

**Neonatal Network Series**  
**Number 1**

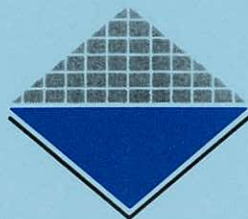
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**Australian & New Zealand**  
**Neonatal Network**  
**1994**

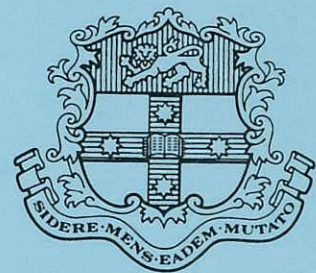
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**Deborah Donoghue**

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AUSTRALIAN INSTITUTE OF  
**HEALTH & WELFARE**



**Australian Institute of Health and Welfare  
National Perinatal Statistics Unit  
Neonatal Network Series  
Number 1**

**Australian & New Zealand  
Neonatal Network  
1994**

**Deborah Donoghue**

Coordinators:

**Paul Lancaster  
David Henderson-Smart  
Brian Darlow**

**AIHW National Perinatal Statistics Unit  
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The AIHW National Perinatal Statistics Unit is an external unit of the Australian Institute of Health and Welfare and is based at the University of Sydney.

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# Contributing NICUs

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Neonatal Intensive Care Units (NICUs), *city in which they are located*, and Directors of the units that have contributed data for infants born during the 1994 calendar year are:

## **New South Wales**

John Hunter Hospital, *Newcastle*, Dr Andrew Gill  
King George V Memorial Hospital, *Sydney*, Dr Nick Evans  
Liverpool Hospital, *Sydney*, Dr Robert Guaran  
The Nepean Hospital, *Sydney*, Dr Lyn Downe  
Prince of Wales Children's Hospital, *Sydney*, Dr Barry Duffy  
Royal Alexandra Hospital for Children, *Sydney*, Dr Andrew Berry  
Royal Hospital for Women, *Sydney*, Dr Howard Chilton  
Royal North Shore Hospital, *Sydney*, Dr Garth Leslie  
Westmead Hospital, *Sydney*, Dr Elizabeth John

## **Victoria**

Mercy Hospital for Women, *Melbourne*, Associate Professor John Drew  
Monash Medical Centre, *Melbourne*, Professor Victor Yu  
Royal Women's Hospital, *Melbourne*, Dr Neil Roy

## **Queensland**

Kirwan Hospital for Women, *Townsville*, Dr Graham Reynolds  
Mater Misericordiae Mothers' Hospital, *Brisbane*, Dr David Tudehope  
Royal Women's Hospital, *Brisbane*, Dr David Cartwright

## **Western Australia**

King Edward Memorial Hospital for Women, *Perth*, Dr Alfred Grauaug  
Princess Margaret Hospital for Children, *Perth*, Dr Patrick Pemberton

## **South Australia**

Queen Victoria Hospital (now Women's and Children's Hospital), *Adelaide*, Dr Ross Haslam

## **Tasmania**

Royal Hobart Hospital, *Hobart*, Dr Graham Bury

## **New Zealand:**

Christchurch Women's Hospital, *Christchurch*, Dr Brian Darlow  
Middlemore Hospital, *Auckland*, Dr Jacqueline Stack  
Waikato Hospital, *Hamilton*, Dr David Bouchier



# Abbreviations

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

# Highlights

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- In 1994, the cohort for data collection was all liveborn infants who were admitted to a hospital with a Neonatal Intensive Care Unit (NICU) and who were also born at less than 32 completed weeks' gestation, or born with a birthweight less than or equal to 1500 grams. Twenty-two of the 29 NICUs in Australia and New Zealand contributed data in the first year, and not all units collected all variables. These data should be regarded as a pilot year, and the findings interpreted with caution. All NICUs have agreed to contribute data from 1995.
- There were 2,723 infants who met the ANZNN criteria admitted to the contributing NICUs in 1994. Of these infants, 2,447 were less than 32 weeks' gestation and 2,165 were less than or equal to 1500 grams.
- The use of antenatal corticosteroids to enhance fetal lung maturation is widespread in Australia and New Zealand. This treatment was used in 66.6% of infants who were born at less than 32 weeks gestation in this cohort.
- Seven hundred and twenty-nine (26.8%) infants were from a multiple pregnancy compared with 2.7% for all Australian and New Zealand births in 1994. There was one set of quadruplets and 89 infants born to triplet pregnancies.
- More than half (56.1%) of the infants were born by caesarean section, although the rate of caesarean varied with the gestational age of the infant. In Australia in 1993, 19% of infants were born by caesarean section.
- Respiratory distress is a major cause of morbidity in these infants, with more than half (57.5%) of the infants diagnosed as having respiratory distress syndrome. Forty-two per cent of the infants received exogenous surfactant.
- The majority of infants (68.0%) had a normal initial head ultrasound examination, but 6.4% did have a significant (Grade III or IV) intraventricular haemorrhage. Five per cent of eligible infants were not examined. No cysts or ventricular dilatation was seen in 88.4% of the later head ultrasound recordings, which were available for three-quarters of the infants.
- Overall the majority of these infants (89.8%) survived to go home. The survival of these infants is predominantly dependent on gestational age and birth weight. For example, at 24 weeks' gestation, only 58% of the infants without lethal congenital malformations survived, while after 27 weeks more than 90% of infants went home. The survival rate for infants born weighing more than 900 grams was also more than 90%. Importantly, these survival rates refer to those infants who were admitted to a nursery in a hospital with a NICU.
- After their care in a hospital with a specialist neonatal unit, nearly half of the infants (45.6%) were transferred to nurseries in hospitals without intensive care prior to their discharge home. Almost the same proportion (47.7%) went directly home, and a few were transferred to other NICUs before going home.
- The duration of stay in hospital for infants who survive is related to both gestation and weight at birth. These infants are usually discharged home around their due date. Overall, the median duration of stay in a hospital with a NICU was 28 days for those transferred to another hospital before going home and 58 days for those who went directly home. The median age at death was three days.
- Continued data collection will ensure accurate and detailed information is available for the parents and clinicians of these infants, for other health professionals and for the general community.

# 1 Background and philosophy of ANZNN

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## 1.1 History

The Directors of Neonatal Intensive Care Units (NICUs) around Australia met several times to discuss the concept of an Australian audit of clinical care in these units. Overseas there had been an increasing tendency to form networks to pool data on neonatal morbidity and mortality, and thus provide quality assurance for this resource-consuming care. Some Australian and New Zealand units were already contributing to these data collections. Concurrently, networking, collaboration and cooperation had been hallmarks of perinatal care in Australia and New Zealand. Thus, in July 1993 at a meeting in Hobart, it was decided that a network should be set up, and ANZNN was born.

At the same time, the Health Care Committee of 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 (AIHW NPSU), 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 p xvi)'

The prospective data collection commenced for babies born from 1 January 1994. At that time most Australian units had agreed in principle to join the network. However, for some, data collection did not begin in practice until 1995 (see page viii for a list of participating units).

Currently, all units have offered to contribute data for 1995. New Zealand joined the group at the November 1994 Advisory Committee meeting and their representative was elected to the Coordinating Committee. While it was proposed that New Zealand units commence data collection in 1995, three units submitted some prospectively collected data for 1994.

Thus, from 1995, all twenty-three NICUs in Australia and all six NICUs in New Zealand have agreed to contribute to the neonatal network.

## 1.2 Structure

The Australian and New Zealand Neonatal Network (ANZNN) is set up under the National Perinatal Statistics Unit (NPSU), an external unit of the Australian Institute of Health and Welfare (AIHW) at the University of Sydney. The structure of ANZNN comprises three Coordinators, Associate Professor Paul Lancaster, Professor David Henderson-Smart and Dr Brian Darlow. The Advisory Committee is made up of the Directors (or their nominees) of each participating Australian and New Zealand NICU. This group meets twice a year, once in association with the Australian Perinatal Society Congress. The role of the Advisory Committee is to advise the ANZNN and to approve use of the data. The full-time Senior Research Assistant at AIHW NPSU is currently funded by sponsorship from Glaxo Wellcome Australia, and there is a part-time Research Nurse located in Christchurch, whom Glaxo Wellcome New Zealand sponsors.

## 1.3 Aim

The aim of the Australian & New Zealand Neonatal Network (ANZNN) 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 ANZNN Advisory Committee Meeting, Auckland, NZ, 2 April 1995.*

## 1.4 Objectives

The objectives of the Australian & New Zealand Neonatal Network (ANZNN) 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 ANZNN Advisory Committee Meeting, Auckland, NZ, 2 April 1995.*

## 1.5 Confidentiality guidelines

Confidentiality guidelines were devised and agreed to by the Advisory Committee to provide an unambiguous framework for the handing 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 ANZNN Advisory Committee Meeting, Auckland, NZ, 2 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 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). As the ANZNN is part of the AIHW National Perinatal Statistics Unit, it is bound by Australian Institute of Health and Welfare Act, and thus confidentiality of any information covering another person must be upheld. The Act also allows for the data provider to place conditions on the use, release and publication of information. Data will be only released to the Australian Institute of Health and Welfare in a form agreed to by the Advisory Committee.

The essential purpose of the NMD is to provide national unit record data on babies meeting specified criteria who have been admitted to Neonatal Intensive Care Units (NICU), 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 1 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, under the auspices of the AIHW National Perinatal Statistics Unit.
2. The Custodians of the data will be the ANZNN Coordinators, David Henderson-Smart at King George V Hospital, Sydney, Paul Lancaster at the AIHW National Perinatal Statistics Unit, University of Sydney, and Brian Darlow at the Christchurch School of Medicine, Christchurch, New Zealand. 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. The Clinical Reporting System (CRS) data management system is being used for data processing and all data sent to the coordinating centre will be in the form of CRS data files, as ASCII data, or on appropriate forms.

## **C Conditions for use and release of the data**

1. Use of the data would entail agreement by the Advisory Committee (Directors, or their nominee, of each contributing NICU) and the Coordinators (David Henderson-Smart, Paul Lancaster and Brian Darlow).
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.
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 Coordinators.
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 back-up 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.

# 2 Personnel

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## 2.1 Coordinators

There are three coordinators:

- ▶ Associate Professor Paul Lancaster is the Director of the Australian Institute of Health and Welfare National Perinatal Statistics Unit, University of Sydney
- ▶ Professor David Henderson-Smart is a neonatologist at King George V Memorial Hospital, the Professor of Perinatal Medicine at the University of Sydney, Director of the NSW Perinatal Services Network and was the Chair of the Health Care Committee Expert Panel on Perinatal Morbidity.
- ▶ Dr Brian Darlow is a neonatologist at Christchurch Women's Hospital and Senior Lecturer at the Christchurch School of Medicine, University of Otago, New Zealand.

## 2.2 Advisory Committee

The Advisory Committee consists of the Director of each NICU or a nominee, and the Coordinators. Currently there are 29 Directors and 3 Coordinators on the Committee. The Coordinators are listed above and the Directors are listed under Contributing Neonatal Intensive Care Units on page viii.

## 2.3 Research staff

During most of 1994, Sharon Kidd carried out the administration of the ANZNN and analysis of preliminary data in a part-time position.

The day-to-day running of the ANZNN is now in the hands of the Senior Research Assistant. Deborah Donoghue was appointed to that position in late November 1994. The duties include taking minutes at the meetings, general administration, visiting the units and maintaining contact with them, and also data entry, verification, tabulation and presentation.

Deborah trained as a nurse at the Royal Alexandra Hospital for Children, Sydney until 1977. She was awarded the Australian College of Paediatric Young Investigator award in 1988 for her involvement in research into the development of brainstem auditory evoked responses in preterm and term infants. She has also been an audit officer for the NSW Neonatal Intensive Care Units Study during which time she was a member of the NICUS Committee and the Health Care Committee Expert Panel on Perinatal Morbidity.

The Research Nurse, Louise Brass, was appointed in April 1995 and deals with the local issues in New Zealand. Louise completed her nursing training in 1977 and worked in Southland and Christchurch neonatal units from 1983 to 1994. In addition to her ANZNN role, Louise works as a system administrator for Canterbury Health. Louise's role is to assist the contributing NZ units with organising data collection, validation of data and general correspondence between Australian research units and New Zealand.

## 2.4 Activities

The ANZNN Advisory Committee met twice in 1994, in Sydney during March and in Newcastle in November, then in Auckland in April 1995 and in Sydney in November 1995.

# 3 Data set

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## 3.1 Registration criteria

The cohort for 1994 was all live born infants who were admitted to a Neonatal Intensive Care Unit during their first admission to hospital, who were also:

- < 32 completed weeks' gestation, or
- $\leq$  1500 grams birthweight.

In 1994, not all units collected data on the full cohort of infants (see Appendix 3). While all units used the  $\leq$ 1500 grams birthweight criteria, five of the twenty-two units collected information only on those infants born at < 31 completed weeks' gestation. This was due to previous commitments to other databases.

## 3.2 Data set variables

The sixty variables to be collected and their definitions for the 1994 collection are listed in Appendix 1. Although they have since been refined, the meanings have altered little.

In 1994, not all units collected all variables (see Appendix 3). It was decided to use whatever data were available for the 1994 collection as long as it met the agreed definitions. For this reason, the proportion of 'missing' or 'unknown' is large for many data items. The data for 1995 are more complete.

## 3.3 Data collection

Data are collected in the hospitals by either the filling out the specific ANZNN forms (see Appendix 1) or by incorporating the ANZNN data items into the local NICU audit. Not all variables were collected by all units in 1994. Appendix 3 lists the variables proposed for collection and the proportion of infants for whom they were collected. It was decided to proceed with whatever data were available to address the technical difficulties of a large data collection.

Data are transferred to the ANZNN central office either on forms, and then entered onto a database, or electronically. Confidentiality guidelines (section 1.5) are followed.

## 3.4 Data verification

Missing or anomalous data are identified and queried soon after entry onto the main database. A full data verification process will be instituted in 1996. Five randomly selected records will be checked at each unit, and also in the database by the research staff. Quantification of errors and ways of minimising them have begun.

## 3.5 Data

The data in this report are for the first year and are known to be incomplete. It was decided to collect any data that met the definitions from the contributing hospitals. The aim was to initiate the data collection and involve as many units as possible. In this way, this first year's data should be regarded as a pilot of the network with much scope for improving the completeness of data and collaborative participation.

# 4 Results

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## 4.1 In general

A total of 2,723 infants who met the ANZNN criteria were admitted to the twenty-two contributing Neonatal Intensive Care Units (NICUs) throughout Australian and New Zealand. Of these infants, 2,447 were born at less than 32 weeks gestation (Table 1, page 19) and 2,165 were born at less than or equal to 1500 grams (Table 2). These data do not represent the full cohort of infants admitted to a NICU, as many infants of higher gestations and birthweight require assistance and observation.

In 1994, there were 258,051 births registered in Australia (Australian Bureau of Statistics, 1995) and 58,100 in New Zealand (Statistics New Zealand, 1995). The ANZNN cohort represents 0.86% of the 316,151 total births for the two countries.

It should be noted that not all units collected all variables in this initial year of data collection (Appendix 3). Also, in some units, only abnormal results were recorded, such as grade III retinopathy of prematurity, but normal findings at eye examinations were not always recorded. With this in mind, the information given here should be interpreted cautiously.

### 4.1.1 Nursery beds

There are two types of beds in NICUs. The first are generally described as *ventilator* or *intensive care* or *level 3* beds and are used for infants when they receive mechanical assistance with breathing or special procedures. In 1994 there were 187 of these beds available for newborn infants in the twenty-two hospitals that participated in the network data collection. The other type of beds are for newborn infants who do not need such specialised and intensive treatment. These are known as *special care* or *level 2* or *step-down* beds. NICUs have both types of beds in varying numbers (Table 3). It is important to note that in some hospitals there may be a number of other beds for neonates that do not come under the auspices of the NICU. The number of ventilator beds available for newborn infants compared to the total number of nursery beds and the number of births at a hospital can reflect many factors, including the type of unit and local referral patterns (Figure 2). Note that the order of the NICUs in Figure 1 does not relate to the order of NICUs in Figure 2 or in Table 3.

### 4.1.2 Number of infants

The number of infants who met the ANZNN registration criteria admitted to each unit in 1994 varied from very few to nearly three hundred (Figure 1). This reflects both the size of the unit, whether or not the unit was in a specialised children's hospital, and the patient mix. It also reflects (in 1994 data) whether the data collection was for the full cohort of infants born at < 32 weeks (n=17 NICUs) or for those born at less than 1500 grams (n=22 NICUs). The percentage of the infants who were born weighing  $\leq$  1500 grams and cared for in the NICU also varied widely when compared to the total number of live births at that hospital during 1994 (Figure 2). The proportion of liveborn infants born at < 1500 grams in Australia in 1992 was 1.0% (Lancaster P, Huang J & Lin M, 1996).



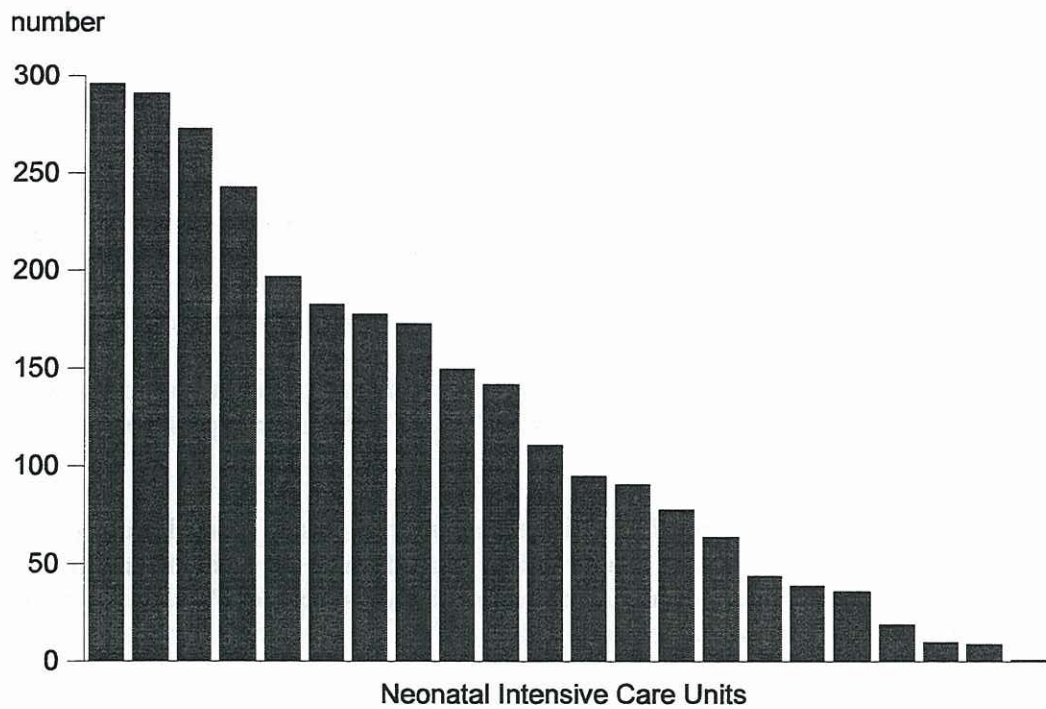


Figure 1: Number of infants in the ANZNN cohort admitted to each of the contributing Neonatal Intensive Care Units, 1994

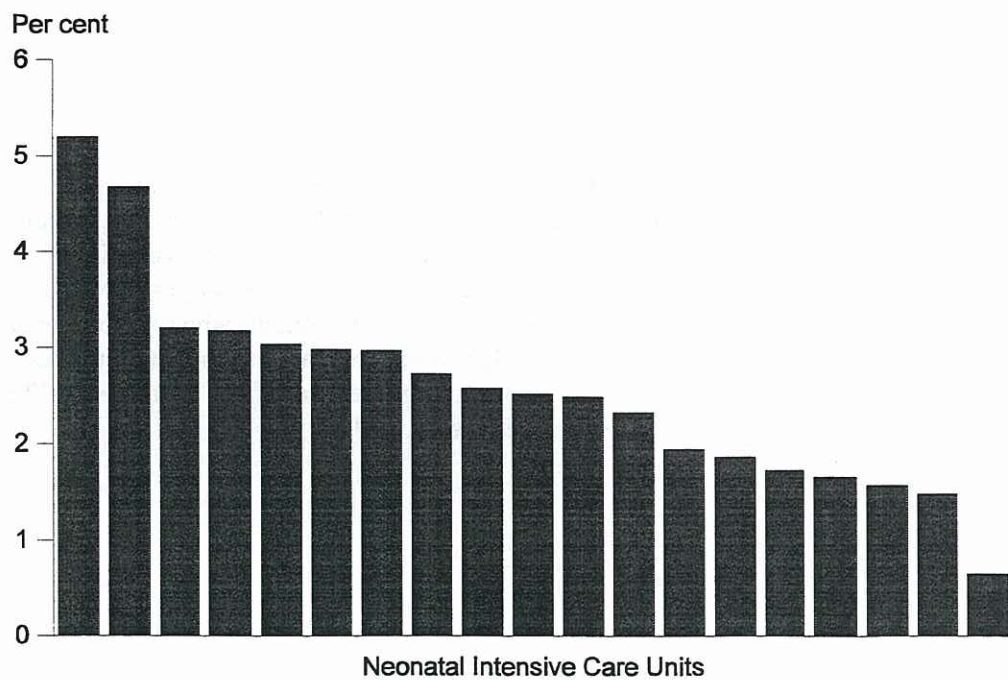


Figure 2: Number of infants born at  $\leq 1500$  grams and admitted to the NICU as a proportion of all infants born in that hospital in 1994

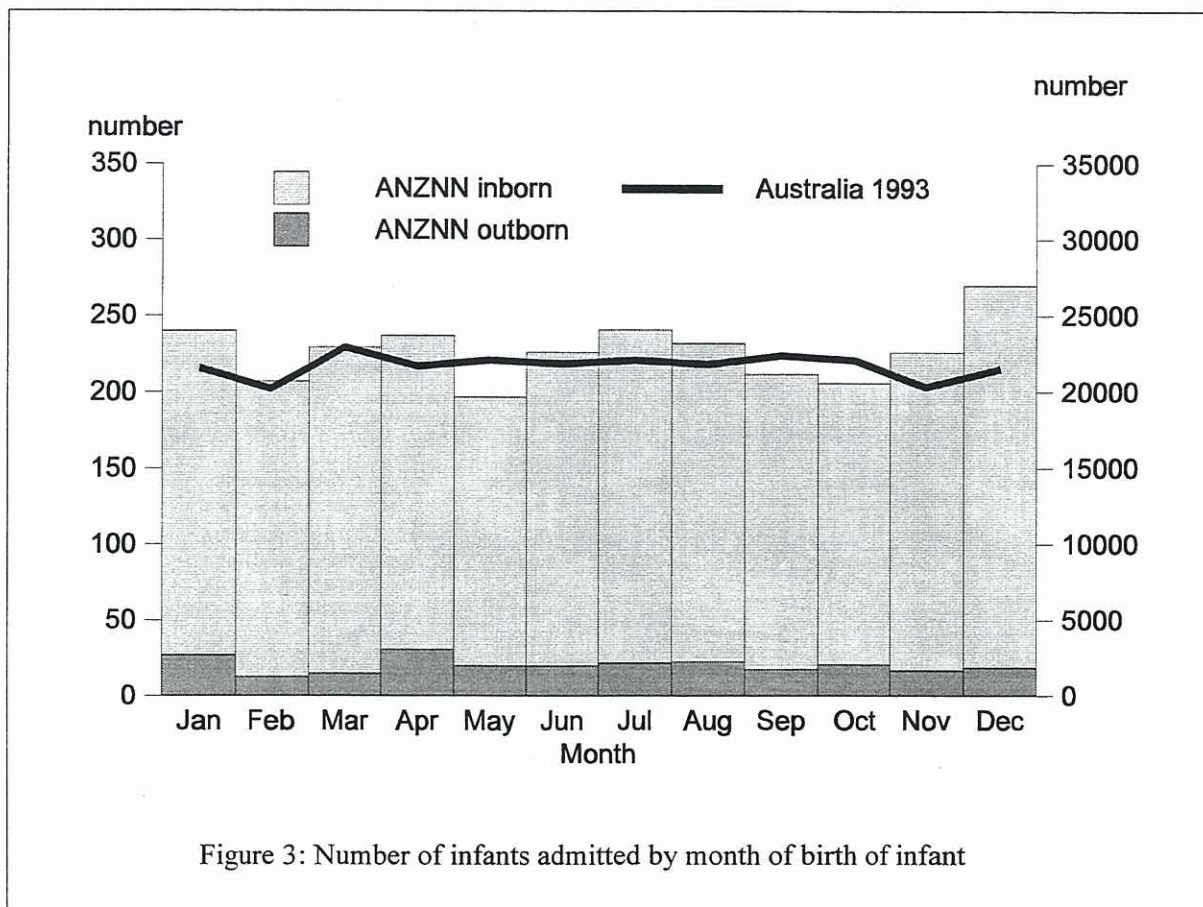


Figure 3: Number of infants admitted by month of birth of infant

### 4.1.3 Admissions per month

The rate of admissions to the NICUs of infants in this cohort was constant across the year for both inborn infants and those who were born elsewhere (Figure 3). The births in Australia in 1993 demonstrated a bimodal peak during February and September (Lancaster P, Huang J & Lin M 1996). When the neonatal network data were compared to those for infants born in Australia in 1993, there was no difference ( $p > 0.01$ ).

## 4.2 Mother

### 4.2.1 Maternal age

Maternal age ranged from 14 to 47 years in this group, and was skewed towards the upper end. This was statistically significantly different ( $p < 0.001$ ) to that of published data for infants born in Australia in 1994 (Australian Bureau of Statistics, 1995) and those born in New Zealand in 1994 (Statistics New Zealand, 1995) (Figure 4). Note that data for New Zealand is transformed in Figure 4 by a factor of 4.5 to allow the data to be plotted on the same axis as that for Australia. Data were not collected in 1,187 (43.6%) of cases, so these differences must be read with caution.

### 4.2.2 Maternal ethnicity

Maternal ethnicity was collected to monitor the proportion of infants from the major ethnic groups, especially indigenous populations. Mother's self report as to ethnic origin was recorded for 1,656 infants (60.8%) (Figure 5, Table 4). The low proportion of infants with recorded data suggests that these data should be interpreted cautiously. This variable of maternal ethnicity was expanded to include both Polynesian and Maori when all New Zealand units joined the network in 1995.

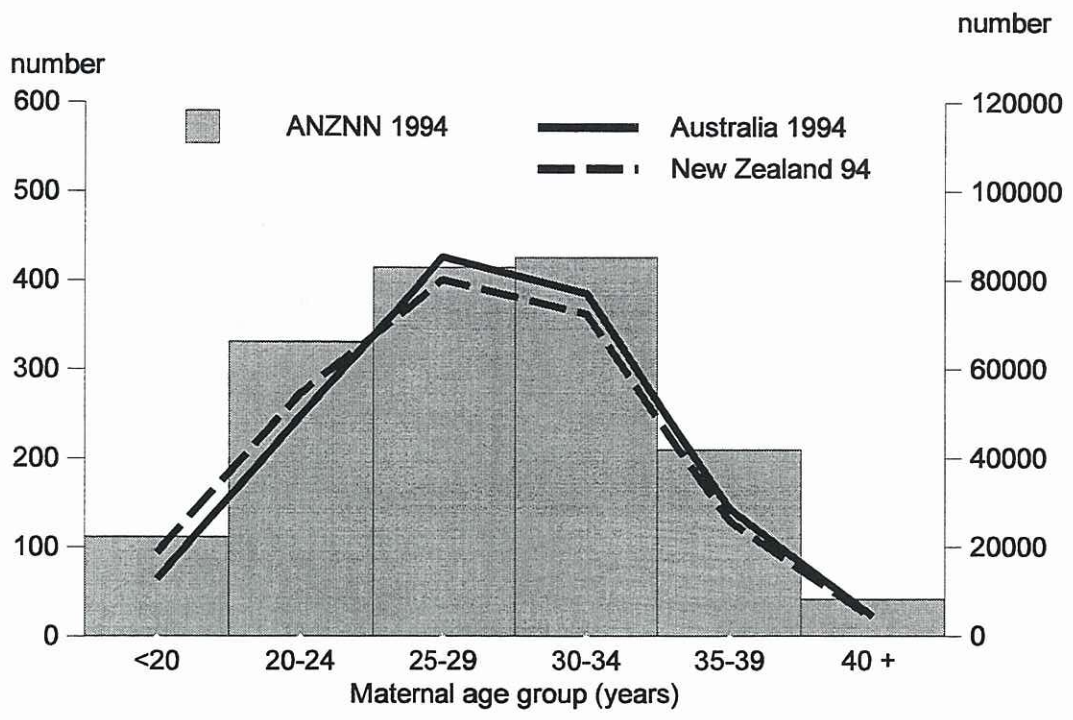


Figure 4: Maternal age at time of infant's birth

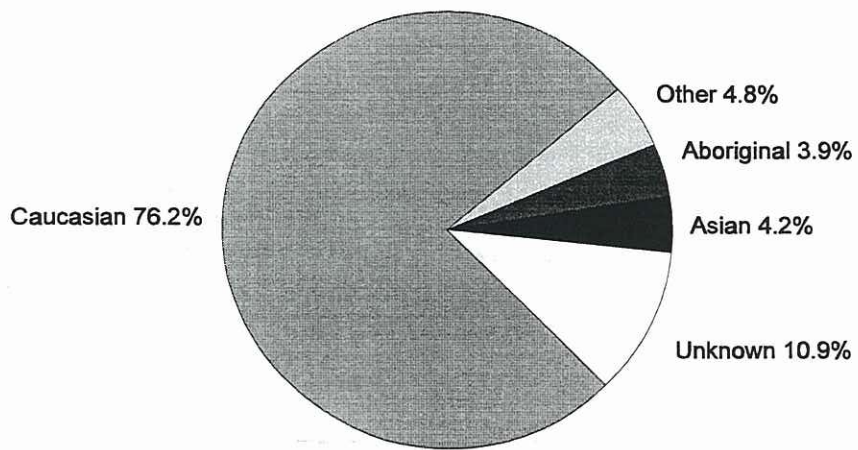


Figure 5: Proportion of infants by maternal ethnic group

## 4.3 Antenatal

### 4.3.1 Presenting antenatal problem

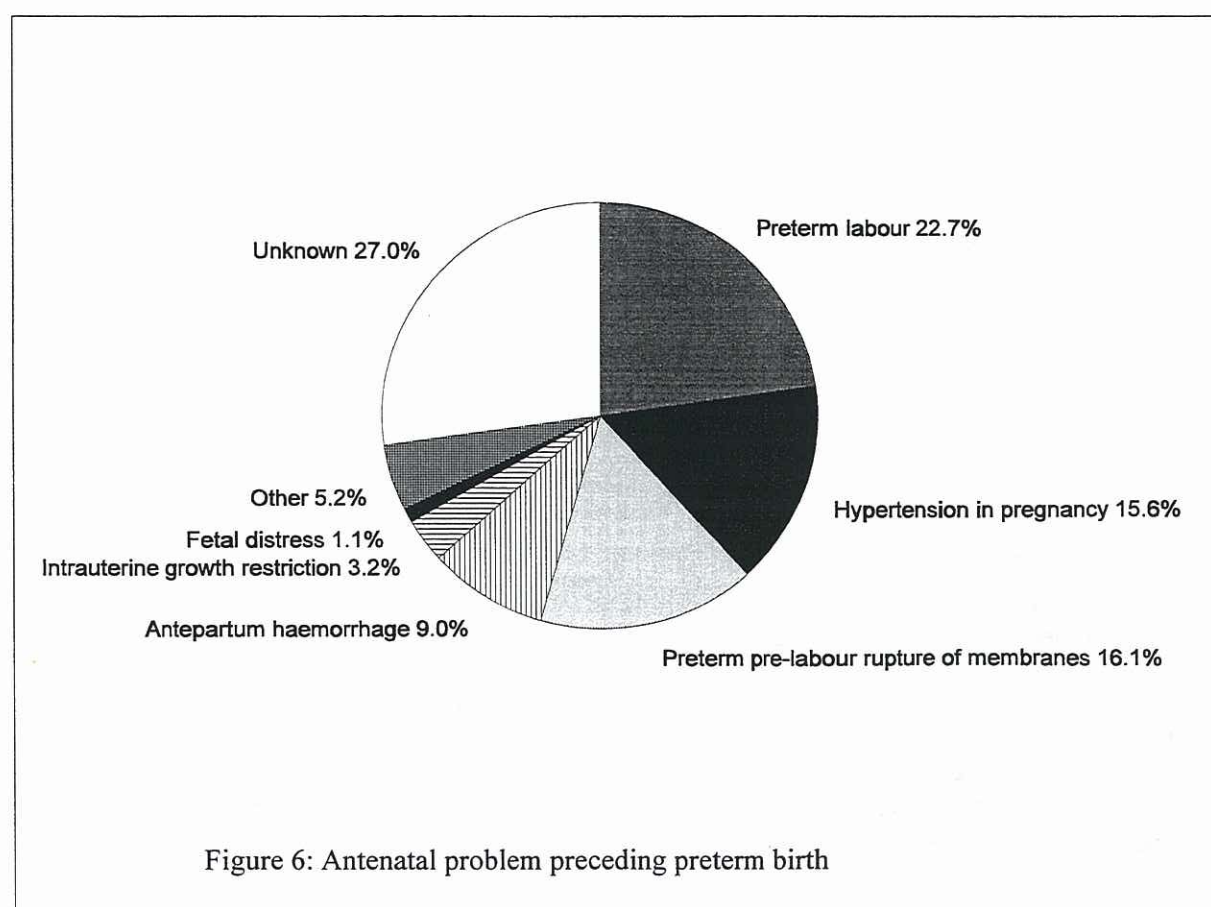
Data were collected on the presenting obstetric problem that led to the infant's preterm birth and subsequent admission to a NICU. Not unexpectedly, preterm labour represented nearly a quarter (22.7%) of the presenting problems. The next most common conditions were the preterm, pre-labour rupture of membranes (when the waters break prior to labour commencing) and hypertension in pregnancy (Figure 6). Data were not collected for 833 (30.6%) infants.

### 4.3.2 Transfers in

Infants are usually cared for in the hospital in which they are born. However, preterm infants may need to be transferred to a hospital with a NICU. In cases where this can be anticipated, the infant and mother can be transferred prior to the birth (in utero) or the mother can book in at the hospital. Of the infants cared for in a participating NICU, 246 (9.0%) infants were transferred after they were born, 29 of these to a children's hospital as their primary destination (Tables 5, 6).

### 4.3.3 Antenatal corticosteroids

The use of antenatal corticosteroids to enhance fetal lung maturation is widespread in Australia and New Zealand. This therapy is administered at least 24 hours prior to birth and has been reported to have protective effects on other systems, such as reducing the incidence of necrotising enterocolitis and intraventricular haemorrhage. It has been recommended that glucocorticosteroids be administered to women in whom birth is likely before 34 weeks' gestation (Health Care Committee Expert Panel on Perinatal Morbidity, 1995). This treatment was used in 66.6% of infants who were born at less than 32 weeks gestation in this cohort and 67.1% for those infants born between 24 and 30 weeks gestation inclusive (Tables 7, 8). Data were not collected for 611(22.5%) infants.



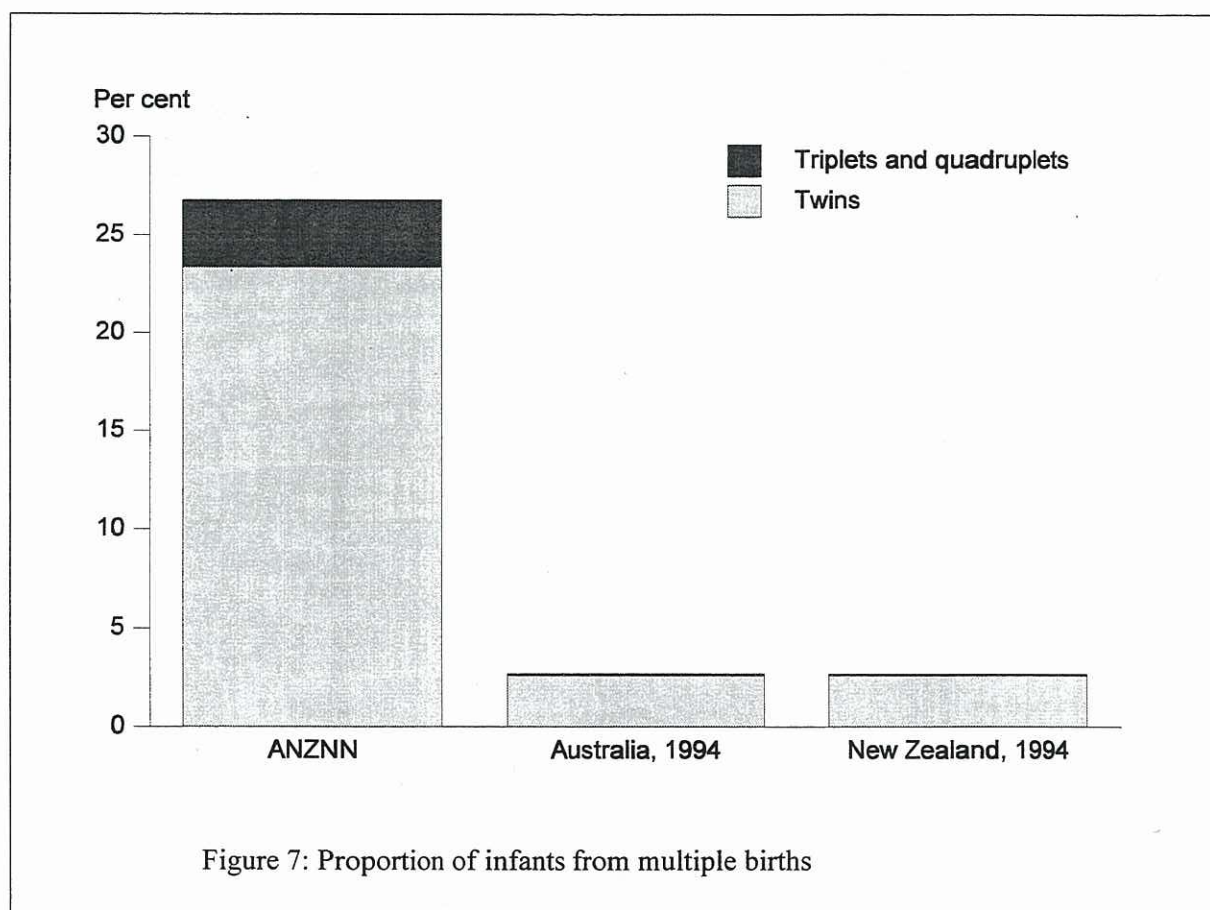
## 4.4 Baby

### 4.4.1 Gender

There were 1,471 (54.0%) males and 1,252 (46.0%) females among the infants in this cohort, slightly in excess of the proportion of males (51.4%) among all births in Australia (Australian Bureau of Statistics, 1995). There were no infants with an indeterminate gender at birth.

### 4.4.2 Multiple births

In this cohort, 729 (26.8%) infants were from a multiple pregnancy compared with 2.7% for all Australian and New Zealand births in 1994 (Figure 7, Australian Bureau of Statistics, 1995; Statistics New Zealand, 1995). There was one set of quadruplets and 89 infants born from triplet pregnancies. This large proportion of infants from a multiple pregnancy is not surprising as the incidence of preterm birth increases with the number of infants from that pregnancy. For example, 30% of all triplets are born at less than 32 weeks gestation (Health Care Committee Expert Panel on Perinatal Morbidity, 1995 p 22).



## 4.5 Birth

### 4.5.1 Condition at birth

The Apgar score is a clinical indicator used to denote an infant's condition at birth. The proportion of all Australian infants with a low Apgar score (ie < 4) was 2.8% at 1 minute (Lancaster P, Huang J & Pedisich E, 1995). In this group of very preterm infants, there were 551 (24.0%) infants with such an Apgar score at 1 minute (data not available for 425 infants). This reflects an increased need for assistance at birth. There is a recommendation that an appropriate paediatric staff member attend the birth of all infants born at <34 weeks' gestation to assist with resuscitation if needed (Health Care Committee Expert Panel on Perinatal Morbidity, 1995). Nine hundred and forty-four (45%) infants were assisted by endotracheal intubation in labour ward (data were not available for 555 infants).

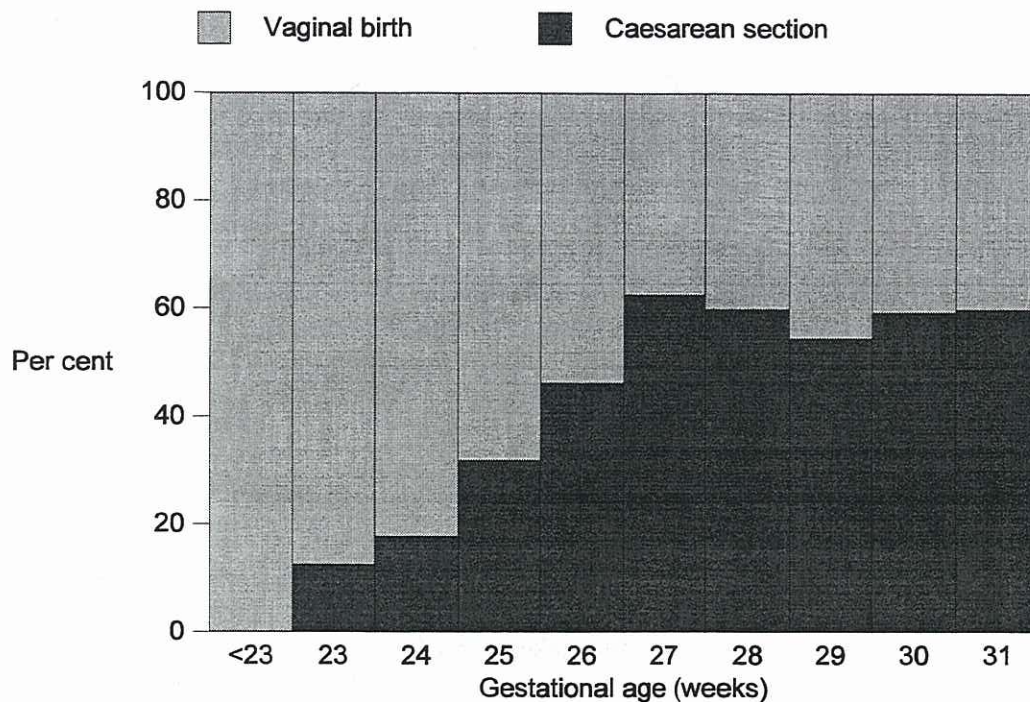


Figure 8: Mode of birth of infants by gestational age

#### 4.5.2 Mode of birth

The manner of birth of these infants was 43.9% vaginally and 56.1% by caesarean section (Tables 11, 12). The caesarean section rate for all births in Australia in 1993 was 19.0% (Lancaster P, Huang J & Lin M, 1996). The rate of caesarean sections for this cohort rate varied with the gestational age of the infant (Figure 8). Data were not available for 296 infants.

The presentation of the infants of the ANZNN cohort was predominantly cephalic (59.9%) while 24.9% were breech, 4.5% were transverse or other and 10.7% unknown (Tables 13, 14). This was vastly different to that reported for the entire Australian population where 95.2% were cephalic and 4.3% were breech (Lancaster P, Huang J & Lin M, 1996). For infants born vaginally, cephalic presentation occurred in 71.5% births, while 19.0% were breech and 8.0% were unknown.

### 4.6 Morbidity

Preterm birth is often associated with neonatal morbidity. Outcome measures that are identifiable while the infant is in hospital are a focus of this data collection. Morbidity outcomes of these infants are primarily related to the immaturity of their various physical systems which presents in divergent ways.

#### 4.6.1 Necrotising enterocolitis

Necrotising enterocolitis (NEC) is a disease of the gut, usually at the level of the colon, and is a common cause of death and morbidity in the preterm infants. Its cause is unknown, although studies have associated it with a variety of factors including very low gestational age and ischaemic events. In this group of infants, NEC was proven in 84 (3.3%) of the 2,568 (94.3%) infants for whom these data were reported.

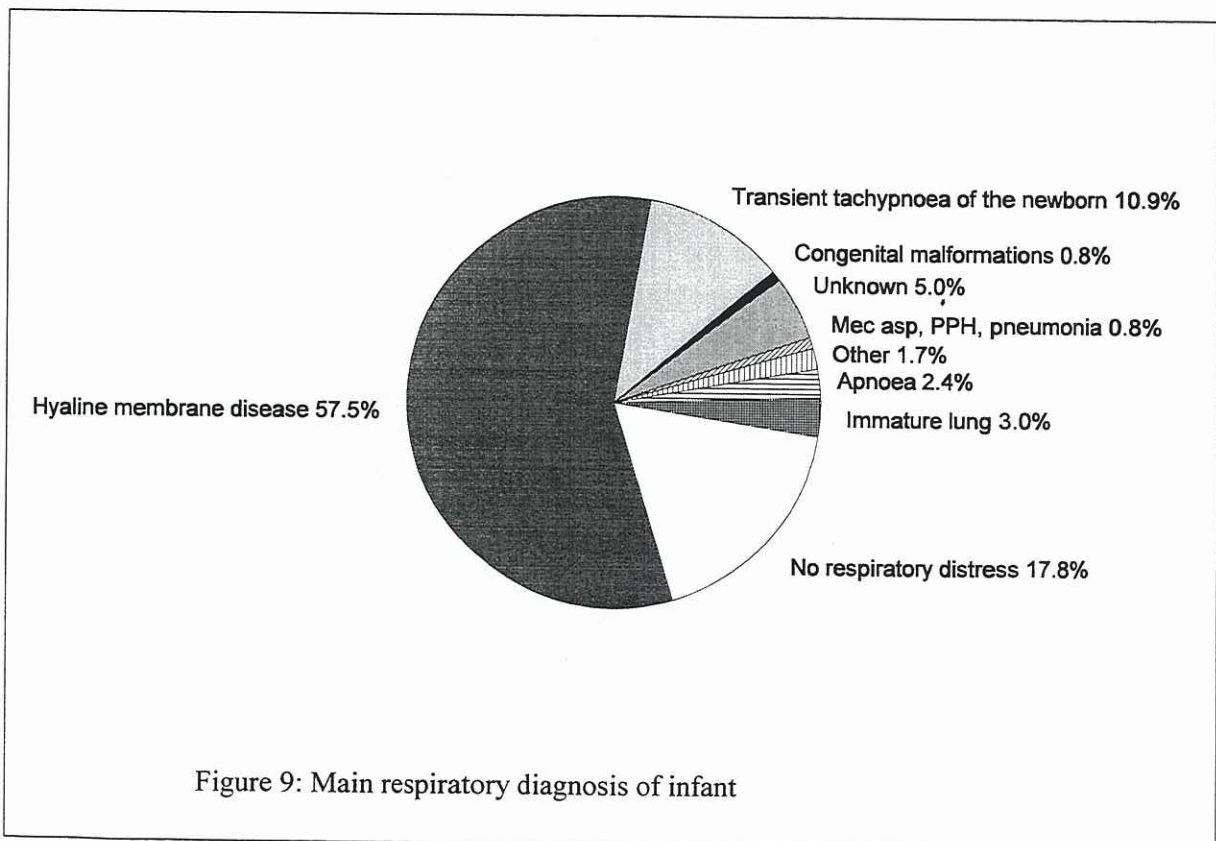
## 4.6.2 Cerebral ultrasound

It is usual to image the head of very preterm infants to observe for both intraventricular haemorrhage (IVH), and the formation of cysts and ventricular dilatation (hydrocephalus). The first ultrasound is generally done during the first week of life to detect signs of IVH, and grades III and IV are of concern as they are markers of cerebral damage (Tables 18, 19). The majority of infants (68.0%) did not have any such haemorrhage. However, 157 (6.4%) of the infants examined did have significant haemorrhage. Sixty nine infants died before having an ultrasound and 149 (6.1%) survived but did not have an ultrasound.

A later ultrasound is done at 4 to 6 weeks of age to detect cystic lesions and ventricular distension. The timing of the collection of these data were not always recorded. However, the results of later ultrasound examinations were available for 70.4% of the infants. No abnormality on ultrasound were noted for 91.0% of these infants. Hydrocephalus was an uncommon event (2.7%), porencephalic cysts were noted in 2.2% and periventricular leukomalacia was seen in 3.0% of infants.

## 4.6.3 Respiratory distress

Respiratory distress is a major cause of morbidity in these infants, and only 17.8% had *no respiratory distress* as their main diagnosis (Figure 9). More than half (57.5%) of the infants had *hyaline membrane disease* (respiratory distress syndrome). Data were not available for 55 (2.0%) infants. The respiratory support provided for these very preterm infants takes many forms. There are two major categories of assisted ventilation, intermittent positive pressure respiration (IPPR) and continuous positive airways pressure (CPAP). Both require specialised nursing, medical and paramedical care and utilise a large amount of resources. The duration of these treatments increases, on average, with decreasing gestational age (Table 15). Supplemental oxygen requirements also increase with gestational age (Table 15). In fact, in this group, 112 infants were known to be treated with supplemental oxygen after they were discharged from hospital. Exogenous surfactant was introduced in Australia and New Zealand in 1991 as a treatment primarily for hyaline membrane disease. In 1994, the 2 types in use were *Exosurf* and *Survanta*, and they were given to 1,023 (41.4%) of the 90.8% of infants where this information was available (Tables 16, 17). In addition, 157 (6.4%) infants had a pulmonary airleak that required drainage (data were not available for 9.3% infants).



## 4.6.4 Eyes

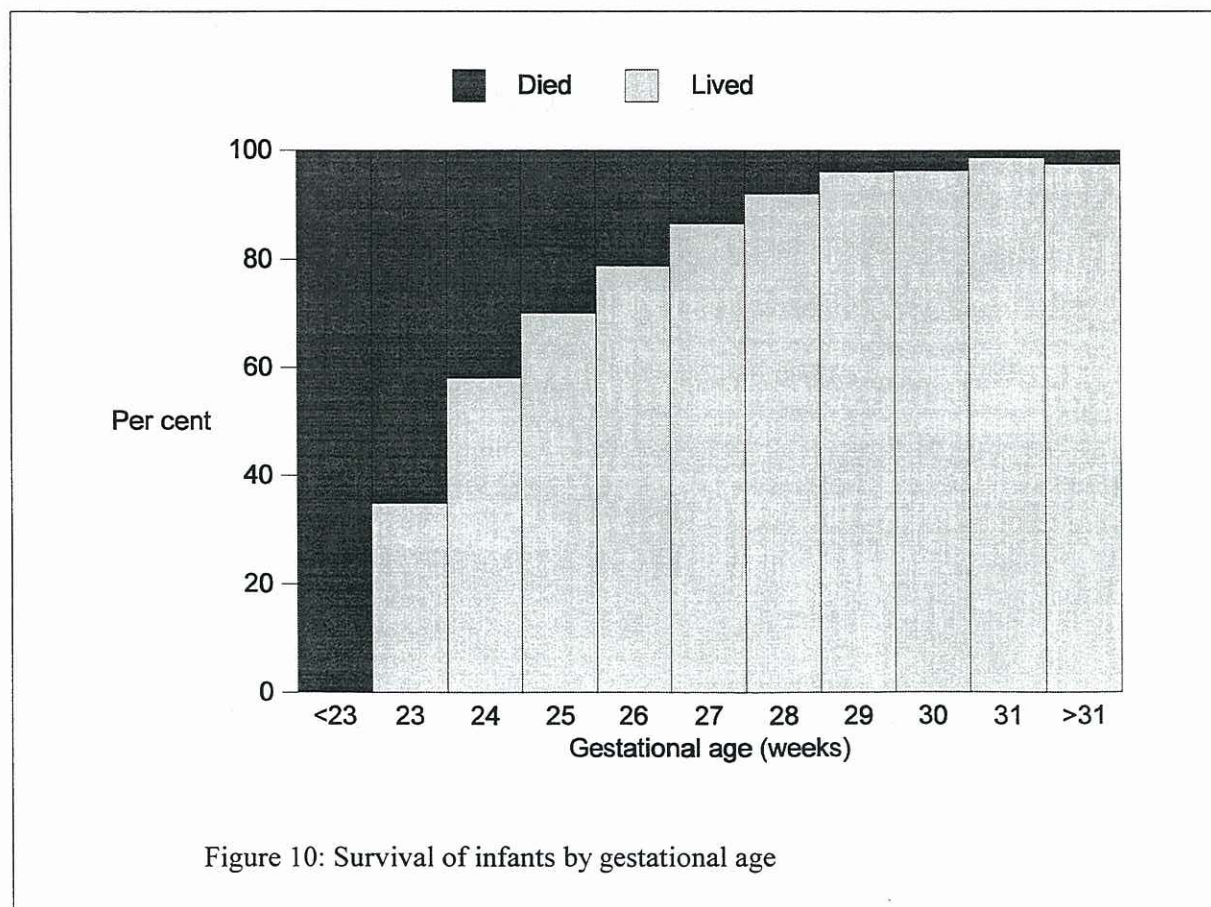
Eye examinations are carried out during the infant's hospitalisation to monitor the vascularisation of the eye. When this is disrupted, retinopathy of prematurity (ROP) can result. If ROP reaches Stages III or IV, therapy with a laser or cryotherapy may be necessary. There is a recommendation that eye examinations be carried out at 4 to 6 weeks of age and then fortnightly until eyes have matured (Health Care Committee Expert Panel on Perinatal Morbidity, 1995). For the 1,823 infants who were still in their registration hospital at 4 weeks of age, 36.7% were known to have no ROP. Data were not available for 508 (27.9%) infants. Seventy (3.8%) infants had significant eye disease and 26 of these infants received therapy for this.

## 4.7 Outcome

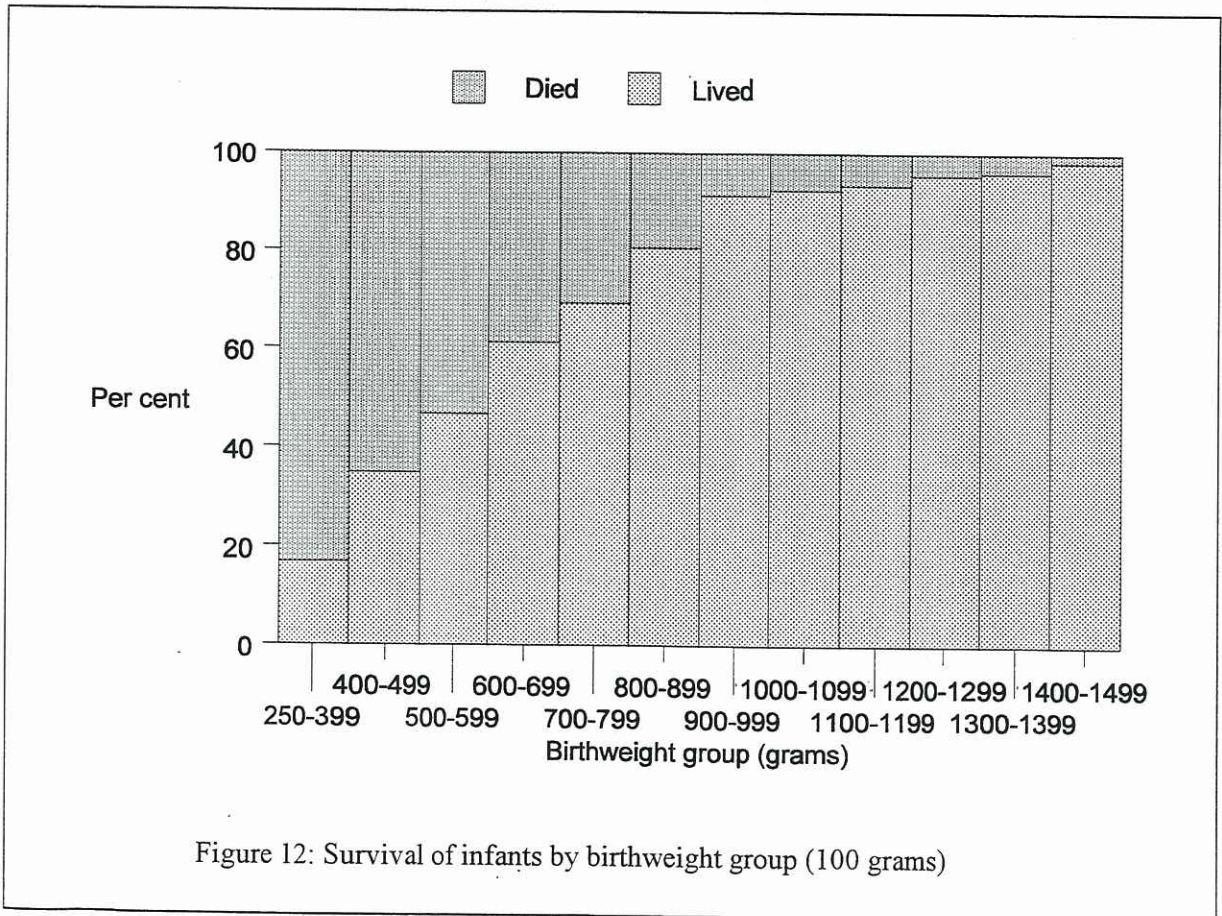
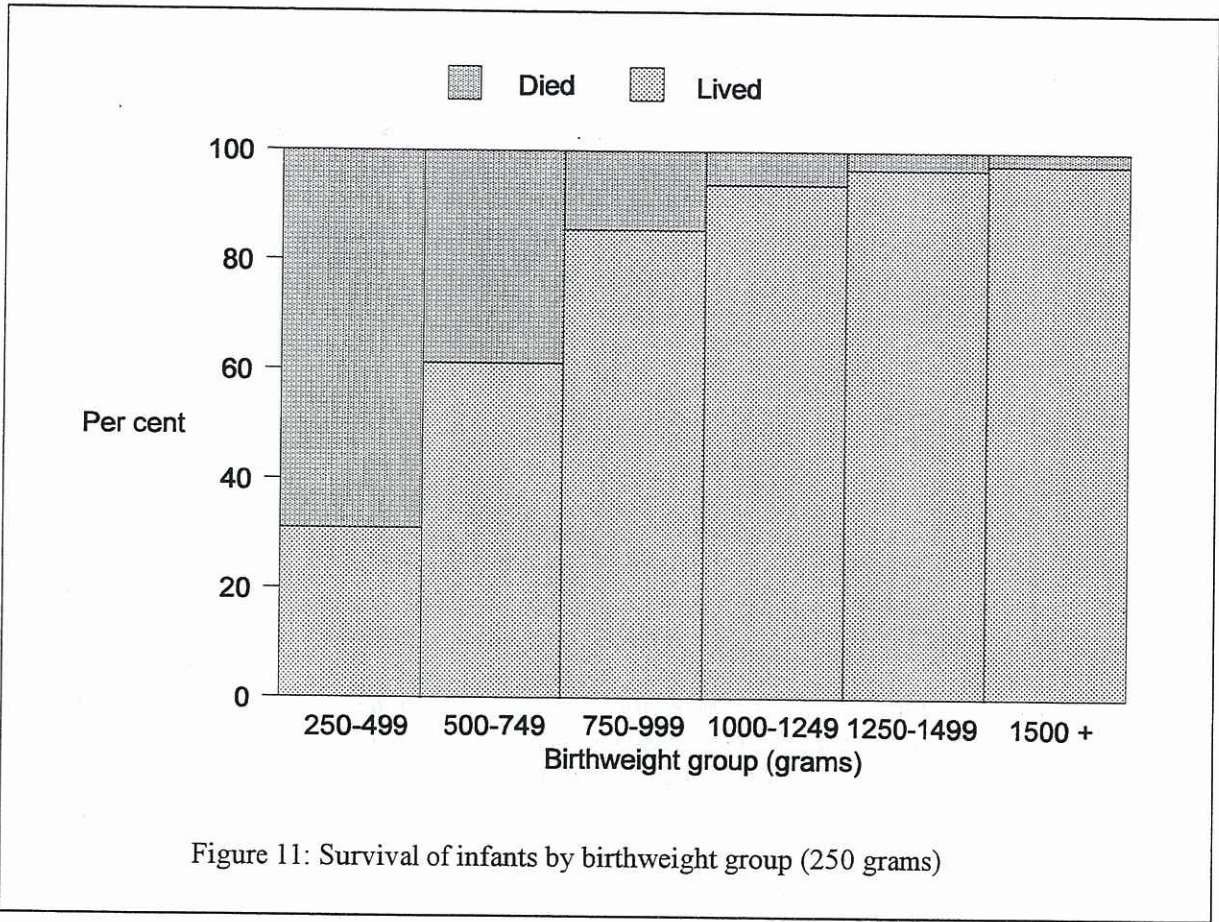
### 4.7.1 Survival

The majority of these infants (89.8%) survived to go home. The survival of infants is dependent on many factors. For those infants who did not have known congenital malformations contributing to their death (*lethal congenital malformations*), gestational age at birth and birthweight are important. For this reason, data are generally presented for infants without lethal congenital malformations by both gestation and birthweight criteria (Figures 10, 11 and 12). Data in these three figures are presented as survival to discharge home for infants without lethal congenital malformations. Birthweight data were divided into 250 gram and 100 gram groups as either of these groupings may be used in statistical or clinical analysis. To give a full picture of survival in these infants, data are provided as survival to 7 days, to 28 days (neonatal death) and to discharge to home (Tables 20, 21 and 22). The interrelationship of both gestation and size at birth are also clinically relevant in the management of these infants (Table 23).

*The data in this report are different to that usually reported for State or national populations as it represents only those infants admitted to a nursery in a hospital with a Neonatal Intensive Care Unit. The data do not include infants who were stillborn or who died in labour ward.*



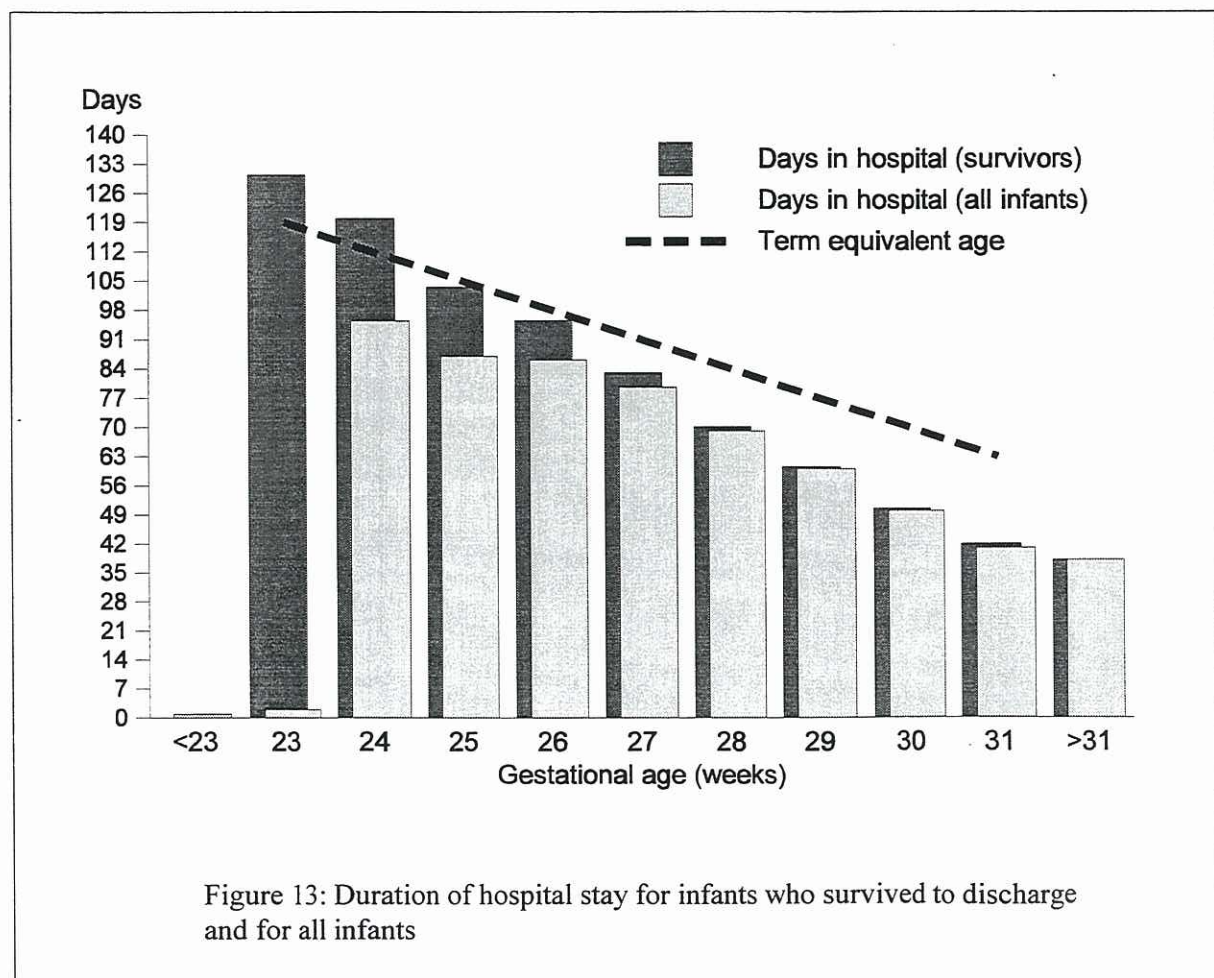




## 4.7.2 Discharge from hospital

After their care in a hospital with a specialist neonatal unit, nearly half of the infants (45.6% of surviving infants) were transferred to other hospitals with less intensive nurseries (*Level 1* or *Level 2*) prior to their discharge to home (Tables 24, 25). Some infants (6.8%) required admission to other NICUs either for surgery, or because that NICU was closer to home or, occasionally, because the neonatal unit of their birth did not have an intensive care bed available. The other half of these very preterm infants (47.7%) went directly home from the NICU.

The duration of stay in the hospital of registration is related to maturity at birth, to survival and to whether or not the infant is transferred prior to discharge (Table 26). Total duration of stay in any hospital is also related to maturity at birth and survival (Figure 13). Infants who survive are usually discharged home around their due date (term equivalent age, see Figure 13, dashed line). This is a usually a couple of weeks after the baby was due for the extremely preterm infant, and a week or so after term equivalent age for those born at 25 to 26 weeks. Infants born after 27 weeks' gestation are, on the average, discharged before they were due. The average length of stay in hospital is quite different when all infants, both those who survive and those who do not, are considered (Figure 13, median duration of stay shown in days).



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# Tables

**Table 1: Number of infants in each gestational age group, 1994**

	<23	23	24	25	26	27	28	29	30	31	>31	Total
Number	8	43	101	159	206	262	313	359	488	508	276	2,723

Note: Data are for all liveborn infants admitted to one of the twenty-two contributing NICUs.

**Table 2: Number of infants in each birthweight group, 1994**

	250-399	400-499	500-599	600-699	700-799	800-899	900-999	1000-1099	1100-1199	1200-1299	1300-1399	1400-1499	1500+	Total
Number	6	23	60	126	182	190	199	242	280	256	311	290	558	2,723

	250-499	500-749	750-999	1000-1249	1250-1499	1500	Total
Number	29	275	482	660	719	558	2,723

Note: Data are for all liveborn infants admitted to one of the twenty-two contributing NICUs.

**Table 3: Number of intensive care cots for newborn infants and the total number of beds in each contributing NICU during 1994**

	Individual NICUs																		Total				
No. of ventilator beds	3	4	4	4	6	6	6	6	6	7	7	8	8	10	11	11	12	12	12	12	14	18	187
Total number of beds	13	18	18	22	20	20	26	28	28	14	30	29	32	54	26	44	41	58	60	60	52	60	753

Note:

1. In some hospitals, there are beds for neonates that do not fall under the auspices of the NICU.

**Table 4: Maternal ethnicity, 1994**

	Unknown	Aboriginal	Asian	Caucasian	Other
New Zealand data(a)	-	not available	not available	80.3%	19.7%
Australian data (b)	-	2.9%	6.3%	89.3%	1.5%
ANZNN population (c)	10.9%	3.9%	4.2%	76.2%	4.8%

*Note:*

- (a) Statistics New Zealand, 1995. Data are for all live births, 'other' is made up of 12.3% Maori and 7.4% Pacific Island Polynesian.
- (b) Australia's Mother's & Babies, 1995. Data are for infants born in 1992. Mother's country of birth only is given, and thus this will underestimate the numbers of those of 'Asian' and 'other' ethnic backgrounds.
- (c) Percentages given as proportion of known data, ie not available excluded.

**Table 5: Source of referral to the hospital of registration by gestational age, 1994**

	<23	23	24	25	26	27	28	29	30	31	>31	Total
Inborn	8	35	91	143	189	241	281	326	442	458	263	2,477
Outborn	-	8	10	16	17(2)	21(1)	32(5)	33(2)	46(8)	50(5)	13(6)	246(29)
<b>Total</b>	<b>8</b>	<b>43</b>	<b>101</b>	<b>159</b>	<b>206</b>	<b>262</b>	<b>313</b>	<b>359</b>	<b>488</b>	<b>508</b>	<b>276</b>	<b>2,723</b>

*Note:* Infants admitted to children's hospitals are shown in brackets.

**Table 6: Source of referral to the hospital of registration by birthweight group, 1994**

	250 - 499	500 - 749	750 - 999	1000-1249	1250-1499	1500+	Total
Inborn	26	252	441	602	643	513	2,477
Outborn	3	23(2)	41(1)	58(6)	76(12)	45(8)	246(29)
<b>Total</b>	<b>29</b>	<b>275</b>	<b>482</b>	<b>660</b>	<b>719</b>	<b>558</b>	<b>2,723</b>

*Note:* Infants admitted to children's hospitals are shown in brackets.

**Table 7: Antenatal corticosteroid use by gestational age, all infants, 1994**

	<23	23	24	25	26	27	28	29	30	31	>31	Total
Unknown	-	4	7	12	7	17	7	15	14	30	9	122
Data not available	8	11	20	31	37	27	56	54	88	99	57	488
None	-	12	26	35	54	57	84	90	147	132	96	733
Given	-	16	48	81	108	161	166	200	239	247	114	1,380
<b>Total</b>	<b>8</b>	<b>43</b>	<b>101</b>	<b>159</b>	<b>206</b>	<b>262</b>	<b>313</b>	<b>359</b>	<b>488</b>	<b>508</b>	<b>276</b>	<b>2,723</b>

**Table 8: Antenatal corticosteroid use by birthweight group, all infants, 1994**

	250 - 499	500 - 749	750 - 999	1000-1249	1250-1499	1500+	Total
Unknown	2	17	23	21	28	31	122
Data not available	12	55	81	106	130	104	488
None	7	64	124	180	213	145	733
Given	8	139	254	353	348	278	1,380
<b>Total</b>	<b>29</b>	<b>275</b>	<b>482</b>	<b>660</b>	<b>719</b>	<b>558</b>	<b>2,723</b>

**Table 9 : Plurality by gestational age, 1994**

	<23	23	24	25	26	27	28	29	30	31	>31	Total
Quadruplets	-	-	-	-	-	-	-	-	4	-	-	4
Triplets	-	-	3	2	15	2	6	9	24	16	12	89
Twins	4	9	32	36	39	72	75	76	101	126	66	636
Singleton	4	34	66	121	152	188	232	274	359	366	198	1,994
<b>Total</b>	<b>8</b>	<b>43</b>	<b>101</b>	<b>159</b>	<b>206</b>	<b>262</b>	<b>313</b>	<b>359</b>	<b>488</b>	<b>508</b>	<b>276</b>	<b>2,723</b>

**Table 10: Plurality by birthweight group, 1994**

	250 - 499	500 - 749	750 - 999	1000-1249	1250-1499	1500+	Total
Quadruplets	-	-	-	1	3	-	4
Triplets	-	13	16	21	29	10	89
Twins	12	70	100	170	165	119	636
Singleton	17	192	366	468	522	429	1,994
<b>Total</b>	<b>29</b>	<b>275</b>	<b>482</b>	<b>660</b>	<b>719</b>	<b>558</b>	<b>2,723</b>

**Table 11: Mode of birth by gestational age, 1994**

	<23	23	24	25	26	27	28	29	30	31	>31	Total
Unknown	-	-	-	-	-	2	1	-	-	-	-	3
Data not available	2	3	11	24	20	18	36	34	40	73	35	296
Vaginal	6	35	74	92	100	91	111	148	183	175	51	1,066
Caesarean	-	5	16	43	86	151	165	177	265	260	190	1,358
<b>Total</b>	<b>8</b>	<b>43</b>	<b>101</b>	<b>159</b>	<b>206</b>	<b>262</b>	<b>313</b>	<b>359</b>	<b>488</b>	<b>508</b>	<b>276</b>	<b>2,723</b>

**Table 12: Mode of birth by birthweight group, 1994**

	250 - 499	500 - 749	750 - 999	1000-1249	1250-1499	1500+	Total
Unknown	-	-	1	-	2	-	3
Data not available	7	31	50	60	77	71	296
Vaginal	12	141	195	214	260	244	1,066
Caesarean	10	103	236	386	380	243	1,358
<b>Total</b>	<b>29</b>	<b>275</b>	<b>482</b>	<b>660</b>	<b>719</b>	<b>558</b>	<b>2,723</b>

**Table 13: Presentation at birth by gestational age, 1994**

	<23	23	24	25	26	27	28	29	30	31	>31	Total
Unknown	5	10	12	14	20	19	23	40	41	38	35	257
Data not available	2	3	12	26	21	26	39	42	45	77	36	329
Vertex	-	21	44	70	102	140	162	193	294	275	133	1,434
Breech	1	8	28	42	51	64	78	68	90	100	65	595
Other	-	1	5	7	12	13	11	16	18	18	7	108
<b>Total</b>	<b>8</b>	<b>43</b>	<b>101</b>	<b>159</b>	<b>206</b>	<b>262</b>	<b>313</b>	<b>359</b>	<b>488</b>	<b>508</b>	<b>276</b>	<b>2,723</b>

**Table 14: Presentation at birth by birthweight group, 1994**

	250 - 499	500 - 749	750 - 999	1000-1249	1250-1499	1500+	Total
Unknown	4	35	44	59	72	43	257
Data not available	7	34	59	68	85	76	329
Vertex	9	121	249	347	393	315	1,434
Breech	7	77	107	157	146	101	595
Other	2	8	23	29	23	23	108
<b>Total</b>	<b>29</b>	<b>275</b>	<b>482</b>	<b>660</b>	<b>719</b>	<b>558</b>	<b>2,723</b>

**Table 15: Assistance with breathing: median duration (and interquartile range) of assisted ventilation and supplemental oxygen by gestational age, 1994**

		<23	23	24	25	26	27	28	29	30	31	>31
IPPR	median	1	3	27	23	15	8	5	3	3	3	2
	range (2)	1-1	1-46	4-45	4-35	5-29	3-20	2-9	1-6	2-5	1-4	1-4
	n	5	41	93	149	189	227	268	269	270	221	64
	no therapy	3	2	6	6	13	24	37	90	212	285	211
CPAP	median	-	16	20	16	15	9	7	4	2	2	2
	range (2)	-	6.5-30	7-30	6-29	2-25	4-20	2-19	1-10	1-5	1-4	1-4
	n	-	11	37	77	115	141	167	156	164	153	35
	no therapy	8	31	66	62	70	83	109	159	285	341	227
Supplemental oxygen	median	1.5	2	52	54	48.5	40	14	4	4	2	1
	range (2)	1-2	1-76	3-91	4-97	8-79	8-67	3-39	1-28	1-11	1-7	1-3
	n	6	41	89	143	186	227	272	306	373	340	148
	no therapy	-	-	-	-	1	1	3	12	54	81	84

*Note:*

1. Duration is in days
2. Range is interquartile range (25%th-75%th percentile)
3. Infants may have received IPPR and / or CPAP and / or supplemental oxygen therapy
4. Data not available for some items for some infants

**Table 16: Surfactant usage by gestational age, 1994**

	<23	23	24	25	26	27	28	29	30	31	>31	Total
Unknown	1	6	2	7	8	12	16	11	17	7	1	88
Data not available	-	6	8	20	21	29	29	25	46	49	17	250
None	3	5	24	37	49	73	115	180	277	358	241	1,362
<i>Exosurf</i>	-	8	36	60	78	96	105	96	91	70	15	655
<i>Survanta</i>	3	17	30	31	46	49	46	44	48	24	2	340
other	1	1	1	4	4	3	2	3	9	-	-	28
<b>Total</b>	<b>8</b>	<b>43</b>	<b>101</b>	<b>159</b>	<b>206</b>	<b>262</b>	<b>313</b>	<b>359</b>	<b>488</b>	<b>508</b>	<b>276</b>	<b>2,723</b>

**Table 17: Surfactant usage by birthweight group, 1994**

	250-499	500-749	750-999	1000-1249	1250-1499	1500+	Total
Unknown	2	15	21	19	19	12	88
Data not available	2	27	41	68	65	47	250
None	7	60	151	324	459	361	1,362
<i>Exosurf</i>	11	93	165	171	115	100	655
<i>Survanta</i>	7	77	96	70	55	35	340
other	-	3	8	8	6	3	28
<b>Total</b>	<b>29</b>	<b>275</b>	<b>482</b>	<b>660</b>	<b>719</b>	<b>558</b>	<b>2,723</b>



**Table 18: Presence of intraventricular haemorrhage by gestational age, 1994**

	<23	23	24	25	26	27	28	29	30	31	>31	Total
Data not available	1	3	5	14	15	19	24	27	45	70	36	259
Infant not examined	1	7	14	15	12	8	9	15	38	71	29	219
None	5	14	36	76	107	158	203	245	327	309	195	1,675
Grade 1	-	5	17	16	20	32	44	46	43	46	12	281
Grade 2	-	3	15	13	21	23	16	14	19	5	3	132
Grade 3	-	6	6	16	15	10	7	4	10	6	1	81
Grade 4	1	5	8	9	16	12	10	8	6	1	-	76
<b>Total</b>	<b>8</b>	<b>43</b>	<b>101</b>	<b>159</b>	<b>206</b>	<b>262</b>	<b>313</b>	<b>359</b>	<b>488</b>	<b>508</b>	<b>276</b>	<b>2,723</b>

**Table 19: Presence of intraventricular haemorrhage by birthweight group, 1994**

	250 - 499	500 - 749	750 - 999	1000-1249	1250-1499	1500+	Total
Data not available	1	22	35	56	74	71	259
Infant not examined	3	25	27	24	42	98	219
None	12	133	273	435	496	326	1,675
Grade 1	9	35	56	76	62	43	281
Grade 2	2	23	39	33	20	15	132
Grade 3	2	20	23	19	14	3	81
Grade 4	-	17	29	17	11	2	76
<b>Total</b>	<b>29</b>	<b>275</b>	<b>482</b>	<b>660</b>	<b>719</b>	<b>558</b>	<b>2,723</b>

**Table 20: Survival of infants without lethal congenital malformations by gestational age, 1994**

	<23	23	24	25	26	27	28	29	30	31	>31	Total
<i>Total admitted</i>	8	43	101	159	206	262	313	359	488	508	276	2,723
No. with lethal cong malf.	-	-	1	2	3	1	1	9	2	8	4	31
No. alive at 7 days(a)	-	21	72	121	179	242	294	341	477	497	269	2,513
No. alive at 28 days(a)	-	19	63	114	167	233	292	339	470	494	265	2,455
No. discharged to home (a)	-	15	58	110	160	226	287	336	468	493	265	2,418
<b>% survival to discharge (a)</b>	-	<b>34.9</b>	<b>58.0</b>	<b>70.1</b>	<b>78.8</b>	<b>86.6</b>	<b>92.0</b>	<b>96.0</b>	<b>96.3</b>	<b>98.6</b>	<b>97.4</b>	<b>89.8</b>

(a) No lethal congenital malformation

**Table 21: Survival of infants by birthweight group (250 grams), 1994**

	250 - 499	500 - 749	750 - 999	1000-1249	1250-1499	1500+	Total
<i>Total admitted</i>	29	275	482	660	719	558	2,724
No. with lethal cong malf.	-	3	8	5	5	10	31
No. alive at 7 days(a)	13	197	430	628	704	537	2,513
No. alive at 28 days(a)	10	180	411	623	694	532	2,455
No. discharged to home(a)	9	166	405	614	690	534	2,418
<b>% survival to discharge (a)</b>	<b>31.0</b>	<b>61.0</b>	<b>85.4</b>	<b>93.7</b>	<b>96.5</b>	<b>97.5</b>	<b>89.8</b>

(a) No lethal congenital malformation

**Table 22: Survival of infants by birthweight group (100 grams), 1994**

	250 -399	400 -499	500 -599	600 -699	700 -799	800 -899	900 -999	1000 -1099	1100 -1199	1200 -1299	1300 -1399	1400 -1499	1500 +	Total
<i>Total admitted</i>	6	23	60	126	182	190	199	242	280	256	311	291	558	2,724
No. with lethal cong malf.	-	-	-	2	3	4	2	2	1	5	1	1	10	31
No. alive at 7 days(a)	1	13	33	93	152	163	187	229	266	243	308	287	537	2,513
No. alive at 28 days(a)	1	11	29	87	142	152	182	227	263	241	302	285	532	2,455
No. discharged to home(a)	1	8	28	76	138	150	180	222	261	240	298	285	534	2,418
<b>% survival to discharge (a)</b>	<b>16.7</b>	<b>34.8</b>	<b>46.7</b>	<b>61.3</b>	<b>77.1</b>	<b>80.6</b>	<b>91.4</b>	<b>92.5</b>	<b>93.6</b>	<b>95.6</b>	<b>96.1</b>	<b>98.3</b>	<b>97.4</b>	<b>89.8</b>

(a) No lethal congenital malformation

**Table 23: Survival to discharge for infants without lethal congenital malformations by gestational age and birthweight groups, 1994**

	<23	23	24	25	26	27	28	29	30	31	>32	Total
250-499 gm	- 4	1 6	1 6	1 4	3 3	- 2	1 2	-	2 2	-	-	9 29
500-749 gm	- 4	12 33	44 77	40 66	19 30	20 26	13 17	9 9	4 5	2 2	3 3	166 272
750-999 gm	-	2 4	13 17	66 82	103 129	87 99	62 67	36 36	14 16	14 15	8 9	405 474
1000-1249 gm	-	-	-	3 5	34 40	101 113	136 145	116 122	104 110	53 53	67 67	614 655
1250-1499 gm	-	-	-	-	1 1	18 21	69 75	131 136 9	165 167	128 130	178 184	90 714
1500 + gm	-	-	-	-	-	-	6 6	44 47	179 186	296 300	9 9	534 548
Total	- 8	15 43	58 100	110 157	160 203	226 261	287 312	336 350	468 486	493 500	265 272	2,418 2,692

*Note:*

1. Presented as alive at discharge / total number of infants
2. No lethal congenital malformations

**Table 24: Mode of separation by gestational age, 1994**

	<23	23	24	25	26	27	28	29	30	31	>31	Total
Died	8	28	43	49	46	35	25	22	20	15	11	302
Transferred to other hospital	-	3	21	45	55	95	119	134	238	269	124	1,103
Transferred to NICU hospital	-	3	5	13	23	13	25	32	19	18	13	164
Discharged home	-	9	32	52	82	119	144	171	211	206	128	1,154
<b>Total</b>	<b>8</b>	<b>43</b>	<b>101</b>	<b>159</b>	<b>206</b>	<b>262</b>	<b>313</b>	<b>359</b>	<b>488</b>	<b>508</b>	<b>276</b>	<b>2,723</b>

**Table 25: Mode of separation by birthweight group, 1994**

	250-499	500 - 749	750 - 999	1000-1249	1250-1499	1500+	Total
Died	20	109	76	44	29	24	302
Transferred to other hospital	2	57	144	276	355	269	1,103
Transferred to NICU hospital	-	19	45	43	33	24	164
Discharged home	7	90	217	297	302	241	1,154
<b>Total</b>	<b>29</b>	<b>275</b>	<b>482</b>	<b>660</b>	<b>719</b>	<b>558</b>	<b>2,723</b>

**Table 26: Stay in registration hospital. Median duration (and interquartile range) by gestational age, 1994**

		<23	23	24	25	26	27	28	29	30	31	>31
Died	median	1	1	3	1	3.5	5	4	1	4	5.5	15
	range (1)	0-1	0-2	1-9	0-4	1-11.5	2-17	2-6.5	0-3	1-12	1-10	4-21
	n	8	26	41	46	44	32	24	22	17	12	9
Transferred (2)	median		89	96	73	64	54.5	45.5	28	24	16	19
	range (1)	-	46-124	49-115	57-98	43-86	41-71.5	30-61	17-43	13-36	9-27	11-26
	n		8	28	61	80	112	142	166	259	288	138
Discharged to home	median		125	115	106	93	82.5	69	61	50	42	37.5
	range (1)	-	105-135	100-122.5	91-129	82-109	71-96	60-83	53-70.5	40-58	35-50	29-44
	n		9	30	52	81	118	143	171	211	206	128
Data not available		-	-	2	-	1	-	4	-	1	2	1

Note:

1. Range is interquartile range (25th-75th percentiles)
2. Infants who died after transfer are included in *transferred* only.

# Appendix 1 Definitions of data items in 1994

## 1.1 Definition format

Definitions at the time of the 1994 data collection are in the following format:

**Label on form**<sup>1, 2 or 3</sup>: Definition of the item. Only data that comply with this definition should be used. If in doubt, either use unknown, fully describe the infant's condition on the form or in an accompanying letter, or contact the data base manager.

**Options offered** - definition of the option. Only one option to be chosen.

(*Definition sources* 1 Definitions as proposed for, or part of National Health Data Dictionary (NHDD), or  
2 Definition as for International Neonatal Network  
3 Definition as for NSW Neonatal Intensive Care Audit

## 1.2 Terms used

**Live born**<sup>1(Item NB-3), 3</sup>: Live birth is the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which, after such separation, breaths or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached; each product of such a birth is considered live born. Stillbirth is a fetal death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400g or more birth weight; the death is indicated by the fact that after such separation, the foetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles. (This is the same as the WHO definition of fetal death, except that there are no limits of gestational age or birth weight for the WHO definition).

**Registration hospital**<sup>3</sup>: Hospital of registration is the first Neonatal Intensive Care Unit (NICU) that the infant remains in for longer than four hours. If the infant is transferred, for the purpose of this study, she / he is considered to be in the next hospital from the time the transport team arrives to collect her / him. If the infant dies within four hours, she/he is registered to the unit where she/he dies. Information is coded.

## 1.3 Minimum dataset variables

### 1.3.1 Mother

**Maternal name**<sup>3</sup>: Mother's surname as registered in the hospital of birth of the infant. This information is valuable for tracing information on the child. All possible aliases should be kept, as it is possible for the mother to change surname between the birth and registration hospital. This data is not transferred to the central data base.

**Maternal hospital record number**<sup>1(Item P2), 3</sup>: Maternal hospital identification number at the hospital of the infant's birth. If the mother is not admitted to any hospital (say in case of home birth), or you do not wish to supply the hospital identification number, use some other code number allocated exclusively to this mother.

**Age**<sup>1(Item MP7), 3</sup>: Mother's age on the date of her newborn baby's birth (in completed years).

**Previous preterm birth**<sup>3(derived)</sup>: Has this mother ever had a previous birth that was at less than 37 completed weeks' gestation and more than 20 completed weeks?

**Previous perinatal death**<sup>3(derived)</sup>: Has this mother ever had a previous perinatal loss ie an infant with a birth weight of more than 400 grams or a gestational age of > 20 completed weeks, who died during the first 28 days of life?

**Assisted conception**<sup>3</sup>: Infertility treatment used to conceive this pregnancy? Disregard any treatment for a previous pregnancy.

*Unknown* - information not available

*None* - no infertility treatment used for this pregnancy.

*Hyperovulation* - any hormone therapy used to assist conception.

*IVF / GIFT etc* - any method of in-vitro fertilisation, includes in-vitro fertilisation, gamete intrafallopian transfer, zygote intrafallopian transfer, etc.

*Other* - other infertility treatment not mentioned above, including artificial insemination.

**Ethnicity**<sup>2(derived), 3(except polynesian)</sup>: Ethnic origin of the mother of child. Use ethnicity that mother calls herself

*Unknown* - information not available.

*Aboriginal or Torres Strait Islander*<sup>1(Item MP11/P7)</sup> - a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community with which she is associated. (ie Aboriginality is determined by patient self-identification).

*Asian* - includes all whose ethnic background originates from the countries of Asia, South East Asia and Indian subcontinent; includes say, Fijian Indian.

*Caucasian* - includes all of Caucasoid heritage, including European, Russian, Middle Eastern and Arabic.

*Other* - includes African Negroes, American Blacks and Indians, Inuit and Melanesian. There is a separate category for Polynesian.

*Polynesian* - includes all of Polynesian background, including Maori.

### 1.3.2 Antenatal

**Source of referral**<sup>3(derived)</sup>: Source of referral to the NICU where the infant is registered. Use most recent referral if more than one.

*Unknown* - information not available

*Booked at tertiary obstetric hospital* - Mother booked into a tertiary obstetric hospital (ie has a NICU) and not transferred during the most recent admission.

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

*Ex-utero retrieval* - Infant retrieved from any other hospital by specialist neonatal transport retrieval team.

*Ex-utero transfer* - Infant transferred from any other hospital, but not by a specialist neonatal retrieval team. This includes transport by ambulance.

*Other* - includes born in transit, not booked and not transferred.

**Presenting antenatal problem**<sup>3</sup>: The presenting problem is the antenatal complication that the mother presented with in this pregnancy that started the train of events that lead to the infant's birth. If not an obstetric problem, eg motor vehicle accident, use other.

*Unknown* - presenting problem unknown.

*PPROM* - Preterm pre-labour rupture of membranes - confirmed rupture of membranes prior to the onset of labour, and before 37 completed week's gestation. Any duration of membrane rupture.

*PTL* - Preterm labour - regular painful contractions with progressive cervical dilatation commencing before 37 completed week's gestation.

*PIH* - Pregnancy induced hypertension - elevation of maternal blood pressure to 140 mmHg systolic or 85 mmHg diastolic on two readings at least four hours apart, or an elevation in systolic of 30 mmHg or diastolic of 15 mmHg from blood pressure in the first trimester.

*APH* - Antepartum Haemorrhage - significant haemorrhage in the time from 20 weeks gestation to the end of the second stage of labour. Excludes a 'show'.

*IUGR* - suspected intra-uterine growth restriction, - confirmed by more than one obstetric ultrasound.

*Fetal distress* - any fetal distress leading to intervention by obstetric team.

*Other* - other problem not specified elsewhere.

*None* - No presenting problem, the infant must be born after 36 weeks gestation.

**Other complications**<sup>1(Item ME), 3:</sup> Any other antenatal complications present, in addition to that listed in presenting antenatal problem.

**PROM**<sup>3:</sup> Prolonged rupture of membranes - confirmed spontaneous membrane rupture for more than 24 hours before birth.

**PTL**<sup>3:</sup> Preterm Labour - Regular painful contractions with progressive cervical dilatation commencing before 37 completed weeks' gestation.

**PIH**<sup>3:</sup> Pregnancy induced hypertension - elevation of maternal blood pressure to 140 mmHg systolic or 85 mmHg diastolic on two readings at least four hours apart, or an elevation in systolic of 30 mmHg or diastolic of 15 mmHg from blood pressure in first trimester.

**APH**<sup>3:</sup> Antepartum Haemorrhage - significant haemorrhage in the time from 20 weeks gestation to the end of second stage of labour. This excludes a 'show'.

**IUGR**<sup>3:</sup> Suspected intra-uterine growth restriction of this foetus - confirmed by more than one obstetric ultrasound.

**Fetal distress**<sup>3:</sup> Fetal distress - any fetal distress of any foetus that lead to intervention by obstetric team.

**Other**<sup>3:</sup> Other significant antenatal complication, not specified.

**Corticosteroids (for lungs)**<sup>2(partial) 3:</sup> Corticosteroids given antenatally via any route to the mother to enhance fetal lung maturation. Excludes steroids given for other reasons. If the information of the time of doses given is not available, but two doses are known to have been given appropriately, then use 'complete'.

*Unknown* - information not available.

*None* - corticosteroids not ever given during this pregnancy to enhance fetal lung maturation.

*< 24 hrs* - first dose given < 24 hours prior to this infant's birth.

*Complete* - all doses of corticosteroids given according to local hospital protocol. Also, both doses of corticosteroids have been given for > 24 hours and < eight days before infant's birth. If two courses given, and one is "complete", use this option. If the information of the time of doses given is not available, but two doses are known to have been given appropriately, then use 'complete'.

*> 7 days* - steroids given more than seven days before infant's birth. If two courses given, and one is "complete", use complete.

**TRH**<sup>3:</sup> Was Thyrotrophic Releasing Hormone administered to the mother during the pregnancy?

**Plurality**<sup>1 (Item MP27), 3:</sup> Number of births resulting from this pregnancy. (The plurality of a pregnancy is determined by the number of foetuses that remain in utero at 20 weeks' gestation and that are subsequently delivered as separate births. This definition of plurality excludes foetuses aborted before completed 20 weeks or foetuses compressed in the placenta at 20 or more weeks (foetus papyraceous). If gestation is unknown, only foetuses weighing 400 grams or more are taken into account in determining plurality.)

*Singleton* - only one baby born.

*Twins* -

*Triplets* -

*Quads* -

*More !* - Quintuplets, sextuplets etc.

**Birth order**<sup>1 (Item NB-2, coding different), 3:</sup> Order in which this newborn baby was born. (If singleton, then the birth order is 0. If the first born of a multiple pregnancy, then the birth order is 1. If the 2nd born, then the order is 2, etc. If the plurality (see above) is greater than one, then give the order of birth of this infant, even if other infants of this pregnancy do not qualify for registration.)

### 1.3.3 Baby

**NICU Hosp no.<sup>3</sup>:** Hospital identification number of this baby at the hospital of registration for ANZNN data collection.

**DOB<sup>1</sup>(Item NB-1/P5), 2, 3:** Newborn baby's date of birth. (dd/mm/yy).

**DOA<sup>1</sup>(Item P24), 2(derived), 3:** Date of first admission of this infant to the hospital of registration for ANZNN data collection.

**Sex<sup>1</sup>(Item NB-4/P4), 3:** Sex of the newborn baby at birth.

*Unknown* - information not available

*Male* -

*Female* -

*Ambiguous* - or indeterminate no chromosome tests available, and ambiguous genitalia.

**Birth weight<sup>1</sup>(Item NB-5/P51), 2, 3:** The first weight of the baby obtained after birth (Record in grams.) Birth weight should preferably be measured within the first hour of life before significant postnatal weight loss has occurred.

**Gestation<sup>1</sup>(Item MP14), 2, 3:** The duration of the pregnancy in completed weeks derived from clinical assessment. Accurate information on the date of the last menstrual period may not be available for every pregnancy; menstrual irregularity and other factors may influence whether gestational age can be accurately derived from the last menstrual period (LMP). In these circumstances, clinical estimates of gestational age can be obtained during pregnancy or by examination of the infants after birth. The gestational age of the infant is an important determinant of transfer of babies from neonatal special care and intensive care.

### 1.3.4 Birth

**Place of Birth<sup>3</sup>:** Place of infant's birth

*Unknown* - information not available

*Non tertiary hospital* - born in a hospital without a neonatal intensive care nursery.

*Tertiary hospital* - Born in a hospital with a neonatal intensive care nursery.

*Home birth* - birth planned for and occurred at home.

*Born before arrival* - born at home (unplanned), or in an ambulance, or in a car etc.

**Presentation<sup>1</sup>(Item MP20), 2, 3:** Presenting part of the foetus (ie at lower segment of the uterus) at birth.

*Unknown* - information not available, not stated

*Vertex* - including face and brow

*Breech* - legs or feet were facing the cervix

*Other* - includes transverse.

**Birth<sup>3(derived)</sup>:** Mode of birth

*Unknown* - information not available

*Normal vaginal* - Vaginal delivery, includes vaginal breech

*Instrument* - vaginal birth using instrument. Includes forceps, rotations and vacuum extractions.

*Caesarean section in labour* - caesarean performed after commencement of regular painful contractions with progressive cervical dilatation.

*Caesarean section, no labour* - caesarean section performed prior to labour (commencement of regular painful contractions with progressive cervical dilatation).

**Apgar (1 min)<sup>1</sup> (Item NB-6), 3:** Apgar score at 1 minute. Numerical score to evaluate the newborn baby's condition at one minute.

**Apgar (5 min)<sup>1</sup>(Item NB-6), 2, 3:** Apgar score at 5 minutes. Numerical score to evaluate the newborn baby's condition at five minutes.



**Intubated at resuscitation**<sup>1 (Item NB-7, partial), 3</sup>: Active measures taken shortly after birth to assist newborn baby. Endo tracheal intubation. (This does not include intubation for tracheal aspiration or intubation in the NICU after resuscitation has been completed).

**Major congenital anomaly**<sup>1, 2, 3</sup>: Structural or anatomical abnormalities that are present at birth, usually resulting from abnormal development in the first trimester of pregnancy. (That is one having an adverse effect on function. An exclusion list of minor abnormalities is supplied).

**Specify**<sup>1 (Item NB-13), 2, 3</sup>: Specify the major congenital abnormality(s) present at birth. Either use names or ICD-9 codes.

### 1.3.5 First 12 Hours

**Temperature on admission**<sup>2, 3</sup>: Temperature on admission to Neonatal Intensive Care Unit (NICU), or soonest to admission to registration unit. Use rectal temperature or, if not available, per axillae. Record temperature in degrees Celsius.

**Appropriate FiO<sub>2</sub>: highest**<sup>2, 3</sup>: Highest appropriate fractional inspired oxygen (FiO<sub>2</sub>) recorded as a percentage, between admission to NICU and 12 hours after birth. If the infant 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 side. If the infant is admitted at say, four hours of age, record the highest appropriate FiO<sub>2</sub> between four and 12 hours of age. Appropriate range is when: arterial partial inspired oxygen (PaO<sub>2</sub>) or transcutaneous partial oxygen pressure (TcPO<sub>2</sub>) is 50-80 mmHg, or if FiO<sub>2</sub> is more than 25%, oxygen saturation (SaO<sub>2</sub>) is 88-95%, or if FiO<sub>2</sub> is less than 25%, SaO<sub>2</sub> is more than 88%.

**Appropriate FiO<sub>2</sub>: lowest**<sup>2, 3</sup>: Lowest appropriate fractional inspired oxygen (FiO<sub>2</sub>) recorded as a percentage, between admission to NICU and 12 hours after birth. (Otherwise, definition the same as for highest appropriate FiO<sub>2</sub>).

**Worst BE**<sup>2, 3</sup>: Worst base deficit (mmol/l) recorded between admission to NICU and 12 hours after birth. If the infant is admitted at say, four hours of age, record the worst base excess measured between four and 12 hours of age.

### 1.3.5 Morbidity

**Main respiratory diagnosis**<sup>3</sup>: Main respiratory diagnosis for infant.

*Unknown* - information not available

*Normal* - normal lungs, no respiratory disease

*TTN* - Transient Tachypnoea of the Newborn - mild respiratory failure, usually fractional inspired oxygen < 30%, with normal or nonspecific chest X-ray - no cause found. Assisted ventilation rare.

*HMD* - Hyaline membrane disease - increasing respiratory distress or O<sub>2</sub> requirements, or need for ventilatory support from the first six hours of life with a chest X-ray showing generalised reticulo-granular pattern ± air bronchogram.

*Mec Asp* - Meconium aspiration - respiratory distress following aspiration of meconium with chest X-ray showing patchy opacities and / or over distension.

*Pneumonia* - respiratory distress with proven or suspected infection (toxic blood count), and chest X-ray showing persisting opacities.

*PPH* - Persistent pulmonary hypertension - echocardiatic (shunting) or clinical evidence (O<sub>2</sub> requirement unexplained by chest X-ray, or loud P<sub>2</sub>, or differential pre and post ductal transcutaneous partial oxygen pressure (TcPO<sub>2</sub>)).

*Immature lung* - respiratory failure in extremely preterm infants (< 29 weeks). That is, a clear chest X-ray with poorly defined branching / tapering pattern.

*Apnoea* - recurrent pauses in breathing of > 20 seconds, or for < 20 seconds and associated with bradycardia or desaturation.

*Cong Abn* - Congenital abnormality was the primary reason for respiratory distress, eg diaphragmatic hernia (anomaly needs to be listed under congenital abnormality field).

**Main respiratory diagnosis** (*continues*)

*Other* - unspecified other respiratory disease.

**Surfactant**<sup>2(derived), 3(derived)</sup>: Type of artificial surfactant used

*Unknown* - information not available

*None* - none ever given (does not include incomplete administration).

*Exosurf* - any treatment using "Exosurf"

*Survanta* - any treatment using "Survanta"

*Other* - other artificial surfactant given

**Air leak requiring drainage**<sup>2, 3</sup>: Air leak requiring drainage (either transient or continuous).

**Days of IPPR**<sup>3</sup>: Total number of days of assisted intermittent positive pressure ventilation (at any rate). Four consecutive hours in any one 24-hour period constitute a day. The highest level of assisted ventilation therapy for any 24-hour period is the one used.

**Days of CPAP**<sup>3(derived)</sup>: Total number of days of continuous positive airways pressure via any route. Four consecutive hours in any one 24-hour period constitute a day. The highest level of assisted ventilation therapy for any 24-hour period is the one used.

**Date of final added O<sub>2</sub>**<sup>2, 3</sup>: Date supplemental O<sub>2</sub> finally ceased (appropriately). If oxygen is ceased, and then the infant required more supplemental O<sub>2</sub> 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 RSV, oxygenation after surgery, etc.

**Home O<sub>2</sub>**<sup>3</sup>: Was supplemental oxygen used at home after discharge from hospital? Must have required supplemental oxygen in hospital.

**Proven NEC**<sup>2(derived), 3(derived)</sup>: Proven necrotising enterocolitis (NEC). That is having symptoms of NEC plus a proven radiological diagnosis or proven at operation or post mortem. Radiological signs include intramural or intra-hepatic air, perforation or a 'fixed loop'.

**No. of episodes proven infection**<sup>3(derived)</sup>: The total number of separate episodes of proven systemic infection. There must be clinical or radiological signs of infection together with growth of a known pathogen from a systemic site (blood, bone, cerebro spinal fluid, lung, urine, etc) - does not include tracheal aspirate.

**IVH (max grade R or L)**<sup>2(derived), 3</sup>: Worst level of intraventricular haemorrhage (IVH) seen on either side by either ultrasound or post mortem examination.

*None* - ultrasound / post mortem shows no haemorrhage.

*Grade1* - subependymal germinal matrix haemorrhage

*Grade2* - intraventricular haemorrhage with no ventricular dilatation

*Grade3* - intraventricular haemorrhage with ventricle distended with blood.

*Grade4* - intraparenchymal haemorrhage.

*Not examined* - by ultrasound or post mortem.

**Worst head ultrasound: Date**<sup>2, 3</sup>: Date of the cerebral ultrasound scan closest to six weeks that demonstrates the worst problems during the initial hospital admission.

**Ventricles<sup>2, 3</sup>:** Ventricular size at the ultrasound closest to six weeks, as in above date (see graph (Levene). Ventricular index is measured (in mm) as the furthest lateral extent of each ventricle from the midline measured at the level of the Foramen of Monro

*Unknown* - information not available, includes not scanned

*No dilatation* - ventricle size is less than 97<sup>th</sup> centile.

*Dilatation* - ventricle size > 97<sup>th</sup> centile, but less than 4 mm greater than 97<sup>th</sup> centile.

*Hydrocephalus* - ventricle size is more than 4 mm larger than 97<sup>th</sup> centile, or hydrocephalus present that required a shunt or any form of drainage (permanent or transient).

**Cyst<sup>2, 3</sup>:** Parenchymal cysts seen at the scan closest to six weeks.

*Unknown* - information not available, includes not scanned.

*No cysts* - seen

*Porencephalic cyst(s)* - Parenchymal lesions corresponding to grade 4 intraventricular haemorrhage

*PVL* - Periventricular leukomalacia refers to the ischaemic brain injury effecting the periventricular white matter.

**ROP (worst stage R or L)<sup>3</sup>:** Worst stage of retinopathy of prematurity (ROP) in either eye during the initial hospital admission. (International classification: Committee for the Classification of Retinopathy of Prematurity).

*None seen* - no changes seen

*Stage I* - demarcation line present

*Stage II* - ridge present

*Stage III* - ridge with extra-retinal fibrovascular proliferation.

*Stage IV* - retinal detachment

*Not examined* - no eye examination

**Therapy for ROP<sup>3</sup>:** Any therapy for retinopathy of prematurity (ROP) ie laser or cryotherapy.

### 1.3.6 Outcome

**Died<sup>2, 3</sup>:** Did this infant die prior to discharge from hospital?

**Date of death<sup>2, 3</sup>:** Date of death of infant

**Post Mortem<sup>2, 3</sup>:** Was a post mortem performed?

**Immediate cause of death<sup>2, 3</sup>:** Immediate cause of death.

**Sent to another hospital<sup>2(derived), 3</sup>:** Was the infant transferred to another hospital nursery during this admission?

**Specify hospital<sup>2, 3(derived)</sup>:** Specify the name of the hospital to which the infant was transferred. If the infant 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. This information is used to trace the progress of the infant and to monitor its movement so that her / his outcome can be noted. Use the most significant hospital here.

**Date of discharge or transfer<sup>2, 3(derived)</sup>:** Date of discharge to home, or transfer to the above hospital. If the infant 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. This information is used to trace the progress of the infant and to monitor its movement so that her / his outcome can be noted. Use the most significant date here.

**Date of discharge to home<sup>1(Item NB-10/P26), 2(derived), 3</sup>:** Date on which a newborn baby completes an episode of care after birth. Formal separation is the administrative process by which a hospital records the completion of treatment and / or care and accommodation of a patient.

**Ventricles<sup>2, 3</sup>:** Ventricular size at the ultrasound closest to six weeks, as in above date (see graph (Levene). Ventricular index is measured (in mm) as the furthest lateral extent of each ventricle from the midline measured at the level of the Foramen of Monro

*Unknown* - information not available, includes not scanned

*No dilatation* - ventricle size is less than 97<sup>th</sup> centile.

*Dilatation* - ventricle size > 97<sup>th</sup> centile, but less than 4 mm greater than 97<sup>th</sup> centile.

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*Unknown* - information not available, includes not scanned.

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*PVL* - Periventricular leukomalacia refers to the ischaemic brain injury effecting the periventricular white matter.

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### 1.3.6 Outcome

**Died<sup>2, 3</sup>:** Did this infant die prior to discharge from hospital?

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**Specify hospital<sup>2, 3(derived)</sup>:** Specify the name of the hospital to which the infant was transferred. If the infant 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. This information is used to trace the progress of the infant and to monitor its movement so that her / his outcome can be noted. Use the most significant hospital here.

**Date of discharge or transfer<sup>2, 3(derived)</sup>:** Date of discharge to home, or transfer to the above hospital. If the infant 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. This information is used to trace the progress of the infant and to monitor its movement so that her / his outcome can be noted. Use the most significant date here.

**Date of discharge to home<sup>1(Item NB-10/P26), 2(derived), 3</sup>:** Date on which a newborn baby completes an episode of care after birth. Formal separation is the administrative process by which a hospital records the completion of treatment and / or care and accommodation of a patient.

Mother's name: [ \_\_\_\_\_ ]

(not to be sent from hospital)

## AUSTRALIAN & NEW ZEALAND NEONATAL NETWORK

INFANTS ADMITTED TO NICU & < 32 WEEKS or  $\leq$ 1500gm

### MOTHER:

Mat. identity no. (of child's birth): \_\_\_\_\_ Age: \_\_\_\_\_ years  
Previous preterm birth: y / n Previous perinatal death: y / n  
Assisted conception: unknown / none / hyperov / IVF, GIFT / other Ethnicity: unknown / aboriginal / asian / caucasian

### ANTENATAL:

Source of referral: unknown / booked at tertiary hospital / in-utero transfer / ex-utero retrieval / ex-utero transfer / other  
Presenting antenatal problem: unknown / PPRM / PTL / PIH / APH / IUGR / fetal distress / other  
Other complications: y / n, specify PROM: y / n PTL: y / n PIH: y / n  
APH: y / n IUGR: y / n fetal distress: y / n other: y / n  
Corticosteroids (for lungs): unknown / none / < 24hrs / complete / > 7days TRH: y / n  
Plurality: singleton / twins / triplets / quads / more! Birth order: \_\_\_\_\_ (0=singleton, 1=1st of multe preg)

### BABY:

NICU Hosp no.: \_\_\_\_\_ DOB: \_\_\_\_/\_\_\_\_/\_\_\_\_ DOA: \_\_\_\_/\_\_\_\_/\_\_\_\_  
Sex: unknown / male / female / ambiguous Birthweight: \_\_\_\_\_ grams Gestation: \_\_\_\_\_ complete wks

### BIRTH:

Place of Birth: unknown / non-tertiary hospital / tertiary hospital / homebirth / born before arrival  
Presentation: unknown / vertex / breech / other Birth: unk / vaginal / instrument / c.section, labour / c.section, no labour  
Apgar (1 min): \_\_\_\_\_ (5 min): \_\_\_\_\_ Intubated at resusc: y / n  
Major congenital anomaly: y / n, specify: \_\_\_\_\_

### 1st 12 HRS:

Temp on admission: \_\_\_\_\_ °C Approp FiO<sub>2</sub>: hi: \_\_\_\_\_%, lo: \_\_\_\_\_% Worst BE: \_\_\_\_\_mmol/l

### MORBIDITY:

Main respiratory diagnosis: unkn / normal / TTN / HMD / Mec Asp / Pneumonia / PPH / Immature Lung / Apnoea / Cong Abn / other  
Surfactant: unknown / none / Exosurf / Survanta / other Air leak with drainage: y / n  
Days of IPPR: \_\_\_\_\_ Days of CPAP: \_\_\_\_\_  
Date of final added O<sub>2</sub>: \_\_\_\_/\_\_\_\_/\_\_\_\_ Home O<sub>2</sub>: y / n  
Proven NEC: y / n No. of episodes proven infection: \_\_\_\_\_  
IVH (max grade R or L): none / gd 1 / gd 2 / gd 3 / gd 4 / not examined Worst head ultrasound: Date: \_\_\_\_/\_\_\_\_/\_\_\_\_  
Ventricles: unknown / no dilatation / dilatation / hydrocephalus Cyst: unknown / no cysts / porencephalic cysts / PVL  
ROP (worst stage R or L): none / 1 / 2 / 3 / 4 / not examined Therapy for ROP: y / n

### OUTCOME:

Died: y / n Date of death: \_\_\_\_/\_\_\_\_/\_\_\_\_ Post Mortem : y / n  
Immediate cause of death: \_\_\_\_\_  
Sent to another hospital: y / n, Specify hospital: \_\_\_\_\_  
Date of transfer: \_\_\_\_/\_\_\_\_/\_\_\_\_ Date of discharge to home: \_\_\_\_/\_\_\_\_/\_\_\_\_

## Appendix 2 Participating hospitals in 1994

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Christchurch Women's Hospital, Christchurch New Zealand

Type of hospital:	Perinatal referral centre
Number of livebirths in 1994:	3,790
Number of established ventilator beds:	6
Total number of beds for newborn infants:	20

John Hunter Hospital, Locked Bag 1 Hunter Region Mail Centre Newcastle NSW 2310

Type of hospital:	Perinatal referral centre
Number of livebirths in 1994:	3,960
Number of established ventilator beds:	8
Total number of beds for newborn infants:	29

King Edward Memorial Hospital for Women, Bagot Road Subiaco WA 6005

Type of hospital:	Perinatal referral centre
Number of livebirths in 1994:	4,742
Number of established ventilator beds:	18
Total number of beds for newborn infants:	60

King George V Memorial Hospital, Missenden Road Camperdown NSW 2050

Type of hospital:	Perinatal referral centre
Number of livebirths in 1994:	4,770
Number of established ventilator beds:	8
Total number of beds for newborn infants:	32

Kirwan Hospital for Women, Thuringowa Drive Kirwan Qld 4814

Type of hospital:	Perinatal referral centre
Number of livebirths in 1994:	1,622
Number of established ventilator beds:	4
Total number of beds for newborn infants:	18

Liverpool Hospital, PO Box 103 Liverpool NSW 2170

Type of hospital:	Perinatal referral centre
Number of livebirths in 1994:	2,457
Number of established ventilator beds:	3 from 13/10/1994
Total number of beds for newborn infants:	13

Mater Misericordiae Mother's Hospital, Raymond Terrace South Brisbane Qld 4101

Type of hospital:	Perinatal referral centre
Number of livebirths in 1994:	7,648
Number of established ventilator beds:	12
Total number of beds for newborn infants:	60

Mercy Hospital for Women, Clarendon Street East Melbourne Vic 3002

Type of hospital:	Perinatal referral centre
Number of livebirths in 1994:	5,582
Number of established ventilator beds:	10
Total number of beds for newborn infants:	54

Middlemore Hospital, Private Bag 93311 Otahuhu Auckland 6 New Zealand

Type of hospital:	Perinatal centre
Number of livebirths in 1994:	4,323
Number of established ventilator beds:	4
Total number of beds for newborn infants:	20

Monash Medical Centre, Clayton Road Clayton Vic 3168

Type of hospital:	Perinatal referral centre
Number of livebirths in 1994:	3,799
Number of established ventilator beds:	11
Total number of beds for newborn infants:	44

Nepean Hospital, PO Box 63 Penrith NSW 2747

Type of hospital:	Perinatal referral centre
Number of livebirths in 1994:	2,948
Number of established ventilator beds:	6
Total number of beds for newborn infants:	28

Prince of Wales Children's Hospital, High Street Randwick NSW 2031

Type of hospital:	Children's centre
Number of established ventilator beds:	7
Total number of beds for newborn infants:	14

Princess Margaret Hospital for Children, GPO Box D134 Perth WA

Type of hospital:	Children's centre
Number of established ventilator beds:	6
Total number of beds for newborn infants:	20

Queen Victoria Hospital (*now Women's & Children's Hosp*), King William Rd Adelaide SA 5006

Type of hospital:	Perinatal referral centre
Number of livebirths in 1994:	2,690
Number of established ventilator beds:	14
Total number of beds for newborn infants:	52

Royal Alexandra Hospital for Children, PO Box 3515 Parramatta NSW 2124 (from 24/10/95)

Type of hospital:	Children's centre
Number of established ventilator beds:	7
Total number of beds for newborn infants:	30

Royal Hobart Hospital, Argyle Street Hobart Tas 7000  
Type of hospital: Perinatal referral centre  
Number of livebirths in 1994: 2,035  
Number of established ventilator beds: 4  
Total number of beds for newborn infants: 18

Royal Hospital for Women, Oxford Street Paddington NSW 2021  
Type of hospital: Perinatal referral centre  
Number of livebirths in 1994: 3,894  
Number of established ventilator beds: 6  
Total number of beds for newborn infants: 28

Royal North Shore Hospital, Pacific Highway St Leonards NSW 2065  
Type of hospital: Perinatal Referral Centre  
Number of livebirths in 1994: 2,366  
Number of established ventilator beds: 6  
Total number of beds for newborn infants: 26

Royal Women's Hospital, PO Royal Brisbane Hospital Qld 4029  
Type of hospital: Perinatal referral centre  
Number of livebirths in 1994: 5,183  
Number of established ventilator beds: 12  
Total number of beds for newborn infants: 60

Royal Women's Hospital, Grattan Street Carlton Vic 3053  
Type of hospital: Perinatal referral centre  
Number of livebirths in 1994: 7,174  
Number of established ventilator beds: 12  
Total number of beds for newborn infants: 58

Waikato Hospital, Private Bag 3200 Hamilton New Zealand  
Type of hospital: Perinatal referral centre  
Number of livebirths in 1994: 3,095  
Number of established ventilator beds: 11  
Total number of beds for newborn infants: 26

Westmead Hospital, Hawkesbury Road Westmead NSW 2145  
Type of hospital: Perinatal referral centre  
Number of livebirths in 1994: 4,219  
Number of established ventilator beds: 12  
Total number of beds for newborn infants: 41





## Appendix 4 1994 publications

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### 4.1 Publications in 1994 by NICU staff in Australia and New Zealand

#### 4.1.1 Articles

Anderson N, Allan R, Darlow B & Malpas T 1994. Diagnosis of intraventricular haemorrhage in the newborn: value of sonography via the posterior fontanel. *Am J Roentgenology* 163:893–896.

Beeby PJ, Elliott EJ, Henderson Smart DJ & Rieger ID 1994. Predictive value of umbilical artery pH in preterm infants. *Arch Dis Child* 71:F93–96.

Botham S & Isaacs D 1994. Incidence of apnoea and bradycardia in the preterm infant following triple antigen immunisation. *J Mat & Child Health* 30:533–535.

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Chabra S, Arnold JD, Leslie GI, Bowen JR, Earl J & Wood F 1994. Vitamin A status in preterm neonates with and without chronic lung disease. *J Paediatr Child Health* 30:432–435.

Chang J & Gray P 1994. Aminophylline therapy and cerebral blood flow velocity in preterm infants. *J Paediatric Child Health* 30:123.

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- Ford RPK, Mitchell EA & Taylor BJ 1994. Well health care and the sudden infant death syndrome. *J Paediatr Child Health* 30:140–143.
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