Gestational age group								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–43	
	Number								
Not transferred	63	263	291	356	505	614	1,160	2,635	5,887
Level III hospital	7	32	60	73	55	50	55	99	431
Level II hospital	9	112	289	447	896	798	643	549	3,743
Children’s hospital	16	37	40	33	26	22	44	192	410
Not stated	0	0	0	0	0	0	0	2	2
Total	95	444	680	909	1,482	1,484	1,902	3,477	10,473
	Per cent								
Not transferred	66.3	59.2	42.8	39.2	34.1	41.4	61.0	75.8	56.2
Level III hospital	9.5	25.2	42.5	49.2	60.5	53.8	33.8	15.8	4.1
Level II hospital	7.4	7.2	8.8	8.0	3.7	3.4	2.9	2.8	35.7
Children’s hospital	16.8	8.3	5.9	3.6	1.8	1.5	2.3	5.5	3.9
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

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 97.1% of ANZNN registrants in 2016 who survived to discharge to home. The median length of stay was 26 days with an interquartile range of 9–51 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 231,767 days in hospital, babies born between 32 and 36 weeks spent 83,386 days and babies born at term spent 42,924 days in hospital.

TABLE 29: Median length of stay for level III registrants who survived until discharge home by gestational age, 2016

Gestational age (completed weeks)	Number of babies	Median LOS (in days)	Interquartile range (in days)
<24	51	133	113–148
24	158	117.5	108.5–140.5
25	201	110	96.5–127
26	261	91	82–108.5
27	374	82	73–97
28	376	73	63–85
29	506	60	52–69
30	701	48	42–58
31	764	40	34–48
32	815	33	27–40
33	646	25	21–32
34	705	20	15–26
35	576	14	10–20
36	581	10	6–19
37	695	8	5–17
38	766	7	4–15
39	745	7	4–14
40	702	6	4–12
41	420	5	4–10
≥42	28	9	4–17
Total	10,071	26	9–51

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

Survival of the ANZNN registrants

In 2016, 96.2% 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 2016, there were 402 neonatal deaths, of which 195 occurred in the early neonatal period that is within seven days of birth (Table 30). Mortality was highest among babies born before 29 weeks gestation with a survival rate at discharge increasing week on week from 53.7% for babies born before 24 weeks to 95.7% 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 1.0% of registrants, with most occurring in babies born between 36–39 weeks gestation (Table 30).

TABLE 30: Survival to discharge home for level III registrants by gestational age at birth, 2016

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	95	0	70	58	51	53.7
24	215	<5	190	170	158	73.5
25	229	<5	221	211	201	87.8
26	286	<5	276	265	261	91.3
27	394	0	390	381	374	94.9
28	393	<5	386	382	376	95.7
29	516	<5	512	508	506	98.1
30	711	<5	704	703	701	98.6
31	771	<5	768	765	764	99.1
32	828	10	823	818	815	98.4
33	656	<5	648	647	646	98.5
34	713	5	707	706	705	98.9
35	588	<5	583	579	576	98.0
36	601	10	589	585	581	96.7
37	716	12	707	703	695	97.1
38	798	15	778	769	766	96.0
39	776	14	762	755	745	96.0
40	726	8	710	704	702	96.7
41	432	5	426	424	420	97.2
≥42	29	0	28	28	28	96.6
Total	10,473	100	10,278	10,161	10,071	96.2

Note: 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, 2016

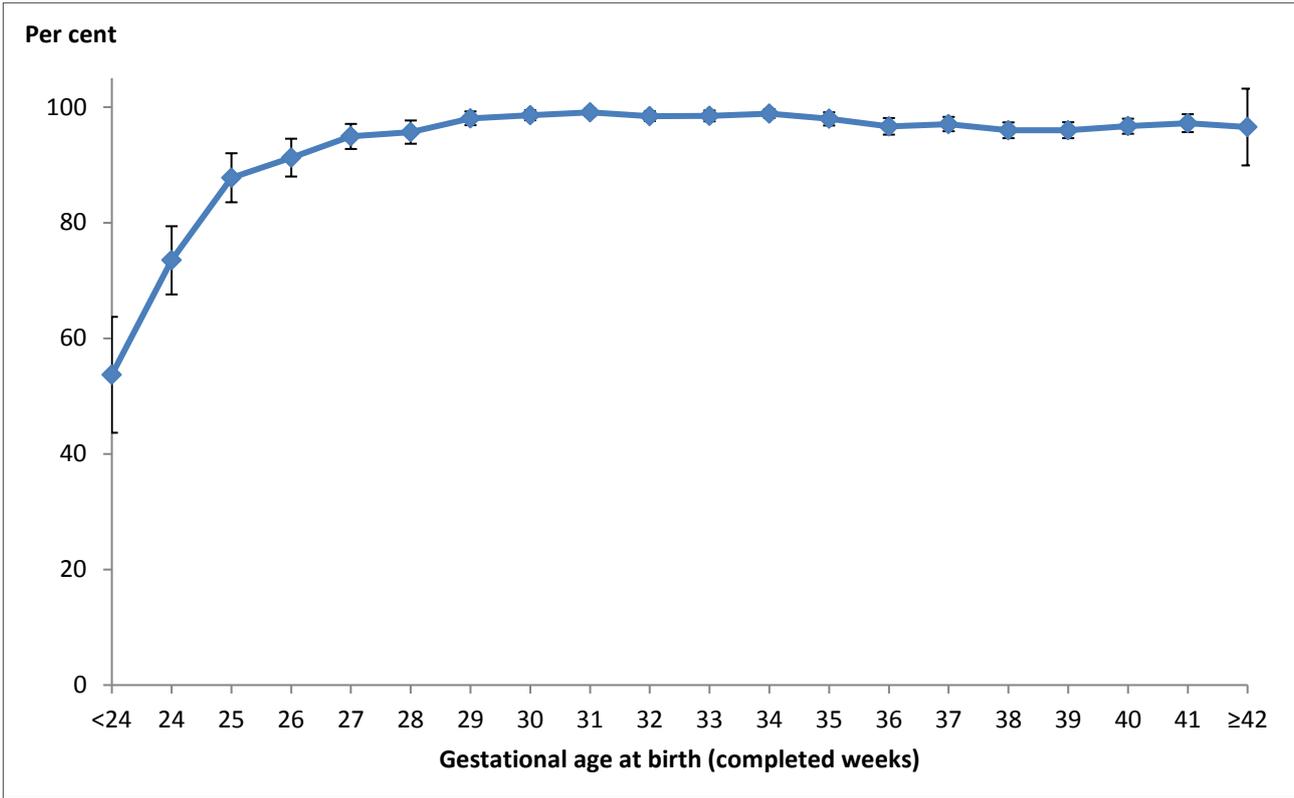
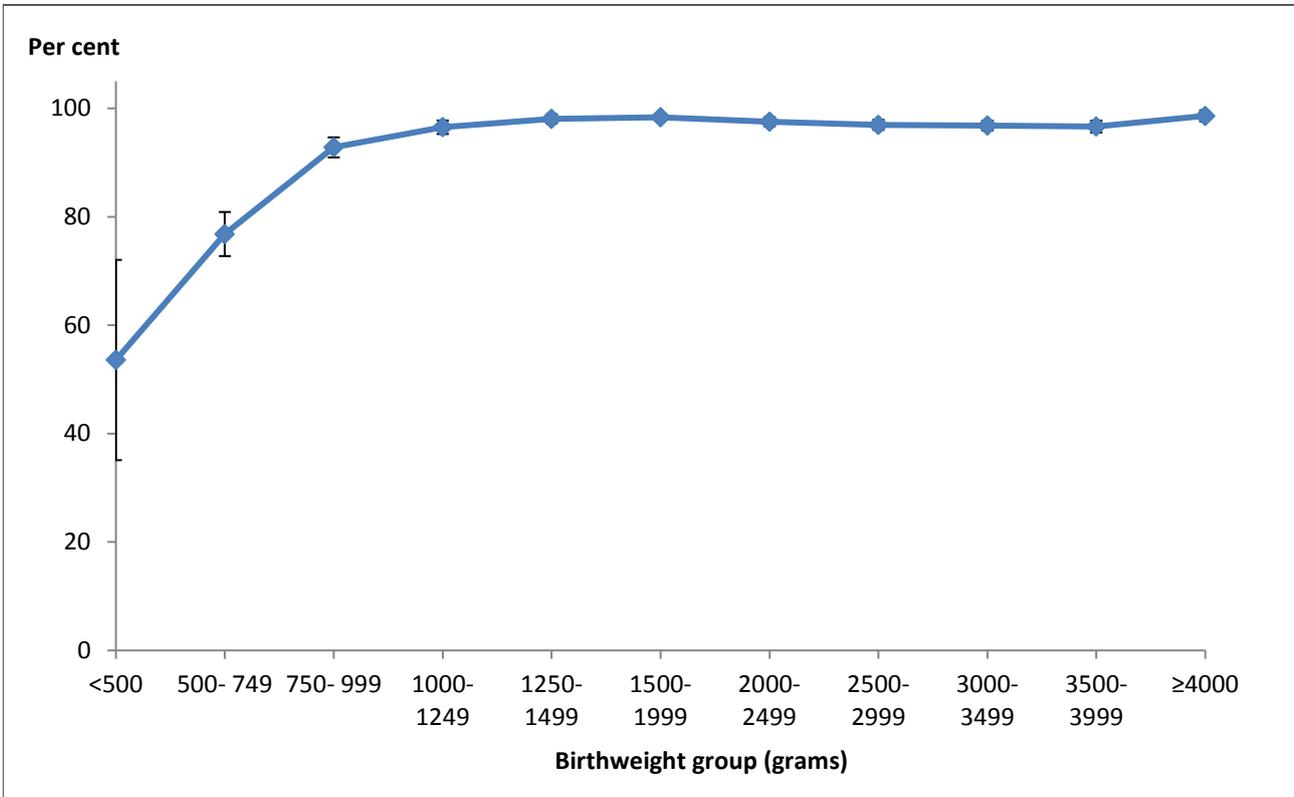


FIGURE 9: Survival of level III registrants to discharge home (with 95% CI) by birthweight group, 2016



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 14 in Australia that are members of the ANZNN. Altogether, 26 level II units contributed data for this 2016 report.

In 2016, 1,341 babies fulfilled the ANZNN criteria for registration to a level II unit. Of those babies, 4.3% were born at less than 32 weeks gestation and 3.7% 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 2016 was over 120.

TABLE 31: Level II registrants by gestational age group, 2016

Gestational age group	Number of babies	Per cent	Cumulative per cent
<30	10	0.7	0.7
30–31	47	3.5	4.3
All babies <32 weeks gestation	57	4.3	
32–33	198	14.8	19.0
34–36	397	29.6	48.7
37–43	688	51.3	100.0
Total	1,340	100.0	

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

TABLE 32: Level II registrants by birthweight group, 2016

Birthweight group (grams)	Number of babies	Per cent	Cumulative per cent
<1,200	9	0.7	0.7
1,200–1,299	5	0.4	1.0
1,300–1,399	14	1.0	2.1
1,400–1,499	21	1.6	3.7
All babies <1,500g birthweight	49	3.7	
1,500–1,999	158	11.8	15.4
2,000–2,499	268	20.0	35.4
2,500–2,999	243	18.1	53.5
3,000–3,499	273	20.4	73.9
3,500–3,999	225	16.8	90.7
≥4,000	125	9.3	100.0
Total	1,341	100.0	

Note: Birthweight groups below 1,200g have been combined to maintain confidentiality of small numbers.

Three in five of the level II registrants, 826 babies (61.6%), were born to Caucasian mothers, 50.0% of whom were born preterm. The number of registrants born to Maori mothers was 153 (11.4%), and 74 (48.4%) were born preterm. There were 42 babies (3.1%) born to Pacific Islander mothers.

There were 807 male (60.2%) and 534 female (39.8%) registrants in the audit. 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, 27.0% did not present with any maternal complications. Among babies born before 37 weeks, 36.5% of mothers had presented with preterm labour (Table 33).

TABLE 33: Mothers of level II registrants presenting antenatal problem by gestational age group, 2016

Presenting antenatal problem	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
	Number					
No antenatal problems	0	0	0	5	355	360
Preterm pre-labour rupture of membranes	<5	14	43	82	<5	145
Preterm labour	6	17	70	137	8	238
Hypertension in pregnancy	0	<5	32	n.p.	28	108
Antepartum haemorrhage	<5	7	24	31	n.p.	73
Intrauterine growth restriction	0	<5	7	27	20	n.p.
Fetal distress	0	<5	16	33	151	203
Other problem	0	1	6	35	106	148
Congenital anomalies	0	0	0	<5	<5	<5
Not stated	0	0	0	2	6	8
Total	10	47	198	397	688	1,340
	Per cent					
No antenatal problems	0.0	0.0	0.0	1.3	52.1	27.0
Preterm pre-labour rupture of membranes	n.p.	29.8	21.7	20.8	0.6	10.9
Preterm labour	60.0	36.2	35.4	34.7	1.2	17.9
Hypertension in pregnancy	0.0	n.p.	16.2	n.p.	4.1	8.1
Antepartum haemorrhage	n.p.	14.9	12.1	7.8	n.p.	5.5
Intrauterine growth restriction	0.0	n.p.	3.5	6.8	2.9	n.p.
Fetal distress	0.0	n.p.	8.1	8.4	22.1	15.2
Other problem	0.0	2.1	3.0	8.9	15.5	11.1
Congenital anomalies	0.0	0.0	0.0	n.p.	n.p.	n.p.
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 one baby.

Previous preterm births were reported by 155 (11.6%) of the mothers of level II registrants and 60 mothers (4.5%) had had a previous perinatal death(s).

Most mothers (87.4%) of level II registrants had booked into a level II hospital for delivery. Of the level II registrants born before 34 weeks gestation, 70.2% 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, 2016

Antenatal corticosteroids	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
	Number					
None	<5	7	47	n.p.	670	955
Incomplete course	7	13	61	n.p.	<5	135
Complete course	<5	n.p.	72	84	5	187
Completed >7 days prior to birth	0	<5	14	23	<5	42
Not stated	0	1	4	9	7	21
Total	10	47	198	397	688	1,340
	Per cent					
None	n.p.	15.2	24.2	n.p.	98.4	72.4
Incomplete course	70.0	28.3	31.4	n.p.	n.p.	10.2
Complete course	n.p.	n.p.	37.1	21.6	0.7	14.2
Completed >7 days prior to birth	0.0	n.p.	7.2	5.9	n.p.	3.2
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 one baby.

Vaginal and assisted delivery was the most common method of birth for 50.8% of level II registrants (Table 35). Of those who were delivered by caesarean section, just over half (51.2%) of these occurred before the onset of labour.

TABLE 35: Method of delivery for level II registrants by gestational age group, 2016

Method of delivery	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
	Number					
Vaginal ^(a)	<5	20	74	n.p.	412	675
Caesarean ^(b)	n.p.	27	122	n.p.	270	653
Not stated	0	0	2	4	6	12
Total	10	47	198	397	688	1,340
	Per cent					
Vaginal	n.p.	42.6	37.8	n.p.	60.4	50.8
Caesarean	n.p.	57.4	62.2	n.p.	39.6	49.2
Total	100.0	100.0	100.0	100.0	100.0	100.0

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

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

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

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

Gestational age was not provided for one baby.

Characteristics of level II babies

Among the 1,341 babies registered to level II units, 129 were from multiple births (9.6%). There were 807 male births.

A low Apgar score of less than 4 at one minute of age was recorded for 17.4% of babies and 10.0% of them required endotracheal intubation in the labour ward to assist in their adaptation to extrauterine life.

Non-specific respiratory distress (72.0%) was the major reason for assisted ventilation for level II registrants, followed by hyaline membrane disease (14.1%) (Table 36).

For level II registrants, the median duration of assisted ventilation by IPPV was 5 hours and 17 hours by CPAP (Table 37).

TABLE 36: Indication for respiratory support for level II registrants by gestational age group, 2016

Indication for respiratory support	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
	Number					
No respiratory support	0	9	12	7	<5	n.p.
Non-specific respiratory distress	<5	n.p.	111	287	542	960
Hyaline membrane disease	n.p.	19	64	74	n.p.	188
Meconium aspiration syndrome	0	0	<5	<5	52	55
Pneumonia	0	0	<5	<5	24	27
Persistent pulmonary hypertension	0	0	0	<5	7	n.p.
Apnoea	0	<5	5	11	n.p.	23
Congenital anomaly	0	0	0	<5	<5	<5
Other	0	0	3	9	24	36
Peri-surgery	0	0	0	0	0	0
Newborn encephalopathy	0	0	0	0	5	5
Not stated	0	0	1	2	3	6
Total	10	47	198	397	688	1,340
	Per cent					
No respiratory support	0.0	19.1	6.1	1.8	n.p.	n.p.
Non-specific respiratory distress	n.p.	n.p.	56.3	72.7	79.1	72.0
Hyaline membrane disease	n.p.	40.4	32.5	18.7	n.p.	14.1
Meconium aspiration syndrome	0.0	0.0	n.p.	n.p.	7.6	4.1
Pneumonia	0.0	0.0	n.p.	n.p.	3.5	2.0
Persistent pulmonary hypertension	0.0	0.0	0.0	n.p.	1.0	n.p.
Apnoea	0.0	n.p.	2.5	2.8	n.p.	1.7
Congenital anomaly	0.0	0.0	0.0	n.p.	n.p.	n.p.
Other	0.0	0.0	1.5	2.3	3.5	2.7
Peri-surgery	0.0	0.0	0.0	0.0	0.0	0.0
Newborn encephalopathy	0.0	0.0	0.0	0.0	0.7	0.4
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 one baby.

TABLE 37: Duration of assisted ventilation use by level II registrants by gestational age group, 2016

Median & Interquartile range	Gestational age group					Total
	<30	30–31	32–33	34–36	37–43	
IPPV (hours)						
Median	18	76	4	1	5	5
IQR	5–26	76–76	4–5	1–1	4–11	4–26
CPAP (hours)						
Median	61	37.5	24	18	13	17
IQR	32–237	22–50	13–51	10–35	8–24	9–30

Note: IQR = Interquartile range.

Eye examination

Screening for retinopathy of prematurity (ROP) was reported for only 22 of the 27 eligible babies born at less than 31 weeks gestational age and/or weighing less than 1,250 grams at birth (81.5% compared to 83.7% of eligible level III registrants). Most were reported as normal except for three babies who had stage 1 ROP and one baby with stage 2 ROP.

Cerebral ultrasound

Of the 57 babies born at less than 32 weeks, 46 (80.7%) had a cerebral ultrasound in the first week after birth. 41 of them were reported as normal, that is no intraventricular haemorrhage (IVH), four reported a grade 1 IVH, and one reported a grade 2 IVH. Most babies who did not have an early cerebral ultrasound reported at this time were born at 31 weeks gestation. A late cerebral ultrasound was reported for 29 babies and all had normal reports.

Other morbidities

Septicaemia was proven in ten babies, including six before day two, that is less than 48 hours. There were no cases of necrotising enterocolitis. Major congenital anomalies were reported for eight babies, of which none required major surgery and one registrant died due to congenital anomalies.

Level II transfers

In total 103 level II registrants were transferred to other units, 67 were transferred to a level I or another level II unit, 31 were transferred to a level III unit and the remaining five to a children’s hospital.

Survival

There were 1,327 level II registrants who survived to discharge home (99.0%). Five babies died within the first seven days of birth and a further one baby died before discharge home (Table 38). One baby was reported to have had a lethal congenital anomaly.

TABLE 38: Survival to discharge home for level II registrants by gestational age group, 2016

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	10	9	9	9	90.0
30–31	47	47	47	46	97.9
32–33	198	198	198	197	99.5
34–36	397	397	397	393	99.0
37–43	688	685	685	682	99.1
All babies	1,340	1,336	1,336	1,327	99.0

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

6. Extremely preterm follow-up, 2010–2013 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 2010 to 2013 births. All infants born from 2010 to 2013 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 4,611 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 232 (5.0%) of the eligible ANZNN registrants born from 2010 to 2013.

Follow-up rate

From 2010 to 2013, 5,475 extremely preterm and/or extremely low birthweight babies were registered to the ANZNN, with 4,611 (84.2%) 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 one NICU was unable to submit post-discharge data for 2010, 2012 and 2013 births and one NICU was unable to submit post-discharge data for 2011 and 2013 births before the publication of this Report. The 187 eligible survivors registered to these NICUs were excluded from further outcome analysis.

Of the 4,424 eligible survivors registered to NICUs that were able to submit data, 3,523 (79.6%) had outcome data available. There were 34 infants who died after discharge and 3,489 who had a follow-up assessment. Outcome data were not available for 901 (20.4%) infants, with 856 (19.3%) 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 79.5% (3,489 of 4,390). The follow-up rate was seen to decrease with increasing gestational age and increasing birthweight (Table 39 & Table 40).

Of the 3,489 infants who were followed-up, 3,082 (88.3%) had a formal developmental assessment. For the remaining 407 (11.7%) infants, some follow-up information was obtained but a formal developmental assessment was not completed.

FIGURE 10: Flowchart of 2010–2013 follow-up cohort

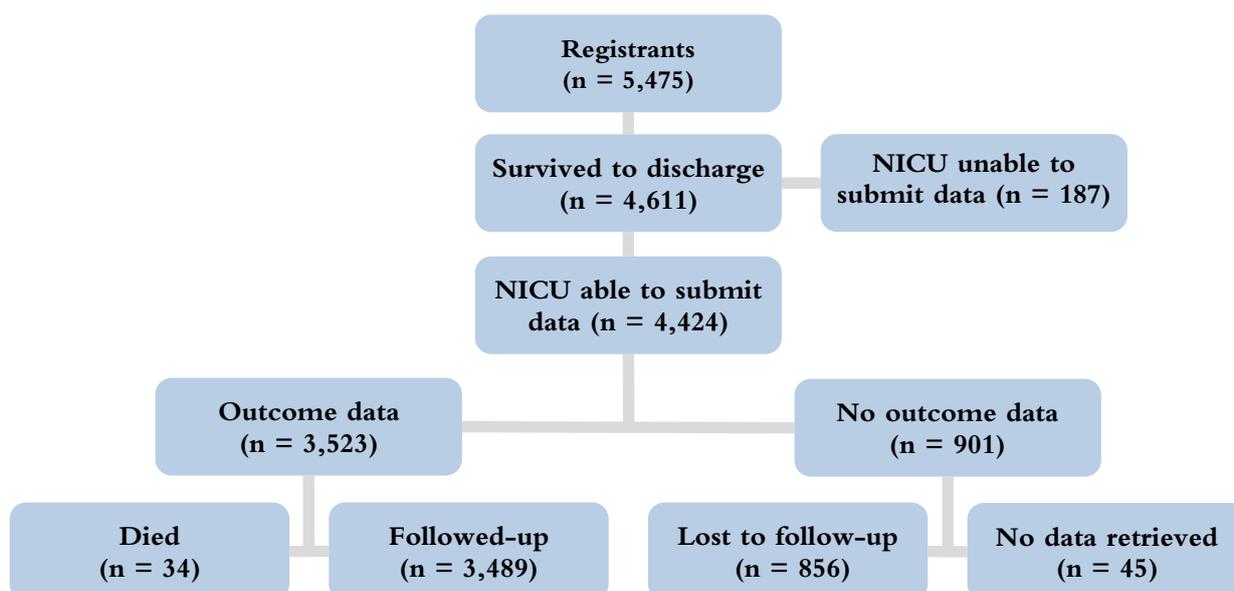


TABLE 39: Births, survival and 2–3 year follow-up of extremely preterm and/or extremely low birthweight infants by gestational age, 2010–2013 births

	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28 ^(a)	
Number							
Registrants	232	726	947	1,194	1,319	1,057	5,475
Survived to discharge	118	479	758	1,057	1,207	992	4,611
Per cent							
Survived to discharge ^(b)	50.9	66.0	80.0	88.5	91.5	93.9	84.2
Number							
NICU not included	7	30	29	46	41	34	187
Follow-up cohort ^(c)	111	449	729	1,011	1,166	958	4,424
▪ Died post-discharge	0	<5	8	5	12	n.p.	34
▪ Follow-up assessment ^(d)	99	370	579	817	893	731	3,489
▪ No outcome data	12	n.p.	142	189	261	n.p.	901
Per cent							
Follow-up rate ^(e)	89.2	83.0	80.3	81.2	77.4	76.8	79.5

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 117 infants assessed at <18 months corrected age and 21 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, 2010–2013 births

	Birthweight group (grams)							Total
	<500	500-599	600-699	700-799	800-899	900-999	≥1000 ^(a)	
Number								
Registrants	134	381	777	885	1,074	1,211	1,013	5,475
Survived to discharge	64	255	562	719	957	1,130	924	4,611
Per cent								
Survived to discharge ^(b)	47.8	66.9	72.3	81.2	89.1	93.3	91.2	84.2
Number								
NICU not included	1	10	24	36	35	40	41	187
Follow-up cohort ^(c)	63	245	538	683	922	1,090	883	4,424
▪ Died post-discharge	<5	<5	<5	6	5	9	8	34
▪ Follow-up assessment ^(d)	56	215	436	554	724	834	670	3,489
▪ No outcome data	n.p.	n.p.	n.p.	123	193	247	205	901
Per cent								
Follow-up rate ^(e)	91.8	88.1	81.5	81.8	79.0	77.2	76.6	79.5

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 117 infants assessed at <18 months corrected age and 21 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 25.1 months with an interquartile range of 24.0–29.1 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 96.6% of infants with a follow-up assessment at 18 months corrected age or older, and of these, 208 (6.4%) had a diagnosis of cerebral palsy. The movement ability of 201 (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, 100 (49.8%) infants were graded as level 1, 42 (20.9%) as level 2, 24 (11.9%) as level 3, 14 (7.0%) as level 4 and 21 (10.4%) as level 5 (Table 41).

Of the 138 infants who were assessed at less than 18 months corrected age or whose corrected age at assessment was unknown, there were four cases of moderate 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, 2010–2013 births

Cerebral Palsy (CP)	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
No CP	79	300	498	700	803	650	3,030
CP	10	43	45	53	30	27	208
▪ Mild Level 1	<5	n.p.	20	27	15	13	100
▪ Moderate Level 2–3	<5	13	18	13	10	n.p.	66
▪ Severe Level 4–5	<5	5	7	13	<5	<5	35
▪ Level unknown	<5	<5	0	0	<5	<5	7
Not stated	4	13	18	31	26	21	113
Total^(a)	93	356	561	784	859	698	3,351
	Per cent						
No CP	88.8	87.5	91.7	93.0	96.4	96.0	93.6
CP	11.2	12.5	8.3	7.0	3.6	4.0	6.4
▪ Mild Level 1	n.p.	n.p.	3.7	3.6	1.8	1.9	3.1
▪ Moderate Level 2–3	n.p.	3.8	3.3	1.7	1.2	n.p.	2.0
▪ Severe Level 4–5	n.p.	1.5	1.3	1.7	n.p.	n.p.	1.1
▪ Level unknown	n.p.	n.p.	0.0	0.0	n.p.	n.p.	0.2

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

(a) Excludes 117 infants assessed at <18 months corrected age and 21 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 96.9% of infants with a follow-up assessment and of these, only 13 (0.4%) were recorded as being blind (< 6/60 in the better eye). Six (46.2%) 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 3,463 infants assessed at nine months corrected age or older as hearing devices would only likely be fitted from this age.

Information about the use of hearing devices was available for 97.4% of infants with a follow-up assessment at nine months corrected age or older. Of these, eight (0.2%) infants were fitted with a unilateral hearing aid, 38 (1.1%) infants with bilateral hearing aids, ten (0.3%) infants with a cochlear implant and six (0.2%) infants with a cochlear implant and hearing aids. The proportion of infants with hearing devices was approximately double among those 24 weeks gestational age or younger (4.0%) compared with any other gestational age group (1.3–2.1%).

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. Congenital anomalies or conditions that were identified by the ANZNN Follow-up Subcommittee as being common side-effects of prematurity were not excluded from cognitive, language and motor delay analyses and functional impairment analyses.

There were 37 infants who were identified as having a congenital anomaly that could cause developmental delay, and these infants were excluded from cognitive, language and motor delay analyses and functional impairment analyses (Table 42 to Table 46). Of those excluded, there were 19 infants with congenital central nervous system malformations, including absent septum pellucidum, agenesis of corpus callosum, cerebral cysts, encephalomalacia, holoprosencephaly, hydrocephalus, lissencephaly, meningomyelocele, microcephaly, schizencephaly, septo-optic dysplasia, other reduction anomalies of brain, and other specified congenital malformations of the brain. Also excluded were 17 infants with genetic disorders or chromosomal anomalies, including chromosome deletion, chromosome duplication, Crouzon syndrome, Klinefelter syndrome, Menkes syndrome, Prader-Willi syndrome, Trisomy 21, unspecified trisomy or partial trisomy of autosomes, and tuberous sclerosis. The remaining infant was excluded due to other congenital malformations affecting development.

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 2,844 infants assessed by the Bayley Scales of Development-III, 67 infants assessed by the Griffiths Mental Developmental Scales, 32 infants assessed by the Wechsler Preschool and Primary Scale of Intelligence (WPPSI) and 16 infants assessed by the Stanford-Binet Intelligence Scales. It should be noted that motor and language subscale scores were not available for the few infants who were assessed by WPPSI or Stanford-Binet 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.

For the purposes of this report, 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 were defined 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. It should be noted that the definition of mild, moderate and severe delay used in this report may be at variance with other reporting definitions.

Additionally, there were 24 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 eleven infants without formal developmental assessment had a severe impairment recorded (two with severe cerebral palsy and blindness, eight with severe cerebral palsy and one with a clinical assessment of severe impairment), severe cognitive, language or motor delay could not be reliably assigned to these infants.

Overall, there were 438 (14.7%) infants with mild to severe cognitive delay, 770 (27.7%) with mild to severe language delay and 501 (17.9%) with mild to severe motor delay (Table 42 to Table 44). It should be noted that language delays are difficult to assess in infants at two years of age, especially for infants who speak a language other than English. Furthermore, mild language delays detected in this age group may not reflect a problem or disability at later ages.

TABLE 42: Cognitive delay at 2–3 year follow-up by gestational age for Bayley, Griffiths, WPPSI and Stanford-Binet assessments, 2010–2013 births

Cognitive delay	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
Number							
None	58	254	430	604	661	525	2,532
Mild	n.p.	36	51	62	70	n.p.	293
Moderate	<5	11	12	19	12	n.p.	70
Severe	6	15	15	15	11	0	62
Not stated ^(a)	0	3	1	0	4	5	13
Total^(b)	82	319	509	700	758	602	2,970
Per cent							
None	70.7	80.4	84.6	86.3	87.7	87.9	85.6
Mild	n.p.	11.4	10.0	8.9	9.3	n.p.	9.9
Moderate	n.p.	3.5	2.4	2.7	1.6	n.p.	2.4
Severe	7.3	4.7	3.0	2.1	1.5	0.0	2.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

(b) Infants assessed by Bayley, Griffiths, WPPSI or Stanford-Binet at ≥18 months corrected age or older or unable to be assessed due to severe delay. Excludes 37 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, 2010–2013 births

Language delay	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
Number							
None	46	194	326	490	551	400	2,007
Mild	15	53	92	106	117	104	487
Moderate	6	40	36	38	32	43	195
Severe	8	16	16	19	16	13	88
Not stated ^(a)	7	12	33	34	31	41	158
Total^(b)	82	315	503	687	747	601	2,935
Per cent							
None	61.3	64.0	69.4	75.0	77.0	71.4	72.3
Mild	20.0	17.5	19.6	16.2	16.3	18.6	17.5
Moderate	8.0	13.2	7.7	5.8	4.5	7.7	7.0
Severe	10.7	5.3	3.4	2.9	2.2	2.3	3.2
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 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 37 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, 2010–2013 births

Motor delay	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
None	56	224	378	554	610	472	2,294
Mild	n.p.	51	73	60	80	n.p.	347
Moderate	<5	17	18	27	14	n.p.	96
Severe	6	10	10	14	7	11	58
Not stated ^(a)	4	13	24	32	36	31	140
Total^(b)	82	315	503	687	747	601	2,935
	Per cent						
None	71.8	74.2	78.9	84.6	85.8	82.8	82.1
Mild	n.p.	16.9	15.2	9.2	11.3	n.p.	12.4
Moderate	n.p.	5.6	3.8	4.1	2.0	n.p.	3.4
Severe	7.7	3.3	2.1	2.1	1.0	1.9	2.1
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 37 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 2,543 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, 22 infants who met at least one of the criteria for severe impairment, but had missing data for one or more outcomes, and 24 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, nine were 24 weeks, ten were 25 weeks, ten were 26 weeks, ten were 27 weeks and three were 28 weeks gestational age or older.

Of the 2,589 infants where functional impairment could be graded, there were 934 (36.1%) infants with any degree of functional impairment, including 571 (22.1%) with a mild impairment, 237 (9.2%) with a moderate impairment and 125 (4.8%) with a severe impairment. Functional impairment was most prevalent and most severe among infants who were born at younger gestational ages (Table 45). Of the 934 infants with any degree of functional impairment, 297 (31.8%) were classified based on language delays alone.

TABLE 45: Severity of functional impairment at 2–3 year follow-up by gestational age, 2010–2013 births

Functional impairment	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
None	34	149	269	421	445	337	1,655
Mild	18	64	107	118	149	116	572
Moderate	10	46	44	48	45	44	237
Severe	8	21	25	32	21	18	125
Incomplete formal test ^(a)	12	36	61	73	91	86	359
Other formal test	2	3	7	24	19	16	71
No formal test	8	33	43	62	82	69	297
Total^(b)	92	352	556	778	852	686	3,316
	Per cent						
None	48.6	53.2	60.4	68.0	67.4	65.4	63.9
Mild	25.7	22.9	24.0	19.1	22.6	22.5	22.1
Moderate	14.3	16.4	9.9	7.8	6.8	8.5	9.2
Severe	11.4	7.5	5.6	5.2	3.2	3.5	4.8
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 outcomes.

(b) Excludes 117 infants assessed at <18 months corrected age and 21 infants with unknown corrected age at assessment. Also excludes 37 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. This table includes 297 infants with a mild, moderate or severe functional impairment classification based on language delay alone.

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 outcomes, 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, 548 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 548 infants, together with the 2,589 infants graded in Table 45, there were 447 (14.2%) infants with moderate to severe functional impairment. Moderate to severe functional impairment was seen to decrease with increasing gestational age (Table 46). Of these 447 infants with

moderate to severe functional impairment, there were 148 (33.1%) infants classified with moderate to severe functional impairment based on language delay alone.

TABLE 46: Infants with or without moderate to severe functional impairment at 2–3 year follow-up by gestational age, 2010–2013 births

Functional impairment	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
Moderate-severe impairment	22	87	88	91	83	76	447
Without moderate-severe impairment	65	249	450	649	719	558	2,690
Not stated ^(a)	5	16	18	38	50	52	179
Total^(b)	92	352	556	778	852	686	3,316
	Per cent						
Moderate- severe impairment	25.3	25.9	16.4	12.3	10.3	12.0	14.2
Without moderate-severe impairment	74.7	74.1	83.6	87.7	89.7	88.0	85.8
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 117 infants assessed at <18 months corrected age and 21 infants with unknown corrected age at assessment. Also excludes 37 infants with a congenital anomaly known to impair development.

Note: Not stated data are excluded from per cent calculations. This table includes 148 infants with a moderate-severe functional impairment classification based on language delay alone.

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 3,348 infants assessed at 18 months corrected age or older. Of these infants with computable percentiles, 10.2% fell below the 3rd percentile for weight for age, 16.8% for length/height for age, 7.2% for head circumference for age and 5.9% 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, 2010–2013 births

Weight for age centile	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
<3	7	23	56	53	42	126	307
3–9	13	41	62	62	54	108	340
10–90	62	239	352	494	572	375	2,094
>90	7	23	38	80	94	20	262
Not stated	4	30	53	95	97	69	348
Total^(a)	93	356	561	784	859	698	3,351
	Per cent						
<3	7.9	7.1	11.0	7.7	5.5	20.0	10.2
3–9	14.6	12.6	12.2	9.0	7.1	17.2	11.3
10–90	69.7	73.3	69.3	71.7	75.1	59.6	69.7
>90	7.9	7.1	7.5	11.6	12.3	3.2	8.7
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(a) Excludes 117 infants assessed at <18 months corrected age and 21 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, 2010–2013 births

Length/height for age centile	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
<3	15	43	87	93	80	164	482
3–9	15	41	62	83	77	98	376
10–90	48	212	309	434	491	320	1,814
>90	6	17	30	58	68	22	201
Not stated	9	43	73	116	143	94	478
Total^(a)	93	356	561	784	859	698	3,351
	Per cent						
<3	17.9	13.7	17.8	13.9	11.2	27.2	16.8
3–9	17.9	13.1	12.7	12.4	10.8	16.2	13.1
10–90	57.1	67.7	63.3	65.0	68.6	53.0	63.1
>90	7.1	5.4	6.1	8.7	9.5	3.6	7.0
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(a) Excludes 117 infants assessed at <18 months corrected age and 21 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, 2010–2013 births

Head circumference for age centile	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
<3	11	22	36	27	28	60	184
3–9	9	28	38	47	24	58	204
10–90	54	188	322	425	458	362	1,809
>90	9	28	53	95	120	39	344
Not stated	10	90	112	190	229	179	810
Total^(a)	93	356	561	784	859	698	3,351
	Per cent						
<3	13.3	8.3	8.0	4.5	4.4	11.6	7.2
3–9	10.8	10.5	8.5	7.9	3.8	11.2	8.0
10–90	65.1	70.7	71.7	71.5	72.7	69.7	71.2
>90	10.8	10.5	11.8	16.0	19.0	7.5	13.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(a) Excludes 117 infants assessed at <18 months corrected age and 21 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, 2010–2013 births

Weight for height centile	Gestational age (completed weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
<3	<5	16	28	34	n.p.	66	169
3–9	7	22	43	48	49	75	244
10–90	n.p.	243	360	481	n.p.	424	2,101
>90	11	32	55	103	115	38	354
Not stated	9	43	75	118	143	95	483
Total^(a)	93	356	561	784	859	698	3,351
	Per cent						
<3	n.p.	5.1	5.8	5.1	n.p.	10.9	5.9
3–9	8.3	7.0	8.8	7.2	6.8	12.4	8.5
10–90	n.p.	77.6	74.1	72.2	n.p.	70.3	73.3
>90	13.1	10.2	11.3	15.5	16.1	6.3	12.3
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 117 infants assessed at <18 months corrected age and 21 infants with unknown corrected age at assessment.

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

Respiratory and gastrointestinal tract

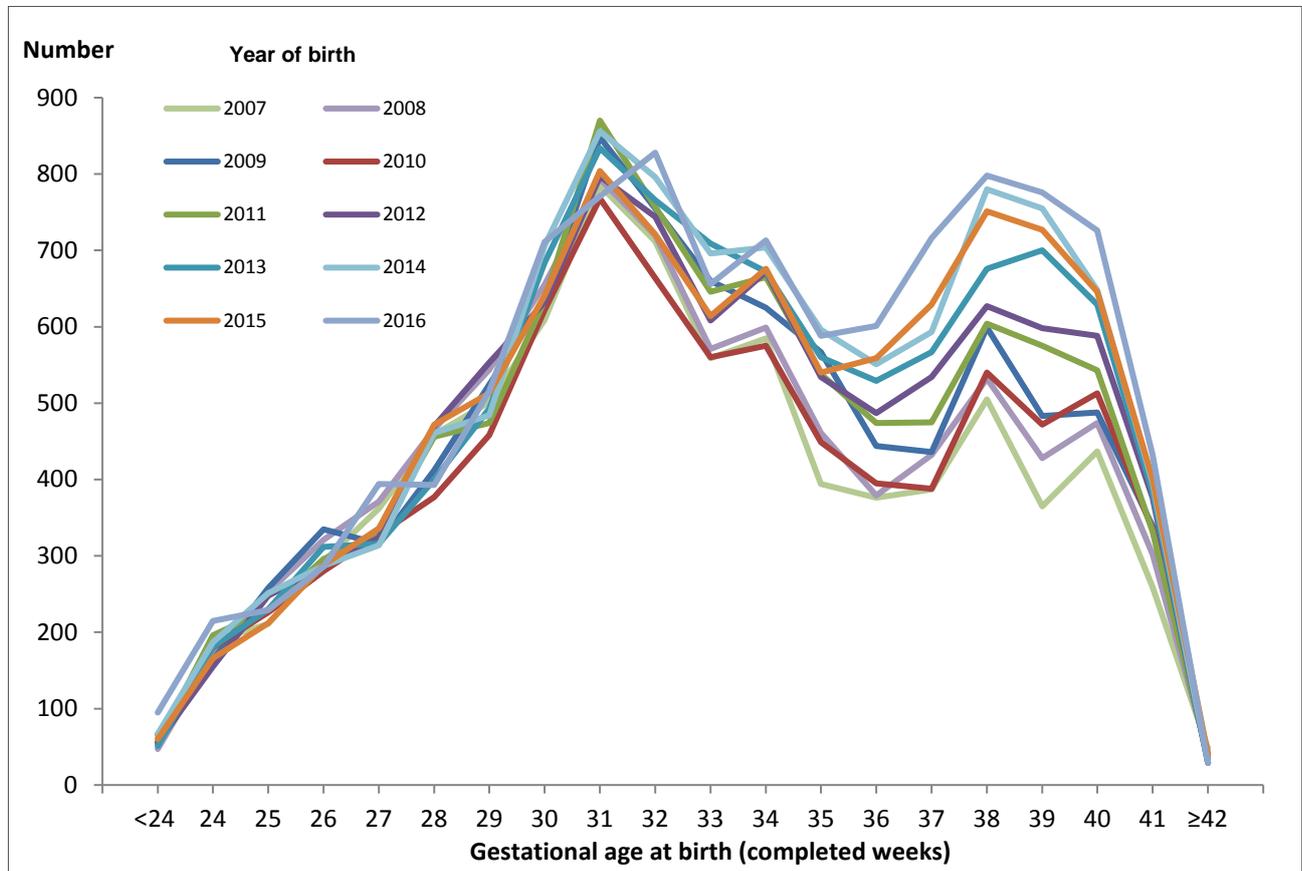
Respiratory and gastrointestinal tract (GIT) complications such as respiratory distress syndrome and necrotising enterocolitis commonly affect extremely premature babies and can lead to ongoing disease. Of the 3,208 infants with data available on the use of respiratory support, ten (0.3%) were supported by tracheostomy and 24 (0.7%) were supported by supplemental oxygen at the time of 2–3 year follow-up. One-third (32.4%) of infants receiving respiratory support were less than 25 weeks gestational age.

One infant was reported as receiving parenteral nutrition for nutritional support, and intragastric tube feeding via a percutaneous endoscopic gastronomy tube or nasogastric tube was reported for 78 (2.4%) of the 3,203 infants with nutritional support data at the time of 2–3 year follow-up. It should be noted that seven of the 79 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 (3.7%) and infants 28 weeks gestational age or older who weighed less than 1,000 grams at birth (3.4%).

APPENDICES

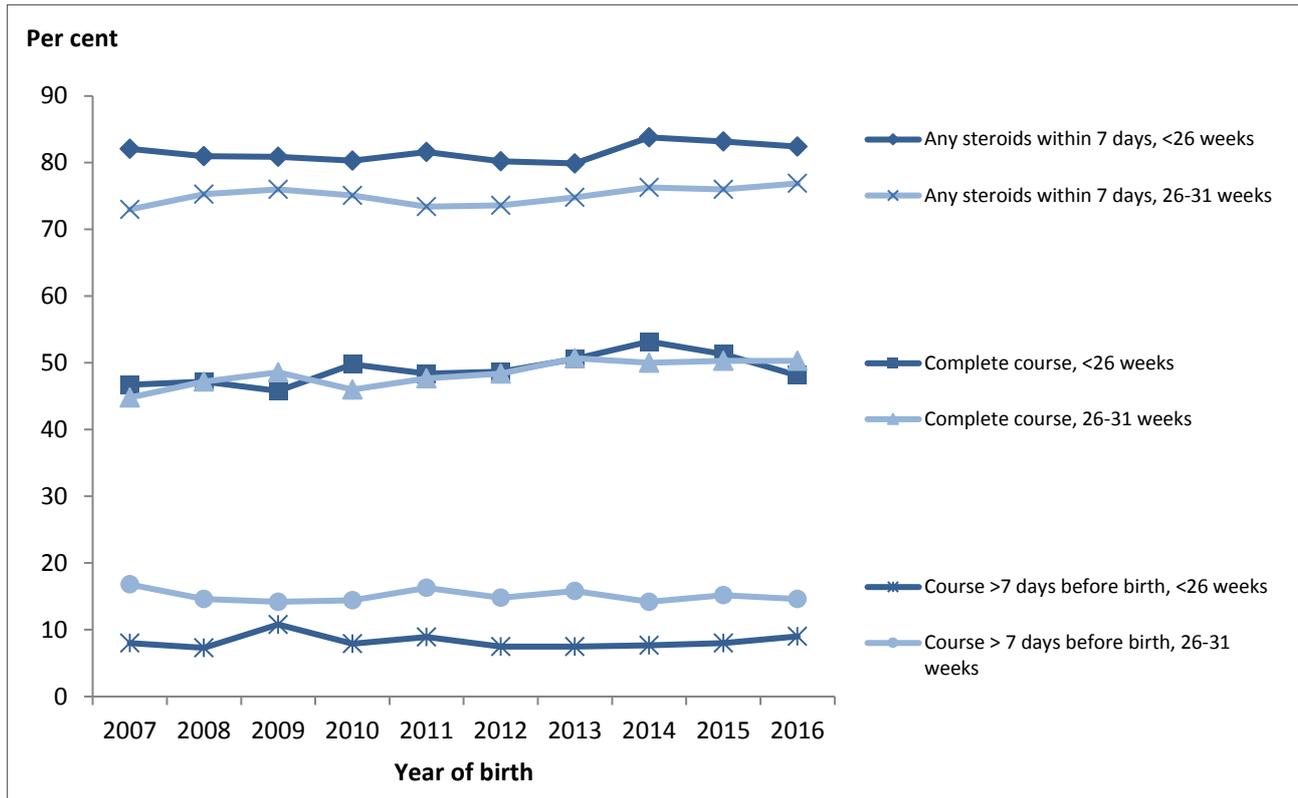
Appendix 1: Trends

FIGURE 11: Trends in gestational age at birth of level III registrants, 2007–2016



Note: Data on the ANZNN registrants from two level III NICUs were not included in 2010. Please refer to www.anznn.net for colour version.

FIGURE 12: Trends in the use of corticosteroids for mothers of babies less than 32 weeks gestation, 2007–2016



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, 2007–2016

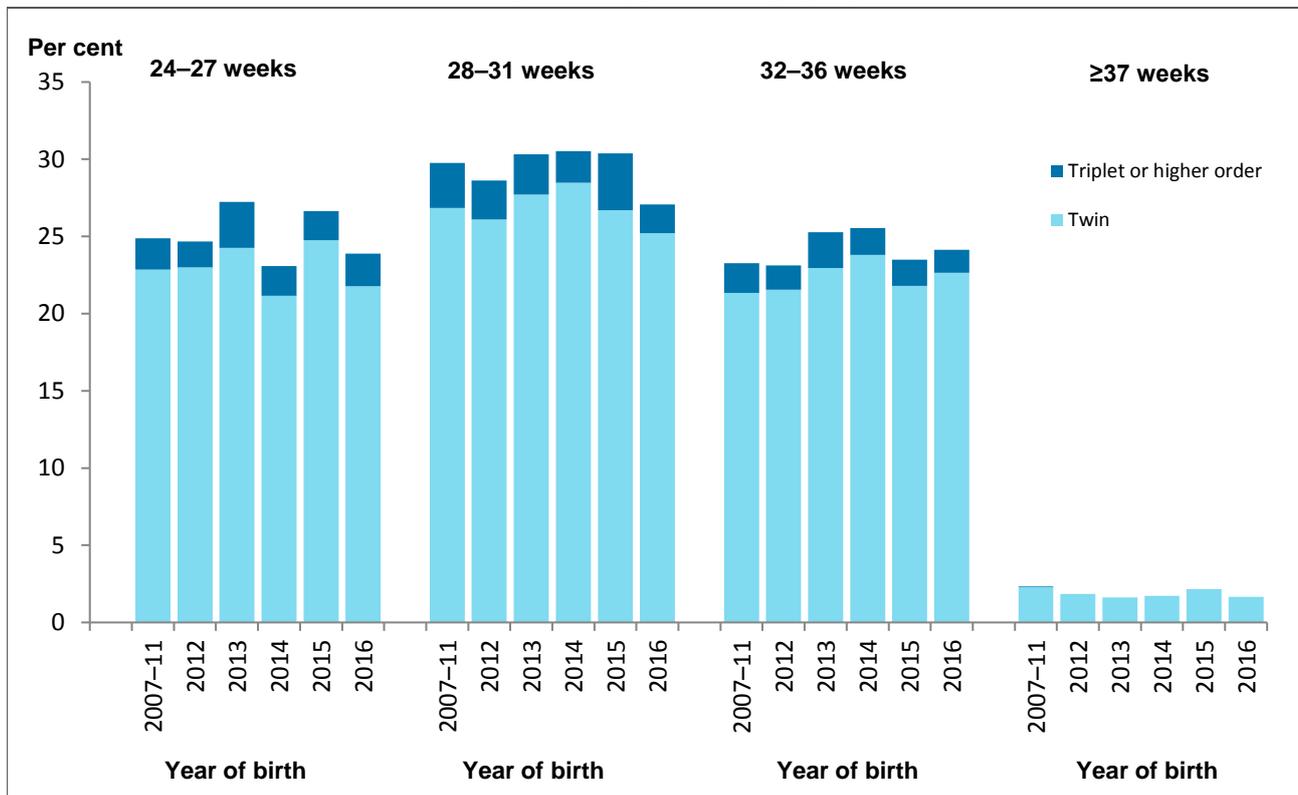


FIGURE 14: Trends in method of birth for level III registrants by year of birth, 2007–2016

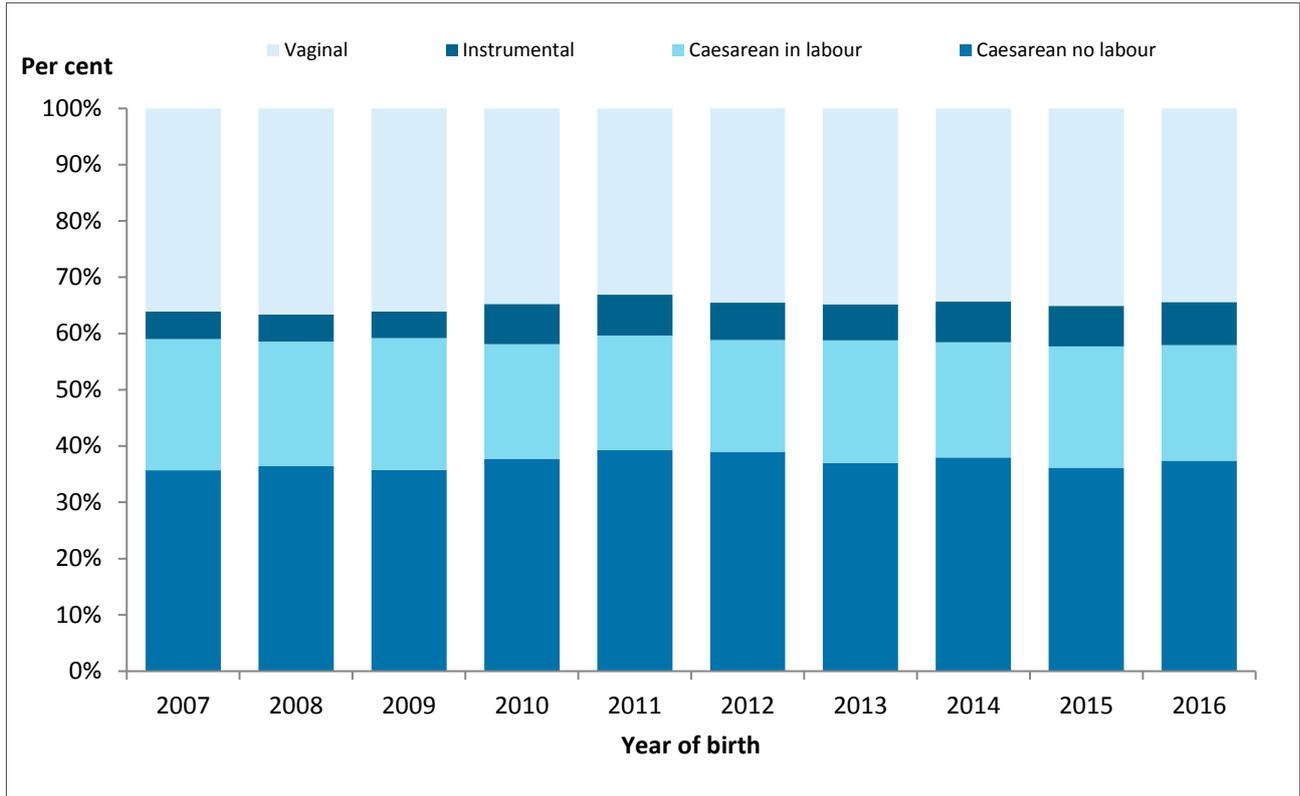


FIGURE 15: Trends in referral source to level III NICU by year of birth, 2007–2016

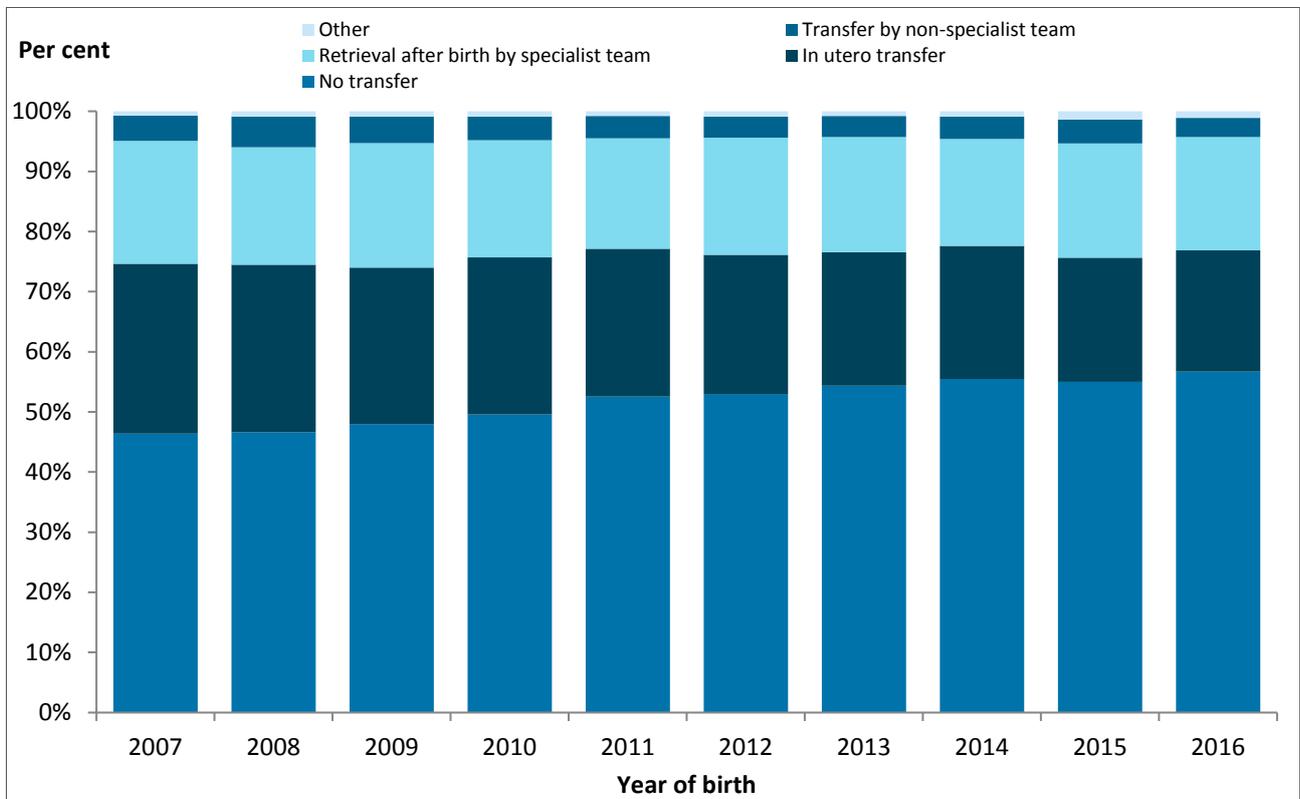


FIGURE 16: Trends in mode of transport to level III NICU, 2007–2016

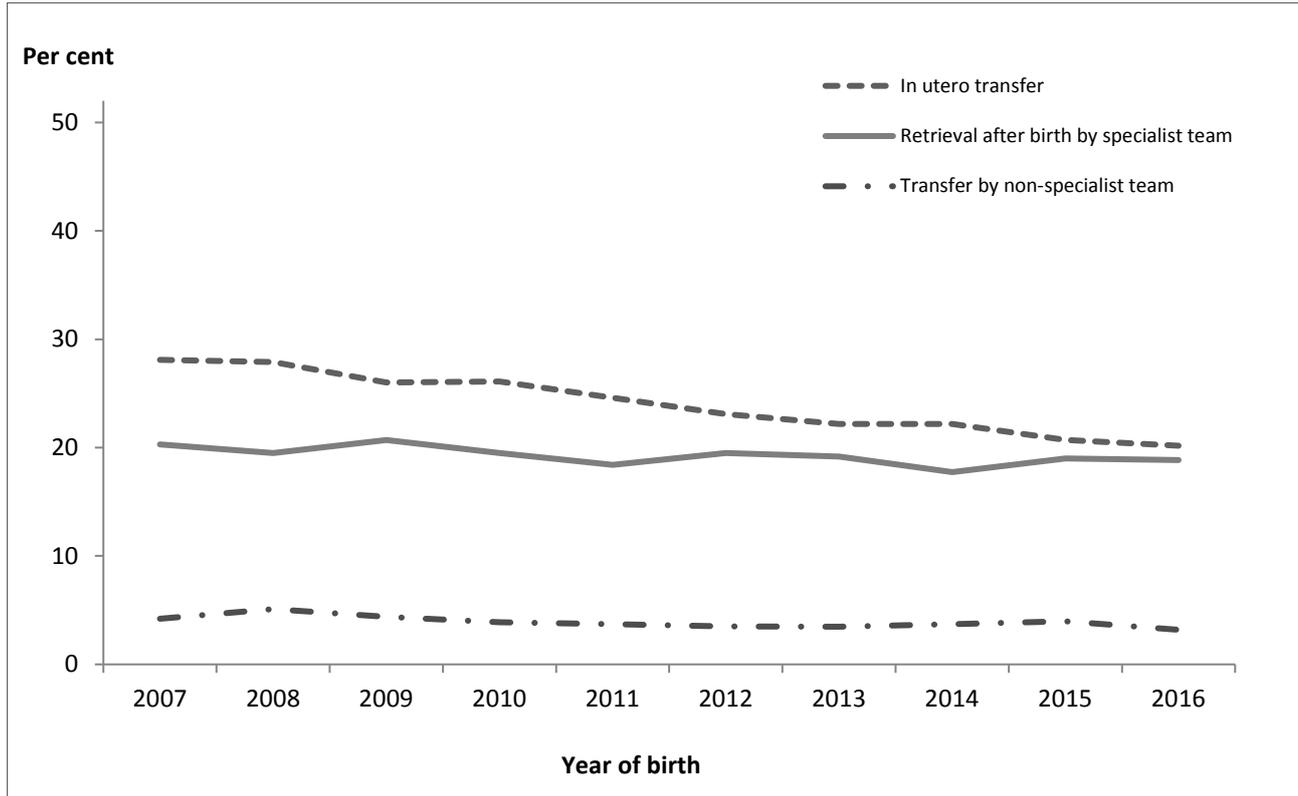


FIGURE 17: Trends in mode of assisted ventilation for level III registrants, 2007–2016

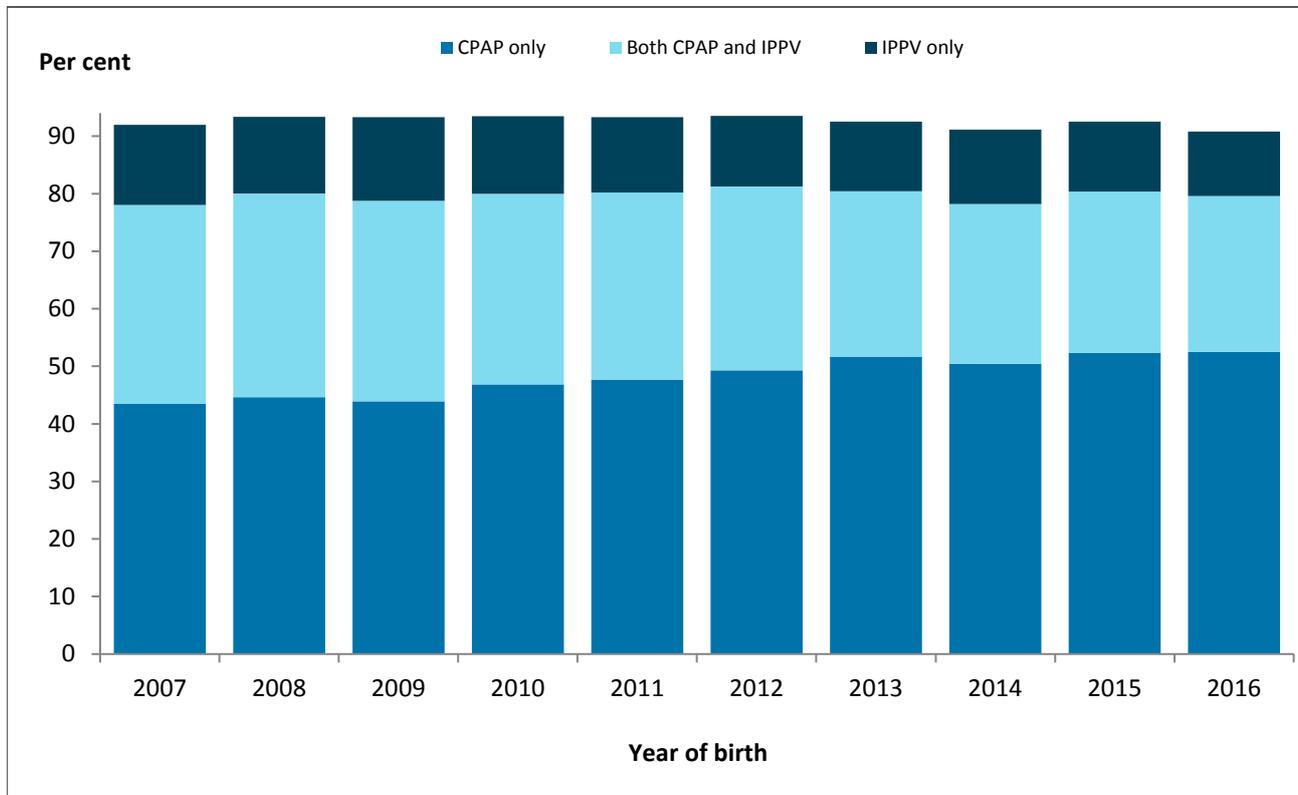


FIGURE 18: Trends in provision of intermittent positive pressure ventilation and continuous positive pressure ventilation by year of birth for level III registrants ventilated, 2007–2016

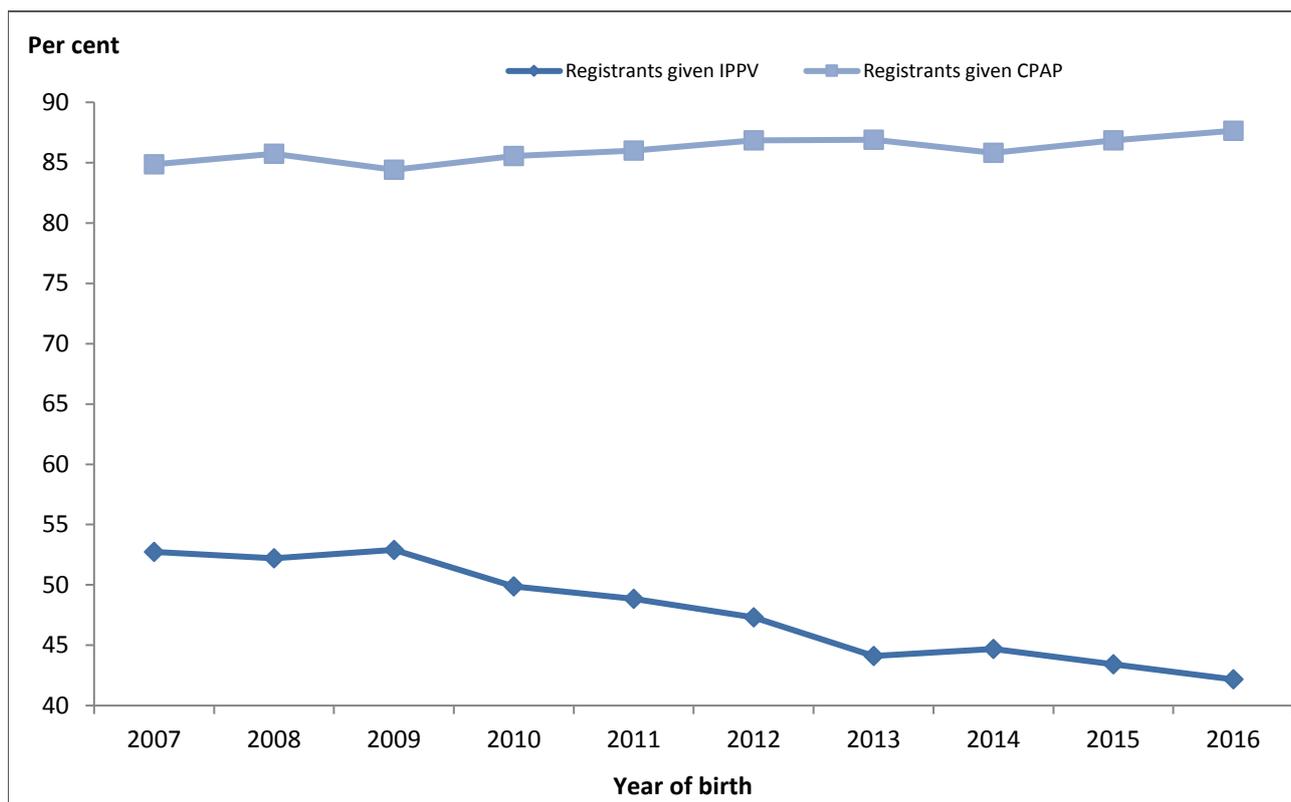


FIGURE 19: Trends in the use of CPAP as the only form of ventilation by gestational age for level III registrants, 2007, 2010, 2013–2016

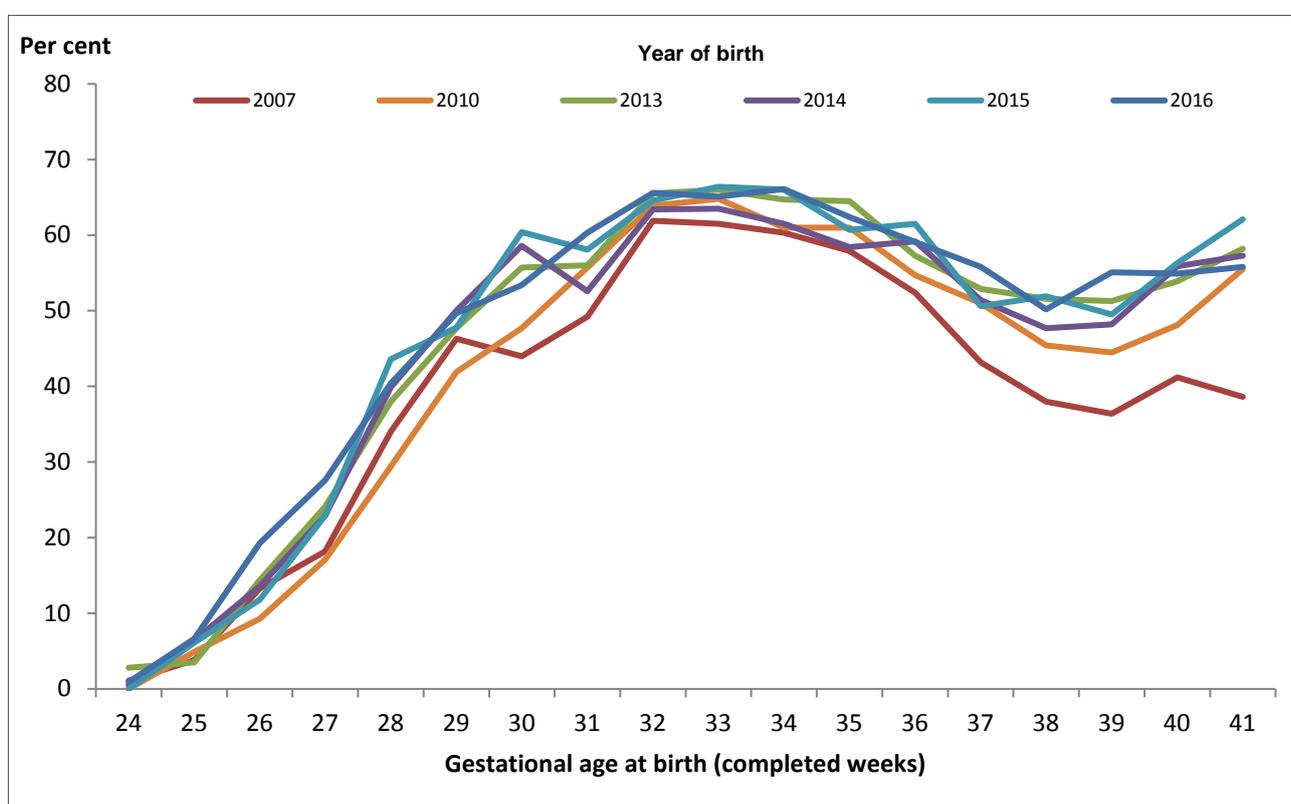
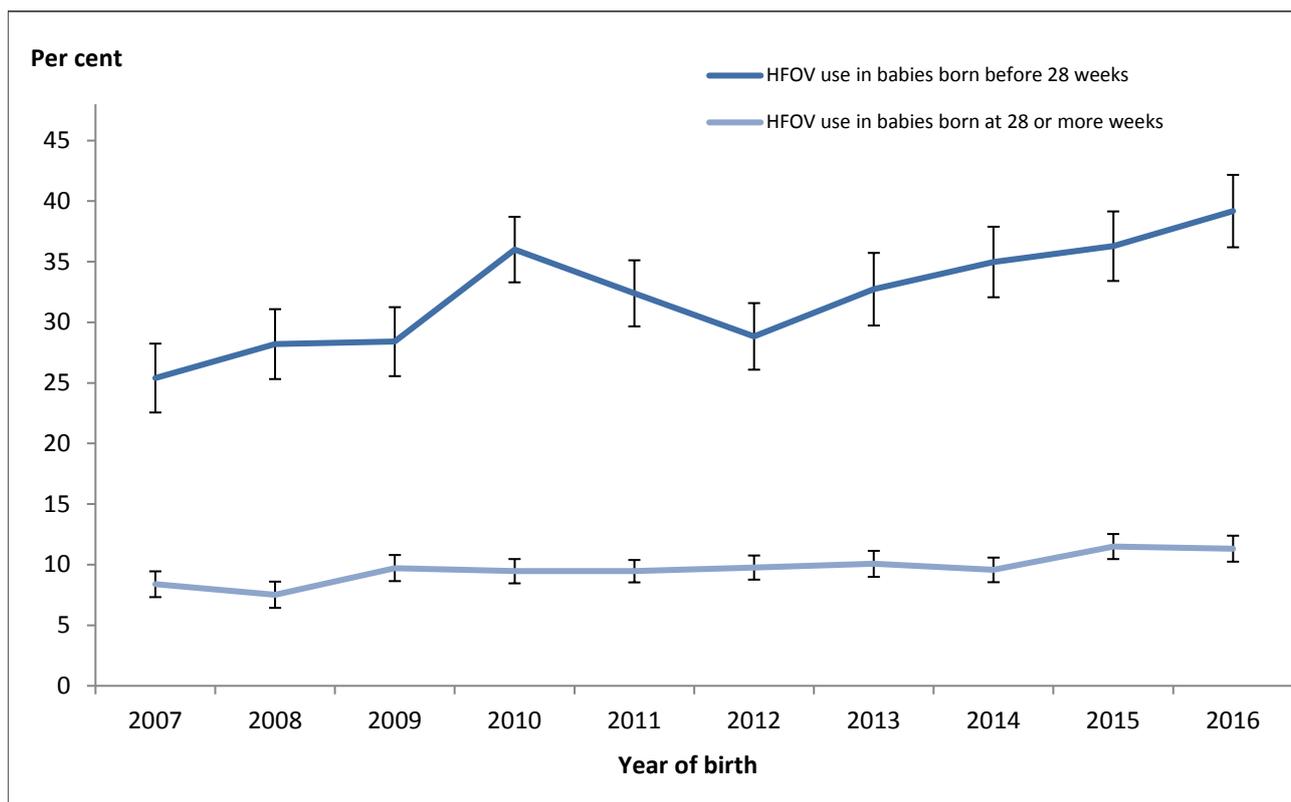
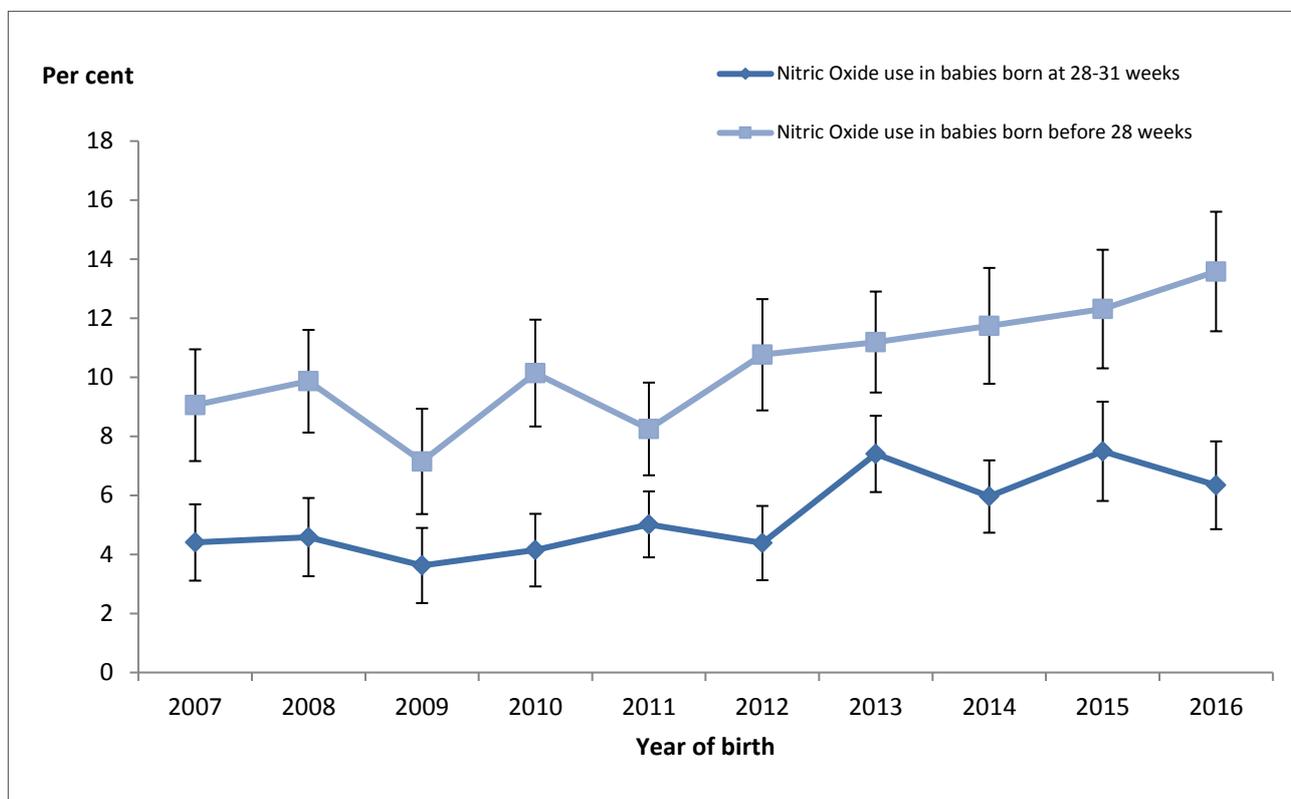


FIGURE 20: Trends in provision of high frequency oscillatory ventilation (with 95% CI) for level III registrants born before 28 weeks and at 28 or more weeks gestation, 2007–2016



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, 2007–2016



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, 2007–2016

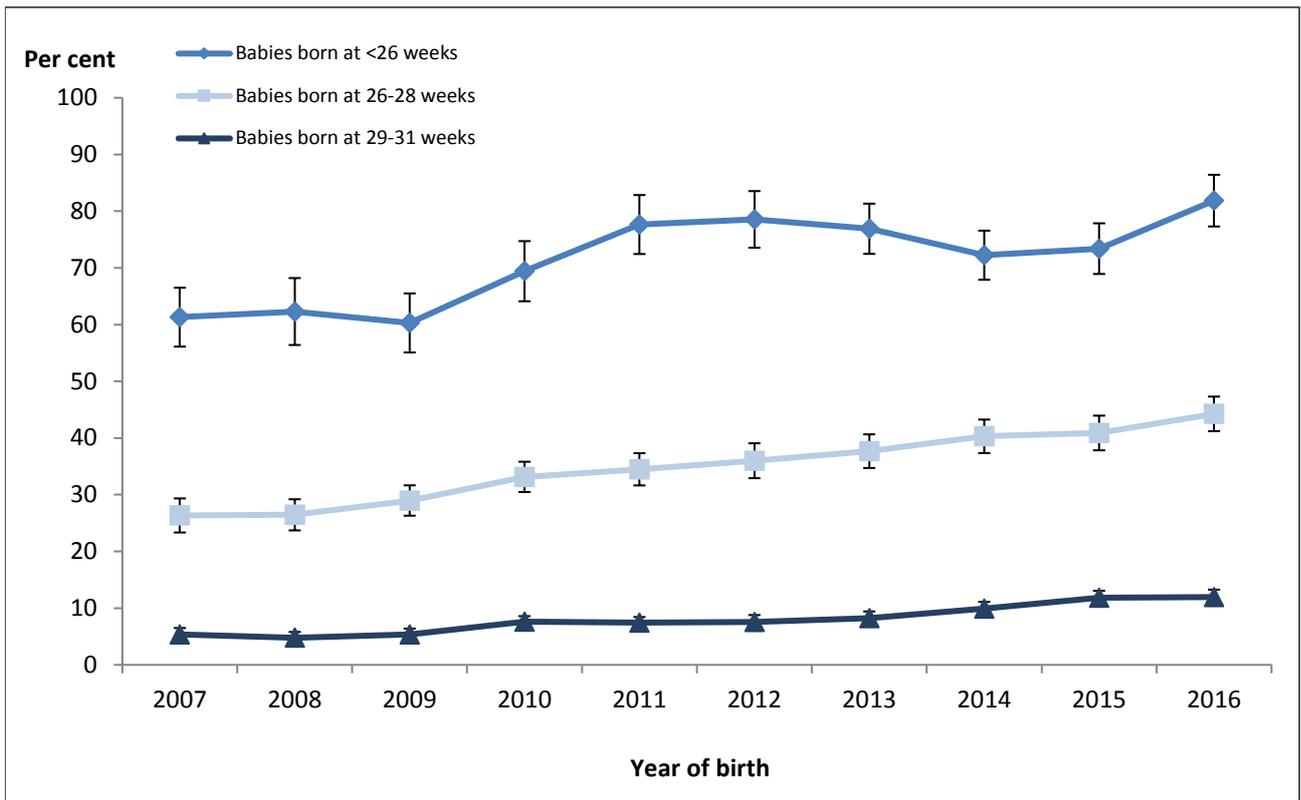


FIGURE 23: Stage 3 or 4 retinopathy of prematurity and treated retinopathy among babies born before 31 weeks gestation and/or birthweight of less than 1,250 grams who survived to 36 weeks corrected age for level III registrants, 2007–2016

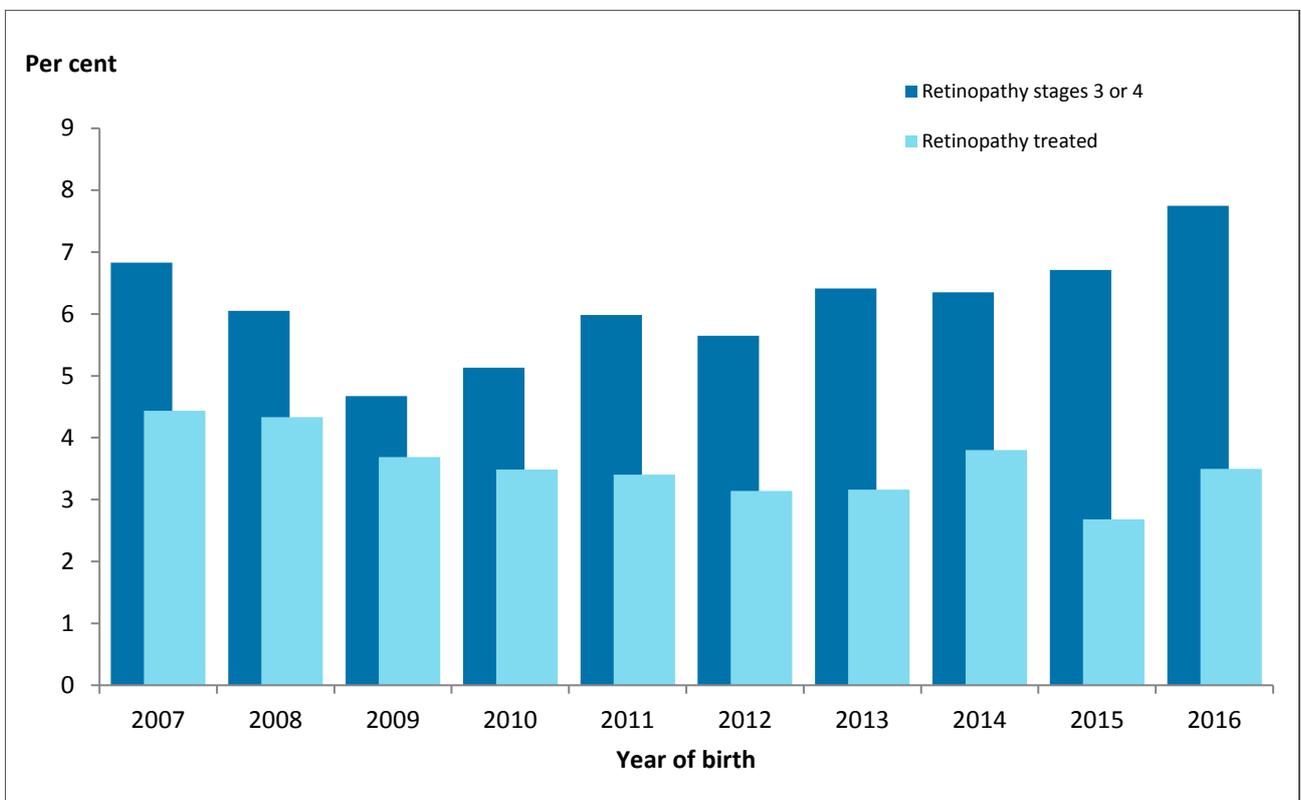


FIGURE 24: Trends in grade 3 or 4 intraventricular haemorrhage (with 95% CI) in babies born at less than 32 weeks gestation who survived to day 3 for level III registrants, 2007–2016

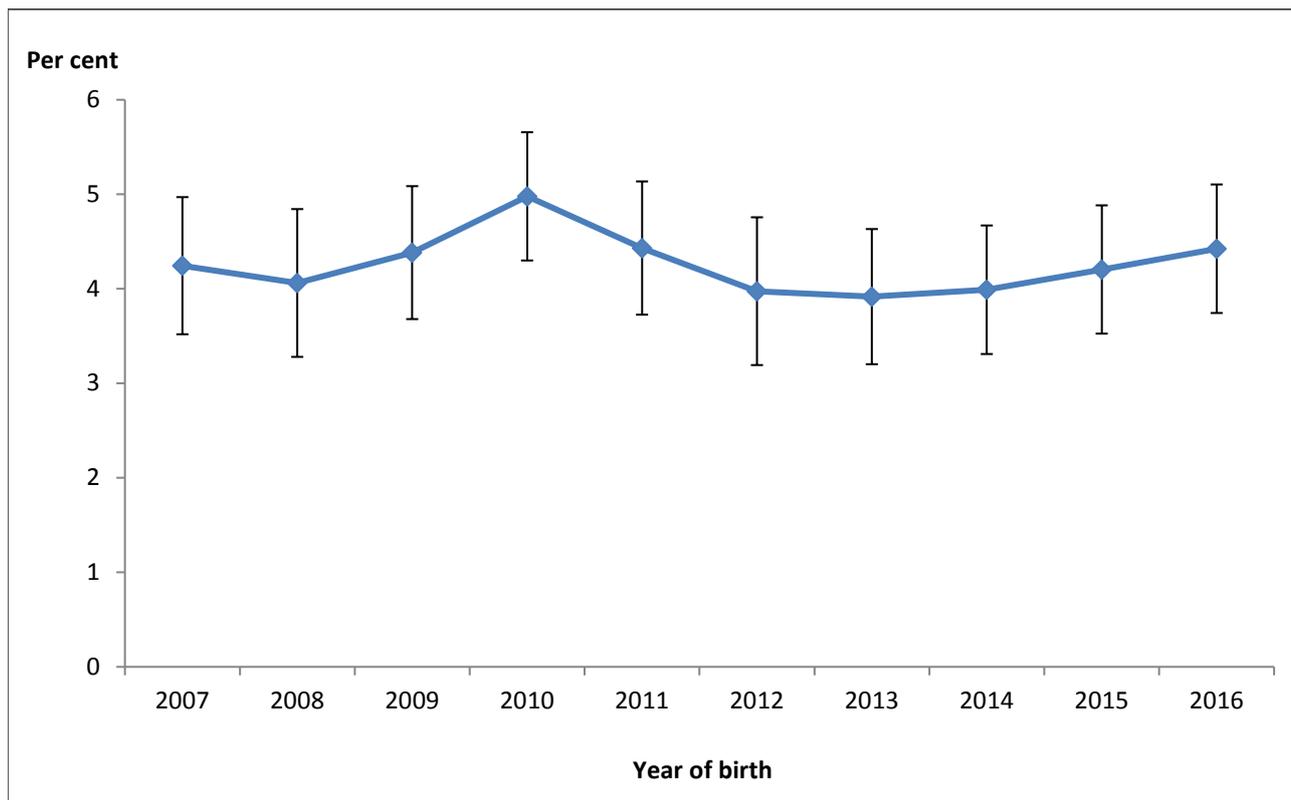


FIGURE 25: Incidence of early sepsis for level III registrants by gestational age group, 2012–2016

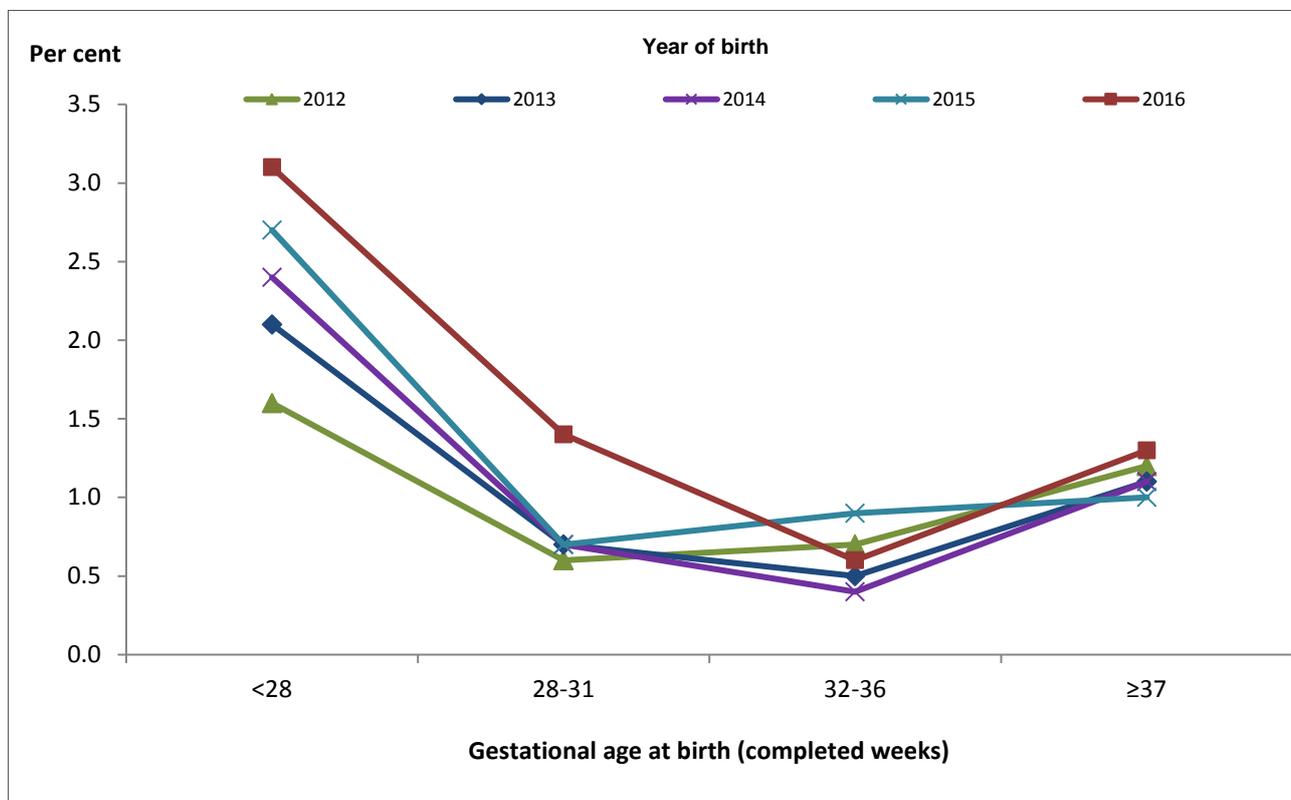
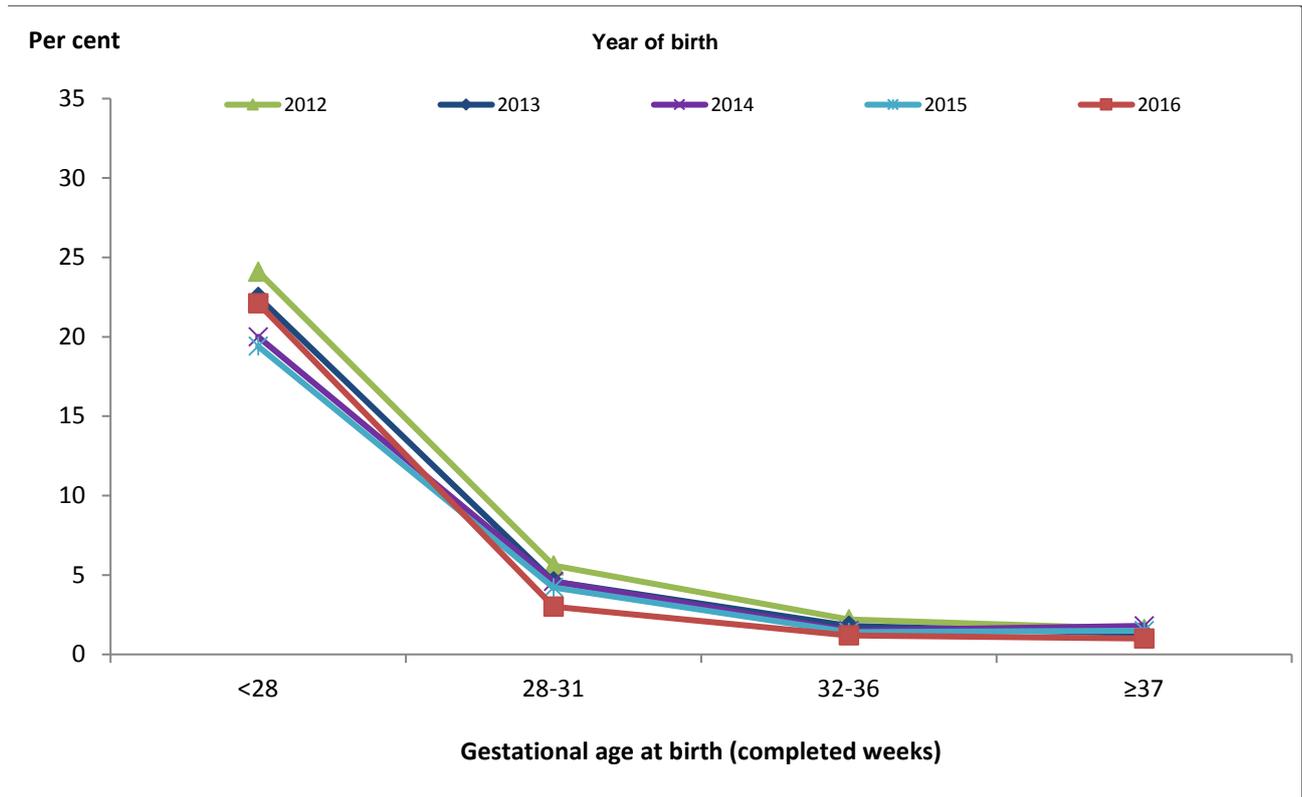


FIGURE 26: Incidence of late sepsis for level III registrants by gestational age group, 2012–2016



Appendix 2: Data tables by birthweight

TABLE 51: Antenatal corticosteroid use for level III registrants by birthweight group, 2016

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	26	46	70	92	272	489	850	1,119	832	n.p.	4,216
Incomplete course	<5	123	195	196	244	484	259	110	30	6	<5	1,655
Course completed	21	218	392	435	529	730	389	154	73	26	16	2,983
Completed > 7 days	<5	40	111	124	155	236	149	78	33	15	n.p.	949
Not stated	0	7	6	7	20	39	57	123	193	158	60	670
Total	28	414	750	832	1,040	1,761	1,343	1,315	1,448	1,037	505	10,473
Per cent												
None	n.p.	6.4	6.2	8.5	9.0	15.8	38.0	71.3	89.2	94.7	n.p.	43.0
Incomplete course	n.p.	30.2	26.2	23.8	23.9	28.1	20.1	9.2	2.4	0.7	n.p.	16.9
Course completed	75.0	53.6	52.7	52.7	51.9	42.4	30.2	12.9	5.8	3.0	3.6	30.4
Completed > 7 days	n.p.	9.8	14.9	15.0	15.2	13.7	11.6	6.5	2.6	1.7	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, 2016

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	n.p.	310	545	608	674	1,209	n.p.	1,185	1,421	1,037	504	8,558
Twins	6	93	193	195	343	515	283	130	27	0	1	1,786
Triplets and higher orders	<5	11	12	29	23	36	n.p.	0	0	0	0	128
Not stated	0	0	0	0	0	1	0	0	0	0	0	1
Total	28	414	750	832	1,040	1,760	1,343	1,315	1,448	1,037	505	10,473
Per cent												
Singleton	n.p.	74.9	72.7	73.1	64.8	68.7	n.p.	90.1	98.1	100.0	99.8	81.7
Twins	21.4	22.5	25.7	23.4	33.0	29.3	21.1	9.9	1.9	0.0	0.2	17.1
Triplets and higher orders	n.p.	2.7	1.6	3.5	2.2	2.0	n.p.	0.0	0.0	0.0	0.0	1.2
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 53: Method of birth for level III registrants by birthweight group, 2016

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	9	153	221	223	293	549	464	505	556	429	194	3,596	
Vaginal instrumental birth	0	5	11	16	24	84	78	131	224	158	68	799	
Caesarean in labour	<5	93	169	171	174	378	272	n.p.	290	225	110	2,145	
Caesarean no labour	n.p.	162	346	421	547	745	527	n.p.	376	224	129	3,910	
Not stated	0	1	3	1	2	5	2	2	2	2	1	4	23
Total	28	414	750	832	1,040	1,761	1,343	1,315	1,448	1,037	505	10,473	
	Per cent												
Vaginal	32.1	37.0	29.6	26.8	28.2	31.3	34.6	38.5	38.5	41.4	38.7	34.4	
Vaginal instrumental birth	0.0	1.2	1.5	1.9	2.3	4.8	5.8	10.0	15.5	15.3	13.6	7.6	
Caesarean in labour	n.p.	22.5	22.6	20.6	16.8	21.5	20.3	n.p.	20.1	21.7	22.0	20.5	
Caesarean no labour	n.p.	39.2	46.3	50.7	52.7	42.4	39.3	n.p.	26.0	21.6	25.7	37.4	
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	

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

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

TABLE 54: Level of hospital of birth for level III registrants by birthweight group, 2016

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	28	384	666	722	916	1,481	1,081	951	1,022	719	352	8,322
Non-tertiary	0	23	74	100	n.p.	269	251	347	n.p.	299	146	2,045
Not born in a hospital ^(a)	0	5	7	8	n.p.	9	9	13	<5	16	5	83
Not stated	0	2	3	2	2	2	2	4	1	3	2	23
Total	28	414	750	832	1,040	1,761	1,343	1,315	1,448	1,037	505	10,473
	Per cent											
Tertiary	100.0	93.2	89.2	87.0	88.2	84.2	80.6	72.5	70.6	69.5	70.0	79.6
Non-tertiary	0.0	5.6	9.9	12.0	n.p.	15.3	18.7	26.5	n.p.	28.9	29.0	19.6
Not born in a hospital ^(a)	0.0	1.2	0.9	1.0	n.p.	0.5	0.7	1.0	n.p.	1.5	1.0	0.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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, 2016

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	28	380	663	723	908	1,440	1,019	892	955	686	352	8,046
Specialist retrieval team	0	21	66	86	112	277	250	349	401	277	133	1,972
Non-specialist team	0	5	9	12	9	22	55	61	79	66	16	334
Other	0	8	11	10	11	22	18	12	12	8	4	116
Not stated	0	0	1	1	0	0	1	1	1	0	0	5
Total	28	414	750	832	1,040	1,761	1,343	1,315	1,448	1,037	505	10,473
Per cent												
Not transported	100.0	91.8	88.5	87.0	87.3	81.8	75.9	67.9	66.0	66.2	69.7	76.9
Specialist retrieval team	0.0	5.1	8.8	10.3	10.8	15.7	18.6	26.6	27.7	26.7	26.3	18.8
Non-specialist team	0.0	1.2	1.2	1.4	0.9	1.2	4.1	4.6	5.5	6.4	3.2	3.2
Other	0.0	1.9	1.5	1.2	1.1	1.2	1.3	0.9	0.8	0.8	0.8	1.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

TABLE 56: Exogenous surfactant use by level III registrants by birthweight group, 2016

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	39	n.p.	409	711	1,326	1,097	1,124	1,302	952	452	7,611
Curosurf	24	372	522	365	278	358	204	164	120	70	46	2,523
Survanta	<5	<5	28	54	47	n.p.	38	27	23	n.p.	6	314
Curosurf and Survanta	0	<5	<5	<5	<5	<5	<5	0	0	<5	0	11
Other or unknown surfactant	0	0	0	n.p.	n.p.	0	n.p.	0	2	0	1	7
Not stated	0	0	2	2	1	0	1	0	1	0	0	7
Total	28	414	750	832	1,040	1,761	1,343	1,315	1,448	1,037	505	10,473
Per cent												
None	n.p.	9.4	n.p.	49.3	68.4	75.3	81.7	85.5	90.0	91.8	89.5	72.7
Curosurf	85.7	89.9	69.8	44.0	26.8	20.3	15.2	12.5	8.3	6.8	9.1	24.1
Survanta	n.p.	n.p.	3.7	6.5	4.5	n.p.	2.8	2.1	1.6	n.p.	1.2	3.0
Curosurf and Survanta	0.0	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	0.0	0.0	n.p.	0.0	0.1
Other or unknown surfactant	0.0	0.0	0.0	n.p.	n.p.	0.0	n.p.	0.0	0.1	0.0	0.2	0.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

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

TABLE 57: Assisted ventilation for level III registrants by birthweight group, 2016

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	19	341	689	735	811	1,484	1,099	988	1,053	753	363	8,335
Invasive ventilation	26	373	550	400	305	473	405	454	511	355	164	4,016
▪ IPPV given	26	373	549	400	305	471	405	454	508	355	164	4,010
▪ HFOV given	20	209	161	56	30	42	27	41	70	52	30	738
NO given	9	72	53	30	15	26	32	61	106	81	50	535
Total in each birthweight group	28	414	750	832	1,040	1,761	1,343	1,315	1,448	1,037	505	10,473
Per cent												
CPAP given	67.9	82.4	91.9	88.3	78.0	84.3	81.8	75.1	72.7	72.6	71.9	79.6
IPPV given	92.9	90.1	73.2	48.1	29.3	26.7	30.2	34.5	35.1	34.2	32.5	38.3
Per cent of babies given invasive ventilation												
HFOV given	76.9	56.0	29.3	14.0	9.8	8.9	6.7	9.0	13.7	14.6	18.3	18.4
NO given	34.6	19.3	9.6	7.5	4.9	5.5	7.9	13.4	20.7	22.8	30.5	13.3

Note: Groups are not mutually exclusive.

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

TABLE 58: Medians and interquartile ranges of assisted ventilation for level III registrants by birthweight group, 2016

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	518	304	86	26	24	20	42	51	52	50	57	47
IQR	275–1,124	85–633	20–289	11–84.5	11–62	9–47	15–89	20.5–99	22–100	20–99	18–105.5	16–125
CPAP (hours)												
Median	729	974	795	217	76.5	36	24	20	16	14	15	36
IQR	189–1,225	557–1,296	315–1,144	76–688	25–184	17–83	10–54	9–48	7–37	7–34	8–30	13–123

Note: IQR = Interquartile range

TABLE 59: Chronic lung disease for level III registrants by birthweight group, 2016

Chronic lung disease (CLD)	Birthweight group (grams)							Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	≥2000	
	Number							
No CLD	10	132	376	609	958	1,723	5,637	9,445
CLD	18	282	374	223	82	38	11	1,028
Total	28	414	750	832	1,040	1,761	5,648	10,473
	Per cent							
No CLD	35.7	31.9	50.1	73.2	92.1	97.8	99.8	90.2
CLD	64.3	68.1	49.9	26.8	7.9	2.2	0.2	9.8
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

TABLE 60: Respiratory support (airway support or supplemental oxygen therapy) for level III registrants who survived to day 28 by birthweight group, 2016

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	9	100	349	774	1,599	1,253	1,235	1,359	980	483	8,141
Respiratory support on day 28	20	330	608	461	249	137	65	50	50	27	17	2,014
▪ survived to discharge home	15	309	596	454	246	133	57	40	43	22	15	1,930
▪ died before discharge	5	21	12	7	<5	<5	8	10	7	5	<5	84
Not stated	0	2	1	0	0	0	0	1	1	1	0	6
Total in each birthweight group	20	341	709	810	1,023	1,736	1,318	1,286	1,410	1,008	500	10,161
	Number											
Respiratory support on day 28 and given home oxygen	7	113	116	37	26	10	5	8	7	<5	<5	336
	Per cent											
No respiratory support on day 28	0.0	2.7	14.1	43.1	75.7	92.1	95.1	96.1	96.5	97.3	96.6	80.2
Respiratory support on day 28	100.0	97.3	85.9	56.9	24.3	7.9	4.9	3.9	3.5	2.7	3.4	19.8
▪ survived to discharge home	75.0	93.6	98.0	98.5	98.8	97.1	87.7	80.0	86.0	81.5	88.2	95.8
▪ died before discharge	25.0	6.4	2.0	1.5	1.2	2.9	12.3	20.0	14.0	18.5	11.8	4.2
	Per cent											
Respiratory support on day 28 and given home oxygen ^(a)	46.7	36.6	19.5	8.1	10.6	7.5	8.8	20.0	16.3	18.2	20.0	17.4

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

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

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

TABLE 61: Transfer after registration of level III registrants by level of destination hospital by birthweight group, 2016

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	19	244	323	344	376	674	750	879	1,087	814	377	5,887
Level III hospital	<5	28	64	56	63	57	42	46	41	16	n.p.	431
Level II hospital	<5	91	315	402	581	1,005	519	331	255	159	n.p.	3,743
Children's hospital	<5	51	48	30	20	25	32	59	65	46	n.p.	410
Not stated	0	0	0	0	0	0	0	0	0	2	0	2
Total	28	414	750	832	1,040	1,761	1,343	1,315	1,448	1,037	505	10,473
Per cent												
Not transferred	67.9	58.9	43.1	41.3	36.2	38.3	55.8	66.8	75.1	78.6	74.7	56.2
Level III hospital	n.p.	6.8	8.5	6.7	6.1	3.2	3.1	3.5	2.8	1.5	n.p.	4.1
Level II hospital	n.p.	22.0	42.0	48.3	55.9	57.1	38.6	25.2	17.6	15.4	n.p.	35.7
Children's hospital	n.p.	12.3	6.4	3.6	1.9	1.4	2.4	4.5	4.5	4.4	n.p.	3.9
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 62: Retinopathy of prematurity for level III registrants by birthweight group, 2016

Retinopathy of prematurity (ROP)	Birthweight group (grams)						Total
	<500	500-749	750-999	1000-1249	1250-1499	≥1500	
Number							
No ROP	<5	81	321	573	525	n.p.	2,031
Stage 1 ROP	<5	n.p.	144	101	n.p.	22	367
Stage 2 ROP	<5	91	150	62	27	n.p.	344
Stage 3 ROP	8	101	69	12	<5	0	n.p.
Stage 4 ROP	0	<5	0	0	0	0	<5
Not examined	10	84	64	74	413	6,386	7,031
Not stated	0	0	2	10	30	462	504
Total	28	414	750	832	1,040	7,409	10,473
Per cent							
No ROP	n.p.	24.5	46.9	76.6	87.9	n.p.	69.1
Stage 1 ROP	n.p.	n.p.	21.1	13.5	n.p.	3.9	12.5
Stage 2 ROP	n.p.	27.6	21.9	8.3	4.5	n.p.	11.7
Stage 3 ROP	44.4	30.6	10.1	1.6	n.p.	0.0	n.p.
Stage 4 ROP	0.0	n.p.	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

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 who survived to day 3 by birthweight group, 2016^(a)

Intraventricular haemorrhage	Birthweight group (grams)						Total
	<500	500-749	750-999	1000-1249	1250-1499	≥1500	
	Number						
None	17	217	535	663	746	1,796	3,974
Grade 1	5	50	89	64	78	141	427
Grade 2	<5	53	52	24	19	26	175
Grade 3	<5	19	16	14	5	9	64
Grade 4	0	36	26	10	9	11	92
Not examined	2	17	21	52	177	5,366	5,635
Total	26	392	739	827	1,034	7,349	10,367
	Per cent						
None	70.8	57.9	74.5	85.5	87.0	90.6	84.0
Grade 1	20.8	13.3	12.4	8.3	9.1	7.1	9.0
Grade 2	4.2	14.1	7.2	3.1	2.2	1.3	3.7
Grade 3	4.2	5.1	2.2	1.8	0.6	0.5	1.4
Grade 4	0.0	9.6	3.6	1.3	1.1	0.6	1.9
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, 2016

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	15	279	621	770	1,007	1,719	1,314	1,283	1,414	1,023	491	9,936
Sepsis at <48 hrs ^(a)	0	13	12	10	10	20	12	9	22	7	8	123
Sepsis at ≥48 hrs ^(a)	12	117	114	50	23	21	17	22	12	6	6	400
Babies alive on day 2	28	399	743	n.p.	n.p.	1,751	n.p.	1,310	1,435	1,028	n.p.	10,401
Babies who did not survive to day 2	0	15	7	<5	<5	10	<5	5	13	9	<5	72
Total in each birthweight group	28	414	750	832	1,040	1,761	1,343	1,315	1,448	1,037	505	10,473
	Per cent											
No sepsis ^(b)	53.6	67.4	82.8	92.5	96.8	97.6	97.8	97.6	97.7	98.6	97.2	94.9
Sepsis at <48 hrs ^(b)	0.0	3.1	1.6	1.2	1.0	1.1	0.9	0.7	1.5	0.7	1.6	1.2
Sepsis at ≥48 hrs ^(c)	42.9	29.3	15.3	6.0	2.2	1.2	1.3	1.7	0.8	0.6	1.2	3.8

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, 2016

Birthweight group (grams)	Number of babies	Median LOS (days)	Interquartile range (days)
<500	15	152	140–187
500-749	318	114	100–136
750-999	696	88	75–109
1,000-1,249	803	66	53–80
1,250-1,499	1,020	48	37–59
1,500-1,999	1,732	36	27–45
2,000-2,499	1,310	21	15–29
2,500-2,999	1,275	11	6–19
3,000-3,499	1,402	7	4–14
3,500-3,999	1,002	6	4–11
≥4,000	498	6	4–13
Total	10,071	26	9–51

TABLE 66: Survival to discharge home for level III registrants by birthweight group, 2016

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	28	0	24	20	15	53.6
500-749	414	<5	369	341	318	76.8
750-999	750	<5	731	709	696	92.8
1,000-1,249	832	<5	823	810	803	96.5
1,250-1,499	1,040	5	1,027	1,023	1,020	98.1
1,500-1,999	1,761	16	1,745	1,736	1,732	98.4
2,000-2,499	1,343	17	1,327	1,318	1,310	97.5
2,500-2,999	1,315	15	1,296	1,286	1,275	97.0
3,000-3,499	1,448	22	1,419	1,410	1,402	96.8
3,500-3,999	1,037	13	1,014	1,008	1,002	96.6
≥4,000	505	<5	503	500	498	98.6
Total	10,473	100	10,278	10,161	10,071	96.2

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

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 2016 who qualified as high-risk neonates were requested from each participating unit in June 2017 with a deadline of August 2017. The data was submitted to the ANZNN by each participating unit through an 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 2018. 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 airway 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 2016 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 2018.
- 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 (e.g. Fijian Indian).
- 3: Caucasian – all 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 (e.g. 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 an 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.

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 (MgSO₄) provided to the mother during the 24 hours immediately before birth, either because of maternal preeclampsia or specifically for fetal neuro-protection.

Coding:

- 0: unknown – information not available.
- 1: MgSO₄ not given at all.
- 2: MgSO₄ course stopped > 24 hours before birth.
- 3: MgSO₄ commenced > 24 hours before birth and stopped < 24 hours before birth.
- 4: MgSO₄ commenced between 4 to 24 hours before birth.
- 5: MgSO₄ commenced within 4 hours of birth.
- 6: MgSO₄ given but details not known.
- 7: MgSO₄/placebo given for randomised trial.

Guide for use: In the case of planned birth, MgSO₄ is recommended to be commenced as close to four hours before birth as possible, however if birth is planned or expected to occur sooner than four hours, administration is recommended, as there is still advantage likely from administration within this time.

Plurality

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

Coding:

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

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

Birth order

Definition: Order of each baby of a multiple birth.

Coding: Single-digit number representing birth order.

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

Date of birth

Definition: Date of birth of the patient.

Coding: DD / MM / YYYY

Admission date

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

Coding: DD / MM / YYYY

Apgar score (1 minute)

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

Coding: 2-digit number representing Apgar score.

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

Apgar score (5 minute)

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

Coding: 2-digit number.

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

Intubated at resuscitation

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

Coding:

99: unknown.

0: no, intubation was not necessary in labour ward.

-1: yes, intubation necessary in labour ward.

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

Congenital anomalies

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

Coding:

99: unknown.

0: no major congenital malformations noted.

-1: yes, major congenital malformation noted.

Specified congenital anomalies

Definition: Detail of the major congenital malformation.

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

Temperature on admission

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

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

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

Worst base excess

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

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

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

Main respiratory diagnosis

Definition: Main indication for respiratory support.

Coding:

- 0: unknown.
- 1: normal – no respiratory support.
- 2: non-specific – any non-specific respiratory distress 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 airway 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.

Respiratory support at 36 weeks post menstrual age

Definition: Status of respiratory support at 36 weeks and 0 days / post menstrual age 252 days.

Coding:

0: unknown.

1: no respiratory support.

2: low flow air +/- oxygen with feeds (≤ 1 L/min).

3: low flow oxygen (≤ 1 L/min).

4: oxygen via head box or incubator.

5: high flow > 1 L/min.

6: nasal CPAP.

7: nasal ventilation (includes nasal high frequency).

8: endotracheal CPAP or ventilation (includes high frequency).

9: endotracheal tube alone.

10: tracheostomy CPAP or ventilation (includes high frequency).

11: tracheostomy alone.

Guide for use: Supersedes "Chronic lung disease".

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

Date assessed

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

Coding: DD / MM / YYYY

Corrected age in months

Definition: Age in months corrected for prematurity based on the age the child would be if the pregnancy had gone to term (40 weeks).

Coding: Number representing the number of months to one decimal place

Guide for use: The age when performance is no longer influenced by prematurity and the need to use corrected age is controversial. However objective evidence supports the need to make this allowance up to approximately 8 years of age. To calculate corrected age in months, use the formula:

$(\text{Date Assessed} - \text{Estimated Date of Confinement}) / (365.25 / 12)$

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.

Other disability

Definition: Other disabilities.

Coding:

99: unknown.

0: no other disabilities.

-1: yes, other disabilities.

Description of other disabilities

Definition: Description of other disabilities. Include ICD-10 code if known.

Coding: Free text field representing description of other disabilities and ICD-10 codes if known.

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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