

report of the

Australian & New Zealand Neonatal Network 2000

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Abbreviations

A full explanation of definitions used for the Australian and New Zealand Neonatal Network audit of high-risk babies during 2000 is given in Appendix 1. Please refer to this section for any abbreviations that may appear in the report that are not outlined in this section.

ANZNN – Australian and New Zealand Neonatal Network

APH – Antepartum haemorrhage (a complication of pregnancy) – see Appendix 1 for definitions

BE – Base excess

BW – Birthweight (in grams) – see Appendix 1 for definitions

CPAP – Continuous positive airways pressure (a form of assisted ventilation) – see Appendix 1 for definitions

DOA – Date of admission to the nursery – see Appendix 1 for definitions

DOB – Date of birth – see Appendix 1 for definitions

FiO₂ – Fractional inspired oxygen (measures amount of supplemental oxygen) – see Appendix 1 for definition

GA – Gestational age (measured in completed weeks) – see Appendix 1 for definition

HMD – Hyaline membrane disease (a respiratory disorder) – see Appendix 1 for definitions

ICD.9 CM – International Classification of Diseases 9th revision clinical modification.

IPPV – Intermittent positive pressure ventilation (a form of assisted mechanical ventilation) – see Appendix 1 for definition

IUGR – Intrauterine growth restriction (a complication of pregnancy) – see Appendix 1 for definition

IVH – Intraventricular haemorrhage (a brain disorder) – see Appendix 1 for definition

Level II – a nursery for babies who require intermediate care – see section 3.2 for definition

Level III – a nursery for babies who require intensive care – see section 3.2 for definition

n – Number

NEC – Necrotising enterocolitis (a gut disorder) – see Appendix 1 for definitions

NHMRC – National Health and Medical Research Council of Australia

NICU – Neonatal Intensive Care Unit

NPSU – National Perinatal Statistics Unit

O₂ – Oxygen

PIH – Hypertension in pregnancy (a complication of pregnancy) – see Appendix 1 for definition

PMA – Post menstrual age (gestational age plus chronological age, in weeks)

PPROM – Preterm pre-labour rupture of the membranes (a complication of pregnancy) – see Appendix 1 for definition

PROM – Prolonged rupture of membranes (a complication of pregnancy) – see Appendix 1 for definition

PTL – Preterm labour (a complication of pregnancy) – see Appendix 1 for definition

PVL – Periventricular leukomalacia (a brain disorder) – see Appendix 1 for definition

ROP – Retinopathy of prematurity (an eye disorder) – see Appendix 1 for definition

S_aO₂ – Oxygen saturation (a method of monitoring levels of oxygen in the blood)

T_cPO₂ – Transcutaneous partial pressure of oxygen (another method of monitoring levels of oxygen in the blood)

WHO – World Health Organisation

ACT – Australian Capital Territory

NSW – New South Wales

NT – Northern Territory

NZ – New Zealand

Qld – Queensland

SA – South Australia

Tas – Tasmania

Vic – Victoria

WA – Western Australia

Highlights

The Australian & New Zealand Neonatal Network (ANZNN) is a voluntary collaboration of all 28 level III Neonatal Intensive Care Units (NICUs) in both countries. All 13 level II nurseries in New Zealand and the level II nursery in Tasmania are also members of the ANZNN. This network continues to conduct an ongoing prospective audit of the most at-risk babies admitted for care in neonatal nurseries. The audit looks at factors that may affect the outcomes of babies that can be measured while in hospital.

During 2000, 6385 babies met the registration criteria of the ANZNN audit and were admitted a III NICU. An additional 319 babies who met the criteria were admitted to a level II nursery and not transferred to a level III nursery within 28 days of birth.

For the babies registered to a level II nursery, 57 were born at less than 32 weeks' gestation, 46 were less than 1500 gm at birth, 275 received assisted ventilation and 11 babies received major surgery (registration criteria groups are not mutually exclusive). These figures are similar to those seen in 1999.

There were 3285 babies born at less than 32 weeks' gestation registered to the level III NICU audit in 2000. Assisted ventilation (either intermittent positive pressure ventilation or continuous positive airways pressure) was given to 5985 babies, and 778 received major surgery.

The ANZNN level III cohort represents 2.23% of the total births for the two countries, a similar rate to that seen in 1999 (2.25%). However, this rate had increased steadily from 1.8% in 1995 until 1999. The most marked increase has been in the numbers of babies receiving assisted ventilation who are born at more than 31 weeks' gestation and the number of babies born very preterm. Babies born in New Zealand in 2000 who were registered to the ANZNN high-risk cohort from both level III and Level III nurseries comprised 3.43% of the total livebirths.

As this audit has been conducted in all level III NICUs since 1995, trends in the data can be examined. For example the NHMRC's Clinical practice guidelines for care around preterm birth recommend that corticosteroids should be considered for the mother before a baby is born preterm. This treatment greatly reduces the chances of problems with breathing or bleeding into the brain or of death for the baby. ANZNN's audit has demonstrated a significant increase in the use of antenatal corticosteroids in babies born at less than 32 weeks' gestation and admitted to a NICU. This increase was from 78.8% in 1995 to 84.9% in 2000, a high rate by international standards.

Similarly, the NHMRC recommends the use of exogenous surfactant for the respiratory disease hyaline membrane disease where infants are intubated for mechanical ventilation. The percentage of these babies receiving this therapy has risen from 80% in 1995 to 89% in 2000.

We began monitoring the use of high-frequency ventilation as a new technology in 1996. That year 258 received that type of assisted ventilation and in 2000 this rose to 441 babies. The total number of babies receiving assisted ventilation who were more than 31 weeks' gestation at birth has risen from 2475 in 1995 to 3186 in 2000. Half of these babies (n: 1828, 57%) were born at 32-36 weeks gestation. The mode of treating these mildly preterm babies is changing, with the use of continuous positive airways pressure as the only form of assistance increasing from 214 in 1995 to 903 in 2000.

There has been no real change in the rates of survival of these fragile babies since 1995. Overall 92.0% survived to go home, with better than 95% survival for babies born at more than 28 week's gestation since 1998.

These population-based data allow a comprehensive account of outcomes for high-risk babies born in the region.

1. Organistation of the ANZNN

1.1 History

In July 1993, the Directors of the Australian level III Neonatal Intensive Care Units (NICUs) collaborated to establish a network to monitor the care of high- risk newborn infants. This was to be accomplished by pooling data to provide quality assurance for this resource-consuming care. Such networking, collaboration and cooperation have long been hallmarks of perinatal care in the region.

The National Health and Medical Research Council's Expert Panel on Perinatal Morbidity recommended that 'The Australian Institute of Health and Welfare National Perinatal Statistics Unit, in collaboration with the directors and staff of all neonatal intensive care units, should develop a national minimum data set and implement a data collection to monitor mortality and morbidity of infants admitted to such units'. (Health Care Committee Expert Panel on Perinatal Morbidity, 1995).

The prospective audit of high-risk infants commenced for babies born from 1st January 1994. All level III units in Australia and New Zealand have contributed to the audit for babies born from 1st January 1995.

In 1998, all the level II units in New Zealand joined the network and began contributing to the audit. The level II unit in Tasmania joined ANZNN in 1999.

1.2 Structure

The Australian and New Zealand Neonatal Network (ANZNN) consists of an Advisory Committee and an Executive Committee. The Advisory Committee is made up of the Directors (or their nominee) of each of the participating units and the academic neonatologists in the region. The role of the Advisory Committee is to advise and direct the ANZNN, and to approve use of the data. This Committee meets formally once a year, in association with the Perinatal Society of Australia and New Zealand's annual congress. These meetings were held in Brisbane Qld in 2000, in Canberra ACT in 2001 and in Christchurch New Zealand in 2002.

The Executive Committee is made up from ANZNN representatives. There are currently 5 members of the Executive who are concerned with the network's running.

Members of this committee include Kaye Bowden who brings her expertise as an audit officer and follow-up coordinator at Monash Medical Centre, Victoria. Dr David Cartwright is the Director of Neonatology at the Royal Women's Hospital in Brisbane, Qld and has a special interest in databases. Professor Brian Darlow has the Chair of Paediatrics at Christchurch School of Medicine and is a neonatologist at Christchurch Women's Hospital, New Zealand. A/Professor Paul Lancaster from the Department of Paediatrics at the University of New South Wales was Director of the Australian Institute of Health and Welfare's National Perinatal Statistics Unit until late 2001. David Henderson-Smart is Professor of Perinatal Medicine at the University of Sydney and Director of the NSW Pregnancy and Newborn Services Network and the Centre for Perinatal Health Services Research. Penny Waterson was our consumer representative March 2001. She was chairperson of SANDS Australia and a member of Maternity Alliance.

Staff members of the network include Deborah Donoghue who has been the coordinator/ researcher since the network's inception. Anne Cust was the Project Officer primarily responsible for the level II nurseries and the day to day running of the audit from August 99. She recently left and has been replaced by Rachel Jones.

1.3 Funding

We also gratefully acknowledge the very generous ongoing sponsorship from Abbott Australasia Pty Ltd. and Abbott Laboratories New Zealand who have been our major sponsors since 1997. The ANZNN was established in 1994 from seeding funding generously contributed by Glaxo Wellcome Australia Ltd. and Glaxo Wellcome New Zealand Ltd.

In 1997 there was an unanimous decision by the ANZNN Advisory Committee for each unit to contribute an annual sum for membership of the network and for the individual unit feedback.

2. Data set

2.1 Registration criteria

The Australian & New Zealand Neonatal Network's (ANZNN) audit of high-risk infants admitted to a newborn nursery includes all liveborn babies who were admitted to a hospital with a level III Neonatal Intensive Care Unit (NICU) at less than 28 days (and during their first hospitalisation), or who were transferred from a labour ward with the intention of admission to the unit and met the following criteria:

- < 32 completed weeks' gestation; or
- < 1500 grams birth weight; or
- received assisted ventilation (mechanical ventilation including intermittent positive pressure ventilation or continuous positive airways pressure) for four or more consecutive hours; or
- received major surgery.

Babies who died at less than 4 hours who were receiving assisted ventilation are also included.

From 1st January 1998, the audit was extended to include all babies meeting the above criteria who were admitted for care to a level II nursery in New Zealand. From January 1st 1999, the level II nursery in Tasmania also joined the audit.

The hospital of registration for a baby 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 were registered to the first level II centre that they remained in for 4 or more hours .

For the purpose of this report, babies transferred were considered to be admitted to the hospital to which they were transferred from the time the transport team arrived to collect them.

2.2 Data set variables

The variables and their definitions for the 2000 audit are listed in Appendix 1.

As reported in previous years most units collected the complete data set and we continue to use the data available for the audit as long as it meets the agreed definitions. In a few instances, some units continue to record only abnormal results, such as grade III retinopathy of prematurity, while normal findings at eye examinations are not recorded. Data which are expressed as percentages exclude missing and unknown data.

2.3 Data collection

Data are collected in the participating units by either filling out the specific ANZNN forms or by incorporating the ANZNN data items into the local audit. Data are then transferred to the ANZNN database either electronically or on paper forms. Confidentiality guidelines (Appendix 5.3) are adhered to with identifying information removed and replaced by codes at the individual units.

2.4 Data verification

Missing or anomalous data are identified and queried soon after entry onto the main database. Quantification of errors and the implementation of practices to minimise errors are continually refined. A data verification study was conducted in 1996 and reported in the 1995 annual report (Donoghue DA 1997).

3 Results - babies registered to level III nurseries

3.1 In general

There were 6835 babies born during 2000 who met the Australian and New Zealand Neonatal Network's (ANZNN) criteria for high-risk audit and were admitted to one of the 28 level III neonatal intensive care units (NICUs) throughout Australia and New Zealand. Of these, 3285 babies were born at less than 32 weeks' gestation (Figure 1 page 11; Table 1 page 24) and 2826 were born weighing less than 1500 grams (Table 2). Assisted ventilation (intermittent positive pressure ventilation (IPPV) and/or continuous positive airways pressure (CPAP) was given to 5985 babies of any gestation or birthweight and a total of 778 babies received major surgery.

All 13 level II nurseries in New Zealand and the level II nursery in Tasmania are also members of the ANZNN. The 319 babies who met our criteria for high-risk audit and are registered to those units are discussed in section 4 (page 21).

While the 'high-risk' criteria generally represent the sickest babies they do not include all babies admitted to a NICU. Many babies require other assistance and observation.

In 2000 there were 306,241 babies born alive in Australia and New Zealand (249,636 were registered in Australia (Australian Bureau of Statistics, 2001) and 56,605 in New Zealand (Statistics New Zealand, 2000)). Thus the ANZNN cohort now represents 2.23% of all livebirths for the two countries a rate that has increased steadily from 1.8% in 1995. This increase appears to be due to the number of mildly preterm babies receiving assisted ventilation, and reflects the increase in the number of babies born at less than 32 weeks' gestation (Figures 1 and 2, Nassar and Sullivan, 2001).

In this report, babies are referred to as 'preterm' if they are born at less than 37 completed weeks' gestation, and 'term' if born at 37 weeks' gestation or more. Data in the tables are by birthweight group and gestational age group (adapted from WHO groups and NSW Health's role delineation guidelines). Data in figures are given by gestational age divisions. In our region gestation is well documented, and it is gestation that is known prior to birth not weight.

3.1.1 Levels of neonatal care

Care for the newborn is provided at three levels. 'Level I' care is for normal healthy term babies, some of whom may require short-term observation during the first few hours of life.

Level II or 'special care' refers to a nursery that generally deals with babies who are born at 32 to 36 weeks' gestation or weighing about 1500 to 2500 grams at birth. It includes the care for babies who require intravenous therapy or antibiotics, and/or those who are convalescing after intensive care, and/or those who need monitoring of their heart rate or breathing, and/or those who need short-term oxygen therapy.

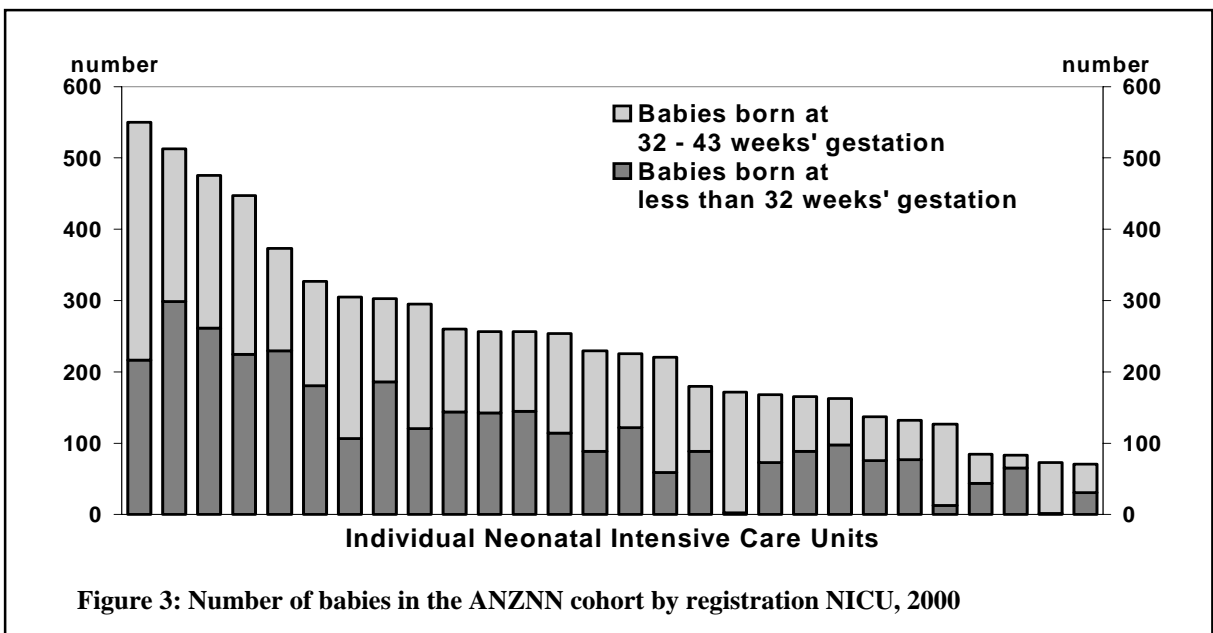
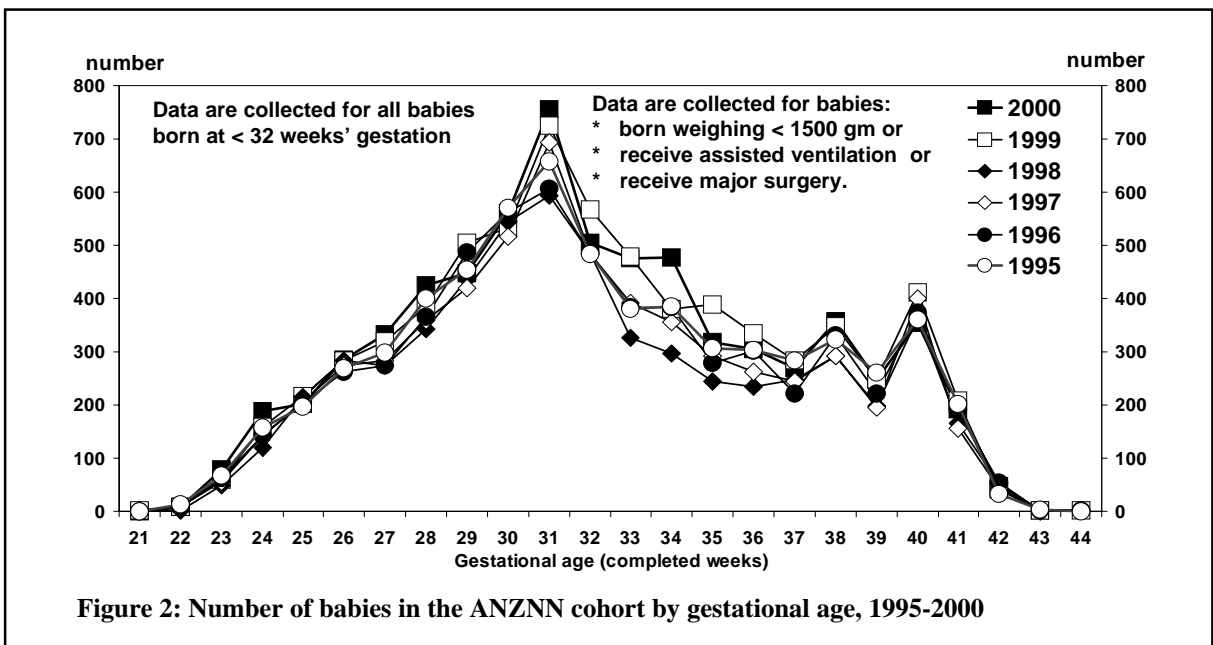
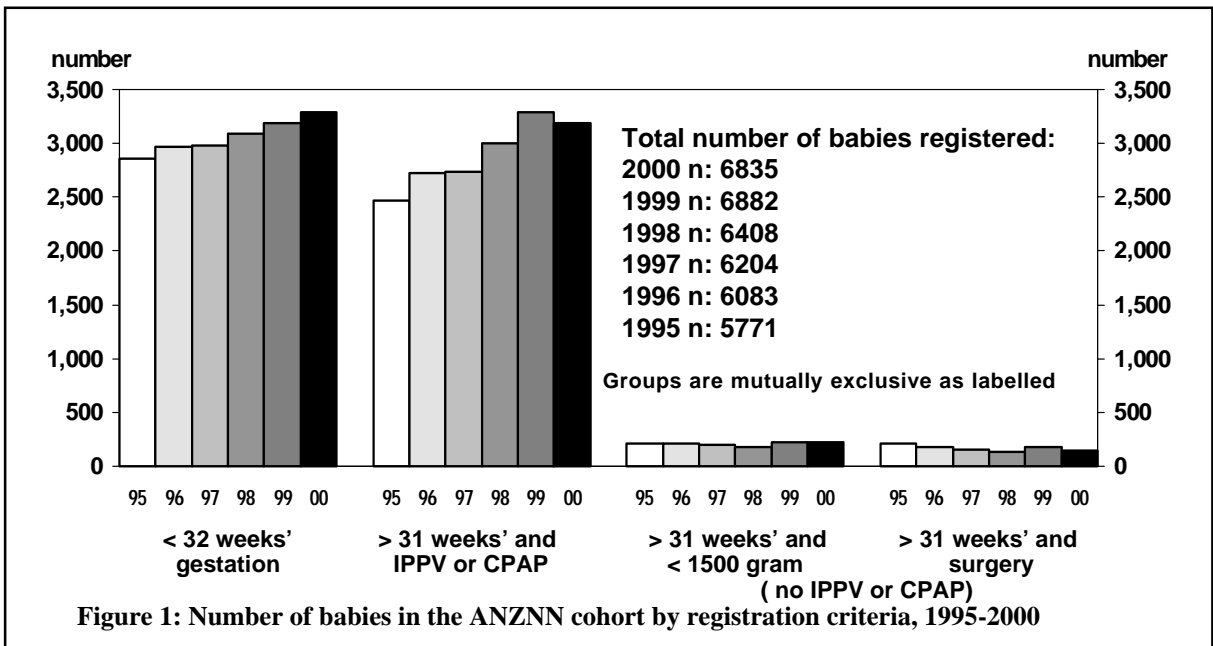
Level III or intensive care refers to the needs of newborn infants who require more specialised care and treatment. It includes most babies born at less than 32 weeks' gestation or less than 1500 grams birthweight, and others who may require intravenous feeding, and/or surgery, and/or cardiorespiratory monitoring for management of apnoea or seizures, and/or require assisted ventilation (IPPV or CPAP), and/or supplemental oxygen over 40% or long-term oxygen.

Hospitals with a level III NICU provide all of these levels of care and are referred to in this report as tertiary hospitals. There were 28 level III NICUs in Australia and New Zealand in 2000 with 985 beds for babies. This number has reduced from 29 due to the amalgamation of the two units in Western Australia.

It is important to note that some hospitals may have other beds for babies that do not come under the auspices of the NICU. Hospitals which do not have a level III NICU may provide the level II and level I care needed for infants and are referred to as non-tertiary hospitals and are reported in section 4.

3.1.2 Numbers of babies per unit

During 2000, the number of babies who met the criteria for this audit ranged from approximately 70 to 550 babies (Figure 3) per unit. These numbers reflect both the size of the unit and the case mix of patients.



3.2 The mother

While the primary focus of this audit is on the outcomes of high-risk babies, factors known to affect the risk of preterm birth are recorded for each baby. Data are collected per baby, not confinements.

An example of maternal factors affecting the outcome of the baby is maternal age. When the mother's age is either lower or higher than average, this can be associated with poor outcome. For ANZNN babies born at less than 32 weeks' gestation there were more babies born to teenage mothers (7.2% (99% Confidence Interval (CI): 6.1 - 8.4%) compared to 5.1% for all Australian births in 1999). This was also true for mothers over 34 years (20.2% (99% CI: 18.3 - 22%) compared to 16.4% for Australia in 1999; Nassar & Sullivan, 2001).

The ethnicity of the mother of each baby is reported for 98.9% of babies registered in New Zealand. Mothers identified themselves as Maori for 18.7% of the babies, as Pacific Islander for 11.2% of babies and as Caucasian for 64.1% of babies. These figures are similar to those reported for the New Zealand population (Demographic Trends 2001).

Ethnicity was not recorded well in our data for babies registered to Australian units where the compliance was only 75.6%. Of those mothers who reported their ethnicity, 85.3% were Caucasian. Mothers were identified as Aboriginal or Torres Strait Islander for 5.6% of babies, a rate higher than that seen in the Australian population (3.07%, Australian Bureau of Statistics 2000).

3.3 Antenatal events

3.3.1 Antenatal corticosteroids

Corticosteroids are administered to the mother prior to a preterm birth to enhance the maturation of the baby's lungs. The first randomised controlled trial of its use was undertaken in New Zealand in 1970 (Liggins & Howie 1972). A systematic review of 34 such trials by Crowley in 2000 reported antenatal steroids to be efficacious in helping to mature the lungs and prevent death. The review also showed protective effects for other systems, such as reducing the incidence of necrotising enterocolitis and intraventricular haemorrhage, without harmful effects for mother or baby. In 1996, the NHMRC recommended that maternal corticosteroids be considered before all births at less than 34 weeks' gestation in order to improve neonatal outcomes (Clinical practice guidelines for care around preterm birth 1997).

This therapy was given to the mothers of 2663 (84.9%) babies born at less than 32 weeks' gestation. (Figure 4, Tables 3 and 4; treatment is 'complete' when two or more doses of steroids are given with at least one dose 24 hours prior to the birth. 'Incomplete' is when steroids are given less than 24 hours or more than a week before the birth; data were available for 95.5% of babies).

The range of use of any antenatal corticosteroids for all babies born at less than 32 weeks gestation was 83.0% to 90.3%, with a median of 89.0% (hospitals with less than 10 such babies (n: 2) were excluded).

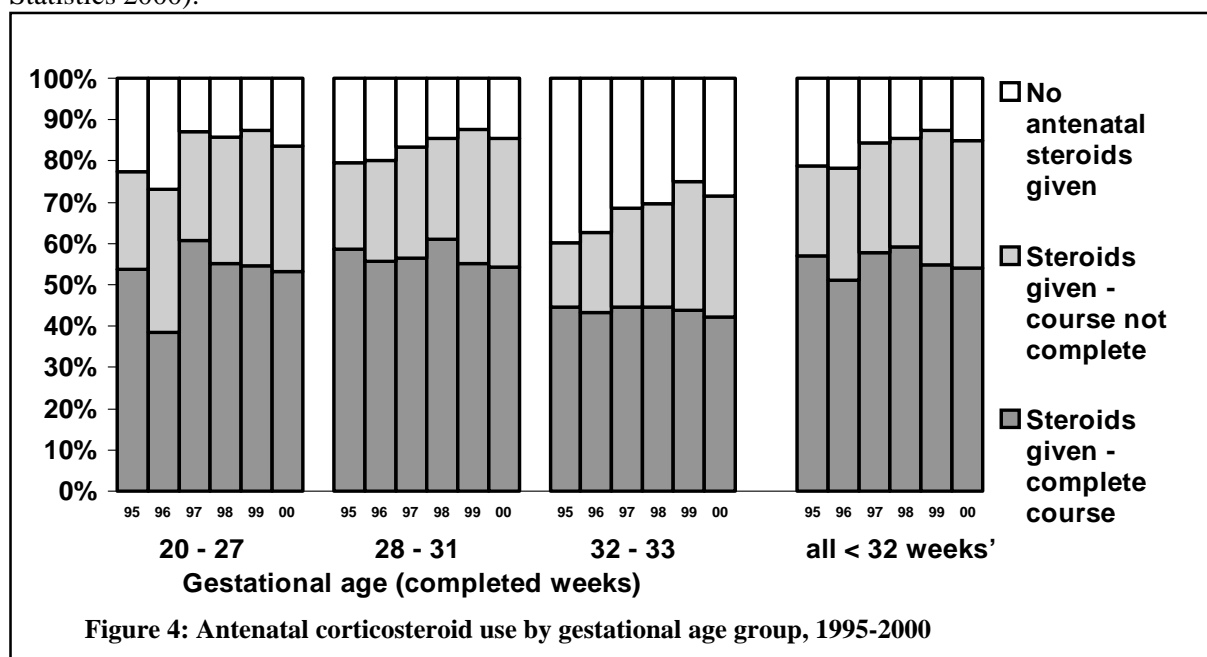
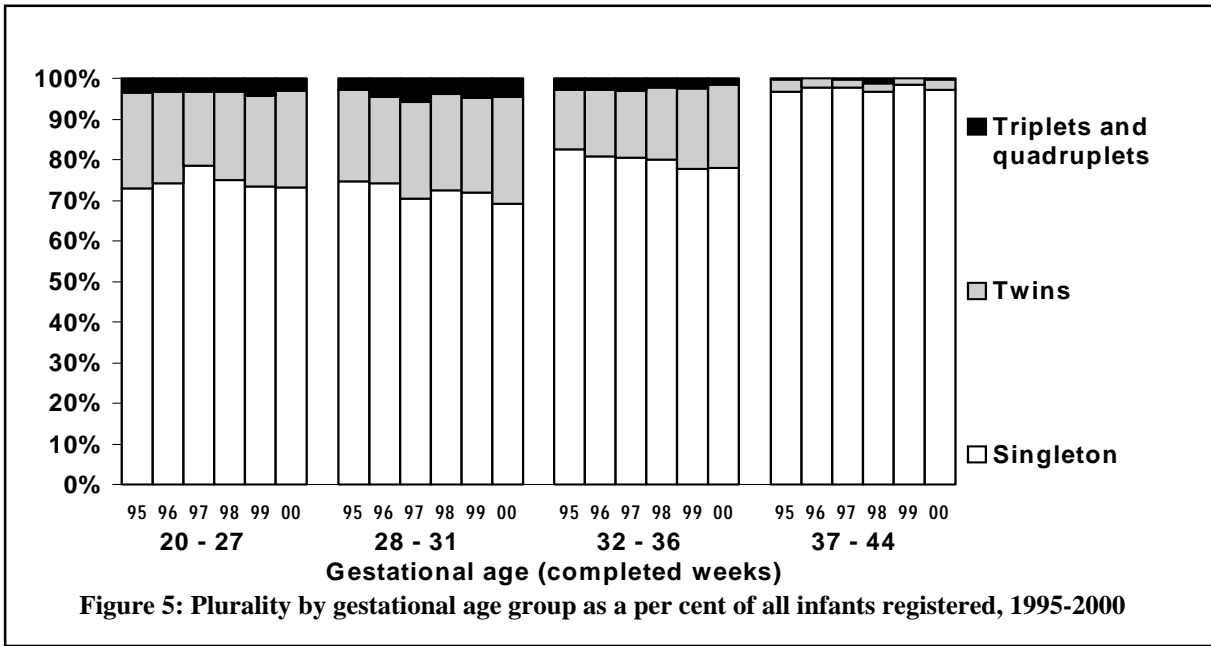


Figure 4: Antenatal corticosteroid use by gestational age group, 1995-2000



3.3.2 Antenatal problems

Data were collected on the obstetric problem that led to the mother's most recent stay in hospital, and thus the baby's birth and subsequent admission to NICU.

Preterm labour was the predominant (34.8%) presenting obstetric problem for babies born at less than 32 weeks' gestation, and its influence increased with decreasing gestation. Pre-labour, preterm rupture of the membranes accounted for another 22.9% of obstetric problems. Data are presented for the number of babies (not the number of confinements) and were recorded in 86.5% of cases.

In the mildly preterm group (born at 32 to 36 weeks' gestation), the presenting antenatal problem was distributed more evenly over the given range of complications. However preterm labour still represented 30.7% with preterm pre-labour rupture of the membranes and pregnancy induced hypertension each representing 15% of the presenting antenatal problems.

For babies born at term, nearly half (48.0%) had no antenatal problem that could be identified on their admission to hospital or the labour ward. However, in this selected group of high-risk babies, 17.9% were noted to have 'fetal distress' and 8.4% had 'antenatal detection of a fetal malformation' as their presenting antenatal problem. Other obstetric problems examined included pregnancy induced hypertension, antepartum haemorrhage and intra-uterine growth restriction.

3.4 The baby

3.4.1 Gender

Each year, slightly more male babies are born than female babies, with boys accounting for 51.4% of all live births in Australia in 2000 (Australian Bureau of Statistics, 2001). The proportion of males in our data was 57.1% (n: 3903) compared to 42.8% females (n: 2927). Two babies had ambiguous or uncertain gender during the neonatal period and three were unknown. For babies born at less than 32 weeks' gestation 53.2% (1747) were male. This proportion rose to 61.3% for babies born at term.

3.4.2 Multiple births

Babies from multiple births have an increased risk of being preterm and of having other morbidities independent of their prematurity (Clinical practice guidelines for care around preterm birth 1997). A total of 1474 (21.6%) babies in our cohort were from a multiple birth with 163 (2.4%) babies born from triplet pregnancies and 8 (0.1%) were quadruplets (Figure 5, Tables 5 and 6).

For babies born at less than 32 weeks' gestation, 29.6% were from a multiple birth. Three-quarters of the triplets (76.7%) and all eight quadruplets were very preterm. For the babies born at 32 to 36 weeks' gestation, the proportion from a multiple pregnancy dropped to 22.1%. Only 2.8% of term babies were from a multiple birth, similar to that usually seen in the Australian population (2.8%, Australian Bureau of Statistics 1997).

3.5 Birth

3.5.1 Place of birth

Babies are usually cared for in the hospital in which they are born. However, some high-risk babies may need to be transferred to a hospital with a level III NICU. When this can be anticipated, both the mother and baby may be transferred prior to the birth (in-utero) or the mother can 'book' at that hospital. The NHMRC clinical practice guidelines for care around preterm birth (1997) recommend that, wherever possible, births at less than 33 weeks' should occur in a perinatal centre with a NICU.

The majority of babies born at less than 33 weeks' gestation in our cohort were born in a perinatal centre (n: 3709; 87.5%). At term, the proportion of babies born in a tertiary centre decreased to 54.5%. Overall 77.3% of the babies in our cohort were born in a perinatal centre (Tables 7 and 8).

The reason for an infant's transfer after birth may include a precipitous preterm birth in a hospital without a NICU or no bed was available in the hospital of birth. The reason could also include a pre-planned birth in a hospital with a NICU to ensure a managed transfer to a specialised children's unit, or the unexpected need for intensive care treatment in a term baby, such as for meconium aspiration syndrome.

After birth, a total of 1541 babies were transferred to a level III NICU by a specialist retrieval team who have training for the care of sick newborn (Tables 9 and 10). Nearly half (42.5%, n: 655) of the 'retrieved' babies were born at term. Most retrieved babies (88.2%) were born in a non-tertiary centre, but 136 (9%) were transferred from another hospital with a NICU. Of the babies retrieved from a tertiary centre, 96 (70.6%) were term or mildly preterm and received surgery.

A further 155 babies were transferred by a non-specialist team such as ambulance or the flying doctor service. Twenty-seven 27 babies arrived by other means such as being born enroute to the hospital.

For babies born at less than 28 week's gestation, 136 (12.4% of all babies in that gestational age group and 91.3% of those transported in this gestational age group) were retrieved by a specialist team immediately after birth.

3.5.2 Method of birth

The method of birth varied with gestational age (Tables 11 and 12). However more than half (56.6%) were born by caesarean section, and of these half (57.1%) occurred before the onset of labour (also known as an 'elective' caesarean). This proportion was similar for all age groups. Data were available for 97.7% of babies.

The caesarean section rate for all confinements in Australia in 1999 was 21.9%. Notably, this rate rose to 48.7% for twin pregnancies and to 56.4% for singleton babies born at 500 to 1500 grams. Pregnancies where the baby presented in the breech position at term were mostly delivered by caesarean (82.4%, Nassar and Sullivan, 2001).

At term, babies are usually born with their head presenting first in the vagina (cephalic, 94.9% of all confinements in Australia, Nassar and Sullivan, 2001). For babies born at term in our cohort, 93.7% were cephalic while 5.1% were breech, and 1.2% were transverse or other (data were available for 91.3% of cases). For the babies born at less than 32 weeks' gestation only 64.2% were cephalic, while 30.1% were breech.

3.5.3 Condition at birth

The Apgar score is a clinical indicator used to denote a baby's condition at birth and is scored from 0 to 10. A low score (less than 4 at one minute) indicates that a baby that needs assistance with their adaptation to extrauterine life in the form of specialised resuscitation. This occurs in 2.3% of babies born in Australia each year (Nassar and Sullivan, 2001). In the ANZNN cohort, 352 (24.9%) term babies had a low Apgar score as did 614 (18.9%) of babies born at less than 32 weeks. This suggests that a need for assistance at birth can occur at any gestation, and that all staff attending a birth should be skilled in resuscitation. Data were available for 98.1% of babies.

The NHMRC's clinical practice guidelines for care around preterm birth (1997) recommend that ideally very preterm births should be attended by a member of the NICU staff, and those at less than 34 weeks' should be attended by someone with up-to-date skills in endotracheal intubation (passing a tube into the windpipe). In our data 1431, 43.9%) babies born at less than 32 weeks' had endotracheal intubation to aid resuscitation at birth (data available for 99.3% of babies). Overall 2009 (29.90%) babies in our cohort were intubated while in the labour ward.

3.6 Morbidity

There is a high rate of morbidity amongst babies admitted to a level III NICU, principally associated with preterm birth or complications arising in babies born at term such as the need for respiratory assistance or major surgery. This audit focuses on outcome measures that are identifiable while the baby is in hospital.

3.6.1 Respiratory distress

Respiratory distress is a major cause of morbidity and accounts for a large proportion of the use of resources in these high-risk babies. As receiving respiratory assistance for four or more hours is an eligibility criteria for this audit, only 840 (12.3%) babies did not have respiratory support.

There are two main forms of mechanical assistance with breathing, intermittent positive pressure ventilation (IPPV) which involves endotracheal intubation, and continuous positive airways pressure (CPAP). Both require specialised nursing, medical and paramedical care and utilise a large component of available resources.

A total of 5985 babies received assistance with ventilation and were admitted to a level III NICU (Tables 13 and 14). Most of these babies received either 'IPPV only' (n: 1683) or a combination of IPPV and CPAP (n: 2290). Note that by ANZNN definitions, if a baby is 'weaned' from IPPV using CPAP, use of CPAP will only show in our data if that weaning process took more than one day (Appendix 1). However, 2073 babies received 'CPAP only', an increase from 1721 last year and

a continuation of the trend observed since 1995 (Figure 6). The total duration of IPPV for all babies in our cohort born during 2000 was 31254 days, and CPAP was delivered for 40297 days. This given a combined total of 71551 ventilator 'days' (Tables 13 and 14; see Appendix 1).

The treatment and aetiology of respiratory distress changes with maturity (Figure 7), thus gestational age groups are discussed separately.

3.6.1.1 Babies born at less than 32 weeks' gestation

All babies born at less than 32 weeks gestation are part of this audit, hence 288 babies (8.8%) received no respiratory support of any kind, including supplemental oxygen.

A total of 2799 (85.2%) of babies had mechanical assistance with breathing (IPPV and/or CPAP). Of these babies, 'CPAP only' was the treatment for 744 babies (26.6% of those ventilated). The duration of ventilation increases on average, with decreasing gestational age (Tables 13 and 14). The duration of IPPV for these very preterm babies was 22623 'days' or 72.4% of all IPPV 'days' recorded for babies admitted to a level III NICU). Duration of CPAP was 35049 'days' (87.0% of total CPAP 'days'). HMD was the predominant respiratory diagnosis for babies born at < 32 weeks' gestation (68.0%, Figure 7).

High-frequency oscillation is mechanical ventilation given at 8 - 15 hertz per second, in contrast to conventional IPPV which gives about one breath per second. There were 327 (16.4%) very preterm babies who received this therapy.

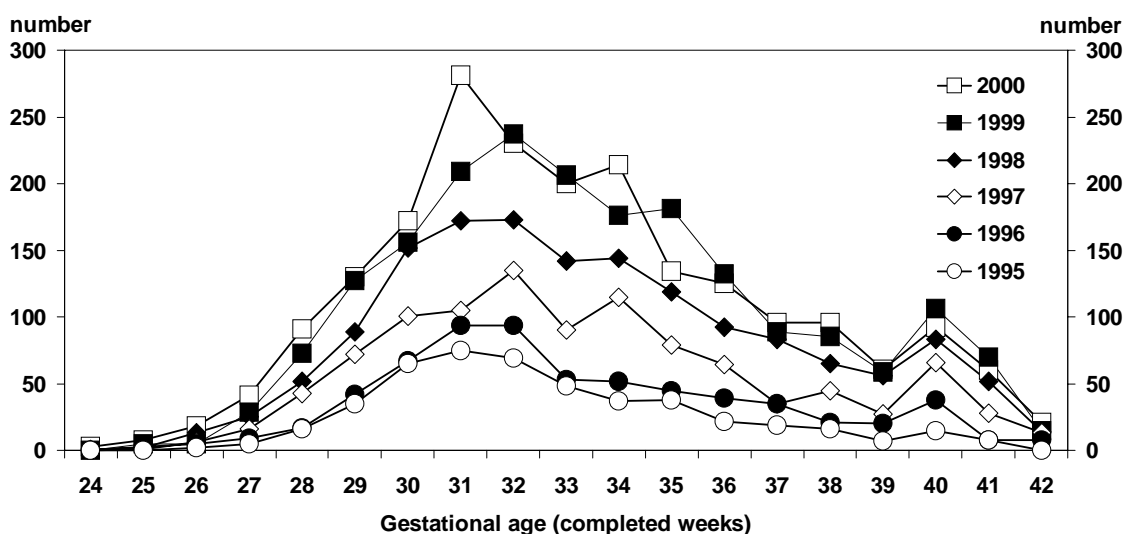
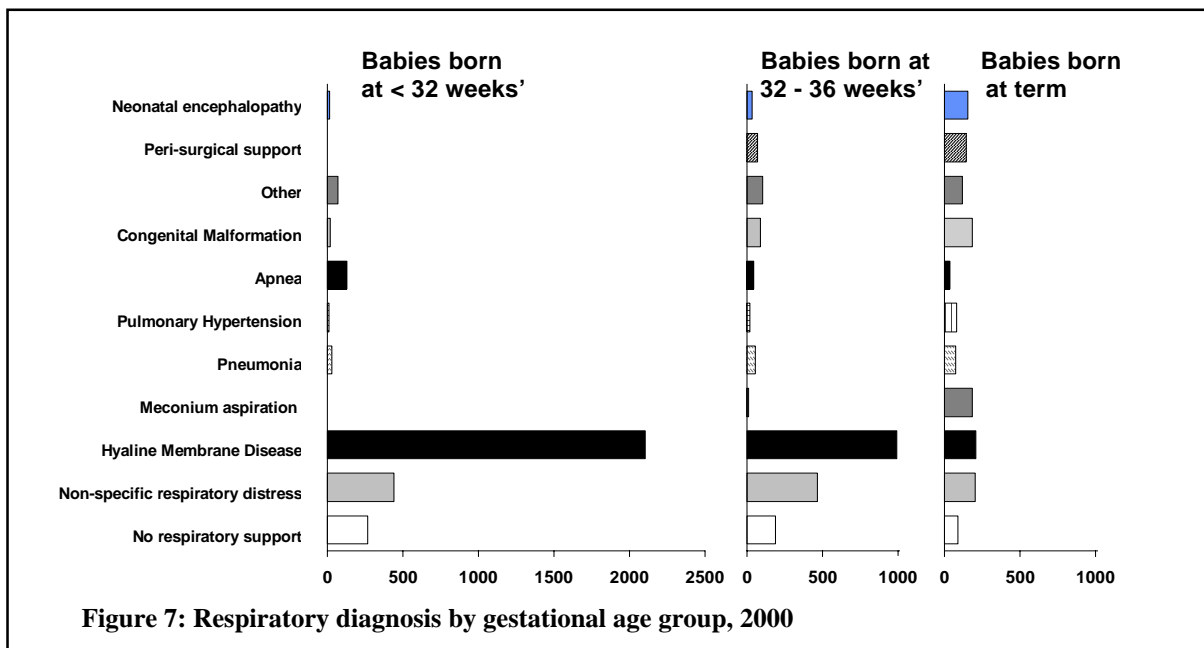


Figure 6: Number of babies receiving CPAP as their only form of assisted ventilation by gestational age, 1995-2000



Nitric oxide is a gas inhaled in very tiny amounts to dilate the pulmonary blood vessels and is used mostly in the treatment of pulmonary hypertension (Barrington & Finer 2000). Seventy-four very preterm babies were treated with nitric oxide. Pulmonary airleak requiring any drainage was seen in 147 babies (5.2% of those ventilated).

Oxygen therapy was given to most of the babies (82.1%) in this group, for a total for 95350 oxygen 'days'. Supplemental oxygen was given to 281 babies (9.5% of survivors) after they went home from hospital. Of these, 203 (72.2%) babies were born at less than 28 weeks' gestation (Table 15). Chronic lung disease is defined as babies born at less than 32 weeks' gestation who require respiratory support (supplemental oxygen and/or assisted ventilation) at 36 weeks post menstrual age (gestational age plus age after birth). There were 752 babies who met this definition (25.3% of survivors, Tables 15 and 16).

3.6.1.2 Babies born at 32 to 36 weeks gestation

A total of 1828 (87.8%) babies born at 32 to 36 weeks gestation received IPPV and/or CPAP. CPAP alone was given to 903 babies, half (49.4%) of those ventilated, and 100 more than last year (Figure 6). Again, the main respiratory diagnosis was HMD (n: 992, 47.8%, Figure 7). High frequency ventilation was given to 49 babies (3.4% of those receiving IPPV) and 27 received nitric oxide (Table 13). Airleak was seen in only 68 babies (3.7% of those ventilated). Eighteen babies required oxygen after discharge to home (Tables 15 and 16).

ANZNN entry criteria primarily involves ventilatory assistance in this gestational age group. Only 188 (9.0%) babies received no respiratory support at all.

3.6.1.3 Babies born at term

The main indication for respiratory support in term babies was also HMD (n: 205, 14.0%). However non-specific respiratory distress, meconium aspiration syndrome, newborn encephalopathy, the presence of a congenital malformation and surgery were also major reasons for respiratory support.

A total of 1358 term babies received IPPV and/or CPAP, with 109 receiving CPAP alone (8.0% of those ventilated). There was a reduction in the use of both high frequency ventilation (n: 121) and nitric oxide (n: 205). ECMO (extracorporeal membrane oxygenation) was given to only 4 babies. Airleak requiring drainage was observed in 77 babies.

3.6.1.4 Exogenous surfactant

Exogenous surfactant is a treatment primarily for HMD and is given via an endotracheal tube. Its efficacy was confirmed by systematic reviews of randomised controlled trials in 1996 (Soll 1999) and this treatment is recommended (NHMRC Clinical practice guidelines for care around preterm birth 1997). There were 2408 babies who were intubated for more than four hours and had a main respiratory diagnosis of HMD. Exogenous surfactant was given to 2146 (89.1%, data unavailable for 17) of these babies.

3.6.2 Cerebral ultrasound

Ultrasound imaging of the head of very preterm babies is performed to detect both intraventricular haemorrhage (IVH), and the formation of cysts and ventricular dilatation (hydrocephalus). An initial ultrasound is generally performed during the first week of life to detect signs of IVH. These IVHs are graded according to an internationally recognised method (Papile et al. 1978) with grades III and IV of concern as they are markers of possible later disability. For babies born at less than 32 weeks' gestation, 2357 (78.4%) did not have an IVH detected (Figure 8, Tables 19 and 20). Our reporting may include autopsy findings.

Asignificant haemorrhage (grade III or IV) was detected in 189 (6.3%) of the babies. The proportion of babies with significant haemorrhage increases as gestation decreases, but the absolute number of babies decreases (Figure 8). Significant haemorrhage has decreased from 8.0% in 1995, to 7.0% in 1996, 5.9% in 1997, 6.5% in 1998 and 6.1% in 1999. This remains a statistically significant trend ($\chi^2_{MH}: 6.8$ $p < 0.01$). Of the 277 (8.5%) babies who were not examined, 22.7% died during their first two days of life, and 62.1% were born at 30-31 weeks' gestation, a group that some units do not routinely assess.

The later ultrasound detects cystic lesions (such as periventricular leukomalacia, porencephalic cysts, encephaloclastic porencephaly) and hydrocephalus. There were 1650 very preterm babies who survived to day 27, did not have congenital hydrocephalus and had an ultrasound dated at least 3 weeks after birth. The ultrasound was reported as normal for 1481 (89.8%).

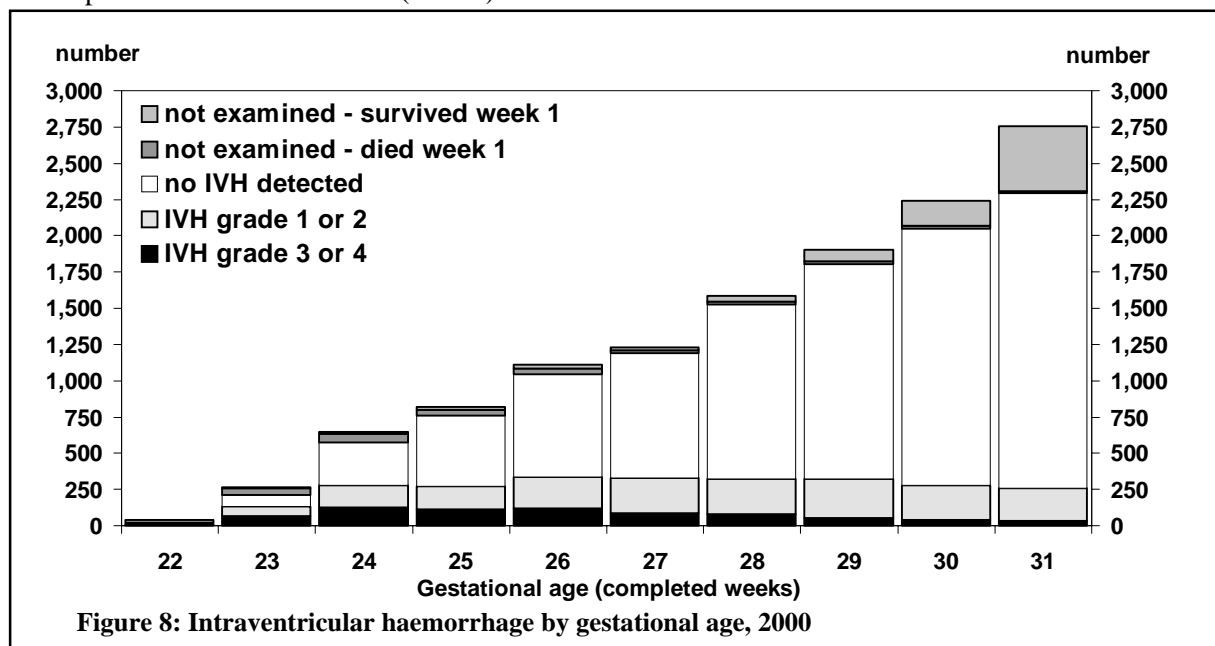
Post-haemorrhagic hydrocephalus was detected in 28 (1.7%) babies, porencephalic cysts in 40 (2.4%) and periventricular leukomalacia in 52 (3.1%). Two infants had encephaloclastic porencephaly, a devastating disease of the outer parts of the brain surface. One baby had been demonstrated to have a grade IV IVH on initial scan, however the other did not have an IVH detected. Both babies were born at less than 29 weeks gestation, one infant dying from sepsis while the other survived to go home.

3.6.3 Necrotising enterocolitis

Necrotising enterocolitis (NEC) is a disease of the gut, usually affecting the large intestine (colon). It is a cause of death and morbidity in preterm infants and occasionally in term infants. The cause of NEC is unknown, but it has been associated with factors such as very low gestational age and hypoxic events (Beeby & Jeffery).

During 2000, 125 babies were proven to have NEC, half of whom (n: 68, 54.4%) were born at less than 28 weeks' gestation. A third (n: 42, 33.6%) of all babies with NEC died during their first hospitalisation. NEC was reported as the cause of death in 30 of the 37 cases where the details were reported.

The reported occurrence of this disease varies greatly. The annual rate of NEC seen in babies born at less than 32 weeks in our cohorts have been 3.2% (95% Confidence Intervals: 2.7, 3.9) in 2000, 2.8% in 1999, 3.9% in 1998, 3.0% in 1997, 7.8% in 1996 and 4.0% in 1995.



3.6.4 Eye examinations

Eyes are examined to monitor the vascularisation of the eyes of very preterm babies which when disrupted, can result in retinopathy of prematurity (ROP). Staging criteria for ROP were set by the International committee for the classification of retinopathy of prematurity (1984). If a baby's eye reaches threshold Stage III plus or Stage IV, treatment with a laser or cryotherapy may be necessary. NHMRC clinical practice guidelines for care around preterm birth (1997) recommends that unless there is local data to the contrary, infants born at less than 32 weeks' or less than 1500 g should be screened for ROP.

The criteria most commonly used for screening in our region are babies born at less than 31 weeks' gestation or less than 1250 grams birthweight. There were 2385 babies within this group who survived to 36 weeks' post menstrual age (ie after the eye is fully vascularised). Of these, 1367 (71.0%) babies are known to have no ROP (Tables 21 and 22). The results of the examination were not available or the baby fell outside the local criteria or an examination was not performed for 459 babies (19.6%). Other babies may have their eyes examined, but this is at the discretion of the neonatologist, and they are not reported here.

Significant eye disease (Stages III or IV) was seen in 125 babies (6.5% of those with results noted) and 68 were reported to have been treated. Our data does not currently report threshold disease and thus cannot differentiate those with grade III disease who may require treatment. ANZNN definitions also require that the worst stage of ROP is recorded, even if the retinopathy resolves with subsequent development of the eye.

3.6.5 Neonatal infection

Systemic infection is potentially a severe morbidity for babies with an attributable mortality rate of around 10% (Isaacs et al. 1995). In this cohort, infection is recorded as the number of separate episodes of proven systemic infection at any time and from any site. This includes infection of the blood (septicaemia), cerebro-spinal fluid (meningitis), urine (urinary tract infection) and/ or lung (pneumonia, Isaacs et al. 1995). The infection may occur early (during the first 48 hours of life) or later (after 48 hours).

A proven systemic infection was reported for 927 (13.6%) babies in our high-risk cohort. This proportion rose to 22.2% for babies born at less than 32 weeks' gestation. Nearly half (41.9%) of babies born at less than 28 weeks' gestation had at least one major infection during their hospitalisation. Data are known for 99.8% of babies in the cohort. Of the babies with proven infection 136 or 14.6% died, however, their death was not necessarily due to infection.

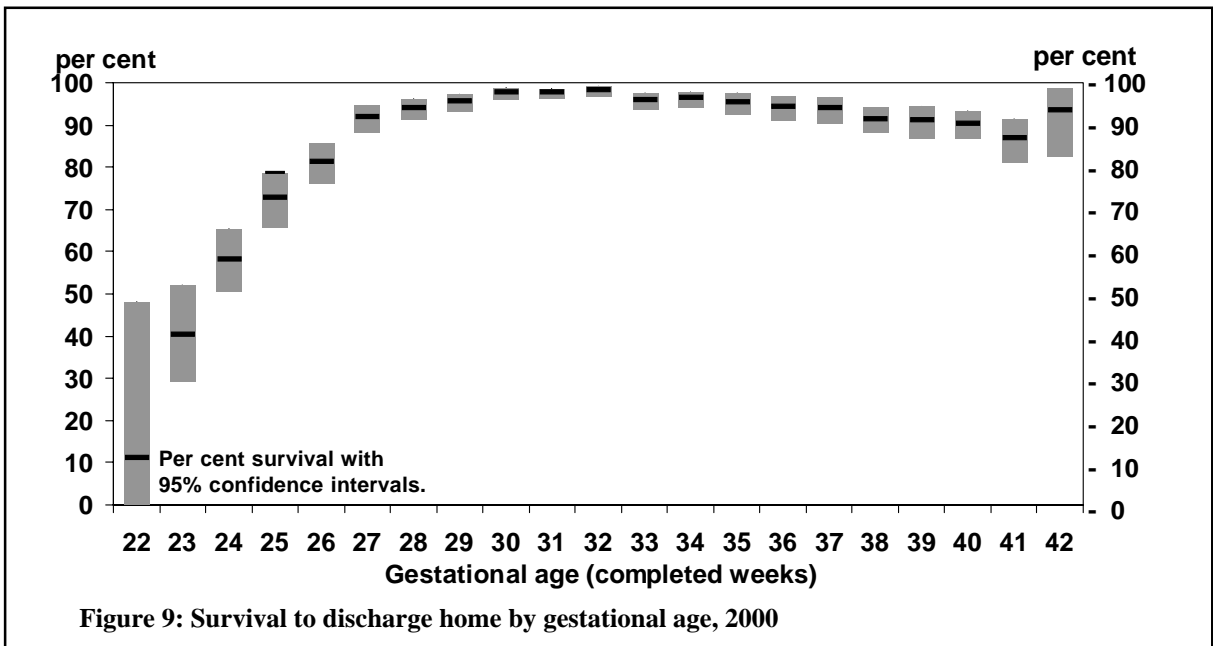
3.6.6 Neonatal surgery

Surgery in the newborn is a specialised field, carried out in only a limited number of centres such as children's hospitals, or perinatal centres in general hospitals with substantial paediatric departments. The definition of major surgery is the opening of a body cavity, and these babies often need specialist care to stabilise their condition both before, during and after the operation. Some other procedures such as laser treatment for retinopathy of prematurity (section 3.6.5) are conducted at perinatal centres. The babies in this cohort include only those who were admitted to a NICU as part of their first admission to hospital. Many other babies undergo surgery during their first weeks of life but they either go home first, or are admitted to paediatric units such as for cardiac surgery. There were 778 babies who had major surgery in our cohort.

Half (n: 379, 48.7%) of the babies having surgery were born at term. Half of these term babies (n: 197, 52.0%) were born in a perinatal centre and nearly half of them (n: 79, 40.1%) had an antenatal diagnosis of a fetal malformation, allowing the birth to be planned close to expert care. Major congenital malformations were detected in most (n: 342, 90.2%) of the term babies having surgery. Ten (2.6%) of the term babies who had major surgery died, and their death could be directly attributed to a congenital malformation in 7 (70%) term babies.

For babies born at 32 to 36 weeks' gestation, 181 had major surgery. Eighteen (6.6%) of these babies died and this death was attributed to a congenital malformation in 16 of the 18 (88.9%) cases where the cause of death was reported. Two-thirds (n: 128, 70.7%) of these babies were born in a perinatal centre and only 38 (21.0%) had an antenatal diagnosis of a fetal malformation.

Two hundred and eighteen babies had surgery. A major anomaly was seen in 48 (22.0%) babies and in only 6 babies did this lead to their death.



3.7 Outcome

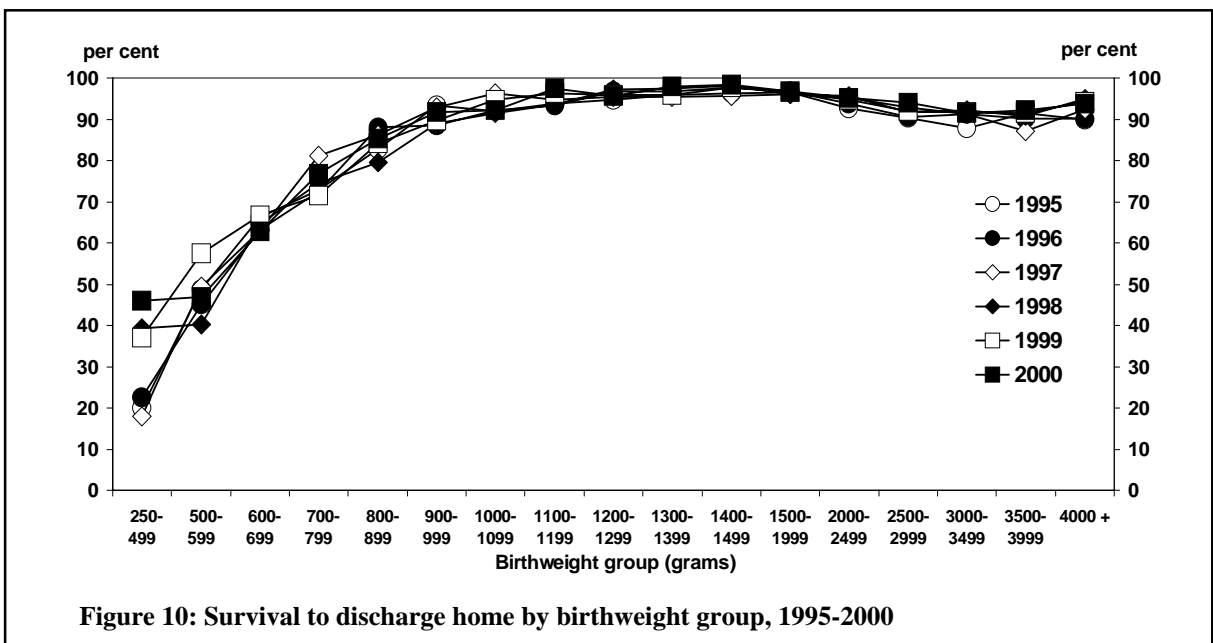
3.7.1 Survival

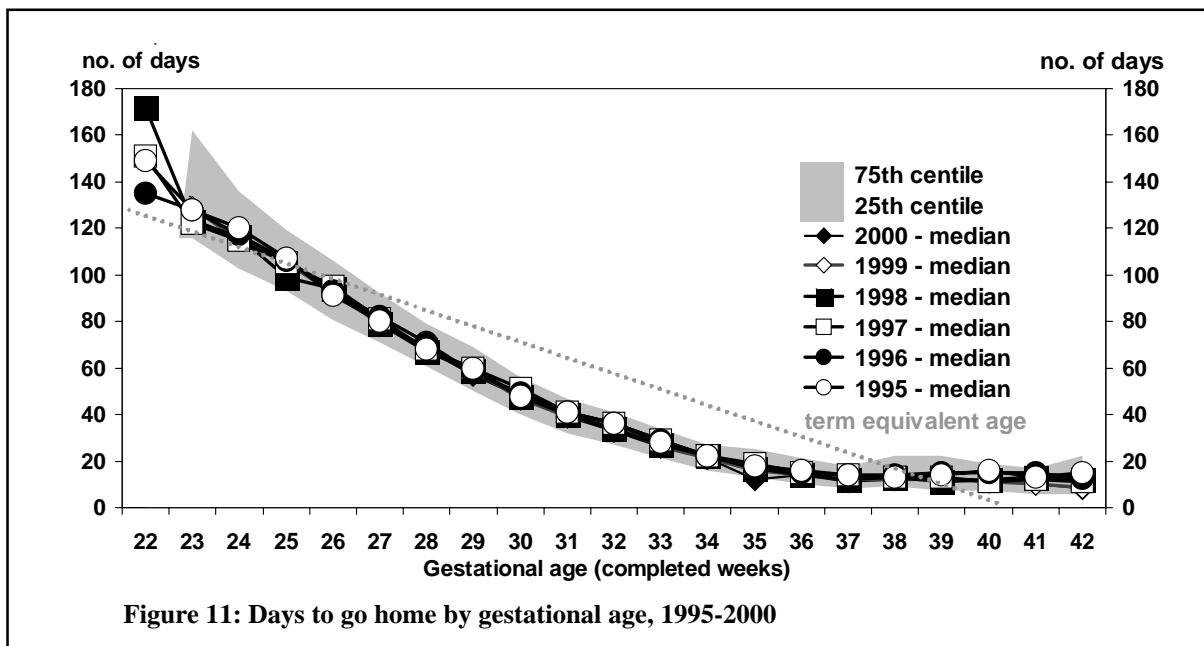
Overall, the majority of babies in this high-risk cohort survived to go home (92.0%). Survival is dependent on many factors, including gestational age and birthweight. These data are presented as survival to discharge home by week of gestational age and by birthweight group (Figures 9 and 10, Tables 23 and 24).

To provide a comprehensive picture these data are reported as survival to 7 days, to 28 days (neonatal death) and to discharge home. The presence of a major congenital malformation that contributed to the death of the baby (lethal congenital malformation) is noted.

Survival rates have not changed in the past 5 years (Figure 9, $\chi^2_{MH} > 0.01$ for the 6 gestational age epochs). More than 95% survival is seen for babies born at 29 to 35 weeks' gestation, then falls at term. When death occurred, it was during the first two days of life for 184 (33.7%) babies and within the first week for more than half (n: 312, 57.1%) of the babies who died. The death of 115 babies (21.1% of those who died) could be directly attributed to a major congenital malformation.

These data differ from that usually reported for State or National populations as they represent only those high-risk babies who were admitted to a level III NICU. They do not include babies who were stillborn, died in labour ward or who died in hospitals without a NICU.





3.7.2 Discharge from registration NICU

After their stay in newborn intensive care, babies go to a level II nursery in either the same hospital or another centre. In 2000, of the 6289 babies who survived to go home, half (n: 3130; 49.8%) went home from their original hospital of registration. This rate was higher for term babies (63.9%) than for babies born at less than 32 weeks' gestation (43.3%). There were also 2636 (41.9%) babies 'back transferred' to a hospital without a NICU. The rates were again different between babies born at term (22.6%) and those born very preterm (49.3%).

Discharge data has been received from over 300 hospitals across Australia and New Zealand to provide outcome information for the babies covered in this audit.

Some babies (n: 581, 8.5% of total but 18.0% of those transferred) went to other hospitals with a NICU for surgery, or because that centre was closer to home or occasionally because their hospital of birth did not have a level III NICU bed available.

Data given in Tables 25 and 26 pertain to all babies, not just those who survived.

3.7.3 Going home

The total amount of time spent in hospital is related to many factors (especially maturity at birth) and there is wide variation in an individual's length of stay (Tables 27 and 28). However, surviving extremely preterm babies are usually discharged home around their due date (term equivalent age, Figure 11) and preterm babies usually go home a few weeks before term.

Term babies who receive intensive care for respiratory support or surgery tend to stay in hospital for one to three weeks. In contrast, data for all babies born in Australia during 1999 who survived to go home, tended to go home from their hospital of birth before 7 days (88.1%, Nassar and Sullivan, 2001).

Over the period 1995 to 2000, there has been little change in the median length of stay of ANZNN babies when considering time in hospital against gestational age at birth (Figure 11). These data are for all survivors and include time spent in peripheral hospitals. These discharge data are now available for 95.9% of all babies in the cohort.

4 Results - babies registered to level II nurseries

4.1 In general

Level II nurseries have special care facilities to manage mildly or moderately ill infants, with varying levels of resources for neonatal intensive care (Section 3.1.1). Since 1998, all 13 level II hospitals in New Zealand have been members of the ANZNN and contributed to the audit of high-risk infants admitted to their nurseries. The level II nursery in Tasmania joined the ANZNN in 1999.

The registration criteria are unchanged (Section 2.1) allowing an audit of the full cohort of liveborn babies admitted to a nursery in New Zealand and in Tasmania born at less than 32 weeks' gestation, or less than 1500 grams birthweight, or who received assisted ventilation for 4 or more hours. Infants receiving surgery were also included, although those who went directly to a paediatric or cardiac unit without a neonatal unit are not included.

Babies who were transferred to a level III NICU within 28 days of birth were registered to that level III nursery, and are reported in section 3 of this report. Babies were registered to level II hospitals if their hospital stay was entirely within non-tertiary hospitals, or they were transferred to a level III NICU after 28 days, or they were transferred to a children's hospital without being admitted to a level III nursery.

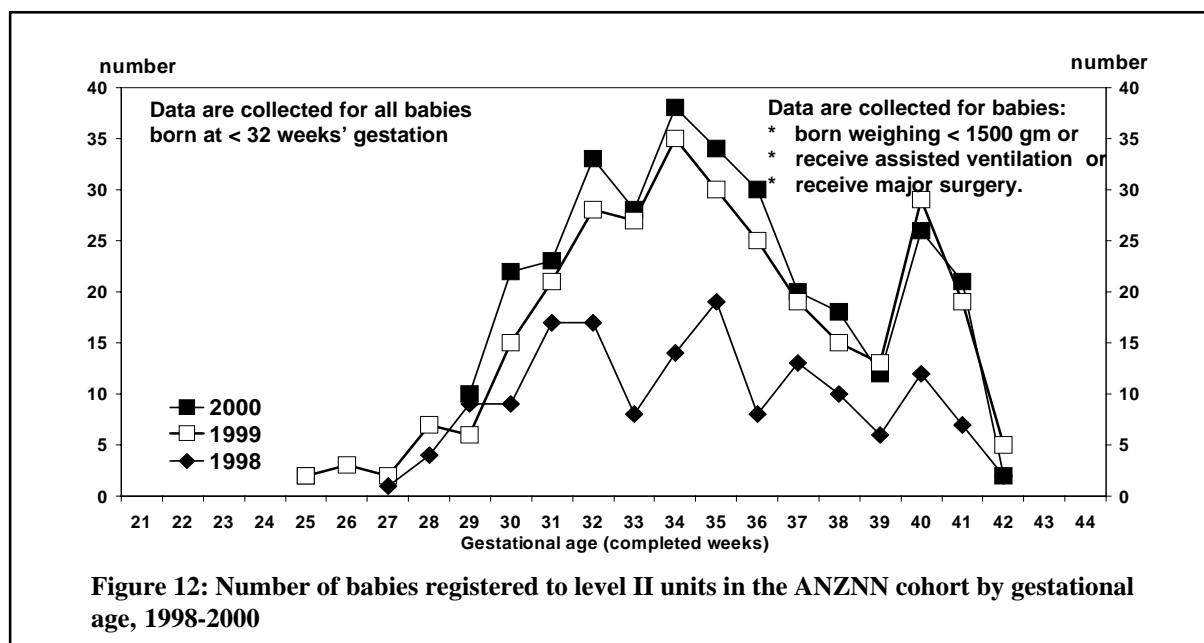
There were 319 babies who fulfilled the ANZNN criteria and were registered to one of the level II hospitals (Figure 12, Tables 29 and 30). This number continues to increase, despite the fact that one nursery was only able to submit data for the first 6 months of 2000. Of the babies, 57 (17.9%) were born at less than 32 weeks' gestation, 46 (14.4%) were born weighing less than 1500 grams, 275 (86.2%) babies received assisted ventilation and 11(3.5%) babies received major surgery. The number of babies registered to each level II centre ranged from none to 63 in 2000.

4.2 Antenatal

Antenatal corticosteroids were administered to the mothers of 44 of the 57 (77.2%) of babies born at less than 32 weeks' gestation, with 63.6% receiving a complete course.

As with the babies registered to level II units, the most common obstetric problems that led to the baby's birth for very preterm babies was preterm labour (35.1%) and preterm pre-labour rupture of membranes (28.1%). There was a similar pattern for the babies born at 32-36 weeks' gestation, but for babies born at term, 56.0% had no identifiable antenatal problem. The only major problem was fetal distress (22.0%).

The majority of babies (84.0%) were booked at the level II hospital to which they were registered.



4.3 Baby and birth

As expected, there were more male babies (n: 203, 64.0%) than females (n: 114, 36.0%; two babies did not have sex recorded). There were 34 (10.7%) babies from a multiple pregnancy, the proportion decreasing from 21.8% for very preterm babies to 5.1% at term.

The majority of babies were born vaginally (54.8%). Another 26.6% were born by caesarian section before the onset of labour had occurred. A low Apgar score (less than 4 at 1 minute) was recorded in 41 babies (12.9%) and 31 babies required endotracheal intubation in labour ward to assist in their adaptation to extrauterine life.

4.4 Morbidity

4.4.1 Respiratory disease

No respiratory support was needed by 30 (9.4%) babies. Of those requiring support, non-specific respiratory distress (n: 159, 55.0%) and hyaline membrane disease (HMD; n: 79, 27.3%) were the most common reasons. Meconium aspiration syndrome was seen in 19 (19.4%) term babies.

Assisted ventilation (IPPV and/or CPAP) was given to 275 babies in this cohort. CPAP only was given to 228 (82.9%) of these babies. The duration of assisted ventilation was comparatively short with a median of 1 day (interquartile range 1- 3). The total 'days' of IPPV were 128 and 569 'days' for CPAP. For the 36 babies born at < 32 weeks' gestation requiring assisted ventilation, the median duration was 3.5 days (interquartile range: 3 - 5); for the 145 mildly preterm babies the median was 2 days (inter-quartile range 1 - 3); and for the 95 term babies the median was 1 day (interquartile range 1- 2).

Exogenous surfactant was given to all 26 babies receiving IPPV for HMD. Airleak requiring drainage was seen in 7 babies. No baby registered to level II had nitric oxide or high frequency oscillation.

Two hundred and fifty (78.3% of the cohort) babies received supplemental oxygen therapy for a total of 1231 'days' (median: 2, interquartile range: 1-5) . Babies born at < 32 weeks' gestation received oxygen for a median of 2 days (inter-quartile range 1- 6), with 3 babies requiring support at 36 weeks post menstrual age. Of the 4 babies who received supplemental oxygen after going home, one was less than 32 weeks' gestation.

4.4.2 Other morbidities

The initial head ultrasound showed no IVH for 34 (79.1%) babies born at less than 32 weeks' (43 of the 57 (75.4%) eligible babies had an ultrasound). A significant haemorrhage (Grade III or IV) was seen in only one baby in this age group, but was also detected in 2 more mature babies. No major abnormality was shown for the 20 (35.0% of those eligible) babies who had a late head ultrasound.

Thirty-eight babies were eligible for an eye examination for retinopathy of prematurity (ROP, ie born at less than 31 weeks or less than 1250 grams). Twenty-seven (71.1%) babies were examined but only one baby had significant ROP (Stage 3 or 4) and that baby received treatment.

Systemic infection was seen in 14 (4.2%) babies with a rate of 7.0% for infants born at less than 32 weeks' gestation to 8.1% at term. No baby had necrotising enterocolitis.

4.5 Outcome

In this cohort, 311 (97.5%, Table 31) babies survived to go home. This reflects the more mature gestation and overall lower risk of these babies compared to the cohort registered to a level III NICU. All deaths occurred within two weeks of birth. Discharge data were available for 309 of the 319 babies (96.9%).

Babies born at term who survived to go home tended to stay in hospital for a week (median days: 6; interquartile range: 5 - 9). For babies born at 32 to 36 weeks', the median stay was 18 days (interquartile range: 12-29); and for very preterm babies the median stay in hospital was 46 days (interquartile range 40-54).

4.6 Level III - level II transfers

There were 241 babies who were registered to a ANZNN level III nursery and then transferred to one of the level II hospitals described in this section (Chapter 4). Some babies continued to receive assisted ventilation (IPPV n: 1 and CPAP n: 14) and/or supplemental oxygen (n: 38; 15.8%) on transfer. The median equivalent at transfer to the level II hospitals was 15 days (interquartile range 15 - 33). Most of the transferred babies (n: 150, 62.2%) were born at < 32 weeks' . The median age at transfer for these babies was 24 days (interquartile range 6-41).

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Appendix 1

Definitions of data items for audit in 2000

Definitions are authorised by the Advisory Committee of the Australian and New Zealand Neonatal Network as they are introduced into the dataset. The source of these definitions include those that exist in the National Health Data Dictionary (of Australia); definitions from Australasian collaborative groups; definitions used in multicentre randomised controlled trials in which ANZNN units had participated; and finally definitions in general use in Australia and New Zealand.

For brevity, only the sections relating to the definition, classification/coding, guide for use and comments have been presented here. For a more detailed view of the definitions currently in use, please see our website at:

<http://www.usyd.edu.au/cphsr/anznn/defn.html>

There were no substantial changes made to the variables collected or the definitions used in the data set for babies born in 2000. Please see section 2.1 for registration criteria for the audit.

1.1 Minimum dataset variables

Registration hospital

The hospital of registration for a baby 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 were registered to the first level II centre that they remained in for 4 or more hours .

Classification/coding:

numeric code representing the registration hospital

Guide for use:

Babies who were transferred were considered to be admitted to the hospital to which they were transferred from the time the transport team arrived to collect them. If a baby dies within four hours, they are registered to unit where they die.

Maternal age

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

Classification/coding:

2-digit number representing the number of completed years.

Previous preterm birth

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

Classification/coding:

0 = no previous preterm birth

1 = yes, there was a previous preterm birth

99 = unknown

Previous perinatal death

This mother has had a previous perinatal loss.

Classification/coding:

0 = no previous perinatal death

1 = yes, has had a previous perinatal death

99 = unknown

Guide for use:

A perinatal loss is when an baby with a birth weight 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

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

Classification/coding:

0 = unknown - information not available.

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. Includes in-vitro fertilisation gamete intra-fallopian transfer, zygote IFT, 4 = other - other infertility treatment not mentioned above, including artificial insemination.

Guide for use:

Disregard any treatment for a previous pregnancy.

Ethnicity of mother

Ethnic origin of the mother of baby, as identified by the mother.

Classification/coding:

- 0 = unknown - information not available.
- 1 = Aboriginal or Torres Strait Islander - a woman of Aboriginal or Torres Strait Islander (TI) descent who identifies as an Aboriginal or TI and is accepted as such by the community with which she is associated (Dept. Aboriginal Affairs, Constitutional Sect 1981).
- 2 = Asian - women whose ethnic background originates from the countries of Asia, South East Asia and Indian subcontinent. Includes say Fijian Indian.
- 3 = Caucasian - women of Caucasoid heritage, includes European, Russian, Middle Eastern and Arabic.
- 4 = other - includes African Negroes, Inuit, American Blacks and Indians, Melanesian.
- 5 = other Pacific Islander - women of Pacific Islander background, excluding Maori.
- 6 = Maori - determined by maternal self-identification.

Source of referral

Source of referral to the hospital where baby is registered.

Classification/coding:

- 0 = unknown - information not available.
- 1 = booked at tertiary obstetric hospital - mother booked at a hospital with a NICU and was not transferred during the most recent admission.
- 2 = in-utero transfer from obstetric hospital - mother transferred during most recent admission, baby in utero.
- 3 = ex-utero retrieval - baby retrieved from any other hospital by a specialist neonatal transport retrieval team using appropriate equipment.
- 4 = ex-utero transfer - baby transferred from any other hospital, by a non specialist transfer method. This includes transport by ambulance.
- 5 = other - includes born in transit, 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 during admission, baby in utero.
- 8 = ex-utero retrieval to this level II unit - baby retrieved from any other hospital by a specialist neonatal transport retrieval team.
- 9 = ex-utero transfer to this level II unit - baby transferred from any other hospital, by a non-specialist transfer method, including ambulance

Guide for use:

Use most recent referral if more than one.

Presenting antenatal problem

The antenatal complication that the mother presented with, in this pregnancy, that started the train of events that lead to the baby's birth.

Classification/coding:

- 0 = unknown - presenting problem unknown.
- 1 = preterm pre-labour rupture of membranes-confirmed spontaneous rupture of membranes (ROM) occurring prior to the onset of labour, and before 37 completed weeks' gestation. ROM is defined as the obvious gush of clear amniotic fluid from the vagina, or (if fluid is available) by differentiation with urine and vaginal secretions¹¹
- 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. Baby must be born at term.
- 9 = antenatal diagnosis of fetal malformation.

Other antenatal complications

The presence of any other antenatal complications, in addition to that listed in presenting antenatal problem.

Classification/coding:

- 0 = no other antenatal complications present
- 1 = yes other antenatal complications present
- 99 = unknown

Prolonged rupture of membranes

Confirmed spontaneous rupture of membranes (ROM) for more than 24 hours before birth of the baby. ROM is diagnosed by the obvious gush or clear amniotic fluid from the vagina, or (if fluid is available) by differentiation with urine and vaginal secretions ¹¹.

Classification/coding:

- 0 = no, membranes intact or ruptured < 24 hours
- 1 = yes, membranes ruptured for > 24 hours
- 99 = unknown

Preterm labour

The presence of regular painful contractions, leading to progressive effacement and dilatation of the cervix, eventually leading to the birth of the baby⁵ and commencing before 37 completed weeks gestation.

Classification/coding:

- 0 = no, labour did not commence before term
- 1 = yes, labour commenced in the preterm period
- 99 = unknown

Hypertension in pregnancy

A systolic blood pressure (SBP) \geq 140 mmHg and /or diastolic BP (DBP) \geq 90 mmHg; or a rise in SBP \geq 25 mmHg and/or a rise in DBP \geq 15 mmHg from blood pressure reading before conception or in the first trimester (confirmed by two readings six hours apart)¹.

Classification/coding:

- 0 = no hypertension in pregnancy detected
- 1 = yes, hypertension in pregnancy diagnosed
- 99 = unknown

Antepartum haemorrhage

Significant haemorrhage in the time from 20 weeks gestation to the end of second stage of labour. This excludes a 'show'.

Classification/coding:

- 0 = no antepartum haemorrhage noted
- 1 = yes, antepartum haemorrhage
- 99 = unknown

Suspected intrauterine growth restriction

A condition of the fetus in which it fails to reach its genetically predetermined full growth potential due to intrinsic or extrinsic factors¹⁴- based on more than one obstetric ultrasound.

Classification/coding:

- 0 = no intra-uterine growth restriction present
- 1 = yes, intrauterine growth restriction suspected
- 99 = unknown

Fetal distress

Any 'distress' of this fetus leading to intervention by the obstetric team.

Classification/coding:

- 0 = no intervention necessary
- 1 = yes, obstetric intervention required
- 99 = unknown

Antenatal diagnosis of fetal malformation

Fetal malformation diagnosed prior to birth by any method.

Classification/coding:

- 0 = no
- 1 = yes, malformation detected prior to birth
- 99 = unknown

Other antenatal complication

Other significant antenatal complication, not specified.

Classification/coding:

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

Antenatal corticosteroids for fetal lung enhancement

Corticosteroids given antenatally via any route to the mother at a time likely to enhance fetal lung maturation. Excludes corticosteroids given for other reasons.

Classification/coding:

- 0 = unknown - information not available.
- 1 = none - corticosteroids not ever given during this pregnancy at a time likely to enhance fetal lung maturation.
- 2 = less than 24 hours - first dose given at less than 24 hours prior to this baby's birth.
- 3 = complete - more than one dose of corticosteroids given, and first dose was given $>$ 24 hours and $<$ 8 days before baby's birth.
- 4 = more than 7 days - steroids given at $>$ 7 days before the baby's birth. If two courses given, and one is 'complete', use complete.

Guide for use:

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

Plurality

The total number of births resulting from this pregnancy.

Classification/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:

Plurality of a pregnancy is determined by the number of live births or by the number of fetuses that remain in utero at 20 weeks' gestation and that are subsequently born separately. In multiple pregnancies or, if gestational age is unknown, only live births of any birthweight or gestational age, or fetuses weighing 400 g or more are taken into account in determining plurality. Fetuses aborted before 20 completed weeks or fetuses compressed in the placenta at 20 or more weeks are excluded.

Birth order

The order of each baby of a multiple birth.

Classification/coding:

- A single digit numeric field representing birth order
- 0 = singleton.
- 1 = first of a multiple birth
- 2 = second of a multiple birth. etc
- 8 = other.

Date of birth

Date of birth of the patient.

Classification/coding:

DD / MM / YYYY

Admission date

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

Classification/coding:

DD / MM / YYYY

Sex

The sex of the patient.

Classification/coding:

0 = unknown - information not available.

1 = male -

2 = female -

3 = ambiguous - or indeterminate.

Infant weight

The first weight of the baby obtained after birth.

Classification/coding:

4 digit numbered field representing the birth-weight in grams.

Guide for use:

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

Gestational age

The estimated gestational age of the baby in completed weeks as determined by clinical assessment.

Classification/coding:

2 digit numbered field representing the number of completed weeks.

Guide for use:

This is derived from clinical assessment when accurate information on the date of the last menstrual period is not available for this pregnancy.

Place of birth

Place of baby's birth

Classification/coding:

0 = unknown - information not available

1 = non tertiary hospital - born in a hospital without a neonatal intensive care nursery.

2 = tertiary hospital - born in a hospital with a level III neonatal intensive care nursery.

3 = home birth - birth planned for and occurred at home.

4 = born before arrival - baby was born at home (unplanned), or in an ambulance, a car etc.

Hospital of birth

Name of the hospital in which the infant was born.

Classification/coding:

numeric code as for registration hospital.

Presentation at birth

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

Classification/coding:

0 = unknown - information not available

1 = cephalic - including face and brow

2 = breech - legs or feet were facing the cervix

3 = other - includes transverse.

Mode of birth

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

Classification/coding:

0 = unknown - information not available.

1 = vaginal - vaginal birth, includes vaginal breech

2 = instrument - vaginal birth using instrument.

Includes forceps, rotations, vacuum extraction.

3 = caesarean section in labour - caesarean performed after the commencement of labour.

Also known as emergency caesarean section.

4 = caesarean section, no labour - caesarean section performed prior to labour commencing

Also known as elective caesarean section.

Apgar score (1 minute)

Numerical score to evaluate the baby's condition at 1 minute after birth.

Classification/coding:

2 digit numeric field representing the 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)

Numerical score to evaluate the baby's condition at 5 minutes after birth.

Classification/coding:

2 digit numeric field representing the Apgar score

Intubated at resuscitation

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

Classification/coding:

0 = no, intubation not necessary in labour ward

1 = yes, intubation necessary in labour ward

99 = unknown

Guide for use:

Does not include intubation for tracheal aspiration or intubation in NICU after resuscitation complete

Congenital malformations

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

Classification/coding:

0 = no major congenital malformations noted

1 = yes, major congenital malformation noted

99 = unknown

Guide for use:

Coding to the disease classification of ICD-10 is the preferred method of coding admitted patients.

Comment:

Exclusion list of minor abnormalities is at the end of this set of definitions.

Specified congenital malformations

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

Classification/coding:

ICD-10

Temperature on admission

Temperature on admission to NICU or soonest to admission to registration unit. Use rectal temperature or, if not available, per axillae.

Classification/coding:

3-digit numbered field representing temperature measured in degrees Celsius, correct to 1 decimal place.

Guide for use:

If the baby is transported from a peripheral area by a specialist neonatal retrieval team, admission (for the purpose of this study) is considered to commence when the retrieval team arrive at the baby's bedside. If the baby is more than twelve hours old at admission to the registration unit or when the specialist neonatal team arrives (whichever is earlier), or if an admission temperature is not recorded, use '0' to denote missing.

Highest appropriate inspired oxygen

Highest appropriate inspired oxygen (FiO₂), recorded as percentage, between admission to NICU and 12 hours after birth. Appropriate range is when arterial P_aO₂ or TcPO₂ is 50-80 mmHg, or if FiO₂ is more than 25%, SaO₂ is 88-95%, or if FiO₂ is less than 25%, SaO₂ is more than 88%.

Classification/coding:

3 digit numbered field representing FiO₂ recorded as a percentage.

Guide for use:

as for "temperature on admission"; use '0' to denote missing.

Lowest appropriate inspired oxygen

Lowest appropriate FiO₂ recorded as percentage, between admission to NICU and 12 hours after birth. Appropriate range as for 'Highest appropriate inspired oxygen'

Classification/coding:

3 digit numbered field representing FiO₂ recorded as a percentage.

Guide for use:

as for "temperature on admission".

Worst base excess

Worst base deficit (mml/l) recorded between admission to neonatal intensive care unit and 12 hours after birth.

Classification/coding:

3 digits correct to one decimal place. May have negative values.

Guide for use:

as for "temperature on admission"; use '99' to denote missing.

Main respiratory diagnosis

Main indication for respiratory support of baby.

Classification/coding:

0 = unknown - information not available

1 = normal - no respiratory disease and no respiratory support.

2 = non specific - any non-specific respiratory distress in term and preterm infants requiring support (combines "transient tachypnoea of the newborn" and "immature lung").

3 = hyaline membrane disease - increasing respiratory distress or O₂ requirements, or need for ventilator support from the first 6 hours of life with chest xray showing generalised reticulo-granular pattern, +/- air bronchogram

4 = meconium aspiration - Respiratory distress presenting from immediately after birth to 12 hours of age. Hypoxia, tachypnoea, gasping respirations, and often signs of underlying asphyxia. Chest xray shows over-expansion of lungs with widespread coarse, fluffy infiltrates⁶.

5 = pneumonia - respiratory distress with proven or suspected infection (toxic blood count), and chest xray showing persisting opacities.

6 = persistent pulmonary hypertension -echocardiatic (shunting or clinical evidence (oxygen requirement unexplained by chest xray or loud P₂, or differential pre and post ductal TCPO₂).

8 = apnoea - recurrent pauses in breathing > 20 seconds, or < 20 secs assoc. with bradycardia or desaturation requiring intervention

9 = congenital malformation - congenital malf. was the primary reason for respiratory distress, eg diaphragmatic hernia (malf. needs to be listed under congenital malformation field).

main respiratory diagnosis continued

- 10 = other - unspecified other respiratory disease.
11 = peri surgical - respiratory 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^{12a}

Guide for use:

For a diagnosis other than 'normal' the baby must have received some respiratory support (added oxygen and/or assisted ventilation for 4 or more consecutive hours, or died at < 4 hours). If more than one diagnosis is possible, use the condition that was most serious. eg, severe HMD requiring surfactant replacement and mechanical ventilation plus later apnoea requiring CPAP would be coded as 'HMD'. However, diaphragmatic hernia with mild HMD would be coded as 'congenital abnormality'.

Exogenous surfactant

Any treatment with exogenous surfactant.

Classification/coding:

- 0 = unknown - information not available
1 = none - no exogenous surfactant ever given.
2 = Exosurf - any treatment using 'Exosurf'
3 = Survanta - any treatment using 'Survanta'
4 = other - other artificial surfactant given
5 = both - Exosurf and Survanta were both used

Guide for use:

Includes incomplete administration.

Air leak requiring drainage

The presence of any form of air leak requiring drainage (either transient or continuous drainage). Pulmonary airleaks may include pneumothorax, pulmonary interstitial emphysema, pneumomediastinum, pneumopericardium, pneumoperitoneum, and subcutaneous or surgical emphysema¹².

Classification/coding:

- 0 = no air leak requiring drainage present.
1 = yes, air leak requiring drainage
99 = unknown

Days of intermittent positive pressure ventilation

Total number of days of intermittent positive pressure ventilation (IPPV) via an endotracheal tube, at any rate. Four consecutive hours in any one 24 hour period constitutes a day.

Classification/coding:

- 3 digit numbered field representing IPPV days.

Guide for use:

see days of continuous positive airways pressure.

Days of continuous positive airways pressure

Total number of days of continuous positive airways pressure (CPAP) ventilation. Four consecutive hours in any one 24 hour period constitutes a day.

Classification/coding:

- 3 digit numbered field representing CPAP days.

Guide for use:

The highest level of assisted ventilation for any 24 hour period is used. Eg. if the baby received 8 hours of CPAP, then 5 hours of IPPV, then 11 hours of head box oxygen in any one 24 hour period, this is recorded as one 'IPPV' day.

High frequency ventilation

Mechanical ventilation presented at high frequencies (small tidal volumes presented at frequencies > 4Hz) initiated for this baby⁷.

Classification/coding:

- 0 = high frequency ventilation never initiated
1 = yes, high frequency ventilation was initiated
99 = unknown

Nitric oxide

Nitric oxide used in any form or dose for respiratory support of the baby.

Classification/coding:

- 0 = no, nitric oxide therapy never used
1 = yes, nitric oxide therapy used
99 = unknown

Extracorporeal membrane oxygenation

An extracorporeal circuit (ECMO) established to divert baby's blood to a membrane lung for oxygenation initiated for the baby.

Classification/coding:

- 0 = no, ECMO never initiated
1 = yes, ECMO initiated
99 = unknown

Date of final added oxygen therapy

Date supplemental oxygen ceased (appropriately).

Classification/coding:

DD / MM / YYYY

Guide for use:

Four consecutive hours in any one 24 hour period constitutes a 'day'. Any route of added oxygen is included. If oxygen is ceased, and then the baby requires oxygen again for the same illness, use final day of all the days that oxygen was used. Do not include days of oxygen for subsequent illnesses eg RSV, surgery.

If the baby was not given supplemental oxygen leave blank. If the baby received only say, 5 hours of oxygen on day one, use the date of birth.

Chronic lung disease

The infant received any respiratory support (supplemental oxygen or any form of assisted ventilation) for a chronic pulmonary disorder on the day the infant reached 36 weeks' post menstrual age (PMA).

Classification/coding:

0 = no chronic lung disease.

1 = yes, infant did require respiratory support for a chronic pulmonary disorder at 36 wks PMA.

99 = unknown

Guide for use:

Four consecutive hours in any one 24 hour period constitutes the use of respiratory support on that day. The day the infant reaches 36 weeks is the infant's gestational age (completed weeks) plus chronological age (days). Eg, an infant born at 28 weeks' and 4 days' gestation on January 1st, is 36 weeks' PMA on 26th February. This item is for infants born at less than 32 weeks' gestation .

Home oxygen therapy

Supplemental oxygen was used by the baby at home after discharge from hospital.

Classification/coding:

0 = no supplemental oxygen used at home

1 = yes, home oxygen therapy

99 = unknown

Guide for use:

Must have required supplemental oxygen in hospital, and date of final added oxygen therapy must be date of discharge to home.

Proven necrotising enterocolitis

Diagnosis of necrotising enterocolitis is definite.

Classification/coding:

0 = no necrotising enterocolitis (NEC) proven

1 = yes, NEC proven

99 = unknown

Guide for use:

Definite NEC includes having at least four of the symptoms listed below, plus a profile consistent with definite NEC as listed below, plus the baby warranted treatment which included nil by mouth and antibiotics. NEC symptoms must include at least one systemic sign (apnoea, bradycardia, temperature instability or lethargy) and one intestinal sign (residuals > 25% of previous feed on 2 consecutive occasions, abdominal distension, vomiting or faecal blood) and may also include dilated bowel. A profile consistent with definite NEC includes at least one of the following: abdominal wall cellulitis and palpable abdominal mass, or pneumatosis intestinalis, or portal vein gas, or a persistent dilated loop on serial Xrays, or a surgical or post mortem diagnosis².

Number of episodes of proven infection

The total number of separate episodes of proven bacteria, fungal or viral systemic infections.

Classification/coding:

2 digit number representing the number of episodes of proven infection.

Guide for use:

Systemic sepsis is defined as a clinical picture consistent with sepsis, plus either a positive bacterial or fungal culture of blood and/ or cerebrospinal fluid, or a positive urine culture by sterile collection only. Infections with coagulase-negative staphylococci, and other potential contaminants, or group streptococcal antigen detected in urine are included only if the baby is considered clinically septic & there is supporting evidence such as raised white cell count or thrombocytopenia. Viral infections are proven by culture and/or haematological results consistent with infection (adapted from ¹⁰).

Neonatal surgery

Did this baby have surgery that involved opening a body cavity?

Classification/coding:

0 = no

1 = yes

99 = unknown

Maximum grade of intraventricular haemorrhage

Worst level of intraventricular haemorrhage (IVH) seen on either side by either ultrasound or post mortem examination.

Classification/coding:

0 = none - ultrasound/post mortem shows no IVH

1 = grade 1 - subependymal germinal matrix IVH

2 = grade 2 - IVH with no ventricular distension.

3 = grade 3 - IVH ventricle distended with blood.

4 = grade 4 - intraparenchymal haemorrhage¹³

5 = not examined - by ultrasound or post mortem

Date of late head ultrasound

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

Classification/coding:

DD / MM / YYYY

Ventricular Index

Ventricular index (VI) measured as the furthest lateral extent of each ventricle from the midline measured at the level of Foramen of Monroe¹².

Classification/coding:

2 digit number representing the VI in millimeters.

Guide for use:

To be recorded if ventricular dilatation present.

Ventricle size

Ventricular size at the ultrasound closest to six weeks of age as in above date. Ventricular index is measured as above¹².

Classification/coding:

- 0 = unknown - information not available, includes not scanned.
- 1 = no dilatation - ventricle size \leq 97th centile.
- 2 = dilatation - ventricle size $>$ 97th centile, but less than or equal to 4 mm $>$ 97th centile.
- 3 = hydrocephalus - ventricle size $>$ 4 mm larger than 97th centile, or hydrocephalus present that required a shunt or any form of drainage (permanent or transient).

Cerebral cystic formations

Changes in brain parenchyma seen at the scan closest to six weeks of age:

Classification/coding:

- 0 = unknown - information not available, includes not scanned.
- 1 = no cysts - none seen on ultrasound
- 2 = porencephalic cyst(s) - Parenchymal lesions corresponding to grade 4 IVH.
- 3 = periventricular leukomalacia - ischaemic brain injury affecting the periventricular white matter in the boundary zones supplied by terminal branches of the both the centripetal and centrifugal arteries⁸
- 4 = encephaloclastic porencephaly - relatively late development on cerebral ultrasound scan of extensive dense and cystic lesions involving the periphery of the brain⁴.

Retinopathy of prematurity examination

The examination of eyes for retinopathy of prematurity was completed beyond the period when eye disease likely.

Classification/coding:

- 0 = examination not completed.
- 1 = yes, eyes examined beyond period when eye disease likely.
- 99 = unknown

Retinopathy of prematurity

Worst stage of retinopathy of prematurity in either eye prior to going home.

Classification/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 detachment⁹.
- 5 = not examined - no eye examination performed

Therapy for retinopathy of prematurity

Any therapy used to treat retinopathy of prematurity (ROP) i.e. laser or cryotherapy.

Classification/coding:

- 0 = no therapy for ROP received
- 1 = yes, therapy given for ROP
- 99 = unknown

Died

The death of this baby prior to discharge from hospital

Classification/coding:

- 0 = no, survived to discharge to home.
- 1 = yes, died
- 99 = unknown

Date of death

Date of death of baby.

Classification/coding:

DD / MM / YYYY

Post Mortem

A post mortem examination was performed.

Classification/coding:

- 0 = no post mortem performed
- 1 = yes, a post mortem was performed
- 99 = unknown

Immediate cause of death

Classification/coding:

unspecified free field

Guide for use:

Cause of death is to be described in morbid anatomical terms.

Death due to congenital malformation

The death of the infant may be directly attributed to the congenital malformation.

Classification/coding:

- 0 = no
- 1 = yes, death is attributable to a congenital malf.
- 99 = unknown

Guide for use:

Must be coded as “yes” for major congenital malformation and “yes” for died

Transferred to another hospital

The baby was transferred to another hospital nursery before going home.

Classification/coding:

- 0 = no, never transferred
- 1 = yes, transferred
- 99 = unknown

Specify hospital of transfer

Name of hospital to which the baby was transferred.

Classification/coding:
unspecified free field

Date of transfer

Date on which a newborn baby completes an episode of care after birth in the hospital of registration. Formal separation is the administrative process by which a hospital records the completion of treatment and/or care and accommodation of a patient.

Classification/coding:
DD / MM / YYYY

Guide for use:

Use the most significant date.

Discharge date

Date on which and admitted patient completes an episode of care.

Classification/coding:
DD / MM / YYYY

Comment:

All data collection ceases when the baby is discharged to home.

1.2 Minor congenital malformations

Skin

Skin cysts; non calvernous; single small haemangioma; benign skin neoplasms; nevus flammeu; birth mark; mongolian spots; cutis marmorata; cafe au lait spots; scalp defects, cutis aplasia; lanugo excessive or persistent; accessory nipple; pilonidal or sacral dimple.

Skull

Brachycephaly, dolichcephaly, plagiocephaly; craiotabes; large, small or absent fontanelles; macrocephaly; head asymmetry.

Face

Facial palsy; facial asymmetry; micrognathia; flat or wide nasal bridge, upturned nose, or other minor nose malformation.

Eyes

Esotropia, exotropia strabismus; nystagmus; blue sclera; brushfield spots; epicanthal folds; eye slant (upward or downward); narrow palpebral fissures; nasolacrimal duct obstruction or dacryostenosis.

Ears

Ear tags; bat, cauliflower, elfin, lop, pointed, posteriorly rotated, or low-set ears; darwin's tubercle; preauricular sinus, cyst or pit; macrotia.

Mouth, tongue & palate

Tongue-tie; tongue cyst; ranula; cleft gum; macroglossia; microglossia; natal teeth; big, wide or small lips; high-arched palate; bifid uvula; neck; redundant neck skin folds; webbing of neck; short neck.

Cardiovascular system

Patent ductus arteriosus or foramen ovale (gestational age <37 weeks or birthweight <1500g); cardiomegaly; mild, trivial or physiological valvular regurgitation; dextroposition of the heart; heart block; persistent fetal circulation; single umbilical artery.

Respiratory system

Hypoplastic lungs (gestational age < 37 weeks); laryngeal stridor; laryngomalacia.

Gastrointestinal system

Hepatomegaly; splenomegaly; anal tags; anal or rectal fissures; merkel's diverticulum; inguinal hernia in males; inguinal hernia in females (birth-weight <2500g); umbilical hernia (skin covered).

Urogenital system

Imperforate hymen; prominent clitoris; fusion of vulva; vaginal or hymenal tags; cyst of vagina, canal of nuck or ovary; hydrocele; undescended testes (gestational age < 37 weeks or bithweight < 2500g); small penis; chordee; patent urachus or urachal cyst; ectopic kidney.

Limb

Skin tags on hands and feet; partial syndactyly of toe, webbing of toe; brachydactyly, unspec.; clinodactyly; camptdactyly; flexion deformity of digits; long fingers and toes; nail hypoplasia; enlarged or hypertrophic nails; widely spaced 1st and 2nd toes; overlapping toes; tibial torsion or bowing; genu valgum, varum or recurvatum; dislocation or subluxation of knee; hallux valgus; hallux varus; talipes calcaneovalgus equinovarus; cervical rib, other extra ribs; rocker-bottom feet; simian or sydney lines, abnormal palmar creases; hip subluxation, clicky hips.

Other conditions

Balanced autosomal translocations; birth injuries; cephalohaemotoma; cystic fibrosis; enzyme deficiencies; hydrops fetalis; meconium ileus; metabolic disorder; pyloric stenosis; sterno-mastoid tumor; toricollis; volvulus.

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Appendix 2

Units participating in the ANZNN in 2000

2.1 Hospitals with level III nurseries

	births	beds*
New South Wales		
Children's Hospital at Westmead	–	20
John Hunter Hospital	3631	29
Liverpool Health Service	3238	23
Nepean Hospital	3531	28
Royal Hospital for Women	3946	34
Royal North Shore Hospital	1746	26
RPA Women and Babies	3955	32
Sydney Children's Hospital	–	20
Westmead Hospital	3919	39
Victoria		
Mercy Hospital for Women	5173	54
Monash Medical Centre	4305	48
Royal Children's Hospital	–	23
Royal Women's Hospital	5001	58
Queensland		
Mater Mother's Hospital	6493	60
Royal Women's Hospital	3698	66
The Townsville Hospital	1752	28
South Australia		
Flinders Medical Centre	2322	35
Women's and Children's Hospital	n/a	44
Western Australia		
King Edward Memorial and Princess Margaret Hospitals	4773	80
Tasmania		
Royal Hobart Hospital	2008	16
Australian Capital Territory		
Canberra Hospital	2227	24
Northern Territory		
Royal Darwin Hospital	1576	18
New Zealand		
Christchurch Women's Hospital	4204	37
Dunedin Hospital	1751	16
Middlemore Hospital	6250	20
National Women's Hospital	8054	59
Waikato Hospital	3042	29
Wellington Women's Hospital	3430	31

2.2 Hospitals with level II nurseries

	births	beds*
Tasmania		
Launceston General Hospital	1670	15
New Zealand		
Gisborne Hospital	721	6
Hastings Hospital	1958	15
Hutt Hospital	n/a	8
Nelson Hospital	898	6
Palmerston North Hospital	1811	17
Rotorua Hospital	1381	10
Southland Hospital	n/a	6
Taranaki Base Hospital	1412	8
Tauranga Hospital	1854	10
Timaru Hospital	599	4
Wanganui Hospital	738	4
Whakatane Hospital	659	3
Whangarei Area Hospital	1388	8

* 'births' refers to the number of livebirths in that hospital in 2000;
'beds' refers to the number of beds for newborn infants associated with that nursery.

Appendix 3

Publications by the staff of participating units

3.1 Journal articles

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Appendix 4

Clinical trials underway in 2000

4.1 Studies where the treatment occurs before birth

ACTOMgSO₄ - Australasian collaborative trial of magnesium sulphate for the prevention of mortality and cerebral palsy in infants born very preterm.

ACTORDS - Australasian collaborative trial of repeated prenatal steroids to women at risk of preterm birth to reduce neonatal morbidity.

HOPE Trial - Prevention of recurrent pre-eclampsia by folic acid and supplementation in women with hyperhomocysteinaemia.

ORACLE - Medical Research Council's preterm antibiotic uncertainty study.

4.2 Studies where the treatment occurs after birth

BOOST - Benefits of oxygen saturation targeting - a randomised controlled trial assessing the effects of two different oxygen saturation targeting ranges on the long term growth and development of preterm infants.

CAP Trial - Caffeine for Apnea of Prematurity Trial. A multicentre randomised trial testing if avoidance of methylxanthines (caffeine) in the prevention or treatment of apnoea of prematurity reduces the risk of adverse outcomes for infants weighing 500-999 grams at birth.

DART Trial - Multicentre randomised trial of postnatal dexamethasone use in tiny babies: does it do more good than harm?

KanMed Baby Warmer Trial: an evaluation of thermal responses, weight gain and maternal perceptions.

UKOS trial - Multicentre randomised trial of HFOV (high frequency oscillation ventilation) to prevent chronic lung disease in very preterm babies.

Randomised trial of dopamine vs dobutamine in very preterm babies with low systemic blood flow - a single centre study.

Randomised trial of two different dexamethasone regimens for prevention of chronic lung disease - a single centre study. .

Randomised trial of selective head cooling following perinatal asphyxia - an international multi-centre study.

The effectiveness of oral sucrose in the reduction of pain associated with heel lancing in hospitalised infants: a randomised controlled trial.

Randomised double cross over study of assisted control ventilation versus intermittent ventilation in preterm babies weaning off ventilation

A randomised controlled trial to test the effectiveness of a family centred community based preventive intervention for illicit drug using mothers.

Appendix 5

ANZNN Documentation

5.1 Aim

The aim of the Australian & New Zealand Neonatal Network is 'to improve the care of high-risk newborn infants and their families in Australia and New Zealand through collaborative audit and research'.

As revised at the Australian & New Zealand Neonatal Network Advisory Committee Meeting, Auckland, NZ, 2nd April 1995.

5.2 Objectives

The objectives of the Australian & New Zealand Neonatal Network are:

1. To provide a core data set that will:
 - i Identify trends and variations in morbidity or mortality warranting further study.
 - ii Enhance the ability to carry out multicentre studies and randomised controlled trials.
 - iii Provide information on neonatal outcomes adjusted for case mix and disease severity to participating neonatal units to assist with quality improvement.
2. Monitor the use of new technologies eg surfactant usage by patient type and outcome.
3. Develop and evaluate a clinical risk score for babies in Australian and New Zealand neonatal units (mortality and morbidity).
4. Develop and assess clinical indicators for perinatal care through neonatal outcomes.

As revised at the Australian & New Zealand Neonatal Network Advisory Committee Meeting, Auckland, NZ, 2nd April 1995.

5.3 Confidentiality guidelines

Confidentiality guidelines were devised and agreed to by the Advisory Committee to provide an unambiguous framework for the handling of data that met the strict criteria of governing bodies. These guidelines are set out in full below.

Confidentiality guidelines for the collection, processing, and analysis of data from the national minimum data set of the Australian & New Zealand Neonatal Network.

As revised at the Australian & New Zealand Neonatal Network Advisory Committee Meeting, Auckland, NZ, 2nd April 1995.

The purpose of these guidelines is to set out the principles under which the National Minimum Data set (NMD) 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 Australian & New Zealand Neonatal Network (ANZNN).

The essential purpose of the NMD is to provide national unit record data 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 / 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; and
- as 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 the data retrospectively from 1st January 1994.

A Principles of ownership and maintenance of the data

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

2. The Custodians of the data will be the ANZNN Executive. All queries related to the NMD should be referred to a Custodian, who will address them personally or refer them to the appropriate source person.

B Conditions for collection of the data

It is expected that all participating NICUs will collect an agreed-upon minimum set of data in a standardised format. Data entry on to hard-copy data forms or into an electronic data form will be performed at the respective NICU.

C Conditions for use & release of data

1. Use of the data would entail agreement by the Advisory Committee (Directors, or their nominee, of each contributing NICU) and the Executive.

2. Data will not be published or supplied with any patient identifying information.

3. Data will not be published or supplied with any NICU or State / Territory / nation identifying information without the written approval of all the NICU Directors of the State / Territory or nation concerned.

4. External requests for a hard copy of patient de-identified data will be made in writing to the data custodians. Any requests for data that could potentially identify a unit or State / Territory / nation will be referred to the Advisory Committee.

External requests for patient de-identified data on computer disk will be made in writing to the data custodians, and then referred to the Advisory Committee.

Requests in writing must be in the form of a one page research proposal. A confidentiality agreement must be signed by the person(s) requesting data prior to the release of the data.

4a. Requests for data involving unit identifying data analysis - if a Director had not responded within six (6) weeks (having received a reminder at three (3) weeks), then it was to be assumed that the Director did not object to the project and consent is given.

4b. Requests for individual patient data that did not identify unit or region – the Coordinators (or the new expanded Coordinator panel) could approve the request in principle and notify the members of the Advisory Committee in writing, seeking replies only if there are objections. If no objections are received within 4 weeks then the data is released. When there are any objections then written approval of all members should be obtained as in 4a.

4c. Data requests tabled at the annual meeting do not have to go to attendees for approval only to those who did not attend. Responses as in 4b.

5. Publication of data in any form must be endorsed in writing by seventy-five percent (75%) of the Advisory Committee prior to the material being submitted for publication. The mechanism for this will be by prior notification and then endorsement at an Advisory Committee meeting, or by faxing each committee member.

All published data must acknowledge the ANZNN Advisory Committee and Executive.

6. Data will be released annually in a report provided free to each participating Director. This report will summarise the pooled, de-identified data. This report will be distributed widely after the majority of the Advisory Committee agree on content and form.

Data will also be released to each Director in electronic form with their own unit data identified, and the rest of the data completely de-identified.

D Conditions for security of the data

Patient-identifiable data should not leave the site of the ANZNN. The electronic version of this data will be maintained on a single central computer protected by password. All hard copy patient identifiable data and electronic backup files will be kept in locked cabinets. Master lists of code material will be kept in a separate locked area.

All rooms and offices used by ANZNN are locked when not in use. Filing cabinets containing data are locked when not in use. Computerised data are protected by passwords known only to each person who has access to computerised data.

Security disposal of data is available through use of designated bags or a shredding machine.

Australia is a country of approximately 18.5 million people and has about 250,000 births each year. As the smallest continent with an area of 7.5 million square kilometres, we are 8 to 10 hours ahead of Greenwich Mean Time.

New Zealand is a further two hours ahead of Australia and has a population of 3.6 million with 57,000 births annually and a land area of 266,000 square kilometres.



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