

# 2018

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



**UNSW**  
SYDNEY

**ANZNN**

# 2018

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## REPORT OF THE AUSTRALIAN AND NEW ZEALAND NEONATAL NETWORK

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**UNSW**  
SYDNEY

**ANZNN**

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

ISBN: 978-0-7334-3931-5

Suggested citation:

Chow, S.S.W., Creighton, P., Chambers, G.M., Lui, K. 2020.

Report of the Australian and New Zealand Neonatal Network 2018. Sydney: ANZNN.

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Published by the Australian and New Zealand Neonatal Network 2020

Designed and printed by Green Print Centre at UNSW Sydney

Please note that there is the potential for minor revisions of data in this report.  
Please check the online version at < **www.anznn.net** > for any amendments.

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## Acknowledgements

This is the twenty-third report of the Australian and New Zealand Neonatal Network (ANZNN), the eleventh report in the current format and the seventh 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’.

We would like to acknowledge all the units involved in the provision of data for this report. The ANZNN greatly 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 for their commitment and guidance for all the activities of the ANZNN: Kei Lui (Chairperson), Chad Andersen, David Barker, Malcolm Battin, Georgina Chambers, Lucy Cooke, Anjali Dhawan, Andy Gill, Barbara Hammond, Jim Holberton, Rod Hunt, Natalie Merida, Linda Ng, Karen Nothdurft, Jane Pillow, Victor Samuel Rajadurai and Javeed Travadi.

Particular thanks to the ANZNN Data Collection and Operation Committee, namely Jim Holberton (Chairperson), Jo Brooks, Georgina Chambers, Andy Gill, Rod Hunt, Elizabeth Hurron, Simon Lam, Linda McLaughlin, Peter Marshall, Karen Nothdurft, Himanshu Popat and Victor Samuel Rajadurai. The Follow-up Subcommittee comprising of Elizabeth Hurron (Chairperson), Peter Anderson, Nicola Austin, Jeanie Cheong, Vanessa Ellison, Jim Holberton, Prasanna Kumar, Ingrid Rieger, Mary Sharp and Rachel Taufer were instrumental in advising the data collection and analysis for the Extremely Preterm Follow-up chapter.

We would also like to acknowledge Evelyn Karantonis and Hina Salimuddin for proofreading this report, and for running the data validation queries and liaising with the audit officers and data managers at each participating unit to finalise the neonatal data 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 (NPESU) 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 2018.
- Chapter 2:** ‘Babies registered to level III units’ provides information and characteristics on the ANZNN registrants in 2018 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 2018.
- Chapter 4:** ‘Characteristics of level III registrants’ provides information about the babies admitted to a level III neonatal unit during 2018.
- Chapter 5:** ‘Babies registered to level II units’ provides information about babies registered to the level II special care baby units during 2018.
- Chapter 6:** ‘Extremely preterm follow-up, 2012–2015 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 2012 to 2015.
- Appendices:** Appendix 1 presents 10-year trends.  
Appendix 2 presents data tables by birthweight for 2018.  
Appendix 3 describes 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

ANZNN	Australian and New Zealand Neonatal Network	IQR	interquartile range
APH	antepartum haemorrhage	IUGR	intrauterine growth restriction
CI	confidence interval	IVF	in vitro fertilisation
CLD	chronic lung disease	IVH	intraventricular haemorrhage
CPAP	continuous positive airway pressure	MgSO <sub>4</sub>	magnesium sulphate
CRIB	Clinical Risk Index for Babies	NEC	necrotising enterocolitis
ECMO	extracorporeal membrane oxygenation	NICU	neonatal intensive care unit
g	gram	NPESU	National Perinatal Epidemiology and Statistics Unit
GIFT	gamete intra-fallopian transfer	O <sub>2</sub>	oxygen
GMFCS	gross motor function classification system	PCR	polymerase chain reaction
HFOV	high frequency oscillatory ventilation	PMA	post menstrual age
HMD	hyaline membrane disease	PPROM	preterm pre-labour rupture of membranes
ICD-10-AM	The International Statistics Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification	PVL	periventricular leukomalacia
IPPV	intermittent positive pressure ventilation	ROP	retinopathy of prematurity
		SD	standard deviation
		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: 23)*

Nadia Badawi (Co-director), Himanshu Popat (Co-director), Rob Halliday, Caroline Karskens, Christine Jorgensen

##### John Hunter Hospital

*(NICU & special care beds: 43)*

Larissa Korostenski (Director), Javeed Travadi, Rebecca Glover, Lynne Cruden, 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: 27)*

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

##### RPA Women and Babies

*(NICU & special care beds: 34)*

Mark Greenhalgh (Director), Ingrid Rieger, Crista Wocadlo, Shelley Reid

##### Sydney Children's Hospital

*(NICU & special care beds: 4)*

Andrew Numa (Director), Janelle Young

##### Westmead Hospital

*(NICU & special care beds: 44)*

Melissa Luig (Director), Melissa Ross, Tracey Anne Goyen, Jane Baird, Gemma Lowe

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

*(New South Wales and Australian Capital Territory)*

Barbara Bajuk, Janette Tommasi, Sara Sedgley, Mark Leckie

#### Australian Capital Territory

##### The Canberra Hospital

*(NICU & special care beds: 29)*

Hazel Carlisle (Director), Allana Carter, Judith Smith, Laura Maher

#### Victoria

##### Mercy Hospital for Women

*(NICU & special care beds: 58)*

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

##### Monash Medical Centre

*(NICU & special care beds: 64)*

Alice Stewart (Director), Elizabeth Carse, Kenneth Tan, Rose Li, Marie Hayes

##### Royal Children's Hospital

*(NICU & special care beds: 34)*

Rod Hunt (Director), Jo Brooks

##### Royal Women's Hospital

*(NICU & special care beds: 60)*

Carl Kuschel (Director), Lex Doyle (Professor of Neonatology), Jeanie Cheong, 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: 33)*

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

##### Mater Mothers' Hospital

*(NICU & special care beds: 79)*

Pita Birch (Director), Elizabeth Hurron, Karen Nothdurft, Leith Poulsen

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

*(NICU & special care beds: 71)*

Pieter Koorts (Director), David Cartwright, Linda McLaughlin, Melissa Lai, Anja Lipponer

## **The Townsville Hospital**

*(NICU & special care beds: 44)*

Guan Koh (Director), Prasanna Kumar, Gary Alcock, Louise McIlldowie

## **South Australia**

### **Flinders Medical Centre**

*(NICU & special care beds: 35)*

Peter Marshall (Director), Vanessa Ellison, Edith van Loon

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

*(NICU & special care beds: 49)*

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

## **Western Australia**

### **King Edward Memorial and Perth Children's Hospitals**

*(NICU & special care beds: 137)*

Mary Sharp (Director), Karen Simmer, Rolland Kohan, Steven Resnick, Rebecca Thomas, Shripada Rao, Andy Gill, Jane Pillow, Damber Shrestha

## **Northern Territory**

### **Royal Darwin Hospital**

*(NICU & special care beds: 25)*

Peter Morris (Director), Charles Kilburn, Dennis Bonney, Deborah Ribbon, Connie Yui

## **Newborn emergency transport services**

### **Newborn & paediatric Emergency Transport Service (NETS, NSW)**

Andrew Berry (Director)

### **Paediatric Infant Perinatal Emergency Retrieval (PIPER, Victoria)**

Michael Stewart (Director)

### **Neonatal Retrieval Service (NeoRESQ, Queensland)**

Lucy Cooke (Director)

### **Newborn Emergency Transport Service of Western Australia (NETS, WA)**

Jonathan Davis (Director)

## **SAAS MedSTAR Kids (South Australia)**

John Craven (Director)

## **New Zealand**

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

*(NICU & special care beds: 41)*

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

### **Dunedin Hospital**

*(NICU & special care beds: 16)*

Liza Edmonds (Director), 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, Sabine Huth

### **Waikato Hospital**

*(NICU & special care beds: 41)*

Jutta van den Boom (Director), David Bouchier, Phil Weston, Arun Nair, Claire West

### **Wellington Regional Hospital**

*(NICU & special care beds: 40)*

Vaughan Richardson (Director), Helen Miller, Harshad Patel, Jackie Chin-Poy, Claire Jacobs

## **Singapore\***

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

*(NICU & special care beds: 32)*

Bin Huey Quek (Director), Victor Samuel Rajadurai, Kee Thai Yeo, Rowena Dela Puerta

## **Hong Kong\***

### **Prince of Wales Hospital\***

*(NICU & special care beds: 82)*

Alan So (Director), Simon Lam, Peggy Chan, Xuelian Wang

\*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)*

Ahmed Khan (Director), Adam Buckmaster, 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

##### Tamworth Hospital

*(Special care beds: 6)*

Genaro Domingo (Director), Therese Madden

##### Wagga Wagga Base 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)*

Clare Collins (Director), Martin Wright, Thao  
Lu, Jennifer Francis, Rosalynn Pszczola, Nikka  
Pasion

#### The Northern Hospital

*(Special care beds: 15)*

Wei Qi Fan (Director), Ann Hood, Barbara  
Risshitelli

### Queensland

#### Cairns Hospital

*(Special care beds: 22)*

Neil Archer (Director), Sue McMahon

#### Logan Hospital

*(Special care beds: 16)*

Jan Cullen (Director), Pamela McErlean, Angela  
Geraghty

#### Mackay Base Hospital

*(Special care beds: 8)*

Jacinta Tobin (Director), Kerry Topping, Belinda  
Van Hees, Jan Sologinkin, Joanne Morganson

#### Redcliffe Hospital

*(Special care beds: 10)*

Simon Grew (Director), Marlon Radcliffe,  
Meredith Shallcross

#### Redland Hospital

*(Special care beds: 8)*

Dougie Thomas (Director), Greg Pallas,  
Pamela McErlean, Wendy Bostock

#### Sunshine Coast University Hospital

*(Special care beds: 27)*

Lizelle Weber (Director), Tom Hurley,  
Tonya Gibbs, Janet Rowley

### Northern Territory

#### Alice Springs Hospital

*(Special care beds: 8)*

James Dowler (Director), Deborah Fearon,  
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 Jensen

#### Lower Hutt Hospital

*(Special care beds: 12)*

Sarah Mills (Director), Debbie Bashaw

**Nelson Hospital**

*(Special care beds: 10)*

Peter McIlroy (Director), Nathalie Robinson, Maureen Higgs

**North Shore Hospital**

*(Special care beds: 12)*

Christopher Peterson (Director), Jutta van den Boom, 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 Bocock, Abi Webber

**Tauranga Hospital**

*(Special care beds: 10)*

Anita Lala (Director), Hugh Lees, Heather McAlley, Anna Hayns

**Timaru Hospital**

*(Special care beds: 3)*

Mick Goodwin (Director), Bid Esler, Mark Liddy

**Waitakere Hospital**

*(Special care beds: 12)*

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

**Wairau Hospital**

*(Special care beds: 4)*

David Bond (Director)

**Whakatane Hospital**

*(Special care beds: 5)*

Silvia Croker (Director), John Malcolm, Chris Moyes, Margret Norris, Lee Willetts, Katherine Dumaual

**Whanganui Hospital**

*(Special care beds: 4)*

David Montgomery (Director), Barbara Hammond

**Whangarei Area Hospital**

*(Special care beds: 8)*

David Barker (Director), Ransford Addo, Janine Whale, Merophy Brown, Georgia Kidd

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

Georgina Chambers (Director), Sharon Chow, Prudence Creighton, Evelyn Karantonis, Hina Salimuddin

# 1. Organisation of the ANZNN

## History

A prospective audit of high-risk infants 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 followed by an NICU in Hong Kong in 2017, bringing the total of NICU members to 31. For the purposes of this report, data submitted by the Singaporean and Hong Kong NICU members have not been included.

In 1998, all the level II units in New Zealand joined the Network and began contributing data. The level II unit in Tasmania, Australia joined in 1999 and level II units within Australia continue to join with a total of eighteen units contributing data in 2018.

## Aims and objectives

The ANZNN clinical quality registry aims 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 the following objectives:

- provide 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
- monitor the clinical indicators for perinatal care and improving clinical practice while maintaining national standards of evidence-based care
- monitor the use of new technologies, e.g. high flow/oxygen air usage by patient type and outcome
- achieve consistency in national data collections.

Each year, an annual report of the ANZNN clinical quality registry is published as part of the *Report of the Australian and New Zealand Neonatal Network* series.

## 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 Sydney). The arrangement is managed under a memorandum of understanding (MOU) between the ANZNN and UNSW Sydney.

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 director (or their nominee) of each participating unit, academic neonatologists and regional representatives of neonatal nurses. 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.

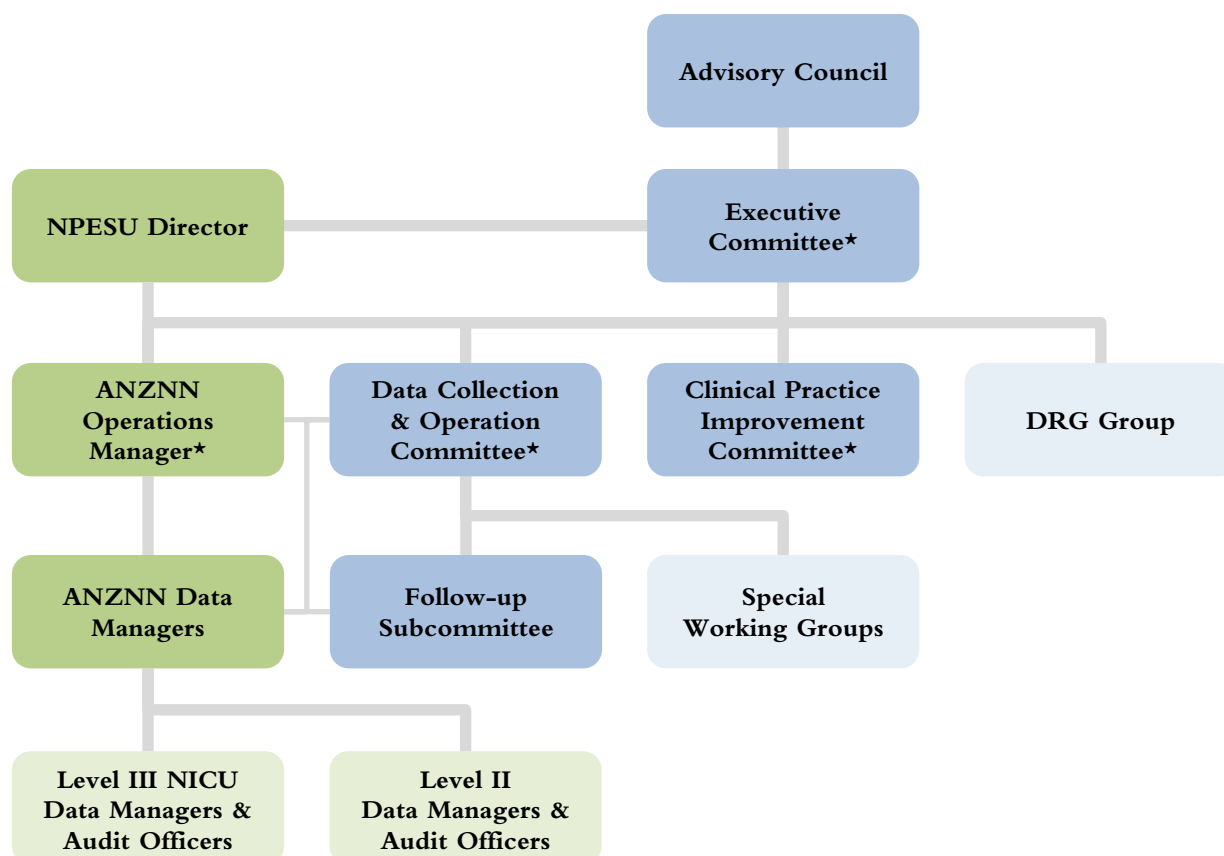
The Executive Committee is an elected committee with regional representation from unit directors, a data manager group representative and neonatal nurse representatives from across the network, and a consumer representative. It oversees the general functioning of the network, finance and decision-making, 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 deals with day-to-day business of the ANZNN and reports to the Executive Committee and Data Collection and Operation Committee.

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

**FIGURE 1: Structure of the ANZNN**



\*ANZNN Management Group – comprised of the Chairs of these committees and the ANZNN Operations Manager.

**Note:** NICU = neonatal intensive care unit.

## Registration criteria

Babies who were admitted to a participating unit during the first 28 days of life and meet one or more of the following criteria are eligible for registration with the ANZNN clinical quality registry:

- 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.

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. Data is collected until the baby's first discharge to home. Babies who were discharged home prior to admission to a participating unit were not eligible for registration in the ANZNN clinical quality registry.

## Funding support

The ANZNN is primarily funded through the annual registration fees from 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 2018 audit are listed in Appendix 5 and are also available on the website < **[www.anznn.net](http://www.anznn.net)** >.



# 2018

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

## Babies born in Australia

There were 8,625 babies registered to the ANZNN from the 23 level III NICUs in Australia, representing 2.7% of the 315,147 notified live births in 2018 (Australian Bureau of Statistics 2019). Of these registrants, 78.4% were born in a hospital with tertiary care facilities. There were 2,841 babies born before 32 weeks gestation representing 32.9% of Australian registrants.

Maternal ethnicity was provided for 91.7% of mothers: 71.1% of the mothers of these babies identified as Caucasian and 16.0% as Asian. Nearly one in thirteen mothers (7.5%) identified as Aboriginal or Torres Strait Islander, which was more than the proportion reported in all births in Australia in 2018 (4.9%) (Australian Bureau of Statistics 2019).

Among Australian NICU admissions registered to the ANZNN, 1,552 were from multiple births representing 18.0% of ANZNN admissions in Australia in 2018.

Male babies were over-represented among NICU admissions – 59.0% of the Australian ANZNN registrants, compared with 51.4% among live births in Australia (Australian Bureau of Statistics 2019).

Assisted ventilation was provided for 7,972 babies (2.5% of live births) and continuous positive airway pressure (CPAP) was the only form of respiratory assistance for 4,863 babies.

## Babies born in New Zealand

There were 2,026 babies who met ANZNN registration criteria from the six level III NICUs in New Zealand representing 3.5% of the 58,020 live births registered in New Zealand in 2018 (Statistics New Zealand 2019). Of these registrants, 86.4% were born in a hospital with tertiary care facilities. There were 576 babies born before 32 weeks gestation representing 28.4% of New Zealand registrants.

Maternal ethnicity was reported for 99.7% of the New Zealand registrants. The percentage of Caucasian mothers was 46.8%. A higher proportion of mothers identified themselves as Maori (19.1%) compared to 12.6% of mothers identified as Pacific Islander and 18.0% as Asian.

Among New Zealand NICU admissions registered to the ANZNN, 264 were from multiple births representing 13.0% of ANZNN admissions in New Zealand in 2018.

Male babies were also over-represented among NICU admissions in New Zealand – 58.0% of the New Zealand registrants compared to 51.2% of total live births in New Zealand (Statistics New Zealand 2019).

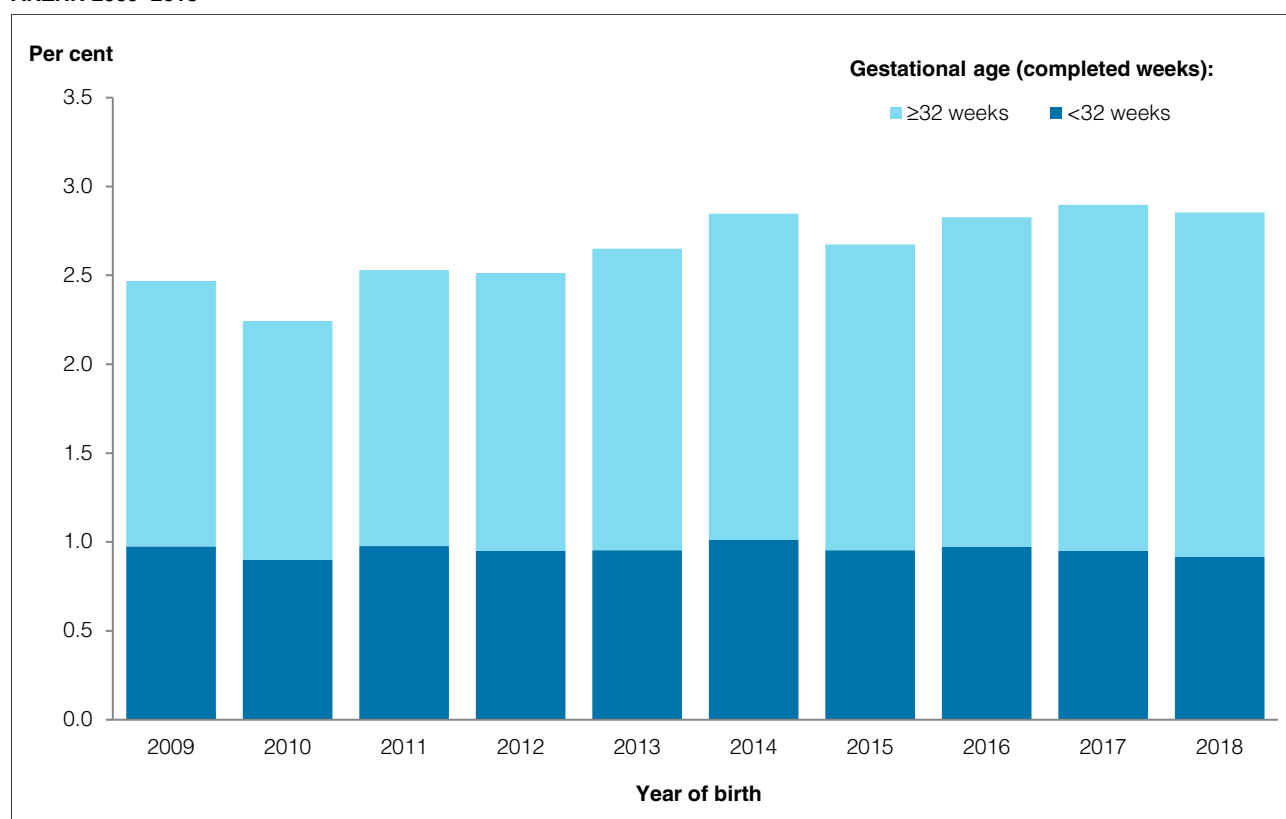
Assisted ventilation was given to 1,913 babies representing 3.3% of all live births with 1,352 babies receiving CPAP as the only form of respiratory assistance (2.3% of all live births).

## 2. Babies registered to level III units

This section includes data on the ANZNN registrants from all 29 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 born in 2018 and admitted to an NICU in Australia and New Zealand, 10,651 fulfilled the registration criteria for inclusion in the ANZNN clinical quality registry. The population represents 2.9% of the 373,167 live births in the two countries in 2018 (Australian Bureau of Statistics 2019; Statistics New Zealand 2019) (Figure 2), unchanged from 2.9% in 2017. The number of registrants in 2018 was 30 less than in 2017.

**FIGURE 2: Proportion of liveborn babies in Australia and New Zealand who were ANZNN level III registrants, by year of birth, ANZNN 2009–2018**



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

Of the 10,651 ANZNN registrants born in 2018, there were 3,417 (32.1%) babies born before 32 weeks gestation and 7,234 babies born at 32 weeks or more (67.9%). Of the registrants born before 32 weeks gestation, 94.8% received assisted ventilation. The major indication for assisted ventilation in this age group was hyaline membrane disease.

The largest level III NICU in Australia and New Zealand registered just over 1,020 babies in 2018, the smallest just under 40 (Figure 3). The median number of babies registered to an ANZNN unit was 313.

The gestational age at birth and birthweight for babies qualifying for inclusion in the ANZNN 2018 level III audit is set out in Tables 1 and 2 respectively. The number of babies qualifying under each registration criteria is set out in Figure 4, and the 10-year trend (2009–2018) 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, ANZNN 2018

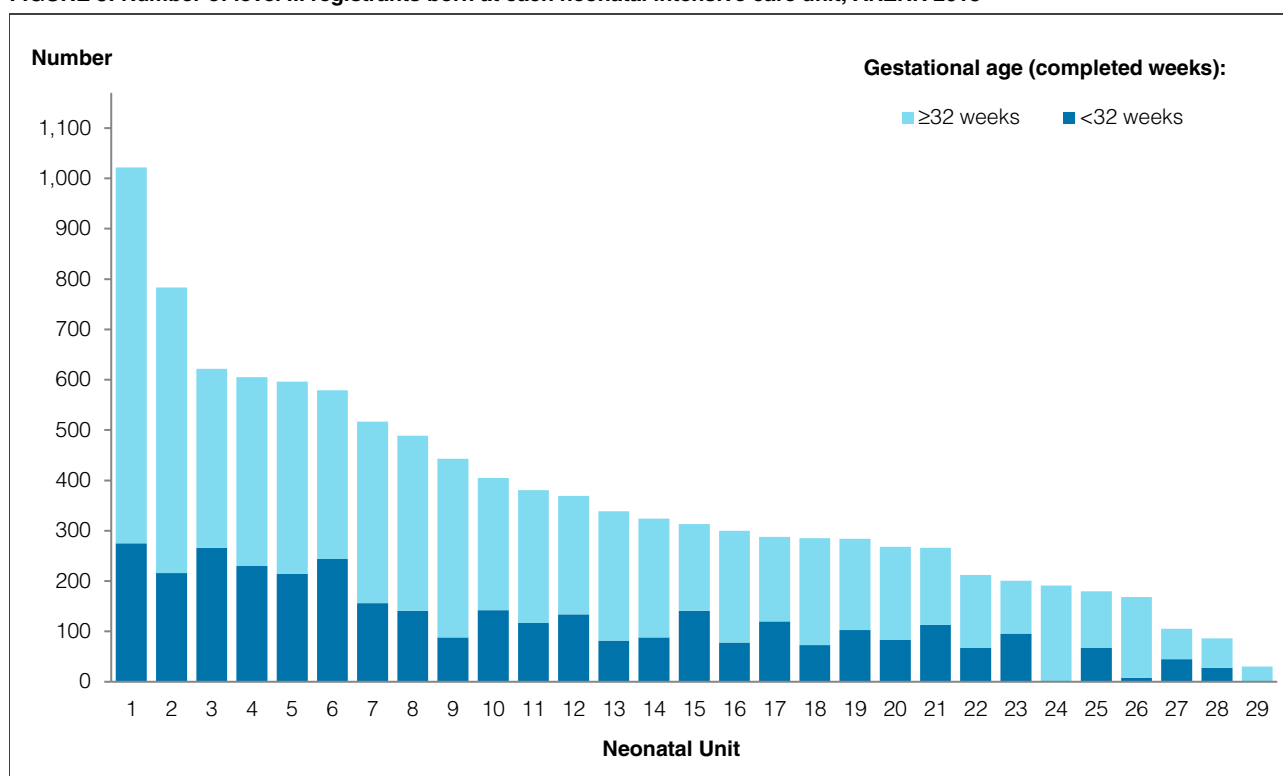


TABLE 1: Level III registrants born at each completed week of gestation, ANZNN 2018

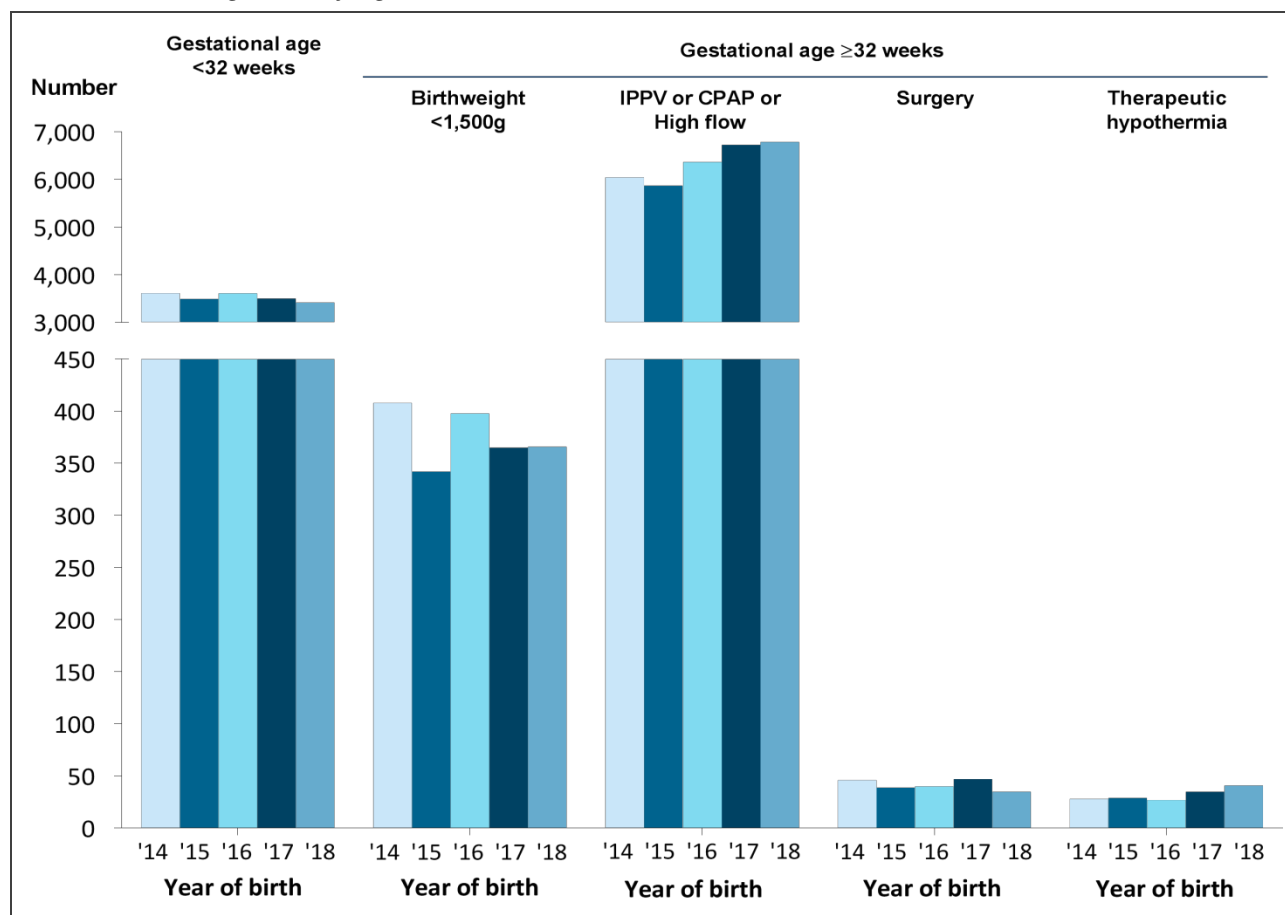
Gestational age (weeks)	Number of babies	Percent	Cumulative percent
<24	95	0.9	0.9
24	197	1.8	2.7
25	211	2.0	4.7
26	280	2.6	7.4
27	364	3.4	10.8
28	375	3.5	14.3
29	460	4.3	18.6
30	594	5.6	24.2
31	841	7.9	32.1
<b>All babies &lt;32 weeks</b>	<b>3,417</b>	<b>32.1</b>	
32	735	6.9	39.0
33	653	6.1	45.1
34	724	6.8	51.9
35	657	6.2	58.1
36	655	6.1	64.2
37	865	8.1	72.4
38	923	8.7	81.0
39	895	8.4	89.4
40	715	6.7	96.1
41	380	3.6	99.7
≥42	32	0.3	100.0
<b>Total</b>	<b>10,651</b>	<b>100.0</b>	

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

**TABLE 2: Level III registrants in each birthweight group, ANZNN 2018**

Birthweight (grams)	Number of babies	Percent	Cumulative percent
<500	45	0.4	0.4
500–599	105	1.0	1.4
600–699	203	1.9	3.3
700–799	225	2.1	5.4
800–899	248	2.3	7.8
900–999	280	2.6	10.4
1,000–1,099	262	2.5	12.8
1,100–1,199	323	3.0	15.9
1,200–1,299	335	3.1	19.0
1,300–1,399	409	3.8	22.9
1,400–1,499	419	3.9	26.8
<b>All babies &lt;1,500g birthweight</b>	<b>2,854</b>	<b>26.8</b>	
1,500–1,999	1,684	15.8	42.6
2,000–2,499	1,387	13.0	55.6
2,500–2,999	1,394	13.1	68.7
3,000–3,499	1,629	15.3	84.0
3,500–3,999	1,179	11.1	95.1
≥4,000	524	4.9	100.0
<b>Total</b>	<b>10,651</b>	<b>100.0</b>	

**FIGURE 4: Level III registrants by registration criteria, ANZNN 2014–2018**



**Note:** Babies are assigned to the first registration criteria that they meet in the following order: (i) gestational age <32 weeks, (ii) birthweight <1,500g, (iii) received 4 or more hours of IPPV, CPAP or high flow, (iv) received major surgery, (v) received therapeutic hypothermia.

## 3. Mothers of level III registrants

### Maternal age

While there are many determinants of perinatal outcome, an important one is maternal age. In 2018, the age of mothers of neonates registered as high-risk ranged from 15 years to over 55 years. The highest proportion of registrant mothers was aged 30–34 years (33.2%) followed by mothers aged 25–29 years (25.3%). Together they accounted for nearly three in five of the mothers (58.5%) of ANZNN registrants in 2018 (Table 3). In 2018, the proportion of babies born to teenage mothers decreased slightly (by 0.5%) from 2017, and those born to mothers in the 35–39 age group increased slightly, from 19.5% in 2017 to 20.5%.

One in three of the babies born to teenage mothers (33.4%) were born at less than 32 weeks completed gestation, while 31.7% 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, ANZNN 2018**

Maternal age (years)	Gestational age (weeks)								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
	Number								
Less than 20	5	16	18	30	28	31	65	97	290
20–24	24	61	85	102	183	146	223	439	1,263
25–29	n.p.	101	157	205	341	327	517	n.p.	2,670
30–34	31	139	216	274	452	445	669	1,277	3,503
35–39	13	72	123	159	310	328	419	740	2,164
40 and over	<5	18	44	56	107	99	123	n.p.	670
Not stated	0	1	1	9	14	12	20	34	91
<b>Total</b>	<b>95</b>	<b>408</b>	<b>644</b>	<b>835</b>	<b>1,435</b>	<b>1,388</b>	<b>2,036</b>	<b>3,810</b>	<b>10,651</b>
	Per cent								
Less than 20	5.3	3.9	2.8	3.6	2.0	2.3	3.2	2.6	2.7
20–24	25.3	15.0	13.2	12.3	12.9	10.6	11.1	11.6	12.0
25–29	n.p.	24.8	24.4	24.8	24.0	23.8	25.6	n.p.	25.3
30–34	32.6	34.2	33.6	33.2	31.8	32.3	33.2	33.8	33.2
35–39	13.7	17.7	19.1	19.2	21.8	23.8	20.8	19.6	20.5
40 and over	n.p.	4.4	6.8	6.8	7.5	7.2	6.1	n.p.	6.3
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

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

### Previous antenatal history

A previous preterm delivery was reported by 1,069 (10.0%) mothers of babies registered to ANZNN while 341 mothers (3.2%) reported a previous perinatal loss.

### Assisted conception

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

There were 910 (8.5%) pregnancies resulting from assisted conception in the ANZNN 2018 cohort with most (86.7%) following IVF treatment. Of the pregnancies resulting from assisted conception, 55.8% of the mothers were more than 34 years of age at the time of giving birth, compared with 51.7% in 2017.

## 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 99.7% of 2018 ANZNN registrants. The mothers of one-fifth of registrants (19.6%) presented with preterm labour while fetal distress (16.5%) was the second highest presenting antenatal problem (Table 4).

The maternal antenatal complications for registrants born at 37–44 weeks, 32–36 weeks and less than 32 weeks gestational age are set out in Figure 5. For women who gave birth before 32 weeks gestation and women who gave birth at 34–36 weeks gestation, the most common presenting antenatal problem was preterm labour (33.9% and 27.5% respectively) followed by preterm pre-labour rupture of membranes (23.1% and 14.0% respectively).

Overall 86.2% of mothers of registrants had a pregnancy complication recorded. Among women who gave birth at term, just over one in three (37.4%) were recorded as having no maternal presenting antenatal problem.

**TABLE 4: Mother's presenting antenatal problem for level III registrants by gestational age, ANZNN 2018**

Presenting antenatal problem	Gestational age (weeks)								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
	Number								
No antenatal problems	0	0	0	0	0	0	8	1,425	1,433
Preterm pre-labour rupture of membranes	28	100	155	173	331	225	284	45	1,341
Preterm labour	50	169	223	303	413	360	559	5 <sup>(a)</sup>	2,082
Hypertension in pregnancy	<5	n.p.	60	115	217	178	181	119	899
Antepartum haemorrhage	12	55	69	72	140	113	138	79	678
Intrauterine growth restriction	0	12	30	23	81	129	177	109	561
Fetal distress	<5	29	84	104	174	n.p.	248	914	1,756
Other problem	0	14	23	36	66	159	319	754	1,371
Congenital anomalies	0	<5	0	8	12	n.p.	116	335	495
Not stated	0	1	0	1	1	1	6	25	35
<b>Total</b>	<b>95</b>	<b>408</b>	<b>644</b>	<b>835</b>	<b>1,435</b>	<b>1,388</b>	<b>2,036</b>	<b>3,810</b>	<b>10,651</b>
Per cent									
No antenatal problems	0.0	0.0	0.0	0.0	0.0	0.0	0.4	37.6	13.5
Preterm pre-labour rupture of membranes	29.5	24.6	24.1	20.7	23.1	16.2	14.0	1.2	12.6
Preterm labour	52.6	41.5	34.6	36.3	28.8	26.0	27.5	0.1	19.6
Hypertension in pregnancy	n.p.	n.p.	9.3	13.8	15.1	12.8	8.9	3.1	8.5
Antepartum haemorrhage	12.6	13.5	10.7	8.6	9.8	8.1	6.8	2.1	6.4
Intrauterine growth restriction	0.0	2.9	4.7	2.8	5.6	9.3	8.7	2.9	5.3
Fetal distress	n.p.	7.1	13.0	12.5	12.1	n.p.	12.2	24.1	16.5
Other problem	0.0	3.4	3.6	4.3	4.6	11.5	15.7	19.9	12.9
Congenital anomalies	0.0	n.p.	0.0	1.0	0.8	n.p.	5.7	8.9	4.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

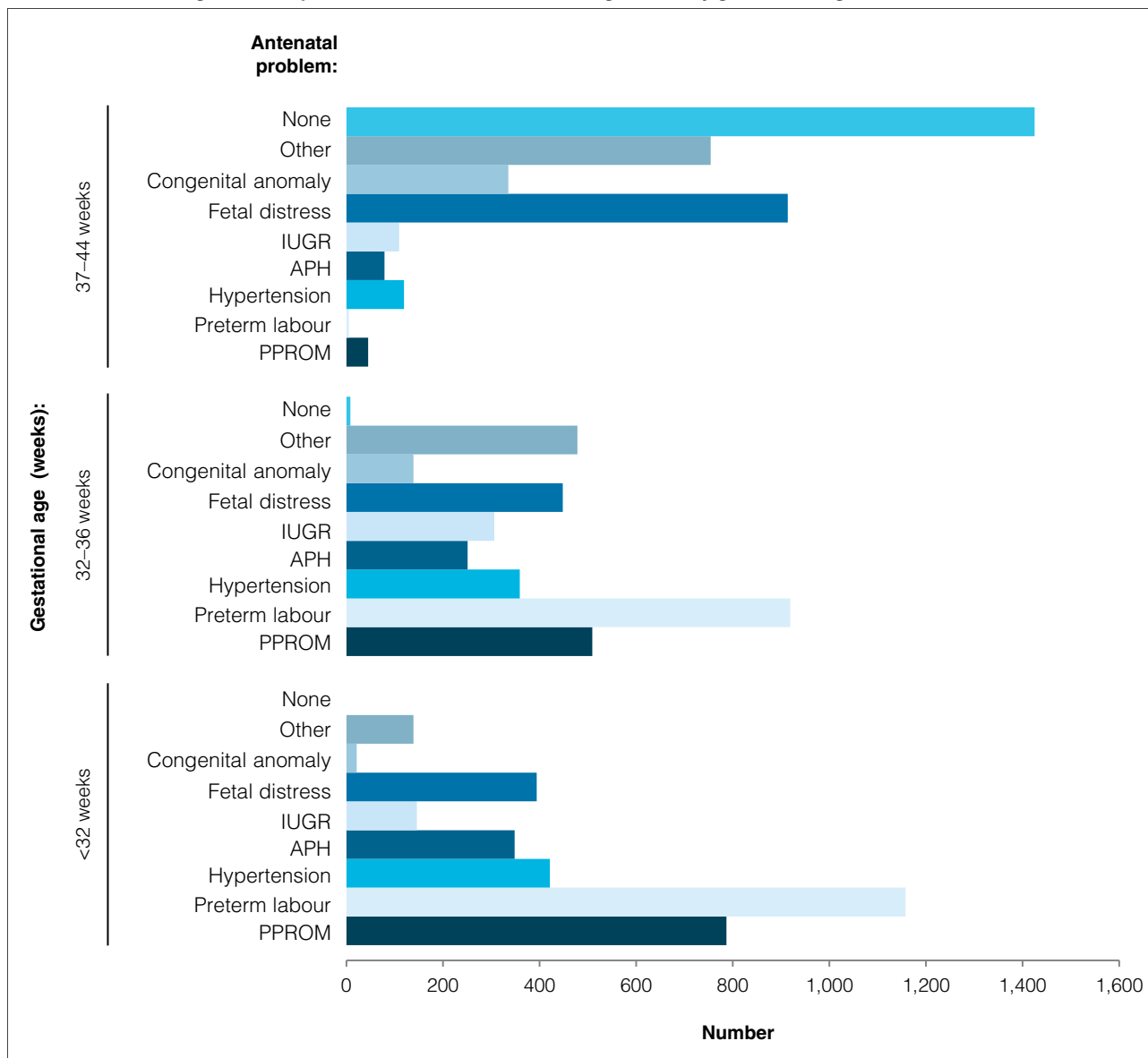
*n.p.* Data not published to maintain confidentiality of small numbers.

*(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, ANZNN 2018**



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

PPROM = preterm pre-labour rupture of membranes. APH = antepartum haemorrhage. IUGR = intrauterine growth restriction.

## 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 34<sup>th</sup> 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.

Table 5 presents antenatal corticosteroids use for mothers of ANZNN registrants in each gestational age group. In 2018, 89.5% of mothers of ANZNN registrants born before 34 weeks of gestation received one or more doses of antenatal corticosteroids, leaving 10.5% of mothers of registrants in this group who did not report receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 14.3% received them more than seven days prior to giving birth.

For mothers of ANZNN registrants born before 32 weeks of gestation, 90.9% received one or more doses of antenatal corticosteroids and 9.1% mothers of registrants in this group did not report receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 14.3% received them more than seven days prior to giving birth (Table 5). The 10-year trend (2009–2018) 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, ANZNN 2018**

	Gestational age (weeks)								
Antenatal corticosteroids	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
	Number								
None	n.p.	35	44	72	131	182	n.p.	3,178	4,600
Incomplete course	33	116	164	243	371	364	276	23	1,590
Complete course within 7 days of birth	47	227	346	406	708	661	542	72	3,009
Given >7 days prior to birth	<5	30	88	109	215	169	n.p.	44	866
Not stated	0	0	2	5	10	12	64	493	586
<b>Total</b>	<b>95</b>	<b>408</b>	<b>644</b>	<b>835</b>	<b>1,435</b>	<b>1,388</b>	<b>2,036</b>	<b>3,810</b>	<b>10,651</b>
	Per cent								
None	n.p.	8.6	6.9	8.7	9.2	13.2	n.p.	95.8	45.7
Incomplete course	34.7	28.4	25.5	29.3	26.0	26.5	14.0	0.7	15.8
Complete course within 7 days of birth	49.5	55.6	53.9	48.9	49.7	48.0	27.5	2.2	29.9
Given >7 days prior to birth	n.p.	7.4	13.7	13.1	15.1	12.3	n.p.	1.3	8.6
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

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

## Magnesium sulphate

Babies born at less than 32 weeks gestation are at high risk of neurologic injury during labour and immediately after birth. Antenatal administration of magnesium sulphate (MgSO<sub>4</sub>) to very preterm babies has been demonstrated to provide neuroprotection (Crowther et al 2003, Rouse 2009, Conde-Agudelo and Romero 2009).

For mothers of ANZNN registrants born at less than 32 weeks of gestation, 56.0% were given antenatal MgSO<sub>4</sub> (Table 6).

**TABLE 6: Magnesium sulphate use for mothers of level III registrants by gestational age, ANZNN 2018**

TABLE 3. Magnesium sulphate use for mothers of twins in registries by gestational age, AHEAD 2016										
	Gestational age (weeks)									
Magnesium sulphate	<24	24	25	26	27	28	29	30	31	Total
Number										
None	18	46	63	71	100	111	138	335	606	1,488
Complete course	26	55	68	82	89	105	120	82	93	720
Incomplete course	34	69	55	85	111	100	118	119	87	778
Given but details unknown	16	25	23	42	62	57	76	48	43	392
Not stated or clinical trial	1	2	2	0	2	2	8	10	12	39
<b>Total</b>	<b>95</b>	<b>197</b>	<b>211</b>	<b>280</b>	<b>364</b>	<b>375</b>	<b>460</b>	<b>594</b>	<b>841</b>	<b>3,417</b>
Per cent										
None	19.1	23.6	30.1	25.4	27.6	29.8	30.5	57.4	73.1	44.0
Complete course	27.7	28.2	32.5	29.3	24.6	28.2	26.5	14.0	11.2	21.3
Incomplete course	36.2	35.4	26.3	30.4	30.7	26.8	26.1	20.4	10.5	23.0
Given but details unknown	17.0	12.8	11.0	15.0	17.1	15.3	16.8	8.2	5.2	11.6
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

**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 gestation

Multiple gestation 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 2018, 17.1% of ANZNN registrants were reported as being from a multiple gestation pregnancy, and of these, the greatest percentage were twins (92.3%). Of the 2018 ANZNN registrants from multiple gestation pregnancies, 50.1% were born before 32 weeks gestation and 95.5% were born before 37 weeks gestation (Table 7). The 10-year trend (2009–2018) for multiple gestation pregnancies is represented by Figure 13 in Appendix 1.

**TABLE 7: Plurality of level III registrants by gestational age, ANZNN 2018**

Plurality	Gestational age (weeks)								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
Number									
Singletons	81	304	485	640	997	954	1,646	3,728	8,835
Twins	14	98	149	185	396	383	369	82	1,676
Triplets and higher orders	0	6	10	10	42	51	21	0	140
<b>Total</b>	<b>95</b>	<b>408</b>	<b>644</b>	<b>835</b>	<b>1,435</b>	<b>1,388</b>	<b>2,036</b>	<b>3,810</b>	<b>10,651</b>
Per cent									
Singletons	85.3	74.5	75.3	76.6	69.5	68.7	80.8	97.8	82.9
Twins	14.7	24.0	23.1	22.2	27.6	27.6	18.1	2.2	15.7
Triplets and higher orders	0.0	1.5	1.6	1.2	2.9	3.7	1.0	0.0	1.3
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

## 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 two in five (60.1%) of the 2018 registrants, the method of birth was caesarean section with 64.4% of caesarean sections occurring before the onset of labour. One-third of registrants (32.3%) were non-instrumental vaginal births (Table 8). The rate of birth by caesarean section has gradually increased from 49.8%, since the first data collection in 1995, to 58.9% in 2017. The 2018 data shows an increase of 1.2% from 2017.

The most common method of birth for registrants born before 24 weeks gestation was non-instrumental vaginal birth (67.4%) (Table 8). The 10-year trend (2009–2018) for method of birth is represented by Figure 14 in Appendix 1.

**TABLE 8: Method of birth for level III registrants by gestational age, ANZNN 2018**

	Gestational age (weeks)								
Method of birth	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
Vaginal birth	n.p.	164	207	255	412	n.p.	548	1,451	3,424
Vaginal instrumental birth	<5	9	17	19	61	n.p.	109	561	819
Caesarean section in labour	15	114	149	201	298	263	403	825	2,268
Caesarean section no labour	15	120	271	359	660	757	967	955	4,104
Not stated	0	1	0	1	4	3	9	18	36
<b>Total</b>	<b>95</b>	<b>408</b>	<b>644</b>	<b>835</b>	<b>1,435</b>	<b>1,388</b>	<b>2,036</b>	<b>3,810</b>	<b>10,651</b>
Per cent									
Vaginal birth	n.p.	40.3	32.1	30.6	28.8	n.p.	27.0	38.3	32.3
Vaginal instrumental birth	n.p.	2.2	2.6	2.3	4.3	n.p.	5.4	14.8	7.7
Caesarean section in labour	15.8	28.0	23.1	24.1	20.8	19.0	19.9	21.8	21.4
Caesarean section no labour	15.8	29.5	42.1	43.0	46.1	54.7	47.7	25.2	38.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

## 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 2018, 80.0% of all babies and 88.3% of babies less than 32 weeks gestation at birth were born in a tertiary centre equipped with an NICU; 19.2% of all ANZNN registrants were born in a non-tertiary hospital; while 0.8% of registrants were not born in a hospital (Table 9).

**TABLE 9: Level of hospital of birth for level III registrants by gestational age, ANZNN 2018**

Level of birth hospital	Gestational age (weeks)								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
Number									
Tertiary hospital	88	362	568	713	1,283	1,190	1,604	2,702	8,510
Non-tertiary hospital	7	41	69	112	n.p.	n.p.	422	1,055	2,046
Not born in a hospital <sup>(a)</sup>	0	5	6	9	<5	n.p.	7	51	88
Not stated	0	0	1	1	0	0	3	2	7
<b>Total</b>	<b>95</b>	<b>408</b>	<b>644</b>	<b>835</b>	<b>1,435</b>	<b>1,388</b>	<b>2,036</b>	<b>3,810</b>	<b>10,651</b>
Per cent									
Tertiary hospital	92.6	88.7	88.3	85.5	89.4	85.7	78.9	71.0	80.0
Non-tertiary hospital	7.4	10.0	10.7	13.4	n.p.	n.p.	20.8	27.7	19.2
Not born in a hospital <sup>(a)</sup>	0.0	1.2	0.9	1.1	n.p.	n.p.	0.3	1.3	0.8
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

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

## Transport after birth to a level III NICU

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

In 2018, 22.6% of ANZNN registrants were transferred to an NICU after birth. Of these the greatest percentage (81.7%) were transported by a specialist team with 14.4% transported by a non-specialist team (Table 10). The 10-year trend (2009–2018) for mode of transport to a level III NICU is represented by Figure 15 and Figure 16 in Appendix 1.

**TABLE 10: Mode of transport to level III NICU after birth for level III registrants by gestational age, ANZNN 2018**

Mode of Transport	Gestational age (weeks)								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
	Number								
Not transported	87	352	569	707	1,271	1,167	1,538	2,544	8,235
Specialist retrieval team	5	41	56	101	138	185	422	1,022	1,970
Non-specialist team	<5	<5	13	12	17	23	56	221	347
Other	<5	n.p.	6	15	9	13	19	19	94
Not stated	0	0	0	0	0	0	1	4	5
Total	95	408	644	835	1,435	1,388	2,036	3,810	10,651
	Per cent								
Not transported	91.6	86.3	88.4	84.7	88.6	84.1	75.6	66.8	77.4
Specialist retrieval team	5.3	10.0	8.7	12.1	9.6	13.3	20.7	26.9	18.5
Non-specialist team	n.p.	n.p.	2.0	1.4	1.2	1.7	2.8	5.8	3.3
Other	n.p.	n.p.	0.9	1.8	0.6	0.9	0.9	0.5	0.9
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

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

## Breastfeeding at discharge

Data on breastfeeding at discharge were available for 99.4% of the babies born at less than 32 weeks gestation and/or less than 1,500 grams at birth who survived to discharge to home. Among registrants who provided data on breastfeeding, 77.2% were breastfed at discharge. The rate of breastfeeding at discharge of surviving extremely preterm babies (born at less than 28 weeks gestation) was 71.0% compared to 79.5% 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 51.4% of combined live births in both countries in 2018 (Australian Bureau of Statistics 2019; Statistics New Zealand 2019). The percentage was higher among ANZNN registrants with male births representing 58.8%. For registrants born at less than 32 weeks gestation, 55.0% were male; of births at term, 62.4% 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, the ANZNN only collected data on babies on whom endotracheal intubation was performed; in 2018, 15.7% of registrants were intubated in the delivery suite to establish independent respiration and heart rate. For babies born before 32 weeks the percentage was 31.5% and for babies born at term the percentage was 9.1%.

### 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 16.1% of ANZNN registrants, with 3.6% of registrants recording an Apgar score of less than 4 at five minutes of age. Among the babies who had low Apgar scores of less than 4 at one minute, 37.4% of babies were born at less than 32 weeks and 38.1% were born at term (Table 11).

**TABLE 11: Apgar scores at birth for level III registrants by gestational age, ANZNN 2018**

Apgar score distribution by gestational age, 2010									
	Gestational age (weeks)								
Apgar score	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Apgar score at 1 minute									
Median	3.5	5	5	6	7	7	8	8	7
IQR	2–5	3–6	3–7	5–8	5–8	5–8	5–9	5–9	5–9
Apgar score at 5 minutes									
Median	7	7	8	8	9	9	9	9	8
IQR	5–8	6–8	6–9	7–9	8–9	8–9	7–9	7–9	7–9

*Note: IQR = Interquartile range*

### Admission temperature

The body temperature at admission to the NICU, or temperature nearest to admission to the registration unit, was reported for 94.5% of ANZNN registrants in 2018. 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, sex, gestation and birthweight 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 36.6°C; the median temperature increased slightly with increasing gestational age at birth. The lowest median temperature recorded was 36.2°C by the youngest babies, i.e. those born at less than 24 weeks gestation (Table 12).

**TABLE 12: Admission body temperature for level III registrants by gestational age, ANZNN 2018**

Gestational age (weeks)	Number of babies	Temperature (°C)	
		Median	Interquartile range
<24	95	36.2	35.5–36.7
24–25	408	36.5	36.0–36.9
26–27	644	36.6	36.2–37.1
28–29	835	36.6	36.2–37.0
30–31	1,435	36.6	36.2–36.9
32–33	1,388	36.6	36.1–36.9
34–36	2,036	36.6	36.2–36.9
37–44	3,810	36.7	36.4–37.0
<b>Total</b>	<b>10,651</b>	<b>36.6</b>	<b>36.2–37.0</b>

## Indication for respiratory support

In 2018, only 2.5% 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 41.5%. Non-specific respiratory distress accounted for 34.4% of babies, surgery for 3.8%, while meconium aspiration syndrome and congenital anomaly each accounted for 3.3% (Table 13).

For babies born before 37 weeks gestation, HMD (59.7%) remained the most common indication for respiratory support. For babies born at term, non-specific respiratory distress (46.6%) was the most common indication followed by meconium aspiration syndrome (9.0%) and HMD (8.3%) (Table 13). The 10-year trend (2009–2018) 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, ANZNN 2018**

Indication for respiratory support	Gestational age (weeks)								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
	Number								
No respiratory support	0	<5	0	7	98	50	n.p.	59	261
Non-specific respiratory distress	<5	7	25	n.p.	302	509	962	1,766	3,647
Hyaline membrane disease	n.p.	390	607	722	959	698	n.p.	315	4,401
Meconium aspiration syndrome	0	0	0	0	0	0	6	342	348
Pneumonia	0	0	0	0	0	<5	n.p.	139	149
Persistent pulmonary hypertension	0	n.p.	<5	7	6	<5	29	143	200
Apnoea	0	0	<5	6	n.p.	25	52	54	163
Congenital anomaly	0	0	<5	n.p.	9	19	66	252	354
Other	0	<5	<5	<5	21	41	93	259	422
Peri-surgery	0	0	0	0	<5	n.p.	105	271	400
Newborn encephalopathy	0	0	0	5	<5	n.p.	45	192	258
Not stated	0	0	3	2	9	9	7	18	48
<b>Total</b>	<b>95</b>	<b>408</b>	<b>644</b>	<b>835</b>	<b>1,435</b>	<b>1,388</b>	<b>2,036</b>	<b>3,810</b>	<b>10,651</b>
	Per cent								
No respiratory support	0.0	n.p.	0.0	0.8	6.8	3.6	n.p.	1.5	2.5
Non-specific respiratory distress	n.p.	1.7	3.9	n.p.	21.2	36.9	47.4	46.6	34.4
Hyaline membrane disease	n.p.	95.6	94.7	86.7	67.3	50.6	n.p.	8.3	41.5
Meconium aspiration syndrome	0.0	0.0	0.0	0.0	0.0	0.0	0.3	9.0	3.3
Pneumonia	0.0	0.0	0.0	0.0	0.0	n.p.	n.p.	3.7	1.4
Persistent pulmonary hypertension	0.0	n.p.	n.p.	0.8	0.4	n.p.	1.4	3.8	1.9
Apnoea	0.0	0.0	n.p.	0.7	n.p.	1.8	2.6	1.4	1.5
Congenital anomaly	0.0	0.0	n.p.	n.p.	0.6	1.4	3.3	6.6	3.3
Other	0.0	n.p.	n.p.	n.p.	1.5	3.0	4.6	6.8	4.0
Peri-surgery	0.0	0.0	0.0	0.0	n.p.	n.p.	5.2	7.1	3.8
Newborn encephalopathy	0.0	0.0	0.0	0.6	n.p.	n.p.	2.2	5.1	2.4
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

**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.

In 2018, a quarter of ANZNN registrants (26.4%) were administered exogenous surfactant (Table 14). There were 2,067 babies who received intermittent positive pressure ventilation for HMD in 2018. Exogenous surfactant was given to 1,898 of these babies (91.8%). There were 169 babies diagnosed with HMD who were not given exogenous surfactant.

**TABLE 14: Exogenous surfactant use for level III registrants by gestational age, ANZNN 2018**

Exogenous surfactant	Gestational age (weeks)								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
Number									
None	<5	21	127	339	1,009	1,095	1,752	n.p.	7,841
Surfactant given	n.p.	387	517	496	426	293	284	n.p.	2,810
▪ via endotracheal tube	88	347	452	405	357	240	248	288	2,425
▪ via catheter	<5	35	56	74	60	50	33	n.p.	333
▪ via other or unknown method	1	5	9	17	9	3	3	5	52
<b>Total</b>	<b>95</b>	<b>408</b>	<b>644</b>	<b>835</b>	<b>1,435</b>	<b>1,388</b>	<b>2,036</b>	<b>3,810</b>	<b>10,651</b>
Per cent									
None	n.p.	5.1	19.7	40.6	70.3	78.9	86.1	n.p.	73.6
Surfactant given	n.p.	94.9	80.3	59.4	29.7	21.1	13.9	n.p.	26.4
▪ via endotracheal tube	92.6	85.0	70.2	48.5	24.9	17.3	12.2	7.6	22.8
▪ via catheter	n.p.	8.6	8.7	8.9	4.2	3.6	1.6	n.p.	3.1
▪ via other or unknown method	1.1	1.2	1.4	2.0	0.6	0.2	0.1	0.1	0.5
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

## 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 2018, 92.8% 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 via any route is recorded. The 10-year trend (2009–2018) for assisted ventilation is represented in Figures 17 to 19 in Appendix 1.

In 2018, IPPV was given for a total of 534,234 hours to ANZNN registrants and CPAP was given for 1,724,093 hours. The total number of hours of ventilation equates to each baby receiving 8.8 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 2018 remains CPAP with 58.4% of registrants receiving CPAP only, 9.5% receiving IPPV only and 25.0% receiving both CPAP and IPPV.

In addition to IPPV and CPAP, babies may have received high frequency oscillatory ventilation (HFOV), nitric oxide or extracorporeal membrane oxygenation (ECMO). HFOV is administered via an endotracheal tube, and is usually given in conjunction with IPPV. In 2018, 22.2% of registrants who received IPPV also received HFOV. However, 34 babies received HFOV without at least four hours of IPPV. The use of HFOV among individual units varied between 1.2% and 15.5% with the highest percentage of babies receiving HFOV born at less than 24 weeks (81.1%) followed by babies born at 24–25 weeks gestation (54.9%) (Table 16). The 10-year trend (2009–2018) for HFOV is represented in Figure 20 in Appendix 1.



**TABLE 15: Duration of assisted ventilation use for level III registrants by gestational age, ANZNN 2018**

Duration of assisted ventilation	Gestational age (weeks)								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
IPPV (hours)									
Median	331	260	60	23	20	25	46.5	52	48
IQR	70–769	82–577	17–185	10–68	9–47.5	10–77	20–110	22–104	17–135
CPAP (hours)									
Median	921	1154	833	262.5	70	32	21	16	38
IQR	552–1,383	785–1,409	445–1,124	106–630	32–143	15–72	10–48	8–39	13–125.5

**Note:** IQR = Interquartile range. IPPV = intermittent positive pressure ventilation. CPAP = continuous positive airway pressure.

In 2018, 25 registrants received ECMO of whom the majority were born at term. The percentage of ANZNN registrants who received nitric oxide was 5.4%. The use of nitric oxide continues to have a U-shaped distribution with the highest percentage of babies to receive nitric oxide born at less than 24 weeks (30.9%) (Table 16). The 10-year trend (2009–2018) for nitric oxide is represented in Figure 21 in Appendix 1.

**TABLE 16: Assisted ventilation for level III registrants by gestational age, ANZNN 2018**

	Gestational age (weeks)								
Ventilation type	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
Invasive ventilation	94	385	476	388	342	282	524	1,187	3,678
▪ HFOV given	77	224	158	67	53	31	59	152	821
▪ IPPV given	94	385	475	386	342	282	522	1,184	3,670
Nitric oxide given	29	73	60	33	34	26	58	260	573
CPAP given	51	353	621	797	1,249	1,218	1,658	2,931	8,878
Total in each age group	95	408	644	835	1,435	1,388	2,036	3,810	10,651
Per cent									
IPPV given	98.9	94.4	73.8	46.2	23.8	20.3	25.6	31.1	34.5
CPAP given	53.7	86.5	96.4	95.4	87.0	87.8	81.4	76.9	83.4
Per cent of babies given invasive ventilation									
HFOV given <sup>(a)</sup>	81.9	58.2	33.2	17.3	15.5	11.0	11.3	12.8	22.3
Nitric oxide given <sup>(a)</sup>	30.9	19.0	12.6	8.5	9.9	9.2	11.1	21.9	15.6

<sup>(a)</sup> Denominator is babies given ventilation via endotracheal tube (IPPV and/or HFOV).

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

HFOV = high frequency oscillatory ventilation. IPPV = intermittent positive pressure ventilation. CPAP = continuous positive airway pressure.

## 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 3,417 babies born before 32 weeks gestation, 94.8% were given assisted ventilation in the form of IPPV or CPAP. For registrants in this age group CPAP was the only form of ventilation for 45.5% and IPPV was the only form of ventilation for 4.9% of registrants. Both IPPV and CPAP were given to 44.3% of registrants.

The total duration of IPPV for these very preterm babies was 342,235 hours, and the duration of CPAP was 1,420,681 hours.

Of the babies born before 32 weeks gestational age and given IPPV in 2018, 34.2% were given HFOV while 13.6% of these babies were given nitric oxide (Table 16).

Among 2018 ANZNN registrants born at less than 32 weeks gestation, 3,211 (94.0%) survived to day 28. Of these, 52.8% of registrants received respiratory support (airway support or supplemental oxygen therapy) at 28 days of age, with 19.9% of them discharged on home oxygen (Table 17).

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

Among the babies born at 32–36 weeks gestation, 92.1% received assisted ventilation. Non-specific respiratory distress was the main reason for ventilation. Total duration of CPAP use by registrants in this gestational age group was 161,943 hours and IPPV use was 75,110 hours.

Of the babies born at 32–36 weeks gestation and given IPPV in 2018, 10.9% were given HFOV while 10.4% of these babies were given nitric oxide (Table 16).

## Ventilation in babies born at term

The main indication for respiratory support in term babies was non-specific respiratory distress (46.4%). This group required 116,889 hours of IPPV and 141,469 hours of CPAP.

Of the babies born at term and given IPPV in 2018, 12.6% were given HFOV while 22.0% of these babies were given nitric oxide (Table 16). There were 18 babies born at term who received 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 varies 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 the 2018 ANZNN registrants, 10,299 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, 22.1% 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, ANZNN 2018**

Respiratory support (airway support or oxygen)	Gestational age (weeks)								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
Number									
No respiratory support on day 28	0	7	37	292	1,145	1,287	1,893	3,563	8,224
Respiratory support on day 28	46	321	572	517	265	78	102	164	2,065
▪ survived to discharge home	40	305	562	507	n.p.	n.p.	96	142	1,990
▪ died before discharge	6	16	10	10	<5	<5	6	22	75
Not stated	0	5	2	2	0	1	0	0	10
Total in each age group	46	333	611	811	1,410	1,366	1,995	3,727	10,299
Number									
Respiratory support on day 28 and given home oxygen	19	117	121	59	n.p.	n.p.	29	45	451
Per cent									
No respiratory support on day 28	0.0	2.1	6.1	36.1	81.2	94.3	94.9	95.6	79.9
Respiratory support on day 28	100.0	97.9	93.9	63.9	18.8	5.7	5.1	4.4	20.1
▪ survived to discharge home	87.0	95.0	98.3	98.1	n.p.	n.p.	94.1	86.6	96.4
▪ died before discharge	13.0	5.0	1.7	1.9	n.p.	n.p.	5.9	13.4	3.6
Per cent									
Respiratory support on day 28 and given home oxygen <sup>(a)</sup>	47.5	38.4	21.5	11.6	15.6	26.7	30.2	31.7	22.7

*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 is a form of non-invasive respiratory support for premature babies. Humidified blended air and oxygen mix is administered through a high flow device via high flow nasal cannula.

In 2018, nasal high flow therapy was reported for 3,440 babies (32.3%) of all level III registrants (Table 18), compared with 8.1% in 2009. Of the babies receiving nasal high flow therapy, 63.1% were reported to have received a minimum rate of 2–4 litres per minute while 73.9% received a maximum of 6–8 litres per minute.

**TABLE 18: Nasal high flow respiratory support for level III registrants by gestational age, ANZNN 2018**

	Gestational age (weeks)								
Nasal high flow	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
High flow	37	275	506	577	547	256	405	836	3,439
No high flow	58	133	138	258	888	1,132	1,631	2,974	7,212
<b>Total</b>	<b>95</b>	<b>408</b>	<b>644</b>	<b>835</b>	<b>1,435</b>	<b>1,388</b>	<b>2,036</b>	<b>3,810</b>	<b>10,651</b>
Per cent									
High flow	38.9	67.4	78.6	69.1	38.1	18.4	19.9	21.9	32.3
No high flow	61.1	32.6	21.4	30.9	61.9	81.6	80.1	78.1	67.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

## Parenteral nutrition

Intravenous parenteral nutrition 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 3,783 ANZNN registrants born at less than 32 weeks gestation and/or less than 1,500g at birth, 3,152 (83.3%) received parenteral nutrition during admission (Table 19). The median duration of parenteral nutrition reported was 212 hours.

Some babies are discharged home with a nasogastric tube in place to allow gavage or infusion feeding at home. Of those who received parenteral nutrition, 7.7% of babies were discharged home on gavage feeds.

**TABLE 19: Parenteral nutrition for level III registrants by gestational age, ANZNN 2018**

	Gestational age (weeks)										
Parenteral nutrition	<24	24	25	26	27	28	29	30	31	≥32 <sup>(a)</sup>	Total
Number											
Parenteral nutrition	90	191	206	275	n.p.	362	427	n.p.	529	237	3,152
No parenteral nutrition	5	6	5	5	<5	13	33	n.p.	312	129	631
<b>Total</b>	<b>95</b>	<b>197</b>	<b>211</b>	<b>280</b>	<b>364</b>	<b>375</b>	<b>460</b>	<b>594</b>	<b>841</b>	<b>366</b>	<b>3,783</b>
Number											
Home gavage feeding	6	26	25	35	n.p.	21	28	n.p.	25	22	243
Per cent											
Parenteral nutrition	94.7	97.0	97.6	98.2	n.p.	96.5	92.8	n.p.	62.9	64.8	83.3
No parenteral nutrition	5.3	3.0	2.4	1.8	n.p.	3.5	7.2	n.p.	37.1	35.2	16.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>
Per cent											
Home gavage feeding <sup>(b)</sup>	6.7	13.6	12.1	12.7	8.0	5.8	6.6	5.5	4.7	9.3	7.7

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

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

*(b)* Denominator is babies who received parenteral nutrition.

## Chronic lung disease

Chronic lung disease (CLD) is a complication of premature lung development and the trauma of early respiratory support (supplemental oxygen and/or assisted ventilation). 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, 9.2% of babies in 2018 were reported to have had respiratory support at 36 weeks PMA, and of these, 23 (2.3%) died prior to discharge to home. The prevalence of CLD continues to be highest in babies born less than 27 weeks gestation. The highest percentage was in those babies born at less than 24 weeks gestation (90.2%) who survived to 36 weeks PMA (Table 20). Not all babies survived to 36 weeks PMA and therefore CLD status could not be defined in these babies. The 10-year trend (2009–2018) for CLD is represented by Figure 22 in Appendix 1.

**TABLE 20: Chronic lung disease at 36 weeks post menstrual age for level III registrants by gestational age, ANZNN 2018**

Chronic lung disease (CLD)	Gestational age (weeks)									Total
	<24	24	25	26	27	28	29	30	31	
Number										
No CLD	<5	24	44	112	181	239	328	497	n.p.	2,180
CLD	n.p.	119	130	149	161	121	112	88	n.p.	984
Did not survive to 36 weeks PMA	54	53	35	18	19	13	16	9	16	233
Not stated	0	1	2	1	3	2	4	0	7	20
Total	95	197	211	280	364	375	460	594	841	3,417
Per cent										
No CLD	n.p.	16.8	25.3	42.9	52.9	66.4	74.5	85.0	n.p.	68.9
CLD	n.p.	83.2	74.7	57.1	47.1	33.6	25.5	15.0	n.p.	31.1
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 and babies who did not survive to 36 weeks PMA are excluded from per cent calculations.

PMA = Post menstrual age

Of the ANZNN registrants born at less than 32 weeks, 321 (9.4%) babies were treated with systemic corticosteroids. Of these, 264 were reported to have had respiratory support at 36 weeks, while 56 (17.4%) 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, ANZNN 2018**

Gestational age (weeks)									
Air leak	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
Air leak	12	30	25	18	32	33	84	177	411
No air leak	83	378	619	817	1,403	1,355	1,952	3,633	10,240
Total	95	408	644	835	1,435	1,388	2,036	3,810	10,651
Per cent									
Air leak	12.6	7.4	3.9	2.2	2.2	2.4	4.1	4.6	3.9
No air leak	87.4	92.6	96.1	97.8	97.8	97.6	95.9	95.4	96.1
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

## 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 4.9% of ANZNN registrants in 2018. Of these babies,

53.2% were born at less than 28 weeks gestation, 69.6% were born at less than 32 weeks gestation and 99.0% of registrants survived up to 2 days of life (Table 22). Episodes of both early and late sepsis were reported in nine babies. The 5-year trends (2014–2018) 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, ANZNN 2018**

Sepsis	Gestational age (weeks)								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
	Number								
No sepsis	52	271	546	795	1,388	1,363	1,999	3,716	10,130
Sepsis at <48 hrs <sup>(a)</sup>	7	10	13	8	15	13	10	53	129
Sepsis at ≥48 hrs <sup>(a)</sup>	37	129	87	34	32	13	27	44	403
Babies alive on day 2	81	397	638	830	1,426	1,381	2,022	3,791	10,566
Babies who did not survive to day 2	14	11	6	5	9	7	14	19	85
<b>Total in each age group</b>	<b>95</b>	<b>408</b>	<b>644</b>	<b>835</b>	<b>1,435</b>	<b>1,388</b>	<b>2,036</b>	<b>3,810</b>	<b>10,651</b>
	Per cent								
No sepsis <sup>(b)</sup>	54.7	66.4	84.8	95.2	96.7	98.2	98.2	97.5	95.1
Sepsis at <48 hrs <sup>(b)</sup>	7.4	2.5	2.0	1.0	1.0	0.9	0.5	1.4	1.2
Sepsis at ≥48 hrs <sup>(c)</sup>	45.7	32.5	13.6	4.1	2.2	0.9	1.3	1.2	3.8

(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 197 (1.8%) of ANZNN registrants in 2018, as identified by isolation or identification of an organism by polymerase chain reaction (PCR) testing, 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 2018 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 2018 registrants, 25.8% were eligible for ROP examination and of these eligible registrants, 82.3% were examined and had the results of their eye examination recorded.

Of those ANZNN registrants who were eligible for an eye examination, 212 died before their ROP status could be determined. Of those examined, 7.5% had stage 3 or 4 eye disease (Table 23, Figure 6) and of these babies, 47.9% received surgical treatment. The 10-year trend (2009–2018) 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, ANZNN 2018**

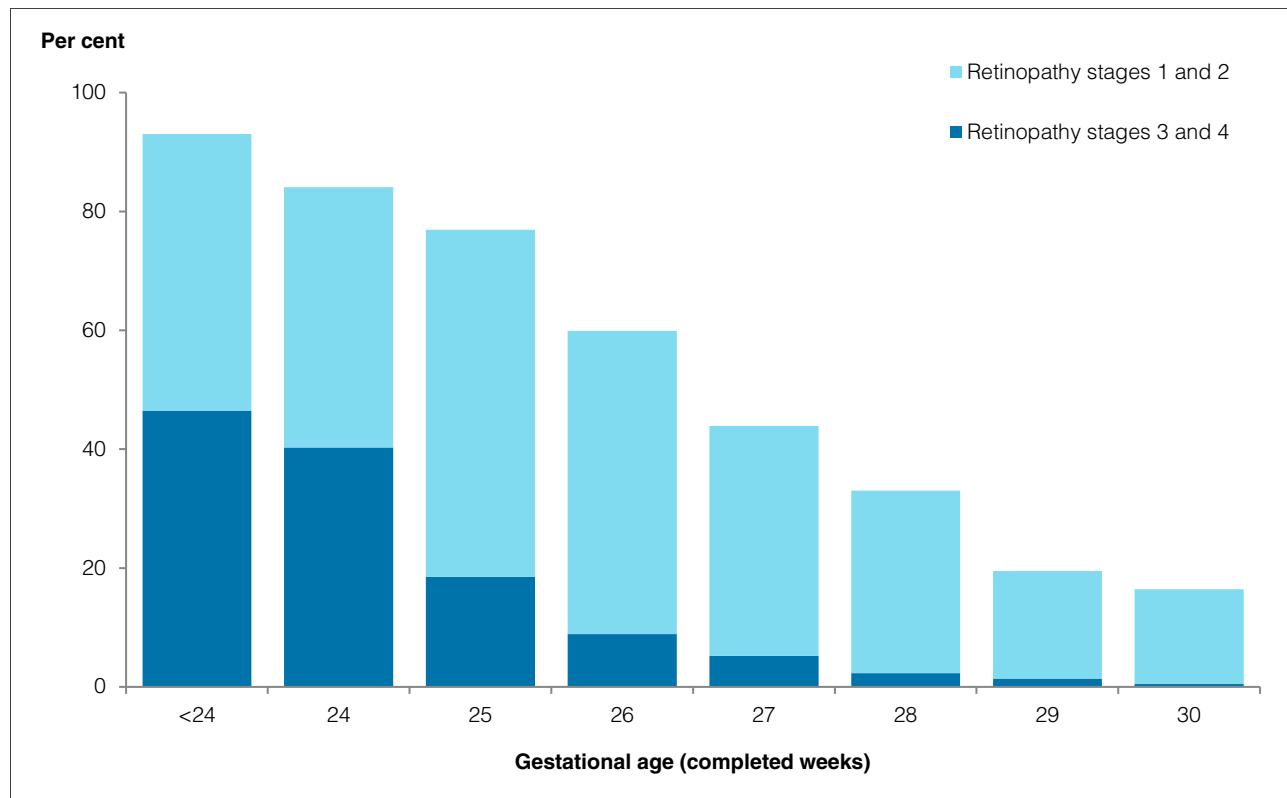
Retinopathy of prematurity (ROP)	Gestational age (weeks)									Total
	<24	24	25	26	27	28	29	30	≥31 <sup>(a)</sup>	
Number										
No ROP	<5	23	n.p.	104	193	236	n.p.	310	130	1,383
Stage 1	<5	n.p.	37	67	73	67	55	45	n.p.	369
Stage 2	19	50	67	65	60	41	22	14	8	346
Stage 3	20	56	31	23	18	8	5	<5	<5	163
Stage 4	0	<5	<5	0	0	0	<5	<5	0	6
Not examined	51	52	33	21	20	22	33	207	26	465
Not stated	1	1	0	0	0	1	1	16	1	21
<b>Total</b>	<b>95</b>	<b>197</b>	<b>211</b>	<b>280</b>	<b>364</b>	<b>375</b>	<b>460</b>	<b>594</b>	<b>177</b>	<b>2,753</b>
Per cent										
No ROP	n.p.	16.0	n.p.	40.2	56.1	67.0	n.p.	83.6	86.7	61.0
Stage 1	n.p.	n.p.	20.8	25.9	21.2	19.0	12.9	12.1	n.p.	16.3
Stage 2	44.2	34.7	37.6	25.1	17.4	11.6	5.2	3.8	5.3	15.3
Stage 3	46.5	38.9	17.4	8.9	5.2	2.3	1.2	n.p.	n.p.	7.2
Stage 4	0.0	n.p.	n.p.	0.0	0.0	0.0	n.p.	n.p.	0.0	0.3
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

*(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, ANZNN 2018**



## Intraventricular haemorrhage

An initial cerebral 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 3,417 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, of which 3,348 survived to day 3 and 92.3% had an examination recorded. A normal report was recorded for 81.7% of these 2018 ANZNN registrants.

There were 141 babies reported to have grade 3 or 4 IVH representing 4.2% of the babies born before 32 weeks gestation. Of the babies who had a grade 3 IVH, 29.2% were unilateral, while 75.0% of grade 4 IVH cases were unilateral. The incidence of IVH, particularly of severe grades, is 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 (69.5%) of these babies born before 25 weeks gestation (Table 24, Figure 7). The 10-year trend (2009–2018) 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, ANZNN 2018**

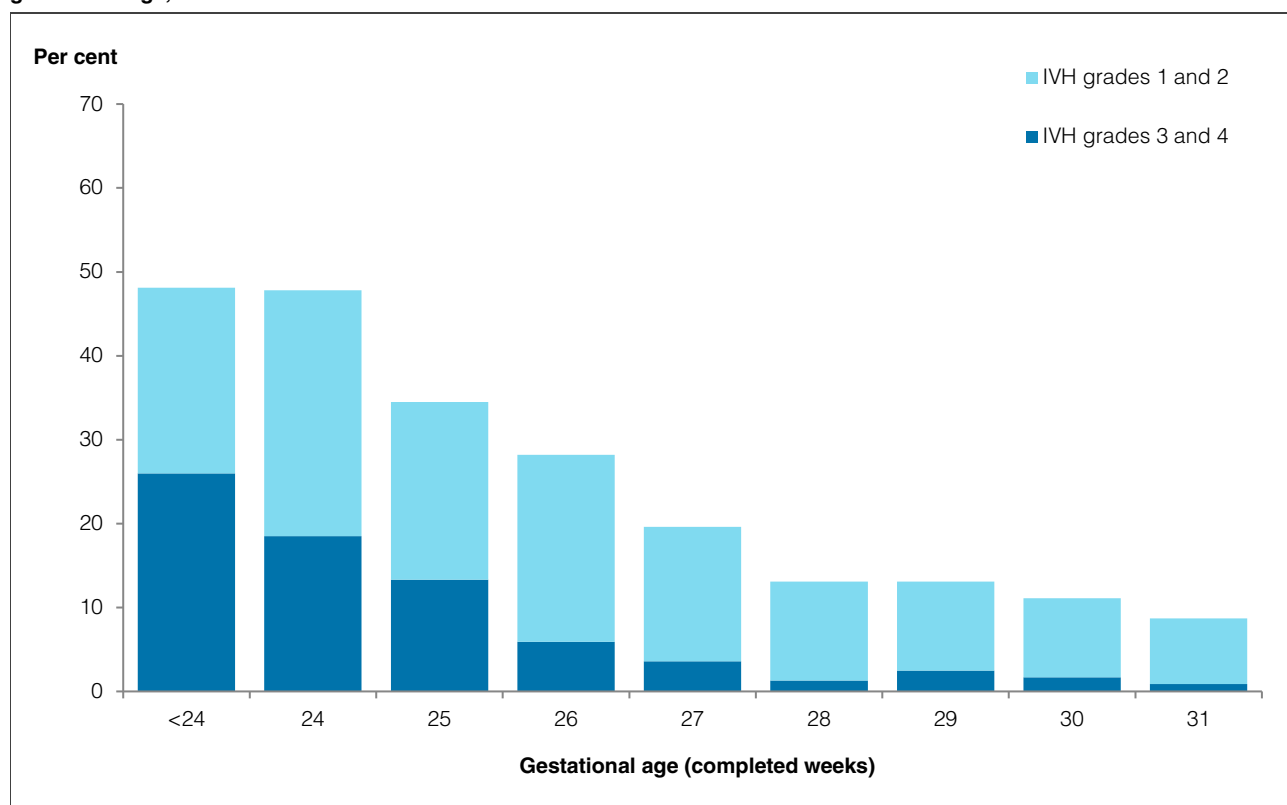
Intraventricular haemorrhage	Gestational age (weeks)									Total
	<24	24	25	26	27	28	29	30	31	
	Number									
None	40	96	133	196	287	323	385	465	601	2,526
Grade 1	6	18	20	31	37	33	n.p.	40	n.p.	256
Grade 2	11	36	23	30	n.p.	11	14	n.p.	13	167
Grade 3	6	7	9	5	<5	<5	<5	<5	5	45
Grade 4	14	27	18	11	9	<5	8	6	<5	96
Not examined	0	0	1	2	1	0	12	67	175	258
<b>Total</b>	<b>77</b>	<b>184</b>	<b>204</b>	<b>275</b>	<b>358</b>	<b>372</b>	<b>455</b>	<b>590</b>	<b>833</b>	<b>3,348</b>
Per cent										
None	51.9	52.2	65.5	71.8	80.4	86.8	86.9	88.9	91.3	81.7
Grade 1	7.8	9.8	9.9	11.4	10.4	8.9	n.p.	7.6	n.p.	8.3
Grade 2	14.3	19.6	11.3	11.0	n.p.	3.0	3.2	n.p.	2.0	5.4
Grade 3	7.8	3.8	4.4	1.8	n.p.	n.p.	n.p.	n.p.	0.8	1.5
Grade 4	18.2	14.7	8.9	4.0	2.5	n.p.	1.8	1.1	n.p.	3.1
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

**Note:** Not 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, ANZNN 2018**



## 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 3,417 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, 3,348 survived until day 3 and late ultrasound results were available for 2,129 (63.6%) of these babies. A normal report of no cysts was recorded for 96.3% of these registrants, 0.8% reported porencephalic cysts and 2.9% reported periventricular leukomalacia (PVL) (Table 25). Of the 62 babies who were reported with PVL, 13 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, ANZNN 2018**

	Gestational age (weeks)									
Cerebral ultrasound results	<24	24	25	26	27	28	29	30	31	Total
Number										
No cysts	38	n.p.	150	204	n.p.	291	n.p.	n.p.	n.p.	2,038
Porencephalic cysts	<5	<5	<5	0	<5	0	<5	<5	<5	16
Periventricular leukomalacia	<5	11	<5	13	7	7	5	5	10	62
Not stated	52	62	56	63	83	77	133	243	532	1,301
<b>Total</b>	<b>95</b>	<b>197</b>	<b>211</b>	<b>280</b>	<b>364</b>	<b>375</b>	<b>460</b>	<b>594</b>	<b>841</b>	<b>3,417</b>
Per cent										
No cysts	88.4	n.p.	96.8	94.0	n.p.	97.7	n.p.	n.p.	n.p.	96.3
Porencephalic cysts	n.p.	n.p.	n.p.	0.0	n.p.	0.0	n.p.	n.p.	n.p.	0.8
Periventricular leukomalacia	n.p.	8.1	n.p.	6.0	2.5	2.3	1.5	1.4	3.2	2.9
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

## Therapeutic hypothermia

Therapeutic hypothermia is the intentional cooling of an infant to a core temperature of less than 35°C (generally 33–34°C). The evidence in support for controlled hypothermia, initiated before 6 hours of age, as a means of limiting the reperfusion injury that follows perinatal asphyxia in term infants has been evolving over the last 10 years.

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 2018, 327 (6.4%) of the ANZNN registrants born at more than 34 weeks gestation received therapeutic hypothermia, and of these, 79.2% 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 81.0% 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 2018, the percentage of babies with confirmed NEC was 1.4%. Of these babies, 62.3% were born before 28 weeks gestation with 55.2% of them undergoing surgery, and 18.2% were born between 28–31 weeks gestation with surgery required for 42.9% of them. In total, 45 registrants died from NEC. The number of registrants with confirmed NEC is similar to that in 2017 (Table 26).

**TABLE 26: Necrotising enterocolitis in level III registrants by year of birth, ANZNN 2009–2018**

Necrotising enterocolitis	Year of birth									
	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018
Number										
Babies born at <28 weeks										
▪ NEC	94	112	78	87	75	64	81	91	105	96
▪ No NEC	1,032	964	1,025	980	1,015	1,039	981	1,126	1,046	1,051
▪ Not stated	2	4	5	2	0	3	4	2	0	0
Babies born at 28-31 weeks										
▪ NEC	34	41	36	35	27	21	40	37	25	28
▪ No NEC	2,384	2,182	2,401	2,417	2,384	2,484	2,383	2,353	2,325	2,242
▪ Not stated	0	4	0	2	0	2	6	1	1	0
Babies born at ≥32 weeks										
▪ NEC	19	21	14	14	19	26	27	30	27	30
▪ No NEC	5,410	4,903	5,626	5,778	6,200	6,515	6,267	6,832	7,151	7,201
▪ Not stated	2	4	1	3	1	4	9	1	1	3
<b>Total in each birth year</b>	<b>8,977</b>	<b>8,235</b>	<b>9,186</b>	<b>9,318</b>	<b>9,721</b>	<b>10,158</b>	<b>9,798</b>	<b>10,473</b>	<b>10,681</b>	<b>10,651</b>
Per cent										
NEC <28 weeks <sup>(a)</sup>	8.3	10.4	7.1	8.2	6.9	5.8	7.6	7.5	9.1	8.4
NEC 28-31 weeks <sup>(b)</sup>	1.4	1.8	1.5	1.4	1.1	0.8	1.7	1.5	1.1	1.2
NEC ≥32 weeks <sup>(c)</sup>	0.3	0.4	0.2	0.2	0.3	0.4	0.4	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 2018, 53 (0.5%) of ANZNN registrants had a confirmed diagnosis of spontaneous intestinal perforation. Of these, five babies were also reported to have a confirmed NEC diagnosis. Of babies born before 28 weeks gestation, 28 (2.4%) 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 2018, there were 945 ANZNN registrants who had major surgery, of whom over half (54.9%) were born at term. Of registrants born in a hospital, 72.3% were born in a hospital with tertiary care facilities. Of registrants who had major surgery, 76.1% also had a congenital anomaly present with 62.0% of these diagnosed during the antenatal period. 8.7% had surgery for proven NEC. The median length of stay for survivors was 34 days (Table 27).

**TABLE 27: Characteristics of level III registrants who underwent surgery by gestational age, ANZNN 2018**

Characteristics	Gestational age (weeks)								Total
	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	
	Number								
Male	10	34	26	18	20	24	111	317	560
Female	6	26	15	14	9	27	86	202	385
Congenital anomaly present	<5	n.p.	8	12	12	42	169	464	719
Congenital anomaly diagnosed antenatally	0	<5	<5	9	6	26	124	278	446
Proven NEC	8	29	16	9	<5	<5	6	9	82
Hospital of birth:									
▪ Tertiary	n.p.	52	n.p.	n.p.	22	42	153	332	680
▪ Non-tertiary	<5	8	<5	<5	7	9	43	185	260
Median length of stay for survivors (days)	137	143	108	93	73	57	39	22	34
Died before discharge home	8	10	6	<5	<5	<5	6	9	46
<b>Total in each age group</b>	<b>16</b>	<b>60</b>	<b>41</b>	<b>32</b>	<b>29</b>	<b>51</b>	<b>197</b>	<b>519</b>	<b>945</b>
	Per cent								
Male	62.5	56.7	63.4	56.3	69.0	47.1	56.3	61.1	59.3
Female	37.5	43.3	36.6	43.8	31.0	52.9	43.7	38.9	40.7
Congenital anomaly present	n.p.	n.p.	19.5	37.5	41.4	82.4	85.8	89.4	76.1
Congenital anomaly diagnosed antenatally	0.0	n.p.	n.p.	28.1	20.7	51.0	62.9	53.6	47.2
Proven NEC	50.0	48.3	39.0	28.1	n.p.	n.p.	3.0	1.7	8.7
Hospital of birth:									
▪ Tertiary	n.p.	86.7	n.p.	n.p.	75.9	82.4	77.7	64.0	72.0
▪ Non-tertiary	n.p.	13.3	n.p.	n.p.	24.1	17.6	21.8	35.6	27.5
Died before discharge home	50.0	16.7	14.6	n.p.	n.p.	n.p.	3.0	1.7	4.9

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

The median age of mothers of neonates who received major surgery was 31 years. Within the 2018 surgical cohort, 6.3% of pregnancies resulted from assisted conception, compared with 8.5% in the whole cohort. Of the 2018 ANZNN registrants who received major surgery, gastrointestinal procedures were the most commonly performed (46.2%) followed by cardiac procedures (26.2%).

There were 82 (0.8%) babies born in 2018 who received surgery to repair a gastroschisis before discharge to home. Two in five of these babies were male (42.7%) and three in five were born at more than 35 weeks gestation (57.3%). In 2018, 43 babies received surgery to repair a congenital diaphragmatic hernia, of which 53.5% were male and 55.8% were born at more than 37 weeks gestation.

## Congenital anomalies

In 2018, 1,273 ANZNN registrants (12.0%) had one or more major congenital anomalies. For registrants who had a major congenital anomaly, 14.9% were born before 32 weeks gestation, 29.5% were born between 32 and 36 weeks gestation and more than half of registrants (55.5%) were born at term.

Of the ANZNN registrants with major congenital anomalies, over half (52.6%) were diagnosed during the antenatal period with 6.4% of babies recorded as having a fatal congenital anomaly. A higher proportion of babies with congenital anomalies were male (58.8%).

## Transfer from level III NICUs to other units

Once intensive care is no longer required, babies are often ‘down’ transferred to a level II unit, sometimes referred to as a ‘special care baby unit’, either within the same hospital or to another hospital for convalescence before discharge home. In 2018, one third of ANZNN registrants (33.3%) 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 (46.4%) transferred from level III to level II or level I units were born at less than 32 weeks gestation compared to 16.5% born at term.

Some level III registrants required transfer to a specialist children’s hospital and in 2018 these accounted for 3.8% of registrants. Overall, 59.4% of level III registrants were not transferred after registration (Table 28).

**TABLE 28: Transfer after registration of level III registrants by level of destination hospital and gestational age, ANZNN 2018**

	Gestational age (weeks)								
Transfer status	<24	24–25	26–27	28–29	30–31	32–33	34–36	37–44	Total
Number									
Not transferred	64	235	290	323	552	656	1,267	2,933	6,320
Level III hospital	<5	28	36	38	32	36	n.p.	98	322
Level II or I hospital	n.p.	91	278	435	826	671	n.p.	583	3,540
Children’s hospital	17	54	40	33	25	23	73	196	461
Not stated	0	0	0	6	0	2	0	0	8
Total	95	408	644	835	1,435	1,388	2,036	3,810	10,651
Per cent									
Not transferred	67.4	57.6	45.0	39.0	38.5	47.3	62.2	77.0	59.4
Level III hospital	n.p.	22.3	43.2	52.5	57.6	48.4	n.p.	15.3	3.0
Level II or I hospital	n.p.	6.9	5.6	4.6	2.2	2.6	n.p.	2.6	33.3
Children’s hospital	17.9	13.2	6.2	4.0	1.7	1.7	3.6	5.1	4.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

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

## Length of stay until discharge home

Factors that influence a baby's length of stay in hospital include 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 length of stay includes all the time the baby spends in hospital, from the first day of their first admission up to and including the day of their discharge home. The length of stay 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 97.4% of ANZNN registrants in 2018 who survived to discharge to home. The median length of stay was 24 days with an interquartile range of 8–50 days (Table 29). Length of stay 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 216,309 days in hospital, babies born between 32 and 36 weeks spent 86,893 days and babies born at term spent 46,605 days in hospital.

**TABLE 29: Length of stay for level III registrants who survived until discharge home by gestational age, ANZNN 2018**

Gestational age (weeks)	Number of babies	Median length of stay (days)	Interquartile range (days)
<24	40	130	121–144
24	138	123	109–147
25	174	108	97–128
26	258	92	82–106
27	340	81	72–95
28	358	71	61–82
29	441	62	53–70
30	583	50	44–58
31	824	41	35–49
32	724	34	29–42
33	638	26	21–34
34	711	20	16–27
35	642	14	9–21
36	636	10	6–17
37	837	8	5–15
38	894	7	4–16
39	873	6	3–13
40	699	5	4–12
41	371	5	4–11
≥42	31	5	3–10
<b>Total</b>	<b>10,212</b>	<b>24</b>	<b>8–50</b>

**Note:** Survival status was not provided for two babies.

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

## Survival

In 2018, 95.9% of ANZNN registrants survived to go home. These data include babies who were transferred to level II or level I 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 2018, there were 437 neonatal deaths, of which 197 occurred in the early neonatal period that is within seven days of birth (Table 30). Mortality was highest among babies born before 30 weeks gestation with a survival rate at discharge increasing week on week from 42.1% for babies born before 24 weeks to 95.9% for babies born at 29 weeks (Table 30, Figure 8). A similar pattern of increasing survival with increasing birthweight is seen in Figure 9.

Lethal congenital anomaly was the cause of death for 0.8% of registrants, with most occurring in babies born between 35–39 weeks gestation (Table 30).

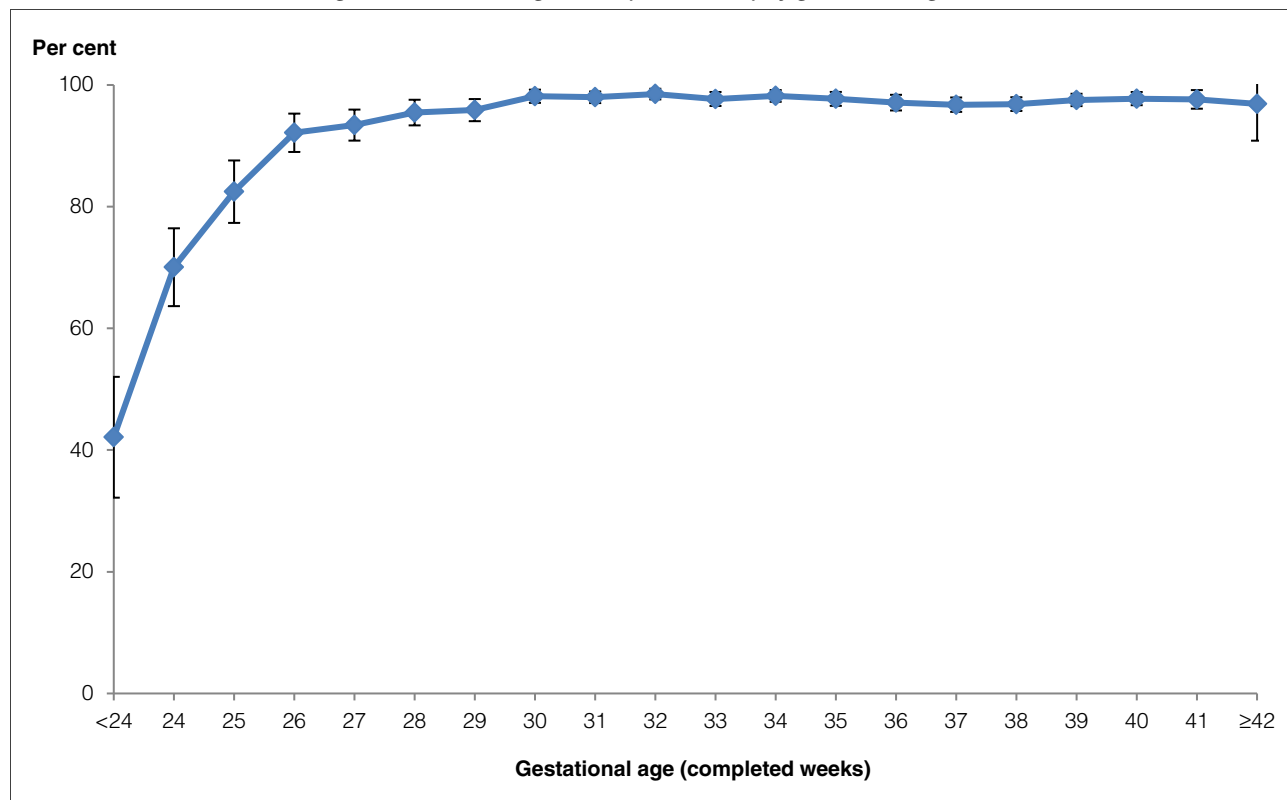
**TABLE 30: Survival to discharge home for level III registrants by gestational age, ANZNN 2018**

Gestational age (weeks)	Number of babies	Lethal congenital anomalies	Babies alive on day 7	Babies alive on day 28	Survived to discharge to home	Per cent survival at discharge to home
<24	95	0	73	46	40	42.1
24	197	<5	176	153	138	70.1
25	211	<5	197	180	174	82.5
26	280	<5	272	264	258	92.1
27	364	0	355	347	340	93.4
28	375	5	371	364	358	95.5
29	460	<5	451	447	441	95.9
30	594	<5	588	585	583	98.1
31	841	5	833	825	824	98.0
32	735	<5	730	726	724	98.5
33	653	5	647	640	638	97.7
34	724	6	718	714	711	98.2
35	657	6	644	643	642	97.7
36	655	6	643	638	636	97.1
37	865	12	853	845	837	96.8
38	923	14	907	899	894	96.9
39	895	7	883	876	873	97.5
40	715	<5	706	704	699	97.8
41	380	<5	375	371	371	97.6
≥42	32	0	32	32	31	96.9
<b>Total</b>	<b>10,651</b>	<b>81</b>	<b>10,454</b>	<b>10,299</b>	<b>10,212</b>	<b>95.9</b>

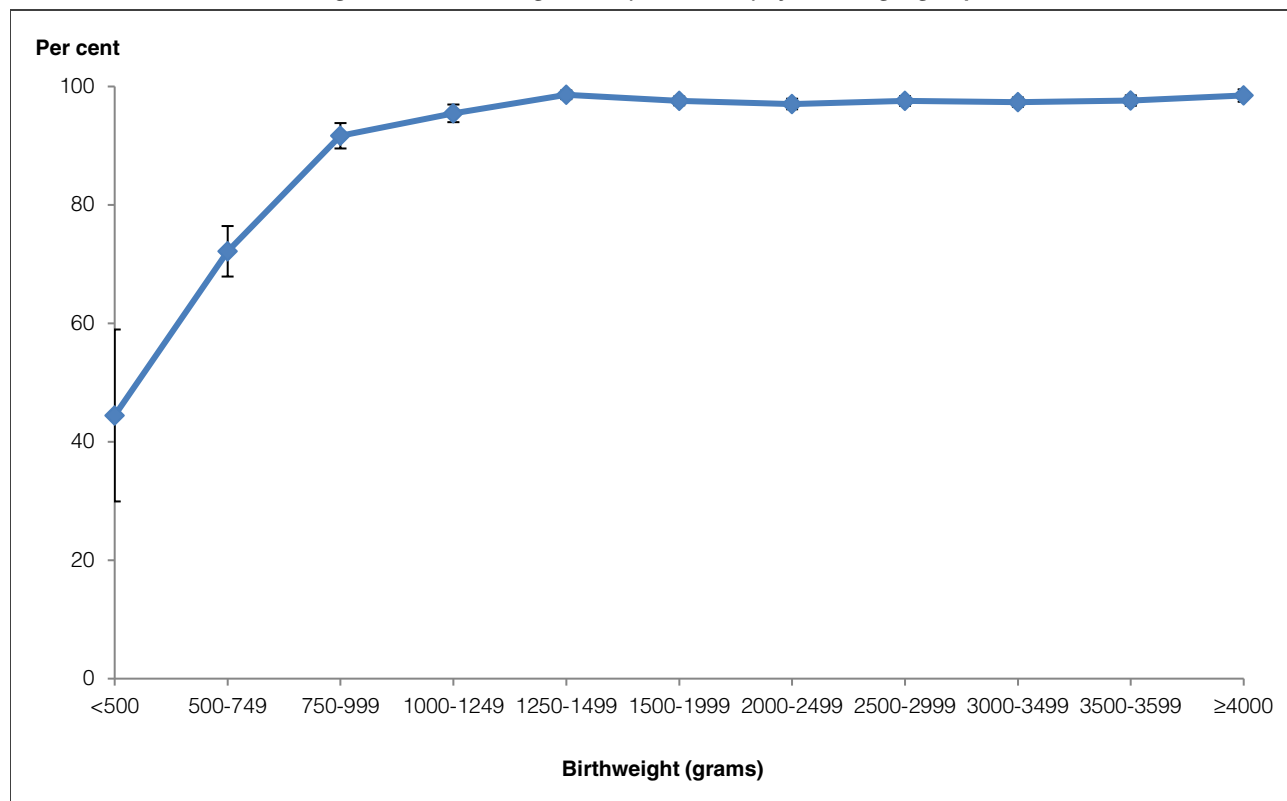
*Note:* Survival status was not provided for two babies.

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

**FIGURE 8: Survival of level III registrants to discharge home (with 95% CI) by gestational age, ANZNN 2018**



**FIGURE 9: Survival of level III registrants to discharge home (with 95% CI) by birthweight group, ANZNN 2018**



## 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 of care for perinatal hospitals is changing and the new classifications for ‘level II’ are now often ‘level IV and V’. For the purposes 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 21 in Australia that are members of the ANZNN. Altogether, 32 level II units contributed data for this 2018 report.

In 2018, 1,780 babies fulfilled the ANZNN criteria for registration to a level II unit. Of those babies, 4.7% were born at less than 32 weeks gestation and 4.2% weighed less than 1,500 grams at birth (Table 31 and Table 32). The highest number of babies registered to a level II unit in 2018 was just under 140.

**TABLE 31: Level II registrants by gestational age, ANZNN 2018**

Gestational age (weeks)	Number of babies	Per cent	Cumulative per cent
<30	7	0.4	0.4
30–31	77	4.3	4.7
<b>All babies &lt;32 weeks gestation</b>	<b>84</b>	<b>4.7</b>	
32–33	271	15.2	19.9
34–36	514	28.9	48.8
37–44	911	51.2	100.0
<b>Total</b>	<b>1,780</b>	<b>100.0</b>	

*Note: Gestational ages below 30 weeks have been combined to maintain confidentiality of small numbers.*

**TABLE 32: Level II registrants by birthweight, ANZNN 2018**

Birthweight (grams)	Number of babies	Per cent	Cumulative per cent
<1,200	9	0.5	0.5
1,200–1,299	9	0.5	1.0
1,300–1,399	16	0.9	1.9
1,400–1,499	40	2.2	4.2
<b>All babies &lt;1,500g birthweight</b>	<b>74</b>	<b>4.2</b>	
1,500–1,999	221	12.4	16.6
2,000–2,499	333	18.7	35.3
2,500–2,999	330	18.5	53.8
3,000–3,499	368	20.7	74.5
3,500–3,999	287	16.1	90.6
≥4,000	167	9.4	100.0
<b>Total</b>	<b>1,780</b>	<b>100.0</b>	

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

Of the level II registrants in 2018, 1,097 babies (61.6%), were born to Caucasian mothers, 50.7% of whom were born preterm. The number of registrants born to Maori mothers was 199 (11.2%), and of these, 94 (47.2%) were born preterm. There were 34 babies (1.9%) born to Pacific Islander mothers.



There were 1,059 male (59.5%) and 714 female (40.1%) registrants in the audit. Gender was not recorded for seven registrants. 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, 27.5% did not present with any maternal complications. Among babies born before 37 weeks, 35.1% of mothers had presented with preterm labour (Table 33).

**TABLE 33: Mothers of level II registrants presenting antenatal problem by gestational age, ANZNN 2018**

Presenting antenatal problem	Gestational age (weeks)				Total
	<32	32–33	34–36	37–44	
No antenatal problems	0	0	<5	n.p.	476
Preterm pre-labour rupture of membranes	17	70	98	15	200
Preterm labour	40	n.p.	171	<5 <sup>(a)</sup>	305
Hypertension in pregnancy	12	37	49	42	140
Antepartum haemorrhage	5	23	46	17	91
Intrauterine growth restriction	<5	20	n.p.	28	98
Fetal distress	5	20	30	130	185
Other problem	<5	n.p.	60	158	231
Congenital anomalies	0	0	<5	n.p.	7
Not stated	0	1	7	39	47
<b>Total</b>	<b>84</b>	<b>271</b>	<b>514</b>	<b>911</b>	<b>1,780</b>
	Per cent				
No antenatal problems	0.0	0.0	n.p.	n.p.	27.5
Preterm pre-labour rupture of membranes	20.2	25.9	19.3	1.7	11.5
Preterm labour	47.6	n.p.	33.7	n.p.	17.6
Hypertension in pregnancy	14.3	13.7	9.7	4.8	8.1
Antepartum haemorrhage	6.0	8.5	9.1	1.9	5.3
Intrauterine growth restriction	n.p.	7.4	n.p.	3.2	5.7
Fetal distress	6.0	7.4	5.9	14.9	10.7
Other problem	n.p.	n.p.	11.8	18.1	13.3
Congenital anomalies	0.0	0.0	n.p.	n.p.	0.4
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

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

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

Previous preterm births were reported by 166 (9.3%) mothers of level II registrants and 56 (3.1%) mothers had had a previous perinatal death(s).

Most mothers (89.3%) of level II registrants had booked into a level II hospital for delivery. Of the level II registrants born before 34 weeks gestation, 68.5% of the mothers were given antenatal corticosteroids within seven days prior to the birth (Table 34).

**TABLE 34: Antenatal corticosteroid use by mothers of level II registrants by gestational age, ANZNN 2018**

Antenatal corticosteroids	Gestational age (weeks)				Total
	<32	32–33	34–36	37–44	
None	16	48	276	839	1,179
Incomplete course	35	79	77	5	196
Complete course within 7 days of birth	22	107	116	16	261
Given >7 days prior to birth	9	28	28	6	71
Not stated	2	9	17	45	73
<b>Total</b>	<b>84</b>	<b>271</b>	<b>514</b>	<b>911</b>	<b>1,780</b>
	Per cent				
	<32	32–33	34–36	37–44	
None	19.5	18.3	55.5	96.9	69.1
Incomplete course	42.7	30.2	15.5	0.6	11.5
Complete course within 7 days of birth	26.8	40.8	23.3	1.8	15.3
Given >7 days prior to birth	11.0	10.7	5.6	0.7	4.2
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

Vaginal and instrumental vaginal delivery were equally as common as caesarean section as the method of birth of level II registrants (Table 35). Of those who were delivered by caesarean section, nearly three in five (57.6%) occurred before the onset of labour.

**TABLE 35: Method of delivery for level II registrants by gestational age, ANZNN 2018**

Method of delivery	Gestational age (weeks)				Total
	<32	32–33	34–36	37–44	
Vaginal birth <sup>(a)</sup>	34	99	206	544	883
Caesarean section <sup>(b)</sup>	50	170	306	360	886
Not stated	0	2	2	7	11
<b>Total</b>	<b>84</b>	<b>271</b>	<b>514</b>	<b>911</b>	<b>1,780</b>
	Per cent				
	<32	32–33	34–36	37–44	
Vaginal birth	40.5	36.8	40.2	60.2	49.9
Caesarean section	59.5	63.2	59.8	39.8	50.1
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

*(a)* Vaginal and instrumental vaginal 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.

## Characteristics of level II babies

Among the 1,780 babies registered to level II units, 190 were from multiple gestation pregnancies (10.7%). There were 1,059 (59.5%) male births and seven babies whose gender was not recorded.

A low Apgar score of less than 4 at one minute of age was recorded for 15.1% of babies and 7.5% of them required endotracheal intubation in the labour ward to assist in their adaptation to extrauterine life.

Non-specific respiratory distress (74.1%) was the major reason for assisted ventilation for level II registrants, followed by hyaline membrane disease (11.6%) (Table 36).

For level II registrants, the median duration of assisted ventilation by intermittent positive pressure ventilation (IPPV) was 12 hours and 17 hours by continuous positive airway pressure (CPAP) (Table 37).

**TABLE 36: Indication for respiratory support for level II registrants by gestational age, ANZNN 2018**

Indication for respiratory support	Gestational age (weeks)				Total
	<32	32–33	34–36	37–44	
No respiratory support	n.p.	13	7	<5	29
Non-specific respiratory distress	45	175	393	695	1,308
Hyaline membrane disease	31	64	81	29	205
Meconium aspiration syndrome	0	0	<5	n.p.	74
Pneumonia	0	<5	11	47	n.p.
Persistent pulmonary hypertension	0	0	<5	n.p.	18
Apnoea	<5	n.p.	11	14	35
Congenital anomaly	0	0	<5	<5	<5
Other	<5	<5	5	20	30
Peri-surgery	0	0	0	0	0
Newborn encephalopathy	0	<5	0	n.p.	n.p.
Not stated	0	4	3	7	14
<b>Total</b>	<b>84</b>	<b>271</b>	<b>514</b>	<b>911</b>	<b>1,780</b>
Indication for respiratory support	Per cent				Total
	<32	32–33	34–36	37–44	
No respiratory support	n.p.	4.9	1.4	n.p.	1.6
Non-specific respiratory distress	53.6	65.5	76.9	76.9	74.1
Hyaline membrane disease	36.9	24.0	15.9	3.2	11.6
Meconium aspiration syndrome	0.0	0.0	n.p.	n.p.	4.2
Pneumonia	0.0	n.p.	2.2	5.2	n.p.
Persistent pulmonary hypertension	0.0	0.0	n.p.	n.p.	1.0
Apnoea	n.p.	n.p.	2.2	1.5	2.0
Congenital anomaly	0.0	0.0	n.p.	n.p.	n.p.
Other	n.p.	n.p.	1.0	2.2	1.7
Peri-surgery	0.0	0.0	0.0	0.0	0.0
Newborn encephalopathy	0.0	n.p.	0.0	n.p.	n.p.
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

**TABLE 37: Duration of assisted ventilation use for level II registrants by gestational age, ANZNN 2018**

Duration of assisted ventilation	Gestational age (weeks)				Total
	<32	32–33	34–36	37–44	
IPPV (hours)					
Median	5	20.5	12	11.5	12
IQR	4.5–13.5	9–28	5–19	9–23	5–19
CPAP (hours)					
Median	36	29	17	14	17
IQR	24–69	13–56	9–37	8–25	9–33

*Note: IQR = Interquartile range. IPPV = intermittent positive pressure ventilation. CPAP = continuous positive airway pressure.*

## Eye examination

Screening for retinopathy of prematurity (ROP) was reported for only 24 of the 40 eligible babies born at less than 31 weeks gestational age and/or weighing less than 1,250 grams at birth (60.0% compared to 82.3% of eligible level III registrants). All were reported as normal.

## Cerebral ultrasound

Of the 84 babies born at less than 32 weeks, 62 (73.8%) had a cerebral ultrasound in the first week after birth. 51 of them were reported as normal, that is, no intraventricular haemorrhage (IVH) and eleven reported a grade 1 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 nearest to six weeks of age was reported for 39 babies, all of whom had normal reports excepting one baby with reported porencephalic cysts.

## Other morbidities

Septicaemia was proven in 19 babies, including 13 before day two, that is, less than 48 hours of age. There were no cases of necrotising enterocolitis. Major congenital anomalies were reported for 44 babies, of which one required major surgery.

## Level II transfers

In total, 148 level II registrants were transferred to other units, 114 were transferred to a level I or another level II unit, 29 were transferred to a level III unit and the remaining five to a children's hospital.

## Survival

There were 1,762 level II registrants who survived to discharge to home (99.0%). Eight babies died within the first seven days of birth (Table 38). Two babies were reported to have had a lethal congenital anomaly.

**TABLE 38: Survival to discharge home for level II registrants by gestational age, ANZNN 2018**

<b>Gestational age (weeks)</b>	<b>All babies</b>	<b>Babies alive on day 7</b>	<b>Babies alive on day 28</b>	<b>Survived to discharge to home</b>	<b>Per cent survival at discharge to home</b>
<30	7	5	5	5	71.4
30–31	77	77	77	77	100.0
32–33	271	270	270	262	96.7
34–36	514	514	514	512	99.6
37–44	911	908	908	906	99.5
<b>All babies</b>	<b>1,780</b>	<b>1,774</b>	<b>1,774</b>	<b>1,762</b>	<b>99.0</b>

*Note: Survival status was not provided for ten babies.*

## 6. Extremely preterm follow-up, 2012–2015 births

### Introduction

Neurological and developmental problems are common among surviving extremely preterm and/or extremely low birthweight babies. 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 2012 to 2015 births. All infants born from 2012 to 2015 at less than 28 weeks gestation or less than 1,000 grams at birth and admitted to one of the 29 level III NICUs in Australia and New Zealand, who survived to discharge to home were eligible for inclusion in the ANZNN 2–3 year follow-up data collection. There were 4,619 infants who fulfilled the criteria for 2–3 year follow-up.

Care should be taken with interpretation of these data as some NICUs were unable to supply follow-up data, totalling 207 (4.5%) eligible ANZNN registrants born from 2012 to 2015. In addition, for NICUs supplying follow-up data, the follow-up rate (as detailed below) should be taken into consideration when interpreting developmental outcome data.

### Follow-up rate

From 2012 to 2015, 5,406 extremely preterm and/or extremely low birthweight babies were registered to the ANZNN, with 4,619 (85.4%) 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 2012, 2013 and 2014 births and another NICU was unable to submit post-discharge data for 2013, 2014 and 2015 births before the publication of this report. The 200 eligible survivors registered to these two NICUs and born during these years were excluded from further outcome analysis.

Post-discharge data were requested for infants who were assessed at 2–3 years of age, corrected for prematurity. Age corrected for prematurity is the age the infant would have been if they had been born on their due date. The target range requested was for assessments at 24–36 months corrected age, with an acceptable range of 18–42 months corrected age. Some outcomes were available for infants who were assessed at less than 18 months corrected age and subsequently lost to follow-up, or whose age at assessment was not recorded. For the purposes of this report, assessments at 18–42 months corrected age are considered informative for 2–3 year follow-up outcomes, and outcomes for infants who were not 18–42 months corrected age at assessment are reported separately.

Of the 4,419 eligible survivors registered to NICUs that were able to submit data, 20 (0.5%) infants died after discharge to home and prior to the 2–3 year follow-up, 3,374 (76.4%) infants had a follow-up assessment at 18–42 months corrected age and 53 (1.2%) had unknown age at follow-up assessment. In addition, there was data submitted for 56 (1.3%) infants who were followed-up earlier than 18 months corrected age and 27 (0.6%) infants who were followed-up at 43 months corrected age or older. The remaining 889 (20.1%) infants were lost to follow-up, and of these, 461 (51.9%) infants were known to have survived to 2–3 years of age but were not followed-up, 421 (47.4%) infants had unknown survival status at 2–3 years of age and seven (0.8%) infants had no post-discharge data retrieved from the NICU (Figure 10). Overall, the rate of follow-up at 2–3 years among surviving eligible infants was 76.7% (3,374 of 4,399), excluding deaths after discharge. The follow-up rate was highest for infants born at less than 25 weeks gestation or who weighed less than 500 grams at birth (Table 39 & Table 40).

Of the 3,374 infants who were followed-up at 18–42 months corrected age, 3,042 (90.2%) had a formal developmental assessment. For the remaining 332 (9.8%) infants, some follow-up information was obtained but a formal developmental assessment was not completed.

Of the 136 infants whose age at assessment was unknown or was outside of the range 18–42 months corrected age, 24 of 56 (42.9%) infants had a formal developmental assessment at less than 18 months corrected age, 21 of 27 (77.8%) infants had a formal developmental assessment at 43 months corrected age or older, and 5 of 53 (9.4%) had a formal developmental assessment at unknown age.

FIGURE 10: ANZNN 2–3 year follow-up cohort of extremely preterm infants, 2012–2015 births

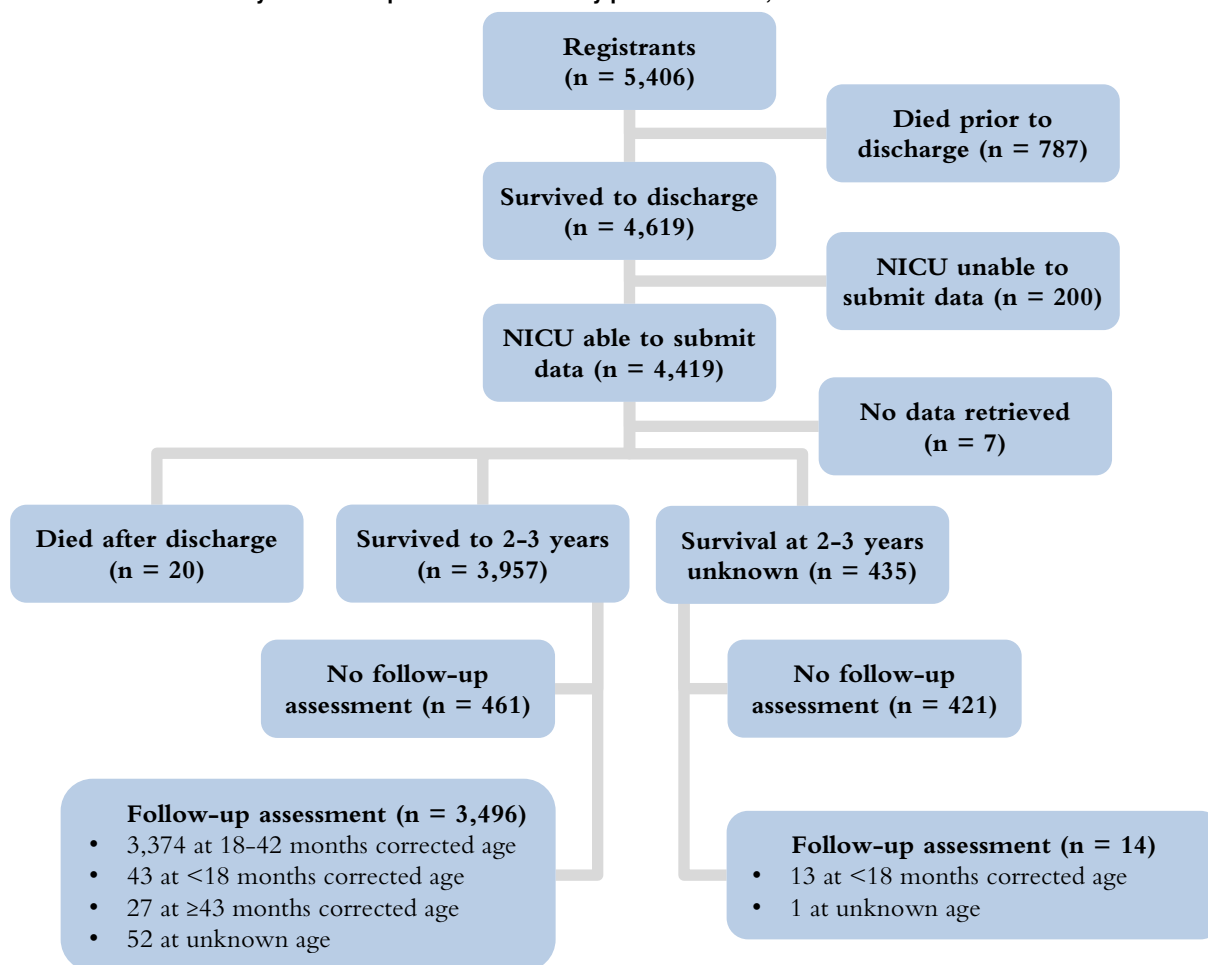


TABLE 39: Births, survival and 2–3 year follow-up of extremely preterm and/or extremely low birthweight infants by gestational age, ANZNN 2012–2015 births

	Gestational age (weeks)						Total
	<24	24	25	26	27	≥28 <sup>(a)</sup>	
Number							
Registrants	234	689	942	1,173	1,293	1,075	5,406
Survived to discharge	116	474	767	1,051	1,205	1,006	4,619
Per cent							
Survived to discharge <sup>(b)</sup>	49.6	68.8	81.4	89.6	93.2	93.6	85.4
Number							
NICU not included	10	37	35	36	40	42	200
Follow-up cohort <sup>(c)</sup>	106	437	732	1,015	1,165	964	4,419
▪ Died post-discharge	<5	<5	<5	<5	5	5	20
▪ Follow-up assessment <sup>(d)</sup>	76	355	578	791	888	686	3,374
▪ No outcome data	n.p.	n.p.	n.p.	n.p.	272	273	1,025
Per cent							
Follow-up rate <sup>(e)</sup>	72.4	81.6	79.3	78.2	76.6	71.5	76.7

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

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

(b) Denominator is all registrants.

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

(d) Infants assessed at 18–42 months corrected age, excluding infants with unknown 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, ANZNN 2012–2015 births**

	Birthweight (grams)							Total
	<500	500-599	600-699	700-799	800-899	900-999	≥1000 <sup>(a)</sup>	
	Number							
Registrants	116	356	758	932	1,046	1,220	978	5,406
Survived to discharge	59	242	560	761	942	1,141	914	4,619
	Per cent							
Survived to discharge <sup>(b)</sup>	50.9	68.0	73.9	81.7	90.1	93.5	93.5	85.4
	Number							
NICU not included	2	13	27	40	38	49	31	200
Follow-up cohort <sup>(c)</sup>	57	229	533	721	904	1,092	883	4,419
▪ Died post-discharge	<5	<5	<5	<5	<5	6	<5	20
▪ Follow-up assessment <sup>(d)</sup>	47	186	419	588	683	787	664	3,374
▪ No outcome data	n.p.	n.p.	n.p.	n.p.	n.p.	299	n.p.	1,025
	Per cent							
Follow-up rate <sup>(e)</sup>	83.9	81.6	79.1	81.8	75.9	72.5	75.5	76.7

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

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

*(b)* Denominator is all registrants.

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

*(d)* Infants assessed at 18–42 months corrected age, excluding infants with unknown 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, a local paediatrician or general practitioner may have examined the child. The median age of assessment was 24.9 months with an interquartile range of 24.0–27.6 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.

Cerebral palsy outcomes were included for infants assessed at 18–42 months corrected age as mild cerebral palsy may be difficult to diagnose prior to this age.

Cerebral palsy was graded using the Gross Motor Function Classification System (GMFCS). For the purposes of this report, mild was defined by GMFCS level 1, moderate by GMFCS level 2 or level 3, and severe by GMFCS level 4 or level 5. It should be noted that the definition of mild, moderate and severe cerebral palsy used in this report may be at variance with other reporting definitions.

Of the 3,374 infants with a follow-up assessment at 18–42 months corrected age, information about cerebral palsy was available for 3,293 (97.6%), and of these, 182 (5.5%) had a diagnosis of cerebral palsy. The movement ability of 174 (95.6%) infants with cerebral palsy was graded by the GMFCS. Of the infants with a GMFCS classification, 91 (52.3%) infants were graded as level 1, 29 (16.7%) as level 2, 21 (12.1%) as level 3, 13 (7.5%) as level 4 and 20 (11.5%) as level 5 (Table 41).



Of the 109 infants who were assessed at less than 18 months corrected age, there were two cases of mild cerebral palsy, two cases of moderate cerebral palsy and two cases of severe cerebral palsy. Of the 27 infants who were assessed at older than 42 months corrected age or whose age at assessment was unknown, there was one case of moderate cerebral palsy.

**TABLE 41: Cerebral palsy at 2–3 year follow-up by gestational age, ANZNN 2012–2015 births**

Cerebral palsy	Gestational age (weeks)						Total
	<24	24	25	26	27	≥28	
	Number						
No cerebral palsy	65	312	516	734	837	647	3,111
Cerebral palsy	9	34	46	34	39	20	182
▪ Mild (Level 1)	6	16	23	17	18	11	91
▪ Moderate (Level 2–3)	<5	n.p.	n.p.	10	n.p.	<5	50
▪ Severe (Level 4–5)	<5	7	8	7	6	<5	33
▪ Level unknown	<5	<5	<5	0	<5	<5	8
Not stated	2	9	16	23	12	19	81
<b>Total<sup>(a)</sup></b>	<b>76</b>	<b>355</b>	<b>578</b>	<b>791</b>	<b>888</b>	<b>686</b>	<b>3,374</b>
	Per cent						
No cerebral palsy	87.8	90.2	91.8	95.6	95.5	97.0	94.5
Cerebral palsy	12.2	9.8	8.2	4.4	4.5	3.0	5.5
▪ Mild (Level 1)	8.1	4.6	4.1	2.2	2.1	1.6	2.8
▪ Moderate (Level 2–3)	n.p.	n.p.	n.p.	1.3	n.p.	n.p.	1.5
▪ Severe (Level 4–5)	n.p.	2.0	1.4	0.9	0.7	n.p.	1.0
▪ Level unknown	n.p.	n.p.	n.p.	0.0	n.p.	n.p.	0.2

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

*(a)* Infants assessed at 18–42 months corrected age.

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

## Vision and hearing

Extremely preterm and/or extremely low birthweight babies are at increased risk of retinopathy of prematurity (ROP) which may result in substantial long term retinal morbidity as well as a risk of amblyopia and strabismus. Of the 3,374 infants with a follow-up assessment at 18–42 months corrected age, 3,306 (98.0%) had data on blindness available, and of these, only eight (0.2%) were recorded as being blind (<6/60 in the better eye). Three (37.5%) of the infants with blindness were born at 24 weeks gestational age or younger.

Of the 136 infants who were followed up at less than 18 months or older than 42 months corrected age or whose corrected age at assessment was unknown, one infant was recorded as being blind.

Permanent congenital, delayed-onset, or progressive hearing loss is also known to be an adverse outcome of extreme prematurity. Additional risk factors for hearing loss include prolonged oxygen supplementation and hyperbilirubinemia.

Information about the use of hearing devices was available for 3,309 (98.1%) of infants with a follow-up assessment at 18–42 months corrected age. Of these, eight (0.2%) infants were fitted with a unilateral hearing aid, 34 (1.0%) infants with bilateral hearing aids, six (0.2%) 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 greatest among those born at 24 weeks gestational age or younger (4.2%) compared with any other gestational age group (1.2–1.4%).

Data on the use of devices for hearing amplification were also available for infants assessed at 9–17 months corrected age, an age range for which hearing devices would likely already be fitted. Data on the use of hearing devices was available for 48 of 53 (90.6%) infants assessed at 9–17 months corrected age, for 26 of 27

(96.3%) infants assessed at 43 months corrected age and for 45 of 53 (84.9%) infants assessed at unknown age. One infant assessed at 9–17 months corrected age and one infant assessed at unknown age were recorded as being fitted with a hearing device. There were no infants assessed at 43 months corrected age or older who were recorded as being fitted with a hearing device.

## Congenital anomalies

Information on congenital anomalies reported for infants with a follow-up assessment was 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.

Of the 3,374 infants assessed at 18–42 months corrected age, there were 24 infants who were identified as having a congenital anomaly that could cause developmental delay. 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 six infants with congenital central nervous system malformations, including encephalomalacia, hydrocephalus, meningomyelocele, microcephaly, septo-optic dysplasia, and other reduction anomalies of brain. Also excluded were 15 infants with genetic disorders or chromosomal anomalies, including chromosome deletion, chromosome duplication, Crouzon syndrome, Klinefelter syndrome, Menkes syndrome, Prader-Willi syndrome, Russell-Silver syndrome, Trisomy 21, and tuberous sclerosis. The remaining three infants were 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. Cognitive, language and motor delay was graded for those infants formally assessed at 18–42 months corrected age only, as mild delays are unlikely to be reliably diagnosed prior to 18 months corrected age or without formal developmental assessment. Results were included for 2,979 infants assessed by the Bayley Scales of Development-III, 21 infants assessed by the Griffiths Mental Developmental Scales, and six infants assessed by the Wechsler Preschool and Primary Scale of Intelligence (WPPSI) or the Stanford-Binet Intelligence Scales. It should be noted that motor and language subscale scores were not available for the infants who were assessed by WPPSI or Stanford-Binet alone.

Results were not included for infants assessed using other developmental assessments including screening assessments such as the Bayley Screening Test, Ages and Stages Questionnaires, or based on clinical assessments by healthcare professionals.

For the purposes of this report, cognitive, language and motor delay were graded as mild, moderate or severe. 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 a mean of 100 (SD 15), these cut-points were defined as follows: severe  $<55$ , moderate 55–69, and mild 70–84. Because 55 is the lowest composite score that can be assigned on the Bayley cognitive scale, cut-points for severe and moderate cognitive delay were adjusted to  $\leq 55$  and 56–69 respectively for infants assessed on this scale. In a general population, approximately 13.6% of infants would be  $-2$  SD to  $<-1$  SD and approximately 2.3% would be  $<-2$  SD relative to the mean. 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 28 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 unless indicated otherwise. While an additional seven infants without formal developmental assessment had a severe impairment recorded (one with blindness and six with severe cerebral palsy), severe cognitive, language or motor delay could not be reliably assigned to these infants.

Overall, there were 470 (15.5%) infants with mild to severe cognitive delay, 833 (29.4%) with mild to severe language delay and 521 (18.1%) 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, ANZNN 2012–2015 births**

	Gestational age (weeks)						
Cognitive delay	<24	24	25	26	27	≥28	Total
Number							
None	44	248	430	608	699	525	2,554
Mild	14	47	46	64	69	71	311
Moderate	<5	12	15	19	13	n.p.	79
Severe	<5	14	17	16	16	n.p.	80
Not stated <sup>(a)</sup>	1	2	2	2	2	1	10
<b>Total<sup>(b)</sup></b>	<b>64</b>	<b>323</b>	<b>510</b>	<b>709</b>	<b>799</b>	<b>629</b>	<b>3,034</b>
Per cent							
None	69.8	77.3	84.6	86.0	87.7	83.6	84.5
Mild	22.2	14.6	9.1	9.1	8.7	11.3	10.3
Moderate	n.p.	3.7	3.0	2.7	1.6	n.p.	2.6
Severe	n.p.	4.4	3.3	2.3	2.0	n.p.	2.6
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

*(a)* Infants 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 18-42 months corrected age or unable to be assessed due to severe delay. Excludes 24 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, ANZNN 2012–2015 births**

	Gestational age (weeks)						
Language delay	<24	24	25	26	27	≥28	Total
Number							
None	30	188	324	488	555	411	1,996
Mild	17	64	98	105	129	108	521
Moderate	n.p.	35	32	41	39	n.p.	208
Severe	<5	17	19	27	21	n.p.	104
Not stated <sup>(a)</sup>	5	19	37	46	53	39	199
<b>Total<sup>(b)</sup></b>	<b>64</b>	<b>323</b>	<b>510</b>	<b>707</b>	<b>797</b>	<b>627</b>	<b>3,028</b>
Per cent							
None	50.8	61.8	68.5	73.8	74.6	69.9	70.6
Mild	28.8	21.1	20.7	15.9	17.3	18.4	18.4
Moderate	n.p.	11.5	6.8	6.2	5.2	n.p.	7.4
Severe	n.p.	5.6	4.0	4.1	2.8	n.p.	3.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

*(b)* Infants assessed by Bayley or Griffiths at 18-42 months corrected age or unable to be assessed due to severe delay. Excludes 24 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, ANZNN 2012–2015 births**

	Gestational age (weeks)						
Motor delay	<24	24	25	26	27	≥28	Total
Number							
None	45	235	381	564	646	494	2,365
Mild	11	49	62	70	82	75	349
Moderate	<5	13	28	21	15	n.p.	106
Severe	<5	14	11	13	15	n.p.	66
Not stated <sup>(a)</sup>	3	12	28	39	39	21	142
<b>Total<sup>(b)</sup></b>	<b>64</b>	<b>323</b>	<b>510</b>	<b>707</b>	<b>797</b>	<b>627</b>	<b>3,028</b>
Per cent							
None	73.8	75.6	79.0	84.4	85.2	81.5	81.9
Mild	18.0	15.8	12.9	10.5	10.8	12.4	12.1
Moderate	n.p.	4.2	5.8	3.1	2.0	n.p.	3.7
Severe	n.p.	4.5	2.3	1.9	2.0	n.p.	2.3
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

*(b)* Infants assessed by Bayley or Griffiths at 18–42 months corrected age or unable to be assessed due to severe delay. Excludes 24 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 2,640 infants assessed at 18–42 months corrected age, 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 defined by physical or neurodevelopmental impairment and graded as mild, moderate or severe according to the following classification: 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); severe (GMFCS level 4 to 5 cerebral palsy, blindness or severe language, cognitive or motor delay). 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, 14 infants who met at least one of the criteria for severe impairment but had missing data for one or more outcomes, and 29 infants who were unable to be assessed due to severe developmental delay were included in the severe category for functional impairment. Of these infants, two were less than 24 weeks, nine were 24 weeks, eleven were 25 weeks, seven were 26 weeks, nine were 27 weeks and five were 28 weeks gestational age or older at birth.

Of the 2,683 infants where functional impairment could be graded, there were 986 (36.7%) infants with any degree of functional impairment, including 608 (22.7%) with a mild impairment, 242 (9.0%) with a moderate impairment and 136 (5.1%) 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 986 infants with any degree of functional impairment, 315 (31.9%) were classified based on language delays alone.

**TABLE 45: Severity of functional impairment at 2–3 year follow-up by gestational age, ANZNN 2012–2015 births**

	Gestational age (weeks)						
Functional impairment	<24	24	25	26	27	≥28	Total
Number							
None	25	154	280	420	473	345	1,697
Mild	16	72	102	130	159	129	608
Moderate	10	40	42	44	50	56	242
Severe	5	23	28	33	24	23	136
Incomplete formal test <sup>(a)</sup>	9	34	62	82	90	74	351
Other formal test	1	0	2	9	11	3	26
No formal test	8	30	58	70	78	46	290
<b>Total<sup>(b)</sup></b>	<b>74</b>	<b>353</b>	<b>574</b>	<b>788</b>	<b>885</b>	<b>676</b>	<b>3,350</b>
Per cent							
None	44.6	53.3	61.9	67.0	67.0	62.4	63.3
Mild	28.6	24.9	22.6	20.7	22.5	23.3	22.7
Moderate	17.9	13.8	9.3	7.0	7.1	10.1	9.0
Severe	8.9	8.0	6.2	5.3	3.4	4.2	5.1
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

(b) Infants assessed at 18–42 months corrected age or unable to be assessed due to severe delay. Excludes 24 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 315 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 ‘with moderate to severe impairment’ was assigned to infants who were assessed at 18–42 months corrected age who had any recorded formal assessment of moderate or severe impairment or developmental delay, or any clinical assessment of severe developmental delay.

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 18–42 months corrected age.
- Infants who did not have moderate or severe functional impairment based on assessment by a health care professional at 18–42 months corrected age. Of these, infants with missing or unknown results for cerebral palsy, hearing or vision were presumed likely to be without moderate or severe impairment. Where infants had a partially completed formal assessment and no clinical assessment was recorded, infants were also presumed likely to be without moderate or severe impairment.

Any remaining infants who had a recorded clinical assessment of moderate developmental delay or delays of uncertain severity in at least one domain were reviewed and classified on a case by case basis.

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 due to insufficient information.

Upon review, 485 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 485 infants, together with the 2,683 infants graded in Table 45, there were 464 (14.6%) infants with moderate to severe functional impairment. Moderate to severe functional impairment decreased with increasing gestational age (Table 46). Of these 464 infants with moderate to severe functional impairment, there were 156 (33.6%) 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, ANZNN 2012–2015 births**

Functional impairment	Gestational age (weeks)						Total
	<24	24	25	26	27	≥28	
Number							
Without moderate-severe impairment	48	260	452	648	747	549	2,704
Moderate-severe impairment	18	75	90	98	90	93	464
Not stated <sup>(a)</sup>	8	18	32	42	48	34	182
<b>Total<sup>(b)</sup></b>	<b>74</b>	<b>353</b>	<b>574</b>	<b>788</b>	<b>885</b>	<b>676</b>	<b>3,350</b>
Per cent							
Without moderate-severe impairment	72.7	77.6	83.4	86.9	89.2	85.5	85.4
Moderate-severe impairment	27.3	22.4	16.6	13.1	10.8	14.5	14.6
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

(b) Infants assessed at 18–42 months corrected age or unable to be assessed due to severe delay. Excludes 24 infants with a congenital anomaly known to impair development.

**Note:** Not stated data are excluded from per cent calculations. This table includes 156 infants with a moderate-severe functional impairment classification based on language delay alone.

## Growth – weight, height and head circumference

For the purposes of this report, growth standards published by the World Health Organization, 2006 were used to determine weight, height and head circumference for age percentiles, and weight for length/height percentiles.

Growth measurements were analysed for 3,395 infants assessed at 18–42 months corrected age. This includes the 3,374 infants who had a follow-up assessment at 18–42 months corrected age and an additional 21 infants who had only growth measurements recorded at this age. Of these infants, 9.6% fell below the 3rd percentile for weight for age, 17.1% for length/height for age, 7.2% for head circumference for age and 4.9% for weight for length/height, after excluding missing measurements. 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). It is highly likely these infants were intrauterine growth restricted (IUGR) and may continue to show a pattern of slower growth.

**TABLE 47: Weight for age at 2–3 year follow-up by gestational age, ANZNN 2012–2015 births**

Weight for age centile <sup>(a)</sup>	Gestational age (weeks)						Total
	<24	24	25	26	27	≥28	
Number							
<3	10	21	51	40	43	123	288
3–9	12	36	61	73	66	116	364
10–90	n.p.	250	352	519	580	n.p.	2,113
>90	<5	19	46	65	100	n.p.	253
Not stated	5	29	72	96	106	69	377
<b>Total<sup>(b)</sup></b>	<b>78</b>	<b>355</b>	<b>582</b>	<b>793</b>	<b>895</b>	<b>692</b>	<b>3,395</b>
Per cent							
<3	13.7	6.4	10.0	5.7	5.4	19.7	9.5
3–9	16.4	11.0	12.0	10.5	8.4	18.6	12.1
10–90	n.p.	76.7	69.0	74.5	73.5	n.p.	70.0
>90	n.p.	5.8	9.0	9.3	12.7	n.p.	8.4
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

(a) Centiles derived from WHO child growth standards, World Health Organization, 2006.

(b) Infants assessed at 18–42 months corrected age.

**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, ANZNN 2012–2015 births**

Length/height for age centile <sup>(a)</sup>	Gestational age (weeks)						Total
	<24	24	25	26	27	≥28	
Number							
<3	17	48	81	80	83	183	492
3–9	<5	44	65	75	87	n.p.	369
10–90	47	216	315	460	515	299	1,852
>90	<5	9	27	52	74	n.p.	184
Not stated	10	38	94	126	136	94	498
<b>Total<sup>(b)</sup></b>	<b>78</b>	<b>355</b>	<b>582</b>	<b>793</b>	<b>895</b>	<b>692</b>	<b>3,395</b>
Per cent							
<3	25.0	15.1	16.6	12.0	10.9	30.6	17.0
3–9	n.p.	13.9	13.3	11.2	11.5	n.p.	12.7
10–90	69.1	68.1	64.5	69.0	67.9	50.0	63.9
>90	n.p.	2.8	5.5	7.8	9.7	n.p.	6.4
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

(a) Centiles derived from WHO child growth standards, World Health Organization, 2006.

(b) Infants assessed at 18–42 months corrected age.

**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, ANZNN 2012–2015 births**

Head circumference for age centile <sup>(a)</sup>	Gestational age (weeks)						Total
	<24	24	25	26	27	≥28	
Number							
<3	14	17	30	31	24	66	182
3–9	8	27	36	44	34	58	207
10–90	n.p.	192	324	418	488	n.p.	1,829
>90	<5	26	49	102	119	n.p.	334
Not stated	15	93	143	198	230	164	843
<b>Total<sup>(b)</sup></b>	<b>78</b>	<b>355</b>	<b>582</b>	<b>793</b>	<b>895</b>	<b>692</b>	<b>3,395</b>
Per cent							
<3	22.2	6.5	6.8	5.2	3.6	12.5	7.1
3–9	12.7	10.3	8.2	7.4	5.1	11.0	8.1
10–90	n.p.	73.3	73.8	70.3	73.4	n.p.	71.7
>90	n.p.	9.9	11.2	17.1	17.9	n.p.	13.1
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

(a) Centiles derived from WHO child growth standards, World Health Organization, 2006.

(b) Infants assessed at 18–42 months corrected age.

**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, ANZNN 2012–2015 births**

Weight for length/height centile <sup>(a)</sup>	Gestational age (weeks)						Total
	<24	24	25	26	27	≥28	
Number							
<3	7	11	20	24	20	60	142
3–9	10	17	41	48	48	72	236
10–90	46	258	361	500	570	436	2,171
>90	5	31	64	93	119	30	342
Not stated	10	38	96	128	138	94	504
<b>Total<sup>(b)</sup></b>	<b>78</b>	<b>355</b>	<b>582</b>	<b>793</b>	<b>895</b>	<b>692</b>	<b>3,395</b>
Per cent							
<3	10.3	3.5	4.1	3.6	2.6	10.0	4.9
3–9	14.7	5.4	8.4	7.2	6.3	12.0	8.2
10–90	67.6	81.4	74.3	75.2	75.3	72.9	75.1
>90	7.4	9.8	13.2	14.0	15.7	5.0	11.8
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

(a) Centiles derived from WHO child growth standards, World Health Organization, 2006.

(b) Infants assessed at 18–42 months corrected age.

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



## Respiratory and gastrointestinal tract

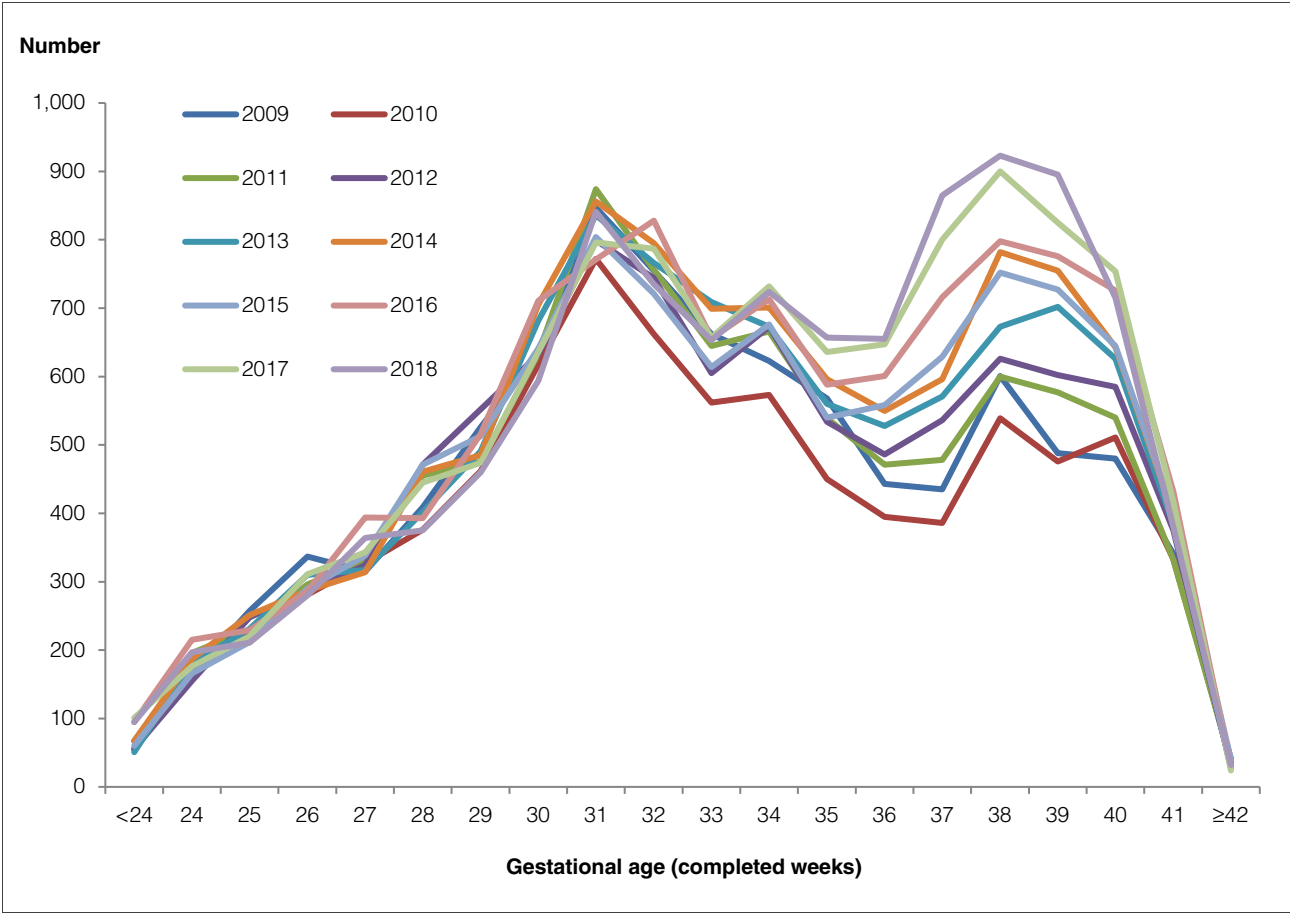
Respiratory and gastrointestinal tract complications, such as respiratory distress syndrome and necrotising enterocolitis, commonly affect extremely premature babies and can lead to ongoing disease. Of the 3,108 infants with data available on the use of respiratory support at 18–42 months corrected age, six (0.2%) were supported by tracheostomy and 19 (0.6%) were supported by supplemental oxygen. Two in five (40.0%) infants receiving respiratory support were born at less than 25 weeks gestational age. Of the 55 infants with data only available at less than 18 months corrected age or unknown corrected age, two were supported by tracheostomy and one was supported by supplemental oxygen which may have ceased by the time of 2–3 year follow-up.

Of the 3,109 infants with nutritional support data at 18–42 months corrected age, two infants were reported as receiving parenteral nutrition and 70 (2.3%) infants were reported as feeding via a percutaneous endoscopic gastronomy tube or nasogastric tube. The prevalence of nutritional support in each gestational age group (completed weeks) was similar and ranged from 2.0–2.6%. Of the 53 infants with data only available at less than 18 months corrected age or unknown corrected age, two were receiving nutritional support which may have ceased by the time of 2–3 year follow-up. Of the 30 infants with data available whose age of assessment was unknown, there were two infants receiving nutritional support. None of the 26 infants assessed at greater than 42 months corrected age were still receiving nutritional support.

# APPENDICES

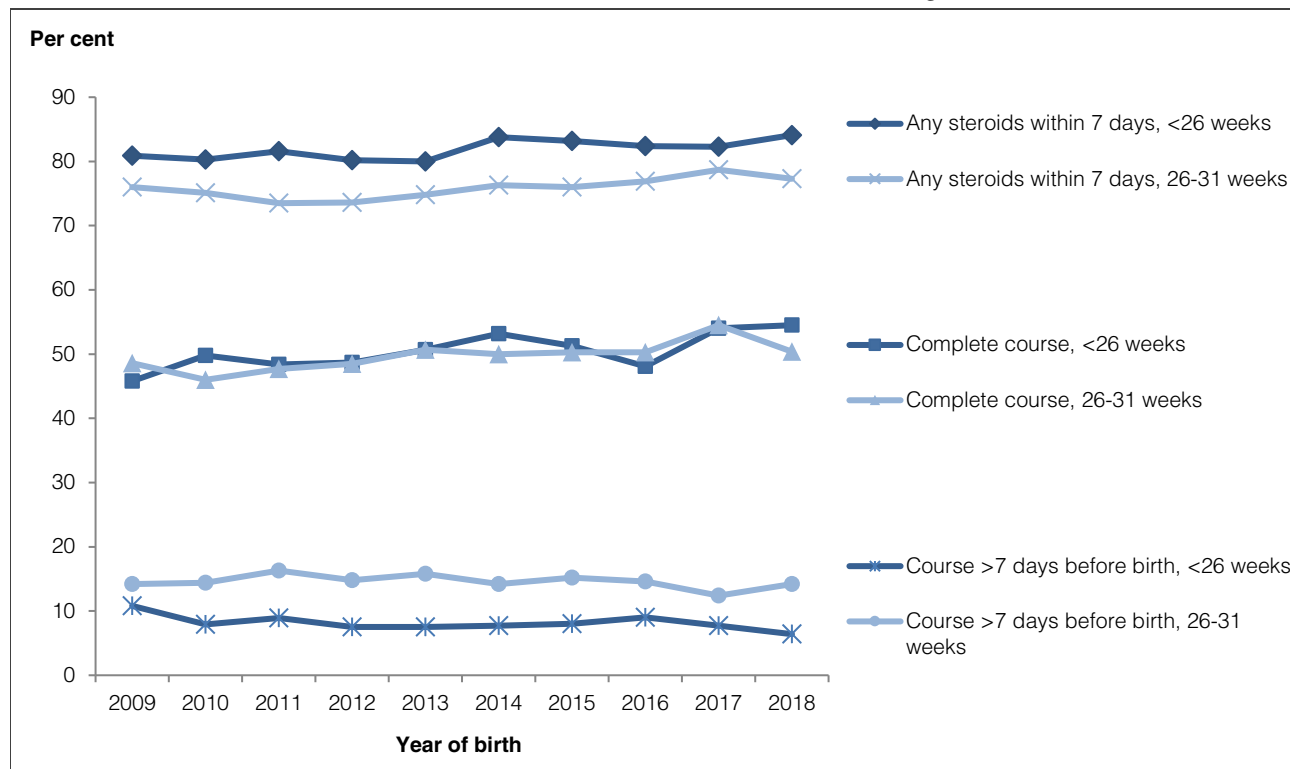
## Appendix 1: Trends

FIGURE 11: Trends in gestational age at birth of level III registrants, ANZNN 2009–2018



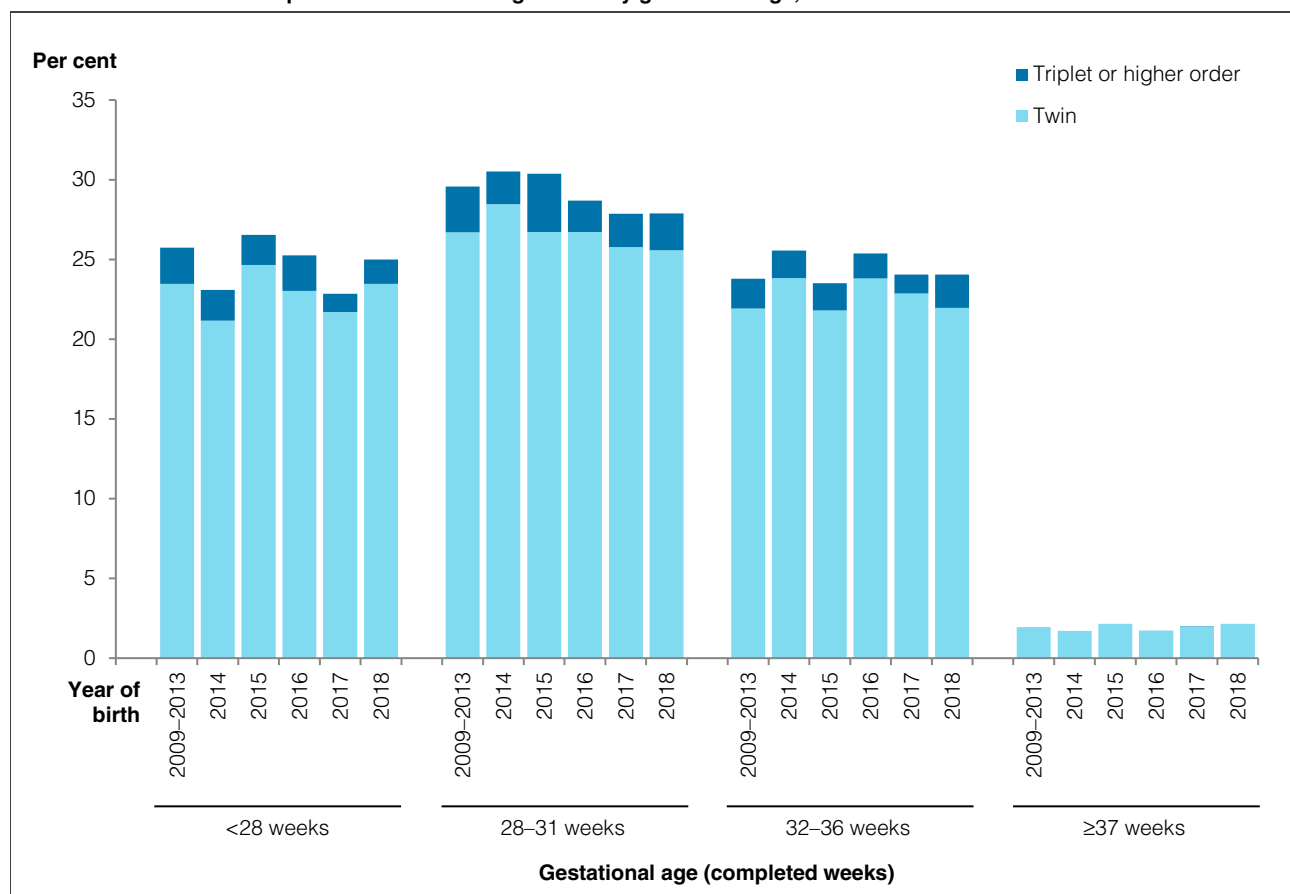
**Note:** Data on the ANZNN registrants from two level III NICUs were not available in 2010.  
Please refer to [www.anznn.net](http://www.anznn.net) for colour version.

**FIGURE 12: Trends in the use of corticosteroids for mothers of babies less than 32 weeks gestation, ANZNN 2009–2018**

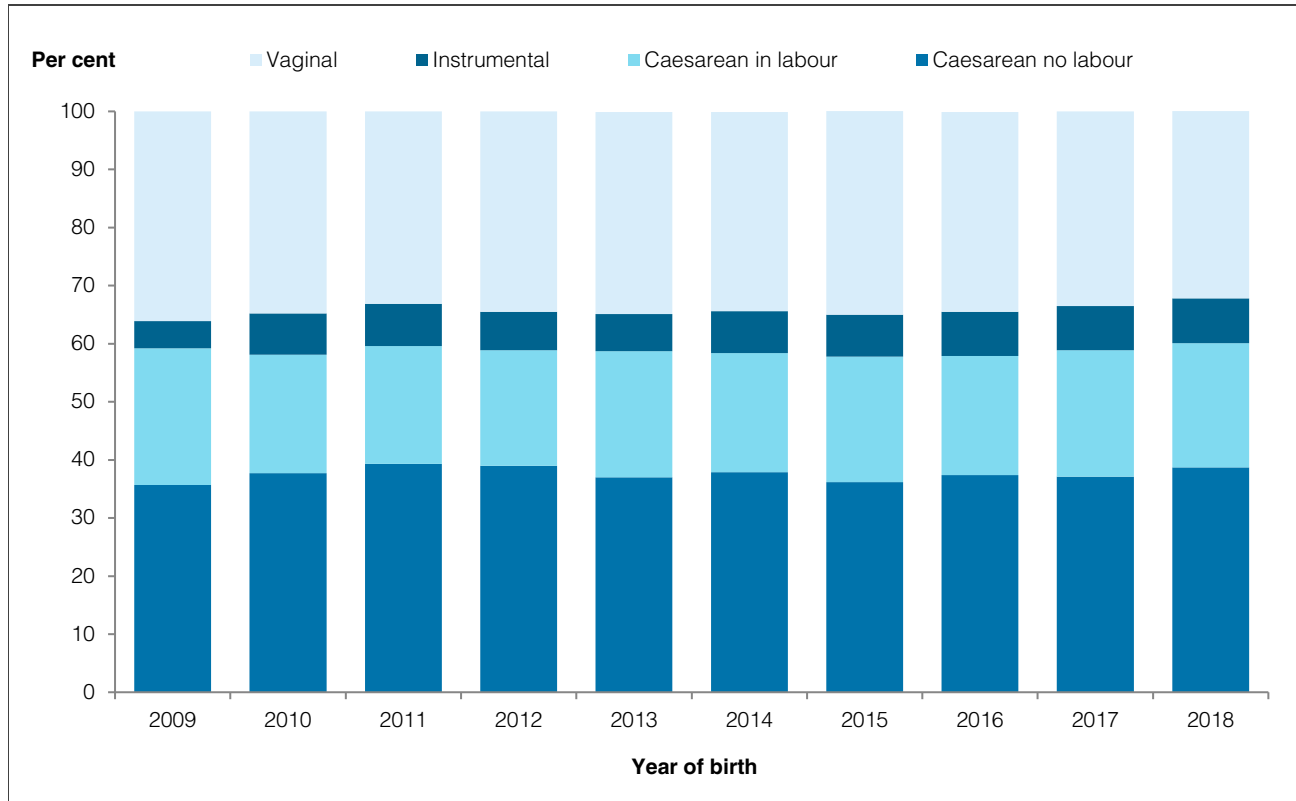


**Note:** Corticosteroid treatment to enhance fetal lung maturation is considered 'complete' when two doses are given, the first dose more than 24 hours and less than 8 days before the baby's birth. 'Any steroids within 7 days' includes babies who received a 'complete course' as well as babies who received their first dose of corticosteroids at less than 24 hours prior to birth.

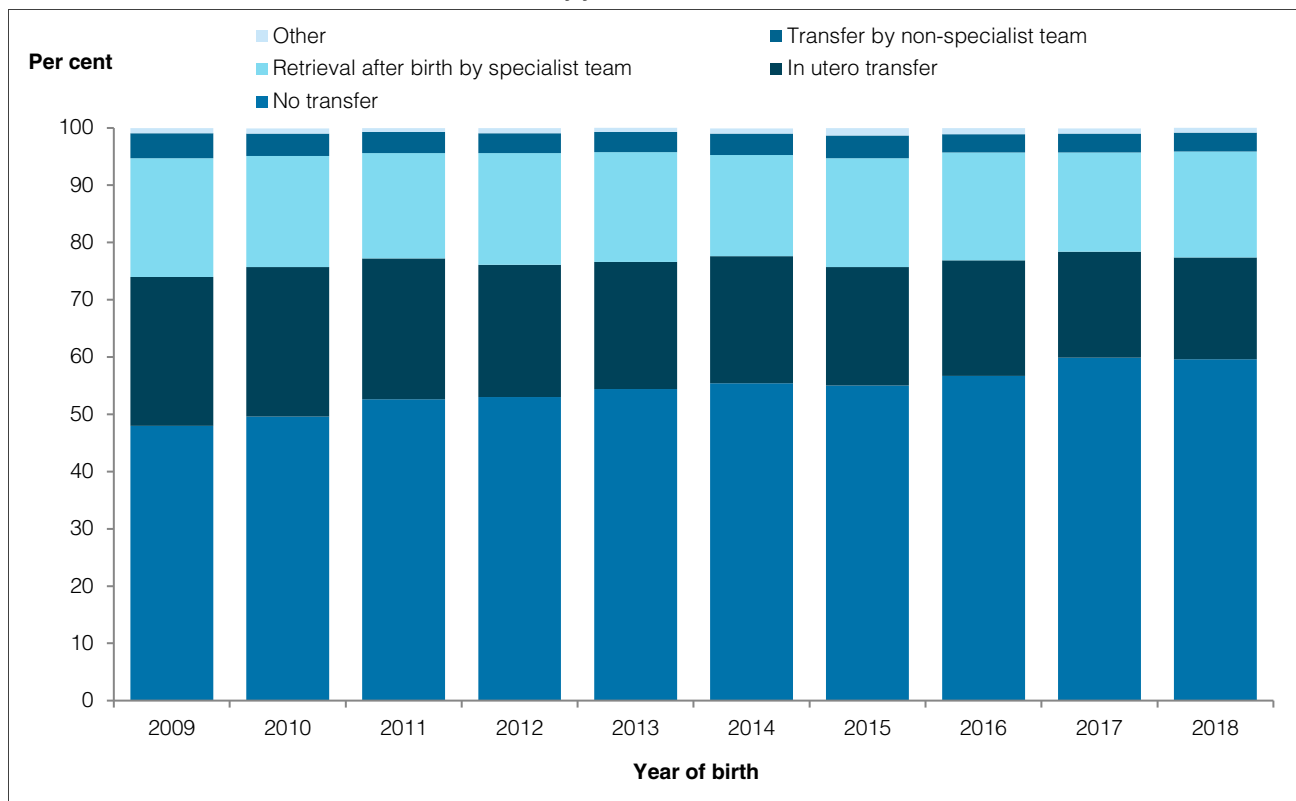
**FIGURE 13: Trends in multiple births of level III registrants by gestational age, ANZNN 2009–2018**



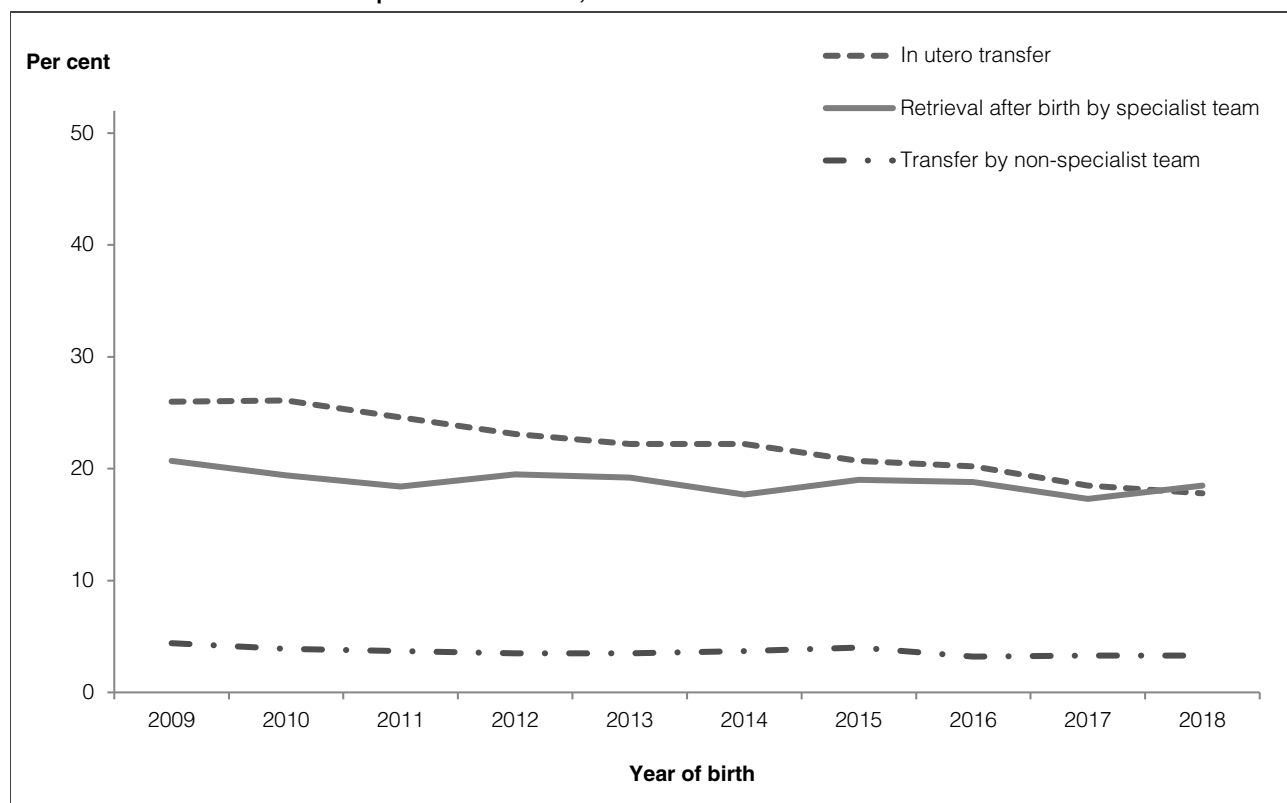
**FIGURE 14: Trends in method of birth for level III registrants by year of birth, ANZNN 2009–2018**



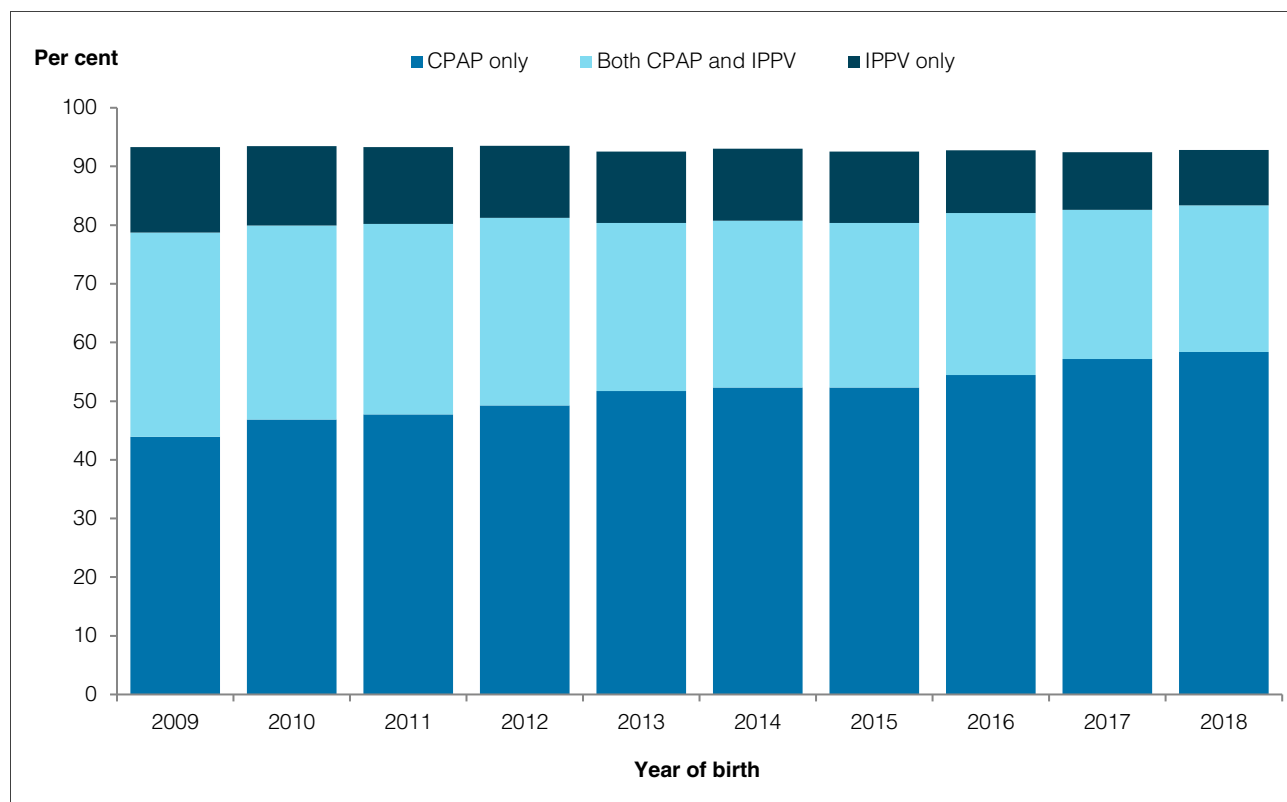
**FIGURE 15: Trends in referral source to level III NICU by year of birth, ANZNN 2009–2018**



**FIGURE 16: Trends in mode of transport to level III NICU, ANZNN 2009–2018**

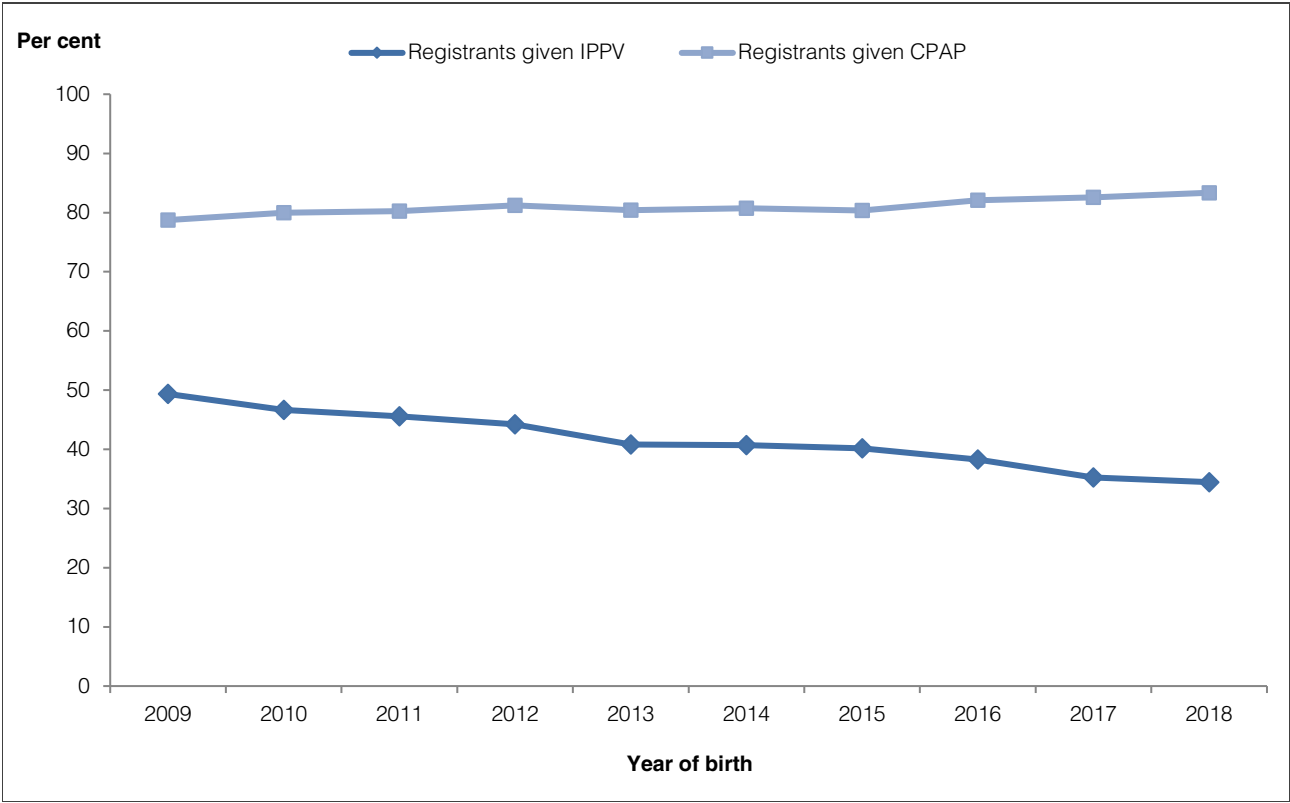


**FIGURE 17: Trends in mode of assisted ventilation for level III registrants, ANZNN 2009–2018**



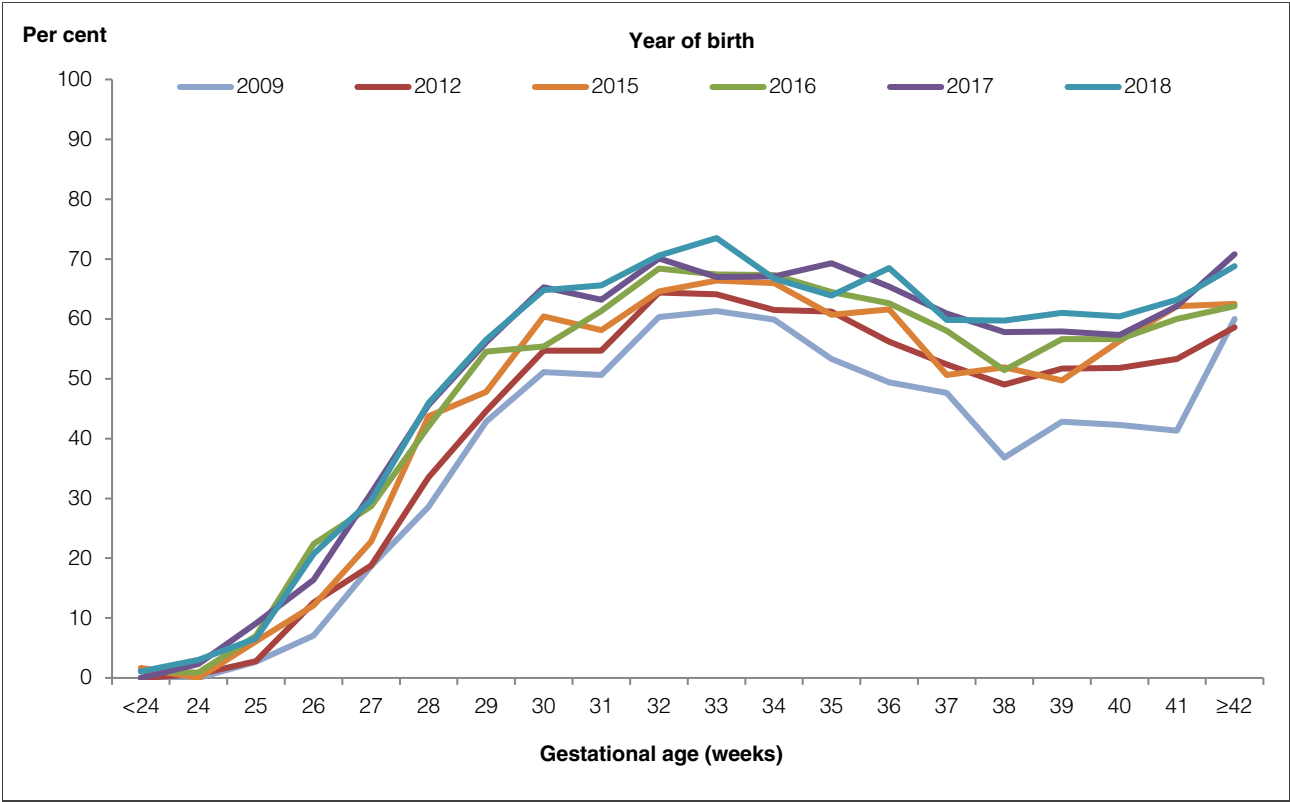
**Note:** CPAP = continuous positive airway pressure. IPPV = intermittent positive pressure ventilation.

**FIGURE 18: Trends in provision of intermittent positive pressure ventilation and continuous positive airway pressure by year of birth for level III registrants ventilated, ANZNN 2009–2018**

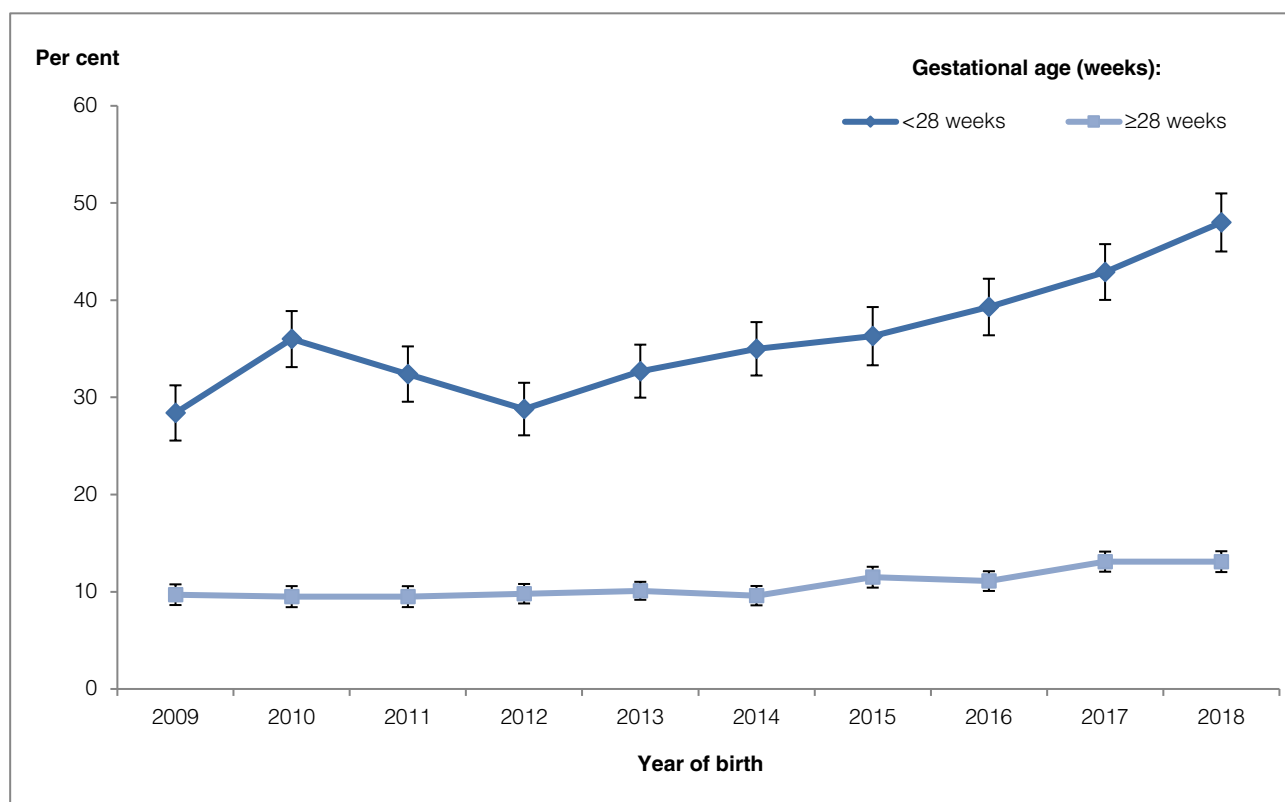


*Note: IPPV = intermittent positive pressure ventilation. CPAP = continuous positive airway pressure.*

**FIGURE 19: Trends in the use of continuous positive airway pressure as the only form of ventilation by gestational age for level III registrants, ANZNN 2009, 2012, 2015–2018**

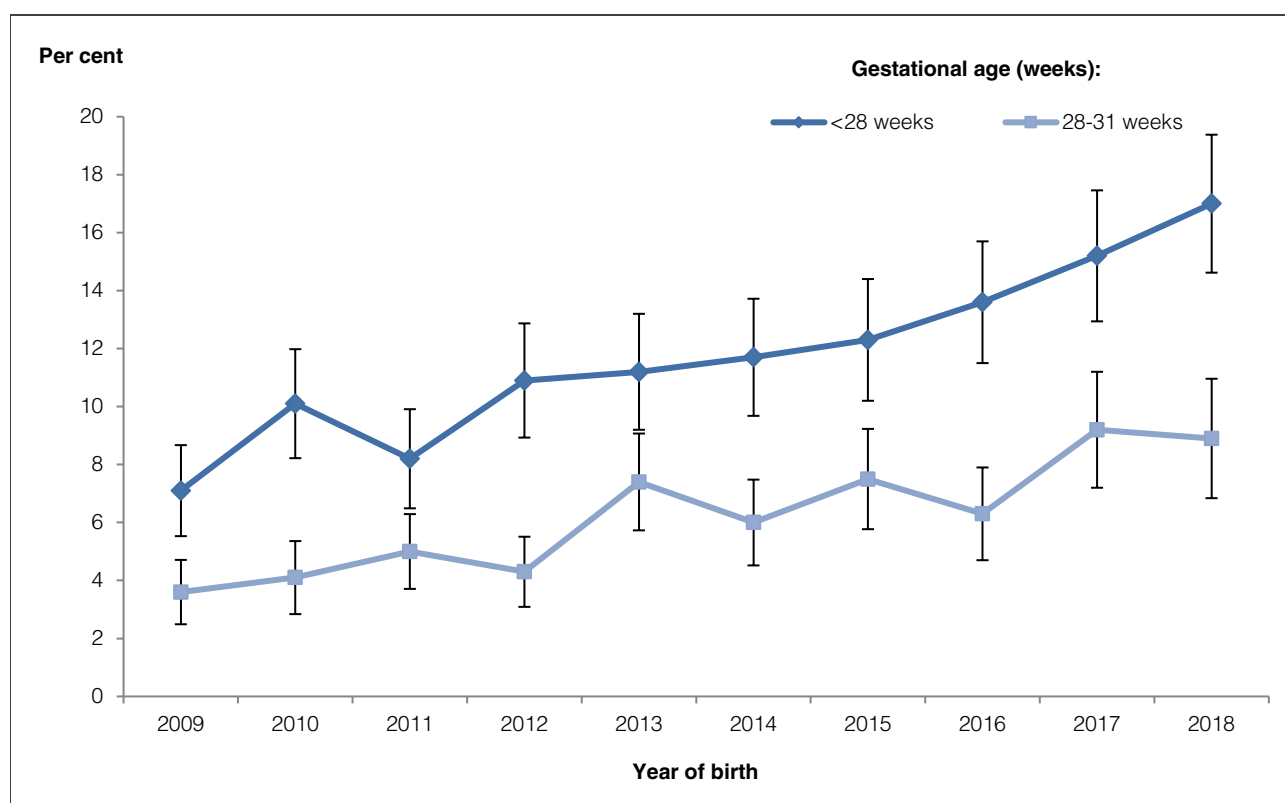


**FIGURE 20: Trends in provision of high frequency oscillatory ventilation (with 95% CI) for level III registrants born before 28 weeks and at 28 or more weeks gestation, ANZNN 2009–2018**



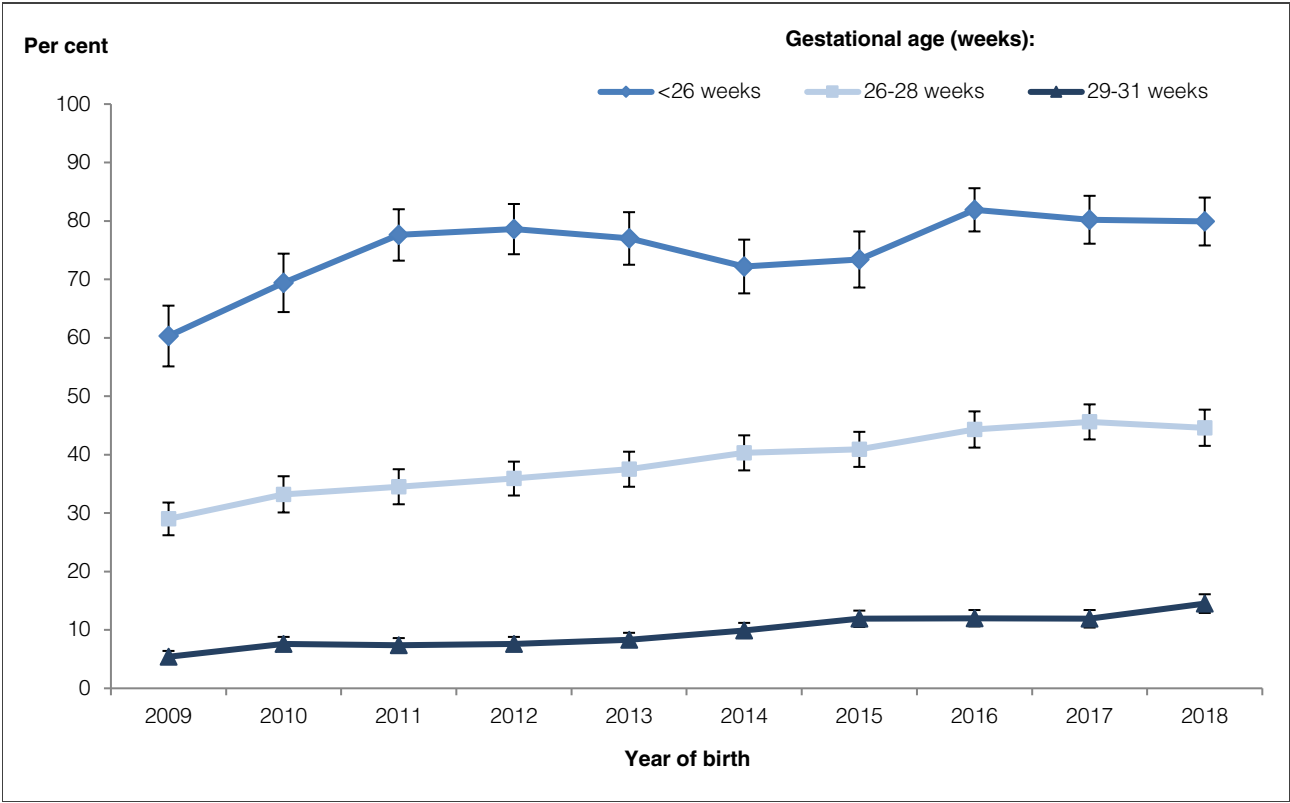
*Note: Results are given as the percentage of babies given intermittent positive pressure ventilation.*

**FIGURE 21: Trends in nitric oxide (with 95% CI) provision for level III registrants born before 28 weeks and 28-31 weeks gestation, ANZNN 2009–2018**

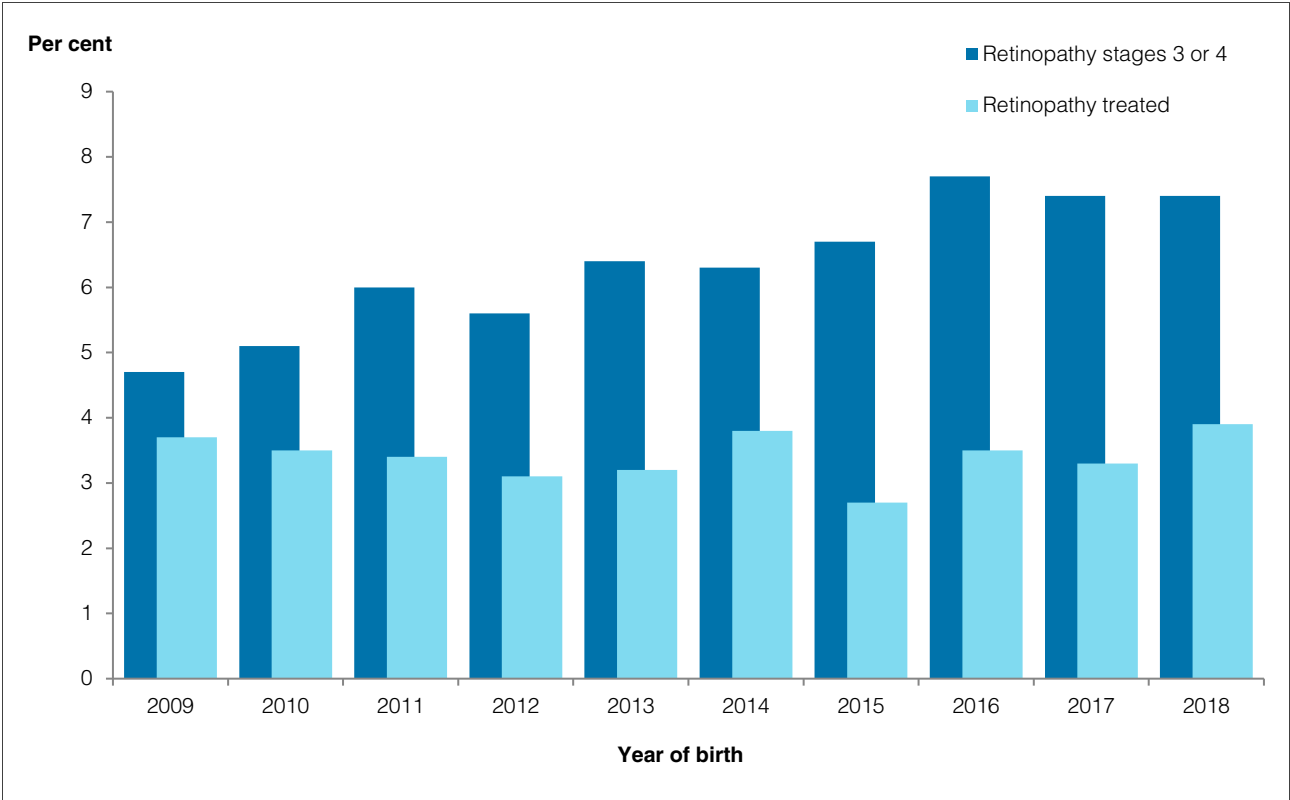


*Note: Results are given as the percentage of babies given intermittent positive pressure ventilation.*

**FIGURE 22: Trends in chronic lung disease (with 95% CI) for level III registrants who survived to 36 weeks post menstrual age, ANZNN 2009–2018**

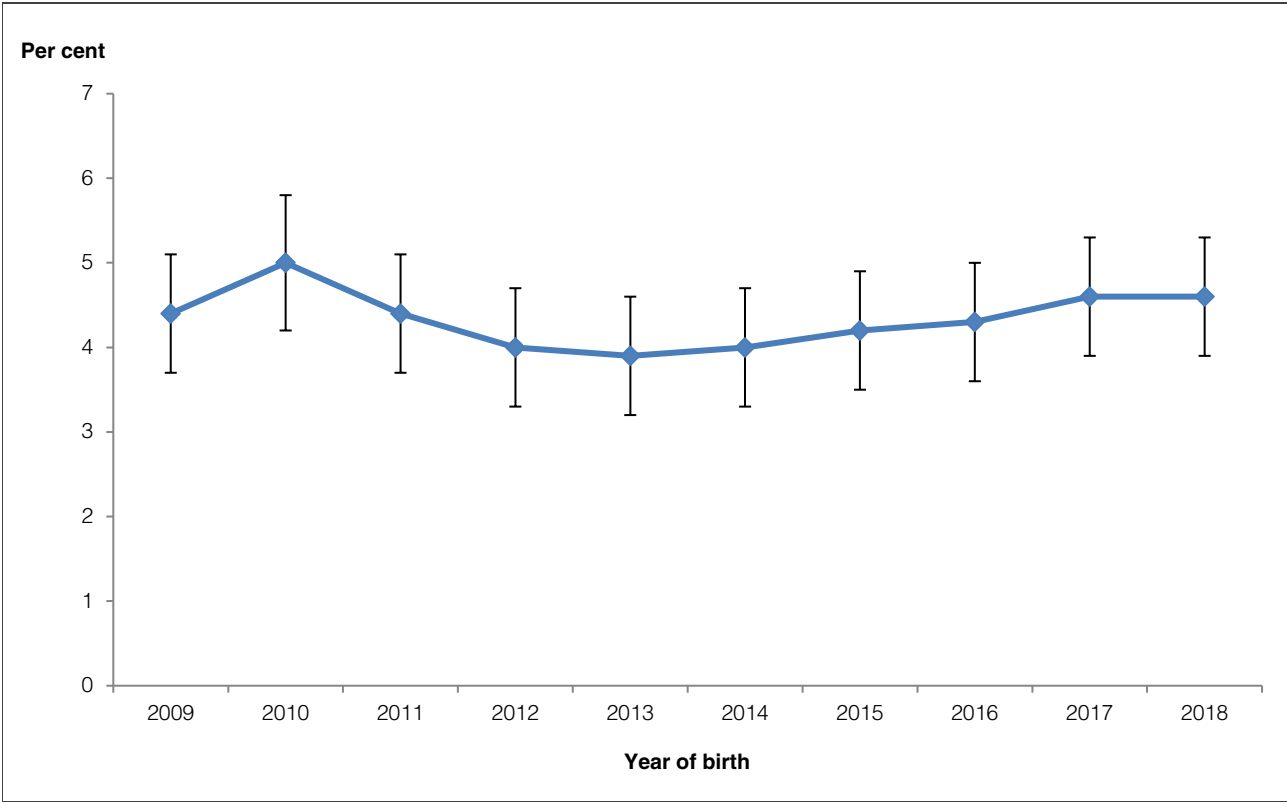


**FIGURE 23: Trends in stage 3 or 4 retinopathy of prematurity and treated retinopathy among babies born before 31 weeks gestation and/or birthweight of less than 1,250 grams who survived to 36 weeks post menstrual age for level III registrants, ANZNN 2009–2018**





**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, ANZNN 2009–2018**



**FIGURE 25: Trends in incidence of early sepsis for level III registrants by gestational age, ANZNN 2014–2018**

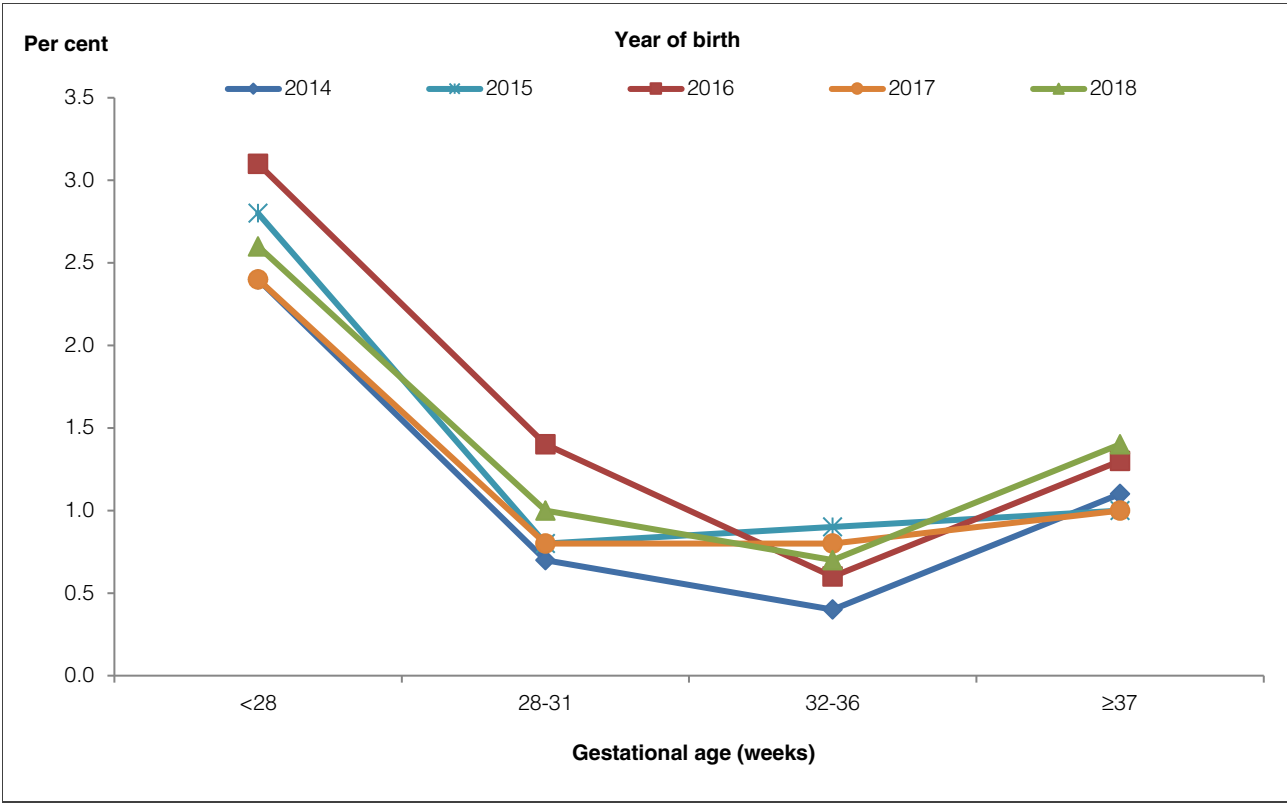
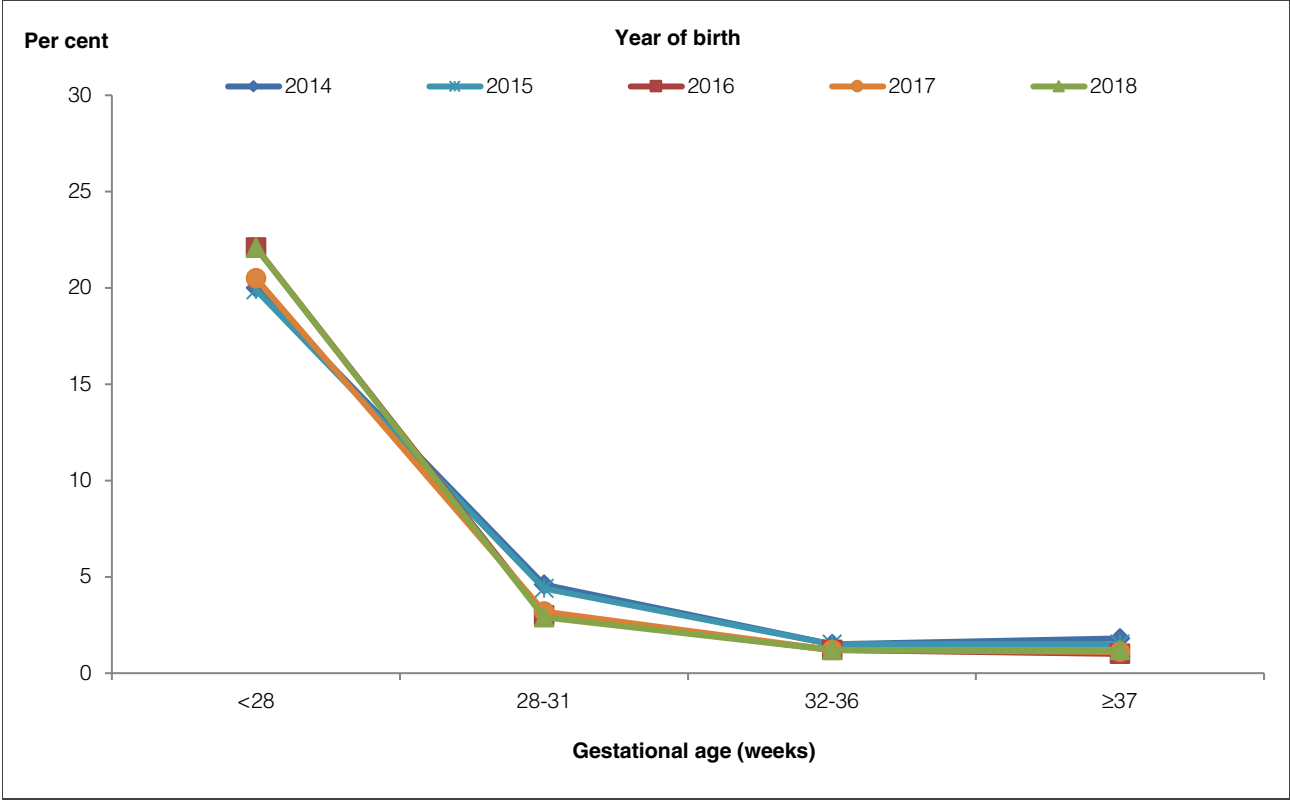


FIGURE 26: Trends in incidence of late sepsis for level III registrants by gestational age, ANZNN 2014–2018



## Appendix 2: Data tables by birthweight

**TABLE 51: Antenatal corticosteroid use for level III registrants by birthweight, ANZNN 2018**

Antenatal corticosteroids	Birthweight (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	30	47	56	112	238	499	913	n.p.	986	446	4,600
Incomplete course	<5	101	159	198	233	442	285	117	n.p.	10	5	1,590
Complete course within 7 days of birth	32	251	359	370	519	776	423	168	83	18	10	3,009
Given >7 days prior to birth	6	42	70	122	124	209	145	92	38	10	8	866
Not stated	0	0	2	4	10	19	35	104	202	155	55	586
<b>Total</b>	<b>45</b>	<b>424</b>	<b>637</b>	<b>750</b>	<b>998</b>	<b>1,684</b>	<b>1,387</b>	<b>1,394</b>	<b>1,629</b>	<b>1,179</b>	<b>524</b>	<b>10,651</b>
	Per cent											
None	n.p.	7.1	7.4	7.5	11.3	14.3	36.9	70.8	n.p.	96.3	95.1	45.7
Incomplete course	n.p.	23.8	25.0	26.5	23.6	26.5	21.1	9.1	n.p.	1.0	1.1	15.8
Complete course within 7 days of birth	71.1	59.2	56.5	49.6	52.5	46.6	31.3	13.0	5.8	1.8	2.1	29.9
Given >7 days prior to birth	13.3	9.9	11.0	16.4	12.6	12.6	10.7	7.1	2.7	1.0	1.7	8.6
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

**TABLE 52: Plurality of level III registrants by birthweight, ANZNN 2018**

Plurality	Birthweight (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
Number												
Singleton	31	333	483	543	678	1,139	1,082	n.p.	1,599	n.p.	n.p.	8,835
Twins	14	84	142	189	288	490	n.p.	143	30	<5	<5	1,676
Triplets and higher orders	0	7	12	18	32	55	n.p.	<5	0	0	0	140
Total	45	424	637	750	998	1,684	1,387	1,394	1,629	1,179	524	10,651
Per cent												
Singleton	68.9	78.5	75.8	72.4	67.9	67.6	78.0	n.p.	98.2	n.p.	n.p.	82.9
Twins	31.1	19.8	22.3	25.2	28.9	29.1	n.p.	10.3	1.8	n.p.	n.p.	15.7
Triplets and higher orders	0.0	1.7	1.9	2.4	3.2	3.3	n.p.	n.p.	0.0	0.0	0.0	1.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

**TABLE 53: Method of birth for level III registrants by birthweight, ANZNN 2018**

Method of birth	Birthweight (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
	Number											
Vaginal birth	8	144	179	192	263	481	451	492	566	443	205	3,424
Vaginal instrumental birth	0	8	6	28	23	62	80	142	235	180	55	819
Caesarean section in labour	<5	80	144	172	200	372	284	n.p.	375	249	117	2,268
Caesarean section no labour	n.p.	192	307	357	510	764	564	n.p.	447	301	145	4,104
Not stated	0	0	1	1	2	5	8	5	6	6	2	36
<b>Total</b>	<b>45</b>	<b>424</b>	<b>637</b>	<b>750</b>	<b>998</b>	<b>1,684</b>	<b>1,387</b>	<b>1,394</b>	<b>1,629</b>	<b>1,179</b>	<b>524</b>	<b>10,651</b>
	Per cent											
Vaginal birth	17.8	34.0	28.1	25.6	26.4	28.6	32.7	35.4	34.9	37.8	39.3	32.3
Vaginal instrumental birth	0.0	1.9	0.9	3.7	2.3	3.7	5.8	10.2	14.5	15.3	10.5	7.7
Caesarean section in labour	n.p.	18.9	22.6	23.0	20.1	22.2	20.6	n.p.	23.1	21.2	22.4	21.4
Caesarean section no labour	n.p.	45.3	48.3	47.7	51.2	45.5	40.9	n.p.	27.5	25.7	27.8	38.7
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

**TABLE 54: Level of hospital of birth for level III registrants by birthweight, ANZNN 2018**

Level of birth hospital	Birthweight (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
	Number											
Tertiary	<5	398	570	666	855	<5	1,124	1,024	1,155	848	376	8,510
Non-tertiary	<5	n.p.	60	77	134	228	253	360	455	316	137	2,046
Not born in a hospital <sup>(a)</sup>	0	<5	7	7	8	<5	10	9	16	15	11	88
Not stated	0	1	0	0	1	1	0	1	3	0	0	7
<b>Total</b>	<b>45</b>	<b>424</b>	<b>637</b>	<b>750</b>	<b>998</b>	<b>1,684</b>	<b>1,387</b>	<b>1,394</b>	<b>1,629</b>	<b>1,179</b>	<b>524</b>	<b>10,651</b>
	Per cent											
Tertiary	n.p.	94.1	89.5	88.8	85.8	n.p.	81.0	73.5	71.0	71.9	71.8	80.0
Non-tertiary	n.p.	n.p.	9.4	10.3	13.4	13.5	18.2	25.8	28.0	26.8	26.1	19.2
Not born in a hospital <sup>(a)</sup>	0.0	n.p.	1.1	0.9	0.8	n.p.	0.7	0.6	1.0	1.3	2.1	0.8
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

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

**TABLE 55: Mode of transport for level III registrants to level III unit after birth by birthweight, ANZNN 2018**

Mode of transport	Birthweight (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
	Number											
Not transported	n.p.	393	559	660	853	1,425	n.p.	965	1,077	813	372	8,235
Specialist retrieval team	0	19	57	71	123	217	254	349	453	305	122	1,970
Non-specialist team	<5	6	8	10	13	28	41	70	91	52	n.p.	347
Other	0	6	13	9	9	14	n.p.	9	7	8	<5	94
Not stated	0	0	0	0	0	0	1	1	1	1	1	5
<b>Total</b>	<b>45</b>	<b>424</b>	<b>637</b>	<b>750</b>	<b>998</b>	<b>1,684</b>	<b>1,387</b>	<b>1,394</b>	<b>1,629</b>	<b>1,179</b>	<b>524</b>	<b>10,651</b>
Per cent												
Not transported	n.p.	92.7	87.8	88.0	85.5	84.6	n.p.	69.3	66.2	69.0	71.1	77.4
Specialist retrieval team	0.0	4.5	8.9	9.5	12.3	12.9	18.3	25.1	27.8	25.9	23.3	18.5
Non-specialist team	n.p.	1.4	1.3	1.3	1.3	1.7	3.0	5.0	5.6	4.4	n.p.	3.3
Other	0.0	1.4	2.0	1.2	0.9	0.8	n.p.	0.6	0.4	0.7	n.p.	0.9
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

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

**TABLE 56: Exogenous surfactant use for level III registrants by birthweight, ANZNN 2018**

Exogenous surfactant	Birthweight (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	34	159	347	674	1,257	1,134	1,194	1,479	1,062	n.p.	7,841
Surfactant given	n.p.	390	478	403	324	427	253	200	150	117	n.p.	2,810
▪ via endotracheal tube	38	353	407	348	269	350	211	178	141	107	23	2,425
▪ via catheter	<5	32	60	48	46	67	38	19	9	7	<5	333
▪ via other or unknown method	0	5	11	7	9	10	4	3	0	3	0	52
Total	45	424	637	750	998	1,684	1,387	1,394	1,629	1,179	524	10,651
Per cent												
None	n.p.	8.0	25.0	46.3	67.5	74.6	81.8	85.7	90.8	90.1	n.p.	73.6
Surfactant given	n.p.	92.0	75.0	53.7	32.5	25.4	18.2	14.3	9.2	9.9	n.p.	26.4
▪ via endotracheal tube	84.4	83.3	63.9	46.4	27.0	20.8	15.2	12.8	8.7	9.1	4.4	22.8
▪ via catheter	n.p.	7.5	9.4	6.4	4.6	4.0	2.7	1.4	0.6	0.6	n.p.	3.1
▪ via other or unknown method	0.0	1.2	1.7	0.9	0.9	0.6	0.3	0.2	0.0	0.3	0.0	0.5
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

**TABLE 57: Assisted ventilation for level III registrants by birthweight, ANZNN 2018**

Ventilation type	Birthweight (grams)											Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	≥4000	
Number												
Invasive ventilation	42	382	437	343	267	422	379	449	507	337	113	3,678
▪ HFOV given	35	247	158	69	36	47	38	44	77	49	21	821
▪ IPPV given	42	382	436	341	267	422	378	446	507	336	113	3,670
Nitric oxide given	15	85	52	31	20	36	38	65	115	86	30	573
CPAP given	29	353	600	677	833	1,472	1,170	1,114	1,290	919	421	8,878
<b>Total in each birthweight group</b>	<b>45</b>	<b>424</b>	<b>637</b>	<b>750</b>	<b>998</b>	<b>1,684</b>	<b>1,387</b>	<b>1,394</b>	<b>1,629</b>	<b>1,179</b>	<b>524</b>	<b>10,651</b>
Per cent												
IPPV given	93.3	90.1	68.4	45.5	26.8	25.1	27.3	32.0	31.1	28.5	21.6	34.5
CPAP given	64.4	83.3	94.2	90.3	83.5	87.4	84.4	79.9	79.2	77.9	80.3	83.4
Per cent of babies given invasive ventilation												
HFOV given <sup>(a)</sup>	83.3	64.7	36.2	20.1	13.5	11.1	10.0	9.8	15.2	14.5	18.6	22.3
Nitric oxide given <sup>(a)</sup>	35.7	22.3	11.9	9.0	7.5	8.5	10.0	14.5	22.7	25.5	26.5	15.6

(a) Denominator is babies given ventilation via endotracheal tube (IPPV and/or HFOV).

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

HFOV = high frequency oscillatory ventilation. IPPV = intermittent positive pressure ventilation. CPAP = continuous positive airway pressure.

**TABLE 58: Duration of assisted ventilation use for level III registrants by birthweight, ANZNN 2018**

Duration of assisted ventilation	Birthweight (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	214	291	91	27	20.5	23	42	47	62	48	48	48
IQR	49–543	74–597	22–256	12–84	10–61	9–66	15–96	19–96	26–120	22–99	19.5–88	17–135
CPAP (hours)												
Median	947	1058	812	311	97	44	25	20	18	15	17	38
IQR	171–1,616	723–1,393	330–1,156	90–737	36–251	19–97	11–60	8–50	8–43	8–34	9–38	13–125.5

**Note:** IQR = Interquartile range. IPPV = intermittent positive pressure ventilation. CPAP = continuous positive airway pressure.

**TABLE 59: Chronic lung disease at 36 weeks post menstrual age for level III registrants by birthweight, ANZNN 2018**

Chronic lung disease (CLD)	Birthweight (grams)							Total
	<500	500-749	750-999	1000-1249	1250-1499	1500-1999	≥2000	
Number								
No CLD	<5	58	265	441	586	751	n.p.	2,180
CLD	n.p.	257	314	204	117	63	n.p.	984
Not stated	0	3	3	4	4	4	2	20
Ineligible <sup>(a)</sup>	23	106	55	101	291	866	6,025	7,467
<b>Total</b>	<b>45</b>	<b>424</b>	<b>637</b>	<b>750</b>	<b>998</b>	<b>1,684</b>	<b>6,113</b>	<b>10,651</b>
Per cent								
No CLD	n.p.	18.4	45.8	68.4	83.4	92.3	n.p.	68.9
CLD	n.p.	81.6	54.2	31.6	16.6	7.7	n.p.	31.1
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

*(a)* Includes babies who did not survive to 36 weeks post menstrual age and babies born at 32 or more weeks gestational age.

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

**TABLE 60: Respiratory support (airway support or supplemental oxygen therapy) for level III registrants who survived to day 28 by birthweight, ANZNN 2018**

Respiratory support (airway support or oxygen)	Birthweight (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	7	67	278	701	1,454	1,267	1,297	1,523	1,127	503	8,224
Respiratory support on day 28	23	321	532	444	283	193	85	67	75	29	13	2,065
▪ survived to discharge home	n.p.	299	518	438	283	n.p.	79	n.p.	63	24	13	1,990
▪ died before discharge	<5	22	14	6	0	<5	6	<5	12	5	0	75
Not stated	1	2	4	1	1	0	1	0	0	0	0	10
<b>Total in each birthweight group</b>	<b>24</b>	<b>330</b>	<b>603</b>	<b>723</b>	<b>985</b>	<b>1,647</b>	<b>1,353</b>	<b>1,364</b>	<b>1,598</b>	<b>1,156</b>	<b>516</b>	<b>10,299</b>
	Number											
Respiratory support on day 28 and given home oxygen	n.p.	113	121	65	41	n.p.	18	n.p.	26	8	<5	451
	Per cent											
No respiratory support on day 28	0.0	2.1	11.2	38.5	71.2	88.3	93.7	95.1	95.3	97.5	97.5	79.9
Respiratory support on day 28	100.0	97.9	88.8	61.5	28.8	11.7	6.3	4.9	4.7	2.5	2.5	20.1
▪ survived to discharge home	n.p.	93.1	97.4	98.6	100.0	n.p.	92.9	n.p.	84.0	82.8	100.0	96.4
▪ died before discharge	n.p.	6.9	2.6	1.4	0.0	n.p.	7.1	n.p.	16.0	17.2	0.0	3.6
	Per cent											
Respiratory support on day 28 and given home oxygen <sup>(a)</sup>	50.0	37.8	23.4	14.8	14.5	13.2	22.8	31.7	41.3	33.3	n.p.	22.7

*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, ANZNN 2018**

Transfer status	Birthweight (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	33	227	301	320	397	721	791	955	1,239	914	422	6,320
Level III hospital	<5	31	26	35	29	46	38	40	39	32	<5	322
Level II or I hospital	n.p.	101	262	374	541	880	512	332	274	180	n.p.	3,540
Children's hospital	5	65	48	18	27	36	46	67	77	53	19	461
Not stated	0	0	0	3	4	1	0	0	0	0	0	8
Total	45	424	637	750	998	1,684	1,387	1,394	1,629	1,179	524	10,651
Per cent												
Not transferred	73.3	53.5	47.3	42.8	39.9	42.8	57.0	68.5	76.1	77.5	80.5	59.4
Level III hospital	n.p.	7.3	4.1	4.7	2.9	2.7	2.7	2.9	2.4	2.7	n.p.	3.0
Level II or I hospital	n.p.	23.8	41.1	50.1	54.4	52.3	36.9	23.8	16.8	15.3	n.p.	33.3
Children's hospital	11.1	15.3	7.5	2.4	2.7	2.1	3.3	4.8	4.7	4.5	3.6	4.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

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

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

**TABLE 62: Retinopathy of prematurity for level III registrants by birthweight, ANZNN 2018**

Retinopathy of prematurity (ROP)	Birthweight (grams)						Total
	<500	500-749	750-999	1000-1249	1250-1499	≥1500	
	Number						
No ROP	5	73	264	500	468	481	1,791
Stage 1 ROP	<5	47	n.p.	103	57	n.p.	382
Stage 2 ROP	5	n.p.	133	n.p.	34	5	348
Stage 3 ROP	n.p.	88	50	11	<5	<5	163
Stage 4 ROP	0	<5	<5	<5	<5	0	6
Not examined	22	101	46	68	405	6,636	7,278
Not stated	0	2	1	6	29	645	683
<b>Total</b>	<b>45</b>	<b>424</b>	<b>637</b>	<b>750</b>	<b>998</b>	<b>7,797</b>	<b>10,651</b>
Per cent							
No ROP	21.7	22.7	44.7	74.0	83.0	93.2	66.6
Stage 1 ROP	n.p.	14.6	n.p.	15.2	10.1	n.p.	14.2
Stage 2 ROP	21.7	n.p.	22.5	n.p.	6.0	1.0	12.9
Stage 3 ROP	n.p.	27.4	8.5	1.6	n.p.	n.p.	6.1
Stage 4 ROP	0.0	n.p.	n.p.	n.p.	n.p.	0.0	0.2
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

**Note:** 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, ANZNN 2018<sup>(a)</sup>**

Intraventricular haemorrhage	Birthweight (grams)						Total
	<500	500-749	750-999	1000-1249	1250-1499	≥1500	
	Number						
None	25	254	479	604	748	1,729	3,839
Grade 1	<5	34	59	58	53	n.p.	310
Grade 2	6	48	50	25	16	30	175
Grade 3	0	15	12	<5	10	n.p.	60
Grade 4	<5	43	23	n.p.	7	12	102
Not examined	2	1	5	33	159	5,840	6,040
<b>Total</b>	<b>40</b>	<b>395</b>	<b>628</b>	<b>737</b>	<b>993</b>	<b>7,733</b>	<b>10,526</b>
Per cent							
None	65.8	64.5	76.9	85.8	89.7	91.3	85.6
Grade 1	n.p.	8.6	9.5	8.2	6.4	n.p.	6.9
Grade 2	15.8	12.2	8.0	3.6	1.9	1.6	3.9
Grade 3	0.0	3.8	1.9	n.p.	1.2	n.p.	1.3
Grade 4	n.p.	10.9	3.7	n.p.	0.8	0.6	2.3
<b>Total</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>	<b>100.0</b>

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

*(a)* 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, ANZNN 2018**

Sepsis	Birthweight (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	34	287	534	698	966	1,638	1,353	1,363	1,587	1,155	515	10,130
Sepsis at <48 hrs <sup>(a)</sup>	0	11	13	9	8	17	12	17	16	18	8	129
Sepsis at ≥48 hrs <sup>(a)</sup>	n.p.	126	94	45	n.p.	30	22	15	27	6	<5	403
Babies alive on day 2	n.p.	403	632	742	n.p.	1,672	1,375	1,387	1,623	1,171	n.p.	10,566
Babies who did not survive to day 2	<5	21	5	8	<5	12	12	7	6	8	<5	85
<b>Total in each birthweight group</b>	<b>45</b>	<b>424</b>	<b>637</b>	<b>750</b>	<b>998</b>	<b>1,684</b>	<b>1,387</b>	<b>1,394</b>	<b>1,629</b>	<b>1,179</b>	<b>524</b>	<b>10,651</b>
Per cent												
No sepsis <sup>(b)</sup>	75.6	67.7	83.8	93.1	96.8	97.3	97.5	97.8	97.4	98.0	98.3	95.1
Sepsis at <48 hrs <sup>(b)</sup>	0.0	2.6	2.0	1.2	0.8	1.0	0.9	1.2	1.0	1.5	1.5	1.2
Sepsis at ≥48 hrs <sup>(c)</sup>	25.0	31.3	14.9	6.1	2.4	1.8	1.6	1.1	1.7	0.5	0.6	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: Length of stay for level III registrants who survived until discharge home by birthweight, ANZNN 2018**

Birthweight (grams)	Number of babies	Median length of stay (days)	Interquartile range (days)
<500	20	122	115–158
500-749	306	117	99–140
750-999	584	86	72–102
1,000-1,249	716	66	53–81
1,250-1,499	984	49	39–62
1,500-1,999	1,643	37	29–46
2,000-2,499	1,346	21	14–29
2,500-2,999	1,360	11	6–19
3,000-3,499	1,586	7	4–15
3,500-3,999	1,151	6	4–12
≥4,000	516	6	4–11
<b>Total</b>	<b>10,212</b>	<b>24</b>	<b>8–50</b>

*Note: Survival status was not provided for two babies.*

**TABLE 66: Survival to discharge home for level III registrants by birthweight, ANZNN 2018**

Birthweight (grams)	Number of babies	Lethal congenital anomalies	Babies alive on day 7	Babies alive on day 28	Survived to discharge to home	Percent survival at discharge home
<500	45	<5	34	24	20	44.4
500-749	424	<5	381	330	306	72.2
750-999	637	<5	622	603	584	91.7
1,000-1,249	750	7	735	723	716	95.5
1,250-1,499	998	6	991	985	984	98.6
1,500-1,999	1,684	12	1,664	1,647	1,643	97.6
2,000-2,499	1,387	18	1,364	1,353	1,346	97.0
2,500-2,999	1,394	13	1,374	1,364	1,360	97.6
3,000-3,499	1,629	12	1,612	1,598	1,586	97.4
3,500-3,999	1,179	6	1,160	1,156	1,151	97.6
≥4,000	524	<5	517	516	516	98.5
<b>Total</b>	<b>10,651</b>	<b>81</b>	<b>10,454</b>	<b>10,299</b>	<b>10,212</b>	<b>95.9</b>

*Note: Survival status was not provided for two babies.*

## Appendix 3: Methods used in this report

The ANZNN data collection was moved to the then-named Perinatal & Reproductive Epidemiology Research Unit, School of Women's & Children's Health, University of New South Wales in June 2008. The historical ANZNN data were received as a Microsoft Access database and archived as a Microsoft SQL Server database.

Data for the ANZNN audit of babies born in 2018 who qualified as high-risk neonates were requested from each participating unit in June 2019 with a deadline of August 2019. 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 2020. Apart from grouping, the data presented in the report reflect the database at that time with one exception: a series of derived data items were generated. These are listed below.

### Derived data items:

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

All data manipulations and analysis for the 2018 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 2018. A renewed agreement extends this period to 1 February 2024.
- 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.

The 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 the ANZNN Executive Committee and the 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. Any hard copy potentially identifiable data are kept in secured and locked safe cabinets. All rooms and offices used by the ANZNN 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. Secure disposal of data is available through use of designated bins 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)  $\geq 140$  mmHg and/or diastolic BP  $\geq 90$  mmHg, or a rise in systolic BP  $\geq 25$  mmHg and/or a rise in diastolic BP  $\geq 15$  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:* Other significant antenatal complication noted for this baby, not specified.

*Coding:*

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

## Sex

*Definition:* The sex of the patient.

*Coding:*

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

## Infant weight

*Definition:* The first weight of the baby after birth.

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

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

## Gestational age

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

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

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

## Place of birth

*Definition:* Place of baby's birth.

*Coding:*

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

## Presentation at birth

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

*Coding:*

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



## Mode of birth

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

*Coding:*

- 0: unknown.
- 1: vaginal – vaginal birth, includes breech.
- 2: instrument – vaginal birth using an instrument – forceps, rotations, vacuum extraction.
- 3: Caesarean section in labour – caesarean performed after the commencement of labour.
- 4: Caesarean section, no labour – caesarean section performed prior to labour commencing.

## Antenatal corticosteroids

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

*Coding:*

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

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

## Magnesium sulphate

*Definition:* Magnesium sulphate ( $\text{MgSO}_4$ ) provided to the mother during the 24 hours immediately before birth, either because of maternal preeclampsia or specifically for fetal neuro-protection.

*Coding:*

- 0: unknown – information not available.
- 1:  $\text{MgSO}_4$  not given at all.
- 2:  $\text{MgSO}_4$  course stopped > 24 hours before birth.

- 3:  $\text{MgSO}_4$  commenced > 24 hours before birth and stopped < 24 hours before birth.
- 4:  $\text{MgSO}_4$  commenced between 4 to 24 hours before birth.
- 5:  $\text{MgSO}_4$  commenced within 4 hours of birth.
- 6:  $\text{MgSO}_4$  given but details not known.
- 7:  $\text{MgSO}_4$ /placebo given for randomised trial.

*Guide for use:* In the case of planned birth,  $\text{MgSO}_4$  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  $\geq 400$  grams are taken into account. Fetuses aborted at < 20 weeks or fetuses compressed in the placenta at or more than 20 weeks are excluded.

## Birth order

*Definition:* Order of each baby of a multiple birth.

*Coding:* Single-digit number representing birth order.

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

## Date of birth

*Definition:* Date of birth of the patient.

*Coding:* DD / MM / YYYY

## Admission date

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

*Coding:* DD / MM / YYYY

## Apgar score (1 minute)

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

*Coding:* 2-digit number representing Apgar score.

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

## Apgar score (5 minute)

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

*Coding:* 2-digit number.

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

## Intubated at resuscitation

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

*Coding:*

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

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

## Congenital anomalies

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

*Coding:*

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

## Specified congenital anomalies

*Definition:* Detail of the major congenital malformation.

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

## Temperature on admission

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

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

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

## Worst base excess

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

*Coding:* 3 digit numbered field representing base excess measured in mmol per litre. 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 (O<sub>2</sub>) requirements, or the need for ventilator support from the first six hours of life with a chest x-ray showing generalised reticulogranular pattern, plus or minus air bronchogram.
- 4: meconium aspiration – 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 – O<sub>2</sub> need unexplained by chest x-ray or loud P2, or differential pre/post ductal TCPO<sub>2</sub>.
- 8: apnoea – recurrent pauses in breathing for more than 20 seconds, or for less than 20 seconds associated with bradycardia or any desaturation requiring intervention.
- 9: congenital malformation – malformation is the primary reason for 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:* A dose of any type of exogenous surfactant was used to treat this baby.

*Coding:*

- 99: unknown.
- 0: no exogenous surfactant given to this baby.
- 1: yes, exogenous surfactant given to this baby.

*Guide for use:* Includes incomplete administration.

## Method of administration of first dose of surfactant

*Definition:* Method used to administer the first dose of surfactant.

*Coding:*

- 0: unknown.
- 1: endotracheal tube.
- 2: catheter (eg. MIST).
- 3: Other – eg. laryngeal mask, aerosolisation.

## 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 (O<sub>2</sub>), high flow, CPAP or mechanical ventilation ceased appropriately.

*Coding:* DD / MM / YYYY

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

## Nasal high flow therapy

*Definition:* Blended air and oxygen mix with a delivery flow of greater than 1 litre per minute 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 ( $\leq 1$ L/min).
- 3: low flow oxygen ( $\leq 1$ 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 nutritia 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

*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 one of the following symptoms:

1. Diagnosis at surgery or post mortem.
2. Radiological diagnosis, a clinical history plus:
  - pneumatosis intestinalis, or
  - portal vein gas, or
  - a persistent dilated loop on serial X-rays.
3. Clinical diagnosis, a clinical history plus abdominal wall cellulitis and palpable abdominal mass.

## Spontaneous intestinal perforation

*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°C (generally 33–34°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 (CSF). 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 fibrovascular proliferation.
- 4: stage IV – retinal detachment.
- 5: not examined – no eye examination.



## Surgical therapy for retinopathy of prematurity

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

*Coding:*

- 99: unknown.
- 0: no surgical therapy for ROP received.
- 1: yes, surgical 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: (Date Assessed – 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)”.

## Reason for lost to follow-up

*Definition:* Main reason child was lost to follow-up at two to three years corrected age.

*Coding:*

- 0: unknown.
- 1: could not be contacted.
- 2: refused/did not attend appointment.
- 3: moved from area – referral to another hospital for follow-up assessment unknown.
- 4: referred to another hospital for follow-up assessment – the registration hospital could not obtain follow-up outcomes from the referral hospital.
- 5: did not meet local criteria for follow-up assessment.
- 6: other.

*Guide for use:* Only one outcome to be used. If child is referred to another hospital for follow-up assessment, the registration hospital should request any two to three year follow-up outcomes from the referral hospital. If the referral hospital fails to provide any follow-up outcomes, record as “Referred to another hospital for follow-up assessment – the registration hospital could not obtain follow-up outcomes from the referral hospital (4)”.

## Place of follow-up assessment

*Definition:* Place of two to three year follow-up assessment.

*Coding:*

- 0: unknown.
- 1: follow-up clinic at registration hospital.
- 2: follow-up clinic at another hospital.
- 3: paediatrician.
- 4: general practitioner.
- 5: outreach clinic.
- 6: other.

*Guide for use:* Only one outcome to be used.

## 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.
- 2: parenteral nutrition.
- 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.

## Reason for incomplete or no formal assessment

*Definition:* Main reason for incomplete or no formal developmental assessment at two to three years corrected age.

*Coding:*

- 0: unknown.
- 1: child too severely delayed.
- 2: child had a behavioural disorder.
- 3: child had a neurosensory impairment.
- 4: child was unwell.
- 5: child was uncooperative.
- 6: first language of child was not English.
- 7: formal assessment not offered at place of follow-up assessment.
- 8: other.

*Guide for use:* only one outcome to be used.

## Clinical assessment of cognitive development

*Definition:* Assessment of cognitive development by a health care professional at two to three years corrected age for infants whose cognitive development was not assessed by a formal developmental test.

*Coding:*

- 0: unknown.
- 1: normal cognitive development or mild cognitive delay.
- 2: moderate cognitive delay.
- 3: severe cognitive delay.
- 4: cognitive delay but severity of delay unknown.
- 5: cognitive development not clinically assessed.

## Clinical assessment of language development

*Definition:* Assessment of language development by a health care professional at two to three years corrected age for infants whose language development was not assessed by a formal developmental test.

*Coding:*

- 0: unknown.
- 1: normal language development or mild cognitive delay.
- 2: moderate language delay.
- 3: severe language delay.
- 4: language delay but severity of delay unknown.
- 5: language development not clinically assessed.

## Clinical assessment of motor development

*Definition:* Assessment of motor development by a health care professional at two to three years corrected age for infants whose motor development was not assessed by a formal developmental test.

*Coding:*

- 0: unknown.
- 1: normal motor development or mild cognitive delay.
- 2: moderate motor delay.
- 3: severe motor delay.
- 4: motor delay but severity of delay unknown.
- 5: motor development not clinically assessed.

## 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.

**Clinical assessment of development:** professional opinion of a healthcare professional regarding the presence and severity of developmental delays for specific domains (cognitive, language and motor development), made in the absence of formal developmental testing.

**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.

**Formal developmental assessment:** includes 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 Development Scales or another developmental test performed by a psychologist, developmental paediatrician, physiotherapist, or other qualified person.

**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** 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.

**Stanford-Binet Intelligence Scales:** assesses the cognitive ability of children, adolescents and adults across five subscales; fluid reasoning, knowledge, quantitative reasoning, visual-spatial processing and working memory.

**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.

**Wechsler Preschool and Primary Scale of Intelligence:** assesses the cognitive development of young children across five subscales; verbal comprehension, visual spatial, fluid reasoning, working memory, and processing speed.

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