

report of the

Australian & New Zealand Neonatal Network 1999

**Deborah Donoghue and
Anne Cust**



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Abbreviations

AIHW	Australian Institute of Health and Welfare	O ₂	Oxygen
ANZNN	Australian and New Zealand Neonatal Network	P _a O ₂	Partial inspired oxygen (a method of measuring oxygenation)—see definitions
NHMRC	National Health and Medical Research Council of Australia	PIH	Hypertension in pregnancy (a complication of pregnancy)—see definitions
NPSU	National Perinatal Statistics Unit	PMA	Post menstrual age (gestational age plus chronological age, in weeks)
WHO	World Health Organisation	PPH	Pulmonary hypertension (a respiratory disorder)—see definitions
APH	Antepartum haemorrhage (a complication of pregnancy)—see definitions	PPROM	Preterm pre-labour rupture of membranes (a complication of pregnancy)—see definitions
BE	Base excess	PROM	Prolonged rupture of membranes (a complication of pregnancy)—see definitions
BW	Birthweight (in grams)—see definitions	PTL	Preterm labour (a complication of pregnancy)—see definitions
CPAP	Continuous positive airways pressure (a form of assisted ventilation)—see definitions	PVL	Periventricular leukomalacia (a brain disorder)—see definitions
DOA	Date of admission	ROP	Retinopathy of prematurity (an eye disorder)—see definitions
DOB	Date of birth	S _a O ₂	Oxygen saturation (a method of measuring oxygenation)
FiO ₂	Fractional inspired oxygen (measures amount of supplemental oxygen)—see definitions	T _c PO ₂	Transcutaneous partial pressure of oxygen (a method of measuring oxygenation)
GA	Gestational age (in completed weeks)—see definitions	TTN	Transient tachypnoea of the newborn (a respiratory disorder)—see definitions
HMD	Hyaline membrane disease (a respiratory disorder)	χ _{MH}	Mantel-Haenzel chi-square, testing statistical significance of trends.
ICD.9.CM	International Classification of Diseases 9 th revision, clinical modification	ACT	Australian Capital Territory
IPPV	Intermittent positive pressure ventilation (a form of assisted ventilation)—see definitions	NSW	New South Wales
IUGR	Intrauterine growth restriction (a complication of pregnancy)—see definitions	NT	Northern Territory
IVF	In vitro fertilisation	NZ	New Zealand
IVH	Intraventricular haemorrhage (a brain disorder)—see definitions	Qld	Queensland
Mec Asp	Meconium aspiration syndrome (a respiratory disorder)—see definitions	SA	South Australia
n	Number	Tas	Tasmania
NEC	Necrotising enterocolitis (a gut disorder)—see definitions	Vic	Victoria
NICU	Neonatal Intensive Care Unit	WA	Western Australia

Highlights

- The Australian & New Zealand Neonatal Network (ANZNN) is a voluntary collaboration of all 29 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 now 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.
- In 1999, 6,882 babies met the registration criteria of the ANZNN audit and were admitted a III NICU. An additional 301 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.
- There were 3,194 babies born at less than 32 weeks' gestation registered to the level III NICU audit. Assisted ventilation (either intermittent positive pressure ventilation or continuous positive airways pressure) was given to 6,043 babies and 844 received major surgery. For the babies registered to a level II nursery, 56 were born at less than 32 weeks' gestation, 45 were less than 1500 gm at birth, 283 received assisted ventilation and 3 babies received major surgery (groups are not mutually exclusive).
- The ANZNN level III cohort represents 2.25% of the total births for the two countries. This rate has been increasing steadily each year from 1.8% in 1995. The most marked increase has been in the numbers of babies receiving assisted ventilation who are born at more than 31 weeks' gestation. When babies registered to the level III and level II nurseries are considered together, they were 2.35% of the total population. Babies born in New Zealand in 1999 who were registered to the ANZNN high-risk cohort formed 3.13% of the total livebirths.
- The audit has been conducted in all level III NICUs since 1995 so trends in the data can be examined. For example, there has been a significant increase in the use of antenatal corticosteroids in babies born at less than 32 weeks' gestation from 78.8% in 1995 to 87.1% in 1999. Giving corticosteroids to the mother before a baby is born preterm greatly reduces the chances of problems with breathing or bleeding into the brain or of death for the baby. This treatment is recommended by NHMRC's Clinical practice guidelines for care around preterm birth. The rate of use of this therapy is high by international standards.
- However, there has been no change in the numbers of babies born in the perinatal centres that have the staff and equipment to care for these high-risk babies. Since 1995, 90% of the very preterm babies and 75% of all the high-risk babies have been born in a perinatal centre.
- The numbers of babies receiving assisted ventilation who were more than 31 weeks' gestation at birth has risen from 2,475 in 1995 to 3,289 in 1999. Their total 'days' of respiratory therapy was 69,671. Five hundred and six babies had a special form of ventilation where the ventilator oscillates the air in the baby's lungs at many hundreds of breaths per minute, an increase from 258 babies in 1996 when we first began monitoring the use of high-frequency ventilation as a new technology. The percentage of babies who received the recommended therapy of exogenous surfactant for hyaline membrane disease that required intubation has risen from 80% in 1995 to 88% in 1999.
- The incidence of a significant haemorrhage into the brain of very preterm infants has decreased significantly to 6.1%, compared to 1995 when 8.0% of very preterm babies had this condition.
- There has been no real change in the rates of survival of these fragile babies since 1995. Overall 91.6% 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 History and structure of the ANZNN

1.1 History

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

The National Health and Medical Research Council's Expert Panel on Perinatal Morbidity had 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 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 level II units in New Zealand joined the audit and the level II unit in Tasmania joined 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 participating units. 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 during March. These meetings were held in Melbourne Vic in 1999, in Brisbane Qld in 2000 and in Canberra ACT in 2001.

The ANZNN Coordinators committee was expanded in 2000 to six members and renamed the ANZNN Executive. The original Coordinators are Professor Brian Darlow, who has the Chair of Paediatrics at Christchurch School of Medicine,

University of Otago and is a neonatologist at Christchurch Women's Hospital, New Zealand; A/Professor Paul Lancaster is the Director of the Australian Institute of Health and Welfare (AIHW) National Perinatal Statistics Unit; and David Henderson-Smart is Professor of Perinatal Medicine, University of Sydney; Director of the Pregnancy and Newborn Services Network and a consultant neonatologist at King George V Hospital.

The new members of the executive include Kaye Bawden, audit officer and follow-up coordinator at Monash Medical Centre, Victoria who represents audit officers; Dr David Cartwright, Director of Neonatology at Royal Women's Hospital in Brisbane, Qld who has a special interest in databases and Ms Penny Waterson who, as a consumer advocate is chairperson of SANDS Australia, and a member of Maternity Alliance.

Deborah Donoghue has been the researcher/coordinator since the network's inception and Anne Cust took up the new position of Project Officer in 1999 and is primarily responsible for the level II nurseries and the day to day running of the audit.

The ANZNN was originally set up under the National Perinatal Statistics Unit, a collaborating unit of the AIHW. This agreement ceased with the completion of the 1998 data collection.

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.

Additionally, in 1997 the ANZNN Advisory Committee voted unanimously 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.

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 network 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 1999 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 the 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 strictly 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

In 1999 6,882 babies met the registration criteria of the Australian and New Zealand Neonatal Network's (ANZNN) audit of high-risk infants and were admitted to one of the 29 level III neonatal intensive care units (NICUs) throughout Australia and New Zealand. Of these 3,194 babies were born at less than 32 weeks' gestation (Figure 1 page 11; Table 1 page 24) and 2,764 were born weighing less than 1500 grams (Table 2). Assisted ventilation (either intermittent positive pressure ventilation (IPPV) or continuous positive airways pressure (CPAP) was administered to 6,043 babies while 844 received major surgery.

All 13 level II nurseries in New Zealand and the level II nursery in Tasmania are now members of the ANZNN and contributed to the audit of high-risk newborn babies in 1999. The 301 babies who met the registration criteria are discussed in section 4 (Page 21).

While these data generally represent the sickest babies they do not represent all babies admitted to a NICU, as many require other assistance and observation. In 1999 there were 305,923 babies born alive in Australia and New Zealand (248,870 were registered in Australia (Australian Bureau of Statistics, 2000) and 57,053 in New Zealand (Statistics New Zealand, 2000)). There has been a small decrease in the total number of live births since 1995.

The ANZNN cohort represents 2.25% of the total births for the two countries. This rate has been increasing steadily each year from 1.8% in 1995. The most marked increase has been in the numbers of babies receiving assisted ventilation who are born at more than 31 weeks gestation (Figures 1 and 2).

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. The data in tables are by gestational age group (adapted from WHO groups and NSW Health role delineation guidelines) and by birthweight group. Data in figures are given by gestational age divisions (Figure 2). Gestation is considered to be well documented in these babies and is the information available prior to the birth.

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. In 1999 there were 29 level III NICUs in Australia and New Zealand with 985 beds for babies. 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

The number of babies who met the criteria for this audit of high-risk babies during 1999 ranged from 60 to more than 500 per annum (Figure 3) per unit. These numbers reflect both the size of the unit and the case mix of patients. The registration unit is the first NICU in which the baby remains for four or more hours.

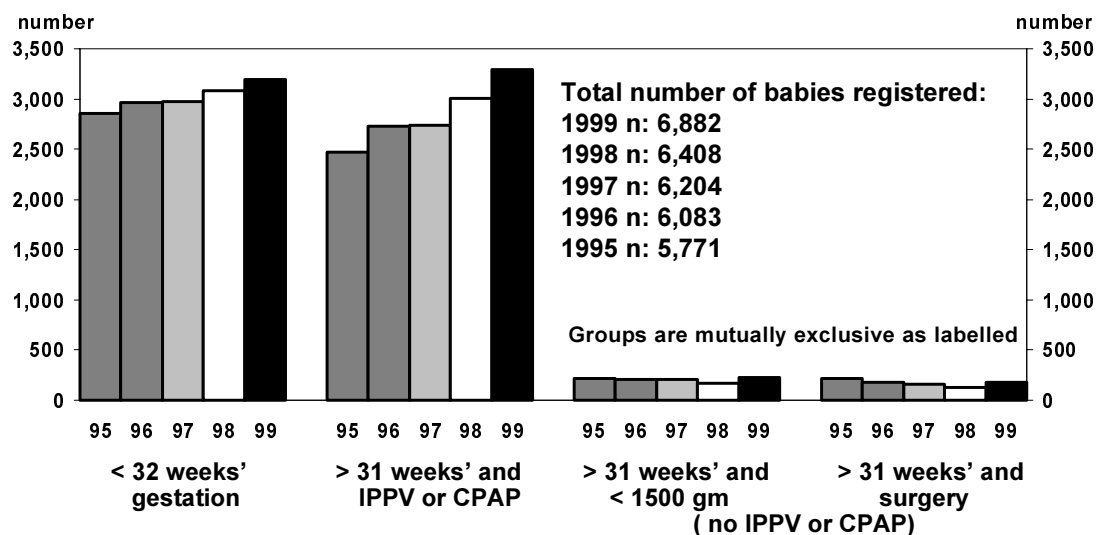


Figure 1: Number of babies in the ANZNN cohort by registration criteria, 1995-1999

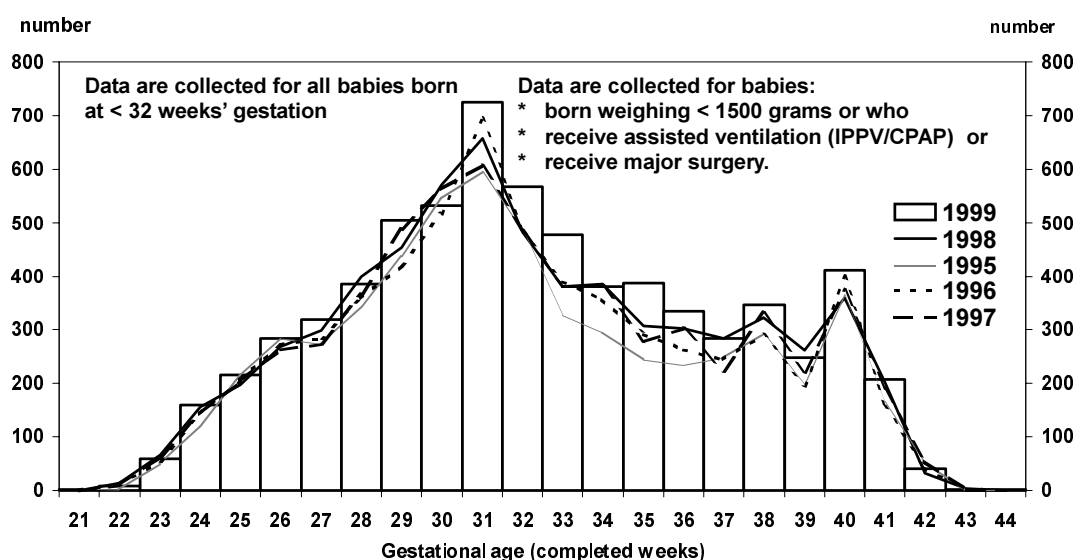


Figure 2: Number of babies in the ANZNN cohort by gestational age, 1995-1999

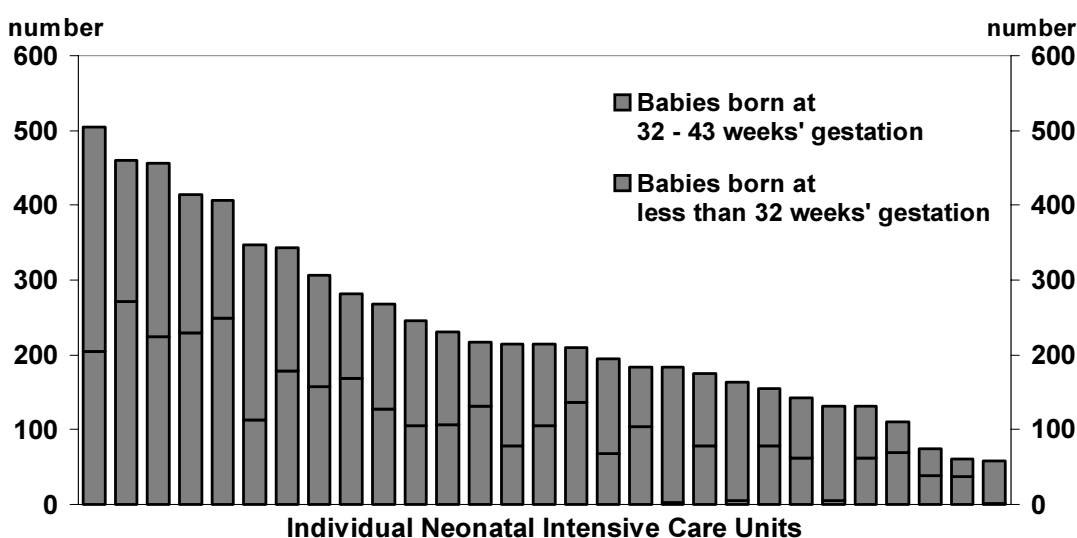


Figure 3: Number of babies in the ANZNN cohort by registration NICU, 1999

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. For example, when maternal age is either lower or higher than average, this can be associated with poor outcome. In the ANZNN group of babies born very preterm (less than 32 weeks' gestation) there were twice as many babies born to teenage mothers as for the whole of Australia (9.3 % compared to 5.1% for Australian births in 1998). There were also twice as many babies born to mothers over 34 years (28.4% compared to 15.8% for Australia in 1998; Nassar et al., 2001). Additionally, having had a previous baby born preterm is a risk factor for a future preterm birth and 440 (18.4%) babies were born to mothers who were in this category.

The ethnicity of the mother is reported for 97.7% of babies registered to units in New Zealand. Mothers identified themselves as Maori for 18.5% of the babies, as Pacific Islander for 9.8% of babies and as Caucasian for 65.6% of babies, similar to figures reported for the New Zealand population (Demographic Trends 2000).

Ethnicity was not recorded as well for babies registered to Australian units where the compliance was only 79.9%. Here, mothers reported their ethnicity as Caucasian in 86.5% of babies. Mothers were identified as Aboriginal or Torres Strait Islander for 5.2% of babies, a rate higher than that seen in the Australian population (3.09%, Australian Bureau of Statistics 1999).

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 (Crowley 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 2,399 (87.1%) babies born < 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 89.9% of babies).

Trend data shows a significant increase in the use of any steroids from 78.8% in 1995 (Figure 4; $\chi_{MH} = 93.6$, $p < 0.001$). These rates are higher than most published rates from around the world (Crowley 1995).

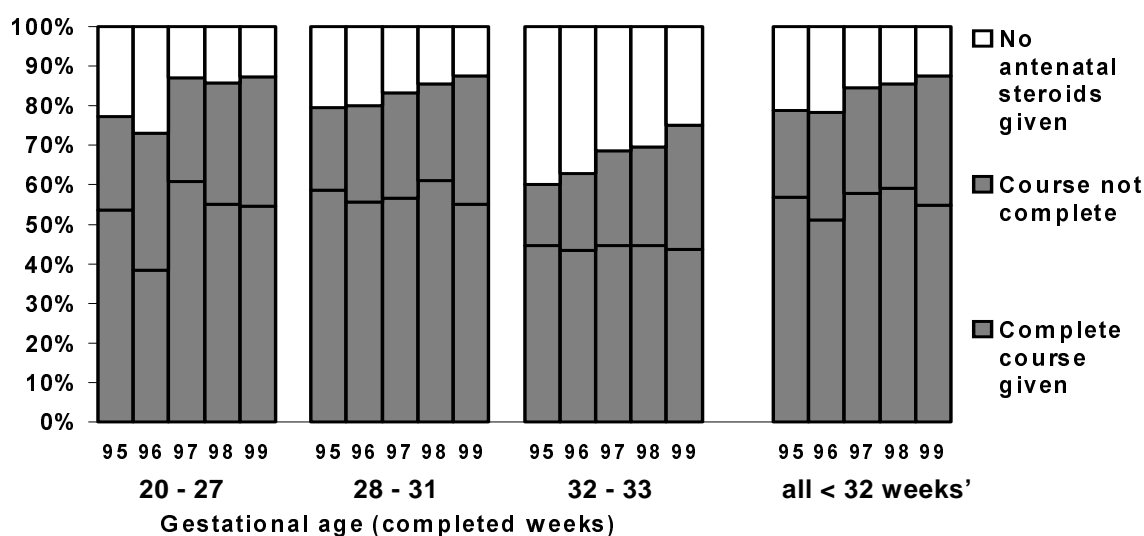
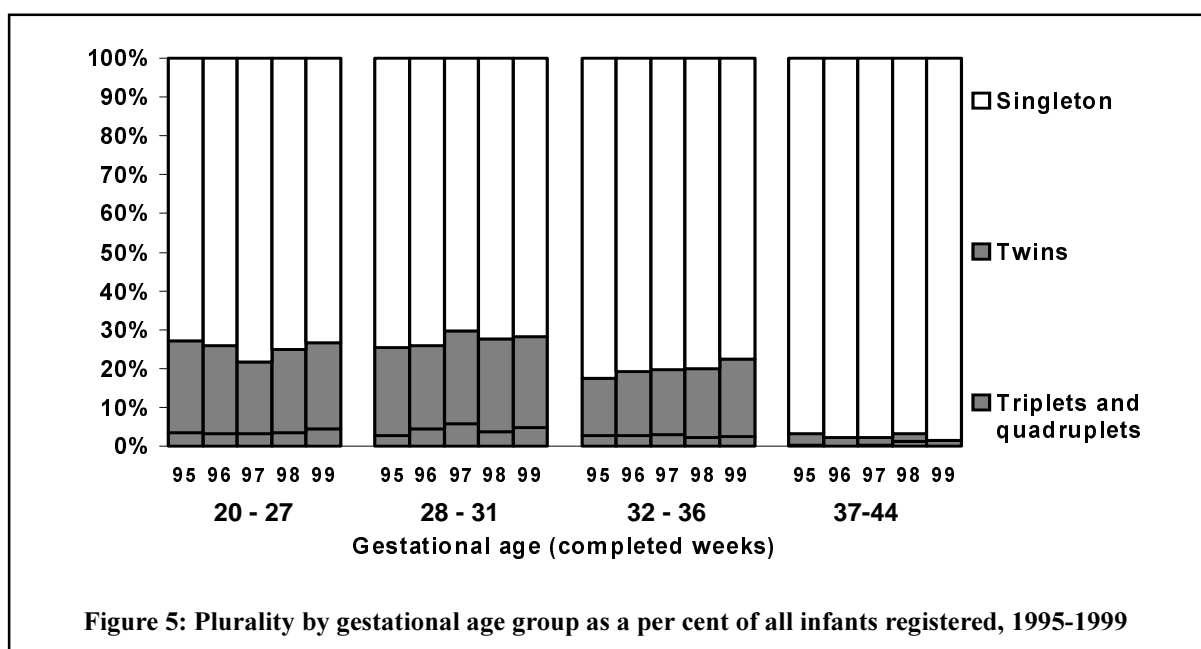


Figure 4: Antenatal corticosteroid use by gestational age group, 1995-1999



3.3.2 Antenatal problems

Data were collected on the obstetric problems that led to the mother's most recent stay in hospital, and thus the baby's birth and subsequent admission to a NICU. Preterm labour represented a third (35.8%) of the presenting obstetric problems for those babies born at less than 32 weeks' gestation. Pre-labour, preterm rupture of the membranes made up another quarter (24.7%) of the presenting problem for these infants. Data are presented for the number of babies (not confinements) and were recorded in 87.3% of cases.

In the mildly preterm group (those 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 nearly a third (29.3%) of these problems. Pre-labour, preterm rupture of the membranes and pregnancy induced hypertension each represented approximately 17% of the presenting antenatal problems.

For babies born at term, nearly half (43.9%) had no antenatal problem that could be identified. 'Antenatal detection of a fetal malformation' was reported to be the presenting antenatal problem for 9.5% of term infants in our cohort. In a few instances, mothers were admitted with 'preterm' antenatal problems and the infant was then born at 'term'. Overall, 56.1% of babies born at term were reported to have at least one antenatal problem, whereas 89.0% of preterm babies had some antenatal problem identified..

3.4 The baby

3.4.1 Gender

Each year, slightly more male babies are born than female babies, with boys accounting for 51.3% of all live births in Australia in 1999 (Australian Bureau of Statistics, 2000). The proportion of males in our data gives a wider differential with more males (57.2%, n: 3,936) than females (42.8%, n: 2,499). Two babies had ambiguous or uncertain gender during the neonatal period. For babies born at less than 32 weeks' gestation 55.8% (1,782) were male. This proportion rose to 58.9% 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). Overall, a total of 1,386 (20.1%) babies in our cohort were from a multiple birth with 186 (2.7%) babies coming from triplet pregnancies and 17 (0.2%) were quadruplets (Tables 5 and 6, Figure 5). The proportion of infants from a multiple birth for babies born at less than 32 weeks' gestation was 27.6%. Three-quarters of the triplets (73.7%) and the quadruplets (71.4%) were born at less than 32 weeks' gestation. For the babies born at 32 to 36 weeks' gestation, the proportion of babies from a multiple pregnancy dropped to 22.4%. For those born at term, 1.5% were from a multiple birth, slightly less than that usually seen in the Australian population in 1997 (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: 3,198, 89.5%). At term, the proportion of babies born in a tertiary centre decreased to 49.5%. Overall 75.1% 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 1,518 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). Most (93.1%) were born in a non-tertiary centre, but 52 (3.4%) were transferred from another tertiary centre. Nearly half (44.3%, n: 673) of 'retrieved' babies were born at term.

A further 196 term babies were transferred by a non-specialist team such as ambulances, flying doctor services and eight term babies arrived by other means such as being born enroute to the hospital or in a car.

For babies born at less than 28 week's gestation, 116 (11.1% 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. Six babies were transferred by a non-specialist team and five babies were transported to the hospital by other means.

3.5.2 Method of birth

The method of birth for these babies varied with gestational age (Tables 11 and 12), however more than half (54.5%) were born by caesarean section. Of the caesarean sections, 60.1% occurred before the onset of labour (also known as an 'elective' caesarean) and this proportion was similar for all age groups after 24 weeks'. A third (37.7%) of term babies were born by caesarean section. Data were available for 96.8% of all ANZNN babies.

The caesarean section rate for all confinements in Australia in 1998 was 21.1%. Notably, this rate rose to 47.5% for twin pregnancies, and to 55.9% for singleton very low birthweight babies (Nassar et al., 2001).

At term, babies are usually born with the head presenting first in the vagina (cephalic, 95.0% of all confinements in Australia, Nassar et al., 2001). For babies born at term in our cohort 92.2% presented head first while 6.0% were breech, and 1.8% were transverse or other (data were available for 88.2% of cases). For the babies born at less than 32 weeks' gestation two thirds (66.7%) presented as cephalic, 28.5% were breech and 4.8% were transverse or other.

3.5.3 Condition at birth

The Apgar score is a clinical indicator (scored from 0 to 10) used to denote a baby's condition at birth. A low score (less than 4 at one minute) indicates that a baby that needs assistance with their adaptation to extra-uterine life in the form of specialised resuscitation. Fortunately, this only occurs in a small proportion of babies (2.5% of babies born in Australia in 1998 Nassar et al., 2001). In the ANZNN cohort, 610 (19.6%) babies born at less than 32 weeks' gestation had a low 1 minute Apgar score (data available for 99.1% of babies). For term babies 317 (21.8%) had an Apgar score of less than 4 at 1 minute. This suggests that an increased need for assistance at birth can occur at any gestation, and that all staff attending a birth should be skilled in resuscitation.

The NHMRC's clinical practice guidelines for care around preterm birth (1997) recommend that births occurring at less than 32 weeks' gestation should ideally be attended by a member of the NICU paediatric staff, and those of less than 34 weeks' should have someone in attendance with up-to-date skills in endotracheal intubation (passing a tube into the windpipe).

For the babies born at less than 32 weeks' gestation in this cohort, half (n: 1,546, 48.8%) were assisted by endotracheal intubation to aid resuscitation at birth (data available for 99.1% of babies). Overall a total of 2,212 (33.0%) babies in our cohort were intubated while in the labour ward in 1999 (data available for 97.3% of babies).

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. One of the eligibility criteria for this audit is receiving respiratory assistance for four or more hours, so it follows that only 545 (8.2%) babies were noted to have no respiratory support.

There are two main forms of mechanical assistance with breathing, intermittent positive pressure ventilation (IPPV) which also 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.

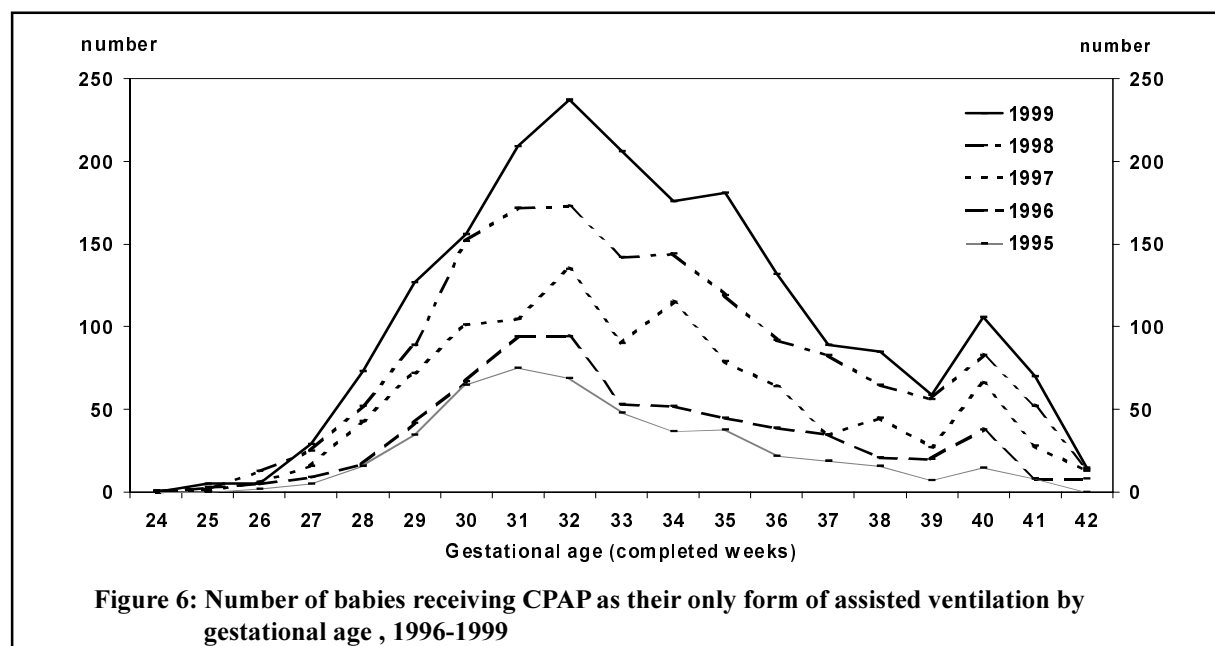
A total of 6,043 babies received assistance with ventilation and were admitted to a level III NICU (Tables 13 and 14). Most of these babies received either 'IPPV only' (n: 2,096) or a combination of IPPV and CPAP (n: 2,226). It should be noted that by definition, if a baby is weaned from IPPV using CPAP, CPAP usage will only show in our data if that weaning process took more than one day (Appendix 1). However, 1,721 babies received 'CPAP only' and this appears to be an increasing trend (Figure 6). The total duration of IPPV for all babies in our cohort in 1999 was 33,173 days, and CPAP was delivered for 36,496 days. This given a combined total of 69,671 ventilator 'days' (Tables 13 and 14; see Appendix 1).

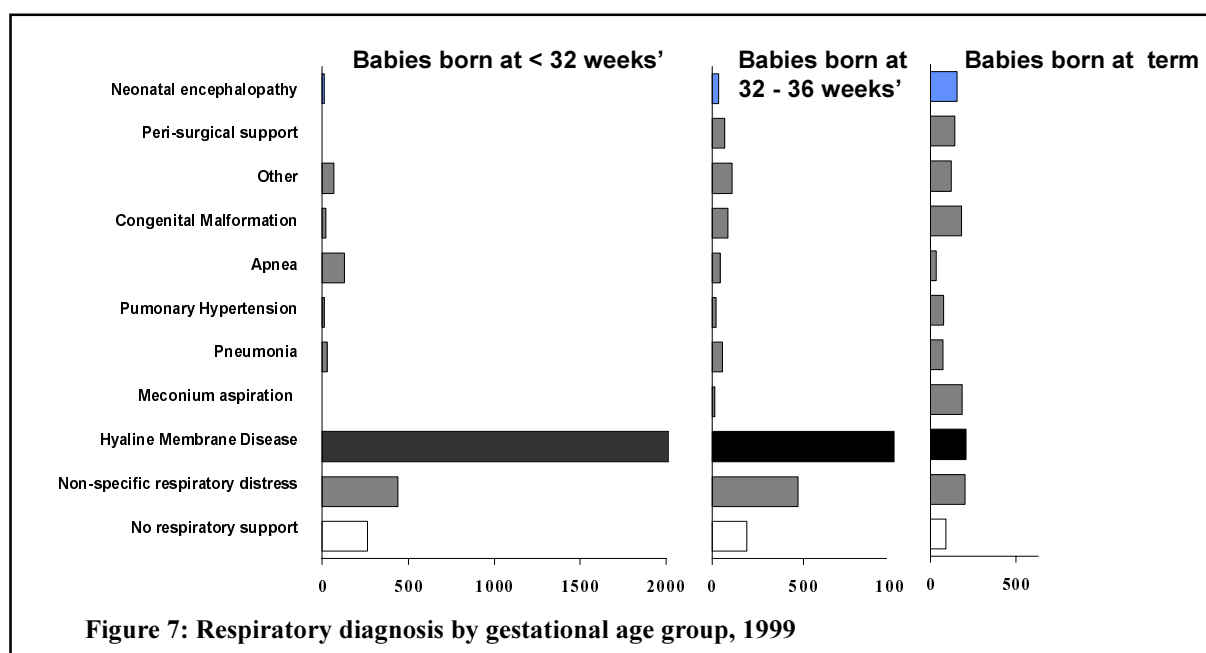
The treatment and aetiology of respiratory distress changes with maturity (Figure 7), thus gestational age groups are discussed separately.

3.6.1.1 Babies born at less than 32 weeks gestation

All babies born at less than 32 weeks gestation are part of the cohort, hence 250 babies (7.8%) received no respiratory support. A total of 2,752 (86.2%) of babies received mechanical assistance with breathing (IPPV and/or CPAP). CPAP alone was the treatment for 578 babies (21% of those ventilated). The duration of ventilation increases on average, with decreasing gestational age (Tables 13 and 14).

The total duration of IPPV for these very preterm babies was 23,915 'days' (72.1% of all IPPV 'days' recorded for babies admitted to a level III NICU). They also received a total of 31,588 CPAP 'days' (86.6% of CPAP 'days').





High-frequency ventilation is mechanical ventilation given at 8 - 15 hertz per second, in contrast to conventional ventilation which gives about one breath per second. Three hundred and fifty-seven babies born at less than 32 weeks' received this therapy (16.4% of babies receiving IPPV).

Eighty very preterm babies received nitric oxide. The respiratory diagnosis was HMD in the majority of cases (70.9%). 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). Pulmonary airleak requiring any drainage was seen in 138 babies (6.3% of those ventilated).

Oxygen therapy was received by most of the babies in this group, for a total for 92,261 oxygen 'days'. Two hundred and fifty babies (8.8% of survivors) were treated with supplemental oxygen after they were discharged from hospital, 189 of these were infants 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 643 babies who met this definition (22.3% of survivors, Tables 15 and 16).

The predominant respiratory diagnosis for babies born at < 32 weeks gestation was HMD (68.1%, Figure 7).

3.6.1.2 Babies born at 32 to 36 weeks gestation

A total of 1,890 (88.0%) babies born at 32 to 36 weeks gestation received IPPV and/or CPAP. CPAP alone was given to 803 babies (42.5% of those ventilated). As ANZNN entry criteria primarily involves ventilatory assistance in this gestational age group, only 257 (12.0%) babies received no mechanical assistance with their breathing. The main respiratory diagnosis remains HMD (n: 992, 47.8%, Figure 7). High frequency ventilation was given to 57 babies and 35 received nitric oxide (Table 13), again primarily for HMD (71.6%). Airleak was seen in only 85 babies (4.5% of those ventilated). Twenty-three babies required oxygen after discharge to home (Tables 15 and 16).

3.6.1.3 Babies born at term

The main indication for respiratory support for term babies was varied (Figure 7). HMD and 'non-specific respiratory distress' accounted for 28% of the group. Meconium aspiration and congenital malformation each made up another 12.5 % of the diagnoses. A total of 1,399 (80.1%) term babies received IPPV and/or CPAP. CPAP alone was given to 578 (41.3% of those ventilated).

Ninety-two babies received high frequency ventilation. Nitric oxide was given to 145 babies (13.7% of those ventilated), primarily to those diagnosed with meconium aspiration syndrome (38.6%) and pulmonary hypertension (24.1%). ECMO (extracorporeal membrane oxygenation) was given to only 4 babies. Eighty-six (5.6%) babies had an airleak requiring drainage.

3.6.1.4 Exogenous surfactant

Exogenous surfactant is a treatment primarily for HMD and is given via an endotracheal tube (i.e. the baby is intubated). Its efficacy was confirmed by systematic reviews of randomised controlled trials in 1996 (for example, Soll 1999) and this treatment is recommended (NHMRC Clinical Practice Guidelines for Care Around Preterm Birth 1997). In ANZNN's cohort there were 2,622 babies who were intubated for more than four hours and had a main respiratory diagnosis of HMD. Exogenous surfactant was given to 2,270 (87.5%, data unavailable for 28) 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. For babies born at less than 32 weeks' gestation 2,321 (78.9%) did not have any IVH detected (Tables 19 and 20). 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. A significant haemorrhage (grade III or IV) was detected in 179 (6.1%) of the babies examined. The previously reported reduction in significant IVH from 8.0% in 1995 has abated, but remains a statistically significant trend ($\chi_{MH}^2: 7.7$ $p < 0.01$; Figure 8). Of the 242 (7.6%) babies who did not have an ultrasound, 17.4% died during their first day of life.

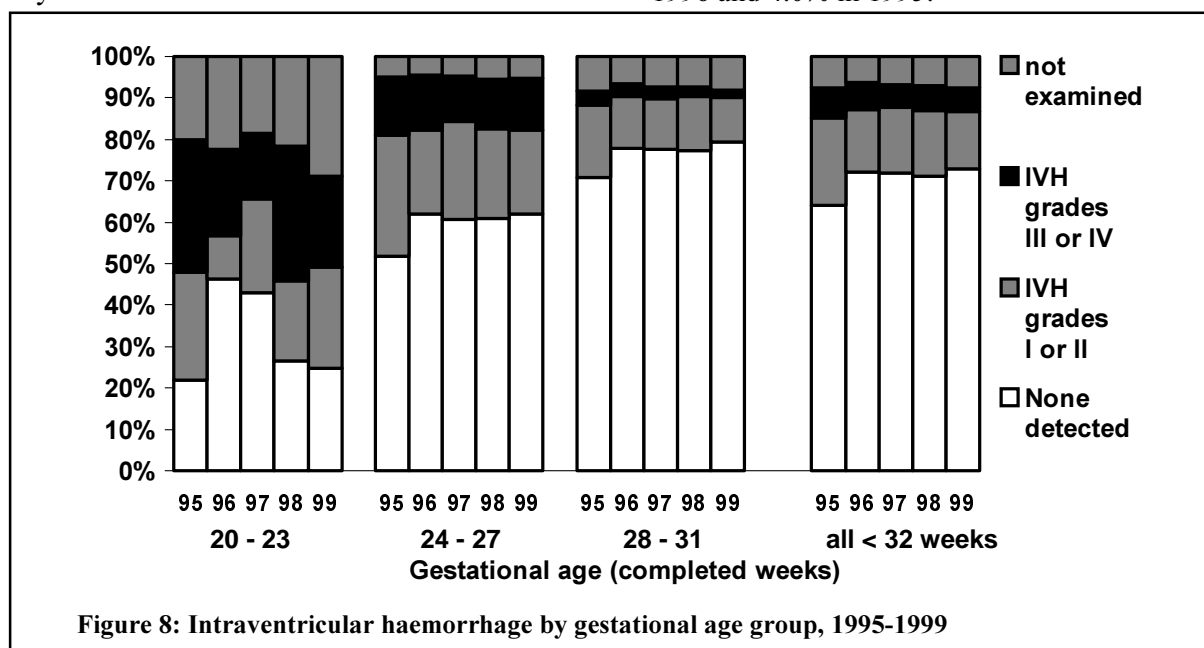
A later ultrasound is done to detect cystic lesions (periventricular leukomalacia or porencephalic cysts) and ventricular dilatation (hydrocephalus). For the 6,371 babies alive after day 27 who did not have congenital hydrocephalus, 156 had a major abnormality on head ultrasound (data not available for 50.1% of babies).

There were 1,692 babies who were born at less than 32 weeks' and who survived to day 28, did not have congenital hydrocephalus and who had an ultrasound recorded on at least day 21 of life. No abnormality was seen for 93.2% (n: 1,534) of these infants. Hydrocephalus was uncommon in this group (n: 30, 1.8%), as were porencephalic cysts (n: 31, 1.8%) and periventricular leukomalacia (n: 71, 4.2%). A further 1,252 (43.2%) babies survived but did not have data available.

3.6.3 Necrotising enterocolitis

Necrotising enterocolitis (NEC) is a disease of the gut, usually affecting the large intestine (colon) and 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).

NEC was proven in 111 babies, half of whom (n: 56, 50.5%) were born at less than 28 weeks' gestation. A third (31.5%) of all babies with NEC died. The reported occurrence of this disease varies greatly. The rates seen in babies born at less than 32 weeks in our cohorts have been 2.8% in 1999, 3.9% in 1998, 3.0% in 1997, 7.8% in 1996 and 4.0% in 1995.



3.6.4 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 (such as blood (septicaemia), cerebrospinal fluid (meningitis), urine (urinary tract infection) or lung (pneumonia; see Isaacs et al. 1995)). This includes early (first 48 hours) and late infection.

A proven systemic infection was reported for 1,109 (14.8%) babies in our high-risk cohort. This proportion rose to 24.6% for babies born at less than 32 weeks' gestation and half (44.7%) of babies born at less than 28 weeks' gestation had at least one major infection during their hospitalisation. Data are known for 94.6% of all babies in the cohort. The variation between units in the rate of at least one episode of proven infection in a baby was 14.7% (interquartile range 10.6 to 19.8%).

3.6.5 Eye examinations

Eye examinations monitor the vascularisation of the eye which when disrupted, can result in retinopathy of prematurity (ROP). There is an agreed staging of ROP (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. The 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.

In ANZNN, the group most commonly screened included babies born at less than 31 weeks' gestation or less than 1250 grams birthweight. There were 2,529 babies who met this criteria who also survived to 36 weeks' post menstrual age (ie after the eye is fully vascularised). Of these babies 1,367 (71.8%) are known to have no ROP (Tables 21 and 22). For 624 babies (24.7%) the results of the examination were not available or the baby fell outside the local criteria for an eye examination or an examination was not performed. Other babies may have their eyes examined, but this is at the discretion of the neonatologist, and those babies are not reported here. It should be noted that one such baby was identified as having

significant eye disease. This baby was born at 31 weeks gestation and had a known congenital malformation.

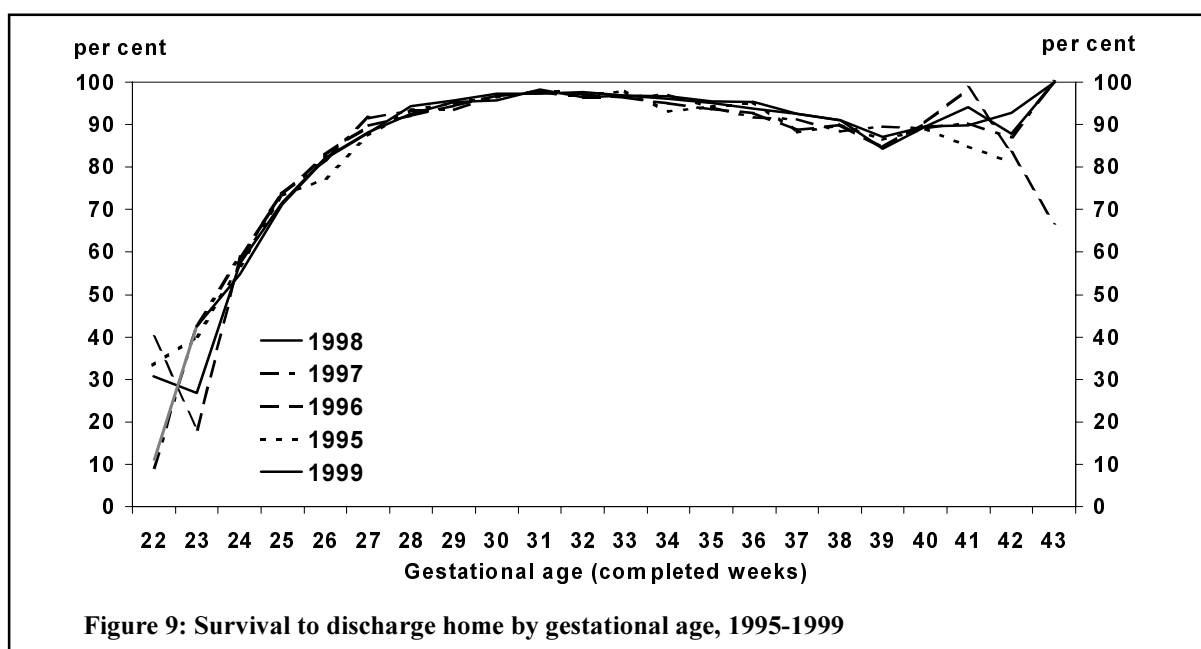
In our reported cohort, significant eye disease was seen in 120 babies (6.3% of those with results noted) and 66 are reported to have been treated. Our data did not report the incidence of threshold disease for these babies and thus cannot differentiate those with Grade III disease who need treatment. It should also be noted that the worst stage of eye disease is recorded, even if the retinopathy resolves to a lower stage with subsequent development of the eye.

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. Newborn infants undergoing major surgery 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 844 babies who had major surgery in our cohort.

Half (n: 419, 49.6%) of the babies having surgery were born at term. Half of these term babies (n: 209, 49.8%) were born in a perinatal centre and again half of them (n: 117, 55.9%) 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: 384, 91.6%) of the term babies having surgery. Overall, 32 (7.6%) of the term babies who had major surgery died. Death could be directly attributed to a congenital malformation in 29 (90.6%) of term babies.

For babies born at 32 to 36 weeks' gestation, 208 had major surgery. Two-thirds (n: 135, 64.9%) of these babies were born in a perinatal centre and 98 (47.1%) had an antenatal diagnosis of a fetal malformation. A total of 176 babies had a congenital malformation diagnosed of which 14 proved to be fatal. Twenty-four (11.5%) of the babies who had surgery in this gestational age group died.



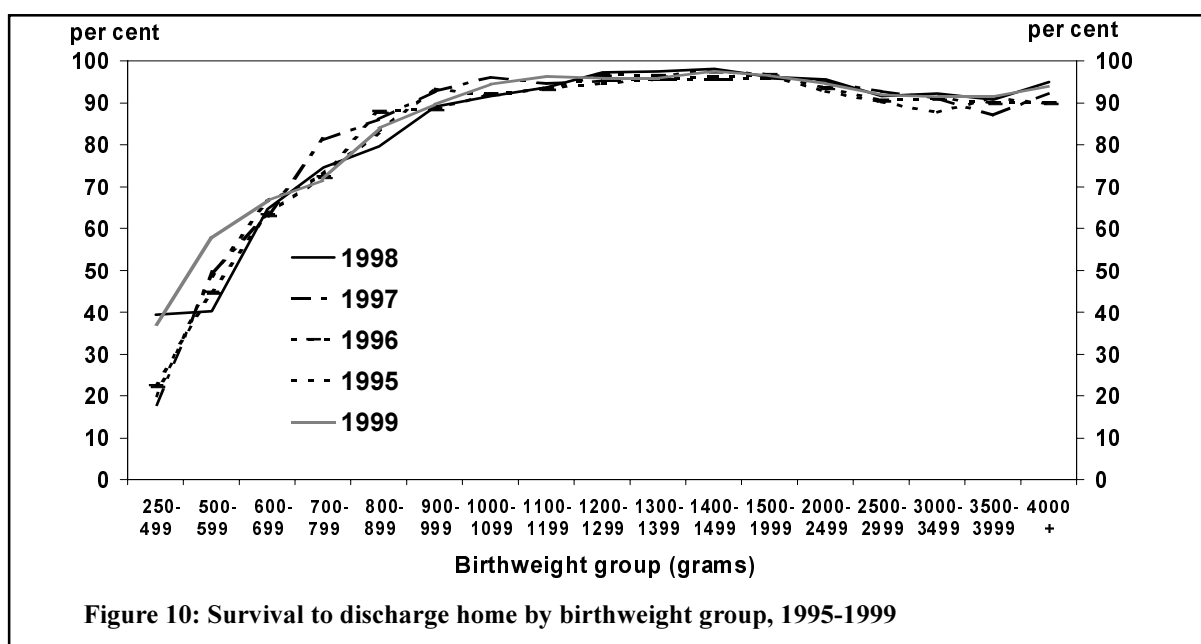
3.7 Outcome

3.7.1 Survival

Overall, the majority of babies in this high-risk cohort survived to go home (91.6%). Survival is dependent on many factors, including gestation 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 lethal congenital malformation (a major malformation that contributes to the death of the baby) is noted.

There has been no real change in survival rates in the past 4 years (Figure 9, $\chi_{MH} > 0.05$ for the 6 gestational age epochs). More than 95% survival is seen for babies born at 29 to 36 weeks' gestation, then falls at term. When death occurred, it was during the first two days of life for 165 (28.4%) babies and within a week for more than half (n: 325, 56.0%) of those who died. The death of 170 babies (2.5% of all babies but 29.3% of those who died) could be directly attributed to a congenital malformation.

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



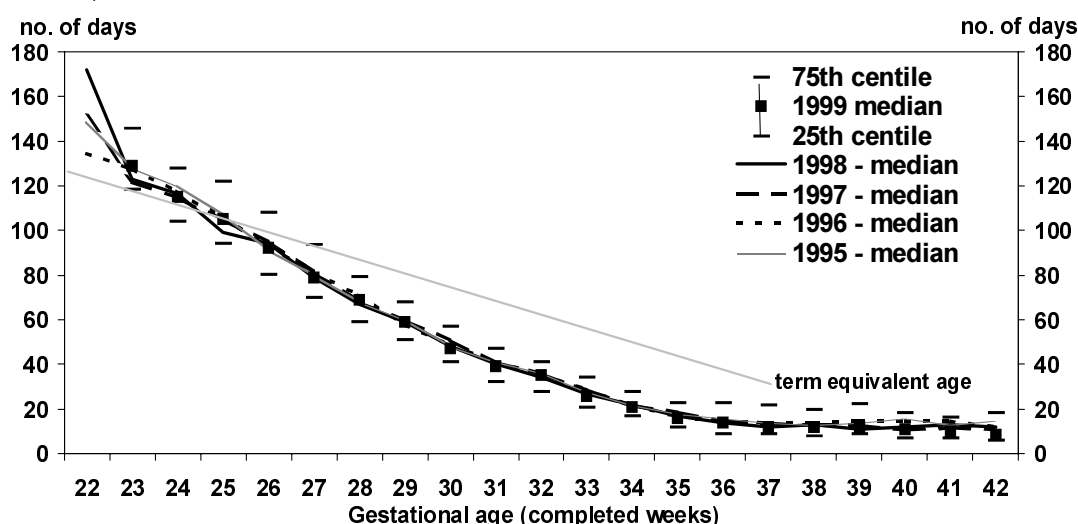


Figure 11: Days to go home by gestational age, 1995-1999

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 1999, nearly half of all babies (n: 3,338, 48.5%) were transferred to nurseries in other hospitals prior to their discharge to home (Tables 25 and 26).

Most babies went to hospitals with Level I or Level II nurseries (n: 2,748, 82.3% of those transferred). Some babies (n: 590, 8.5% of total but 17.7% 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 has been received from nearly 300 hospitals around Australia and New Zealand to provide outcome information for babies covered in this audit.

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, babies born in Australia in 1998 and survived to go home tended to go home from their hospital of birth before 7 days (86.7%, Nassar et al., 2001).

Over the period 1995 to 1999, 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 over 95% 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 1st January 1998, all level II hospitals (n: 13) in New Zealand have been members of the ANZNN and have contributed data to the audit of high-risk infants admitted to neonatal nurseries.

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 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 hospital or a cardiac unit without a neonatal unit are not included. In 1999, one Australian level II hospital also contributed data for babies < 32 weeks' gestation and <1500 grams.

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 who were transferred to a level III NICU after 28 days, or who were transferred to a children's hospital without being admitted to a level III nursery.

There were 301 babies who fulfilled these criteria and were registered to one of the ANZNN level II hospitals (Tables 29 and 30). In New Zealand, babies registered to level II hospitals accounted for 16.6% of all high-risk infants registered to the ANZNN in 1999. This is a significant (χ^2 32.5, $p < 0.001$) increase from 1998, where they accounted for 9.8% of the high-risk cohort.

Of the babies registered to a Level II nursery, 56 (19%) were born at less than 32 weeks' gestation, 45 (15%) were born weighing less than 1500 grams, 283 (94%) babies received assisted ventilation and 3 (1%) babies received major surgery. The number of babies registered to each level II centre ranged from none to 57.

4.2 Antenatal

Antenatal corticosteroids were administered to the mothers of 73% of babies born at less than 32 weeks' gestation, with 55% receiving a complete course (excludes data for one hospital whose data was unavailable due to coding problems). The proportion of babies receiving corticosteroids at 32-33 weeks' gestation was 56%.

For preterm infants, the most common obstetric problems that led to the baby's birth were preterm labour (44%) and preterm pre-labour rupture of membranes (20%). For babies born at term, 49% had no identifiable antenatal problem. However, 22% showed signs of fetal distress, 13 % had hypertension in pregnancy, and 12% had an antepartum haemorrhage or suspected intra-uterine growth restriction .

The majority of babies (89%) were booked at the level II hospital to which they were registered.

4.3 Baby and birth

The median gestational age for babies registered to a level II unit was 35 weeks' (interquartile range 32 - 38; range 25 - 42; Table 29). The median birthweight was 2335 grams (interquartile range is 1805 - 3080; range 730 - 4935; Table 30).

There were more males (63%) than females (37%) in the cohort. Overall, 13% of babies were from a multiple pregnancy, the proportion decreasing from 23% at <32 weeks' gestation to 14% for the mildly preterm babies (32-36 weeks') and 6% at term.

The majority of babies were born vaginally (57%). Another 43% were born by caesarian section, with 45% of caesarian sections occurring before the commencement of labour. There were 13% babies who had a low Apgar of less than 4 at 1 minute, and 2% had a low Apgar at 5 minutes. Nine (3%) babies had a major congenital malformation.

4.4 Morbidity

4.4.1 Respiratory Disease

For preterm infants, the most common indication for respiratory support was hyaline membrane disease (HMD; n: 86, 43%). Non-specific respiratory distress was also common for preterm babies (n: 83, 41%) and term babies (n: 38, 38%). Term babies were more varied in their respiratory diagnoses with 20 (20%) diagnosed with meconium aspiration, 13 (13%) with pneumonia and 9 (9%) with HMD. Exogenous surfactant was given to 88% of the babies known to have HMD and intubated for 4 or more hours.

Two hundred and eighty-three babies received assisted ventilation for 4 or more hours in this cohort. Of those, 241 (85%) had CPAP as their only form of assistance. In the mildly preterm group (32 - 36 weeks') CPAP only was given to 129 of the 139 ventilated babies (93%).

The duration of assisted ventilation was comparatively short; 3 days (interquartile range 2 - 9) for babies born at < 32 weeks' gestation; 2 days (interquartile range 1 - 3) for mildly preterm babies and 1 day (interquartile range 1 - 2) for babies born at term. There was a combined total of 896 ventilator 'days', comprising 752 (84%) CPAP 'days' and 144 (16%) IPPV 'days'.

A total of 277 (93% of the cohort) babies received supplemental oxygen therapy. Babies born at < 32 weeks' gestation received oxygen for a median of 54 days (interquartile range 18 - 79). The median duration of therapy for the other gestational age groups was 1 to 3 days. Six babies developed chronic lung disease and four received home oxygen therapy.

4.4.2 Other morbidities

A total of 45 babies had an eye examination for retinopathy of prematurity (ROP). ROP was detected in 9 (20%) of those examined, including 8 babies with stage 1 or 2 and 1 baby with severe eye disease. Of the babies born at <31 weeks' gestation or <1250 grams, 18 (53%) had an eye examination, and this detected 5 cases of ROP. For babies <32 weeks' gestation, 29 (57%) had their eyes examined and this detected 8 cases of ROP. The proportion of babies with any stage of ROP of those who had an eye examination was 80% for babies <28 weeks' and 17% for babies 28-31 weeks'. All babies <28 weeks' gestation who survived to home had their eyes examined.

Of the 39 (70%) very preterm babies who had an initial head ultrasound, 4 (10%) had grade 1 or more IVH (33% for babies <28 weeks' and 6% for babies 28-31 weeks'), including 1 baby with a severe grade (grade 3+). A further 90 (59%) babies at 32 weeks' or more gestation had an initial head ultrasound, and no IVH was detected in these babies. A late head ultrasound of later than 21 days was performed for 19 (36%) of the very preterm babies who survived to discharge home. Of these, two babies (11%) were found to have an abnormal cystic formation.

Systemic infection was seen in 21 (7.0%) babies with a rate of 13% for infants born at less than 32 weeks' gestation to 4% at term.

4.5 Outcome

Survival in this cohort was good, with 297 (98.7%) babies going home. This rate reflects the more mature gestations and overall lower risk of these babies compared to the cohort admitted to a level III NICU. Survival rates (Table 31) ranged from 71% for babies born at less than 28 weeks' to nearly 100% for the remainder of the babies. All deaths occurred within two days of birth. Discharge data were available for 300 of the 301 babies (99.7%).

The median length of stay in hospital for babies who survived to go home and were born at <32 weeks' was 42 days (interquartile range 37 - 55 days). For babies born at 32 to 36 weeks' the median number of days in hospital was 20 (interquartile range: 14 - 27); and term babies stayed a median of 7 days (5 - 9). Thus, most preterm babies went home before their term equivalent gestation, with babies born at less than 32 weeks' gestation discharged home at a median of 36.3 weeks equivalent gestation. Babies born at 32-36 weeks' gestation went home at a median of 36.9 weeks' equivalent gestation.

There were a further 281 babies who were registered to an ANZNN level III nursery and were then transferred to one of the level II hospitals described in this section before they went home. Some babies continued to receive assisted ventilation and supplemental oxygen on transfer. The median gestational age equivalent at transfer to level II hospitals for preterm infants was 33.2 weeks for babies born at <28 weeks' (n: 66; interquartile range 31.6 - 35.0); 32.1 weeks for babies born at 28 - 31 weeks' (n: 94) and 34.9 for babies born at 32 - 36 weeks' (n: 82).

5 References

- Australian Bureau of Statistics. 2000 *Births 1999*, Canberra: ABS Catalogue No. 3301.0, Government Printing Service.
- Barrington KJ & Finer NN 2000. *Inhaled nitric oxide in preterm newborn infants with respiratory failure*. (Cochrane Review) In: The Cochrane Library Issue 4. Oxford: Update Software.
- Beeby PJ & Jeffery H. 1992 *Risk factors for necrotising enterocolitis: the influence of gestational age*. Arch Dis Child. 67: 432-435.
- Crowley P. 2000. *Corticosteroids prior to preterm delivery*. (Cochrane Review) In: The Cochrane Library Issue 4, 2000. Oxford: Update Software.
- Crowley PA. 1995 *Antenatal corticosteroid therapy: a meta-analysis of the randomized trials, 1972 to 1994*. Am J Obstet Gynecol. 173: 322-335.
- Donoghue D & Cust A . 2000. *Australian and New Zealand Neonatal Network, 1998*. Sydney: AIHW National Perinatal Statistics Unit.
- Donoghue DA 1999. *Australian and New Zealand Neonatal Network, 1996-1997*. Sydney: AIHW National Perinatal Statistics Unit.
- Donoghue DA 1997. *Australian and New Zealand Neonatal Network, 1995*. Sydney: AIHW National Perinatal Statistics Unit.
- Finer NN & Barrington KJ 2000. *Nitric oxide for respiratory failure in infants born at or near term*. (Cochrane Review) In: The Cochrane Library Issue 4. Oxford: Update Software.
- Harding JE, Miles FK, Becroft DM, Allen BC & Knight DB. 1998. Chest physiotherapy may be associated with brain damage in extremely premature infants. J Pediatr. 132: 440-444.
- Health Care Committee Expert Panel on Perinatal Morbidity 1995, *Perinatal Morbidity*, Canberra: Australian Government Publishing Service
- ICD.9.CM 1990. *International Classification of Diseases, 9th revision, Clinical Modification*, Ann Arbor: Edwards Brothers Inc.
- International Committee for the Classification of Retinopathy of Prematurity 1984, *An International classification of retinopathy of prematurity*, Pediatrics 74: 127-133.
- Isaacs D, Barfield CP, Grimwood K, McPhee AJ, Minutillo C & Tudehope DI 1995. *Systemic bacterial and fungal infections in infants in Australian neonatal units*. Australian Study Group for Neonatal Infections. Med J Aust 162: 198-201.
- Liggins GC & Howie RN 1972. *A controlled trial of antepartum glucocorticosteroid treatment for prevention of the respiratory distress syndrome in premature infants*, Pediatrics, 50: 515-525.
- Nassar N, Sullivan EA, Lancaster P & Day P 2001. *Australia's Mothers & Babies, 1998*, AIHW Cat. No. PER 15. Sydney: AIHW National Perinatal Statistics Unit (Perinatal Statistics no 10).
- NHMRC Clinical Practice Guidelines for Care Around Preterm Birth 1997. Canberra: Australian Government Publishing Service.
- Papile LA, Burstein J, Burstein R & Koffler H 1978, *Incidence and evolution of subependymal and intraventricular haemorrhage: A study of babies with birth weights less than 1500 gm*, J. Pediatr 92:529-534.
- Soll, RF, 1999 *Prophylactic natural surfactant extract for preventing mortality and morbidity in preterm infants* (Cochrane Review) In: The Cochrane Library Issue 4, 1999. Oxford: Update Software.
- Statistics New Zealand Te Tari Tatau 2001 *Demographic Trends 200*. Wellington.

6 Tables

6.1 Babies registered to level III nurseries

Table 1: Number of babies in each gestational age group, 1999

Gestational age (completed weeks)	Number	Cumulative per cent	Gestational age (completed weeks)	Number	Cumulative per cent
21	1	0.02	32	567	54.7
22	9	0.15	33	478	61.6
23	59	1.00	34	380	67.1
24	159	3.31	35	388	72.8
25	216	6.45	36	334	77.6
26	284	10.6	37	283	81.7
27	319	15.2	38	347	86.8
28	385	20.8	39	248	90.4
29	505	28.1	40	411	96.3
30	532	35.9	41	208	99.4
31	725	46.4	42	41	99.9
<i>(All babies <32 weeks)</i>	<i>(3,194)</i>		43	1	100.0
			44	2	100.0
			All babies	6,882	

Note: ANZNN cohort includes all babies born at less than 32 weeks' completed gestation. Those babies born above this gestation must be born at less than 1500 grams birthweight, or must require assisted ventilation or major surgery to be included in the cohort.

Table 2: Number of babies in each birthweight group, 1999

Birthweight group (grams)	Number	Cumulative per cent	Birthweight group (grams)	Number	Cumulative per cent
250-499	46	0.67	1500-1999	1,319	59.3
500-599	106	2.21	2000-2499	805	71.0
600-699	192	5.00	2500-2999	731	81.7
700-799	228	8.31	3000-3499	636	90.9
800-899	251	12.0	3500-3999	404	96.8
900-999	263	15.8	4000 and over	223	100.0
1000-1099	297	20.1	All babies	6,882	
1100-1199	300	24.5			
1200-1299	322	29.1			
1300-1399	372	34.5			
1400-1499	387	40.2			
<i>(All babies < 1500g)</i>	<i>(2,764)</i>				

Note: ANZNN cohort includes all babies born at less than 1500 grams. Those babies born above this birthweight must be born at less than 32 weeks' gestation, or must require assisted ventilation or major surgery to be included in the cohort.

Table 3: Antenatal corticosteroid use by gestational age group, babies < 34 weeks' gestation, 1999

Antenatal steroid use	20-23	24-27	28-31	32-33	Babies < 34 weeks'
Number					
None	11	106	237	228	582
Incomplete course	18	203	380	183	784
Course completed	24	478	1,046	400	1,948
Course completed >7 day	2	78	170	104	354
Unknown	11	68	234	92	405
All babies	66	933	2,067	1,007	4,073
Per cent					
None	20.0	12.2	12.9	24.9	15.9
Incomplete course	32.7	23.5	20.7	20.0	21.4
Course completed	43.6	55.3	57.1	43.7	53.1
Course completed >7 day	3.7	9.0	9.3	11.4	9.7
All babies	100.0	100.0	100.0	100.0	100.0

Notes 1. Corticosteroids given antenatally via any route to the mother at a time likely to enhance fetal lung maturation is considered to be 'complete' when more than one dose of corticosteroids is given, and first dose was given more than 24 hours and less than 8 days before the baby's birth.

2. Data for one centre are excluded due to coding problems.

3. 'Unknown' or 'not available' data are excluded from per cent calculations.

Table 4: Antenatal corticosteroid use by birthweight group, babies < 2500 g, 1999

Antenatal steroid use	250-499	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	Babies < 2500 g
Number								
None	3	49	61	91	153	259	389	1,005
Incomplete course	11	84	116	139	139	219	85	793
Course completed	25	204	313	369	434	514	153	2,012
Course completed >7 day	3	27	45	68	61	133	54	391
Unknown	3	32	61	63	108	141	78	486
All babies	45	396	596	730	895	1,266	759	4,687
Per cent								
None	7.1	13.4	11.4	13.7	19.4	23.0	57.1	23.9
Incomplete course	26.2	23.2	21.3	20.8	17.7	19.5	12.5	18.9
Course completed	59.5	56.0	58.5	55.3	55.2	45.7	22.5	47.9
Course completed >7 day	7.2	7.4	8.4	10.2	7.7	11.8	7.9	9.3
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Notes 1. Corticosteroids given antenatally via any route to the mother at a time likely to enhance fetal lung maturation is considered 'complete' when more than one dose of corticosteroids is given, and first dose was given more than 24 hours and less than 8 days before the baby's birth.

2. Data for one centre are excluded due to coding problems.

3. 'Unknown' or 'not available' data are excluded from per cent calculations.

Table 5: Plurality by gestational age group, all babies, 1999

Plurality	20-23	24-27	28-31	32-33	34-36	37-44	All babies
Number							
Singleton	52	716	1,544	727	939	1,518	5,496
Twins	12	221	502	272	156	23	1,186
Triplets	5	35	97	43	6	—	186
Quadruplets	—	6	4	3	1	—	14
Unknown	—	—	—	—	—	—	—
All babies	69	978	2,147	1,045	1,102	1,541	6,882
Per cent							
Singleton	75.4	73.2	71.9	69.7	85.2	98.5	79.7
Twins	17.4	22.6	23.4	26.0	14.2	1.5	17.2
Triplets	7.2	3.6	4.5	4.1	0.5	—	2.7
Quadruplets	—	0.6	0.2	0.3	0.1	—	0.2
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Note: 'Unknown' and 'not available' data are excluded from per cent calculations.

Table 6: Plurality by birthweight group, all babies, 1999

Plurality	250-499	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	4000+	All babies
Number												
Singleton	36	536	606	971	648	685	628	404	222	309	451	5,496
Twins	9	186	262	297	150	46	8	—	1	83	144	1,186
Triplets	1	28	52	49	7	—	—	—	—	25	24	186
Quadruplets	—	7	1	2	—	—	—	—	—	1	3	14
Unknown	—	—	—	—	—	—	—	—	—	—	—	—
All babies	46	757	921	1,319	805	731	636	404	223	418	622	6,882
Per cent												
Singleton	78.3	70.8	65.8	73.6	80.5	93.7	98.7	100.0	99.6	73.9	72.5	79.9
Twins	19.6	24.6	28.4	22.5	18.6	6.3	1.3	—	0.4	19.9	23.2	17.2
Triplets	2.1	3.7	5.7	3.7	0.9	—	—	—	—	6.0	3.9	2.7
Quadruplets	—	0.9	0.1	0.2	—	—	—	—	—	0.2	0.5	0.2
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Note: 'Unknown' and 'not available' data are excluded from per cent calculations.

Table 7: Level of hospital of birth by gestational age group, all babies, 1999

Level of hospital	20-23	24-27	28-31	32-33	34-36	37-44	All babies
Number							
Not born in a hospital	1	10	17	5	6	21	60
Hospital, no level III NICU	6	109	209	167	397	756	1,644
Hospital with level III NICU	62	859	1,919	871	694	750	5,155
Unknown	—	—	2	2	5	14	23
All babies	69	978	2,147	1,045	1,102	1,541	6,882
Per cent							
Not born in a hospital	1.4	1.0	0.8	0.5	0.6	1.4	0.9
Hospital, no level III NICU	8.7	11.2	9.7	16.0	36.2	49.5	24.0
Hospital with Level III NICU	89.9	87.8	89.5	83.5	63.2	49.1	75.1
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Note: 'Unknown' or 'not available' data are excluded from per cent calculations.

Table 8: Level of hospital of birth by birthweight group, all babies, 1999

Level of hospital	250-499	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	4000+	All babies
Number												
Not born in a hospital	—	3	10	9	6	6	6	5	9	3	3	60
Hospital, no level III NICU	1	36	58	82	99	209	221	309	328	207	94	1,644
Hospital with level III NICU	45	379	554	666	816	1,100	574	410	294	192	125	5,155
Unknown	—	—	—	—	—	4	4	7	5	2	1	23
All babies	46	418	622	757	921	1,319	805	731	636	404	223	6,882
Per cent												
Not born in a hospital	—	0.7	1.6	1.2	0.6	0.5	0.7	0.7	1.4	0.7	1.4	0.9
Hospital, no level III NICU	2.2	8.6	9.3	10.8	10.7	15.9	27.6	42.8	51.8	51.6	42.3	24.0
Hospital with level III NICU	97.8	90.7	89.1	88.0	88.7	83.6	71.7	56.5	46.8	47.6	56.3	75.1
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Note: 'Unknown' or 'not available' data are excluded from per cent calculations.

Table 9: Transport type for babies transferred immediately after birth to registration hospital, by gestational age group, 1999

Transportation method	20-23	24-27	28-31	32-33	34-36	37-44	All babies
Number							
Non-specialised transport ^(a)	—	11	26	26	68	196	328
Specialist transport team ^(b)	7	109	205	158	366	673	1,518
All babies	7	120	231	184	434	869	1,846
Per cent							
Non-specialised transport ^(a)	—	9.2	11.3	14.1	15.7	22.6	17.8
Specialist transport team ^(b)	100.0	90.8	88.7	85.9	84.3	77.4	82.2
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(a) Baby is transferred by a non-specialist transfer method, including transport by ambulance.

(b) A specialist neonatal transport retrieval team using appropriate equipment retrieves the baby.

Note: These data represent those babies who qualify for the ANZNN cohort only, and do not include neonates who are transferred to a paediatric intensive care unit, or who are transferred after the perinatal period.

Table 10: Transport type for babies transferred immediately after birth to registration hospital, by birthweight group, 1999

Transportation method	250-499	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	4000+	All babies
Number												
Non-specialised transport ^(a)	—	5	9	6	10	31	51	66	71	54	25	328
Specialist transport team ^(b)	1	34	62	85	97	201	200	281	296	182	79	1,518
All babies	1	39	71	91	107	232	252	347	365	237	104	1,846
Per cent												
Non-specialised transport ^(a)	—	12.8	12.7	6.6	9.3	13.4	20.3	19.0	19.3	22.9	24.0	17.8
Specialist transport team ^(b)	100.0	87.2	87.3	93.4	90.7	86.6	79.7	81.0	80.7	77.1	76.0	82.2
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

(a) Infant is transferred by a non-specialist transfer method, including transport by ambulance.

(b) A specialist neonatal transport retrieval team using appropriate equipment retrieves the baby.

Note: These data represent those babies who qualify for the ANZNN cohort only, and do not include neonates who are transferred to a paediatric intensive care unit, or who are transferred after the perinatal period.

Table 11: Method of birth by gestational age group, all babies, 1999

Mode of birth	20-23	24-27	28-31	32-33	34-36	37-44	All babies
Number							
Vaginal	62	408	717	310	429	741	2,667
Vaginal – with instruments	2	22	64	38	58	139	323
Caesarean section – emergency (labour)	1	242	538	241	193	215	1,430
Caesarean section - elective (no labour)	3	269	768	435	363	318	2,156
Unknown	1	37	60	21	59	128	306
All babies	69	978	2,147	1,045	1,102	1,541	6,882
Per cent							
Vaginal	91.2	43.4	34.4	30.3	41.1	52.4	40.6
Vaginal – with instruments	2.9	2.3	3.1	3.7	5.6	9.8	4.9
Caesarean section – emergency (labour)	1.5	25.7	25.8	23.5	18.5	15.2	21.7
Caesarean section - elective (no labour)	4.4	28.6	36.8	42.5	34.8	22.5	32.8
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Note: 'Unknown' or 'not available' data are excluded from per cent calculations.

Table 12: Method of birth by birthweight group, all babies, 1999

Mode of birth	250-499	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	4000+	All babies
Number												
Vaginal	12	184	196	236	289	503	322	335	290	190	110	2,667
Vaginal – with instruments	1	5	15	14	35	49	40	46	62	36	20	323
Caesarean section – emergency (labour)	2	67	157	176	252	305	167	131	79	56	38	1,430
Caesarean section – elective (no labour)	31	143	234	307	324	418	241	168	161	86	43	2,156
Unknown	—	19	20	24	21	44	35	51	44	36	12	306
All babies	46	418	622	757	921	1,319	805	731	636	404	223	6,882
Per cent												
Vaginal	26.1	46.1	32.6	32.2	32.1	39.5	41.8	49.3	49.0	51.6	52.1	40.6
Vaginal – with instruments	2.2	1.3	2.5	1.9	3.9	3.8	5.2	6.8	10.5	9.8	9.5	4.9
Caesarean section – emergency (labour)	4.3	16.8	26.1	24.0	28.0	23.9	21.7	19.3	13.3	15.2	18.0	21.7
Caesarean section - elective (no labour)	67.4	35.8	38.9	41.9	36.0	32.8	31.3	24.7	27.2	23.4	20.4	32.8
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Note: 'Unknown' or 'not available' data are excluded from per cent calculations.

Table 13: Respiratory support by gestational age group, all babies, 1999

Type of respiratory support		20-23	24-27	28-31	32-33	34-36	37-44	All babies
IPPV	n	67	929	1,178	473	614	1,059	4,322
	median (days)	13	11	3	3	3	3	
	interquartile range	1-45	4-27	2-5	1-4	2-4	2-5	
	no IPPV (n)	2	47	969	572	488	482	2,560
	data not available	—	2	—	—	—	—	2
ECMO	n	—	—	—	—	1	4	5
Nitric oxide	n	3	43	33	13	22	145	260
High freq ventilation	n	29	239	89	26	31	92	506
CPAP	n	29	777	1,410	604	606	519	3,947
	median (days)	21	24	4	2	2	1	
	interquartile range	9-39	12-36	2-9	1-3	1-3	1-2	
	no CPAP (n)	40	199	737	441	496	1,022	2,935
	data not available	—	2	—	—	—	—	2
Oxygen	n	65	952	1,688	785	878	1,186	5,554
	median (days)	15	57	5	3	4	4	
	interquartile range	2-119	16.5-92	2-28.5	1-6	2-6	2-8	
	no oxygen (n)	2	19	447	249	182	227	1,126
	data not available	2	7	12	11	52	128	202
All babies		69	978	2,147	1,045	1,102	1,541	6,882

Note: Median and range (days) are for all babies who received this therapy.

Table 14: Respiratory support by birthweight group, all babies, 1999

Type of respiratory support		250-499	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	4000+
IPPV	n	43	401	523	499	427	671	453	453	439	269	142
	median (days)	7	20	8	4	3	2	3	3	3	3	3
	interquartile range	3-37	4-35	3-21	2-7	2-5	1-4	2-4	2-4	2-5	2-5	2-5
	no IPPV (n)	3	16	98	258	494	648	352	278	197	135	81
	data not available	—	1	1	—	—	—	—	—	—	—	—
CPAP	n	21	292	498	576	515	772	449	349	235	149	89
	median (days)	15	24	19	8	4	2	2	2	2	1	1
	interquartile range	3-42	12-40	7-32	3-21	2-8	1-4	1-3	1-3	1-3	1-2	1-2
	no CPAP (n)	25	125	123	181	406	547	356	382	401	255	134
	data not available	—	1	1	—	—	—	—	—	—	—	—
Oxygen	n	45	404	574	633	649	1,005	670	577	506	312	179
	median (days)	9	69	48	20	4	3	3.5	4	4	4	3
	interquartile range	4-94	14-106	10-81	4-47	2-22	2-7	2-7	2-6	2-8	2-8	2-7
	no Oxygen (n)	1	8	45	120	263	292	115	108	85	59	30
	data not available	—	6	3	4	9	22	20	46	45	33	14
All babies		46	418	622	757	921	1,319	805	731	636	404	223

Note: Median and range (days) are for all babies who received this therapy.

Table 15: Supplemental oxygen dependency by gestational age group, all babies, 1999

Oxygen dependency	20-23	24-27	28-31	32-33	34-36	37-44	All babies
Oxygen therapy at day 28	29	659	430	45	45	46	1,254
Per cent survivors with oxygen therapy on day 28	55.8	79.2	20.5	4.4	4.2	3.2	19.2
Chronic lung disease ^(a)	24	403	216	—	—	—	643
Per cent of survivors with chronic lung disease ^(b)	85.7	52.2	10.4	—	—	—	22.3
Oxygen therapy after discharge to home	11	178	61	10	13	14	287
Data not available	2	7	12	11	52	128	212
All babies	69	978	2,147	1,045	1,102	1,541	6,882

(a) Chronic lung disease is defined as requiring respiratory assistance, ie supplemental oxygen and/or mechanical ventilation and/or continuous positive airways pressure) at 36 weeks post menstrual age (PMA, gestational age plus chronological age) for babies born at less than 32 weeks' gestation.

(b) Calculated as the total number with Chronic Lung Disease as a percentage of those alive at 36 weeks PMA who have oxygen therapy information available (n: 2,878).

Note: 'Unknown' or 'not available' data are excluded from per cent calculations.

Table 16: Supplemental oxygen dependency by birthweight group, all babies, 1999

Oxygen dependency	250-499	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	4000+	All babies
Oxygen therapy at day 28	20	275	369	267	135	98	29	25	23	6	7	1,254
Per cent survivors with oxygen therapy on day 28	47.6	72.4	60.6	35.6	14.7	7.5	3.6	3.5	3.7	1.5	3.2	18.5
Chronic lung disease ^(a)	16	208	228	116	46	26	1	2	—	—	—	643
Per cent of survivors with chronic lung disease ^(b)	84.2	71.2	44.5	17.8	7.2	3.8	—	—	—	—	—	22.3
Oxygen therapy after discharge to home	6	85	103	37	12	17	7	6	7	4	3	287
Data not available	—	6	3	4	9	22	20	46	45	33	14	212
All babies	46	418	622	757	921	1,319	805	731	636	404	223	6,882

(a) Chronic lung disease is defined as requiring respiratory assistance, ie supplemental oxygen and/or mechanical ventilation and/or continuous positive airways pressure) at 36 weeks post menstrual age (PMA, gestational age plus chronological age) for babies born at less than 32 weeks' gestation.

(b) Calculated as the total number with chronic lung disease as a percentage of those alive at 36 weeks PMA who have oxygen therapy information available (n: 2,878).

Note: 'Unknown' or 'not available' data are excluded from per cent calculations.

Table 17: Exogenous surfactant use by gestational age group, all babies, 1999

Surfactant use	20-23	24-27	28-31	32-33	34-36	37-44	All babies
Number							
None	11	169	1,243	700	737	1167	4,027
<i>Exosurf</i>	—	3	14	10	9	8	44
<i>Survanta</i>	58	795	882	325	321	253	2,634
Other / both	—	4	1	—	—	3	8
Unknown	—	7	7	10	35	110	169
All babies	69	978	2,147	1,045	1,102	1,541	6,882
Per cent							
None	15.9	17.4	58.1	67.6	69.1	81.5	60.0
<i>Exosurf</i>	—	0.3	0.6	1.0	0.8	0.6	0.7
<i>Survanta</i>	84.1	81.9	41.2	31.4	30.1	17.7	39.2
Other / both	—	0.4	0.1	—	—	0.2	0.1
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Note: Unknown' or 'not available' data are excluded from per cent calculations.

Table 18: Exogenous surfactant use by birthweight group, all babies, 1999

Surfactant use	250-499	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	4000+	All babies
Number												
None	10	66	179	378	595	835	531	509	447	296	181	4,027
<i>Exosurf</i>	—	—	—	7	7	8	10	4	6	1	1	44
<i>Survanta</i>	36	347	437	371	316	455	244	178	145	76	29	2,634
Other / both	—	2	2	—	1	—	—	—	—	2	1	8
Unknown	—	3	4	1	2	21	20	40	38	29	11	169
All babies	46	418	622	757	921	1,319	805	731	636	404	223	6,882
Per cent												
None	21.7	15.9	29.0	50.0	64.7	64.3	67.6	73.7	74.7	78.9	85.4	60.0
<i>Exosurf</i>	—	—	—	0.9	0.8	0.6	1.3	0.6	1.0	0.3	0.5	0.7
<i>Survanta</i>	78.3	83.6	70.7	49.1	34.4	35.1	31.1	25.8	24.3	20.3	13.7	39.2
Other / both	—	0.5	0.3	—	0.1	—	—	—	—	0.5	0.5	0.1
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Note: Unknown' or 'not available' data are excluded from per cent calculations.

Table 19: Intraventricular haemorrhage by gestational age group, babies born at < 32 weeks' gestation, 1999

Head ultrasound result	20-23	24-25	26-27	28-29	30-31	Babies < 32 weeks'
Number						
None	17	199	407	699	999	2,321
Grade I	10	49	87	103	75	324
Grade II	7	32	28	26	25	118
Grade III	9	29	27	13	8	86
Grade IV	6	35	31	16	5	93
Not examined	20	29	23	32	138	242
Data not available	—	2	—	1	7	10
All babies	69	375	603	890	1,257	3,194
Per cent						
None	34.7	57.8	70.2	81.6	89.8	78.9
Grade I	20.4	14.2	15.0	12.0	6.7	11.0
Grade II	14.3	9.3	4.8	3.0	2.6	4.0
Grade III	18.4	8.4	4.7	1.5	0.7	2.9
Grade IV	12.2	10.2	5.3	1.9	0.5	3.2
All babies	100.0	100.0	100.0	100.0	100.0	100.0

Note: 'Not examined' and 'not available' data are excluded from per cent calculations.

Table 20: Intraventricular haemorrhage by birthweight group, babies born at < 1500 g, 1999

Head ultrasound result	250-499	500-749	750-999	1000-1249	1250-1499	Babies <1500
Number						
None	23	245	421	594	720	2,003
Grade I	2	59	77	81	74	293
Grade II	1	25	30	26	19	101
Grade III	3	30	25	13	9	80
Grade IV	5	28	32	17	9	91
Not examined	12	30	35	26	87	190
Data not available	—	1	2	—	3	6
All babies	46	418	622	757	921	2,764
Per cent						
None	67.7	63.3	72.0	81.3	86.6	78.0
Grade I	5.9	15.3	13.2	11.1	8.9	11.4
Grade II	2.9	6.5	5.1	3.6	2.3	3.9
Grade III	8.8	7.7	4.3	1.8	1.1	3.1
Grade IV	14.7	7.2	5.5	2.3	1.1	3.5
All babies	100.0	100.0	100.0	100.0	100.0	100.0

Note: 'Not examined' and 'not available' data are excluded from per cent calculations.

Table 21: Results of eye examination for ROP for babies born at < 31 weeks' gestation or < 1250g, by gestational age group, 1999

Eye examination result	20-23	24-25	26-27	28-29	30-31	32-44	Eligible babies
Number							
No ROP	2	70	286	590	348	71	1,367
Stage I	5	29	82	63	25	—	204
Stage II	8	79	82	37	8	—	214
Stage III	9	55	38	10	1	—	113
Stage IV	3	2	2	—	—	—	7
<i>Received therapy</i>	7	35	21	2	1	—	66
Not examined / data not available	1	11	32	151	223	206	624
Babies eligible for exam.	27	235	490	700	382	71	1,905
Per cent							
No ROP	7.4	29.8	58.4	84.3	91.1	100.0	71.8
Stage I	18.5	12.3	16.7	9.0	6.5	—	10.7
Stage II	29.6	33.6	16.7	5.3	2.1	—	11.2
Stage III	33.3	23.4	7.8	1.4	0.3	—	5.9
Stage IV	11.1	0.9	0.4	—	—	—	0.4
Babies eligible for exam.	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Notes 1. Indicates worst stage of ROP seen
2. 'Not examined and data not available' data are excluded from per cent calculations.
3. 'Babies eligible for exam.' includes all infants born at less than 31 weeks' gestation or less than 1250 grams who survived who were alive at 36 weeks post menstrual age (when the eye should be fully vascularised). This may not comply with local experience and thus local criteria for eye examination, which may artificially elevate the number of babies in the 'not examined or data not available' category.

Table 22: Results of eye examination for ROP for babies born at < 31 weeks' gestation or < 1250 g, by birthweight group, 1999

Eye examination result	250-499	500-749	750-999	1000-1249	1250-1499	1500-2999	Eligible babies
Number							
No ROP	4	87	299	505	300	172	1,367
Stage I	2	52	67	62	14	7	204
Stage II	9	81	84	28	8	4	214
Stage III	3	53	44	10	3	—	113
Stage IV	—	4	2	1	—	—	7
<i>Received therapy</i>	2	35	22	6	1	—	66
Not examined / data not available	1	13	31	123	154	302	624
Babies eligible for exam.	19	290	527	729	479	485	2,529
Per cent							
No ROP	22.2	31.4	60.3	83.3	92.3	94.0	71.8
Stage I	11.1	18.8	13.5	10.2	4.3	3.8	10.7
Stage II	50.0	29.2	16.9	4.6	2.5	2.2	11.2
Stage III	16.7	19.1	8.9	1.7	0.9	—	5.9
Stage IV	—	1.4	0.4	0.2	—	—	0.4
Babies eligible for exam.	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Table 23: Survival to discharge by gestational age, all babies, 1999

Gestational age (weeks)	All babies admitted	No. with discharge data	No. with lethal cong malform.	No. alive at 7 days	No. alive at 28 days	No. alive at discharge	Per cent survival at discharge
21	1	1	—	—	—	—	—
22	9	9	—	8	8	1	11.1
23	59	57	—	47	44	25	42.4
24	159	156	2	129	112	87	54.7
25	216	209	3	187	176	154	71.3
26	284	274	1	264	255	233	82.0
27	319	313	5	298	290	281	88.4
28	385	362	4	373	365	363	94.3
29	505	482	6	498	496	483	95.6
30	532	517	2	527	526	517	97.2
31	725	695	8	716	711	705	97.2
32	567	547	5	561	557	554	97.7
33	478	463	9	471	469	463	96.9
34	380	364	12	374	371	365	96.1
35	388	375	11	376	372	369	95.1
36	334	319	13	323	319	313	93.7
37	283	270	17	274	272	262	92.6
38	347	335	21	333	333	316	91.1
39	248	239	22	231	224	216	87.1
40	411	390	18	397	395	368	89.5
41	208	201	9	197	191	187	89.9
42	41	37	1	39	38	38	92.7
43	1	1	—	1	1	1	100.
44	2	2	1	2	2	1	50.0
All babies	6,882	6,618	170	6,626	6,527	6,302	91.6

Note: Per cent survival to discharge is calculated from 'number alive at discharge' divided by 'all babies admitted' (the number of babies admitted to the level III NICUs). Hence, the survival calculations include those babies with congenital malformations that are considered to have directly contributed to their death (lethal malformations). Where babies have been transferred to a peripheral hospital and the date of discharge to home is not available (3.8% of all babies) these babies have been assumed to have survived to go home.

Table 24: Survival to discharge by birthweight group, all babies, 1999

Birthweight group (grams)	All babies admitted	No. with discharge data	No. with lethal cong malform.	No. alive at 7 days	No. alive at 28 days	No. alive at discharge	Per cent survival at discharge
250-499	46	45	1	38	42	17	37.0
500-599	106	105	2	84	96	61	57.6
600-699	192	186	2	161	173	128	66.7
700-799	228	222	3	201	215	163	71.5
800-899	251	242	4	235	245	211	84.1
900-999	263	251	3	250	260	236	89.7
1000-1099	297	287	3	291	293	281	94.6
1100-1199	300	288	—	294	298	289	96.3
1200-1299	322	309	7	317	322	309	96.0
1300-1399	372	360	5	366	368	357	96.0
1400-1499	387	375	1	383	387	378	97.7
1500-1999	1,319	1,260	22	1,298	1,311	1,275	96.7
2000-2499	805	780	34	785	800	762	94.7
2500-2999	731	700	31	707	725	672	91.9
3000-3499	636	609	31	608	627	583	91.7
3500-3999	404	383	17	392	401	370	91.6
4000 +	223	216	4	217	220	210	94.2
All babies	6,882	6,618	170	6,627	6,783	6,302	91.6

- Notes
1. Per cent survival to discharge is calculated from 'number alive at discharge' divided by 'all babies admitted' (the number of babies admitted to the level III NICUs). Hence, the survival calculations include those babies with congenital malformations that are considered to have directly contributed to their death (lethal malformations). Where babies have been transferred to a peripheral hospital and the date of discharge to home is not available (3.8% of all babies) these babies have been assumed to have survived to go home.
 2. Data are divided into 100 grams group from 500 grams to 1500 grams, then 500 grams groups.

Table 25: Transfer status, and level of hospital if transferred, by gestational age group, all babies, 1999

Hospital level	20-23	24-27	28-31	32-33	34-36	37-44	All babies
Number							
Not transferred	54	534	933	466	623	934	3,544
Hospital with level I/II nursery	9	338	1,098	522	411	370	2,748
Hospital with level III NICU	2	39	60	20	28	74	223
NICU in children's hospital	4	67	56	37	40	163	367
Data not available	—	—	—	—	—	—	—
All babies	69	978	2,147	1,045	1,102	1541	6,882
Per cent							
Not transferred	78.3	54.6	43.5	44.6	56.5	60.6	51.5
Hospital with level I/II nursery	9	34.6	51.1	50.0	37.3	24.0	39.9
Hospital with level III NICU	2.9	4.0	2.8	1.9	2.5	4.8	3.2
NICU in children's hospital	5.8	6.9	2.6	3.5	3.6	10.6	5.3
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Notes 1. Where a baby was transferred many times, the level of hospital was recorded for the stay of most significance, or as the level 1 or 2 transfer if this was not apparent. This was to allow computation of stay in level 3 NICUs compared to step-down or level 1 or 2 stay.

2. 'Not transferred' refers to babies who went home from or died in their hospital of registration.

3. Not examined' and 'not available' data are excluded from per cent calculations.

Table 26: Transfer status, and level of hospital if transferred, by gestational age group, all babies, 1999

Hospital level	250-499	500-749	750-999	1000-1249	1250-1499	1500-1999	2000-2499	2500-2999	3000-3499	3500-3999	4000+	All babies
Number												
Not transferred	39	249	346	318	393	587	419	430	360	255	148	3,544
Hospital with level I/II nursery	9	115	216	396	481	654	331	226	184	99	41	2,748
Hospital with Level III NICU	1	21	20	20	20	39	22	25	27	20	8	223
NICU in children's hospital	1	33	40	23	27	39	33	50	65	30	26	367
Data not available	—	—	—	—	—	—	—	—	—	—	—	—
All babies	46	418	622	757	921	1,319	805	731	636	404	223	6,882
Per cent												
Not transferred	84.8	59.6	55.6	42.0	42.7	44.5	52.1	58.8	56.6	63.1	66.4	51.5
Hospital with level I/II nursery	9	27.5	34.7	52.3	52.2	49.5	41.1	30.9	28.9	24.5	18.4	39.9
Hospital with level III NICU	2.2	5.0	3.2	2.6	2.2	3.0	2.7	3.4	4.2	5.0	3.6	3.2
NICU in children's hospital	2.2	7.9	6.4	3.0	2.9	3.0	4.1	6.8	10.2	7.4	11.7	5.3
All babies	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Notes 1. Where a baby was transferred many times, the level of hospital was recorded for the stay of most significance, or as the level 1 or 2 transfer if this was not apparent. This was to allow computation of stay in level 3 NICUs compared to step-down or level 1 or 2 stay.

2. 'Not transferred' refers to babies who went home from or died in their hospital of registration.

3. Not examined' and 'not available' data are excluded from per cent calculations.

Table 27: Total days until discharge home from hospital by gestational age group, 1999

Days to discharge	20-23	24-27	28-31	32-33	34-36	37-44
Median (days)	130	94	51	31	18	12
Interquartile range	119–147	79–111	40–64	24–39	12–25	8–20
All survivors with discharge data	24	730	1,977	982	1,003	1,323

Notes 1. Discharge data are available for 6,039 (95.8%) of surviving babies.
2. Data are for all babies, regardless of level of hospital at discharge.

Table 28: Total days until discharge home from hospital by birthweight group, 1999

Days to discharge	250- 499	500- 749	750- 999	1000- 1249	1250- 1499	1500- 1999	2000- 2499	2500- 2999	3000- 3499	3500- 3999	4000+
Median (days)	121	110	83	63	47	36	22	14	12	10	10
Interquartile range	101–145	94–126	69–100	51–76	37–58	28–44	16–29	9–21	8–19	7–17	7–18
All survivors with discharge data	16	264	502	696	859	1,216	737	641	556	349	203

Notes 1. Discharge data are available for 6,039 (95.8%) of surviving babies.
2. Data are for all babies, regardless of level of hospital at discharge.

6.2 Babies registered to level II nurseries

Table 29: Number of babies in each gestational age group, 1999

Gestational age group (completed weeks)	Number	Cumulative per cent
Less than 28	7	2.3
28-31	49	18.6
32-36	145	66.8
More than 37	100	100.0
All babies	301	

Note: ANZNN cohort includes all babies born at less than 32 weeks' completed gestation. Those above this gestation must be born at less than 1500 grams birthweight, or must require assisted ventilation or major surgery.

Table 30: Number of babies in each birthweight group, 1999

Birthweight group (grams)	Number	Cumulative per cent
< 1000	5	1.7
1000-1499	40	15.0
1500-1999	55	33.2
2000-2499	69	56.1
2500-2999	47	71.8
≥3000	85	100.0
All babies	301	

Note: ANZNN cohort includes all babies born at less than 32 weeks' completed gestation. Those above this gestation must be born at less than 1500 grams birthweight, or must require assisted ventilation or major surgery.

Table 31: Survival to discharge by gestational age group, 1999

Gestational age group (completed weeks)	All babies admitted	No. alive at discharge	Per cent survival at discharge
Less than 28	7	5	71.4
28-31	49	48	98.0
32-36	145	145	100.0
More than 37	100	99	99.0
All babies	301	297	98.7

Note: Per cent survival to discharge is calculated from 'number alive at discharge' divided by 'all babies admitted' (the number of babies admitted to the level III NICUs). Hence, the survival calculations include those babies with congenital malformations that are considered to have directly contributed to their death. There were no babies with a lethal congenital malformation in 1999. Where babies have been transferred to a peripheral hospital and the date of discharge to home is not available (1 baby) they have been assumed to have survived to go home.

Appendix 1

Definitions of data items for audit in 1999

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 our 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>

1.1 Minimum dataset variables

Registration hospital

The first hospital with a neonatal intensive care unit that the baby remains in for four or more hours.

Classification/coding:

numeric code representing the registration hospital

Guide for use:

If baby is transferred, she/he is considered to be in the next hospital from the time the transport team arrives to collect her/him. 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 birthweight of more than 400 g 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, etc.

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 assoc. (Dept. Aboriginal Affairs, Constitutional Sect 1981)

2 = Asian - women whose ethnic background originates from the countries of Asia, South East Asia and Indian subcontinent. Incl. say Fijian Indian.

3 = Caucasian - women of Caucasoid heritage, inc. European, Russian, Middle Eastern and Arabic.

4 = Other - includes African Negroes, Inuit, American Blacks and Indians, Melanesian.

5 = Other Polynesian - women of Polynesian background, excluding Maori.

6 = Maori - determined by patient 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 into a hospital with a NICU and was not transferred during the most recent admission.

2 = In-utero transfer from obstetric hospital - Mother transferred during most recent admission, baby in utero.

3 = Ex-utero retrieval - Baby 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.

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 wks gestation. ROM is defined as the obvious gush or 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

Guide for use:

Only one complication to be chosen. If the baby is preterm there must be a presenting problem.

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 were present

99 = unknown

Prolonged rupture of membranes

Confirmed spontaneous membrane rupture for more than 24 hours before birth of the baby. Rupture of the membranes is diagnosed by the obvious gush or clear amniotic fluid from the vagina, or (if fluid is available) by differentiation with urine and vaginal secretions¹¹.

Classification/coding:

0 = no, membranes not ruptured or ruptured < 24 hs

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 in the preterm period

1 = yes, labour commenced in the preterm period

99 = unknown

Hypertension in pregnancy

A systolic blood pressure (SBP) ≥ 140 mmHg and/or diastolic BP (DBP) ≥ 90 mmHg, or rise in SBP ≥ 25 mmHg and/or rise in DBP ≥ 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 was 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 steroids 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 <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 >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 the 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 / YY

Admission date

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

Classification/coding:

DD / MM / YY

Sex

The sex of the patient.

Classification/coding:

0 = Unknown - information not available.

1 = Male -

2 = Female -

3 = Ambiguous - or indeterminate.

Guide for use:

An indeterminate sex category may be necessary for situations such as the classification of perinatal statistics when it is not possible for the sex to be determined.

Infant weight

The first weight of the baby obtained after birth.

Classification/coding:

4 digit numbered field representing 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.

Comment:

The definitions of 'low', 'very low' and 'extremely low' birthweight do not constitute exclusive categories. Low birthweight: < 2,500 g (up to and including 2,499 g); very low birthweight: < 1,500 grams (up to and including 1,499 g); extremely low birthweight: < 1,000 grams (up to and including 999 g) (WHO 1992).

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.

Comment:

Preterm: less than 37 completed weeks (less than 259 days) of gestation. Term: from 37 completed weeks to less than 42 completed weeks (259 to 293 days) of gestation. Post-term: 42 completed weeks or more (294 days or more) of gestation. (WHO 1992).

Hospital of birth

Name of the hospital in which the infant was born.

Classification/coding:

numeric code as for registration hospital.

Guide for use:

Must be coded as when place of birth is "non-tertiary hospital" or "tertiary hospital"

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.

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 and vacuum extractions.

3 = Caesarean section in labour - caesarean performed after the commencement of labour (regular painful contractions, leading to progressive effacement and dilatation of cervix, eventually leading to the birth of the baby). 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 completed.

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-9-CM is the preferred method of coding admitted patients.

Comment:

see Appendix 1 for exclusion list of minor abnormalities.

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-9-CM

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), write 'M' to denote 'missing'. If an admission temperature is not recorded, write 'M'. If electronic data entry does not allow 'M', then, a data set marked as 'complete' with this field marked as missing, will indicate that the data is not available.

Highest appropriate inspired oxygen

Highest appropriate FiO_2 , recorded as percentage, between admission to NICU and 12 hours after birth. Appropriate range is when arterial P_aO_2 or TePO_2 is 50-80 mmHg, or if FiO_2 is more than 25%, SaO_2 is 88-95%, or if FiO_2 is less than 25%, SaO_2 is more than 88%.

Classification/coding:

3 digit numbered field representing FiO_2 recorded as a percentage.

Guide for use: as for "temperature on admission"

Lowest appropriate inspired oxygen

Lowest appropriate FiO_2 recorded as percentage, between admission to NICU and 12 hours after birth. Appropriate range as for 'Highest appropriate inspired oxygen (FiO_2)'

Classification/coding:

3 digit numbered field representing FiO_2 recorded as a percentage.

Guide for use:

as for "temperature on admission"

Worst base excess

Worst base deficit (mmol/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"

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 "TTN" and "immature lung").

3 = Hyaline membrane disease - increasing respiratory distress or O_2 requirements, or need for ventilator support from the first 6 hours of life with a CXR showing generalised reticulo-granular pattern \pm 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. CXR: over-expansion of lungs with widespread coarse, fluffy infiltrates⁶.

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

6 = Persistent pulmonary hypertension -echocardioc (shunting or clinical evidence (O_2 requirement unexplained by CXR or loud P_2 , or differential pre and post ductal TCPO_2).

7 = deleted.

8 = Apnoea - recurrent pauses in breathing of more than 20 seconds, or for less than 20 seconds and associated with bradycardia or desaturation requiring intervention.

(continued next page)

Main respiratory diagnosis (cont)

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

10 = Other - unspecified other respiratory disease.

11 = Peri surgical - indication for respiratory support is surgical intervention. Must have neonatal surgery.

12 = Newborn encephalopathy - a syndrome of disturbed neurological function in an infant with difficulties in 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 form of respiratory support (supplemental oxygen therapy and/or assisted ventilation for four or more four consecutive hours, or died prior to four 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

The dose of any type of exogenous surfactant used to treat this baby.

Classification/coding:

0 = Unknown - information not available

1 = None - no exogenous surfactant ever given to this baby.

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:

The highest level of assisted ventilation therapy for any 24 hour period is used. For example, if the baby has 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.

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:

as for 'Days of IPPV'. The highest level of assisted ventilation for any 24 hour period is used. Eg. if the baby has 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

Assisted mechanical ventilation presented at high frequency (i.e where small tidal volumes are presented at frequencies more than or equal to 4Hz) initiated as respiratory support 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 / YY

Guide for use:

Four consecutive hours in any one 24 hour period constitutes a 'day'. Any route of supplemental oxygen administration is used. If oxygen is ceased, and then the baby required more supplemental oxygen for the same illness, use final day of all the days that supplemental oxygen was used. However, do not include days of oxygen for subsequent illnesses such as oxygenation after surgery, RSV etc. If the baby never received supplemental oxygen leave blank. If the baby received only say, 5 hours of oxygen on day one, use the date of birth. If the baby received supplemental oxygen after discharge from hospital use the discharge date here.

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 weeks 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 considered to be the infant's gestational age (completed weeks) plus chronological age (days). Eg, an infant born at 28 weeks' and four days' gestation on January 1st, is 36 weeks' PMA on 26th February. This item is for infants born at less than 32 weeks' gestation only.

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 more than 25% of previous feed on two 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 X-rays, 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, and 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 were included only if the baby was considered clinically septic and there was 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 major surgery.

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 haemorrhage.
- 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 / YY

Ventricular Index

Ventricular index 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 ventricular index in millimeters.

Guide for use:

To be recorded when ventricular dilatation thought likely (see 'ventricle size - dilatation'). This data will be coded as in item 'ventricle size' using norms for gestation from Levene¹².

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 is \leq 97th centile.
- 2 = Dilatation - ventricle size $>$ 97th centile, but less than or equal to 4 mm greater than 97th centile.
- 3 = Hydrocephalus - ventricle size is more than 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 - refers to the 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 fibrovascular 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 / YY

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

Guide for use:

If the baby is transferred many times, say to another hospital for surgery and then back, or for specialist assessment, and then is transferred to a peripheral hospital, use the latter.

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 / YY

Guide for use:

If the baby is transferred many times, say to another hospital for surgery and then back, or for specialist assessment, and then is transferred to a peripheral hospital, use the latter. Use the most significant date.

Discharge date

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

Classification/coding:

DD / MM / YY

Comment:

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

References:

1. Australasian Society for the Study of Hypertension in Pregnancy 1993, *Management of hypertensive in pregnancy: executive summary*. Med J Aust 158:700-702.
2. Australian NEC Project, Queensland Institute of Medical Research.
3. Bancalari E & Sinclair J 1994, *Mechanical ventilation*, In: Effective care of the newborn, Sinclair JC & Bracken MB, eds., Oxford University Press, Oxford.
4. Cross JH, Harrison CJ, Preston PR, et al, 1992, *Postnatal encephalo-clastic porencephaly - a new lesion?* Arch Dis Child 67:307-311.
5. Crowther C, Enkin M, Keirse MJNC & Brown I 1989, *Monitoring the progress of labour*, In: Effective care in pregnancy and childbirth, Vol. 2, Chalmers I, Enkin M & Keirse MJNC eds, Oxford University Press, Oxford, 833.
6. Halliday HL 1992, *Other acute lung disorders*, In: Effective care of the newborn, Sinclair, JC & Bracken MB, eds., Oxford Uni. Press, Oxford.
7. HIFI Study Group 1989, *High frequency oscillatory ventilation compared with conventional ventilation in the treatment of respiratory failure in preterm babies*, N Eng J Med, 320:88-93.

8. Horbar JD 1992, *Periventricular-intra-ventricular haemorrhage*, In Effective Care of the Newborn, Sinclair JC, Bracken MB & Silverman WA eds., Oxford University Press, Oxford 563.
9. International Committee for the Classification of Retinopathy of Prematurity 1984, *An International classification of retinopathy of prematurity*, Pediatrics 74:127-133.
10. Isaacs D et al 1995, *Systemic bacterial infection and fungal infections in babies in Australian neonatal units*. Med J Aust 162: 198-201.
11. Keirse MJNC, Ohlsson A, Treffers PE, Humphrey HH & Kanhai HHH 1989, *Pre-labour rupture of the membranes preterm*, In: Effective care in pregnancy and childbirth, Vol. 1, Chalmers I, Enkin M & Keirse MJNC. eds., Oxford University Press, Oxford, 666-669.
12. Levene MI 1981, *Measurement of the growth of the lateral ventricles in preterm babies with real-time ultrasound*. Arch Dis Child, 56: 900-904.
- 12a. Nelson & Leviton 1991 Am J Dis Child 145:1325-31.
13. Papile LA, Burstein J, Burstein R & Koffler H 1978, *Incidence and evolution of subependymal and intraventricular haemorrhage: A study of babies with birth weights less than 1500 gm*, J. Pediatrics 92:529-534.
14. Report of the Health Care Committee Expert Panel on Perinatal Morbidity 1995, Perinatal Morbidity, Government Publishing Service, Canberra, 40.
15. Watts JL 1992, *Retinopathy of Prematurity*, In: Effective Care of the Newborn, Sinclair JC, Bracken MB & Silverman WA eds., Oxford University Press, Oxford, 635.

Appendix 1:

Minor congenital malformations

Skin: skin cysts; non calvernous, single small haemangioma; benign skin neoplasms; nevus flammeus; birth mark; mongolian spots; cutis marmorata; café 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/ 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 (ga <37 weeks or bw <1500gm); mild, trivial or physiological valvular regurgitation; cardiomegaly; dextroposition of the heart; heart block; persistent fetal circulation; single umbilical artery.

Respiratory system: hypoplastic lungs (ga < 37 weeks); laryngeal stridor; laryngomalacia

Gastrointestinal system: hepatomegaly; splenomegaly; merkel's diverticulum; anal tags; anal or rectal fissures; inguinal hernia in males; inguinal hernia in female (bw <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 (ga < 37 wks /bw <2500 gm); small penis; chordee; patent urachus or urachal cyst; ectopic kidney

Limbs: skin tags on hands and feet; partial syndactyly of toe, webbing of toe; brachydactyly, unspecified; clinodactyly; camptodactyly; 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; cephalhaemotoma; cystic fibrosis; enzyme deficiencies; hydrops fetalis; meconium ileus; metabolic disorder; pyloric stenosis; sternomastoid tumor; torticollis; volvulus.

Appendix 2

Units participating in the ANZNN in 1999

2.1 Hospitals with level III nurseries

	births	beds*
New South Wales		
John Hunter Hospital	3,618	29
King George V Hospital	3,993	32
Liverpool Health Service	3,130	23
Nepean Hospital	3,307	28
Royal Hospital for Women	3,881	34
Royal North Shore Hospital	1,927	26
The Children's Hospital at Randwick	-	20
The Children's Hospital at Westmead	-	20
Westmead Hospital	4,401	39

Victoria

Mercy Hospital for Women	5,023	54
Monash Medical Centre	4,458	44
Royal Children's Hospital	-	23
Royal Women's Hospital	5,352	58

Queensland

Kirwan Hospital for Women	n/a	34
Mater Mother's Hospital	7,312	60
Royal Women's Hospital	4,296	66

South Australia

Flinders Medical Centre	2,374	35
Women's and Children's Hospital	n/a	44

Western Australia

King Edward Memorial Hosp Women	n/a	60
Princess Margaret Hospital for Children	-	20

Tasmania

Royal Hobart Hospital	2,103	16
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Australian Capital Territory

The Canberra Hospital	n/a	24
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Northern Territory

Royal Darwin Hospital	1,437	18
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New Zealand

Christchurch Women's Hospital	4,016	26
Dunedin Hospital	n/a	16
Middlemore Hospital	6,380	20
National Women's Hospital	7,609	59
Waikato Hospital	2,981	26
Wellington Women's Hospital	3,335	31

2.2 Hospitals with level II nurseries

	births	beds*
Tasmania		
Launceston General Hospital	1,602	15

New Zealand

Gisborne Hospital	674	6
Hastings Hospital	1,852	15
Hutt Hospital	n/a	8
Nelson Hospital	n/a	10
Palmerston North Hospital	1,793	18
Rotorua Hospital	1,524	10
Southland Hospital	n/a	6
Taranaki Hospital	1,227	8
Tauranga Hospital	1,846	10
Timaru Hospital	n/a	4
Wanganui Hospital	n/a	4
Whakatane Hospital	678	3
Whangarei Hospital	1,290	8

* births refers to total livebirths in 1999;
beds refers to beds for newborn infants associated with that nursery.

Appendix 3

Publications by staff of the neonatal nurseries of Australia and New Zealand

3.1 Journal articles

- Adelson PL, Child AG, Giles WB & Henderson-Smart DJ. *Antenatal hospitalisations in New South Wales 1995/ 96*, Med J Aust 1999; 170: 211-215.
- Almonte R, Patole S, Muller R & Whitehall J. *Comparison of two methods of taping peripheral intravenous cannulas*. Indian Pediatr 1999; 36: 494-498.
- Austin BJ, Bollard C & Gunn TR. *Is urethral catheterization a successful alternative to suprapubic aspiration in neonates?* J Paediatr Child Health 1999; 35: 34-36.
- Austin BJ, Croxson MC, Powell KFP, Gunn TR. *The successful containment of Cocksackie B4 infection in a neonatal unit* J Paediatr Child Health 1999; 35:102-104.
- Badawi N, Kurinczuk JJ, Keogh JM, Alessandri LM, O'Sullivan F, Burton PR, Pemberton PJ & Stanley FJ. *Inverse association of risk may be due to easier delivery with elective caesarean section*. BMJ 1999; 318: 1415.
- Barfield CP, Yu VYH, Noma O, Kukita J, Cussen LJ, Oates A & Walker AM. *Cerebral blood volume measured using near-infrared spectroscopy and radiolabels in the immature lamb brain*. Pediatr Res 1999; 46: 50-56.
- Barnett C, Snel A, Omari T, Davidson G, Haslam R & Butler R. *Reproducibility of the 13C-octanoic acid breath test for assessment of gastric emptying in healthy preterm infants*. J Pediatric Gastroenterology & Nutrition 1999; 29: 26-30.
- Barr PA, Buettiker VE & Antony JH. *Efficacy of lamotrigine in refractory neonatal seizures*. Pediatr Neurology 1999; 20:161-163.
- Barr P & Hunt R. *An evaluation of the autopsy following death in a level IV neonatal intensive care unit*. J Paediatr Child Health 1999; 35: 185-189.
- Bloomfield FH, Teele RL, Voss M, Knight DB & Harding JE. *Inter- and intra-observer variability in the assessment of atelectasis and consolidation in neonatal chest radiographs*. Pediatric Radiol 1999; 29: 459-462.
- Browne CA, Colditz PB & Dunster KR. *Effects of maternal smoking on the fetal heart rate response to a vibroacoustic stimulus*. Prenatal Neonatal Med 1999; 4: 405-410.
- Chacko J, Ford WD & Haslam R. *Growth and neurodevelopmental outcome in extremely-low-birth-weight infants after laparotomy*. Pediatr Surgery Inter 1999; 15: 496-499.
- Chant K, Sullivan EA, Forrest JM, Baird LM, Burgess M, Feeson MJ, Tudehope DI & Tilse M. *Varicella -Zoster virus infection in Australia*. ANZ J Public Health 1999; 22: 413-418.
- Chow P, Walker AM & Yu VYH. *Nitric oxide and nitric oxide synthases: Implications on the pathogenesis of neonatal necrotising enterocolitis*. Emirates Med J 1999; 17: 55-59.
- Colditz PB, Buck LJ, Foster K & Lingwood BE. *Can signal processing help prevent brain damage in the newborn*. Proc. fifth intern symposium on signal processing and its applications. 1999; 1: 345-349.
- Colditz PB, Dunster KR, Joy GJ & Robertson IM. *Anetoderma of prematurity in association with electrocardiographic electrodes*. J Am Academy Dermatology 1999; 41:479-481.
- Connors JM, O'Callaghan MJ, Burns YR, Gray PH, Tudehope DI, Mohay H & Rogers YM. *The influence of growth on development outcome in extremely low birthweight infants at 2 years of age*. J Paediatr Child Health 1999; 35: 37-41.
- Cuddihy SL, Anderson NG, Wells JE & Darlow BA. *Cerebellar vermis diameter at cranial sonography for assessing gestational age in low birth weight infants*. Pediatr Radiology 1999; 29: 589-94.
- Cust AE, Donovan TJ & Colditz PB. *Alarm settings for the Marquette 8000 pulse oximeter to prevent hyperoxic and hypoxic episodes*. Paediatr Child Health 1999; 35: 159-162.
- Daftary AS, Patole SK & Whitehall J. *Hypertension-hyponatremia syndrome in neonates: case report and review of literature*. Am J Perinatology 1999; 16: 385-389.

- Daftary AS, Patole SK & Whitehall JS. *Intra-cardiac fungal masses in high-risk neonates: clinical observations*. Acta Paediatrica 1999; 88: 1009-1013.
- Dargaville PA, South M & McDougall PN. *Comparison of two methods of diagnostic lung lavage in ventilated infants with lung disease*. Am J Resp Critical Care Med 1999; 160: 771-777.
- Dargaville PA, South M, Vervaart P & McDougall PN. *Validity of kers of dilution in small volume lung lavage*. Am J Resp Critical Care Med 1999; 160: 778-784.
- Davies M. *Liquid ventilation*. J Paediatr Child Health 1999; 35: 434-437.
- Davies MW & Mehr S. *Ultrasound gel under radiant heat warmers: are preterm infants at risk of burns?* Australasian Soc. Ultrasound Med Bull 1999; 2: 11-15.
- Davis P & Henderson-Smart D. *Post-extubation prophylactic nasal continuous positive airway pressure in preterm infants: systematic review and meta-analysis*. J Paediatr Child Health 1999; 35: 367-371.
- Davis C, Mazzolini A, Mills J & Dargaville P. *A new sensor for monitoring chest wall motion during high-frequency oscillatory ventilation*. Med Eng Phys 1999; 21: 619-23.
- Division of Paediatrics, The Royal Australasian College of Physicians *Ethics of research in children* J Paediatr Child Health 1999; 35: 514-515.
- Dow N, Dickson N, Taylor B, Darlow B, Wong W & Lennon D. *The New Zealand Paediatric Surveillance Unit: establishment and first year of operation*. NZ Public Health Report, 1999; 6: 41-44.
- Doyle LW, Chavasse R, Ford GW, Olinsky A, Davis NM & Callanan C. *Changes in lung function between age 8 and 14 years in children with birth weight of less than 1,501 g*. Pediatric Pulmonology 1999; 27:185-190.
- Doyle LW, Gultom E, Chuang SL, James M, Davis P & Bowman E. *Changing mortality and causes of death in infants 23-27 weeks' gestational age*. J Paediatr Child Health 1999; 35: 255-259.
- Doyle LW, Rogerson S, Chuang SL, James M, Bowman ED & Davis PG. *Why do preterm infants die in the 1990s?* Med J Aust 1999; 170: 528-532.
- Dunster KR. *Physiologic variability in the perinatal period: origins, measurement, and applications*. Fetal Neonatal Physiol Measurement 1999; 26; 801-809.
- Ekert PG, Silke J & Vaux DL. *Caspase inhibitors*. Cell Death & Differentiation 1999; 6: 1081-1086.
- Ekert PG, Silke J & Vaux DL. *Inhibition of apoptosis and clonogenic survival of cells expressing CrmA variant genes: optimal caspase substrates are not necessarily optimal inhibitors*. EMBO Journal 1999; 18: 330-338.
- Elder DE, Hagan R, Evans SF, Benninger HR & French NP. *Hospital admissions in the first year of life in very preterm infants*. J Paediatr Child Health 1999; 35: 145-150.
- Fallis WM & Christiani P. *Neonatal axillary temperature measurements: a comparison of electronic thermometer predictive and monitor modes*. J Obstet Gynecol Neonatal Nursing 1999; 28: 389-394.
- French NP, Hagan R, Evans SF, Godfrey M & Newnham JP. *Repeated antenatal corticosteroids: size at birth and subsequent development*. Am J Obstet Gynecol 1999; 180: 114-121.
- Gray PH, O'Callaghan MJ, Harvey JM, Burke CJ & Payton DJ. *Placental pathology and neurodevelopment of the infant with intrauterine growth restriction*. Develop Med Child Neurol 1999; 41: 16-20.
- Gray PH & Rodwell RL. *Neonatal neutropenia associated with maternal hypertension poses a risk for nosocomial infection*. European J Pediatr 1999; 158: 71-73.
- Hannaford K, Todd DA, Jeffery H, John E, Blyth K & Gilbert GL *Role of ureaplasma urealyticum in lung disease of prematurity* [published erratum appears in Arch Dis Child Fetal Neonatal Ed 2000; 82: F78] Arch Dis Child Fetal Neonatal Ed 1999; 81: F162-167.
- Harding JE. *Nutritional causes and treatments of impaired fetal growth*. J Royal Society of Med 1999; 92: 612-615.
- Harris D. *Advancing neonatal nursing practice*. Nursing New Zealand 1999; 5: 22-23.
- Harvey JM, O'Callaghan MJ & Mohay H. *Executive function of children with extremely low birthweight: a case control study*. Develop Med Child Neurol 1999; 41: 292-297.
- Jeffery HE, Megevand A & Page M. *Why the prone position is a risk factor for sudden infant death syndrome*. Pediatr 1999; 104: 263-269.

- Jensen EC, Harding JE, Bauer MK & Gluckman PD. *Metabolic effects of IGF-1 in the growth retarded fetal sheep*. J Endocrinol 1999; 161: 485-494.
- Keogh JM, Badawi N, Kurinczuk JJ, Pemberton PJ & Stanley FJ. *Group B streptococcus infection, not birth asphyxia*. Aust NZ J Obstet Gynaecol 1999; 39: 108-110.
- Kimble RM, Breier BH, Gluckman PD & Harding JE. *Enteral IGF-1 enhances fetal growth and gastrointestinal development in oesophageal ligated fetal sheep*. J Endocrinology 1999; 162: 227-235.
- Kimble RM, Harding JE & Kolbe A. *The vulnerable stomach in pure oesophageal atresia*. Paediatr Surg Intern 1999; 15: 467-469.
- Kluckow M, Evans N, Leslie G & Rowe J. *Prostacyclin concentrations and transitional circulation in preterm infants requiring mechanical ventilation*. Arch Dis Child Fetal Neonatal Ed 1999; 80: F34-37.
- Koh TH. *Neonatal myiasis: a case report and a role of the Internet*. J Perinatol 1999; 19: 528-29.
- Koh TH, Harrison H & Morley C. *Gestation versus outcome table for parents of extremely premature infants*. J Perinatol 1999; 19: 452-453.
- Kumar RK. *Neonatal jaundice. An update for family physicians*. Aust Family Physician 1999; 28: 679-682.
- Kumar RK. *Neonatal cerebral infarction: an under recognised/ unrecognised cause of neonatal seizures?* Aust J Rural Health 1999; 7: 2-4.
- Kumar RK, Shi EC & Duffy B. *Cisapride and caesarean section: their role in babies with gastroschisis*. J Paediatr Child Health 1999; 35: 181-184.
- Kuschel CA & Harding JE. *Delay of catch-up growth in very low birthweight infants*. NZ Med J. 1999; 112: 94-96.
- Lee TC, Charles BG, Harte GJ, Gray PH, Steer PA & Flenady VJ. *Population pharmacokinetic modelling in very premature infants receiving midazolam during mechanical ventilation: midazolam neonatal pharmacokinetics*. Anesthesiol 1999; 90: 451-457.
- Lingwood BE, Coghlan JP, Ward LC, Charles BG & Colditz PB. *Prediction of aminoglycoside distribution space in neonates by multiple frequency bioelectrical impedance analysis*. European J Clin Pharmacol 1999; 55: 671-676.
- Lingwood BE, Colditz PB & Ward LC. *Bio-medical applications of electrical impedance analysis*. Proc. of fifth intern symposium on signal processing and its applications. 1999; 1: 367-370.
- Lloyd J, Todd DA & John E. *Serial phospholipid analysis in preterm infants: comparison of Exosurf and Survanta*. Early Human Develop 1999; 54: 157-168.
- McClure RJ, Kristensen JH & Grauaug A. *Randomised controlled trial of cisapride in preterm infants*. Arch Dis Child Fetal Neonatal Ed 1999; 80: F174-177.
- MacLennan A for the Cerebral Palsy Taskforce. *A template for defining a causal relationship between acute intrapartum events and cerebral palsy: international consensus statement*. BMJ 1999; 319: 1054-1059.
- McCowan LME, Harding J, Roberts A, Barker S, Ford C & Stewart A. *Administration of low dose aspirin to mothers with small for gestational age fetuses and abnormal umbilical Doppler studies to increase birthweight: a randomised double-blind controlled trial*. Br J Obst Gynaecol 1999; 106: 647-651.
- McCowan L, Harding J, Barker S & Ford C. *Perinatal predictors of growth at six months in small for gestational age babies*. Early Human Devel 1999; 56: 205-216.
- Makrides M, Neumann MA, Simmer K & Gibson RA. *Dietary long-chain polyunsaturated fatty acids do not influence growth of term infants: A randomized clinical trial*. Pediatr 1999; 104: 468-475.
- Malpas TJ & Darlow BA. *Neonatal abstinence syndrome following abrupt cessation of breast-feeding*. New Zealand Med J. 1999; 112: 12-13.
- Meissner HC, Groothuis JR, Rodriguez WJ, Welliver RC, Hogg G, Gray PH, Low R, Simoes EA, Sly P, Miller AK, Nichols AJ, Jorkasky DK, Everitt DE & Thompson KA. *Safety and pharmacokinetics of an intramuscular monoclonal antibody (SB 209763) against respiratory syncytial virus (RSV) in infants and young children at risk for severe RSV disease*. Antimicrobial Agents Chemotherapy 1999; 43: 1183.
- Mildenhall LF, Pavuluri NN & Bowman ED. *Safety of synthetic surfactant use before preterm newborn transport*. J Paediatr Child Health 1999; 35: 530-535.

- Molloy J, Kei J, Smyth V, McPherson B, Young J, Tudehope D, Maurer M, Rankin G, Latham, & Loscher J. *Distortion product otoacoustic emissions in neonates and two month-old infants*. Aust New Zealand J Audiol 1999; 21: 65-76.
- Monteros L, Percival P, Cole J & Evans S. *Effect of nappy liners on temperature stability in very preterm infants*. J Paediatr Child Health 1999; 35: 363-366.
- Morgan C, Newell SJ, Ducker DA, Hodgkinson J, White DK, Morley CJ & Church JM. *Continuous neonatal blood gas monitoring using a multi-parameter intra-arterial sensor*. Arch Dis Child Fetal Neonatal Ed 1999; 80: F93-F98.
- Morley C. *Continuous distending pressure*. Arch Dis Child Fetal Neonatal Ed 1999; 81: F152-156.
- Morley CJ, Davies MW & Mehr S. *Bacteria on toys in neonatal intensive care cots*. Pediatr Res 1999; 45: 900.
- Morley C, Davies M & Mehr S. *The effect of draw-up volume on measured arterial sodium concentration*. Pediatr Res 1999; 45: 924.
- Morrison KE, McKane S, Dargaville PA & Slocombe RF. *Functional and compositional changes in equine pulmonary surfactant in response to exercise*. Equine Vet J Suppl. 1999; 30: 62-66.
- Moyes C. *Immunisation of preterm babies*. New Zealand Med J 1999; 112: 263-264.
- Oliver MH, Bloomfield FH, Harding JE, Breier BH, Bassett NS & Gluckman PD. *The maternal, fetal and postnatal somatotrophic axes in intra-uterine growth retardation*. Biochemical Soc Transactions 1999; 27: 69-73.
- Omari T, Barnett C, Snel A, Davidson G, Haslam R, Bakewell M & Dent J. *Mechanism of gastro-esophageal reflux in premature infants with chronic lung disease*. J Pediatric Surg 1999; 34: 1795-98.
- Omari TI, Benninga MA, Haslam RR, Barnett CP, Davidson GP & Dent J. *Lower esophageal sphincter position in premature infants cannot be correctly estimated with current formulas*. J Pediatr 1999; 135: 522-525.
- Omari TI, Benninga MA, Barnett CP, Haslam RR, Davidson GP & Dent J. *Characterization of esophageal body and lower esophageal sphincter motor function in the very premature neonate*. J Pediatr 1999; 135: 517-521.
- Omari T, Snel A, Barnett C, Davidson G, Haslam R & Dent J. *Measurement of upper esophageal sphincter tone and relaxation during swallowing in premature infants*. Am J Physiology 1999; 277: G862-866.
- Opie GF, Fraser SH, Drew JH & Drew S. *Bacterial endocarditis in neonatal intensive care*. J Paediatr Child Health 1999; 35: 545-548.
- Osborn DA, Lau KC, Uther JB, Coughtrey H & Rochefort MJ. *Radiofrequency catheter ablation in a haemodynamically compromised premature neonate with hydrops fetalis*. J Paediatr Child Health 1999; 35: 406-408.
- Osborn DA, Lui K, Pussell P, Jana AK, Desai AS & Cole M. *T and Tk antigen activation in necrotising enterocolitis: manifestations, severity of illness, and effectiveness of testing*. Arch Dis Child Fetal Neonatal Ed 1999; 80: F192-197.
- Outlaw J, Reid S & Wocadlo C. *Evaluation of a hearing screening program for at-risk infants*. Neonatal, Paediatr Child Health Nurs 1999; 2: 12-17.
- Patole S, Lee J & Whitehall J. *Adenosine infusion in the management of a micropremi neonate with pulmonary hypertension*. Indian Pediatr 1999; 36: 307-310.
- Pennell CE & Tracy MB. *A new method for rapid measurement of lactate in fetal and neonatal blood*. Aust NZ J Obstet Gynaecol 1999; 39: 227-233.
- Pillow JJ, Neil H, Wilkinson MH & Ramsden CA. *Effect of I/E ratio on mean alveolar pressure during high-frequency oscillatory ventilation*. J Applied Physiol 1999; 87: 407-414.
- Powell KF & Gunn TR. *The successful containment of coxsackie B4 infection in a neonatal unit*. J Paediatr Child Health 1999; 35: 102-104.
- Preechagoon Y, Charles B, Piotrovskij V, Donovan T & Van Peer A. *Population pharmaco-kinetics of enterally administered cisapride in young infants with gastro-oesophageal reflux disease*. Br J Clin Pharmacol 1999; 48: 688-693.
- Rashid A, Bhuta T & Berry A. *A regionalised transport service, the way ahead?* Arch Dis Child 1999; 80: 488-492.
- Richardson D, Tarnow-Mordi WO & Lee SK. *Risk adjustment for quality improvement*. Pediatr 1999; 103: 255-265.

- Roberts CL, Algert CS, Peat B & Henderson-Smart DJ. *Small fetal size: a risk factor for breech birth at term.* Int J Gynaecol Obstet, 1999; 67: 1-8.
- Roberts CL & Lancaster PA. *National birthweight percentiles by gestational age for twins born in Australia.* J Paediatr Child Health 1999; 35: 278-282.
- Roberts CL & Lancaster PAL. *National birthweight percentiles by gestational age for twins born in Australia.* J Paed Child Health 1999; 35: 278-282.
- Roberts CL, Taylor L & Henderson-Smart DJ. *Trends in births at and beyond term: evidence of a change?* Br J Obstet Gynaecol, 1999; 106: 937-942.
- Rodwell RL, Gray PH, Tudehope DI, Joyce A, Pillai S, Dow RB, Bell J & Taylor K. *Fatal outcome with the use of standard blood products during evolving neonatal necrotising enterocolitis complicated by Tcryptantigen exposure.* Aus. J. Med Science 1999; 20: 84-88.
- Sabui T, Tudehope DI & Lennon I. *Recurrent late onset Group B Streptococcal infection with parotitis.* J. Paed Child Health 1999; 35: 224-225
- Sabui T, Tudehope DI & Tilse M. *Clinical significance of quantitative blood cultures in newborn infants.* J Paediatr Child Health 1999; 35: 578-581.
- Smyth V, McPherson B, Kei J, Young J, Tudehope D, Maurer M & Rankin G. *Oto-acoustic emission criteria for neonatal hearing screening.* Intern J Pediatric Otorhinolaryngol 1999; 25: 9-15.
- Soilu-Hänninen M, Ekert P, Bucci T, Bartlett PF & Kilpatrick T. *NGF signalling through p75 induces apoptosis in Schwann cells via a Bcl-2 independent pathway.* J Neuroscience 1999; 19: 4828-4838.
- Sowter B, Doyle LW, Morley CJ, Altmann A & Halliday J. *Is sudden infant death syndrome still more common in very low birthweight infants in the 1990s?* Med J Aust. 1999; 17: 411-413.
- Spence K, Greenwood J, McDonald M & Sullivan J. *Processing knowledge in practice: preliminary findings of a study into neonatal intensive care nursing.* J Neonatal Nursing 1999; 5: 27-30.
- Stathis SL, O'Callaghan M, Harvey J & Rogers Y. *Head circumference in ELBW babies is associated with learning difficulties and cognition but not ADHD in the school-aged child.* Develop Med Child Neurol 1999; 41: 375-380.
- Sutton L & Bajuk B. *Population-based study of infants born at less than 28 weeks' gestation in New South Wales, Australia, in 1992-3.* NSW Neonatal Intensive Care Unit Study Group. Paediatr Perinatal Epidemiol 1999; 13: 288-301.
- Swaminathan M, Davies MW & Betheras FR. *Cystic periventricular leukomalacia in a twin to twin transfusion syndrome: a case report.* Australasian Soc Ultrasound Med Bulletin 1999; 2: 25-29.
- Swaminathan M, Davies M, Davis P & Betheras F. *Transverse cerebellar diameter on cranial ultrasound scan in preterm neonates in an Australian population.* J Paediatr Child Health 1999; 35: 346-349.
- Tarnow-Mordi WO, Healy MJ. *Distinguishing between "no evidence of effect" and "evidence of no effect" in randomised controlled trials and other comparisons.* Arch Dis Child. 1999; 80: 210-211.
- Tarnow-Mordi W & Mitra A. *Postnatal dexamethasone in preterm infants is potentially lifesaving, but follow up studies are urgently needed.* BMJ. 1999; 319: 1385-1386.
- Todd D, Cassell C, Kennedy J & John E. *Retinopathy of prematurity in infants < 32 weeks' gestation at birth in New South Wales in 1993 and 1994.* J Paediatr Child Health 1999; 35: 355-357.
- Tually K. *An information processing approach to the early measurement of learning difficulties in preterm and full-term infants.* Aust J Psychol 1999; 51: 100-101.
- Tucker J, Tarnow-Mordi W, Gould C, Parry G, & Marlow N. *UK neonatal intensive care services in 1996.* On behalf of the UK Neonatal Staffing Study Collaborative Group. Arch Dis Child Fetal Neonatal Ed. 1999; 80: F233-234.
- Tuladhar R, Daftary A, Patole SK & Whitehall JS. *Oral gastrograffin in neonates: a note of caution.* Inter J Clin Practice 1999; 53: 565.
- Uemura S, Woodward AA, Amerena R & Drew J. *Early repair of inguinal hernia in premature babies.* Pediatric Surgery Inter 1999; 15:36-39.
- Warren LJ, Simmer K, Roxby D, Grist S, Seshadri R & Morley A. *DNA polymorphism analysis in transfusion-associated graft-versus-host disease.* J Paediatr Child Health 1999; 35, 98-101.
- Webster J & Pritchard M. *Development of evidence-based guidelines in midwifery and gynaecology nursing.* Midwifery 1999; 15, 2-5.

Whitehall JS, Patole SK & Campbell P. *Recombinant human erythropoietin in anemia of prematurity*. Indian Pediatr 1999; 36: 17-27.

Yu VYH. *Management of perinatal asphyxia and assessment of long-term prognosis*. Perinatology: J Perinatal Neonatal Care 1999; 1: 251-266.

Yu VYH. *New strategies for management of neonatal respiratory failure*. Ceylon J Child Health 1999; 28: 3-10.

Yu VYH. *Recent advance in neonatal surfactant replacement therapy*. Ceylon J Child Health 1999; 28: 17-26.

Yu VY. *Enteral feeding in the preterm infant*. Early Human Develop 1999; 56: 89-115.

Zhang J, Penny DJ, Kim NS, Yu VY & Smolich JJ. *Mechanisms of blood pressure increase induced by dopamine in hypotensive preterm neonates*. Arch Dis Child Fetal Neonatal Ed 1999; 81: F99-F104.

3.2 Electronic publications

Askie LM & Henderson-Smart DJ. *Restricted versus liberal oxygen exposure for preventing morbidity and mortality in preterm or low birth weight infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Crowther CA, Alfirevic Z & Haslam RR. *Prenatal thyrotropin-releasing hormone for preterm birth* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Crowther CA & Henderson-Smart DJ. *Phenobarbital prior to preterm birth for preventing neonatal periventricular haemorrhage* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Crowther CA & Henderson-Smart DJ. *Vitamin K prior to preterm birth for preventing neonatal periventricular haemorrhage* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Darlow BA & Graham PJ. *Vitamin A supplementation for preventing morbidity and mortality in very low birthweight infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Davies MW & Davis PG. *Nebulized racemic epinephrine for extubation of newborn infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Duley L & Henderson-Smart DJ. *Drugs for rapid treatment of very high blood pressure during pregnancy* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Duley L, Williams J & Henderson-Smart DJ. *Plasma volume expansion for treatment of women with pre-eclampsia* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Henderson-Smart DJ, Bhuta T, Cools F & Offringa M. *Elective high frequency oscillatory ventilation versus conventional ventilation for acute pulmonary dysfunction in preterm infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Henderson-Smart DJ & Osborn DA. *Kinesthetic stimulation for preventing apnea in preterm infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Henderson-Smart DJ & Steer P. *Methylxanthine treatment for apnea in preterm infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Henderson-Smart DJ & Steer PA. *Doxam treatment for apnea in preterm infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Henderson-Smart DJ & Steer PA. *Prophylactic methylxanthine for preventing of apnea in preterm infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

King J & Flenady V. *Antibiotics for preterm labour with intact membranes* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Kuschel CA & Harding JE. *Fat supplementation of human milk for promoting growth in preterm infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Kuschel CA & Harding JE. *Multicomponent fortified human milk for promoting growth in preterm infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Kuschel CA & Harding JE. *Protein supplementation of human milk for promoting growth in preterm infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Osborn DA. *Thyroid hormone for preventing neurodevelopmental impairment in preterm infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Soll RF & Dargaville P. *Surfactant for meconium aspiration syndrome in full term infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

Spence K & Barr P. *Nasal versus oral intubation for mechanical ventilation of newborn infants* (Cochrane Review). In: The Cochrane Library, Issue 4, 2000. Oxford: Update Software.

3.3 Chapters:

Clarke PM, Morton SMB & Harding JE. *Adult consequences of fetal disease*. In: Fetal Medicine: Basic Science and Clinical Practice. Rodeck CH & Whittle MJ (eds). Churchill Livingstone, London, 1999; 309-315.

Colditz PB, Begg LM & East CE. *Fetal pulse oximetry: Instrumentation and recent clinical experience*. Clinics in Perinatology 1999; 26: 4: 869-880.

Davies MW. *Dr Mark Davies' Potato Delicacy*. In: What's cooking on the 9th floor? Carr J, & Sowter B (eds) Melbourne: Royal Women's Hospital 1999; 19.

Dunster KR. *Physiologic variability in the perinatal period. Origins, measurement and applications*. Clinics in Perinatology 1999; 26: 801-809.

Evans N & Henderson-Smart D. *Cardiorespiratory adaptation to extrauterine life*. In: Fetal Medicine: Basic science and clinical practice. Roek C & Whittle M (eds) Churchill Livingstone, London.

Ling EWY & Yu VYH. *Ethical problems in neonatal intensive care*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science & Technology Publishing, Jiangxi, China, 1999, 856-867.

Morley CJ. *Continuous positive airway pressure*. In: Handbook of Neonatal Respiratory Care, 1999, Sinha S & Donn S (eds) Future Publishing Company Inc. Armonk, NY, USA ; 444-44.

Ng PC, Yu VYH. *Perinatal-neonatal audit*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science & Technology Publishing, Jiangxi, China, 1999, 31-39.

Schiefelbein J. *Genetics and fetal anomalies*. In: Core curriculum for neonatal intensive care nursing. Deacon J & O'Neill P (eds). WB Saunders, Philadelphia.

Vervaaert P, Dargaville PA & Hull J. *Failure of the oxidative stress response in ventilated infants with lung disease*. In: Advances in Critical Care Testing. AVL Medical Instruments AG 1999; 87-100

Yu VYH. *Monitoring the long term neuro-developmental outcome of extremely preterm infants who survive with neonatal intensive care*. In: Prevention Rehab 98. The Second International Congress on Rehabilitation. Haskell SH (ed) Dubai, 1999, 45-60.

Yu VYH. *Intravenous nutrition*. In: Practical Perinatal Care: The Baby Under 1000 grams. Levitt G, Harvey D & Cooke R (eds) Butterworth Heinemann, Oxford 1999, 125-136.

Yu VYH. *Early enteral feeding instead of parenteral nutrition in the VLBW baby*. Proc 4th World Congress of Perinatal Medicine. Voto L, Marguilies M & Cosmi EV (eds) Monduzzi Editore, Bologna, 1999, 451-456.

Yu VYH. *Perinatal management of extreme prematurity*. Proc 4th World Congress of Perinatal Medicine. Voto L, Marguilies M & Cosmi EV (eds) Monduzzi Editore, Bologna, 1999, 531-536.

Yu VYH. *Red cell transfusion in the newborn*. Proc 4th World Congress of Perinatal Medicine. Voto L, Marguilies M & Cosmi EV (eds) Monduzzi Editore, Bologna, 1999, 537-542.

Yu VYH. *Perinatal audit and evidence-based medicine in neonatology*. Proc 4th World Congress of Perinatal Medicine. Voto L, Marguilies M & Cosmi EV (eds) Monduzzi Editore, Bologna, 1999, 621-626.

Yu VYH. *Neonatal and ethical implications of assisted reproduction*. Proc 4th World Congress of Perinatal Medicine. Voto L, Marguilies M, Cosmi EV (eds) Monduzzi Editore, Bologna, 1999, 655-660.

Yu VYH. *Micropremies*. Proc 4th World Congress of Perinatal Medicine. Voto L, Marguilies M, Cosmi EV (eds) Monduzzi Editore, Bologna, 1999, 703-708.

Yu VYH. *Feeding the preterm infant*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science & Technology Publishing, Jiangxi, China, 1999, 225-235.

Yu VYH. *Parenteral nutrition*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science & Technology Publishing, Jiangxi, China, 1999, 247-255.

Yu VYH. *Persistent pulmonary hypertension*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science & Technology Publishing, Jiangxi, China, 1999, 374-380.

Yu VYH. *Outcome of low birthweight infants*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science & Technology Publishing, Jiangxi, China, 1999, 843-851.

Yu VYH. *Parenteral nutrition*. In: Textbook of Neonatology, 3rd ed. Rennie JM & Robertson NRC (eds) Churchill Livingstone, London, 1999, 349-360.

Yu VYH. *Enteral feeding for premature infants*. Proc Nestle Nutrition Education Series IV, University of the Philippines, Manila, Philippines, 1999, 36-58.

Yu VYH. *Role of nutrition in enhancing immunity*. Proc Nestle Nutrition Education Series IV, University of the Philippines, Manila, Philippines, 1999, 59-66.

Yu VYH. *Neonatal surfactant replacement therapy*. In: Recent Advances in Pediatrics, Special Volume 4: Neonatology. Gupte S (ed) Jaypee Brothers Medical Publishers, New Delhi, 1999, 134-149.

Yu VYH & Feng ZK. *Perinatal asphyxia*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science and Technology Publishing, Jiangxi, China, 1999, 135-145.

Yu VYH, Gan TE. *Red blood cell transfusion in the preterm infant*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science & Technology Publishing, Jiangxi, China, 1999, 573-579.

Yu VYH & Jin HZ. *Prevention of respiratory distress syndrome*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science & Technology Publishing, Jiangxi, China, 1999, 269-278.

Yu VYH & Kao LC. *Chronic lung disease*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science and Technology Publishing, Jiangxi, China, 1999, 325-334.

Yu VYH & Ng PC. *Necrotising enterocolitis*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science & Technology Publishing, Jiangxi, China, 1999, 459-472.

Yu VYH & Yu RJ. *Hypoxic-ischaemic encephalopathy*. In: Chinese Neonatology. Zeng ZK, Yu VYH, Tsang RC & Yeung CY (eds) Jiangxi Science & Technology Publishing, Jiangxi, China, 1999, 611-621.

3.4 Books

Feng ZK, Yu VYH, Tsang RC, Yeung CY (eds). *Chinese Neonatology*. Jiangxi Science and Technology Publishing, Jiangxi, China, 1999.

3.5 Publications arising from the ANZNN

Hacking D, Watkins A, Fraser S., Wolfe R, Carlin J & Nolan T *Respiratory distress syndrome and birth order in premature twins* Arch. Dis. Child. Fetal Neonatal Ed. 2001; 84: F117-F121.

Donoghue, DA & Cust AE 2000. *The Australian & New Zealand Neonatal Network, 1998*. Sydney: AIHW National Perinatal Statistics Unit

Donoghue, DA 1999. *The Australian & New Zealand Neonatal Network, 1996-1997*. Sydney: AIHW National Perinatal Statistics Unit

Donoghue, DA 1997. *The Australian & New Zealand Neonatal Network, 1995*. Sydney: AIHW National Perinatal Statistics Unit

Donoghue, DA 1996. *The Australian & New Zealand Neonatal Network, 1994*. Sydney: AIHW National Perinatal Statistics Unit.

Appendix 4

Clinical trials underway in 1999

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

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

RNOTT - Randomised nitric oxide as a tocolytic trial.

Term Breech - the Term Breech trial

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 (funded by NHMRC).

Effect of targeted indomethacin on blood flow to the upper body and brain in very preterm babies (funded by NHMRC).

A randomised trial of volume and dopamine vs volume and dobutamine in preterm babies with low systemic blood flow (funded by NHMRC).

Randomised trial of two different dexamethasone regimens for prevention of chronic lung disease..

Randomised trial of selective head cooling following perinatal asphyxia.

Study of methadone levels in infants of opioid dependent mothers.

Use of renal Doppler ultrasound to diagnose a patent ductus arteriosus

UK oscillatory ventilation study (UKOS)

Caffeine in apnoea: a randomised controlled trial of dose response and population modelling in extremely preterm infants.

CPAP (continuous positive airways pressure) trial.

Kanmed baby warmer trial : an evaluation of thermal responses, weight gain and maternal

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: Kaye Bawden (Monash Medical Centre, Vic), David Cartwright (Royal Women's Hospital, Qld), Brian Darlow (Christchurch School of Medicine, New Zealand), David Henderson-Smart (Pregnancy & Newborn Services Network, NSW), Paul Lancaster (AIHW National Perinatal Statistics Unit, University of NSW) and Penny Waterson (Maternity Alliance, Australia). 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 (Kaye Bawden, David Cartwright, Brian Darlow, David Henderson-Smart, Paul Lancaster and Penny Waterson).

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.

In profile:

Australia is a country of approximately 18.5 million people and has about 250,000 live births per annum. 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 an area of 266,000 square kilometres.



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