2021

REPORT OF THE

# AUSTRALIAN AND NEW ZEALAND NEONATAL NETWORK

UNSW SYDNEY

ANZNN

2021

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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.

# Contents

# Acknowledgements

This is the twenty-sixth report of the Australian and New Zealand Neonatal Network (ANZNN), the fourteenth report in the current format and the tenth 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), David Barker, Malcolm Battin, Georgina Chambers, Manbir Chauhan, Anjali Dhawan, Denise Harrison, Jim Holberton, Rod Hunt, Claire Jacobs, Amy Keir, Melissa Luig, Natalie Merida, Victor Samuel Rajadurai, Naomi Spotswood, Tobias Strunk and Kenneth Tan.

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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 data for this report.

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 2021.

**Chapter 2:** 'Babies registered to level III units' provides information and characteristics on the ANZNN registrants in 2021 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 2021.

**Chapter 4:** 'Characteristics of level III registrants' provides information about the babies admitted to a level III neonatal unit during 2021.

**Chapter 5:** 'Babies registered to level II units' provides information about babies registered to the level II special care baby units during 2021.

**Chapter 6:** 'Extremely preterm follow-up, 2015–2018 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 2015 to 2018.

**Appendices:** Appendix 1 presents 10-year trends.

Appendix 2 presents data tables by birthweight for 2021.

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 |
| APH | antepartum haemorrhage |
| Bayley-III | Bayley Scales of Infant and Toddler Development Third Edition |
| Bayley 4 (A&NZ) | Bayley Scales of Infant and Toddler Development (Australian and New Zealand Standardised 4th edition) |
| CI | confidence interval |
| CLD | chronic lung disease |
| CPAP | continuous positive airway pressure |
| CRIB | Clinical Risk Index for Babies |
| ECMO | extracorporeal membrane oxygenation |
| g | gram |
| GIFT | gamete intra-fallopian transfer |
| GMFCS | gross motor function classification system |
| HFOV | high frequency oscillatory ventilation |
| HMD | hyaline membrane disease |
| ICD-10-AM | The International Statistics Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification |
| IPPV | intermittent positive pressure ventilation |
| IQR | interquartile range |
| IUGR | intrauterine growth restriction |
| IVF | in vitro fertilisation |
| IVH | intraventricular haemorrhage |
| $MgSO_4$ | magnesium sulphate |
| NEC | necrotising enterocolitis |
| NHF | nasal high flow |
| NICU | neonatal intensive care unit |
| NPESU | National Perinatal Epidemiology and Statistics Unit |
| $O_2$ | oxygen |
| PCR | polymerase chain reaction |
| PMA | post menstrual age |
| PPROM | preterm pre-labour rupture of membranes |
| PVL | periventricular leukomalacia |
| 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 current 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, Andrew Bedding, Karina Rogers

#### John Hunter Hospital

*(NICU & special care beds: 43)*
Larissa Korostenski (Director), Alissa Argomand, Stacey Leonard

#### Liverpool Health Service

*(NICU & special care beds: 31)*
Jacqueline Stack (Director), Ian Callander, Kathryn Medlin, Amanda Beasley, Melanie Edmonds

#### 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)*
Srini Bolisetty (Director), Kei Lui, Diane Cameron, Brianna Draskovic

#### Royal North Shore Hospital

*(NICU & special care beds: 27)*
Eveline Staub (Director), Mary Paradisis, Jennifer Bowen, Amy Sparks, Lyn Barnes

#### RPA Women and Babies

*(NICU & special care beds: 34)*
Mark Greenhalgh (Director), 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 Registry

*(New South Wales and Australian Capital Territory)*
Barbara Bajuk, Sara Sedgley, Janette Tommasi, Mark Leckie

### Australian Capital Territory

#### The Canberra Hospital

*(NICU & special care beds: 29)*
Hazel Carlisle (Director), Allana Carter, Judith Smith, Laura Maher, Amanda Dyson, Laura Briguglio, Melanie Rosin

### Victoria

#### Joan Kirner Women's & Children's at Sunshine Hospital

*(Special care beds: 30)*
Clare Collins (Director), Rosalynn Pszczola, Damien Gilby, Elizabeth Noble

#### Mercy Hospital for Women

*(NICU & special care beds: 58)*
Dan Casalaz (Director), Jim Holberton, Emily Burke

#### Monash Medical Centre

*(NICU & special care beds: 64)*
Alice Stewart (Director), Kenneth Tan, Rod Hunt, Rose Li, Emily Johnston, Samantha Tyrer

#### Royal Children's Hospital

*(NICU & special care beds: 34)*
Leah Hickey (Director), Jo Brooks

#### Royal Women's Hospital

*(NICU & special care beds: 60)*
Sue Jacobs (Director), Carl Kuschel, Jeanie Cheong, Alison Martin, Jennifer Walsh

### Tasmania

#### Royal Hobart Hospital

*(NICU & special care beds: 26)*
Tony De Paoli (Director), Peter Dargaville, Naomi Spotswood, Karen Butterley, Ruth Wilson, Charlotte Jenkins

### Queensland

#### Gold Coast Hospital

*(NICU & special care beds: 33)*
Peter Schmidt (Director), Timothy Hong, Kobi Best, Michelle Eley

#### Mater Mothers' Hospital

*(NICU & special care beds: 79)*
Pita Birch (Director), Elizabeth Hurrion, Karen Nothdurft, Leith Poulsen

### Royal Brisbane and Women's Hospital

*(NICU & special care beds: 71)*
Pieter Koorts (Director), Katherine White, David Cartwright, Linda McLaughlin, Melissa Lai, Zuleiga Goder

### Townsville University Hospital

*(NICU & special care beds: 44)*
Gary Alcock (Director), Louise McIldowie, Wendy Kennedy

## South Australia

### Flinders Medical Centre

*(NICU & special care beds: 35)*
Scott Morris (Director), Vanessa Ellison, Edith van Loon

### Women's and Children's Hospital

*(NICU & special care beds: 49)*
Alison Kent (Director), Chad Andersen, Amy Keir, Andy McPhee, Michael Stark, Sara Cadd, Meg Bater

## Western Australia

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

*(NICU & special care beds: 137)*
Mary Sharp (Director), Steven Resnick, Rebecca Thomas, Rolland Kohan, Shripada Rao, Andy Gill, Jane Pillow, Damber Shrestha

## Northern Territory

### Royal Darwin Hospital

*(NICU & special care beds: 25)*
Mantho Kgosiemang (Director), Peter Morris, Dennis Bonney, Deborah Ribbon, Connie Yii

## 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)

Amy Keir (Director)

## New Zealand

### Christchurch Women's Hospital

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

### Dunedin Hospital

*(NICU & special care beds: 16)*
Peter Fowlie (Co-director), Andrew Kelly (Co-director), Liza Edmonds, Frances McCaffrey

### Middlemore Hospital

*(NICU & special care beds: 38)*
Guy Bloomfield (Director), Lindsay Mildenhall, Kristin O'Connor, Kelly Roczniak, Rebecca Griffith

### 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), Miranda Bailey, Christine Jones, Claire West

### Wellington Regional Hospital

*(NICU & special care beds: 40)*
Helen Miller (Co-Director), Angelica Allermo-Fletcher (Co-Director), Harshad Patel, 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), Beverley Lewis

### The Maitland Hospital

*(Special care beds: 8)*
David Rogers (Director), Jessica Crombie, Linda Bailey, Benita Botha

### 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, Danielle Coggan

## Victoria

### The Northern Hospital

*(Special care beds: 15)*
Wei Qi Fan (Director), Pampha Khanal, Angelica Francis

## Queensland

### Bundaberg Hospital

*(Special care beds: 8)*
Matt Wakeley (Director), Christopher Edwards

### Cairns Hospital

*(Special care beds: 22)*
Neil Archer (Director), Sue McMahon, Marg Cuming

### Logan Hospital

*(Special care beds: 16)*
Jan Cullen (Director), Angela Geraghty

### Mackay Base Hospital

*(Special care beds: 8)*
Vasanthakumar Selvarajah (Director), Joanne Morganson

### Redcliffe Hospital

*(Special care beds: 10)*
Simon Grew (Director), Meredith Shallcross, Jeanie Cooper

### Redland Hospital

*(Special care beds: 8)*
Dougie Thomas (Director), Wendy Bostock

### Sunshine Coast University Hospital

*(Special care beds: 27)*
Lizelle Weber (Director), Janet Rowley

## South Australia

### Lyell McEwin Hospital

*(Special care beds: 16)*
Michael Hewson (Director), Penelope Miller

## Northern Territory

### Alice Springs Hospital

*(Special care beds: 8)*
James Dowler (Director), Marion Bates, Suji Thomas, Minnu Jolly

# New Zealand

### Gisborne Hospital

*(Special care beds: 6)*
Shaun Grant (Co-Director), Stanley Ng (Co-Director), Lianne Hollis, Claire Johansen

### Hawkes Bay Hospital

*(Special care beds: 12)*
Daniel Riviere (Director), Mercy Jenson, Margarette Tapgos, Emily Gallagher

### Lower Hutt Hospital

*(Special care beds: 12)*
Sarah Mills (Director), Debbie Bashaw

### Nelson Hospital

*(Special care beds: 8)*
Garth Smith (Director), Nathalie Robinson

### North Shore Hospital

*(Special care beds: 12)*
Christopher Peterson (Director), Kerryn Shaw, Mary Lou Macapondag

### Palmerston North Hospital

*(Special care beds: 17)*
Jeff Brown (Director), Alice Bigwood

### Rotorua Hospital

*(Special care beds: 10)*
Stephen Bradley (Director), Leanne Turvey

### Southland Hospital

*(Special care beds: 6)*
Ian Shaw (Director), Liz Hanning-Baird

### Taranaki Base Hospital

*(Special care beds: 8)*
John Doran (Director), Amanda Thompson

### Tauranga Hospital

*(Special care beds: 12)*
Anita Lala (Director), Anna Hayns

### Timaru Hospital

*(Special care beds: 2)*
Mick Goodwin (Director), Mark Liddy

### Waitakere Hospital

*(Special care beds: 15)*
Christopher Peterson (Director), Stefanie Smith

### Wairau Hospital

*(Special care beds: 4)*
Margaret Andre (Director)

### Whakatane Hospital

*(Special care beds: 4)*
Michael Herd (Director), Kellie Butler

### Whanganui Hospital

*(Special care beds: 4)*
David Montgomery (Director), Barbara Hammond

### Whangarei Area Hospital

*(Special care beds: 8)*
David Barker (Director), Georgia Kidd, Leanne Vazey, Sarah Middlemass

## 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, and another member level II unit became a level III unit in 2020, bringing the total of NICU members to 32. 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 14 units contributing data in 2021.

## 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.

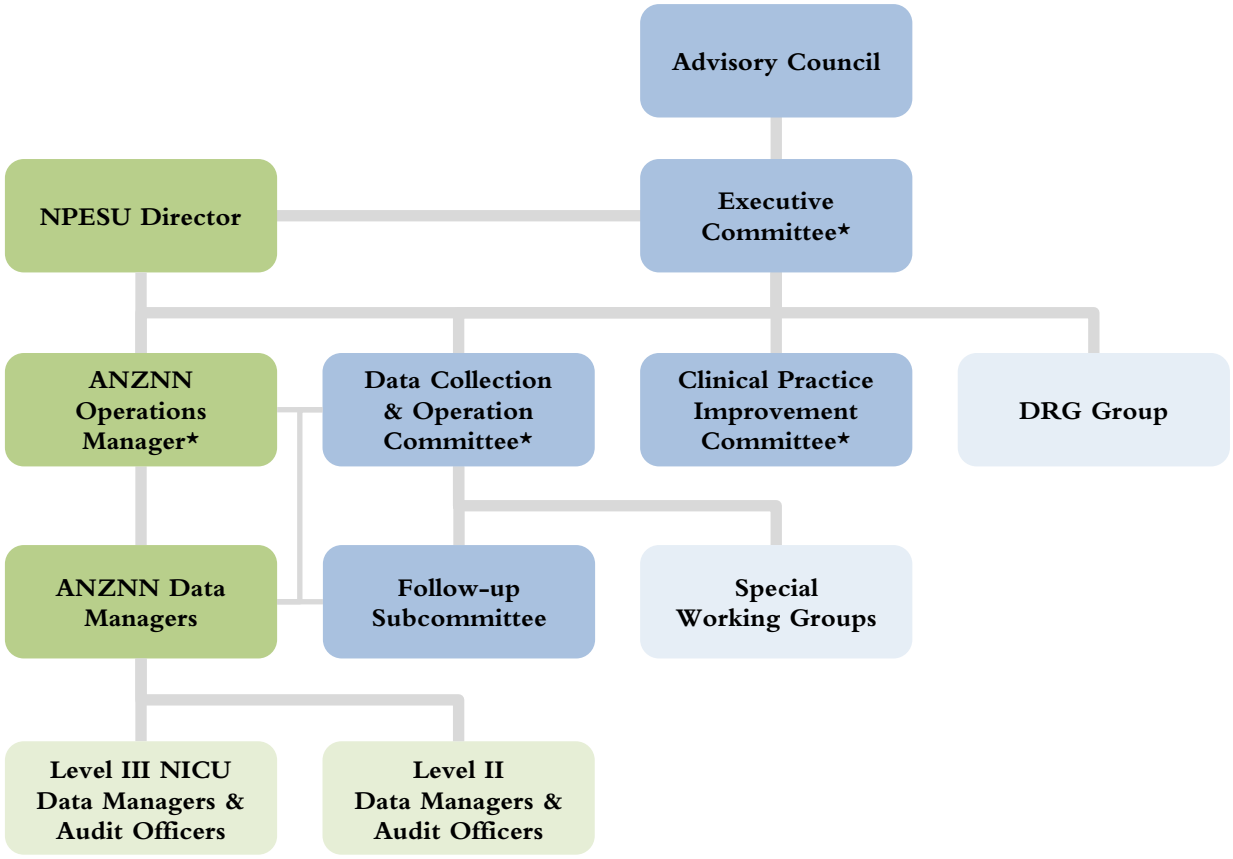
The Executive Committee is an elected committee with regional representation from unit directors, a data manager group representative and neonatal nurse representatives from across the network, and a consumer representative. It oversees the general functioning of the network, finance and decision-making, 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 nasal high flow (NHF) 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.

## Data set variables

The variables used for the 2021 audit are listed in Appendix 5 and are also available on the website < **www.anznn.net** >.

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## Babies born in Australia

There were 9,705 babies registered to the ANZNN from the 24 level III NICUs in Australia, representing 3.1% of the 309,996 notified live births in 2021 (Australian Bureau of Statistics 2022). Of these registrants, 80.8% were born in a hospital with tertiary care facilities. There were 2,892 babies born before 32 weeks gestation representing 29.8% of Australian registrants.

Maternal ethnicity was provided for 95.4% of mothers: 70.8% of the mothers of these babies identified as Caucasian and 15.6% as Asian. One in twelve mothers (8.3%) identified as Aboriginal or Torres Strait Islander, which was higher than the proportion reported in all births in Australia in 2021 (7.6%) (Australian Bureau of Statistics 2022).

Among Australian NICU admissions registered to the ANZNN, 1,655 were from multiple births representing 17.1% of ANZNN admissions in Australia in 2021.

Male babies were over-represented among NICU admissions – 58.0% of the Australian ANZNN registrants, compared with 51.3% among live births in Australia (Australian Bureau of Statistics 2022).

Assisted ventilation (intermittent positive pressure ventilation (IPPV), continuous positive airway pressure (CPAP) or nasal high flow (NHF)) was provided for 9,452 babies (3.0% of live births) and non-invasive ventilation (CPAP or NHF) was the only form of respiratory assistance for 6,405 babies.

## Babies born in New Zealand

There were 2,522 babies who met ANZNN registration criteria from the six level III NICUs in New Zealand representing 4.3% of the 58,659 live births registered in New Zealand in 2021 (Statistics New Zealand 2022). Of these registrants, 86.4% were born in a hospital with tertiary care facilities. There were 664 babies born before 32 weeks gestation representing 26.3% of New Zealand registrants.

Maternal ethnicity was reported for 98.8% of the New Zealand registrants. The percentage of Caucasian mothers was 45.0%. A higher proportion of mothers identified themselves as Maori (22.2%) compared to 12.0% of mothers identified as Pacific Islander and 17.7% as Asian.

Among New Zealand NICU admissions registered to the ANZNN, 332 were from multiple births representing 13.2% of ANZNN admissions in New Zealand in 2021.

Male babies were also over-represented among NICU admissions in New Zealand – 55.9% of the New Zealand registrants compared to 51.2% of total live births in New Zealand (Statistics New Zealand 2022).

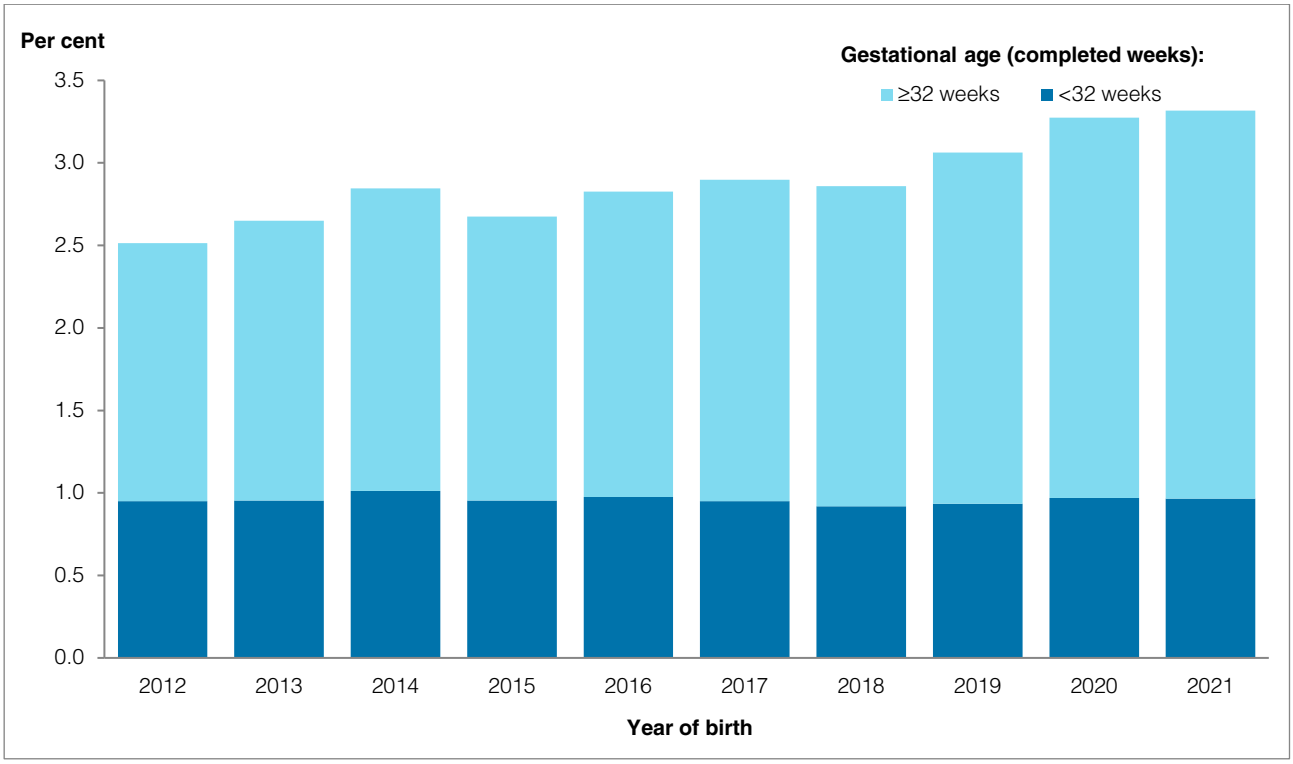
Assisted ventilation (IPPV, CPAP or NHF) was given to 2,481 babies representing 4.2% of all live births with 1,898 babies receiving non-invasive ventilation (CPAP or NHF) as the only form of respiratory assistance (3.2% of all live births).

# 2. Babies registered to level III units

This section includes data on the ANZNN registrants from all 30 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 2021 and admitted to an NICU in Australia and New Zealand, 12,227 fulfilled the registration criteria for inclusion in the ANZNN clinical quality registry. The population represents 3.3% of the 368,655 live births in the two countries in 2021 (Australian Bureau of Statistics 2022; Statistics New Zealand 2022) (Figure 2), compared with 3.3% in 2020. The number of registrants in 2021 was 701 more than in 2020.

**FIGURE 2: Proportion of liveborn babies in Australia and New Zealand who were ANZNN level III registrants, by year of birth, ANZNN 2012–2021**




Of the 12,227 ANZNN registrants born in 2021, there were 3,556 (29.1%) babies born before 32 weeks gestation and 8,671 babies born at 32 weeks or more (70.9%). Of the registrants born before 32 weeks gestation, 97.6% 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 1,100 babies in 2021, the smallest just under 40 (Figure 3). The median number of babies registered to an ANZNN unit was 379.

The gestational age at birth and birthweight for babies qualifying for inclusion in the ANZNN 2021 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 (2012–2021) 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 2021**

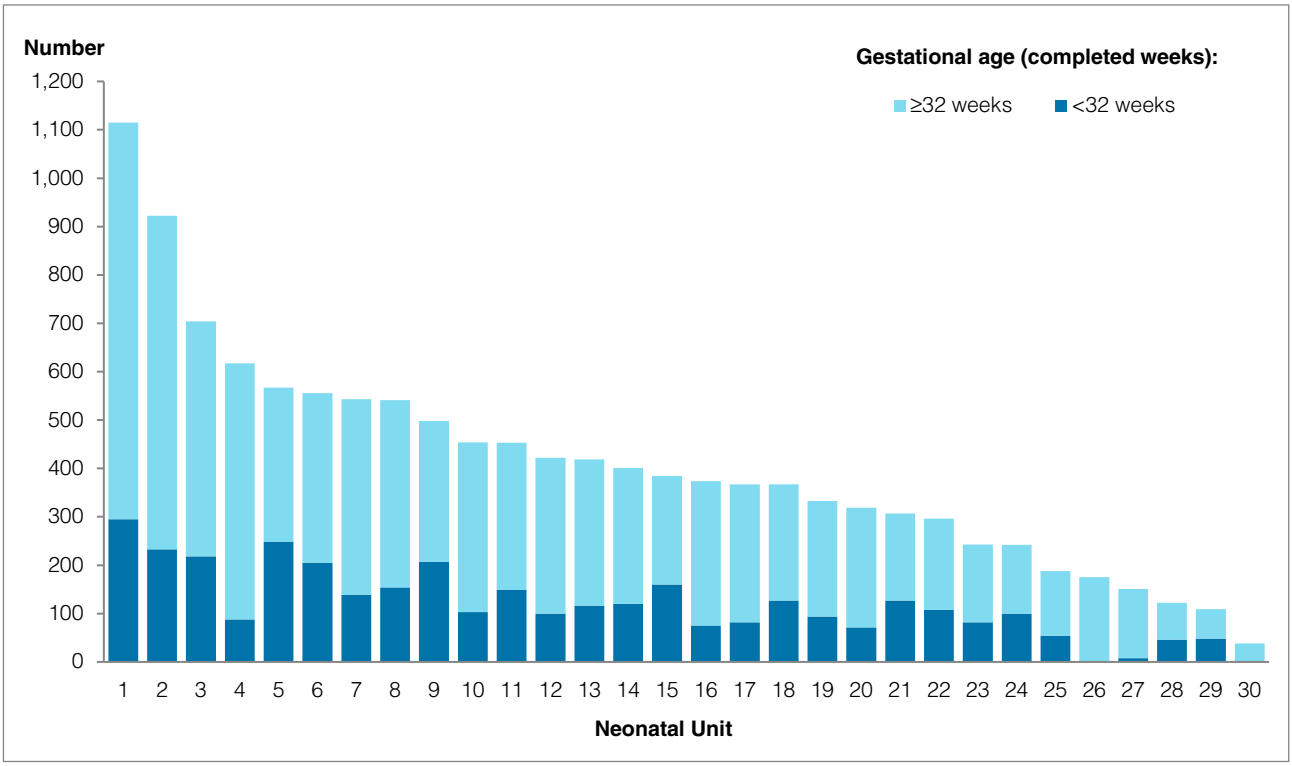



**TABLE 1: Level III registrants born at each completed week of gestation, ANZNN 2021**

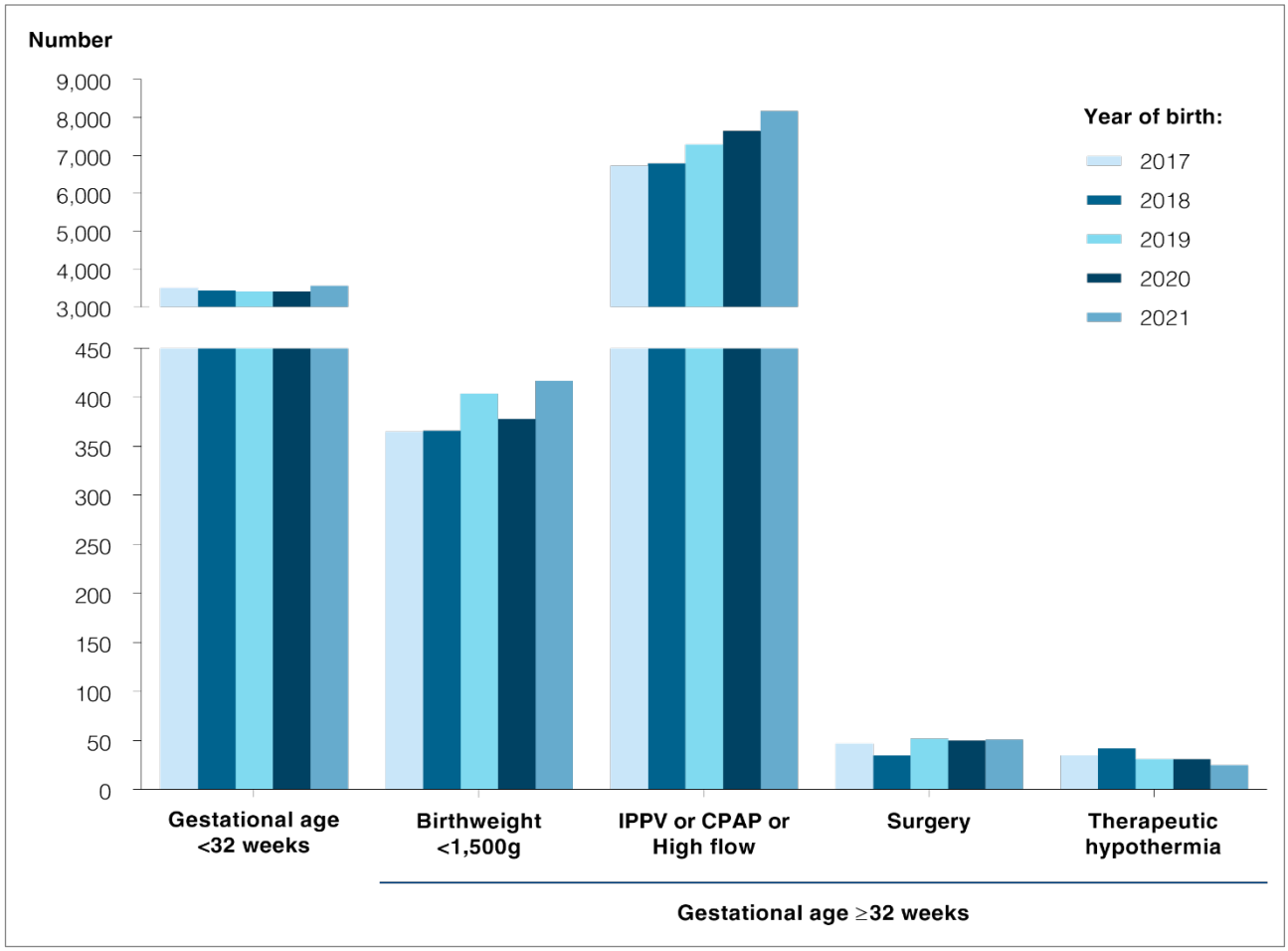
| Gestational age (weeks) | Number of babies | Percent | Cumulative percent |
|---|---|---|---|
| <24 | 136 | 1.1 | 1.1 |
| 24 | 193 | 1.6 | 2.7 |
| 25 | 232 | 1.9 | 4.6 |
| 26 | 288 | 2.4 | 6.9 |
| 27 | 343 | 2.8 | 9.7 |
| 28 | 452 | 3.7 | 13.4 |
| 29 | 508 | 4.2 | 17.6 |
| 30 | 608 | 5.0 | 22.6 |
| 31 | 796 | 6.5 | 29.1 |
| **All babies <32 weeks** | **3,556** | **29.1** | |
| 32 | 817 | 6.7 | 35.8 |
| 33 | 736 | 6.0 | 41.8 |
| 34 | 806 | 6.6 | 48.4 |
| 35 | 704 | 5.8 | 54.1 |
| 36 | 792 | 6.5 | 60.6 |
| 37 | 1000 | 8.2 | 68.8 |
| 38 | 1254 | 10.3 | 79.0 |
| 39 | 1170 | 9.6 | 88.6 |
| 40 | 819 | 6.7 | 95.3 |
| 41 | 523 | 4.3 | 99.6 |
| ≥42 | 50 | 0.4 | 100.0 |
| **Total** | **12,227** | **100.0** | |

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

**TABLE 2: Level III registrants in each birthweight group, ANZNN 2021**

| Birthweight (grams) | Number of babies | Percent | Cumulative percent |
|---|---|---|---|
| <500 | 81 | 0.7 | 0.7 |
| 500–599 | 154 | 1.3 | 1.9 |
| 600–699 | 194 | 1.6 | 3.5 |
| 700–799 | 246 | 2.0 | 5.5 |
| 800–899 | 252 | 2.1 | 7.6 |
| 900–999 | 287 | 2.3 | 9.9 |
| 1,000–1,099 | 319 | 2.6 | 12.5 |
| 1,100–1,199 | 330 | 2.7 | 15.2 |
| 1,200–1,299 | 337 | 2.8 | 18.0 |
| 1,300–1,399 | 409 | 3.3 | 21.3 |
| 1,400–1,499 | 432 | 3.5 | 24.9 |
| **All babies <1,500g birthweight** | **3,041** | **24.9** | |
| 1,500–1,999 | 1,773 | 14.5 | 39.4 |
| 2,000–2,499 | 1,561 | 12.8 | 52.1 |
| 2,500–2,999 | 1,669 | 13.7 | 65.8 |
| 3,000–3,499 | 1,873 | 15.3 | 81.1 |
| 3,500–3,999 | 1,497 | 12.2 | 93.4 |
| ≥4,000 | 813 | 6.6 | 100.0 |
| **Total** | **12,227** | **100.0** | |

**FIGURE 4: Level III registrants by registration criteria, ANZNN 2017–2021**




***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 2021, the age of mothers of neonates registered as high-risk ranged from less than 15 years to over 50 years. The highest proportion of registrant mothers was aged 30–34 years (34.9%) followed by mothers aged 25–29 years (23.9%). Together they accounted for nearly three in five of the mothers (58.8%) of ANZNN registrants in 2021 (Table 3). In 2021, the proportion of babies born to teenage mothers decreased slightly from 2020, and those born to mothers in the 35–39 age group increased slightly, from 21.7% in 2020 to 22.5%.

Over one in three of the babies born to teenage mothers (37.0%) were born at less than 32 weeks completed gestation, while 27.9% 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 2021**

| Maternal age (years) | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | <24 | 24–25 | 26–27 | 28–29 | 30–31 | 32–33 | 34–36 | 37–44 | Total |
| | | | | | Number | | | | |
| Less than 20 | 5 | 14 | 17 | 36 | 32 | 37 | 44 | 96 | 281 |
| 20–24 | 25 | 52 | 76 | 112 | 173 | 146 | 259 | 477 | 1,320 |
| 25–29 | 24 | 119 | 146 | 247 | 302 | 357 | 515 | 1,183 | 2,893 |
| 30–34 | 47 | 124 | 206 | 306 | 494 | 545 | 756 | 1,739 | 4,217 |
| 35–39 | 28 | 91 | 149 | 211 | 312 | 345 | 566 | 1,015 | 2,717 |
| 40 and over | 7 | 24 | 33 | 45 | 75 | 103 | 133 | 237 | 657 |
| Not stated | 0 | 1 | 4 | 3 | 16 | 20 | 29 | 69 | 142 |
| **Total** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | Per cent | | | | |
| Less than 20 | 3.7 | 3.3 | 2.7 | 3.8 | 2.3 | 2.4 | 1.9 | 2.0 | 2.3 |
| 20–24 | 18.4 | 12.3 | 12.1 | 11.7 | 12.5 | 9.5 | 11.4 | 10.0 | 10.9 |
| 25–29 | 17.6 | 28.1 | 23.3 | 25.8 | 21.8 | 23.3 | 22.7 | 24.9 | 23.9 |
| 30–34 | 34.6 | 29.2 | 32.9 | 32.0 | 35.6 | 35.6 | 33.3 | 36.6 | 34.9 |
| 35–39 | 20.6 | 21.5 | 23.8 | 22.0 | 22.5 | 22.5 | 24.9 | 21.4 | 22.5 |
| 40 and over | 5.1 | 5.7 | 5.3 | 4.7 | 5.4 | 6.7 | 5.9 | 5.0 | 5.4 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

***Note:*** *Not stated data are excluded from per cent calculations.*
*Maternal data for babies of a multiple birth are presented for each registrant.*

## Previous antenatal history

A previous preterm delivery was reported by 1,234 (10.1%) mothers of babies registered to ANZNN in 2021 while 359 mothers (2.9%) 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 1,041 (8.5%) pregnancies resulting from assisted conception in the ANZNN 2021 cohort with most (86.2%) following IVF treatment. Of the pregnancies resulting from assisted conception, 54.7% of the mothers were more than 34 years of age at the time of giving birth, compared with 53.5% in 2020.

## 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 99.5% of 2021 ANZNN registrants. The mothers of nearly one in five registrants (18.8%) presented with preterm labour while fetal distress (16.0%) 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 (34.2% and 26.8% respectively) followed by preterm pre-labour rupture of membranes (22.2% and 13.9% respectively).

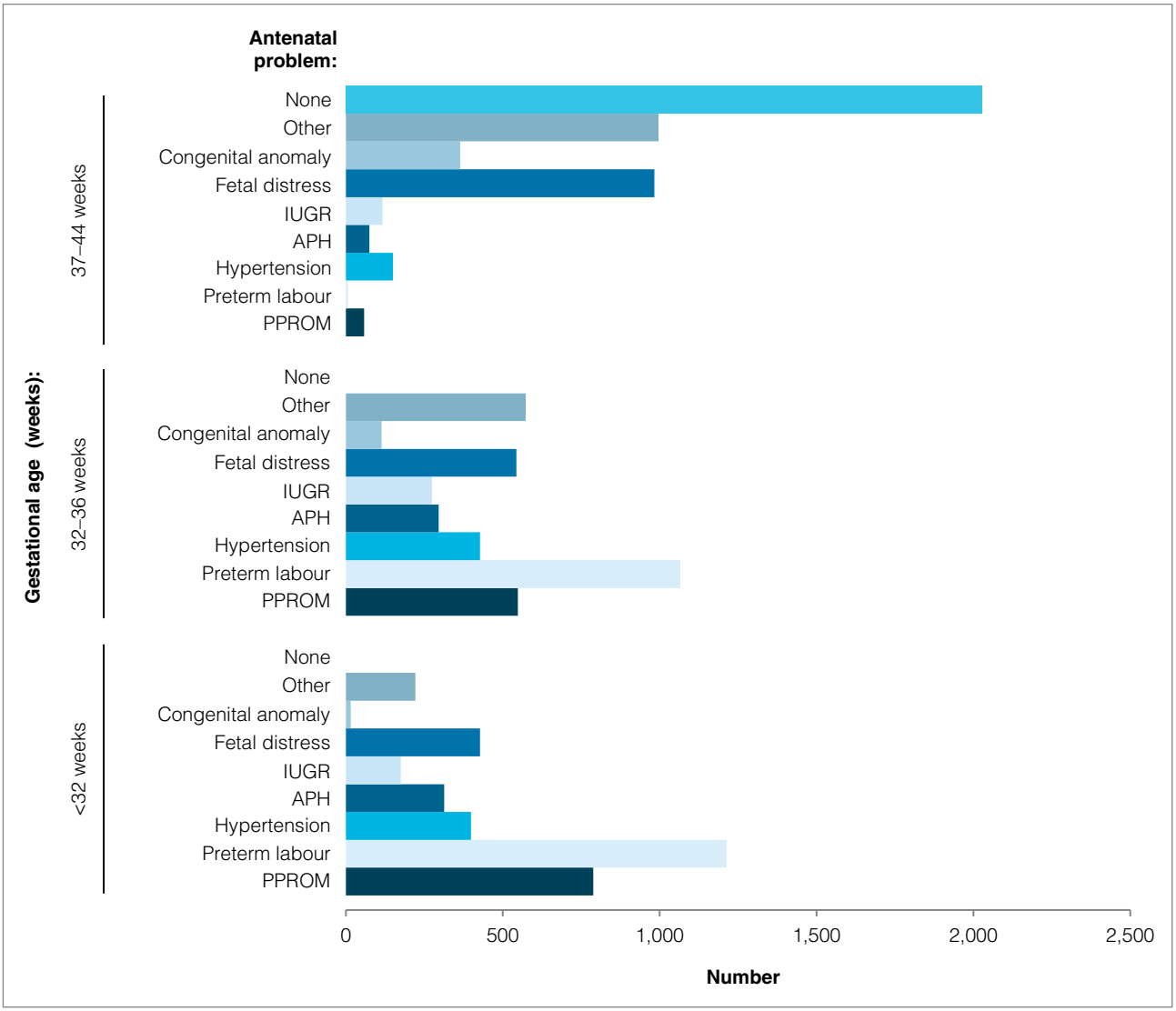
Overall 82.9% of mothers of registrants had a pregnancy complication recorded. Among women who gave birth at term, just over two in five (42.1%) were recorded as having no maternal presenting antenatal problem.

**TABLE 4: Mother's presenting antenatal problem for level III registrants by gestational age, ANZNN 2021**

| | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Presenting antenatal problem** | **<24** | **24–25** | **26–27** | **28–29** | **30–31** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | **Number** | | | | |
| No antenatal problems | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 2,029 | 2,029 |
| Preterm pre-labour rupture of membranes | 29 | 105 | 135 | 209 | 310 | 230 | 318 | 58 | 1,394 |
| Preterm labour | 73 | 189 | 234 | 283 | 434 | 452 | 614 | 6[(a)] | 2,285 |
| Hypertension in pregnancy | <5 | 33 | 66 | n.p. | 183 | 205 | 222 | 150 | 976 |
| Antepartum haemorrhage | 18 | 29 | 59 | 96 | 111 | 145 | 151 | 75 | 684 |
| Intrauterine growth restriction | 0 | 5 | 31 | 63 | 76 | 106 | 168 | 117 | 566 |
| Fetal distress | 7 | 32 | 71 | 127 | 190 | 226 | 317 | 983 | 1,953 |
| Other problem | n.p. | 30 | n.p. | 64 | 89 | 162 | 411 | 996 | 1,790 |
| Congenital anomalies | 0 | 0 | <5 | <5 | 10 | 23 | 91 | 364 | 493 |
| Not stated | 0 | 2 | 2 | 0 | 1 | 4 | 10 | 38 | 57 |
| **Total** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | **Per cent** | | | | |
| No antenatal problems | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 | 42.5 | 16.7 |
| Preterm pre-labour rupture of membranes | 21.3 | 24.8 | 21.5 | 21.8 | 22.1 | 14.8 | 13.9 | 1.2 | 11.5 |
| Preterm labour | 53.7 | 44.7 | 37.2 | 29.5 | 30.9 | 29.2 | 26.8 | 0.1 | 18.8 |
| Hypertension in pregnancy | n.p. | 7.8 | 10.5 | n.p. | 13.0 | 13.2 | 9.7 | 3.1 | 8.0 |
| Antepartum haemorrhage | 13.2 | 6.9 | 9.4 | 10.0 | 7.9 | 9.4 | 6.6 | 1.6 | 5.6 |
| Intrauterine growth restriction | 0.0 | 1.2 | 4.9 | 6.6 | 5.4 | 6.8 | 7.3 | 2.4 | 4.7 |
| Fetal distress | 5.1 | 7.6 | 11.3 | 13.2 | 13.5 | 14.6 | 13.8 | 20.6 | 16.0 |
| Other problem | n.p. | 7.1 | n.p. | 6.7 | 6.3 | 10.5 | 17.9 | 20.8 | 14.7 |
| Congenital anomalies | 0.0 | 0.0 | n.p. | n.p. | 0.7 | 1.5 | 4.0 | 7.6 | 4.1 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
*(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 2021**




***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 34th completed week of gestation with the aim of improving neonatal outcomes by enhancing newborns' maturation. The preferred regimen is more than one dose of antenatal corticosteroids, with the first dose given more than 24 hours and less than eight days before the baby's birth.

Table 5 presents antenatal corticosteroids use for mothers of ANZNN registrants in each gestational age group. In 2021, 89.2% of mothers of ANZNN registrants born before 34 weeks of gestation received one or more doses of antenatal corticosteroids, leaving 10.8% of mothers of registrants in this group who did not report receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 12.9% received them more than seven days prior to giving birth.

For mothers of ANZNN registrants born before 32 weeks of gestation, 91.3% received one or more doses of antenatal corticosteroids and 8.7% mothers of registrants in this group were not reported as receiving any antenatal corticosteroids. Of the mothers who received antenatal corticosteroids, 11.9% received them more than seven days prior to giving birth (Table 5). The 10-year trend (2012–2021) 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 2021**

| | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Antenatal corticosteroids** | **<24** | **24–25** | **26–27** | **28–29** | **30–31** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | **Number** | | | | |
| None | 17 | 33 | 37 | 66 | 140 | 229 | 1,202 | 4,130 | 5,854 |
| Incomplete course | 48 | 102 | 192 | 255 | 373 | 417 | 285 | 15 | 1,687 |
| Complete course within 7 days of birth | 66 | 250 | 334 | 522 | 720 | 693 | 517 | 62 | 3,164 |
| Given >7 days prior to birth | 5 | 40 | 66 | 112 | 162 | 201 | 219 | 36 | 841 |
| Not stated | 0 | 0 | 2 | 5 | 9 | 13 | 79 | 573 | 681 |
| **Total** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | **Per cent** | | | | |
| None | 12.5 | 7.8 | 5.9 | 6.9 | 10.0 | 14.9 | 54.1 | 97.3 | 50.7 |
| Incomplete course | 35.3 | 24.0 | 30.5 | 26.7 | 26.7 | 27.1 | 12.8 | 0.4 | 14.6 |
| Complete course within 7 days of birth | 48.5 | 58.8 | 53.1 | 54.7 | 51.6 | 45.0 | 23.3 | 1.5 | 27.4 |
| Given >7 days prior to birth | 3.7 | 9.4 | 10.5 | 11.7 | 11.6 | 13.1 | 9.9 | 0.8 | 7.3 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

***Note:*** *Not stated data are excluded from per cent calculations.*
*Maternal data for babies of a multiple birth are presented for each registrant.*

## 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 ($MgSO_4$) 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, 62.6% were given antenatal $MgSO_4$ (Table 6).

**TABLE 6: Magnesium sulphate use for mothers of level III registrants by gestational age, ANZNN 2021**

| | Gestational age (weeks) | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Magnesium sulphate** | **<24** | **24** | **25** | **26** | **27** | **28** | **29** | **30** | **31** | **Total** |
| | | | | | | **Number** | | | | |
| None | 31 | 36 | 37 | 49 | 59 | 76 | 115 | 332 | 576 | 1,311 |
| Complete course | 44 | 56 | 83 | 75 | 96 | 136 | 126 | 102 | 82 | 800 |
| Incomplete course | 48 | 71 | 82 | 131 | 137 | 158 | 197 | 145 | 102 | 1,071 |
| Given but details unknown | 12 | 27 | 29 | 32 | 48 | 73 | 64 | 19 | 19 | 323 |
| Not stated or clinical trial | 1 | 3 | 1 | 1 | 3 | 9 | 6 | 10 | 17 | 51 |
| **Total** | **136** | **193** | **232** | **288** | **343** | **452** | **508** | **608** | **796** | **3,556** |
| | | | | | | **Per cent** | | | | |
| None | 23.0 | 18.9 | 16.0 | 17.1 | 17.4 | 17.2 | 22.9 | 55.5 | 73.9 | 37.4 |
| Complete course | 32.6 | 29.5 | 35.9 | 26.1 | 28.2 | 30.7 | 25.1 | 17.1 | 10.5 | 22.8 |
| Incomplete course | 35.6 | 37.4 | 35.5 | 45.6 | 40.3 | 35.7 | 39.2 | 24.2 | 13.1 | 30.6 |
| Given but details unknown | 8.9 | 14.2 | 12.6 | 11.1 | 14.1 | 16.5 | 12.7 | 3.2 | 2.4 | 9.2 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

***Note:*** *Not stated and clinical trial data are excluded from per cent calculations.*
*Maternal data for babies of a multiple birth are presented for each registrant.*

## Multiple 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 2021, 16.3% of ANZNN registrants were reported as being from a multiple gestation pregnancy, and of these, the greatest percentage were twins (92.7%). Of the 2021 ANZNN registrants from multiple gestation pregnancies, 48.1% were born before 32 weeks gestation and 96.6% were born before 37 weeks gestation (Table 7). The 10-year trend (2012–2021) for multiple gestation pregnancies is represented by Figure 13 in Appendix 1.

**TABLE 7: Plurality of level III registrants by gestational age, ANZNN 2021**

| | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Plurality** | **<24** | **24–25** | **26–27** | **28–29** | **30–31** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | **Number** | | | | |
| Singletons | 101 | 313 | 464 | 717 | 1,005 | 1,072 | 1,820 | 4,748 | 10,240 |
| Twins | n.p. | 103 | 154 | 227 | 350 | 439 | n.p. | 68 | 1,842 |
| Triplets and higher orders | <5 | 9 | 13 | 16 | 49 | 42 | n.p. | 0 | 145 |
| **Total** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | **Per cent** | | | | |
| Singletons | 74.3 | 73.6 | 73.5 | 74.7 | 71.6 | 69.0 | 79.1 | 98.6 | 83.7 |
| Twins | n.p. | 24.2 | 24.4 | 23.6 | 24.9 | 28.3 | n.p. | 1.4 | 15.1 |
| Triplets and higher orders | n.p. | 2.1 | 2.1 | 1.7 | 3.5 | 2.7 | n.p. | 0.0 | 1.2 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

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

## 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 three in five (61.3%) of the 2021 registrants, the method of birth was caesarean section with 64.6% of caesarean sections occurring before the onset of labour. One-third of registrants (31.2%) 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 61.3% in 2021.

The most common method of birth for registrants born before 24 weeks gestation was non-instrumental vaginal birth (67.6%) (Table 8). The 10-year trend (2012–2021) 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 2021**

| | 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 | 92 | n.p. | n.p. | 259 | 400 | 339 | 596 | 1,747 | 3,807 |
| Vaginal instrumental birth | 0 | <5 | n.p. | 18 | 46 | 57 | 119 | 666 | 917 |
| Caesarean section in labour | 23 | 124 | 161 | 224 | 296 | 309 | 458 | 1,054 | 2,649 |
| Caesarean section no labour | 21 | 132 | 251 | 458 | 661 | 848 | 1,125 | 1,344 | 4,840 |
| Not stated | 0 | 1 | 2 | 1 | 1 | 0 | 4 | 5 | 14 |
| **Total** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | **Per cent** | | | | |
| Vaginal birth | 67.6 | n.p. | n.p. | 27.0 | 28.5 | 21.8 | 25.9 | 36.3 | 31.2 |
| Vaginal instrumental birth | 0.0 | n.p. | n.p. | 1.9 | 3.3 | 3.7 | 5.2 | 13.8 | 7.5 |
| Caesarean section in labour | 16.9 | 29.2 | 25.6 | 23.4 | 21.1 | 19.9 | 19.9 | 21.9 | 21.7 |
| Caesarean section no labour | 15.4 | 31.1 | 39.9 | 47.8 | 47.1 | 54.6 | 49.0 | 27.9 | 39.6 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
***Note:*** *Not stated data are excluded from per cent calculations.*

## 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 2021, 82.1% of all babies and 90.3% of babies less than 32 weeks gestation at birth were born in a tertiary centre equipped with an NICU; 16.9% of all ANZNN registrants were born in a non-tertiary hospital; while 1.0% 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 2021**

| | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Level of birth hospital** | **<24** | **24–25** | **26–27** | **28–29** | **30–31** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | **Number** | | | | |
| Tertiary hospital | 126 | 385 | 560 | 870 | 1,265 | 1,310 | 1,878 | 3,628 | 10,022 |
| Non-tertiary hospital | n.p. | 32 | 66 | 80 | 130 | n.p. | 409 | 1,114 | 2,060 |
| Not born in a hospital[(a)] | <5 | 8 | 5 | 10 | 5 | n.p. | 13 | 60 | 120 |
| Not stated | 0 | 0 | 0 | 0 | 4 | 5 | 2 | 14 | 25 |
| **Total** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | **Per cent** | | | | |
| Tertiary hospital | 92.6 | 90.6 | 88.7 | 90.6 | 90.4 | 84.6 | 81.7 | 75.6 | 82.1 |
| Non-tertiary hospital | n.p. | 7.5 | 10.5 | 8.3 | 9.3 | n.p. | 17.8 | 23.2 | 16.9 |
| Not born in a hospital[(a)] | n.p. | 1.9 | 0.8 | 1.0 | 0.4 | n.p. | 0.6 | 1.2 | 1.0 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
*(a) These babies were either born before arrival to hospital or born at home.*
***Note:*** *Not stated data are excluded from per cent calculations.*

## Transport after birth to a level III NICU

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

In 2021, 20.0% of ANZNN registrants were transferred to an NICU after birth. Of these the greatest percentage (84.4%) were transported by a specialist team with 11.2% transported by a non-specialist team (Table 10). The 10-year trend (2012–2021) 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 2021**

| | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Mode of Transport** | **<24** | **24–25** | **26–27** | **28–29** | **30–31** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | **Number** | | | | |
| Not transported | 120 | 382 | 546 | 847 | 1,257 | 1,295 | 1,818 | 3,501 | 9,766 |
| Specialist retrieval team | 10 | 35 | 64 | 78 | 126 | 226 | 420 | 1,106 | 2,065 |
| Non-specialist team | <5 | <5 | 11 | 15 | 13 | 20 | n.p. | 165 | 274 |
| Other | <5 | n.p. | 8 | 17 | 8 | 12 | n.p. | 41 | 109 |
| Not stated | 1 | 1 | 2 | 3 | 0 | 0 | 3 | 3 | 13 |
| **Total** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | **Per cent** | | | | |
| Not transported | 88.9 | 90.1 | 86.8 | 88.5 | 89.5 | 83.4 | 79.1 | 72.7 | 80.0 |
| Specialist retrieval team | 7.4 | 8.3 | 10.2 | 8.2 | 9.0 | 14.6 | 18.3 | 23.0 | 16.9 |
| Non-specialist team | n.p. | n.p. | 1.7 | 1.6 | 0.9 | 1.3 | n.p. | 3.4 | 2.2 |
| Other | n.p. | n.p. | 1.3 | 1.8 | 0.6 | 0.8 | n.p. | 0.9 | 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 99.8% 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 73.1% compared to 78.7% for surviving very preterm babies (born at least 28 weeks and less than 32 weeks gestation).

# 4. Characteristics of level III registrants

## Baby gender

Male births exceeded female births in Australia and New Zealand and accounted for 51.3% of combined live births in both countries in 2021 (Australian Bureau of Statistics 2022; Statistics New Zealand 2022). The percentage was higher among ANZNN registrants with male births representing 57.5%. For registrants born at less than 32 weeks gestation, 54.4% were male; of births at term, 60.8% 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 2021, 11.8% of registrants were intubated in the delivery suite to establish independent respiration and heart rate. For babies born before 32 weeks the percentage was 25.4% and for babies born at term the percentage was 6.6%.

## Apgar score at birth

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

An Apgar score of less than 4 at one minute of age was recorded for 16.0% of ANZNN registrants, with 3.8% of registrants recording an Apgar score of less than 4 at five minutes of age. Among the babies who had low Apgar scores of less than 4 at one minute, 35.6% of babies were born at less than 32 weeks and 39.9% were born at term (Table 11).

**TABLE 11: Apgar scores at birth for level III registrants by gestational age, ANZNN 2021**

| | 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 | 6 | 6 | 7 | 7 | 8 | 8 | **7** |
| **IQR** | 2–5 | 3–6 | 4–7 | 4–8 | 5–8 | 5–9 | 6–9 | 5–9 | **5–9** |
| | | | | | **Apgar score at 5 minutes** | | | | |
| **Median** | 6 | 7 | 8 | 8 | 9 | 9 | 9 | 9 | **8** |
| **IQR** | 4–8 | 6–8 | 7–9 | 7–9 | 8–9 | 7–9 | 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 93.1% of ANZNN registrants in 2021. 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. The 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 36.7°C; the median temperature increased slightly with increasing gestational age at birth. The lowest median temperature recorded was 36.6°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 2021**

| Gestational age (weeks) | Number of babies | Temperature (°C) | |
|---|---|---|---|
| | | Median | Interquartile range |
| <24 | 136 | 36.6 | 36.0–37.0 |
| 24–25 | 425 | 36.7 | 36.1–37.1 |
| 26–27 | 631 | 36.7 | 36.3–37.1 |
| 28–29 | 960 | 36.7 | 36.4–37.1 |
| 30–31 | 1,404 | 36.7 | 36.4–37.1 |
| 32–33 | 1,553 | 36.6 | 36.3–37.0 |
| 34–36 | 2,302 | 36.6 | 36.3–37.0 |
| 37–44 | 4,816 | 36.8 | 36.4–37.1 |
| **Total** | **12,227** | **36.7** | **36.4–37.0** |

## Indication for respiratory support

In 2021, only 2.1% of all ANZNN registrants did not receive any form of respiratory support. For the remaining registrants, hyaline membrane disease (HMD) remained the most common indication for respiratory support at 39.7%. Non-specific respiratory distress accounted for 37.3% of babies, while surgery and meconium aspiration syndrome accounted for 3.3% each (Table 13).

For babies born before 37 weeks gestation, HMD (60.1%) remained the most common indication for respiratory support. For babies born at term, non-specific respiratory distress (51.6%) was the most common indication followed by meconium aspiration syndrome (8.2%) (Table 13). The 10-year trend (2012–2021) 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 2021**

| | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Indication for respiratory support** | **<24** | **24–25** | **26–27** | **28–29** | **30–31** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | **Number** | | | | |
| No respiratory support | 0 | <5 | <5 | <5 | 69 | 66 | 51 | 65 | 255 |
| Non-specific respiratory distress | 0 | 9 | 23 | 52 | 261 | 534 | 1,172 | 2,464 | 4,515 |
| Hyaline membrane disease | 130 | 401 | 598 | 880 | 1,005 | 802 | 639 | 347 | 4,802 |
| Meconium aspiration syndrome | 0 | <5 | 0 | 0 | 0 | <5 | 6 | 393 | 402 |
| Pneumonia | 0 | 0 | 0 | <5 | <5 | <5 | 19 | 183 | 211 |
| Persistent pulmonary hypertension | <5 | <5 | 0 | <5 | 5 | 10 | 32 | 162 | 216 |
| Apnoea | <5 | <5 | <5 | 6 | 11 | 26 | 39 | 56 | 142 |
| Congenital anomaly | 0 | 0 | <5 | <5 | 7 | 22 | 83 | 272 | 388 |
| Other | 1 | 5 | 1 | 3 | 17 | 42 | 92 | 306 | 467 |
| Peri-surgery | 0 | 0 | <5 | <5 | <5 | 21 | 92 | 280 | 397 |
| Newborn encephalopathy | <5 | <5 | <5 | <5 | <5 | 14 | 51 | 243 | 315 |
| Not stated | 1 | 2 | 3 | 7 | 21 | 12 | 26 | 45 | 117 |
| **Total** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | **Per cent** | | | | |
| No respiratory support | 0.0 | n.p. | n.p. | n.p. | 4.9 | 4.2 | 2.2 | 1.3 | 2.1 |
| Non-specific respiratory distress | 0.0 | 2.1 | 3.7 | 5.5 | 18.9 | 34.7 | 51.5 | 51.6 | 37.3 |
| Hyaline membrane disease | 96.3 | 94.8 | 95.2 | 92.3 | 72.7 | 52.0 | 28.1 | 7.3 | 39.7 |
| Meconium aspiration syndrome | 0.0 | n.p. | 0.0 | 0.0 | 0.0 | n.p. | 0.3 | 8.2 | 3.3 |
| Pneumonia | 0.0 | 0.0 | 0.0 | n.p. | n.p. | n.p. | 0.8 | 3.8 | 1.7 |
| Persistent pulmonary hypertension | n.p. | n.p. | 0.0 | n.p. | 0.4 | 0.6 | 1.4 | 3.4 | 1.8 |
| Apnoea | n.p. | n.p. | n.p. | 0.6 | 0.8 | 1.7 | 1.7 | 1.2 | 1.2 |
| Congenital anomaly | 0.0 | 0.0 | n.p. | n.p. | 0.5 | 1.4 | 3.6 | 5.7 | 3.2 |
| Other | 0.7 | 1.2 | 0.2 | 0.3 | 1.2 | 2.7 | 4.0 | 6.4 | 3.9 |
| Peri-surgery | 0.0 | 0.0 | n.p. | n.p. | n.p. | 1.4 | 4.0 | 5.9 | 3.3 |
| Newborn encephalopathy | n.p. | n.p. | n.p. | n.p. | n.p. | 0.9 | 2.2 | 5.1 | 2.6 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
***Note:*** *Not stated data are excluded from per cent calculations.*

## 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 2021, nearly a quarter of ANZNN registrants (23.9%) were administered exogenous surfactant (Table 14). There were 1,954 babies who received intermittent positive pressure ventilation for HMD in 2021. Exogenous surfactant was given to 1,780 of these babies (91.1%). There were 174 babies diagnosed with HMD who were not given exogenous surfactant.

**TABLE 14: Exogenous surfactant use for level III registrants by gestational age, ANZNN 2021**

| Exogenous surfactant | Gestational age (weeks) <24 | 24–25 | 26–27 | 28–29 | 30–31 | 32–33 | 34–36 | 37–44 | Total |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | **Number** | | | | |
| None | <5 | 23 | 146 | 444 | 985 | n.p. | 2,008 | 4,491 | 9,300 |
| Surfactant given | 135 | 402 | 485 | 516 | 419 | 351 | 294 | 325 | 2,927 |
| ▪ via endotracheal tube | 128 | 331 | 357 | 373 | 279 | 256 | 217 | 267 | 2,208 |
| ▪ via catheter | n.p. | 57 | 115 | 133 | 130 | n.p. | 60 | 34 | 620 |
| ▪ via other or unknown method | <5 | 14 | 13 | 10 | 10 | n.p. | 17 | 24 | 99 |
| **Total** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | **Per cent** | | | | |
| None | n.p. | 5.4 | 23.1 | 46.3 | 70.2 | n.p. | 87.2 | 93.3 | 76.1 |
| Surfactant given | 99.3 | 94.6 | 76.9 | 53.8 | 29.8 | 22.6 | 12.8 | 6.7 | 23.9 |
| ▪ via endotracheal tube | 94.1 | 77.9 | 56.6 | 38.9 | 19.9 | 16.5 | 9.4 | 5.5 | 18.1 |
| ▪ via catheter | n.p. | 13.4 | 18.2 | 13.9 | 9.3 | n.p. | 2.6 | 0.7 | 5.1 |
| ▪ via other or unknown method | n.p. | 3.3 | 2.1 | 1.0 | 0.7 | n.p. | 0.7 | 0.5 | 0.8 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
***Note:*** *Not stated data are excluded from per cent calculations.*

## Type of assisted ventilation

Assisted ventilation requires specialised nursing, medical and paramedical care and utilises a large component of the available resources. Of the babies registered to the ANZNN in 2021, 97.6% required assisted ventilation for four or more hours.

Two major groups of assisted ventilation are used, those given via endotracheal tube (intermittent positive pressure ventilation (IPPV)) and those without endotracheal tube (continuous positive airway pressure (CPAP), nasal ventilation and nasal high flow (NHF)). For the purposes of this audit, CPAP includes nasal ventilation (CPAP with ventilator breaths). The 10-year trend (2012–2021) for assisted ventilation is represented in Figures 17 to 19 in Appendix 1.

In 2021, IPPV was given for a total of 529,010 hours to ANZNN registrants, CPAP was given for 2,080,446 hours and NHF for 1,212,780 hours. The total number of hours of ventilation equates to each baby receiving 13.0 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 2021 remains CPAP with 48.3% of registrants receiving CPAP only, 4.1% receiving NHF only, 6.6% receiving IPPV only and 23.0% received both invasive (IPPV) and non-invasive (CPAP or NHF) ventilation.

In addition to IPPV, CPAP and NHF, 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 2021, 23.5% of registrants who received IPPV also received HFOV. The use of HFOV among individual units varied between 0.9% and 14.6% with the highest percentage of babies receiving HFOV born at less than 24 weeks (77.0%) followed by babies born at 24–25 weeks gestation (57.4%) (Table 16). The 10-year trend (2012–2021) 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 2021**

| Duration of assisted ventilation | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | <24 | 24–25 | 26–27 | 28–29 | 30–31 | 32–33 | 34–36 | 37–44 | Total |
| | | | | | IPPV (hours) | | | | |
| **Median** | 344.5 | 226 | 57 | 27 | 24 | 33 | 50 | 57 | **54** |
| **IQR** | 88–760 | 67–513 | 19–196 | 12–106 | 12–62 | 13–83 | 19–112 | 25–110 | **20–145** |
| | | | | | CPAP (hours) | | | | |
| **Median** | 1,133 | 1,227.5 | 947 | 331.5 | 92 | 40 | 24 | 17 | **38** |
| **IQR** | 649–1,495 | 912.5–1,516 | 590–1,258 | 135–731 | 38–170 | 19–87 | 12–52 | 8–36 | **14–128** |
| | | | | | NHF (hours) | | | | |
| **Median** | 507 | 431 | 442.5 | 416 | 192.5 | 104 | 58 | 41 | **161** |
| **IQR** | 382–760 | 286–648 | 277–672.5 | 235–674 | 97.5–408 | 53–209 | 24–115 | 19–93 | **50–431** |

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

In 2021, 28 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 (32.6%) (Table 16). The 10-year trend (2012–2021) for nitric oxide is represented in Figure 21 in Appendix 1.

**TABLE 16: Assisted ventilation for level III registrants by gestational age, ANZNN 2021**

| Ventilation type | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | <24 | 24–25 | 26–27 | 28–29 | 30–31 | 32–33 | 34–36 | 37–44 | Total |
| | | | | | Number | | | | |
| Invasive ventilation | 135 | 397 | 418 | 391 | 290 | 304 | 462 | 1,238 | 3,635 |
| ▪ HFOV given | 104 | 228 | 144 | 86 | 45 | 39 | 45 | 167 | 858 |
| ▪ IPPV given | 135 | 396 | 418 | 390 | 289 | 304 | 461 | 1,236 | 3,629 |
| Nitric oxide given | 44 | 87 | 59 | 47 | 27 | 24 | 59 | 308 | 655 |
| CPAP given | 75 | 360 | 606 | 941 | 1,277 | 1,378 | 1,927 | 3,819 | 10,383 |
| NHF given | 61 | 283 | 511 | 722 | 589 | 405 | 489 | 1,083 | 4,143 |
| **Total in each age group** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | Per cent | | | | |
| IPPV given | 99.3 | 93.2 | 66.2 | 40.6 | 20.6 | 19.6 | 20.0 | 25.7 | 29.7 |
| CPAP given | 55.1 | 84.7 | 96.0 | 98.0 | 91.0 | 88.7 | 83.7 | 79.3 | 84.9 |
| NHF given | 44.9 | 66.6 | 81.0 | 75.2 | 42.0 | 26.1 | 21.2 | 22.5 | 33.9 |
| | | | | | Per cent of babies given invasive ventilation | | | | |
| HFOV given[(a)] | 77.0 | 57.4 | 34.4 | 22.0 | 15.5 | 12.8 | 9.7 | 13.5 | 23.6 |
| Nitric oxide given[(a)] | 32.6 | 21.9 | 14.1 | 12.0 | 9.3 | 7.9 | 12.8 | 24.9 | 18.0 |

*(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. NHF = nasal high flow.*

## 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 3,556 babies born before 32 weeks gestation, 97.6% were given assisted ventilation in the form of IPPV, CPAP or NHF. For registrants in this age group CPAP was the only form of ventilation for 21.7%, NHF was the only form of ventilation for 1.0% and IPPV was the only form of ventilation for 4.8% of registrants. Both invasive (IPPV) and non-invasive (CPAP or NHF) were given to 41.0% of registrants.

The total duration of IPPV for these very preterm babies was 330,155 hours, the duration of CPAP was 1,692,700 hours and the duration of NHF was 978,795 hours.

Of the babies born before 32 weeks gestational age and given IPPV in 2021, 37.1% were given HFOV while 16.2% of these babies were given nitric oxide (Table 16).

Among 2020 ANZNN registrants born at less than 32 weeks gestation, 3,336 (93.8%) survived to day 28. Of these, 58.7% of registrants received respiratory support (airway support or supplemental oxygen therapy) at 28 days of age, with 17.5% 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, 96.8% received assisted ventilation. Non-specific respiratory distress was the main reason for ventilation. Total duration of IPPV use by registrants in this gestational age group was 76,587 hours, CPAP use was 207,137 hours and 128,435 hours for NHF.

Of the babies born at 32–36 weeks gestation and given IPPV in 2021, 10.8% were given HFOV while 10.8% 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 (51.2%). This group required 122,268 hours of IPPV, 180,609 hours of CPAP and 105,550 hours of NHF.

Of the babies born at term and given IPPV in 2021, 13.3% were given HFOV while 24.9% of these babies were given nitric oxide (Table 16). There were 26 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 2021 ANZNN registrants, 11,856 babies survived to day 28 and of these, 19.8% 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, 18.3% 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 2021**

| Respiratory support (airway support or oxygen) | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | <24 | 24–25 | 26–27 | 28–29 | 30–31 | 32–33 | 34–36 | 37–44 | Total |
| | | | | | Number | | | | |
| No respiratory support on day 28 | 0 | <5 | 20 | 239 | 1,079 | 1,387 | n.p. | 4,520 | 9,409 |
| Respiratory support on day 28 | 73 | n.p. | 578 | 698 | 313 | 140 | n.p. | 203 | 2,445 |
| ▪ survived to discharge home | 67 | 313 | 563 | 689 | 308 | 133 | 98 | 184 | 2,355 |
| ▪ died before discharge | 6 | n.p. | 15 | 9 | 5 | 7 | n.p. | 19 | 90 |
| Not stated | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 2 |
| **Total in each age group** | **73** | **336** | **598** | **937** | **1,392** | **1,527** | **2,269** | **4,724** | **11,856** |
| | | | | | Number | | | | |
| Respiratory support on day 28 and given home oxygen | 34 | 95 | 98 | 81 | 34 | 31 | 17 | 32 | 422 |
| | | | | | Per cent | | | | |
| No respiratory support on day 28 | 0.0 | n.p. | 3.3 | 25.5 | 77.5 | 90.8 | n.p. | 95.7 | 79.4 |
| Respiratory support on day 28 | 100.0 | n.p. | 96.7 | 74.5 | 22.5 | 9.2 | n.p. | 4.3 | 20.6 |
| ▪ survived to discharge home | 91.8 | 94.3 | 97.4 | 98.7 | 98.4 | 95.0 | 90.7 | 90.6 | 96.3 |
| ▪ died before discharge | 8.2 | n.p. | 2.6 | 1.3 | 1.6 | 5.0 | n.p. | 9.4 | 3.7 |
| | | | | | Per cent | | | | |
| Respiratory support on day 28 and given home oxygen[(a)] | 50.7 | 30.4 | 17.4 | 11.8 | 11.0 | 23.3 | 17.3 | 17.4 | 17.9 |

*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.*

## 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 3,973 ANZNN registrants born at less than 32 weeks gestation and/or less than 1,500g at birth, 3,431 (86.6%) received parenteral nutrition during admission (Table 18). The median duration of parenteral nutrition reported was 185 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, 11.9% of babies were discharged home on gavage feeds.

**TABLE 18: Parenteral nutrition for level III registrants by gestational age, ANZNN 2021**

| | Gestational age (weeks) | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **Parenteral nutrition** | **<24** | **24** | **25** | **26** | **27** | **28** | **29** | **30** | **31** | **≥32[a]** | **Total** |
| | | | | | | **Number** | | | | | |
| Parenteral nutrition | 126 | 188 | 225 | n.p. | 333 | 437 | n.p. | 505 | 525 | 326 | 3,431 |
| No parenteral nutrition | 10 | 5 | 6 | <5 | 10 | 15 | n.p. | 101 | 268 | 88 | 532 |
| Not stated | 0 | 0 | 1 | 0 | 0 | 0 | 1 | 2 | 3 | 3 | 10 |
| **Total** | **136** | **193** | **232** | **288** | **343** | **452** | **508** | **608** | **796** | **417** | **3,973** |
| | | | | | | **Number** | | | | | |
| Home gavage feeding | 20 | 34 | 47 | n.p. | 45 | 53 | n.p. | 36 | 42 | 30 | 407 |
| | | | | | | **Per cent** | | | | | |
| Parenteral nutrition | 92.6 | 97.4 | 97.4 | n.p. | 97.1 | 96.7 | n.p. | 83.3 | 66.2 | 78.7 | 86.6 |
| No parenteral nutrition | 7.4 | 2.6 | 2.6 | n.p. | 2.9 | 3.3 | n.p. | 16.7 | 33.8 | 21.3 | 13.4 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |
| | | | | | | **Per cent** | | | | | |
| Home gavage feeding[b] | 15.9 | 18.1 | 20.9 | 16.4 | 13.5 | 12.1 | 11.0 | 7.1 | 8.0 | 9.2 | 11.9 |

*n.p. Data not published to maintain confidentiality of small numbers.*
*(a) These babies were less than 1,500g at birth.*
*(b) Denominator is babies who received parenteral nutrition.*
***Note:*** *Not stated data are excluded from per cent calculations.*

## Chronic lung disease

Chronic lung disease (CLD) is 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, 9.5% of babies in 2021 were reported to have had respiratory support at 36 weeks PMA, and of these, 25 (2.2%) 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 24 weeks gestation (91.0%) who survived to 36 weeks PMA (Table 19). Not all babies survived to 36 weeks PMA and therefore CLD status could not be defined in these babies. The 10-year trend (2012-2021) for CLD is represented by Figure 22 in Appendix 1.

**TABLE 19: Chronic lung disease at 36 weeks post menstrual age for level III registrants by gestational age, ANZNN 2021**

| Chronic lung disease (CLD) | Gestational age (weeks) | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | <24 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | 31 | Total |
| | | | | | Number | | | | | |
| No CLD | 7 | 12 | 37 | 90 | 159 | 246 | 339 | 494 | 727 | 2,111 |
| CLD | 61 | 122 | 150 | 162 | 171 | 187 | 150 | 101 | 53 | 1,157 |
| Did not survive to 36 weeks PMA | 66 | 57 | 43 | 33 | 12 | 10 | 14 | <5 | n.p. | 247 |
| Not stated | 2 | 2 | 2 | 3 | 1 | 9 | 5 | n.p. | n.p. | 41 |
| **Total** | **136** | **193** | **232** | **288** | **343** | **452** | **508** | **608** | **796** | **3,556** |
| | | | | | Per cent | | | | | |
| No CLD | 10.3 | 9.0 | 19.8 | 35.7 | 48.2 | 56.8 | 69.3 | 83.0 | 93.2 | 64.6 |
| CLD | 89.7 | 91.0 | 80.2 | 64.3 | 51.8 | 43.2 | 30.7 | 17.0 | 6.8 | 35.4 |
| **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, 387 (10.9%) babies were treated with systemic corticosteroids. Of these, 313 were reported to have had respiratory support at 36 weeks, while 73 (18.9%) 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 20).

**TABLE 20: Pulmonary air leak requiring drainage for level III registrants by gestational age, ANZNN 2021**

| Air leak | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | <24 | 24–25 | 26–27 | 28–29 | 30–31 | 32–33 | 34–36 | 37–44 | Total |
| | | | | | Number | | | | |
| Air leak | 18 | 29 | 23 | 34 | 31 | 49 | 77 | 233 | 494 |
| No air leak | 118 | 396 | 608 | 926 | 1,373 | 1,504 | 2,225 | 4,583 | 11,733 |
| **Total** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | Per cent | | | | |
| Air leak | 13.2 | 6.8 | 3.6 | 3.5 | 2.2 | 3.2 | 3.3 | 4.8 | 4.0 |
| No air leak | 86.8 | 93.2 | 96.4 | 96.5 | 97.8 | 96.8 | 96.7 | 95.2 | 96.0 |
| **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 4.1% of ANZNN registrants in 2021. Of these babies, 48.5% were born at less than 28 weeks gestation, 72.4% were born at less than 32 weeks gestation and 99.0% of registrants survived up to 2 days of life (Table 21). Episodes of both early and late sepsis were reported in nine babies. The 5-year trends (2017–2021) for early and late sepsis are represented by Figure 25 and Figure 26 respectively in Appendix 1.

**TABLE 21: Neonatal sepsis for level III registrants by gestational age, ANZNN 2021**

| | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Sepsis** | **<24** | **24–25** | **26–27** | **28–29** | **30–31** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | **Number** | | | | |
| No sepsis | 85 | 314 | 547 | 882 | 1,361 | 1,516 | 2,267 | 4,748 | 11,720 |
| Sepsis at <48 hrs[a] | 6 | 13 | 5 | 10 | n.p. | n.p. | 10 | 33 | 102 |
| Sepsis at ≥48 hrs[a] | 47 | 102 | 81 | 69 | n.p. | n.p. | 25 | 35 | 414 |
| Babies alive on day 2 | 125 | 407 | 622 | 954 | n.p. | n.p. | 2,296 | 4,793 | 12,147 |
| Babies who did not survive to day 2 | 11 | 18 | 9 | 6 | <5 | <5 | 6 | 23 | 80 |
| **Total in each age group** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | **Per cent** | | | | |
| No sepsis[b] | 62.5 | 73.9 | 86.7 | 91.9 | 96.9 | 97.6 | 98.5 | 98.6 | 95.9 |
| Sepsis at <48 hrs[b] | 4.4 | 3.1 | 0.8 | 1.0 | n.p. | n.p. | 0.4 | 0.7 | 0.8 |
| Sepsis at ≥48 hrs[c] | 37.6 | 25.1 | 13.0 | 7.2 | n.p. | n.p. | 1.1 | 0.7 | 3.4 |

*n.p. Data not published to maintain confidentiality of small numbers.*
*(a) Groups are not mutually exclusive.*
*(b) Denominator is all registrants.*
*(c) Denominator is registrants alive at 48 hours.*

Viral infection for the purposes of this audit is defined as the presence of at least one episode of viral infection with initial symptoms occurring following 48 hours after birth. Symptomatic viral infection was reported in 189 (1.5%) of ANZNN registrants in 2021, 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 2021 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 2021 registrants, 24.1% were eligible for ROP examination and of these eligible registrants, 80.8% were examined and had the results of their eye examination recorded.

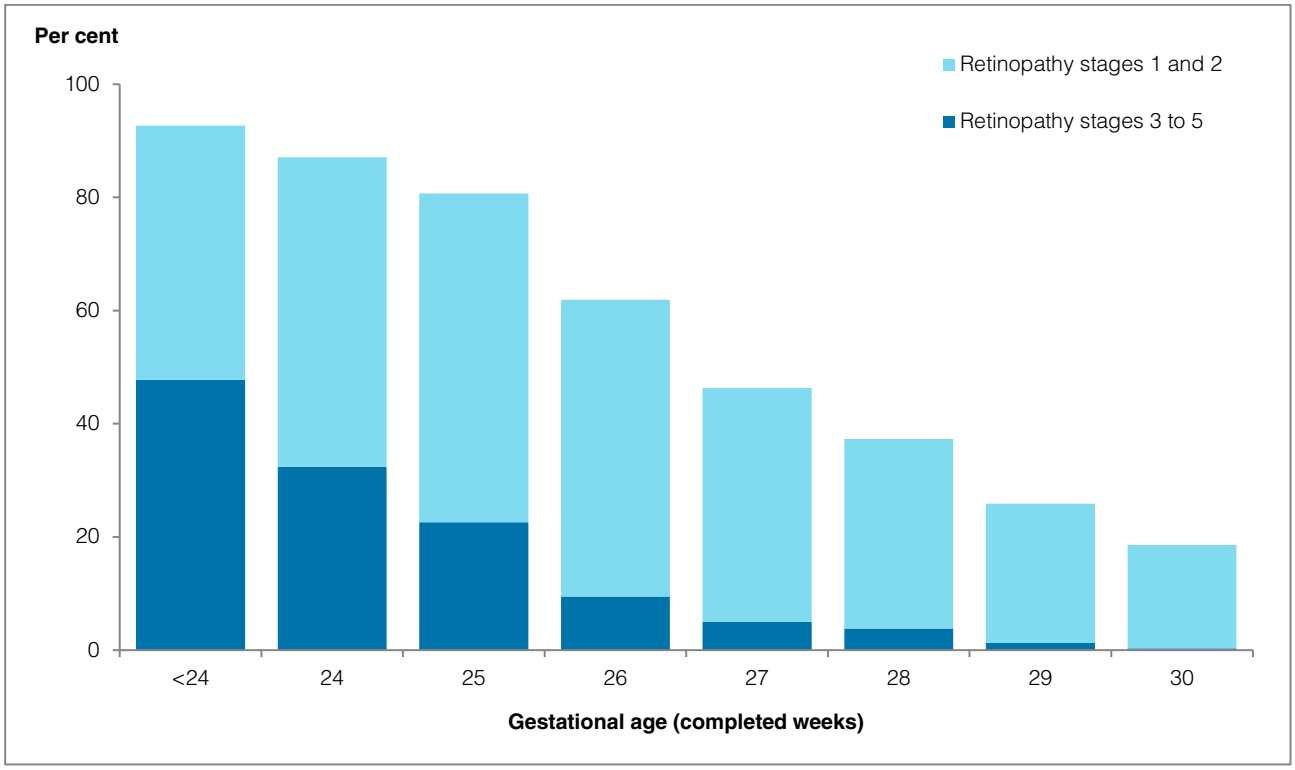
Of those ANZNN registrants who were eligible for an eye examination, 234 died before their ROP status could be determined. Of those examined, 7.7% had stage 3 to 5 ROP (Table 22, Figure 6) and of these babies, 44.3% received surgical treatment. The 10-year trend (2012–2021) for stages 3 to 5 ROP and treatment are represented by Figure 23 in Appendix 1.

**TABLE 22: Retinopathy of prematurity for level III registrants by gestational age, ANZNN 2021**

| Retinopathy of prematurity (ROP) | Gestational age (weeks) | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | <24 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | ≥31[(a)] | Total |
| | Number | | | | | | | | | |
| No ROP | n.p. | n.p. | 36 | 96 | 173 | 264 | n.p. | 315 | 131 | 1,378 |
| Stage 1 | <5 | 18 | 37 | 63 | 71 | n.p. | 81 | 59 | n.p. | 433 |
| Stage 2 | 27 | 58 | n.p. | 69 | 62 | 49 | 32 | n.p. | <5 | 384 |
| Stage 3 | 33 | 43 | 40 | 24 | 16 | 15 | 5 | 0 | 0 | 176 |
| Stage 4 to 5 | 0 | <5 | <5 | 0 | 0 | <5 | <5 | <5 | 0 | 7 |
| Not examined | 67 | 54 | 46 | 36 | 21 | 31 | 49 | 220 | 41 | 565 |
| Not stated | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 |
| **Total** | **136** | **193** | **232** | **288** | **343** | **452** | **508** | **608** | **184** | **2,944** |
| | Per cent | | | | | | | | | |
| No ROP | n.p. | n.p. | 19.4 | 38.1 | 53.7 | 62.7 | n.p. | 81.4 | 91.6 | 57.9 |
| Stage 1 | n.p. | 12.9 | 19.9 | 25.0 | 22.0 | n.p. | 17.6 | 15.2 | n.p. | 18.2 |
| Stage 2 | 39.1 | 41.7 | n.p. | 27.4 | 19.3 | 11.6 | 7.0 | n.p. | n.p. | 16.1 |
| Stage 3 | 47.8 | 30.9 | 21.5 | 9.5 | 5.0 | 3.6 | 1.1 | 0.0 | 0.0 | 7.4 |
| Stage 4 to 5 | 0.0 | n.p. | n.p. | 0.0 | 0.0 | n.p. | n.p. | n.p. | 0.0 | 0.3 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*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 2021**



## 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 3,556 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, of which 3,482 survived to day 3 and 92.8% had an examination recorded. A normal report was recorded for 78.1% of these 2021 ANZNN registrants.

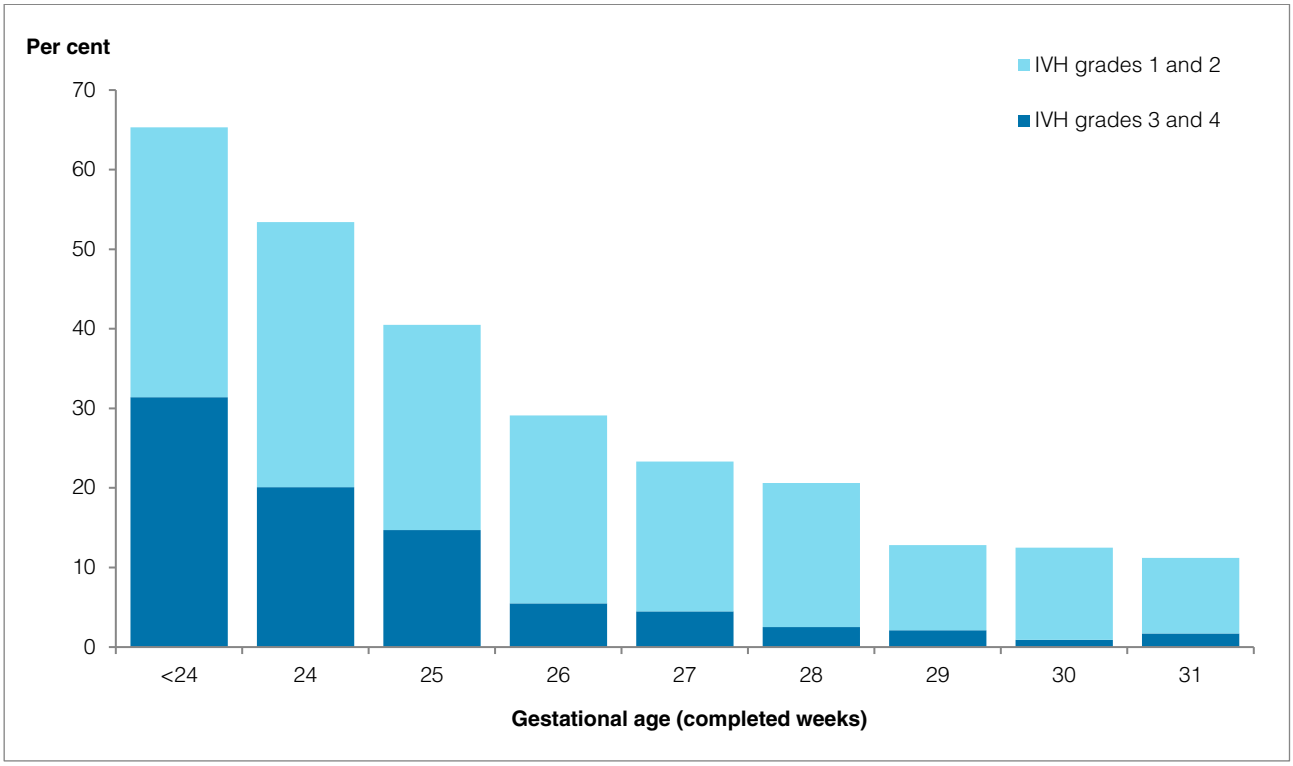
There were 171 babies reported to have grade 3 or 4 IVH representing 4.9% of the babies born before 32 weeks gestation. Of the babies who had a grade 3 IVH, 19.8% were unilateral, while 69.5% of grade 4 IVH cases were unilateral. The incidence of IVH, particularly of severe grades, is shown to be inversely related to gestation. The highest percentage of babies who had grade 4 IVH were born before 26 weeks gestational age, with the majority (69.4%) of these babies born before 25 weeks gestation (Table 23, Figure 7). The 10-year trend (2012–2021) for registrants with grades 3 and 4 IVH who survived to day 3 is represented in Figure 24 in Appendix 1.

**TABLE 23: Intraventricular haemorrhage for level III registrants born before 32 weeks and survived to day 3, by gestational age, ANZNN 2021**

| Intraventricular haemorrhage | Gestational age (weeks) | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | <24 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | 31 | Total |
| | | | | | Number | | | | | |
| None | 41 | 81 | 129 | 195 | 258 | 351 | 425 | 461 | 583 | 2,524 |
| Grade 1 | 12 | 33 | 28 | 39 | 41 | 56 | 36 | 47 | 54 | 346 |
| Grade 2 | 28 | 25 | 28 | n.p. | n.p. | n.p. | 16 | 14 | 8 | 191 |
| Grade 3 | 5 | 8 | 6 | <5 | 5 | <5 | <5 | <5 | 5 | 43 |
| Grade 4 | 32 | 27 | 26 | 11 | 10 | 8 | n.p. | <5 | 6 | 128 |
| Not examined | 2 | 3 | 1 | 4 | 3 | 6 | 14 | 79 | 138 | 250 |
| **Total** | **120** | **177** | **218** | **279** | **339** | **448** | **501** | **606** | **794** | **3,482** |
| | | | | | Per cent | | | | | |
| None | 34.7 | 46.6 | 59.4 | 70.9 | 76.8 | 79.4 | 87.3 | 87.5 | 88.9 | 78.1 |
| Grade 1 | 10.2 | 19.0 | 12.9 | 14.2 | 12.2 | 12.7 | 7.4 | 8.9 | 8.2 | 10.7 |
| Grade 2 | 23.7 | 14.4 | 12.9 | n.p. | n.p. | n.p. | 3.3 | 2.7 | 1.2 | 5.9 |
| Grade 3 | 4.2 | 4.6 | 2.8 | n.p. | n.p. | n.p. | n.p. | n.p. | 0.8 | 1.3 |
| Grade 4 | 27.1 | 15.5 | 12.0 | 4.0 | 3.0 | 1.8 | n.p. | n.p. | 0.9 | 4.0 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
***Note:*** *Not examined data are excluded from per cent calculations.*

**FIGURE 7: Intraventricular haemorrhage in level III registrants born at less than 32 weeks gestation and survived to day 3, by gestational age, ANZNN 2021**




## 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 3,556 babies born at less than 32 weeks gestation eligible for a cerebral ultrasound, 3,482 survived until day 3 and late ultrasound results were available for 2,375 (68.2%) of these babies. A normal report of no cysts was recorded for 96.0% of these registrants, 2.1% reported porencephalic cysts and 1.9% reported periventricular leukomalacia (PVL) (Table 24). Of the 46 babies who were reported with PVL, twelve had extensive leukomalacia involving two or more of the anterior frontal, posterior frontal, parietal, temporal or occipital regions.

**TABLE 24: Late cerebral ultrasound results for level III registrants born before 32 weeks by gestational age, ANZNN 2021**

| Cerebral ultrasound results | Gestational age (weeks) | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **<24** | **24** | **25** | **26** | **27** | **28** | **29** | **30** | **31** | **Total** |
| | | | | | **Number** | | | | | |
| No cysts | 65 | 124 | 160 | 220 | 287 | 368 | 381 | 334 | 339 | 2,278 |
| Porencephalic cysts | <5 | n.p. | 5 | 5 | 8 | 5 | 9 | 6 | 5 | 50 |
| Periventricular leukomalacia | <5 | <5 | 6 | 7 | 5 | 6 | 5 | 5 | 6 | 46 |
| Not stated | 68 | 59 | 61 | 56 | 43 | 73 | 113 | 263 | 446 | 1,182 |
| **Total** | **136** | **193** | **232** | **288** | **343** | **452** | **508** | **608** | **796** | **3,556** |
| | | | | | **Per cent** | | | | | |
| No cysts | 95.6 | 92.5 | 93.6 | 94.8 | 95.7 | 97.1 | 96.5 | 96.8 | 96.9 | 96.0 |
| Porencephalic cysts | n.p. | n.p. | 2.9 | 2.2 | 2.7 | 1.3 | 2.3 | 1.7 | 1.4 | 2.1 |
| Periventricular leukomalacia | n.p. | n.p. | 3.5 | 3.0 | 1.7 | 1.6 | 1.3 | 1.4 | 1.7 | 1.9 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
***Note:*** *Not stated data are excluded from per cent calculations.*

## Therapeutic hypothermia

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

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 2021, 351 (5.6%) of the ANZNN registrants born at more than 34 weeks gestation received therapeutic hypothermia, and of these, 84.3% were cooled for at least 72 hours. Of those babies who did not receive cooling for a full 72 hours, information on the principal reason for non-completion of the full 72 hours of therapeutic hypothermia was available for 82.3% 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 2021, the percentage of babies with confirmed NEC was 1.2%. Of these babies, 58.6% were born before 28 weeks gestation with 54.1% of them undergoing surgery, and 24.1% were born between 28–31 weeks gestation with surgery required for 45.7% of them. In total, 41 registrants died from NEC. The number of registrants with confirmed NEC was more than in 2020 (Table 25).

**TABLE 25: Necrotising enterocolitis in level III registrants by year of birth, ANZNN 2012–2021**

| | Year of birth | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| **Necrotising enterocolitis** | **2012** | **2013** | **2014** | **2015** | **2016** | **2017** | **2018** | **2019** | **2020** | **2021** |
| | **Number** | | | | | | | | | |
| Babies born at <28 weeks | | | | | | | | | | |
| ▪ NEC | 87 | 75 | 64 | 81 | 91 | 105 | 96 | 79 | 92 | 85 |
| ▪ No NEC | 980 | 1,015 | 1,039 | 981 | 1,126 | 1,046 | 1,051 | 1,103 | 1,046 | 1,107 |
| ▪ Not stated | 2 | 0 | 3 | 4 | 2 | 0 | 0 | 0 | 0 | 0 |
| Babies born at 28-31 weeks | | | | | | | | | | |
| ▪ NEC | 35 | 27 | 21 | 40 | 37 | 25 | 28 | 30 | 29 | 35 |
| ▪ No NEC | 2,417 | 2,384 | 2,484 | 2,383 | 2,353 | 2,325 | 2,242 | 2,203 | 2,245 | 2,329 |
| ▪ Not stated | 2 | 0 | 2 | 6 | 1 | 1 | 0 | 0 | 0 | 0 |
| Babies born at ≥32 weeks | | | | | | | | | | |
| ▪ NEC | 14 | 19 | 26 | 27 | 30 | 27 | 30 | 28 | 17 | 25 |
| ▪ No NEC | 5,778 | 6,200 | 6,515 | 6,267 | 6,832 | 7,151 | 7,201 | 7,752 | 8,097 | 8,646 |
| ▪ Not stated | 3 | 1 | 4 | 9 | 1 | 1 | 3 | 0 | 0 | 0 |
| **Total in each birth year** | **9,318** | **9,721** | **10,158** | **9,798** | **10,473** | **10,681** | **10,651** | **11,195** | **11,526** | **12,227** |
| | **Per cent** | | | | | | | | | |
| NEC <28 weeks[(a)] | 8.2 | 6.9 | 5.8 | 7.6 | 7.5 | 9.1 | 8.4 | 6.7 | 8.1 | 7.1 |
| NEC 28-31 weeks[(b)] | 1.4 | 1.1 | 0.8 | 1.7 | 1.5 | 1.1 | 1.2 | 1.3 | 1.3 | 1.5 |
| NEC ≥32 weeks[(c)] | 0.2 | 0.3 | 0.4 | 0.4 | 0.4 | 0.4 | 0.4 | 0.4 | 0.2 | 0.3 |

*(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 2021, 62 (0.5%) of ANZNN registrants had a confirmed diagnosis of spontaneous intestinal perforation. Of these, two babies were also reported to have a confirmed NEC diagnosis. Of babies born before 28 weeks gestation, 36 (3.0%) 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 2021, there were 1,064 ANZNN registrants who had major surgery, of whom over half (53.7%) were born at term. Of registrants born in a hospital, 75.7% were born in a hospital with tertiary care facilities. Of registrants who had major surgery, 70.0% also had a congenital anomaly present with 61.2% of these diagnosed during the antenatal period. 7.2% had surgery for proven NEC. The median length of stay for survivors was 40 days (Table 26).

**TABLE 26: Characteristics of level III registrants who underwent surgery by gestational age, ANZNN 2021**

| | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Characteristics** | **<24** | **24–25** | **26–27** | **28–29** | **30–31** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | **Number** | | | | |
| Male | 7 | 46 | 37 | 37 | 17 | 37 | 113 | 329 | 623 |
| Female | 8 | 29 | 22 | 19 | 15 | 24 | 82 | 242 | 441 |
| Congenital anomaly present | <5 | n.p. | 8 | 13 | 15 | 35 | 156 | 507 | 745 |
| Congenital anomaly diagnosed antenatally | 0 | 0 | <5 | n.p. | 8 | 21 | 115 | 302 | 456 |
| Proven NEC | 6 | 27 | 13 | 14 | <5 | 5 | 6 | <5 | 77 |
| Hospital of birth: | | | | | | | | | |
| ▪ Tertiary | n.p. | 64 | 49 | n.p. | 26 | n.p. | 151 | 380 | 786 |
| ▪ Non-tertiary | <5 | 8 | 8 | <5 | 6 | n.p. | 43 | 175 | 252 |
| Median length of stay for survivors (days) | 141 | 142 | 119 | 95 | 79 | 59 | 38 | 25 | 40 |
| Died before discharge home | 5 | 17 | 5 | 5 | <5 | <5 | 6 | 19 | 63 |
| **Total in each age group** | **15** | **75** | **59** | **56** | **32** | **61** | **195** | **571** | **1,064** |
| | | | | | **Per cent** | | | | |
| Male | 46.7 | 61.3 | 62.7 | 66.1 | 53.1 | 60.7 | 57.9 | 57.6 | 58.6 |
| Female | 53.3 | 38.7 | 37.3 | 33.9 | 46.9 | 39.3 | 42.1 | 42.4 | 41.4 |
| Congenital anomaly present | n.p. | n.p. | 13.6 | 23.2 | 46.9 | 57.4 | 80.0 | 88.8 | 70.0 |
| Congenital anomaly diagnosed antenatally | 0.0 | 0.0 | n.p. | n.p. | 25.0 | 34.4 | 59.0 | 52.9 | 42.9 |
| Proven NEC | 40.0 | 36.0 | 22.0 | 25.0 | n.p. | 8.2 | 3.1 | n.p. | 7.2 |
| Hospital of birth: | | | | | | | | | |
| ▪ Tertiary | n.p. | 85.3 | 83.1 | n.p. | 81.3 | n.p. | 77.4 | 66.5 | 73.9 |
| ▪ Non-tertiary | n.p. | 10.7 | 13.6 | n.p. | 18.8 | n.p. | 22.1 | 30.6 | 23.7 |
| Died before discharge home | 33.3 | 22.7 | 8.5 | 8.9 | n.p. | n.p. | 3.1 | 3.3 | 5.9 |

*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 2021 surgical cohort, 8.9% of pregnancies resulted from assisted conception, compared with 8.5% in the whole cohort. Of the 2021 ANZNN registrants who received major surgery, gastrointestinal procedures were the most commonly performed (64.3%) followed by cardiac procedures (20.7%).

There were 101 (0.8%) babies born in 2021 who received surgery to repair a gastroschisis before discharge to home. Just over half of these babies were male (51.5%) and three in five were born at more than 35 weeks gestation (60.4%). In 2021, 58 babies received surgery to repair a congenital diaphragmatic hernia, of which 46.6% were male and 70.7% were born at more than 37 weeks gestation.

## Congenital anomalies

In 2021, 1,430 ANZNN registrants (11.7%) had one or more major congenital anomalies. For registrants who had a major congenital anomaly, 13.4% were born before 32 weeks gestation, 28.0% were born between 32 and 36 weeks gestation and nearly three in five of registrants (58.5%) were born at term.

Of the ANZNN registrants with major congenital anomalies, half (50.2%) 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 (55.7%).

## Transfer from level III NICUs to other units

Once intensive care is no longer required, babies are often 'down' transferred to a level II unit, sometimes referred to as a 'special care baby unit', either within the same hospital or to another hospital for convalescence before discharge home. In 2021, three in ten ANZNN registrants (29.8%) 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). Over two in five registrants (43.7%) transferred from level III to level II or level I units were born at less than 32 weeks gestation compared to 17.3% born at term.

Some level III registrants required transfer to a specialist children's hospital and in 2021 these accounted for 4.4% of registrants. Overall, 63.3% of level III registrants were not transferred after registration (Table 27).

**TABLE 27: Transfer after registration of level III registrants by level of destination hospital and gestational age, ANZNN 2021**

| | Gestational age (weeks) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Transfer status** | **<24** | **24–25** | **26–27** | **28–29** | **30–31** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | **Number** | | | | |
| Not transferred | 91 | 259 | 297 | 411 | 544 | 750 | 1,480 | 3,910 | 7,742 |
| Level III hospital | 10 | 22 | 52 | 45 | 39 | 43 | 37 | 49 | 297 |
| Level II or I hospital | 22 | 93 | 233 | 452 | 795 | 724 | 698 | 630 | 3,647 |
| Children's hospital | 13 | 51 | 49 | 52 | 26 | 35 | 86 | 226 | 538 |
| Not stated | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 1 | 3 |
| **Total** | **136** | **425** | **631** | **960** | **1,404** | **1,553** | **2,302** | **4,816** | **12,227** |
| | | | | | **Per cent** | | | | |
| Not transferred | 66.9 | 60.9 | 47.1 | 42.8 | 38.7 | 48.3 | 64.3 | 81.2 | 63.3 |
| Level III hospital | 16.2 | 21.9 | 36.9 | 47.1 | 56.6 | 46.6 | 30.3 | 13.1 | 2.4 |
| Level II or I hospital | 7.4 | 5.2 | 8.2 | 4.7 | 2.8 | 2.8 | 1.6 | 1.0 | 29.8 |
| Children's hospital | 9.6 | 12.0 | 7.8 | 5.4 | 1.9 | 2.3 | 3.7 | 4.7 | 4.4 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

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

## Length of stay until discharge home

Factors that influence a baby's length of stay 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 99.0% of ANZNN registrants in 2021 who survived to discharge to home. The median length of stay was 22 days with an interquartile range of 7–48 days (Table 28). 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 239,598 days in hospital, babies born between 32 and 36 weeks spent 99,884 days and babies born at term spent 59,167 days in hospital.

**TABLE 28: Length of stay for level III registrants who survived until discharge home by gestational age, ANZNN 2021**

| Gestational age (weeks) | Number of babies | Median length of stay (days) | Interquartile range (days) |
|---|---|---|---|
| <24 | 67 | 137 | 123–162 |
| 24 | 129 | 124 | 111–145 |
| 25 | 187 | 110 | 99–131 |
| 26 | 255 | 99 | 86–116 |
| 27 | 328 | 86 | 75–99 |
| 28 | 439 | 73 | 64–86 |
| 29 | 489 | 61 | 53–73 |
| 30 | 601 | 50 | 43–60 |
| 31 | 786 | 41 | 35–51 |
| 32 | 800 | 35 | 29–44 |
| 33 | 720 | 26 | 21–34 |
| 34 | 793 | 21 | 16–28 |
| 35 | 691 | 14 | 9–21 |
| 36 | 775 | 10 | 6–18 |
| 37 | 975 | 7 | 4–16 |
| 38 | 1224 | 6 | 3–14 |
| 39 | 1142 | 5 | 3–12 |
| 40 | 801 | 5 | 3–10 |
| 41 | 512 | 5 | 3–9 |
| ≥42 | 50 | 6 | 4–10 |
| **Total** | **11,764** | **22** | **7–48** |

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

## Survival

In 2021, 96.2% 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 29, 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 2021, there were 463 neonatal deaths, of which 228 occurred in the early neonatal period that is within seven days of birth (Table 29). Mortality was highest among babies born before 28 weeks gestation with a survival rate at discharge increasing week on week from 49.3% for babies born before 24 weeks to 95.6% for babies born at 27 weeks (Table 29, Figure 8). A similar pattern of increasing survival with increasing birthweight is seen in Figure 9. The 10-year trend (2012–2021) for survival to discharge to home of registrants is represented in Figure 27 in Appendix 1.

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 29).

**TABLE 29: Survival to discharge home for level III registrants by gestational age, ANZNN 2021**

| 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 | 136 | 0 | 98 | 73 | 67 | 49.3 |
| 24 | 193 | <5 | 169 | 145 | 129 | 66.8 |
| 25 | 232 | <5 | 209 | 191 | 187 | 80.6 |
| 26 | 288 | <5 | 270 | 265 | 255 | 88.5 |
| 27 | 343 | <5 | 337 | 333 | 328 | 95.6 |
| 28 | 452 | 0 | 445 | 442 | 439 | 97.1 |
| 29 | 508 | <5 | 500 | 495 | 489 | 96.3 |
| 30 | 608 | <5 | 605 | 604 | 601 | 98.8 |
| 31 | 796 | <5 | 792 | 788 | 786 | 98.7 |
| 32 | 817 | 9 | 806 | 804 | 800 | 97.9 |
| 33 | 736 | 11 | 730 | 723 | 720 | 97.8 |
| 34 | 806 | 6 | 801 | 798 | 793 | 98.4 |
| 35 | 704 | 8 | 697 | 693 | 691 | 98.2 |
| 36 | 792 | 9 | 785 | 778 | 775 | 97.9 |
| 37 | 1000 | 15 | 990 | 981 | 975 | 97.5 |
| 38 | 1254 | 11 | 1239 | 1229 | 1224 | 97.6 |
| 39 | 1170 | 6 | 1157 | 1149 | 1142 | 97.6 |
| 40 | 819 | <5 | 805 | 803 | 801 | 97.8 |
| 41 | 523 | <5 | 514 | 512 | 512 | 97.9 |
| ≥42 | 50 | 0 | 50 | 50 | 50 | 100.0 |
| **Total** | **12,227** | **92** | **11,999** | **11,856** | **11,764** | **96.2** |

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

**FIGURE 8: Survival of level III registrants to discharge home (with 95% CI) by gestational age, ANZNN 2021**

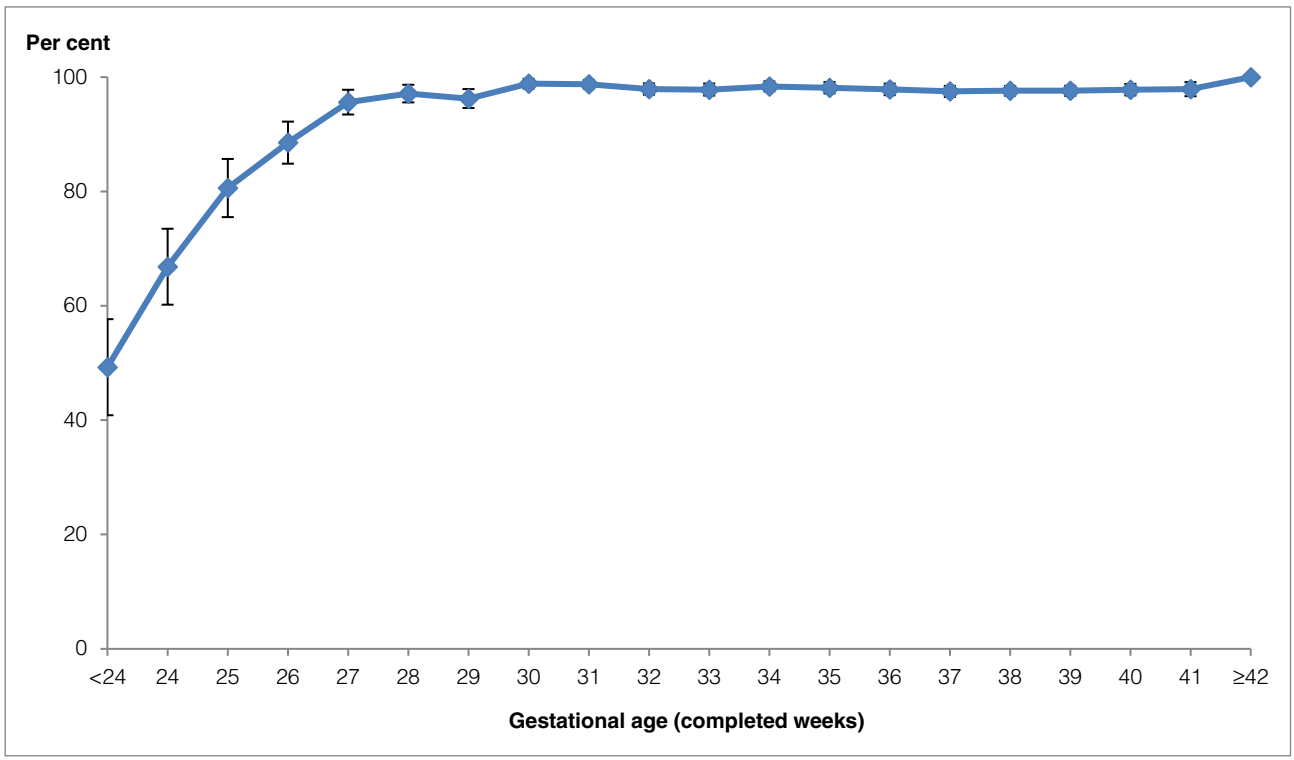
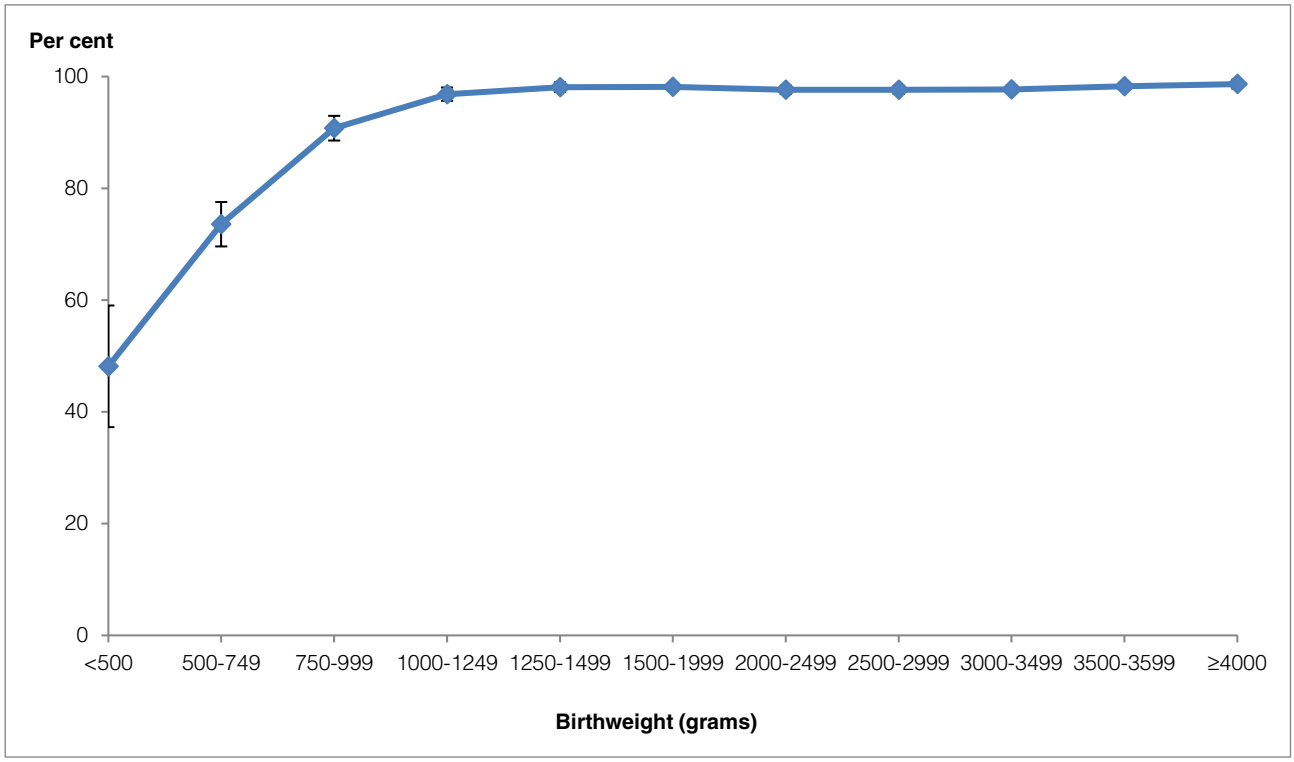



**FIGURE 9: Survival of level III registrants to discharge home (with 95% CI) by birthweight group, ANZNN 2021**



# 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 19 in Australia that are members of the ANZNN. Altogether, 27 level II units contributed data for this 2021 report.

In 2021, 1,969 babies fulfilled the ANZNN criteria for registration to a level II unit. Of those babies, 4.0% were born at less than 32 weeks gestation and 2.5% weighed less than 1,500 grams at birth (Table 30 and Table 31). The highest number of babies registered to a level II unit in 2021 was just over 190.

**TABLE 30: Level II registrants by gestational age, ANZNN 2021**

| Gestational age (weeks) | Number of babies | Per cent | Cumulative per cent |
|---|---|---|---|
| <30 | 13 | 0.7 | 0.7 |
| 30–31 | 65 | 3.3 | 4.0 |
| **All babies <32 weeks gestation** | **78** | **4.0** | |
| 32–33 | 221 | 11.2 | 15.2 |
| 34–36 | 515 | 26.2 | 41.3 |
| 37–44 | 1155 | 58.7 | 100.0 |
| **Total** | **1,969** | **100.0** | |

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

**TABLE 31: Level II registrants by birthweight, ANZNN 2021**

| Birthweight (grams) | Number of babies | Per cent | Cumulative per cent |
|---|---|---|---|
| <1,300 | 10 | 0.5 | 0.5 |
| 1,300–1,399 | 14 | 0.7 | 1.2 |
| 1,400–1,499 | 25 | 1.3 | 2.5 |
| **All babies <1,500g birthweight** | **49** | **2.5** | |
| 1,500–1,999 | 192 | 9.8 | 12.2 |
| 2,000–2,499 | 312 | 15.8 | 28.1 |
| 2,500–2,999 | 369 | 18.7 | 46.8 |
| 3,000–3,499 | 413 | 21.0 | 67.8 |
| 3,500–3,999 | 387 | 19.7 | 87.5 |
| ≥4,000 | 247 | 12.5 | 100.0 |
| **Total** | **1,969** | **100.0** | |

***Note:*** *Birthweight groups below 1,300g have been combined to maintain confidentiality of small numbers.*
*Birthweight was not provided for one baby.*

Of the level II registrants in 2021, 1,064 babies (54.0%), were born to Caucasian mothers, 42.6% of whom were born preterm. The number of registrants born to Maori mothers was 254 (12.9%), and of these, 107 (42.1%) were born preterm. There were 48 babies (2.4%) born to Pacific Islander mothers.

There were 1,196 male (60.7%) and 771 female (39.2%) registrants in the audit. Sex was not recorded for two 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, 33.0% did not present with any maternal complications. Among babies born before 37 weeks, 34.4% of mothers had presented with preterm labour (Table 32).

**TABLE 32: Mothers of level II registrants presenting antenatal problem by gestational age, ANZNN 2021**

| | Gestational age (weeks) | | | | |
|---|---|---|---|---|---|
| **Presenting antenatal problem** | **<32** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | |
| No antenatal problems | 0 | 0 | 0 | 640 | 640 |
| Preterm pre-labour rupture of membranes | 13 | 62 | 123 | 17 | 215 |
| Preterm labour | 39 | 72 | 169 | 0 | 280 |
| Hypertension in pregnancy | 10 | 31 | 56 | 49 | 146 |
| Antepartum haemorrhage | 9 | 29 | 48 | 16 | 102 |
| Intrauterine growth restriction | 0 | 9 | 25 | 35 | 69 |
| Fetal distress | 5 | 9 | 43 | 157 | 214 |
| Other problem | 1 | n.p. | n.p. | n.p. | n.p. |
| Congenital anomalies | 0 | <5 | <5 | <5 | <5 |
| Not stated | 1 | 0 | 3 | 28 | 32 |
| **Total** | **78** | **221** | **515** | **1155** | **1,969** |
| | | | **Per cent** | | |
| No antenatal problems | 0.0 | 0.0 | 0.0 | 56.8 | 33.0 |
| Preterm pre-labour rupture of membranes | 16.9 | 28.1 | 24.0 | 1.5 | 11.1 |
| Preterm labour | 50.6 | 32.6 | 33.0 | 0.0 | 14.5 |
| Hypertension in pregnancy | 13.0 | 14.0 | 10.9 | 4.3 | 7.5 |
| Antepartum haemorrhage | 11.7 | 13.1 | 9.4 | 1.4 | 5.3 |
| Intrauterine growth restriction | 0.0 | 4.1 | 4.9 | 3.1 | 3.6 |
| Fetal distress | 6.5 | 4.1 | 8.4 | 13.9 | 11.0 |
| Other problem | 1.3 | n.p. | n.p. | n.p. | n.p. |
| Congenital anomalies | 0.0 | n.p. | n.p. | n.p. | n.p. |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
***Note:*** *Not stated data are excluded from per cent calculations.*
*Maternal data for babies of a multiple birth are presented for each registrant.*

Previous preterm births were reported by 175 (8.9%) mothers of level II registrants and 40 (2.0%) mothers had had a previous perinatal death(s).

Most mothers (91.0%) of level II registrants had booked into a level II hospital for delivery. Of the level II registrants born before 34 weeks gestation, 71.9% of the mothers were given antenatal corticosteroids within seven days prior to the birth (Table 33).

**TABLE 33: Antenatal corticosteroid use by mothers of level II registrants by gestational age, ANZNN 2021**

| | Gestational age (weeks) | | | | |
|---|---|---|---|---|---|
| **Antenatal corticosteroids** | **<32** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | |
| None | 15 | 44 | 318 | 1,127 | 1,504 |
| Incomplete course | 28 | 81 | n.p. | <5 | 186 |
| Complete course within 7 days of birth | 26 | 80 | n.p. | n.p. | 206 |
| Given >7 days prior to birth | 6 | 14 | n.p. | <5 | 38 |
| Not stated | 3 | 2 | 18 | 12 | 35 |
| **Total** | **78** | **221** | **515** | **1155** | **1,969** |
| | | | **Per cent** | | |
| None | 20.0 | 20.1 | 64.0 | 98.6 | 77.8 |
| Incomplete course | 37.3 | 37.0 | n.p. | n.p. | 9.6 |
| Complete course within 7 days of birth | 34.7 | 36.5 | n.p. | n.p. | 10.7 |
| Given >7 days prior to birth | 8.0 | 6.4 | n.p. | n.p. | 2.0 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
***Note:*** *Not stated data are excluded from per cent calculations.*
*Maternal data for babies of a multiple birth are presented for each registrant.*

Vaginal and instrumental vaginal delivery were equally as common as caesarean section as the method of birth of level II registrants (Table 34). Of those who were delivered by caesarean section, over half (53.7%) occurred before the onset of labour.

**TABLE 34: Method of delivery for level II registrants by gestational age, ANZNN 2021**

| | Gestational age (weeks) | | | | |
|---|---|---|---|---|---|
| **Method of delivery** | **<32** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | |
| Vaginal birth[(a)] | 26 | 84 | 207 | 647 | 964 |
| Caesarean section[(b)] | 52 | 137 | 308 | 508 | 1005 |
| **Total** | **78** | **221** | **515** | **1155** | **1,969** |
| | | | **Per cent** | | |
| Vaginal birth | 33.3 | 38.0 | 40.2 | 56.0 | 49.0 |
| Caesarean section | 66.7 | 62.0 | 59.8 | 44.0 | 51.0 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*(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.*

## Characteristics of level II babies

Among the 1,969 babies registered to level II units, 179 were from multiple gestation pregnancies (9.1%). There were 1,196 (60.7%) male births and two babies whose gender was not recorded.

A low Apgar score of less than 4 at one minute of age was recorded for 16.2% of babies and 4.2% of them required endotracheal intubation in the labour ward to assist in their adaptation to extrauterine life.

Non-specific respiratory distress (80.4%) was the major reason for assisted ventilation for level II registrants, followed by hyaline membrane disease (8.3%) (Table 35).

For level II registrants, the median duration of assisted ventilation by intermittent positive pressure ventilation (IPPV) was 15 hours, 20 hours by continuous positive airway pressure (CPAP) and 45.5 hours by nasal high flow (NHF) (Table 36).

**TABLE 35: Indication for respiratory support for level II registrants by gestational age, ANZNN 2021**

| | Gestational age (weeks) | | | | |
|---|---|---|---|---|---|
| **Indication for respiratory support** | **<32** | **32–33** | **34–36** | **37–44** | **Total** |
| | | | | | |
| No respiratory support | n.p. | <5 | 7 | <5 | 18 |
| Non-specific respiratory distress | 39 | 161 | 422 | 955 | 1,577 |
| Hyaline membrane disease | 31 | 52 | 56 | 24 | 163 |
| Meconium aspiration syndrome | 0 | 0 | <5 | n.p. | 93 |
| Pneumonia | 0 | <5 | <5 | 40 | 45 |
| Persistent pulmonary hypertension | 0 | 0 | <5 | n.p. | n.p. |
| Apnoea | <5 | <5 | 8 | n.p. | 18 |
| Congenital anomaly | 0 | 0 | <5 | 0 | <5 |
| Other | 0 | 1 | 7 | 25 | 33 |
| Peri-surgery | 0 | 0 | 0 | 0 | 0 |
| Newborn encephalopathy | 0 | 0 | <5 | n.p. | 8 |
| Not stated | 1 | 0 | 3 | 3 | 7 |
| **Total** | **78** | **221** | **515** | **1,155** | **1,969** |
| | | | **Per cent** | | |
| No respiratory support | n.p. | n.p. | 1.4 | n.p. | 0.9 |
| Non-specific respiratory distress | 50.6 | 72.9 | 82.4 | 82.9 | 80.4 |
| Hyaline membrane disease | 40.3 | 23.5 | 10.9 | 2.1 | 8.3 |
| Meconium aspiration syndrome | 0.0 | 0.0 | n.p. | n.p. | 4.7 |
| Pneumonia | 0.0 | n.p. | n.p. | 3.5 | 2.3 |
| Persistent pulmonary hypertension | 0.0 | 0.0 | n.p. | n.p. | n.p. |
| Apnoea | n.p. | n.p. | 1.6 | 0.7 | 0.9 |
| Congenital anomaly | 0.0 | 0.0 | n.p. | 0.0 | n.p. |
| Other | 0.0 | 0.5 | 1.4 | 2.2 | 1.7 |
| Peri-surgery | 0.0 | 0.0 | 0.0 | 0.0 | 0.0 |
| Newborn encephalopathy | 0.0 | 0.0 | n.p. | n.p. | 0.4 |
| **Total** | **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 36: Duration of assisted ventilation use for level II registrants by gestational age, ANZNN 2021**

| Duration of assisted ventilation | Gestational age (weeks) | | | | |
|---|---|---|---|---|---|
| | <32 | 32–33 | 34–36 | 37–44 | Total |
| | | | IPPV (hours) | | |
| **Median** | 17 | 3 | 21 | 19.5 | **15** |
| **IQR** | 13–22 | 2–10 | 11.5–29.5 | 10–29 | **5–24** |
| | | | CPAP (hours) | | |
| **Median** | 54 | 29 | 17 | 13 | **16** |
| **IQR** | 21–116 | 14–55 | 9.5–30 | 7.5–23 | **9–29** |
| | | | NHF (hours) | | |
| **Median** | 230 | 92 | 54.5 | 28 | **45.5** |
| **IQR** | 98–429 | 47–142 | 31–103.5 | 17–58 | **21–99** |

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

## Eye examination

Screening for retinopathy of prematurity (ROP) was reported for only 25 of the 32 eligible babies born at less than 31 weeks gestational age and/or weighing less than 1,250 grams at birth (78.1% compared to 80.8% of eligible level III registrants). All were reported as normal except for five babies who had stage 1 ROP.

## Cerebral ultrasound

Of the 78 babies born at less than 32 weeks, 62 (79.5%) had a cerebral ultrasound in the first week after birth. 57 of them were reported as normal, that is, no intraventricular haemorrhage (IVH), and the remaining five reported as 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 41 babies, all of whom had normal reports of no cysts.

## Other morbidities

Septicaemia was proven in 25 babies, including 20 before day two, that is, less than 48 hours of age. There was one case of necrotising enterocolitis. Major congenital anomalies were reported for 16 babies, of which none required major surgery.

## Level II transfers

In total, 85 level II registrants were transferred to other units, 58 were transferred to a level I or another level II unit, 21 were transferred to a level III unit and the remaining six to a children's hospital.

## Survival

There were 1,961 level II registrants who survived to discharge to home (99.6%). Five babies died within the first seven days of birth (Table 37). No babies were reported to have had a lethal congenital anomaly. Survival was unknown for three babies.

**TABLE 37: Survival to discharge home for level II registrants by gestational age, ANZNN 2021**

| Gestational age (weeks) | All babies | Babies alive on day 7 | Babies alive on day 28 | Survived to discharge to home | Per cent survival at discharge to home |
|---|---|---|---|---|---|
| <32 | 78 | 77 | 77 | 77 | 98.7 |
| 32–33 | 221 | 220 | 220 | 219 | 99.1 |
| 34–36 | 515 | 515 | 515 | 514 | 99.8 |
| 37–44 | 1155 | 1152 | 1152 | 1151 | 99.7 |
| **All babies** | **1,969** | **1,964** | **1,964** | **1,961** | **99.6** |

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

# 6. Extremely preterm follow-up, 2015–2018 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 2015 to 2018 births. All infants born from 2015 to 2018 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 4,816 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 75 (1.6%) eligible ANZNN registrants born from 2015 to 2018. 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 2015 to 2018, 5,583 extremely preterm and/or extremely low birthweight babies were registered to the ANZNN, with 4,816 (86.3%) 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 2017 births and another NICU was unable to submit post-discharge data for 2015, 2016, 2017 and 2018 births before the publication of this report. The 74 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 4,742 eligible survivors registered to NICUs that were able to submit data, 34 (0.7%) infants died after discharge to home and prior to the 2-3 year follow-up, 3,728 (78.6%) infants had a follow-up assessment at 18-42 months corrected age and four had unknown age at follow-up assessment. In addition, there was data submitted for 32 (0.7%) infants who were followed-up earlier than 18 months corrected age and ten (0.2%) infants who were followed-up at 43 months corrected age or older. The remaining 934 (19.7%) infants were lost to follow-up, and of these, 694 (74.3%) infants were known to have survived to 2-3 years of age but were not followed-up, 239 (25.6%) infants had unknown survival status at 2-3 years of age and one (0.1%) 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 79.2% (3,728 of 4,708), 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 38 & Table 39).

Of the 3,728 infants who were followed-up at 18-42 months corrected age, 3,121 (83.7%) had a formal developmental assessment. For the remaining 607 (16.3%) infants, some follow-up information was obtained but a formal developmental assessment was not completed.

Of the 46 infants whose age at assessment was unknown or was outside of the range 18-42 months corrected age, seven of 32 (21.9%) infants had a formal developmental assessment at less than 18 months corrected age, one of ten (10.0%) infants had a formal developmental assessment at 43 months corrected age or older, and none had a formal developmental assessment at unknown age.

**FIGURE 10: ANZNN 2–3 year follow-up cohort of extremely preterm infants, 2015–2018 births**

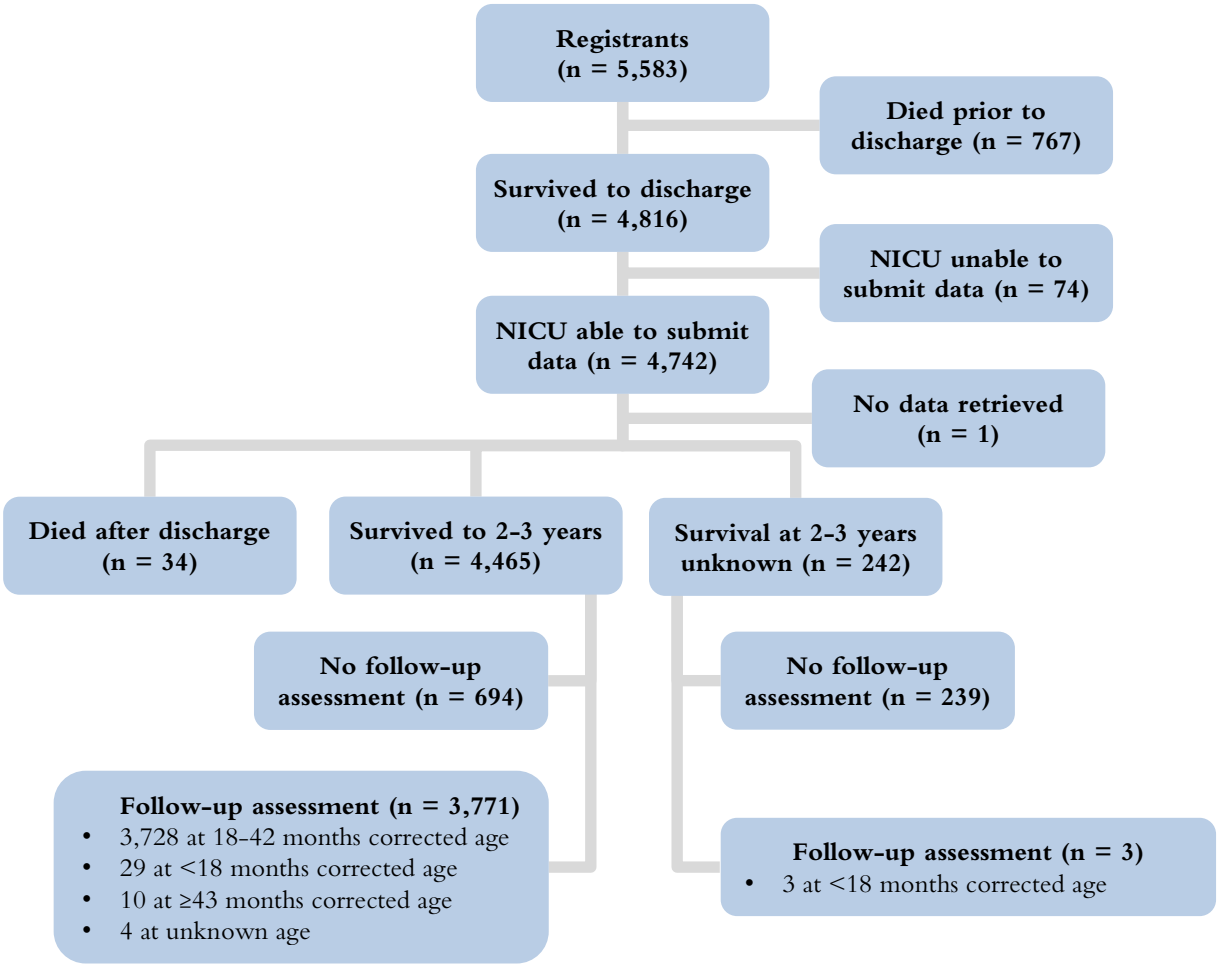



**TABLE 38: Births, survival and 2–3 year follow-up of extremely preterm and/or extremely low birthweight infants by gestational age, ANZNN 2015–2018 births**

| | Gestational age (weeks) | | | | | | |
|---|---|---|---|---|---|---|---|
| | **<24** | **24** | **25** | **26** | **27** | **≥28[a]** | **Total** |
| | | | | **Number** | | | |
| Registrants | 352 | 754 | 875 | 1,168 | 1,442 | 992 | 5,583 |
| Survived to discharge | 181 | 533 | 730 | 1,067 | 1,358 | 947 | 4,816 |
| | | | | **Per cent** | | | |
| Survived to discharge[b] | 51.4 | 70.7 | 83.4 | 91.4 | 94.2 | 95.5 | 86.3 |
| | | | | **Number** | | | |
| NICU not included | 2 | 12 | 12 | 15 | 13 | 20 | 74 |
| Follow-up cohort[c] | 179 | 521 | 718 | 1,051 | 1,345 | 927 | 4,741 |
| ▪ Died post-discharge | <5 | 5 | <5 | 9 | 9 | 7 | 34 |
| ▪ Follow-up assessment[d] | 151 | 444 | 581 | 832 | 1,043 | 677 | 3,728 |
| ▪ No outcome data | n.p. | 72 | n.p. | 210 | 293 | 243 | 979 |
| | | | | **Per cent** | | | |
| Follow-up rate[e] | 84.8 | 86.0 | 81.3 | 79.8 | 78.1 | 73.6 | 79.2 |

*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 39: Births, survival and 2–3 year follow-up of extremely preterm and/or extremely low birthweight infants by birthweight, ANZNN 2015–2018 births**

| | Birthweight (grams) | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | <500 | 500-599 | 600-699 | 700-799 | 800-899 | 900-999 | ≥1000[a] | Total |
| | | | | Number | | | | |
| Registrants | 128 | 377 | 798 | 934 | 1,059 | 1,230 | 1,057 | 5,583 |
| Survived to discharge | 67 | 244 | 612 | 776 | 955 | 1,163 | 999 | 4,816 |
| | | | | Per cent | | | | |
| Survived to discharge[b] | 52.3 | 64.7 | 76.7 | 83.1 | 90.2 | 94.6 | 94.5 | 86.3 |
| | | | | Number | | | | |
| NICU not included | 0 | 1 | 11 | 11 | 19 | 17 | 15 | 74 |
| Follow-up cohort[c] | 67 | 243 | 601 | 765 | 935 | 1,146 | 984 | 4,741 |
| ▪ Died post-discharge | <5 | <5 | 5 | 5 | 6 | 8 | 7 | 34 |
| ▪ Follow-up assessment[d] | 62 | 206 | 498 | 621 | 724 | 855 | 762 | 3,728 |
| ▪ No outcome data | <5 | n.p. | 98 | 139 | 205 | 283 | 215 | 979 |
| | | | | Per cent | | | | |
| Follow-up rate[e] | 93.9 | 85.5 | 83.6 | 81.7 | 77.9 | 75.1 | 78.0 | 79.2 |

*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.*

The follow-up rate varied by birth year, with rates of follow-up of infants born in 2017 and 2018 lower than infants born in 2015 and 2016 (Figure 28 in Appendix 1). Infants born in 2018 were scheduled for follow up assessments in 2020-2021 and during this period many follow-up clinics were closed for some time due to COVID-19 lockdowns. Some clinics were able to catch up on missed appointments, but others prioritised infants who were identified as having greater risk of developmental delays.

Infants born in 2018 had approximately twice the annual rate of informal assessments as those born in 2015-2017, with many clinics using screening questionnaires and/or a video assessment when it was not possible to offer face-to-face appointments during COVID-19 lockdowns; formal developmental follow-up assessments were offered to infants identified as most at risk of delay. Other clinics prioritised appointments based on risk factors for developmental delay, such as gestational age at birth, for example offering face-to-face appointments to those born at gestations less than 26 weeks. Formal assessment of infants born in 2018, and to a lesser extent 2017, may be skewed towards infants with developmental delays.

## 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 24.1-28.1 months, corrected for prematurity.

A formal developmental assessment comprised neurological examination by a developmental paediatrician or physiotherapist, 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. It is important to note that infants affected by cerebral palsy are sometimes not diagnosed until after 2-3 years of age and the severity of diagnosis may change with 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 3,728 infants with a follow-up assessment at 18-42 months corrected age, information about cerebral palsy was available for 3,630 (97.4%) and of these, 250 (6.9%) had a diagnosis of cerebral palsy. The movement ability of 245 (98.0%) infants with cerebral palsy was graded by the GMFCS. Of the infants with a GMFCS classification, 130 (53.1%) infants were graded as level 1, 47 (19.2%) as level 2, 35 (14.3%) as level 3, 14 (5.7%) as level 4 and 19 (7.8%) as level 5 (Table 40).

Of the 32 infants who were assessed at less than 18 months corrected age, there was one case of moderate cerebral palsy, two cases of severe cerebral palsy, and one case of cerebral palsy of unknown severity. Of the 14 infants who were assessed at older than 42 months corrected age or whose age at assessment was unknown, there were two cases of mild cerebral palsy.

**TABLE 40: Cerebral palsy at 2–3 year follow-up by gestational age, ANZNN 2015–2018 births**

| | Gestational age (weeks) | | | | | | |
|---|---|---|---|---|---|---|---|
| **Cerebral palsy** | **<24** | **24** | **25** | **26** | **27** | **≥28** | **Total** |
| | | | | **Number** | | | |
| No cerebral palsy | 125 | 384 | 512 | 761 | 960 | 638 | 3,380 |
| Cerebral palsy | 24 | 50 | 51 | 47 | 55 | 23 | 250 |
| ▪ Mild (Level 1) | 10 | 26 | 26 | 23 | 29 | 16 | 130 |
| ▪ Moderate (Level 2–3) | 9 | n.p. | 20 | 19 | n.p. | <5 | 82 |
| ▪ Severe (Level 4–5) | 5 | 10 | <5 | 5 | 8 | <5 | 33 |
| ▪ Level unknown | 0 | <5 | <5 | 0 | <5 | <5 | 5 |
| Not stated | 2 | 10 | 18 | 24 | 28 | 16 | 98 |
| **Total[(a)]** | **151** | **444** | **581** | **832** | **1,043** | **677** | **3,728** |
| | | | | **Per cent** | | | |
| No cerebral palsy | 83.9 | 88.5 | 90.9 | 94.2 | 94.6 | 96.5 | 93.1 |
| Cerebral palsy | 16.1 | 11.5 | 9.1 | 5.8 | 5.4 | 3.5 | 6.9 |
| ▪ Mild (Level 1) | 6.7 | 6.0 | 4.6 | 2.8 | 2.9 | 2.4 | 3.6 |
| ▪ Moderate (Level 2–3) | 6.0 | n.p. | 3.6 | 2.4 | n.p. | n.p. | 2.3 |
| ▪ Severe (Level 4–5) | 3.4 | 2.3 | n.p. | 0.6 | 0.8 | n.p. | 0.9 |
| ▪ Level unknown | 0.0 | n.p. | n.p. | 0.0 | n.p. | n.p. | 0.1 |

*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. Of the 3,728 infants with a follow-up assessment at 18-42 months corrected age, 3,527 (94.6%) had data on blindness available and of these, 18 (0.5%) were recorded as being blind (<6/60 in the better eye). Ten (55.6%) of the infants with blindness were born at 24 weeks gestational age or younger.

Of the 46 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, two infants were 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 3,678 (98.7%) of infants with a follow-up assessment at 18-42 months corrected age. Of these, four (0.1%) infants were fitted with a unilateral hearing aid, 26 (0.7%) infants with bilateral hearing aids, six (0.2%) infants with a cochlear implant and three (0.1%) 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 (2.8%) compared with any other gestational age group (0.5–0.9%).

Of the 46 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 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 3,728 infants assessed at 18-42 months corrected age, there were 41 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 41 to Table 47). Of those excluded, there were eight infants with congenital central nervous system malformations, including encephalomalacia, holoprosencephaly, hydrocephalus, microcephaly, Moyamoya disease, neurofibromatosis, other reduction anomalies of brain, Pelizaeus-Merzbacher disease and septo-optic dysplasia. Also excluded were 29 infants with genetic disorders or chromosomal anomalies, including chromosomal deletion, chromosomal duplication, Cockayne syndrome, Di-George syndrome, hereditary spastic paraparesis, HUWE1 mutation, hyperphenylalaninemia, Koolen-de Vries syndrome, Noonan syndrome, trisomy 21 and other specified trisomies. The remaining four infants were excluded due to other congenital anomalies or conditions 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 2,836 infants assessed by the Bayley Scales of Infant and Toddler Development-III, 218 infants assessed by the Bayley Scales of Infant and Toddler Development 4 (A&NZ), 34 infants assessed by the Griffiths Mental Developmental Scales, and three infants assessed by the Wechsler Preschool and Primary Scale of Intelligence (WPPSI). It should be noted that motor and language subscale scores were not available for the infants who were assessed by WPPSI 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. As 55 is the lowest composite score that can be assigned on the Bayley cognitive scale, cut-points for severe and moderate cognitive delay were adjusted to ≤55 and 56–69 respectively for infants assessed on this scale. In a general population, approximately 14% of infants would be -2 SD to <-1 SD and approximately 2% 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 nine infants without formal developmental assessment had a severe impairment recorded (three with blindness, three with severe cerebral palsy and three with blindness and severe cerebral palsy), severe cognitive, language or motor delay could not be reliably assigned to these infants.

Overall, there were 584 (18.8%) infants with mild to severe cognitive delay, 952 (32.3%) with mild to severe language delay and 647 (21.6%) with mild to severe motor delay (Table 41 to Table 43). 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, language delays detected in this age group may not reflect a problem or disability at later ages. Of the 132 infants with moderate motor delay, 37 (28.0%) were diagnosed with cerebral palsy, and of the 82 infants with severe motor delay, 48 (58.5%) were diagnosed with cerebral palsy.

In the 2018 birth cohort, and to a lesser extent, the 2017 birth cohort, the population of infants who were formally assessed may be skewed towards infants with developmental delays due to developmental follow-up clinic closures during COVID-19 lockdown periods in 2020 and 2021. Some clinics were only able to offer catch-up assessments to infants most at risk of delays.

It should also be noted that the Bayley 4 (A&NZ) may detect different rates of delay than the Bayley-III. Of the 218 infants assessed by the Bayley 4 (A&NZ), 213 of these were born in 2018.

**TABLE 41: Cognitive delay at 2–3 year follow-up by gestational age for Bayley-III, Bayley 4 (A&NZ), Griffiths and WPPSI assessments, ANZNN 2015–2018 births[a]**

| | Gestational age (weeks) | | | | | | |
|---|---|---|---|---|---|---|---|
| **Cognitive delay** | **<24** | **24** | **25** | **26** | **27** | **≥28** | **Total** |
| | | | | **Number** | | | |
| None | 89 | 269 | 369 | 568 | 767 | 455 | 2,517 |
| Mild | 18 | 74 | 67 | 76 | 74 | 62 | 371 |
| Moderate | 8 | 21 | 15 | 24 | 24 | 18 | 110 |
| Severe | 13 | 18 | 20 | 21 | 20 | 11 | 103 |
| Not stated[b] | 0 | 1 | 4 | 3 | 7 | 3 | 18 |
| **Total[c]** | **128** | **383** | **475** | **692** | **892** | **549** | **3,119** |
| | | | | **Per cent** | | | |
| None | 69.5 | 70.4 | 78.3 | 82.4 | 86.7 | 83.3 | 81.2 |
| Mild | 14.1 | 19.4 | 14.2 | 11.0 | 8.4 | 11.4 | 12.0 |
| Moderate | 6.3 | 5.5 | 3.2 | 3.5 | 2.7 | 3.3 | 3.5 |
| Severe | 10.2 | 4.7 | 4.2 | 3.0 | 2.3 | 2.0 | 3.3 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*(a) The cohort of infants born in 2018 and assessed formally may be skewed towards those at greater risk of developmental delay.*
*(b) Infants assessed by Bayley-III, Bayley 4A&NZ, Griffiths or WPPSI but with no Bayley cognitive subscale composite score, Griffiths performance subscale quotient or WPPSI full scale intelligence quotient recorded.*
*(c) Infants assessed by Bayley-III, Bayley 4A&NZ, Griffiths or WPPSI at 18-42 months corrected age or unable to be assessed due to severe delay. Excludes 41 infants with a congenital anomaly known to impair development.*
***Note:*** *Not stated data (assessments with no cognitive subscale score) are excluded from per cent calculations.*

**TABLE 42: Language delay at 2–3 year follow-up by gestational age for Bayley-III, Bayley 4 (A&NZ) and Griffiths assessments, ANZNN 2015–2018 births[a]**

| | Gestational age (weeks) | | | | | | |
|---|---|---|---|---|---|---|---|
| **Language delay** | **<24** | **24** | **25** | **26** | **27** | **≥28** | **Total** |
| | | | | **Number** | | | |
| None | 61 | 209 | 287 | 454 | 620 | 363 | 1,994 |
| Mild | 37 | 82 | 92 | 116 | 138 | 107 | 572 |
| Moderate | 13 | 47 | 43 | 52 | 51 | 37 | 243 |
| Severe | 12 | 22 | 24 | 28 | 32 | 19 | 137 |
| Not stated[b] | 5 | 22 | 28 | 42 | 50 | 23 | 170 |
| **Total[c]** | **128** | **382** | **474** | **692** | **891** | **549** | **3,116** |
| | | | | **Per cent** | | | |
| None | 49.6 | 58.1 | 64.3 | 69.8 | 73.7 | 69.0 | 67.7 |
| Mild | 30.1 | 22.8 | 20.6 | 17.8 | 16.4 | 20.3 | 19.4 |
| Moderate | 10.6 | 13.1 | 9.6 | 8.0 | 6.1 | 7.0 | 8.2 |
| Severe | 9.8 | 6.1 | 5.4 | 4.3 | 3.8 | 3.6 | 4.7 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*(a) The cohort of infants born in 2018 and assessed formally may be skewed towards those at greater risk of developmental delay.*
*(b) Infants assessed by Bayley-III, Bayley 4A&NZ or Griffiths but with no Bayley language subscale composite score or Griffiths language subscale quotient recorded.*
*(c) Infants assessed by Bayley-III, Bayley 4A&NZ or Griffiths at 18-42 months corrected age or unable to be assessed due to severe delay. Excludes 41 infants with a congenital anomaly known to impair development.*
***Note:** Not stated data (assessments with no language subscale score) are excluded from per cent calculations.*

**TABLE 43: Motor delay at 2–3 year follow-up by gestational age for Bayley-III, Bayley 4 (A&NZ) and Griffiths assessments, ANZNN 2015–2018 births[a]**

| | Gestational age (weeks) | | | | | | |
|---|---|---|---|---|---|---|---|
| **Motor delay** | **<24** | **24** | **25** | **26** | **27** | **≥28** | **Total** |
| | | | | **Number** | | | |
| None | 75 | 254 | 331 | 540 | 716 | 439 | 2,355 |
| Mild | 29 | 70 | 78 | 87 | 98 | 71 | 433 |
| Moderate | 7 | 25 | 29 | 24 | 32 | 15 | 132 |
| Severe | 10 | 19 | 15 | 14 | 15 | 9 | 82 |
| Not stated[b] | 7 | 14 | 21 | 27 | 30 | 15 | 114 |
| **Total[c]** | **128** | **382** | **474** | **692** | **891** | **549** | **3,116** |
| | | | | **Per cent** | | | |
| None | 62.0 | 69.0 | 73.1 | 81.2 | 83.2 | 82.2 | 78.4 |
| Mild | 24.0 | 19.0 | 17.2 | 13.1 | 11.4 | 13.3 | 14.4 |
| Moderate | 5.8 | 6.8 | 6.4 | 3.6 | 3.7 | 2.8 | 4.4 |
| Severe | 8.3 | 5.2 | 3.3 | 2.1 | 1.7 | 1.7 | 2.7 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*(a) The cohort of infants born in 2018 and assessed formally may be skewed towards those at greater risk of developmental delay.*
*(b) Infants assessed by Bayley-III, Bayley 4A&NZ or Griffiths but with no Bayley motor subscale composite score or Griffiths locomotor/gross motor subscale quotient recorded.*
*(c) Infants assessed by Bayley-III, Bayley 4A&NZ or Griffiths at 18-42 months corrected age or unable to be assessed due to severe delay. Excludes 41 infants with a congenital anomaly known to impair development.*
***Note:** Not stated data (assessments with no motor subscale score) are excluded from per cent calculations.*

## Functional impairment

Functional impairment was analysed for 2,634 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, 30 infants who met at least one of the criteria for severe impairment but had missing data for one or more outcomes, and 30 infants who were unable to be assessed or were unable to complete assessment due to severe developmental delay were included in the severe category for functional impairment. Of these infants, six were less than 24 weeks, twelve were 24 weeks, eleven were 25 weeks, twelve were 26 weeks, twelve were 27 weeks and seven were 28 weeks gestational age or older at birth.

Of the 2,694 infants where functional impairment could be graded, there were 1,136 (42.2%) infants with any degree of functional impairment, including 678 (25.2%) with a mild impairment, 267 (9.9%) with a moderate impairment and 191 (7.1%) with a severe impairment. Functional impairment was most prevalent and most severe among infants who were born at younger gestational ages (Table 44). Of the 1,136 infants with any degree of functional impairment, 304 (26.8%) were classified based on language delays alone.

**TABLE 44: Severity of functional impairment at 2–3 year follow-up by gestational age, ANZNN 2015–2018 births[a]**

| | Gestational age (weeks) | | | | | | |
|---|---|---|---|---|---|---|---|
| **Functional impairment** | **<24** | **24** | **25** | **26** | **27** | **≥28** | **Total** |
| | | | | **Number** | | | |
| None | 39 | 141 | 222 | 357 | 516 | 283 | 1,558 |
| Mild | 40 | 101 | 101 | 148 | 158 | 130 | 678 |
| Moderate | 13 | 52 | 52 | 55 | 58 | 37 | 267 |
| Severe | 19 | 34 | 31 | 38 | 44 | 25 | 191 |
| Incomplete formal test[b] | 16 | 57 | 68 | 97 | 118 | 74 | 430 |
| Other formal test | 0 | 2 | 2 | 0 | 4 | 2 | 10 |
| No formal test | 22 | 51 | 99 | 135 | 138 | 108 | 553 |
| **Total[c]** | **149** | **438** | **575** | **830** | **1,036** | **659** | **3,687** |
| | | | | **Per cent** | | | |
| None | 35.1 | 43.0 | 54.7 | 59.7 | 66.5 | 59.6 | 57.8 |
| Mild | 36.0 | 30.8 | 24.9 | 24.7 | 20.4 | 27.4 | 25.2 |
| Moderate | 11.7 | 15.9 | 12.8 | 9.2 | 7.5 | 7.8 | 9.9 |
| Severe | 17.1 | 10.4 | 7.6 | 6.4 | 5.7 | 5.3 | 7.1 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*(a) The cohort of infants born in 2018 and assessed formally may be skewed towards those at greater risk of developmental delay.*
*(b) Infants with Bayley or Griffiths assessments but with missing data for one or more outcomes.*
*(c) Infants assessed at 18-42 months corrected age or unable to be assessed due to severe delay. Excludes 41 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 304 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, they 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, 760 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 760 infants, together with the 2,694 infants graded in Table 44, there were 579 (16.8%) infants with moderate to severe functional impairment. Moderate to severe functional impairment decreased with increasing gestational age (Table 45). Of these 579 infants with moderate to severe functional impairment, there were 188 (32.8%) infants classified with moderate to severe functional impairment based on language delay alone.

**TABLE 45: Infants with or without moderate to severe functional impairment at 2–3 year follow-up by gestational age, ANZNN 2015–2018 births**

| | Gestational age (weeks) | | | | | | |
|---|---|---|---|---|---|---|---|
| **Functional impairment** | **<24** | **24** | **25** | **26** | **27** | **≥28** | **Total** |
| | | | | **Number** | | | |
| Without moderate-severe impairment | 103 | 301 | 426 | 654 | 848 | 543 | 2,875 |
| Moderate-severe impairment | 39 | 114 | 103 | 121 | 129 | 73 | 579 |
| Not stated[(a)] | 7 | 23 | 46 | 55 | 59 | 43 | 233 |
| **Total[(b)]** | **149** | **438** | **575** | **830** | **1,036** | **659** | **3,687** |
| | | | | **Per cent** | | | |
| Without moderate-severe impairment | 72.5 | 72.5 | 80.5 | 84.4 | 86.8 | 88.1 | 83.2 |
| Moderate-severe impairment | 27.5 | 27.5 | 19.5 | 15.6 | 13.2 | 11.9 | 16.8 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*(a) Infants where moderate to severe functional impairment could not be excluded based on the available data.*
*(b) Infants assessed at 18-42 months corrected age or unable to be assessed due to severe delay. Excludes 41 infants with a congenital anomaly known to impair development.*
***Note:** Not stated data are excluded from per cent calculations. This table includes 188 infants with a moderate-severe functional impairment classification based on language delay alone.*

## Neonatal intraventricular haemorrhage and moderate to severe functional impairment

Babies diagnosed with intraventricular haemorrhage (IVH) are at increased risk of long term neurodevelopmental impairment, particularly those with severe grades of IVH. IVH can occur on one or both sides of the brain, with worse long term outcomes associated with bilateral IVH.

There were 4,340 babies born in 2015 to 2018 at less than 28 weeks gestation and who survived to day 3 and were registered to NICUs able to submit post-discharge data. Of these, 4,303 were examined for IVH. Table 46 presents 2-3 year outcomes for this cohort by IVH diagnosis and by gestational age in weeks. Outcomes at 2-3 year follow-up include death from day 4 onwards (including post-discharge), and functional impairment classification at 2-3 year follow-up. Outcome is tabled as unknown for infants lost to follow up or otherwise unable to be classified as with or without functional impairment.

Care should be taken when interpreting outcomes of babies diagnosed with IVH, considering that the diagnosis may influence decisions around continuing intensive care or transitioning to palliative care. In addition, only 2,845 of the 3,764 babies not known to have died before 2-3 years of age were followed up and were able to be classified as with or without moderate to severe functional impairment, leaving 919 (24.4%) with outcome at 2-3 years unknown (Table 46).

There were 4,010 babies born in 2015 to 2018 between 24 to 27 weeks gestation who survived to day 3 and were registered to NICUs able to submit post-discharge data. Of these, 335 were diagnosed with severe (Grade 3 or Grade 4) IVH. Mortality was higher for bilateral severe IVH compared with unilateral severe IVH (Table 47).

**TABLE 46: Functional impairment at 2–3 year follow-up for level III registrants born before 28 weeks gestation surviving to day 3 and examined for neonatal intraventricular haemorrhage by gestational age, ANZNN 2015–2018 births**

| IVH | Gestational age (weeks) | | | | | |
|---|---|---|---|---|---|---|
| **Outcome** | **<24** | **24** | **25** | **26** | **27** | **Total** |
| | | | **Number** | | | |
| **None** | | | | | | |
| Died[a] | 35 | 57 | 51 | 43 | 47 | 233 |
| Moderate-severe impairment | 11 | 59 | 56 | 81 | 99 | 306 |
| Without moderate-severe impairment | 53 | 179 | 292 | 503 | 696 | 1723 |
| Unknown | 16 | 57 | 109 | 191 | 278 | 651 |
| **Total[b]** | **115** | **352** | **508** | **818** | **1120** | **2913** |
| **Grade 1 or 2** | | | | | | |
| Died[a] | 26 | 39 | 19 | 13 | 10 | 107 |
| Moderate-severe impairment | 15 | 39 | 30 | 22 | 21 | 127 |
| Without moderate-severe impairment | 39 | 92 | 113 | 129 | 127 | 500 |
| Unknown | 11 | 21 | 52 | 61 | 56 | 201 |
| **Total[b]** | **91** | **191** | **214** | **225** | **214** | **935** |
| **Grade 3 or 4** | | | | | | |
| Died[a] | 54 | 48 | 47 | 17 | 20 | 186 |
| Moderate-severe impairment | 13 | 18 | 18 | 17 | 9 | 75 |
| Without moderate-severe impairment | 11 | 29 | 21 | 18 | 16 | 95 |
| Unknown | 7 | 14 | 18 | 10 | 12 | 61 |
| **Total[b]** | **85** | **109** | **104** | **62** | **57** | **417** |
| | | | **Per cent** | | | |
| **None** | | | | | | |
| Died[a] | 35.4 | 19.3 | 12.8 | 6.9 | 5.6 | 10.3 |
| Moderate-severe impairment | 11.1 | 20.0 | 14.0 | 12.9 | 11.8 | 13.5 |
| Without moderate-severe impairment | 53.5 | 60.7 | 73.2 | 80.2 | 82.7 | 76.2 |
| **Grade 1 or 2** | | | | | | |
| Died[a] | 32.5 | 22.9 | 11.7 | 7.9 | 6.3 | 14.6 |
| Moderate-severe impairment | 18.8 | 22.9 | 18.5 | 13.4 | 13.3 | 17.3 |
| Without moderate-severe impairment | 48.8 | 54.1 | 69.8 | 78.7 | 80.4 | 68.1 |
| **Grade 3 or 4** | | | | | | |
| Died[a] | 69.2 | 50.5 | 54.7 | 32.7 | 44.4 | 52.2 |
| Moderate-severe impairment | 16.7 | 18.9 | 20.9 | 32.7 | 20.0 | 21.1 |
| Without moderate-severe impairment | 14.1 | 30.5 | 24.4 | 34.6 | 35.6 | 26.7 |

*(a) Includes deaths occurring from day 4 onwards (including post-discharge) until follow up at 2-3 years, excluding 13 infants whose death before discharge to home was directly attributable to a congenital anomaly.*
*(b) Excludes 25 infants surviving to discharge to home with a congenital anomaly known to impair development.*
***Note:** Unknown outcome data are excluded from per cent calculations.*
*IVH = intraventricular haemorrhage.*

**TABLE 47: Functional impairment at 2–3 year follow-up for level III registrants born at 24 to 27 weeks gestation surviving to day 3 and diagnosed with Grade 3 or Grade 4 neonatal intraventricular haemorrhage, ANZNN 2015–2018 births**

| | Outcome | | | | |
|---|---|---|---|---|---|
| IVH | Died[a] | Moderate-severe impairment | Without moderate-severe impairment | Unknown | Total[b] |
| | | | Number | | |
| Grade 3 or Grade 4 unilateral | | | | | |
| ▪ Grade 2 or less on other side | 49 | 28 | 53 | 24 | **154** |
| Grade 3 or Grade 4 bilateral | | | | | |
| ▪ Grade 3 or Grade 4 on both sides | 83 | 34 | 31 | 30 | **178** |
| | | | Per cent | | |
| Grade 3 or Grade 4 unilateral | | | | | |
| ▪ Grade 2 or less on other side | 37.7 | 21.5 | 40.8 | | **100.0** |
| Grade 3 or Grade 4 bilateral | | | | | |
| ▪ Grade 3 or Grade 4 on both sides | 56.1 | 23.0 | 20.9 | | **100.0** |

*(a) Includes deaths occurring from day 4 onwards (including post-discharge) until follow up at 2-3 years, excluding two infants whose death before discharge to home was directly attributable to a congenital anomaly.*
*(b) Excludes one infant surviving to discharge to home with a congenital anomaly known to impair development.*
***Note:** Unknown outcome data are excluded from per cent calculations.*
*IVH = intraventricular haemorrhage.*

## 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 3,713 infants assessed at 18-42 months corrected age. Of these infants, 9.4% fell below the 3rd percentile for weight for age, 13.8% for length/height for age, 8.0% for head circumference for age and 5.6% 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 48 to Table 51). It is highly likely these infants were intrauterine growth restricted (IUGR) and may continue to show a pattern of slower growth.

**TABLE 48: Weight for age at 2–3 year follow-up by gestational age, ANZNN 2015–2018 births**

| | Gestational age (weeks) | | | | | | |
|---|---|---|---|---|---|---|---|
| **Weight for age centile[a]** | **<24** | **24** | **25** | **26** | **27** | **≥28** | **Total** |
| | | | | **Number** | | | |
| <3 | 21 | 36 | 34 | 45 | 64 | 105 | 305 |
| 3–9 | 17 | 51 | 47 | 65 | 77 | 107 | 364 |
| 10–90 | n.p. | 291 | 383 | 534 | 644 | n.p. | 2,291 |
| >90 | <5 | 30 | 31 | 67 | 123 | n.p. | 292 |
| Not stated | 22 | 36 | 83 | 113 | 132 | 75 | 461 |
| **Total[b]** | **151** | **444** | **578** | **824** | **1,040** | **676** | **3,713** |
| | | | | **Per cent** | | | |
| <3 | 16.3 | 8.8 | 6.9 | 6.3 | 7.0 | 17.5 | 9.4 |
| 3–9 | 13.2 | 12.5 | 9.5 | 9.1 | 8.5 | 17.8 | 11.2 |
| 10–90 | n.p. | 71.3 | 77.4 | 75.1 | 70.9 | n.p. | 70.4 |
| >90 | n.p. | 7.4 | 6.3 | 9.4 | 13.5 | n.p. | 9.0 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
*(a) 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: Length/height for age at 2–3 year follow-up by gestational age, ANZNN 2015–2018 births**

| | Gestational age (weeks) | | | | | | |
|---|---|---|---|---|---|---|---|
| **Length/height for age centile[a]** | **<24** | **24** | **25** | **26** | **27** | **≥28** | **Total** |
| | | | | **Number** | | | |
| <3 | 28 | 54 | 53 | 63 | 80 | 144 | 422 |
| 3–9 | 20 | 64 | 58 | 73 | 95 | 83 | 393 |
| 10–90 | 71 | 250 | 340 | 477 | 598 | 315 | 2,051 |
| >90 | 5 | 20 | 24 | 61 | 96 | 23 | 229 |
| Not stated | 27 | 56 | 103 | 150 | 171 | 111 | 618 |
| **Total[b]** | **151** | **444** | **578** | **824** | **1,040** | **676** | **3,713** |
| | | | | **Per cent** | | | |
| <3 | 22.6 | 13.9 | 11.2 | 9.3 | 9.2 | 25.5 | 13.6 |
| 3–9 | 16.1 | 16.5 | 12.2 | 10.8 | 10.9 | 14.7 | 12.7 |
| 10–90 | 57.3 | 64.4 | 71.6 | 70.8 | 68.8 | 55.8 | 66.3 |
| >90 | 4.0 | 5.2 | 5.1 | 9.1 | 11.0 | 4.1 | 7.4 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*(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: Head circumference for age at 2–3 year follow-up by gestational age, ANZNN 2015–2018 births**

| Head circumference for age centile[a] | Gestational age (weeks) | | | | | | |
|---|---|---|---|---|---|---|---|
| | <24 | 24 | 25 | 26 | 27 | ≥28 | Total |
| | | | | Number | | | |
| <3 | 23 | 37 | 30 | 43 | 34 | 61 | 228 |
| 3–9 | 17 | 44 | 35 | 43 | 49 | 55 | 243 |
| 10–90 | 68 | 237 | 315 | 441 | 548 | 361 | 1,970 |
| >90 | 9 | 31 | 49 | 79 | 153 | 28 | 349 |
| Not stated | 34 | 95 | 149 | 218 | 256 | 171 | 923 |
| **Total[b]** | **151** | **444** | **578** | **824** | **1,040** | **676** | **3,713** |
| | | | | Per cent | | | |
| <3 | 19.7 | 10.6 | 7.0 | 7.1 | 4.3 | 12.1 | 8.2 |
| 3–9 | 14.5 | 12.6 | 8.2 | 7.1 | 6.3 | 10.9 | 8.7 |
| 10–90 | 58.1 | 67.9 | 73.4 | 72.8 | 69.9 | 71.5 | 70.6 |
| >90 | 7.7 | 8.9 | 11.4 | 13.0 | 19.5 | 5.5 | 12.5 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*(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 51: Weight for length/height at 2–3 year follow-up by gestational age, ANZNN 2015–2018 births**

| Weight for length/height centile[a] | Gestational age (weeks) | | | | | | |
|---|---|---|---|---|---|---|---|
| | <24 | 24 | 25 | 26 | 27 | ≥28 | Total |
| | | | | Number | | | |
| <3 | 9 | 20 | 19 | 31 | 29 | 64 | 172 |
| 3–9 | 16 | 29 | 39 | 51 | 66 | 68 | 269 |
| 10–90 | 90 | 289 | 364 | 512 | 643 | 398 | 2,296 |
| >90 | 8 | 47 | 54 | 80 | 132 | 37 | 358 |
| Not stated | 28 | 59 | 102 | 150 | 170 | 109 | 618 |
| **Total[b]** | **151** | **444** | **578** | **824** | **1,040** | **676** | **3,713** |
| | | | | Per cent | | | |
| <3 | 7.3 | 5.2 | 4.0 | 4.6 | 3.3 | 11.3 | 5.6 |
| 3–9 | 13.0 | 7.5 | 8.2 | 7.6 | 7.6 | 12.0 | 8.7 |
| 10–90 | 73.2 | 75.1 | 76.5 | 76.0 | 73.9 | 70.2 | 74.2 |
| >90 | 6.5 | 12.2 | 11.3 | 11.9 | 15.2 | 6.5 | 11.6 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*(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 3,580 infants with data available on the use of respiratory support at 18-42 months corrected age, nine (0.3%) were supported by tracheostomy and 28 (0.8%) were supported by supplemental oxygen. Two in five (40.5%) infants receiving respiratory support were born at less than 25 weeks gestational age. Of the 30 infants with data only available at less than 18 months corrected age or unknown corrected age, one was supported by tracheostomy and two were supported by supplemental oxygen which may have ceased by the time of 2-3 year follow-up. None of the ten infants assessed at greater than 42 months corrected age were still receiving respiratory support.

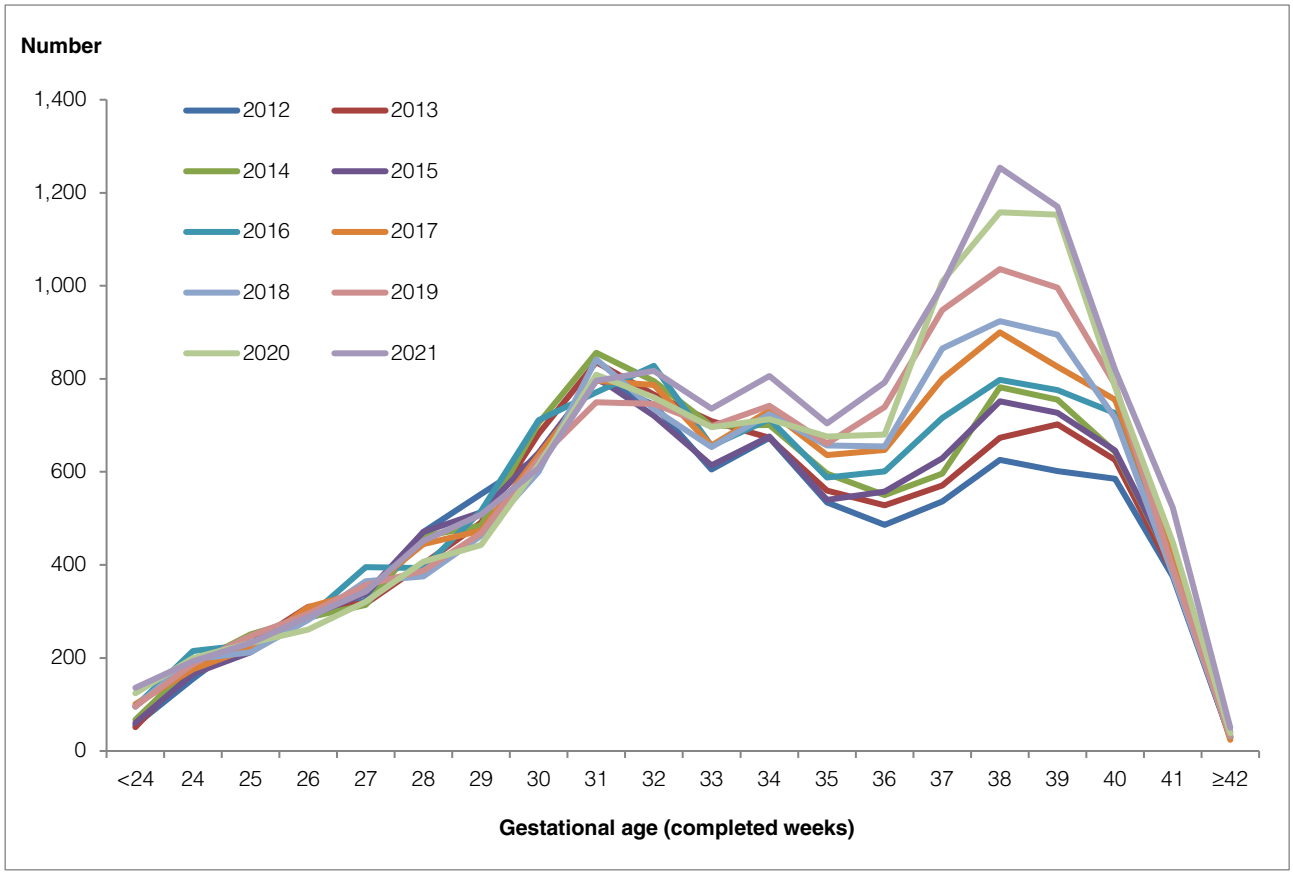
Of the 3,565 infants with nutritional support data at 18-42 months corrected age, one infant was reported as receiving parenteral nutrition and 81 (2.3%) infants were reported as feeding via a percutaneous endoscopic gastronomy tube or nasogastric tube. The prevalence of nutritional support in each gestational age group (completed weeks) ranged from 1.6–3.0%. Of the 30 infants with data only available at less than 18 months corrected age or unknown corrected age, one was receiving nutritional support which may have ceased by the time of 2-3 year follow-up. None of the ten infants assessed at greater than 42 months corrected age were still receiving nutritional support.

# APPENDICES

## Appendix 1: Trends

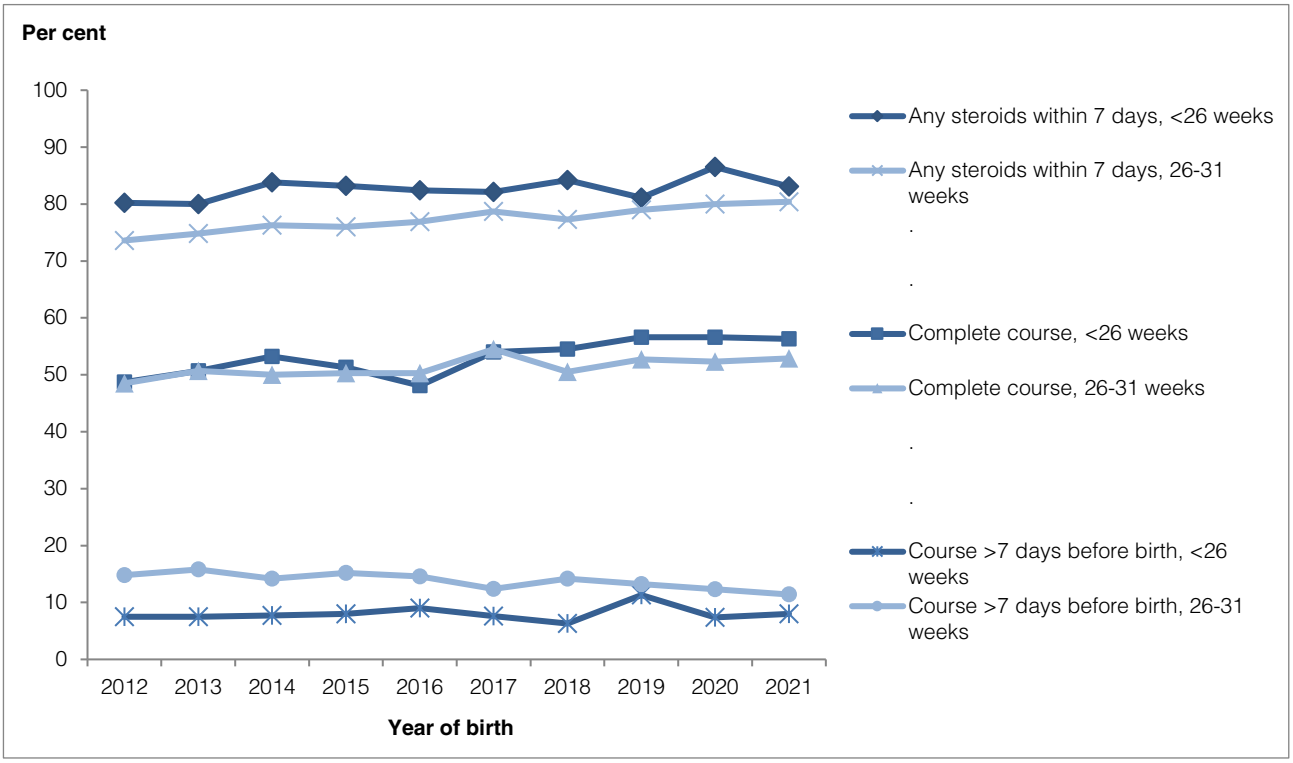
## Babies registered to level III units

**FIGURE 11: Trends in gestational age at birth of level III registrants, ANZNN 2012–2021**




*Please refer to www.anznn.net for colour version.*

**FIGURE 12: Trends in the use of corticosteroids for mothers of babies less than 32 weeks gestation, ANZNN 2012–2021**




***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 2012–2021**

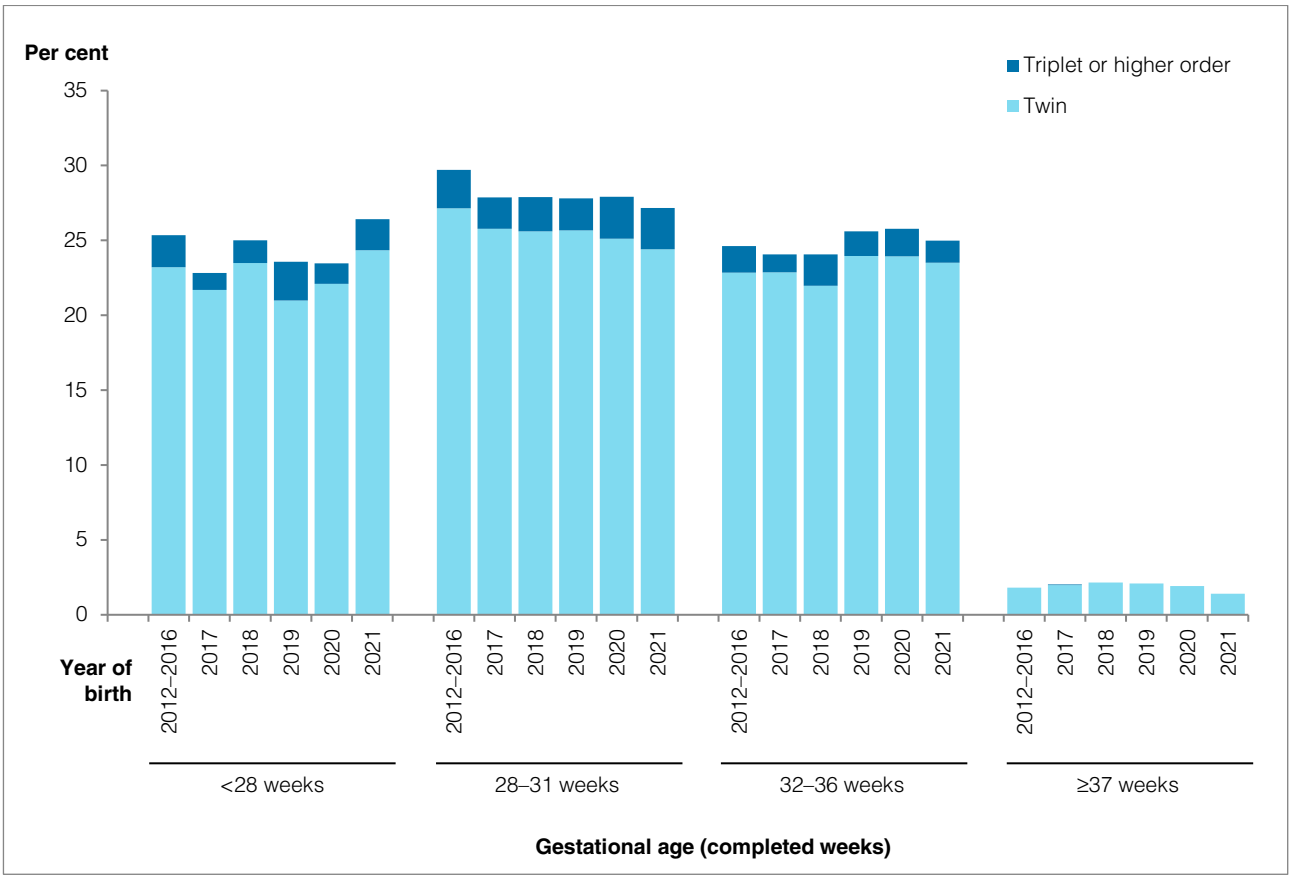


**FIGURE 14: Trends in method of birth for level III registrants by year of birth, ANZNN 2012–2021**

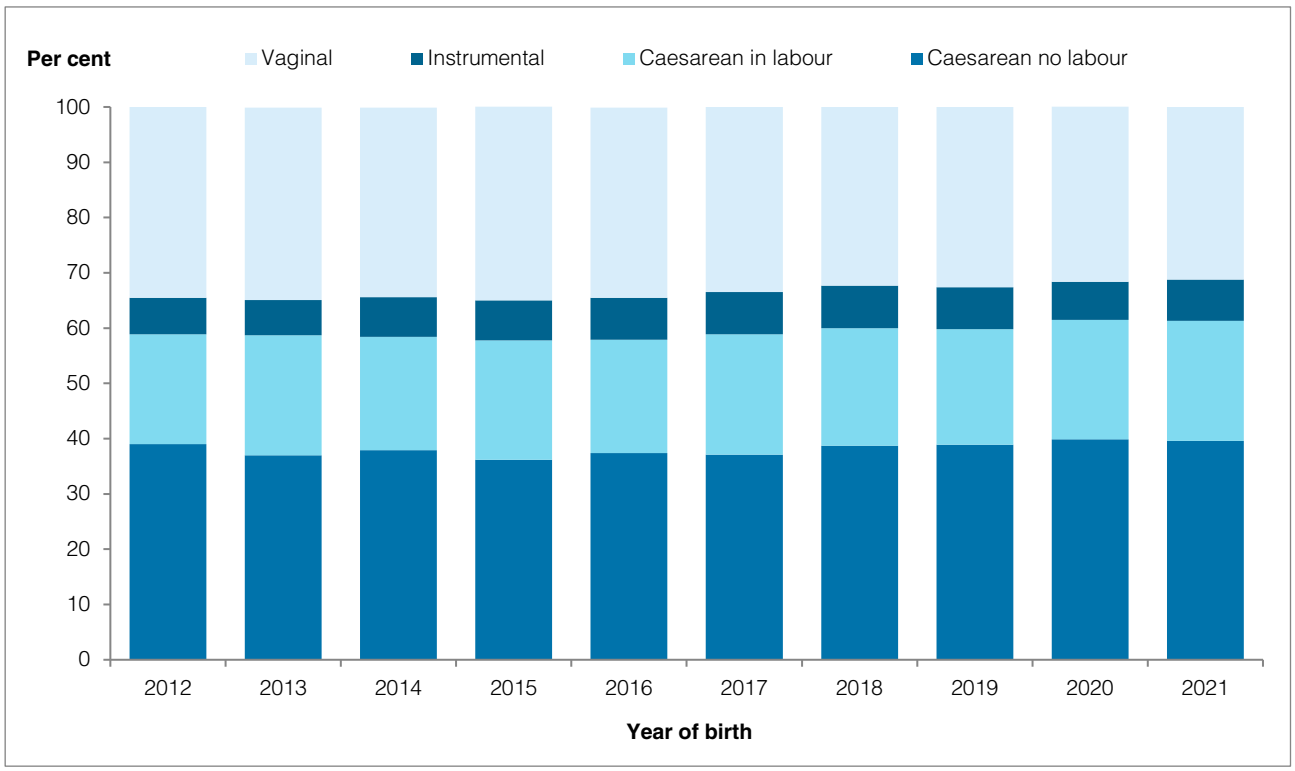



**FIGURE 15: Trends in referral source to level III NICU by year of birth, ANZNN 2012–2021**

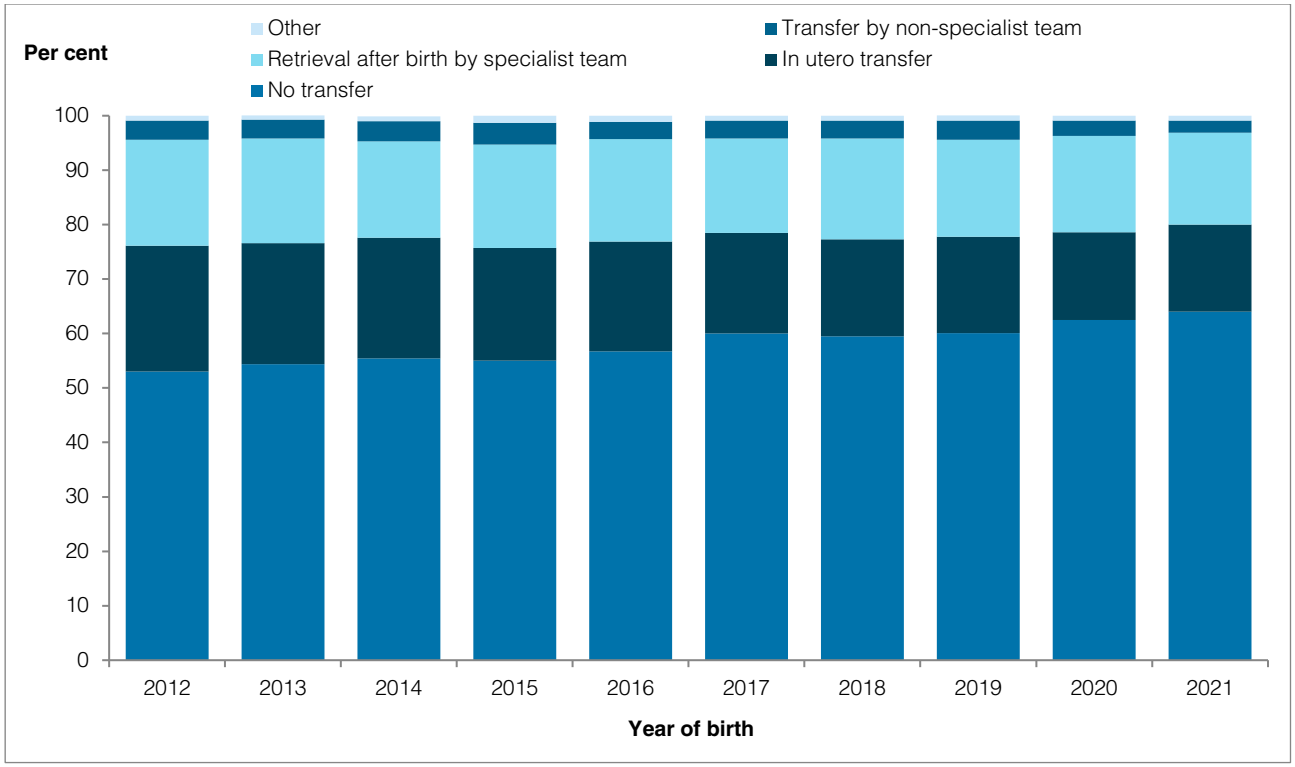


**FIGURE 16: Trends in mode of transport to level III NICU, ANZNN 2012–2021**

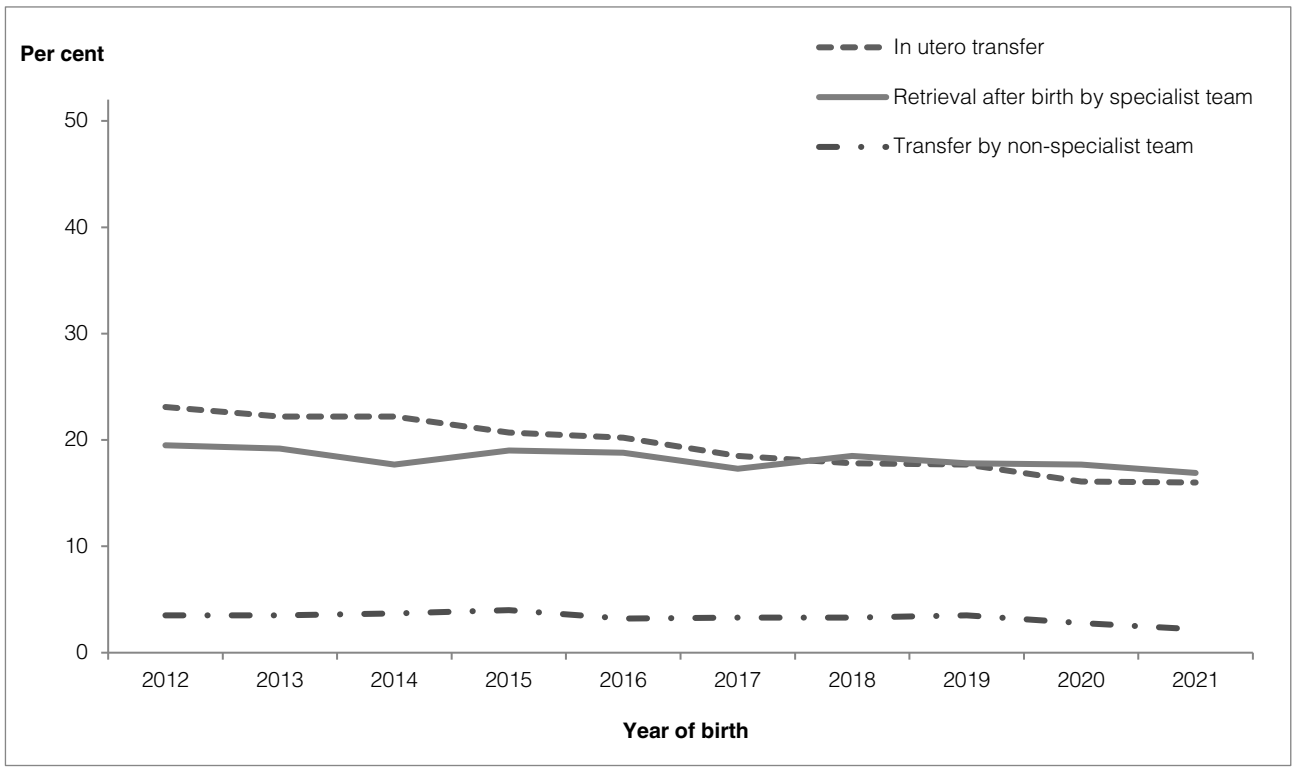
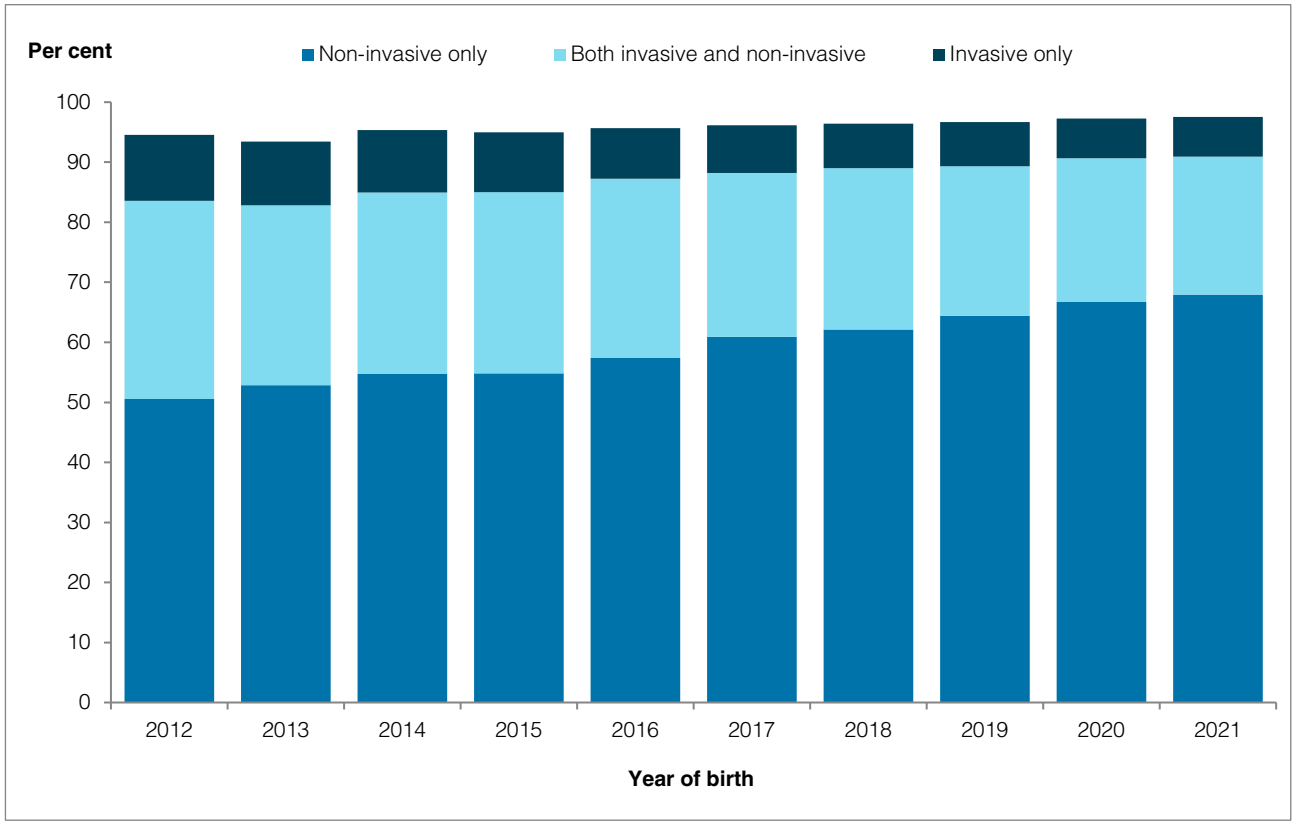
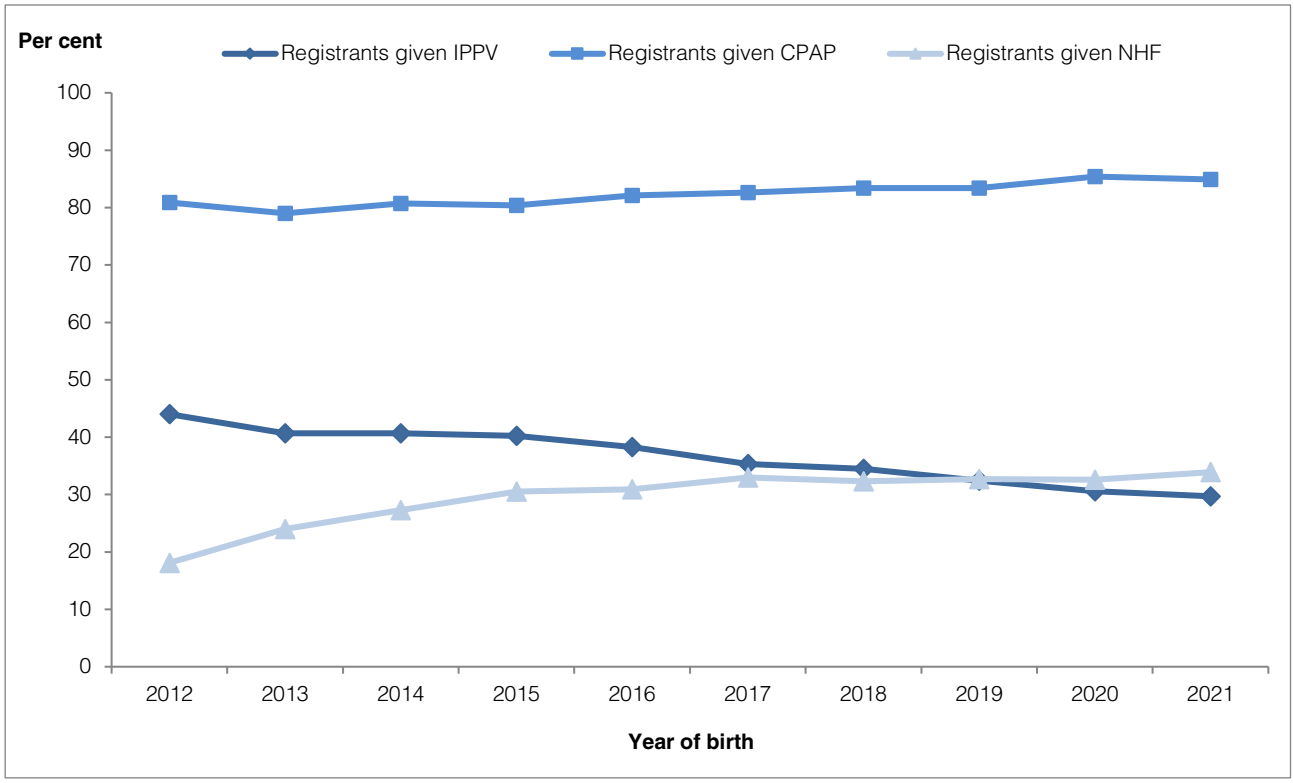



**FIGURE 17: Trends in mode of assisted ventilation for level III registrants, ANZNN 2012–2021**




***Note:*** *Non-invasive ventilation = continuous positive airway pressure (CPAP) or nasal high flow (NHF).*
*Invasive ventilation = intermittent positive pressure ventilation (IPPV).*

**FIGURE 18: Trends in provision of intermittent positive pressure ventilation, continuous positive airway pressure and nasal high flow by year of birth for level III registrants ventilated, ANZNN 2012–2021**




***Note:*** *Groups are not mutually exclusive.*
*IPPV = intermittent positive pressure ventilation. CPAP = continuous positive airway pressure. NHF = nasal high flow.*

**FIGURE 19: Trends in the use of ventilation not requiring endotracheal tube (continuous positive airway pressure or nasal high flow) as the only form of ventilation by gestational age for level III registrants, ANZNN 2012, 2015, 2018–2021**

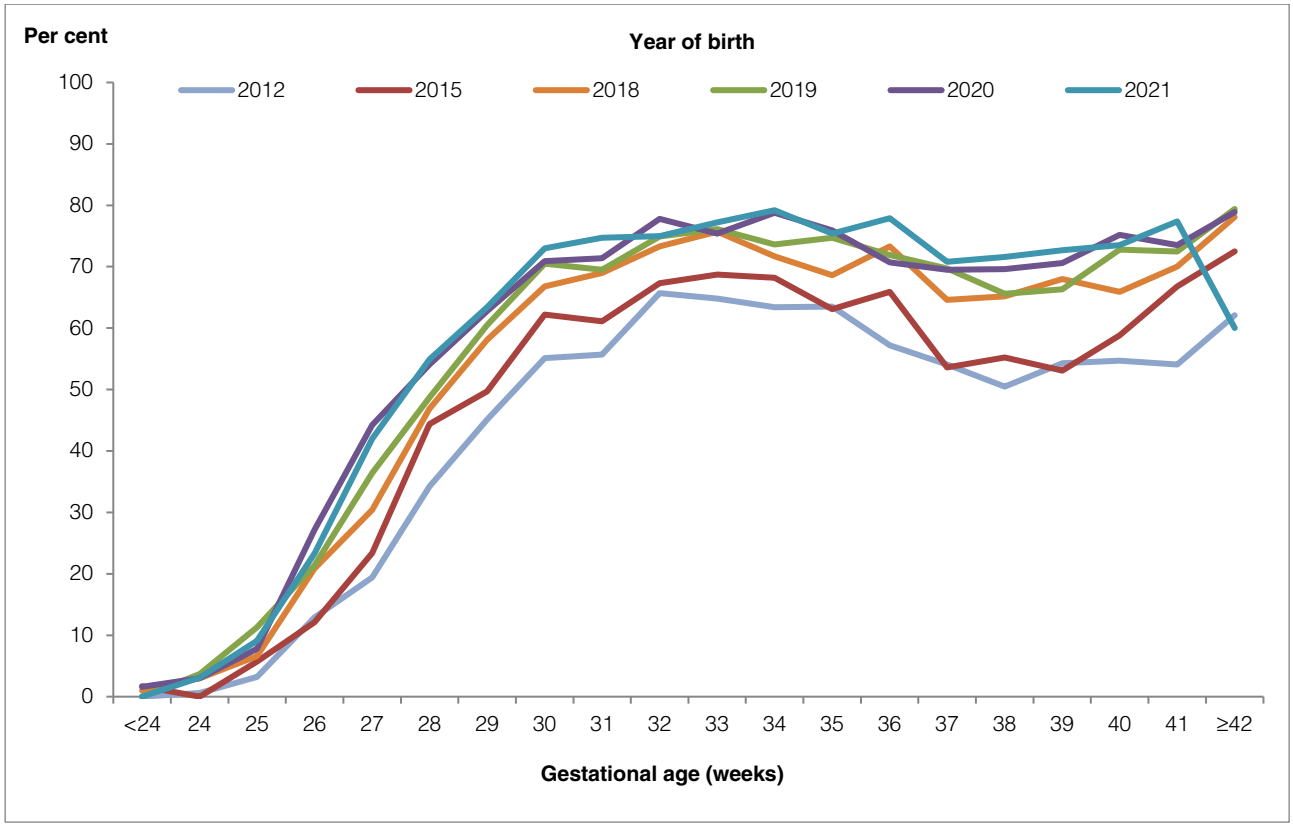
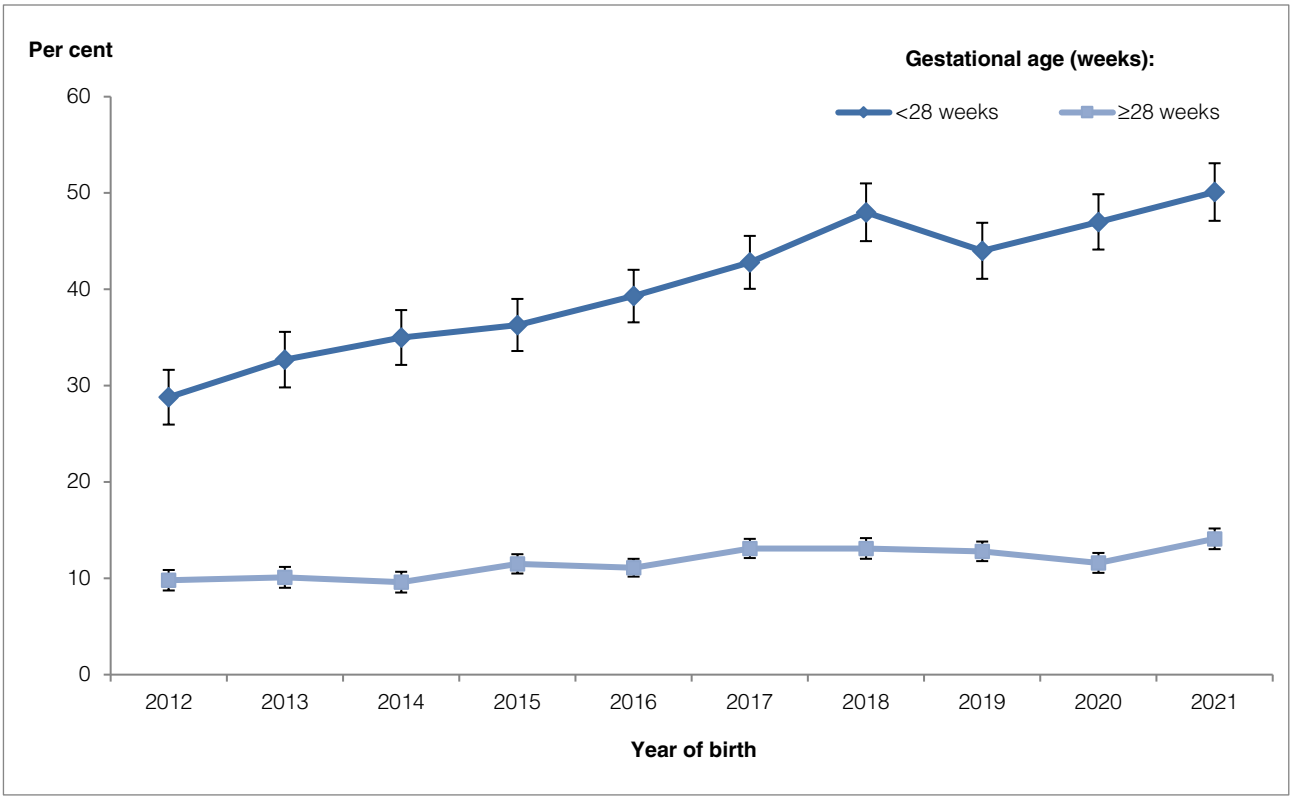
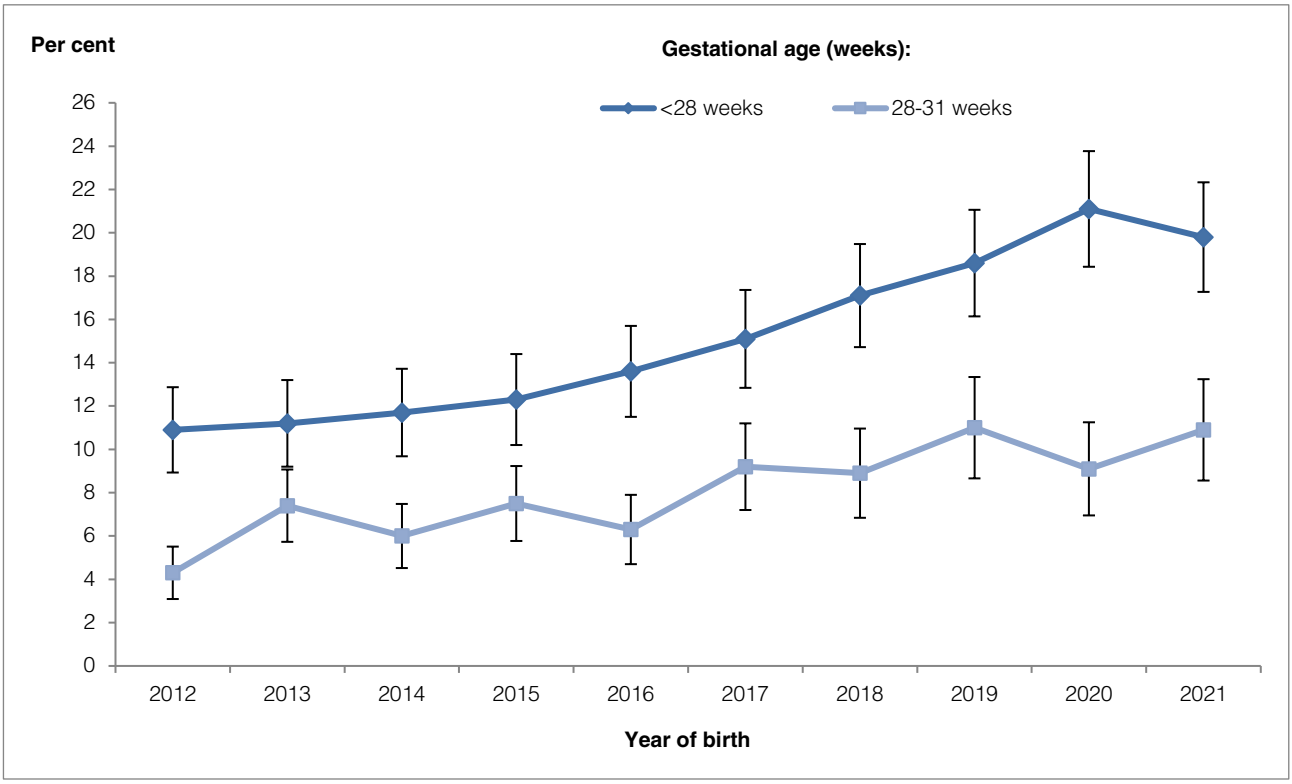


**FIGURE 20: Trends in provision of high frequency oscillatory ventilation (with 95% CI) for level III registrants born before 28 weeks and at 28 or more weeks gestation, ANZNN 2012–2021**




***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 2012–2021**




***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 2012–2021**

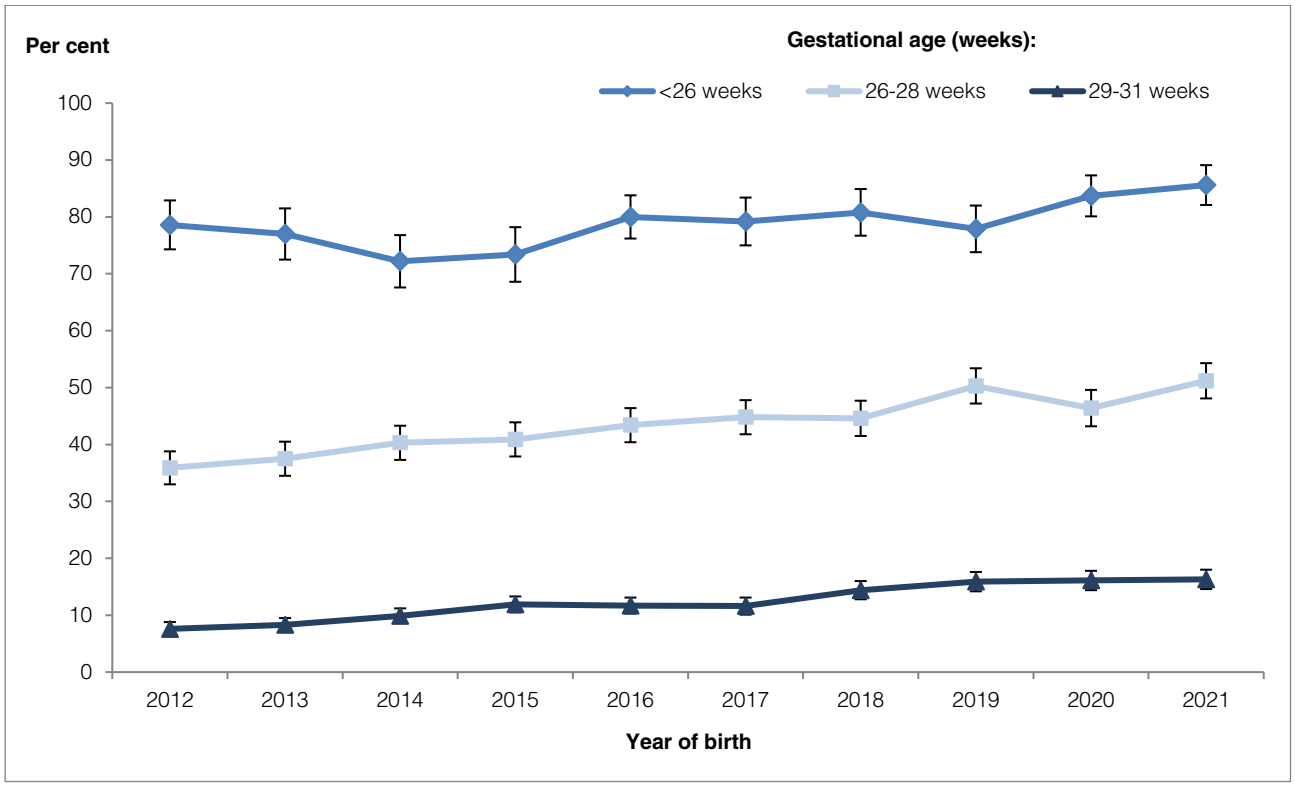



**FIGURE 23: Trends in stage 3 to 5 retinopathy of prematurity and treated retinopathy among babies born before 31 weeks gestation and/or birthweight of less than 1,250 grams who survived to 36 weeks post menstrual age for level III registrants, ANZNN 2012–2021**

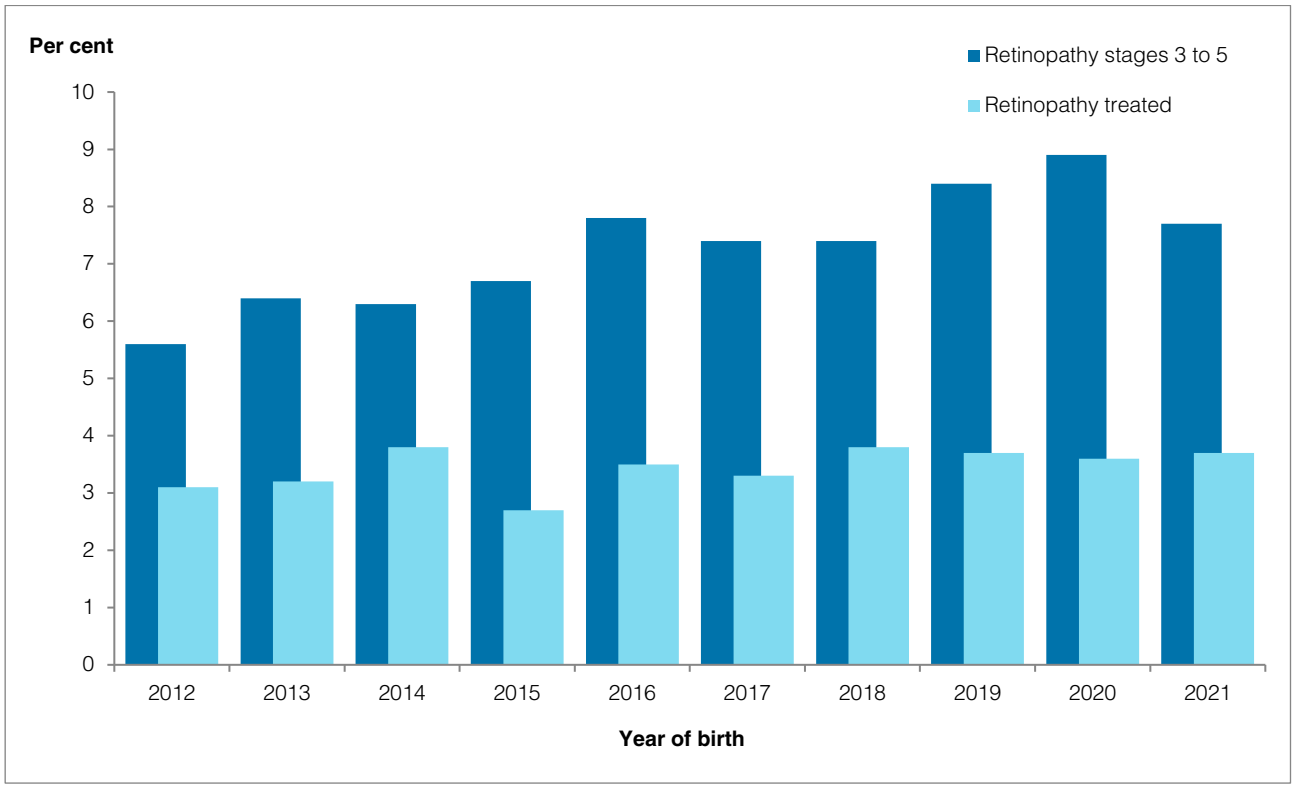


**FIGURE 24: Trends in grade 3 or 4 intraventricular haemorrhage (with 95% CI) in babies born at less than 32 weeks gestation who survived to day 3 for level III registrants, ANZNN 2012–2021**

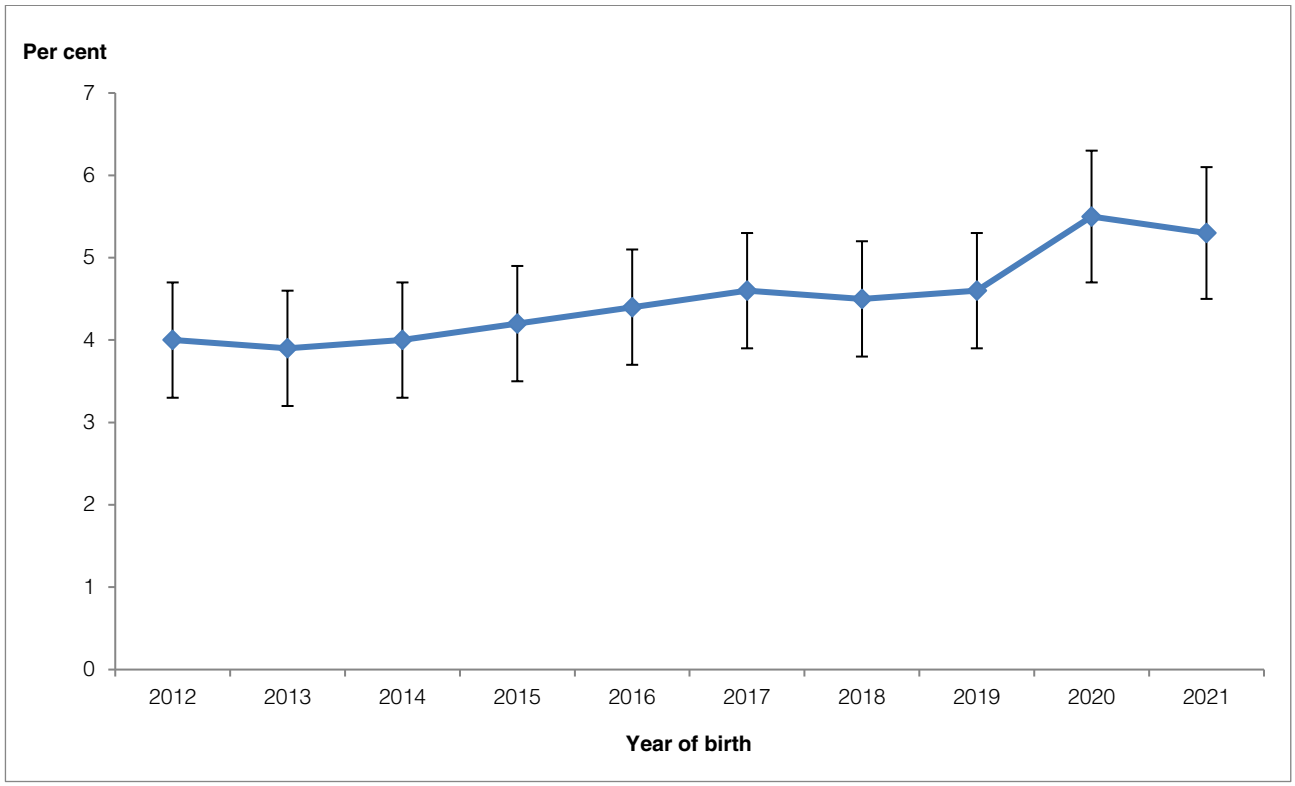



**FIGURE 25: Trends in incidence of early sepsis for level III registrants by gestational age, ANZNN 2017–2021**

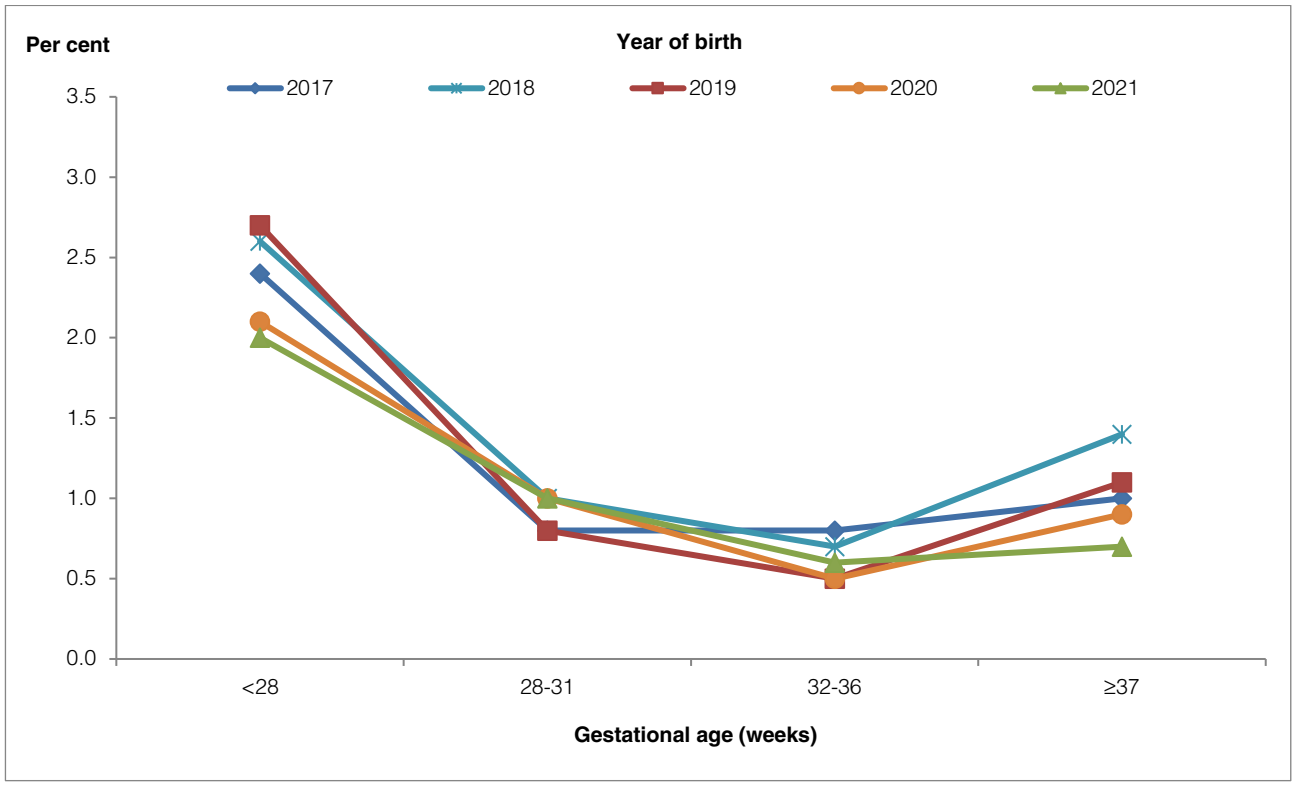


**FIGURE 26: Trends in incidence of late sepsis for level III registrants by gestational age, ANZNN 2017–2021**

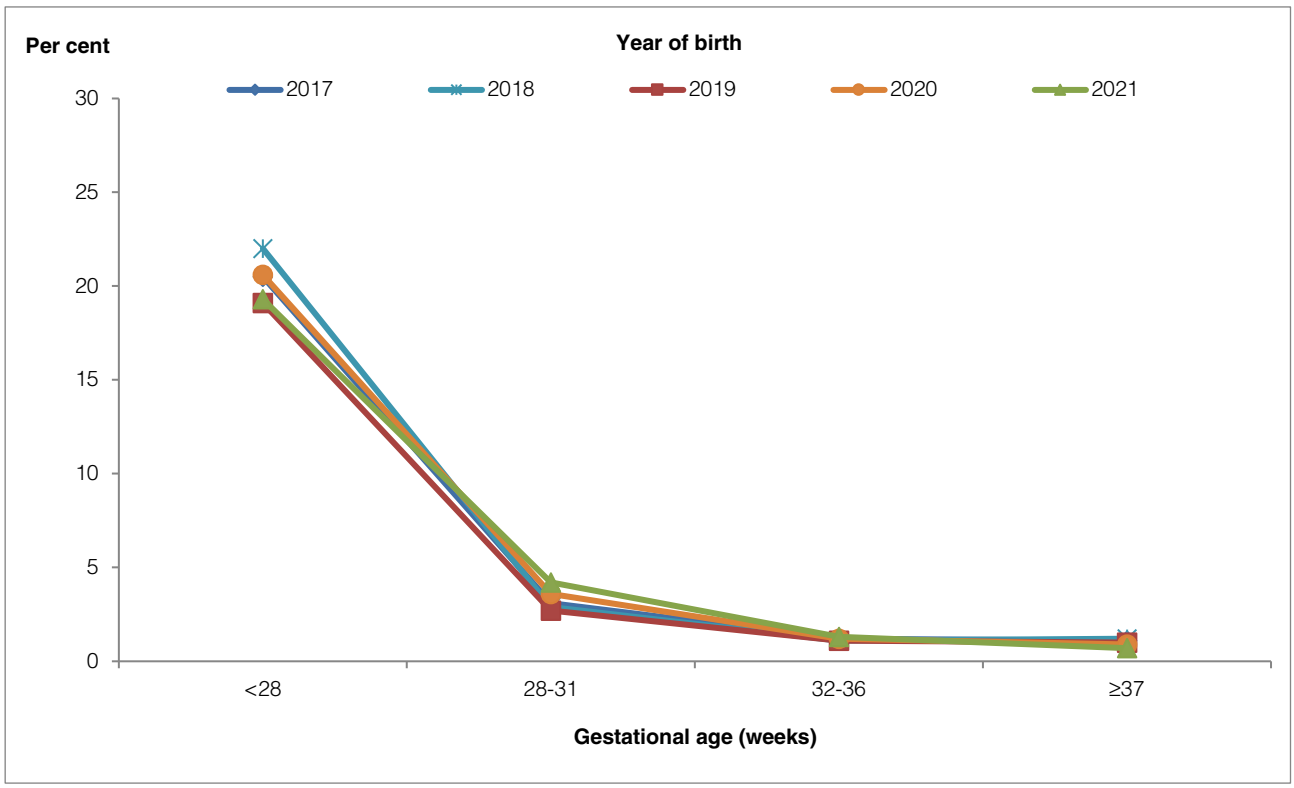
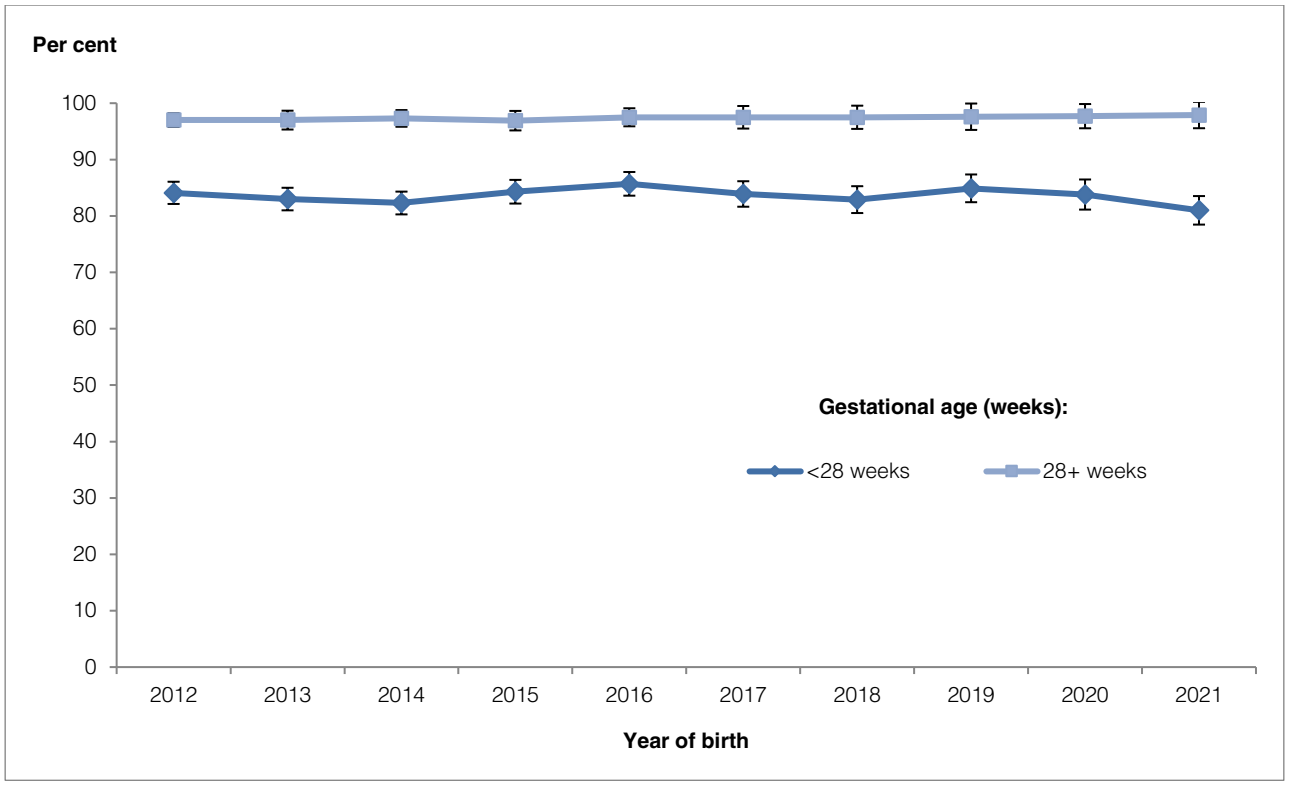



**FIGURE 27: Trends in survival to discharge to home for level III registrants, ANZNN 2012–2021**



# Extremely Preterm Follow-up

**FIGURE 28: Trends in follow-up at 18-42 months corrected age of extremely preterm or extremely low birth weight infants who survived to discharge to home, by year of birth, ANZNN 2009–2018 births**

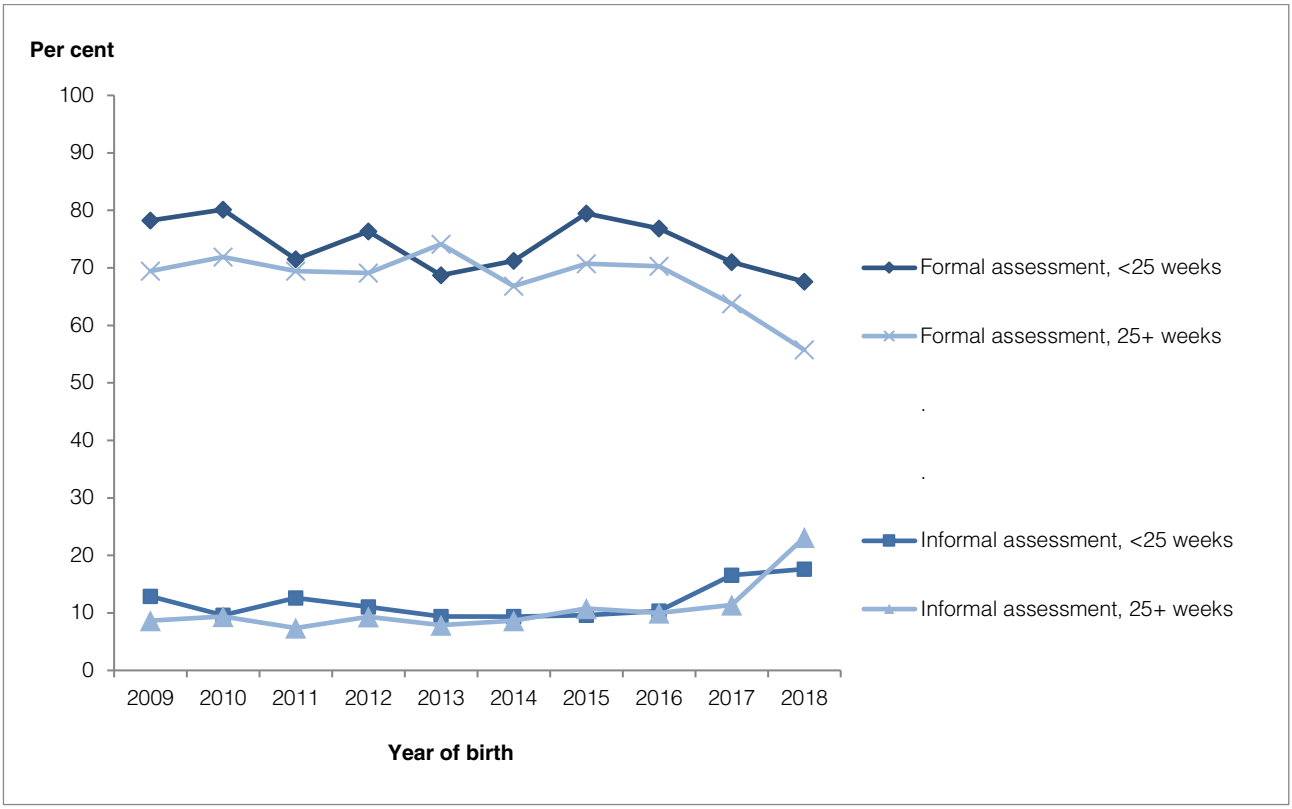
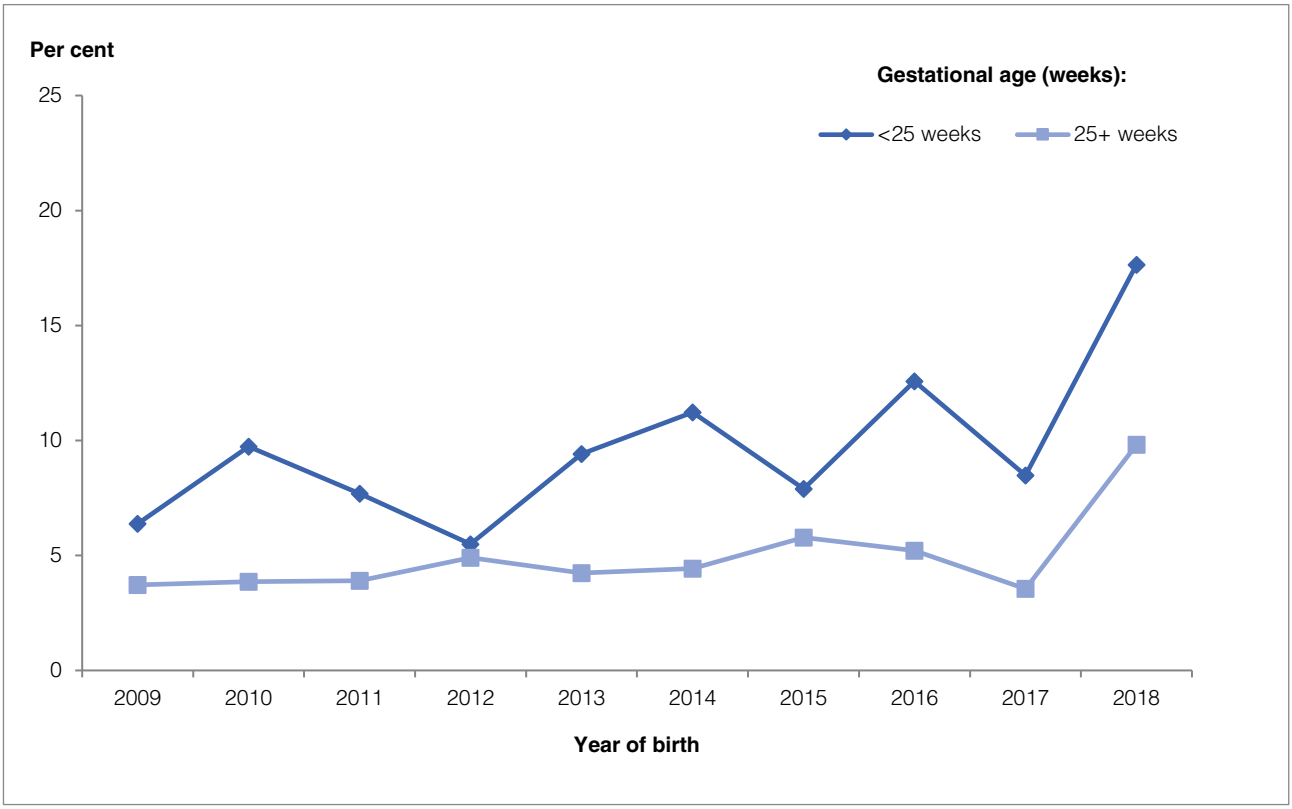
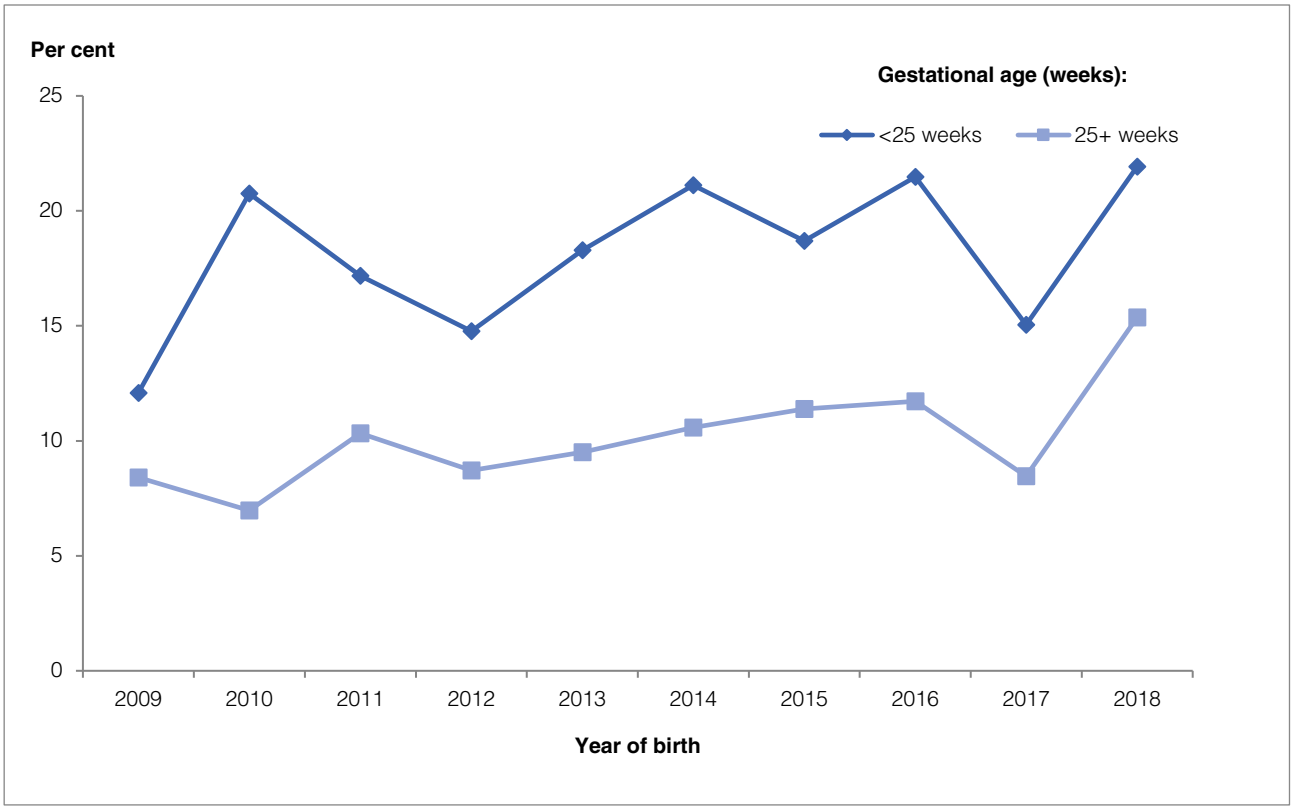



**FIGURE 29: Trends in moderate to severe cognitive developmental delay at 18-42 months corrected age for extremely preterm or extremely low birth weight infants who were formally assessed, by year of birth, ANZNN 2009–2018[(a)]**



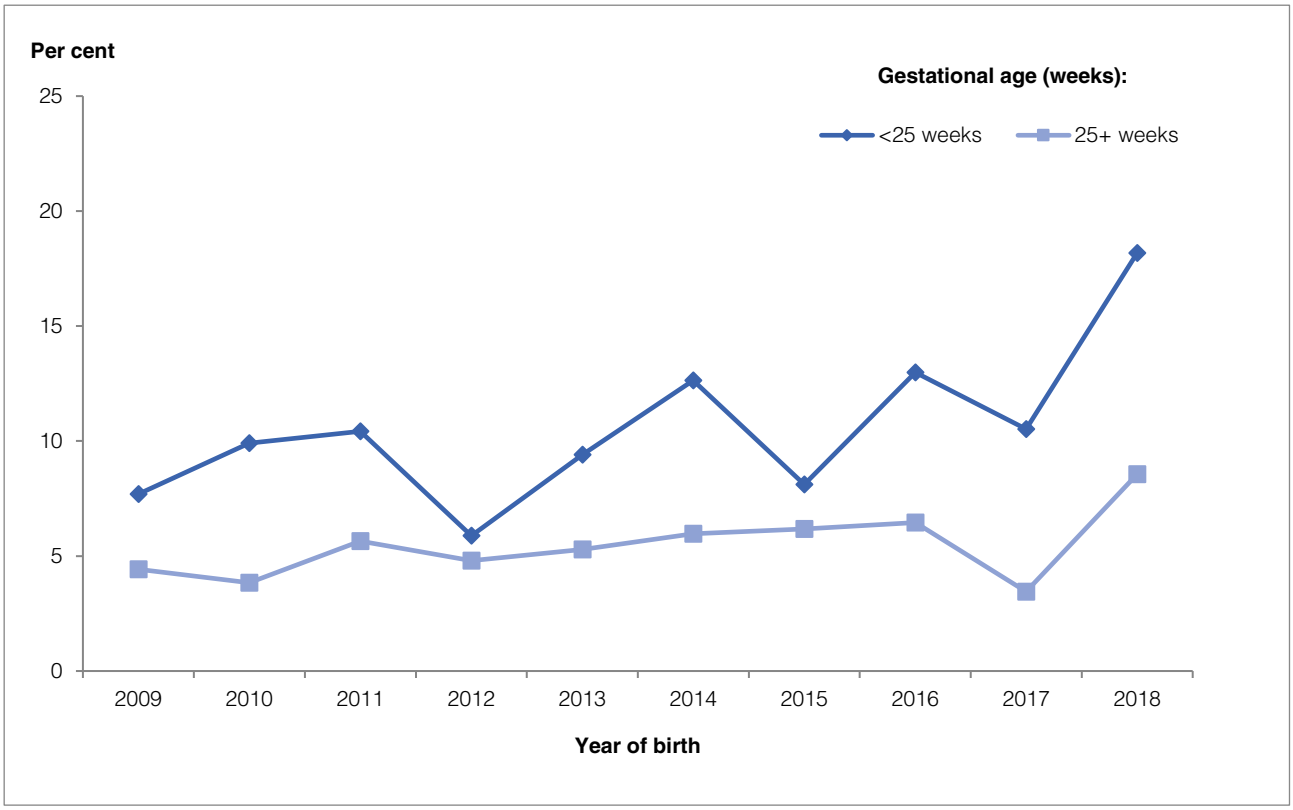

*(a) The cohort of infants born in 2018 and assessed formally may be skewed towards those at greater risk of developmental delay.*

**FIGURE 30: Trends in moderate to severe language developmental delay at 18-42 months corrected age for extremely preterm or extremely low birth weight infants who were formally assessed, by year of birth, ANZNN 2009–2018[(a)]**



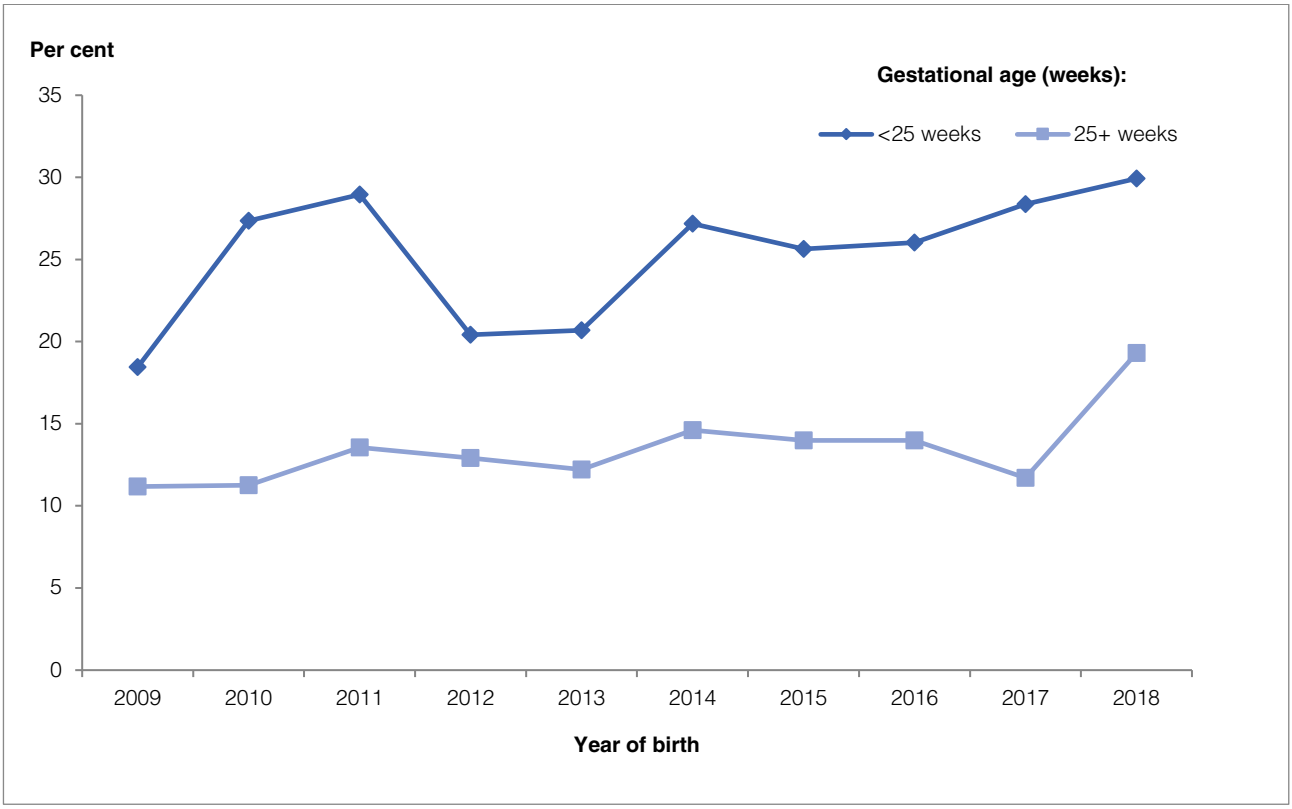

*(a) The cohort of infants born in 2018 and assessed formally may be skewed towards those at greater risk of developmental delay.*

**FIGURE 31: Trends in moderate to severe motor developmental delay at 18-42 months corrected age for extremely preterm or extremely low birth weight infants who were formally assessed, by year of birth, ANZNN 2009–2018[(a)]**




*(a) The cohort of infants born in 2018 and assessed formally may be skewed towards those at greater risk of developmental delay.*

**FIGURE 32: Trends in moderate to severe impairment at 18-42 months corrected age for extremely preterm or extremely low birth weight infants who were able to be assessed, by year of birth, ANZNN 2009–2018**



# Appendix 2: Data tables by birthweight

**TABLE 52: Antenatal corticosteroid use for level III registrants by birthweight, ANZNN 2021**

| | Birthweight (grams) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Antenatal corticosteroids** | **<500** | **500-749** | **750-999** | **1000-1249** | **1250-1499** | **1500-1999** | **2000-2499** | **2500-2999** | **3000-3499** | **3500-3999** | **≥4000** | **Total** |
| | | | | | | **Number** | | | | | | |
| None | 5 | 37 | 42 | 57 | 98 | 294 | 613 | 1191 | 1,560 | 1277 | 680 | 5,854 |
| Incomplete course | 19 | 110 | 171 | 205 | 224 | 487 | 321 | 110 | 26 | 6 | 8 | 1,687 |
| Complete course within 7 days of birth | 51 | 281 | 374 | 445 | 539 | 771 | 438 | 166 | 50 | 28 | 21 | 3,164 |
| Given >7 days prior to birth | 6 | 45 | 71 | 112 | 138 | 203 | 149 | 69 | 28 | 15 | 5 | 841 |
| Not stated | 0 | 0 | 2 | 6 | 3 | 18 | 40 | 133 | 209 | 171 | 99 | 681 |
| **Total** | **81** | **473** | **660** | **825** | **1,002** | **1,773** | **1,561** | **1,669** | **1,873** | **1,497** | **813** | **12,227** |
| | | | | | | **Per cent** | | | | | | |
| None | 6.2 | 7.8 | 6.4 | 7.0 | 9.8 | 16.8 | 40.3 | 77.5 | 93.8 | 96.3 | 95.2 | 50.7 |
| Incomplete course | 23.5 | 23.3 | 26.0 | 25.0 | 22.4 | 27.7 | 21.1 | 7.2 | 1.6 | 0.5 | 1.1 | 14.6 |
| Complete course within 7 days of birth | 63.0 | 59.4 | 56.8 | 54.3 | 54.0 | 43.9 | 28.8 | 10.8 | 3.0 | 2.1 | 2.9 | 27.4 |
| Given >7 days prior to birth | 7.4 | 9.5 | 10.8 | 13.7 | 13.8 | 11.6 | 9.8 | 4.5 | 1.7 | 1.1 | 0.7 | 7.3 |
| **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** |

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

**TABLE 53: Plurality of level III registrants by birthweight, ANZNN 2021**

| | Birthweight (grams) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Plurality** | **<500** | **500-749** | **750-999** | **1000-1249** | **1250-1499** | **1500-1999** | **2000-2499** | **2500-2999** | **3000-3499** | **3500-3999** | **≥4000** | **Total** |
| | | | | | | **Number** | | | | | | |
| Singleton | 60 | 365 | 490 | 574 | 718 | 1,182 | 1,218 | 1,486 | 1,842 | 1,492 | 813 | 10,240 |
| Twins | n.p. | 99 | 160 | 228 | 246 | 546 | 327 | n.p. | 31 | 5 | 0 | 1,842 |
| Triplets and higher orders | <5 | 9 | 10 | 23 | 38 | 45 | 16 | <5 | 0 | 0 | 0 | 145 |
| **Total** | **81** | **473** | **660** | **825** | **1,002** | **1,773** | **1,561** | **1,669** | **1,873** | **1,497** | **813** | **12,227** |
| | | | | | | **Per cent** | | | | | | |
| Singleton | 74.1 | 77.2 | 74.2 | 69.6 | 71.7 | 66.7 | 78.0 | 89.0 | 98.3 | 99.7 | 100.0 | 83.7 |
| Twins | n.p. | 20.9 | 24.2 | 27.6 | 24.6 | 30.8 | 20.9 | n.p. | 1.7 | 0.3 | 0.0 | 15.1 |
| Triplets and higher orders | n.p. | 1.9 | 1.5 | 2.8 | 3.8 | 2.5 | 1.0 | n.p. | 0.0 | 0.0 | 0.0 | 1.2 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

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

**TABLE 54: Method of birth for level III registrants by birthweight, ANZNN 2021**

| | Birthweight (grams) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Method of birth** | **<500** | **500-749** | **750-999** | **1000-1249** | **1250-1499** | **1500-1999** | **2000-2499** | **2500-2999** | **3000-3499** | **3500-3999** | **≥4000** | **Total** |
| | | | | | | **Number** | | | | | | |
| Vaginal birth | 18 | n.p. | 176 | 205 | 231 | 518 | 476 | n.p. | 666 | 568 | 251 | 3,807 |
| Vaginal instrumental birth | 0 | <5 | 5 | 12 | 20 | 72 | 95 | n.p. | 247 | 225 | 83 | 917 |
| Caesarean section in labour | 9 | 92 | 161 | 185 | 185 | 394 | 331 | 348 | 424 | 308 | 212 | 2,649 |
| Caesarean section no labour | 54 | 208 | 315 | 422 | 566 | 788 | 657 | 634 | 535 | 395 | 266 | 4,840 |
| Not stated | 0 | 1 | 3 | 1 | 0 | 1 | 2 | 3 | 1 | 1 | 1 | 14 |
| **Total** | **81** | **473** | **660** | **825** | **1,002** | **1,773** | **1,561** | **1,669** | **1,873** | **1,497** | **813** | **12,227** |
| | | | | | | **Per cent** | | | | | | |
| Vaginal birth | 22.2 | n.p. | 26.8 | 24.9 | 23.1 | 29.2 | 30.5 | n.p. | 35.6 | 38.0 | 30.9 | 31.2 |
| Vaginal instrumental birth | 0.0 | n.p. | 0.8 | 1.5 | 2.0 | 4.1 | 6.1 | n.p. | 13.2 | 15.0 | 10.2 | 7.5 |
| Caesarean section in labour | 11.1 | 19.5 | 24.5 | 22.5 | 18.5 | 22.2 | 21.2 | 20.9 | 22.6 | 20.6 | 26.1 | 21.7 |
| Caesarean section no labour | 66.7 | 44.1 | 47.9 | 51.2 | 56.5 | 44.5 | 42.1 | 38.1 | 28.6 | 26.4 | 32.8 | 39.6 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
***Note:*** *Not stated data are excluded from per cent calculations.*

**TABLE 55: Level of hospital of birth for level III registrants by birthweight, ANZNN 2021**

| | Birthweight (grams) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Level of birth hospital** | **<500** | **500-749** | **750-999** | **1000-1249** | **1250-1499** | **1500-1999** | **2000-2499** | **2500-2999** | **3000-3499** | **3500-3999** | **≥4000** | **Total** |
| | | | | | | **Number** | | | | | | |
| Tertiary | n.p. | 442 | 596 | 756 | 907 | 1,514 | 1,283 | 1,302 | 1,384 | 1,129 | n.p. | 10,022 |
| Non-tertiary | <5 | 22 | 56 | 62 | n.p. | 235 | 261 | 350 | 466 | 343 | 172 | 2,060 |
| Not born in a hospital[(a)] | 0 | 9 | 8 | 7 | <5 | 16 | 12 | 14 | 19 | 20 | n.p. | 120 |
| Not stated | 0 | 0 | 0 | 0 | 0 | 8 | 5 | 3 | 4 | 5 | 0 | 25 |
| **Total** | **81** | **473** | **660** | **825** | **1,002** | **1,773** | **1,561** | **1,669** | **1,873** | **1,497** | **813** | **12,227** |
| | | | | | | **Per cent** | | | | | | |
| Tertiary | n.p. | 93.4 | 90.3 | 91.6 | 90.5 | 85.8 | 82.5 | 78.2 | 74.1 | 75.7 | n.p. | 82.1 |
| Non-tertiary | n.p. | 4.7 | 8.5 | 7.5 | n.p. | 13.3 | 16.8 | 21.0 | 24.9 | 23.0 | 21.2 | 16.9 |
| Not born in a hospital[(a)] | 0.0 | 1.9 | 1.2 | 0.8 | n.p. | 0.9 | 0.8 | 0.8 | 1.0 | 1.3 | n.p. | 1.0 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
*(a) These babies were either born before arrival to hospital or born at home.*
***Note:*** *Not stated data are excluded from per cent calculations.*

**TABLE 56: Mode of transport for level III registrants to level III unit after birth by birthweight, ANZNN 2021**

| | Birthweight (grams) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Mode of transport** | **<500** | **500-749** | **750-999** | **1000-1249** | **1250-1499** | **1500-1999** | **2000-2499** | **2500-2999** | **3000-3499** | **3500-3999** | **≥4000** | **Total** |
| | | | | | | **Number** | | | | | | |
| Not transported | 78 | 432 | 584 | 742 | 889 | 1,494 | 1,238 | 1,253 | 1,330 | 1,108 | 618 | 9,766 |
| Specialist retrieval team | <5 | n.p. | 58 | 63 | 90 | 240 | 275 | 351 | 459 | 329 | 171 | 2,065 |
| Non-specialist team | <5 | <5 | 9 | 10 | 11 | 18 | 41 | 45 | 68 | 50 | 17 | 274 |
| Other | 0 | 7 | 8 | 9 | 11 | 20 | 6 | 19 | 13 | 9 | 7 | 109 |
| Not stated | 0 | 3 | 1 | 1 | 1 | 1 | 1 | 1 | 3 | 1 | 0 | 13 |
| **Total** | **81** | **473** | **660** | **825** | **1,002** | **1,773** | **1,561** | **1,669** | **1,873** | **1,497** | **813** | **12,227** |
| | | | | | | **Per cent** | | | | | | |
| Not transported | 96.3 | 91.9 | 88.6 | 90.0 | 88.8 | 84.3 | 79.4 | 75.1 | 71.1 | 74.1 | 76.0 | 80.0 |
| Specialist retrieval team | n.p. | n.p. | 8.8 | 7.6 | 9.0 | 13.5 | 17.6 | 21.0 | 24.5 | 22.0 | 21.0 | 16.9 |
| Non-specialist team | n.p. | n.p. | 1.4 | 1.2 | 1.1 | 1.0 | 2.6 | 2.7 | 3.6 | 3.3 | 2.1 | 2.2 |
| Other | 0.0 | 1.5 | 1.2 | 1.1 | 1.1 | 1.1 | 0.4 | 1.1 | 0.7 | 0.6 | 0.9 | 0.9 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
***Note:*** *Not stated data are excluded from per cent calculations.*

**TABLE 57: Exogenous surfactant use for level III registrants by birthweight, ANZNN 2021**

| | Birthweight (grams) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Exogenous surfactant** | **<500** | **500-749** | **750-999** | **1000-1249** | **1250-1499** | **1500-1999** | **2000-2499** | **2500-2999** | **3000-3499** | **3500-3999** | **≥4000** | **Total** |
| | | | | | | **Number** | | | | | | |
| None | <5 | 50 | 182 | 424 | 697 | 1,320 | 1,262 | 1,486 | n.p. | 1,397 | 760 | 9,300 |
| Surfactant given | 79 | 423 | 478 | 401 | 305 | 453 | 299 | 183 | 153 | 100 | 53 | 2,927 |
| ▪ via endotracheal tube | 70 | 355 | 356 | 288 | 211 | 324 | 223 | 134 | 123 | 82 | 42 | 2,208 |
| ▪ via catheter | n.p. | 58 | 108 | 101 | 87 | 121 | 71 | 34 | n.p. | 10 | 5 | 620 |
| ▪ via other or unknown method | <5 | 10 | 14 | 12 | 7 | 8 | 5 | 15 | n.p. | 8 | 6 | 99 |
| **Total** | **81** | **473** | **660** | **825** | **1,002** | **1,773** | **1,561** | **1,669** | **1,873** | **1,497** | **813** | **12,227** |
| | | | | | | **Per cent** | | | | | | |
| None | n.p. | 10.6 | 27.6 | 51.4 | 69.6 | 74.5 | 80.8 | 89.0 | n.p. | 93.3 | 93.5 | 76.1 |
| Surfactant given | 97.5 | 89.4 | 72.4 | 48.6 | 30.4 | 25.5 | 19.2 | 11.0 | 8.2 | 6.7 | 6.5 | 23.9 |
| ▪ via endotracheal tube | 86.4 | 75.1 | 53.9 | 34.9 | 21.1 | 18.3 | 14.3 | 8.0 | 6.6 | 5.5 | 5.2 | 18.1 |
| ▪ via catheter | n.p. | 12.3 | 16.4 | 12.2 | 8.7 | 6.8 | 4.5 | 2.0 | n.p. | 0.7 | 0.6 | 5.1 |
| ▪ via other or unknown method | n.p. | 2.1 | 2.1 | 1.5 | 0.7 | 0.5 | 0.3 | 0.9 | n.p. | 0.5 | 0.7 | 0.8 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

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

**TABLE 58: Assisted ventilation for level III registrants by birthweight, ANZNN 2021**

| Ventilation type | Birthweight (grams) <500 | 500-749 | 750-999 | 1000-1249 | 1250-1499 | 1500-1999 | 2000-2499 | 2500-2999 | 3000-3499 | 3500-3999 | ≥4000 | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | **Number** | | | | | | |
| Invasive ventilation | 80 | 414 | 421 | 310 | 229 | 384 | 389 | 449 | 509 | 319 | 131 | 3,635 |
| ▪ HFOV given | 62 | 263 | 146 | 68 | 47 | 37 | 45 | 46 | 69 | 51 | 24 | 858 |
| ▪ IPPV given | 80 | 414 | 419 | 309 | 229 | 384 | 389 | 447 | 508 | 319 | 131 | 3,629 |
| Nitric oxide given | 25 | 106 | 52 | 38 | 23 | 32 | 42 | 77 | 128 | 84 | 48 | 655 |
| CPAP given | 47 | 383 | 628 | 778 | 849 | 1,604 | 1,328 | 1,369 | 1,500 | 1,229 | 668 | 10,383 |
| NHF given | 39 | 310 | 515 | 585 | 472 | 566 | 370 | 333 | 407 | 329 | 217 | 4,143 |
| **Total in each birthweight group** | **81** | **473** | **660** | **825** | **1,002** | **1,773** | **1,561** | **1,669** | **1,873** | **1,497** | **813** | **12,227** |
| | | | | | | **Per cent** | | | | | | |
| IPPV given | 98.8 | 87.5 | 63.5 | 37.5 | 22.9 | 21.7 | 24.9 | 26.8 | 27.1 | 21.3 | 16.1 | 29.7 |
| CPAP given | 58.0 | 81.0 | 95.2 | 94.3 | 84.7 | 90.5 | 85.1 | 82.0 | 80.1 | 82.1 | 82.2 | 84.9 |
| NHF given | 48.1 | 65.5 | 78.0 | 70.9 | 47.1 | 31.9 | 23.7 | 20.0 | 21.7 | 22.0 | 26.7 | 33.9 |
| | | | | | | **Per cent of babies given invasive ventilation** | | | | | | |
| HFOV given[(a)] | 77.5 | 63.5 | 34.7 | 21.9 | 20.5 | 9.6 | 11.6 | 10.2 | 13.6 | 16.0 | 18.3 | 23.6 |
| Nitric oxide given[(a)] | 31.3 | 25.6 | 12.4 | 12.3 | 10.0 | 8.3 | 10.8 | 17.1 | 25.1 | 26.3 | 36.6 | 18.0 |

*(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. NHF = nasal high flow.*

**TABLE 59: Duration of assisted ventilation use for level III registrants by birthweight, ANZNN 2021**

| Duration of assisted ventilation | Birthweight (grams) <500 | 500-749 | 750-999 | 1000-1249 | 1250-1499 | 1500-1999 | 2000-2499 | 2500-2999 | 3000-3499 | 3500-3999 | ≥4000 | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | **IPPV (hours)** | | | | | | |
| **Median** | 231 | 262 | 82.5 | 28 | 27 | 28 | 46 | 55 | 58 | 49 | 52 | **54** |
| **IQR** | 55–556.5 | 79–571 | 24–247 | 13–93 | 12–93 | 12–76 | 20–91 | 22–109 | 26–120 | 22–101 | 19.5–97 | **20–145** |
| | | | | | | **CPAP (hours)** | | | | | | |
| **Median** | 1,168 | 1,172 | 895.5 | 370 | 114 | 51 | 28 | 21 | 18 | 17 | 18 | **38** |
| **IQR** | 590–1,489 | 792–1,499 | 370–1,250.5 | 128–793 | 48–282 | 23–117 | 13–62 | 10–48 | 9–39 | 8–36 | 8–34 | **14–128** |
| | | | | | | **NHF (hours)** | | | | | | |
| **Median** | 534 | 483 | 411 | 387 | 267 | 126 | 73 | 51 | 40 | 38 | 47 | **161** |
| **IQR** | 288–698 | 302–767 | 261–650 | 216–660 | 121–508 | 65–299 | 32–145 | 24–105.5 | 19–103 | 17–72 | 20–90 | **50–431** |

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

**TABLE 60: Chronic lung disease at 36 weeks post menstrual age for level III registrants by birthweight, ANZNN 2021**

| Chronic lung disease (CLD) | Birthweight (grams) | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | <500 | 500-749 | 750-999 | 1000-1249 | 1250-1499 | 1500-1999 | ≥2000 | Total |
| | | | | Number | | | | |
| No CLD | <5 | 44 | 229 | 459 | 547 | 738 | n.p. | 2,111 |
| CLD | n.p. | 310 | 358 | 242 | 126 | 69 | n.p. | 1,157 |
| Not stated | 0 | 5 | 7 | 10 | 9 | 10 | 0 | 41 |
| Ineligible[(a)] | 39 | 114 | 66 | 114 | 320 | 956 | 7,309 | 8,918 |
| **Total** | **81** | **473** | **660** | **825** | **1,002** | **1,773** | **7,413** | **12,227** |
| | | | | Per cent | | | | |
| No CLD | n.p. | 12.4 | 39.0 | 65.5 | 81.3 | 91.4 | n.p. | 64.6 |
| CLD | n.p. | 87.6 | 61.0 | 34.5 | 18.7 | 8.6 | n.p. | 35.4 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
*(a) 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 61: Respiratory support (airway support or supplemental oxygen therapy) for level III registrants who survived to day 28 by birthweight, ANZNN 2021**

| Respiratory support (airway support or oxygen) | Birthweight (grams) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | <500 | 500-749 | 750-999 | 1000-1249 | 1250-1499 | 1500-1999 | 2000-2499 | 2500-2999 | 3000-3499 | 3500-3999 | ≥4000 | Total |
| | | | | | | Number | | | | | | |
| No respiratory support on day 28 | 0 | <5 | 46 | 260 | 641 | 1,504 | 1,428 | 1,547 | n.p. | 1,442 | 777 | 9,409 |
| Respiratory support on day 28 | 44 | n.p. | 572 | 547 | 346 | 242 | 107 | 86 | n.p. | 31 | 27 | 2,445 |
| ▪ survived to discharge home | 39 | 345 | 553 | 539 | n.p. | 236 | 96 | n.p. | 69 | n.p. | 25 | 2,355 |
| ▪ died before discharge | 5 | n.p. | 19 | 8 | <5 | 6 | 11 | <5 | 9 | <5 | <5 | 90 |
| Not stated | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 2 |
| **Total in each birthweight group** | **44** | **369** | **618** | **807** | **987** | **1,746** | **1,535** | **1,633** | **1,840** | **1,473** | **804** | **11,856** |
| | | | | | | Number | | | | | | |
| Respiratory support on day 28 and given home oxygen | 11 | 119 | 106 | 59 | n.p. | 33 | 29 | n.p. | 16 | <5 | 5 | 422 |
| | | | | | | Per cent | | | | | | |
| No respiratory support on day 28 | 0.0 | n.p. | 7.4 | 32.2 | 64.9 | 86.1 | 93.0 | 94.7 | n.p. | 97.9 | 96.6 | 79.4 |
| Respiratory support on day 28 | 100.0 | n.p. | 92.6 | 67.8 | 35.1 | 13.9 | 7.0 | 5.3 | n.p. | 2.1 | 3.4 | 20.6 |
| ▪ survived to discharge home | 88.6 | 94.5 | 96.7 | 98.5 | n.p. | 97.5 | 89.7 | n.p. | 88.5 | n.p. | 92.6 | 96.3 |
| ▪ died before discharge | 11.4 | n.p. | 3.3 | 1.5 | n.p. | 2.5 | 10.3 | n.p. | 11.5 | n.p. | n.p. | 3.7 |
| | | | | | | Per cent | | | | | | |
| Respiratory support on day 28 and given home oxygen[(a)] | 28.2 | 34.5 | 19.2 | 10.9 | 9.6 | 14.0 | 30.2 | 11.0 | 23.2 | 6.9 | 20.0 | 17.9 |

*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 62: Transfer after registration of level III registrants by level of destination hospital by birthweight, ANZNN 2021**

| Transfer status | Birthweight (grams) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | <500 | 500-749 | 750-999 | 1000-1249 | 1250-1499 | 1500-1999 | 2000-2499 | 2500-2999 | 3000-3499 | 3500-3999 | ≥4000 | Total |
| | Number | | | | | | | | | | | |
| Not transferred | 53 | 267 | 326 | 365 | 391 | 788 | 948 | 1,218 | 1,483 | 1,231 | 672 | 7,742 |
| Level III hospital | <5 | 26 | 51 | 41 | 31 | 51 | 34 | 27 | 20 | 7 | n.p. | 297 |
| Level II or I hospital | n.p. | 118 | 240 | 377 | 552 | 890 | 529 | 330 | 273 | 211 | n.p. | 3,647 |
| Children's hospital | 12 | 62 | 43 | 42 | 28 | 43 | 50 | 93 | 97 | 47 | 21 | 538 |
| Not stated | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 0 | 1 | 0 | 3 |
| **Total** | **81** | **473** | **660** | **825** | **1,002** | **1,773** | **1,561** | **1,669** | **1,873** | **1,497** | **813** | **12,227** |
| | Per cent | | | | | | | | | | | |
| Not transferred | 65.4 | 56.4 | 49.4 | 44.2 | 39.0 | 44.5 | 60.7 | 73.0 | 79.2 | 82.3 | 82.7 | 63.3 |
| Level III hospital | n.p. | 5.5 | 7.7 | 5.0 | 3.1 | 2.9 | 2.2 | 1.6 | 1.1 | 0.5 | n.p. | 2.4 |
| Level II or I hospital | n.p. | 24.9 | 36.4 | 45.7 | 55.1 | 50.2 | 33.9 | 19.8 | 14.6 | 14.1 | n.p. | 29.8 |
| Children's hospital | 14.8 | 13.1 | 6.5 | 5.1 | 2.8 | 2.4 | 3.2 | 5.6 | 5.2 | 3.1 | 2.6 | 4.4 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
***Note:*** *Not stated data are excluded from per cent calculations.*

**TABLE 63: Retinopathy of prematurity for level III registrants by birthweight, ANZNN 2021**

| Retinopathy of prematurity (ROP) | Birthweight (grams) | | | | | | |
|---|---|---|---|---|---|---|---|
| | <500 | 500-749 | 750-999 | 1000-1249 | 1250-1499 | ≥1500 | Total |
| | Number | | | | | | |
| No ROP | <5 | n.p. | n.p. | 498 | 423 | 428 | 1,707 |
| Stage 1 ROP | <5 | 66 | 126 | 138 | 74 | n.p. | 440 |
| Stage 2 ROP | 26 | 108 | 138 | 80 | 26 | 7 | 385 |
| Stage 3 ROP | n.p. | 96 | 46 | 21 | <5 | <5 | 177 |
| Stage 4 to 5 ROP | 0 | <5 | <5 | 0 | <5 | 0 | 7 |
| Not examined | 38 | 117 | 76 | 88 | 473 | 8,702 | 9,494 |
| Not stated | 0 | 0 | 0 | 0 | 1 | 16 | 17 |
| **Total** | **81** | **473** | **660** | **825** | **1,002** | **9,186** | **12,227** |
| | Per cent | | | | | | |
| No ROP | n.p. | n.p. | n.p. | 67.6 | 80.1 | 91.5 | 62.8 |
| Stage 1 ROP | n.p. | 18.5 | 21.6 | 18.7 | 14.0 | n.p. | 16.2 |
| Stage 2 ROP | 60.5 | 30.3 | 23.6 | 10.9 | 4.9 | 1.5 | 14.2 |
| Stage 3 ROP | n.p. | 27.0 | 7.9 | 2.8 | n.p. | n.p. | 6.5 |
| Stage 4 to 5 ROP | 0.0 | n.p. | n.p. | 0.0 | n.p. | 0.0 | 0.3 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
***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 64: Intraventricular haemorrhage for level III registrants who survived to day 3 by birthweight, ANZNN 2021[a]**

| Intraventricular haemorrhage | Birthweight (grams) | | | | | | |
|---|---|---|---|---|---|---|---|
| | <500 | 500-749 | 750-999 | 1000-1249 | 1250-1499 | ≥1500 | Total |
| | | | | Number | | | |
| None | 41 | 259 | 473 | 666 | 711 | 1,943 | 4,093 |
| Grade 1 | n.p. | 55 | 66 | 76 | 91 | n.p. | 440 |
| Grade 2 | 6 | 57 | 51 | 34 | 24 | 35 | 207 |
| Grade 3 | <5 | 10 | 14 | 6 | 5 | n.p. | 46 |
| Grade 4 | 11 | 59 | 30 | 11 | 9 | 19 | 139 |
| Not examined | 1 | 6 | 8 | 23 | 156 | 6,981 | 7,175 |
| **Total** | **68** | **446** | **642** | **816** | **996** | **9,132** | **12,100** |
| | | | | Per cent | | | |
| None | 61.2 | 58.9 | 74.6 | 84.0 | 84.6 | 90.3 | 83.1 |
| Grade 1 | n.p. | 12.5 | 10.4 | 9.6 | 10.8 | n.p. | 8.9 |
| Grade 2 | 9.0 | 13.0 | 8.0 | 4.3 | 2.9 | 1.6 | 4.2 |
| Grade 3 | n.p. | 2.3 | 2.2 | 0.8 | 0.6 | n.p. | 0.9 |
| Grade 4 | 16.4 | 13.4 | 4.7 | 1.4 | 1.1 | 0.9 | 2.8 |
| **Total** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** | **100.0** |

*n.p. Data not published to maintain confidentiality of small numbers.*
*(a) Weight criterion for IVH is a birthweight of less than 1,500 grams.*
***Note:*** *Not examined data are excluded from per cent calculations.*

**TABLE 65: Neonatal sepsis for level III registrants by birthweight, ANZNN 2021**

| Sepsis | Birthweight (grams) | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | <500 | 500-749 | 750-999 | 1000-1249 | 1250-1499 | 1500-1999 | 2000-2499 | 2500-2999 | 3000-3499 | 3500-3999 | ≥4000 | Total |
| | | | | | | Number | | | | | | |
| No sepsis | 54 | 355 | 555 | 778 | 955 | 1,715 | 1,532 | 1,647 | 1,852 | 1,476 | 801 | 11,720 |
| Sepsis at <48 hrs[a] | <5 | 13 | 7 | <5 | 10 | 19 | 10 | 6 | 9 | 15 | n.p. | 102 |
| Sepsis at ≥48 hrs[a] | 27 | 108 | 101 | 44 | 37 | 40 | n.p. | 16 | 12 | 6 | <5 | 414 |
| Babies alive on day 2 | n.p. | 457 | 651 | n.p. | 997 | n.p. | n.p. | 1,663 | 1,863 | 1,490 | n.p. | 12,147 |
| Babies who did not survive to day 2 | n.p. | 16 | 9 | n.p. | 5 | <5 | <5 | 6 | 10 | 7 | <5 | 80 |
| **Total in each birthweight group** | **81** | **473** | **660** | **825** | **1,002** | **1,773** | **1,561** | **1,669** | **1,873** | **1,497** | **813** | **12,227** |
| | | | | | | Per cent | | | | | | |
| No sepsis[b] | 66.7 | 75.1 | 84.1 | 94.3 | 95.3 | 96.7 | 98.1 | 98.7 | 98.9 | 98.6 | 98.5 | 95.9 |
| Sepsis at <48 hrs[b] | n.p. | 2.7 | 1.1 | n.p. | 1.0 | 1.1 | 0.6 | 0.4 | 0.5 | 1.0 | n.p. | 0.8 |
| Sepsis at ≥48 hrs[c] | 38.0 | 23.6 | 15.5 | 5.4 | 3.7 | 2.3 | n.p. | 1.0 | 0.6 | 0.4 | n.p. | 3.4 |

*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 66: Length of stay for level III registrants who survived until discharge home by birthweight, ANZNN 2021**

| Birthweight (grams) | Number of babies | Median length of stay (days) | Interquartile range (days) |
|---|---|---|---|
| <500 | 39 | 141 | 126–162 |
| 500-749 | 348 | 117 | 101–139 |
| 750-999 | 599 | 92 | 75–110 |
| 1,000-1,249 | 799 | 68 | 54–82 |
| 1,250-1,499 | 983 | 51 | 39–63 |
| 1,500-1,999 | 1,740 | 38 | 29–48 |
| 2,000-2,499 | 1,524 | 21 | 14–29 |
| 2,500-2,999 | 1,629 | 11 | 5–19 |
| 3,000-3,499 | 1,830 | 6 | 4–13 |
| 3,500-3,999 | 1,471 | 5 | 3–11 |
| ≥4,000 | 802 | 6 | 3–11 |
| **Total** | **11,764** | **22** | **7–48** |

**TABLE 67: Survival to discharge home for level III registrants by birthweight, ANZNN 2021**

| 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 | 81 | <5 | 57 | 44 | 39 | 48.1 |
| 500-749 | 473 | <5 | 417 | 369 | 348 | 73.6 |
| 750-999 | 660 | <5 | 630 | 618 | 599 | 90.8 |
| 1,000-1,249 | 825 | 8 | 815 | 807 | 799 | 96.8 |
| 1,250-1,499 | 1,002 | 6 | 993 | 987 | 983 | 98.1 |
| 1,500-1,999 | 1,773 | 19 | 1,761 | 1,746 | 1,740 | 98.1 |
| 2,000-2,499 | 1,561 | 16 | 1,544 | 1,535 | 1,524 | 97.6 |
| 2,500-2,999 | 1,669 | 16 | 1,644 | 1,633 | 1,629 | 97.6 |
| 3,000-3,499 | 1,873 | 15 | 1,852 | 1,840 | 1,830 | 97.7 |
| 3,500-3,999 | 1,497 | <5 | 1,481 | 1,473 | 1,471 | 98.3 |
| ≥4,000 | 813 | <5 | 805 | 804 | 802 | 98.6 |
| **Total** | **12,227** | **92** | **11,999** | **11,856** | **11,764** | **96.2** |

# 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 2021 who qualified as high-risk neonates were requested from each participating unit in May 2022 with a deadline of July 2022. 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 June 2023. Apart from grouping, the data presented in the report reflect the database at that time with one exception: a series of derived data items were generated. These are listed below.

## Derived data items:

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

All data manipulations and analysis for the 2021 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 31 December 2025.
- 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

ANZNN data is maintained in a secure partition by the University of New South Wales. Access to the server is restricted to designated ports within the NPESU office and access is limited to authorised named staff and further protected by the use of high-level passwords. Access to the server is managed by UNSW IT department. Attempted security breaches are monitored and investigated. The NPESU is located in a restricted access UNSW managed building with all internal doors to the NPESU office accessible only via swipe card by authorised staff and students.

## 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.

## Sex

*Definition:* The sex of the patient.

*Coding:*

0: unknown.

1: male.

2: female.

3: ambiguous or indeterminate.

## Infant weight

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

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

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

## Gestational age

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

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

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

## Place of birth

*Definition:* Place of baby's birth.

*Coding:*

0: unknown.

1: non-tertiary hospital – born in a hospital with no level III NICU.

2: tertiary hospital – born in a hospital with a level III NICU.

3: homebirth – planned.

4: born before arrival – unplanned birth at home, or in an ambulance, a car etc.

## Presentation at birth

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

*Coding:*

0: unknown.

1: cephalic – including face and brow.

2: breech – legs or feet were facing the cervix.

3: other – includes transverse.

## Mode of birth

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

*Coding:*

0: unknown.

1: vaginal – vaginal birth, includes breech.

2: instrument – vaginal birth using an instrument – forceps, rotations, vacuum extraction.

3: Caesarean section in labour – caesarean performed after the commencement of labour.

4: Caesarean section, no labour – caesarean section performed prior to labour commencing.

## Antenatal corticosteroids

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

*Coding:*

0: unknown.

1: none – steroids not given.

2: less than 24 hours – first dose given less than 24 hours prior to this baby's birth.

3: complete – more than 1 dose of steroids given, and 1st dose at more than 24 hours and less than 8 days before birth.

4: given at more than 7 days before baby's birth.

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

## Magnesium sulphate

*Definition:* Magnesium sulphate ($MgSO_4$) provided to the mother during the 24 hours immediately before birth, either because of maternal preeclampsia or specifically for fetal neuro-protection.

*Coding:*

0: unknown – information not available.

1: $MgSO_4$ not given at all.

2: $MgSO_4$ course stopped > 24 hours before birth.

3: $MgSO_4$ commenced > 24 hours before birth and stopped < 24 hours before birth.

4: $MgSO_4$ commenced between 4 to 24 hours before birth.

5: $MgSO_4$ commenced within 4 hours of birth.

6: $MgSO_4$ given but details not known.

7: $MgSO_4$/placebo given for randomised trial.

*Guide for use:* In the case of planned birth, $MgSO_4$ 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 ≥ 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 ($O_2$) 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 – echocardiac (shunting) or clinical evidence – $O_2$ need unexplained by chest x-ray or loud P2, or differential pre/post ductal $TCPO_2$.

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:* The number of hours of any form of CPAP is summed for all instances of this therapy.

## Hours of nasal high flow

*Definition:* Total number of hours of air and oxygen mix delivered through a high flow device in hours.

*Coding:* 4-digit number – nasal high flow hours

*Guide for use:* The number of hours of any form of CPAP is summed for all instances of this therapy.

## Hours of high frequency oscillatory ventilation (HFOV)

*Definition:* Total number of hours of high frequency oscillatory ventilation given via an endotracheal tube, at > 4Hz

*Coding:* 4-digit number – HFOV hours

*Guide for use:* The number of hours of any form of HFOV is summed for all instances of this therapy.

## Hours of nitric oxide

*Definition:* Total number of hours of nitric oxide therapy in any form or dose for respiratory support of the baby.

*Coding:* 4-digit number – nitric oxide hours

*Guide for use:* The number of hours of any form of nitric oxide is summed for all instances of this therapy.

## 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 ($O_2$), 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'.

## 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 (≤1L/min).

3: low flow oxygen (≤1L/min).

4: oxygen via head box or incubator.

5: high flow >1L/min.

6: nasal CPAP.

7: nasal ventilation (includes nasal high frequency).

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

9: endotracheal tube alone.

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

11: tracheostomy alone.

*Guide for use:* Supersedes "Chronic lung disease".

## Post-natal steroids for chronic lung disease

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

*Coding:*

99: unknown.

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

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

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

## Home oxygen therapy

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

*Coding:*

99: unknown.

0: no supplemental oxygen used at home.

-1: yes, home oxygen therapy given.

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

## Neonatal surgery

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

*Coding:*

99: unknown.

0: no major neonatal surgery.

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

## Parenteral nutrition

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

*Coding:*

99: unknown.

0: parenteral nutrition never initiated.

-1: yes, parenteral nutrition initiated.

## Home gavage feeding

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

*Coding:*

99: unknown.

0: no, not discharged with gavage tube.

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

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

## Proven necrotising enterocolitis

*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 fibro-vascular 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.

7: COVID-19 impact – includes not attending appointment or appointment not offered due to COVD-19-related restrictions.

*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

2: Level II

3: Level III

4: Level IV

5: Level V

## Bayley edition

*Definition:* The edition of the Bayley Scales of Infant and Toddler Development assessment used.

*Coding:*

0: unknown.

1: Bayley-III assessment.

2: Bayley 4 (A&NZ) assessment.

## Cognitive composite score

*Definition:* The cognitive scale of the Bayley-III / Bayley 4 (A&NZ) 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 / Bayley 4 (A&NZ) 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 / Bayley 4 (A&NZ) 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 / Bayley 4 (A&NZ) 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 / Bayley 4 (A&NZ) 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 / Bayley 4 (A&NZ) 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 / Bayley 4 (A&NZ) 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.

## 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 Developmental 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.

**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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