9. EXTREMELY PRE-TERM FOLLOW UP

This is the first time that follow up of infants 22–28 weeks gestation has been reported in the Mothers and Babies Report. The information presented in this chapter was obtained from the Neonatal Intensive Care Units' (NICUS) Follow-up Data Collection (see Chapter 3, Data sources).

Registration rate

All infants of 22–28 weeks gestation admitted to a neonatal intensive care unit in NSW or the ACT who survived to hospital discharge were enrolled in the follow up clinic at their registration hospital. Table 106 shows the health area of mother's residence at birth of the 1591 infants who were born between 1 January 1998 and 31 December 2001. The majority of liveborn infants were admitted to a neonatal intensive care unit in all aealth areas.

Overall 1,790/2,595 (69.0 per cent) infants were liveborn, 1,591/1,790 (88.9 per cent) were admitted to a neonatal intensive care unit, 1,236/1,591 (77.7 per cent) survived to hospital discharge, 22/1,236 (1.8 per cent) died post-discharge (Table 107). Live births increased with increasing gestational age from 36.7 per cent at 22 weeks gestation to 88.2 per cent at 28 weeks gestation. Similarly admission to a neonatal intensive care unit increased from 3.5 per cent at 22 weeks gestation to 98.0 per cent at 28 weeks gestation. As expected hospital survival also increased with increasing gestational age from 0 per cent at 22 weeks gestation to 92.2 per cent at 28 weeks gestation.

The major causes of death for the children who died after hospital discharge were sudden infant death syndrome, chronic lung disease, pneumonia, suffocation by overlying and degenerative disease of the nervous system.

There were 1,214 children available for follow up at 2–3 years of age, corrected for prematurity, of these 249 children were not followed up (16 families moved overseas, 17 families moved interstate, and 216 were either lost to follow up or refused the appointment). The follow up rate at 2–3 years of age, corrected for prematurity was 965 (79.5 per cent) children.

TABLE 106

NICUS REGISTRATIONS BY HEALTH AREA OF RESIDENCE, NSW & ACT 1998–2001

Health Area	Total NICUS Registrants		Total NSW & ACT Live births	Registrants per 1,000 live births
	No.	%	No.	
Sydney South West	349	21.9	390	894.9
South Eastern Sydney & Illawarra	224	14.1	255	878.4
Sydney West	260	16.3	289	899.7
Northern Sydney & Central Coast	230	14.5	250	920.0
Hunter & New England	232	14.6	243	954.7
North Coast	36	2.3	59	610.2
Greater Southern	94	5.9	106	886.8
Greater Western	80	5.0	92	869.6
ACT	79	5.0	92	858.7
Interstate	5	0.4	12	416.7
Overseas	2	0.1	2	1000.0
TOTAL	1591	100.0	1790#	888.8

Source: NICUS Data Collection. NSW Centre for Perinatal Health Services Research. NSW Midwives Data Collection 1998–2001. Centre for Epidemiology and Research, NSW Department of Health. ACT Maternal Perinatal Data Collection 1998–2001, ACT Health.
Excludes 15 babies for whom the birth outcome was not known.

TABLE 107

BIRTHS BY NICUS REGISTRATION, HOSPITAL SURVIVAL AND GESTATIONAL AGE, NSW & ACT 1998–2001

Gestational age (weeks)	Total births	NSW & ACT Stillbirths		Live births		NICUS Registrations		Hospital Survival		Died Post-discharge		Available 2–3 years	Refused/ Lost	Assessed Available	
	No.	No.	%	No.	%	No.	%	No.	%	No.	%	No.	No.	No.	%
22	313	198	63.3	115	36.7	4	3.5	0	0.0	0	0.0	0	0	0	0.0
23	271#	149	55.2	121	44.8	63	52.1	18	28.6	1	5.5	17	3	14	82.4
24	335	128	38.2	207	61.8	180	87.0	89	49.4	1	1.1	88	10	78	88.6
25	315	86	27.3	229	72.7	222	96.9	141	63.5	0	0.0	141	13	128	90.8
26	410#	94	23.0	315	77.0	322		254	78.9	9	3.5	245	44	201	82.0
27	423#	74	17.6	346	82.4	337	97.4	307	91.1	5	1.6	302	70	232	76.8
28	528#	61	11.8	457	88.2	463		427	92.2	6	1.4	421	109	312	74.1
TOTAL	2595	790#	30.6	1790#	69.4	1591	88.9	1236	77.7	22	1.8	1214	249	965	79.5

Source: NICUS Data Collection. NSW Centre for Perinatal Health Services Research. NSW Midwives Data Collection 1998–2001. Centre for Epidemiology and Research, NSW Department of Health. ACT Maternal Perinatal Data Collection 1998-2001, ACT Health.
Excludes 15 babies for whom the birth outcome was not known.

Assessment and tools

Children were assessed by the developmental assessment team (91 per cent) at the tertiary hospital in which they received their neonatal care or the closest tertiary hospital to their current place of residence. If the parents were unable to travel to a tertiary hospital then the local paediatrician (7 per cent) or general practitioner (2 per cent) examined the child. The median (25th, 75th) age of assessment was 35.6 (29.1, 36.9) months of age, corrected for prematurity.

A formal developmental assessment comprised hearing by an audiologist, vision by an ophthalmologist or optometrist, neurological examination by a developmental paediatrician or physiotherapist, and a developmental assessment using the Griffiths Mental Developmental Scales or Bayley Scales of Infant Development-II performed by a psychologist or a developmental paediatrician.

Developmental outcome

Of the 965 children with information at 2-3 years of age, corrected for prematurity, 912 (94.5 per cent) had a neurological examination performed. Of these 100 (11.0 per cent) had cerebral palsy. A further 57 (6.3 per cent) children had motor incoordination. The proportion of children with cerebral palsy (mild n=44, moderate n=25 or severe n=31) and motor incoordination decreased with increasing gestational age (Table 108).

Of the 965 children with information at 2–3 years of age, corrected for prematurity, 606 (62.8 per cent) had their eyes examined by an ophthalmologist or optometrist post discharge from hospital. Of these 7 (1.2 per cent) children were bilaterally blind with a visual acuity of less than 6/60 in the better eye. Another 87 children had visual problems including unilateral blindness, or required eye surgery, eye patching, eye drops or corrective lenses. The proportion of children who were blind or who were diagnosed with visual problems decreased with increasing gestational age (Table 109).

TABLE 108

NEUROLOGICAL STATUS AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2001

Gestational age (weeks)	Neurological examination Performed		Normal		Motor Incoordination		Cerebral Palsy		Total Infants	
	No.	%	No.	%	No.	%	No.	%	No.	%
23	14	100.0	7	50.0	5	35.7	2	14.3	14	100.0
24	77	98.7	60	77.9	7	9.1	10	13.0	78	100.0
25	125	97.7	93	74.4	13	10.4	19	15.2	128	100.0
26	193	96.0	158	82.3	10	5.2	25	13.0	201	100.0
27	219	94.4	191	87.2	9	4.1	19	8.7	232	100.0
28	284	91.0	246	86.6	13	4.6	25	8.8	312	100.0
TOTAL	912	94.5	755	82.9	57	6.3	100	11.0	965	100.0

Source: NICUS Follow-up Data Collection. NSW Centre for Perinatal Health Services Research.

TABLE 109

VISUAL STATUS AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2001

Gestational age (weeks)	Visual examination Performed		Visual Problems#		Bilateral Blind		Total Infants	
	No.	%	No.	%	No.	%	No.	%
23	13	92.9	5	38.5	2	15.4	14	100.0
24	67	85.9	14	20.9	1	1.5	78	100.0
25	105	82.0	24	22.9	1	1.0	128	100.0
26	139	69.2	16	11.5	0	0.0	201	100.0
27	94	40.5	13	13.8	0	0.0	232	100.0
28	204	65.4	15	7.4	3	1.5	312	100.0
TOTAL	606	62.8	87	14.4	7	1.2	965	100.0

Source: NICUS Follow-up Data Collection. NSW Centre for Perinatal Health Services Research.
Visual problems include unilateral blindness, eye surgery, eye patching, eye drops, and corrective lenses

Of the 965 children with information at 2–3 years of age, corrected for prematurity, 773 (80.1 per cent) had their hearing tested by an audiologist post discharge from hospital. Of these 40 (5.2 per cent) required bilateral hearing aids or unilateral/bilateral cochlear implants. Another 79 (10.2 per cent) children had hearing problems including unilateral deafness, high frequency deafness or insertion of grommets. The proportion of children who were deaf or had a hearing problem decreased with increasing gestational age (Table 110).

Of the 965 children with information at 2–3 years of age, corrected for prematurity, 809 (83.8 per cent) had a standardised psychological test performed. The majority of children, 609 (85.7 per cent) were assessed using the Griffiths Mental Development Scales, 17 (1.8 per cent) using the Bayley Scales of Development-II and 18 using the Reynell-Zinkin Scales for Visually Impaired Children, Vineland Adaptive Behaviour Scales, Denver Developmental Scales. The proportion of children with a mild (n=99, 12.2 per cent), moderate (n=46, 5.7 per cent) or severe (n=41, 5.1 percent) developmental delay decreased with increasing gestational age (Table 111).

Table 112 shows the proportion of children with any degree of functional disability amongst children assessed at 2–3 years of age, corrected for prematurity. With increasing gestational age the proportion of children diagnosed with mild (n=114, 11.8 per cent), moderate (83, n=8.6 per cent) or severe (n=70, 7.2 per cent) functional disability decreased and concomitantly the proportion of children with no apparent disability increased.

TABLE 110

HEARING STATUS AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2001

Gestational age (weeks)	Hearing examination Performed		Hearing Problems#		Bilateral Deafness		Total Infants	
	No.	%	No.	%	No.	%	No.	%
23	14	100.0	1	7.1	1	7.1	14	100.0
24	66	84.6	9	13.6	9	13.6	78	100.0
25	98	76.6	13	13.3	5	5.1	128	100.0
26	169	84.1	21	12.4	13	7.7	201	100.0
27	177	76.3	20	11.3	6	3.4	232	100.0
28	249	79.8	17	6.8	6	2.4	312	100.0
TOTAL	773	80.1	79	10.2	40	5.2	965	100.0

Source: NICUS Follow-up Data Collection. NSW Centre for Perinatal Health Services Research.
Hearing problems include unilateral deafness, insertion of grommets, high frequency hearing loss, abnormal hearing test.

TABLE 111

DEVELOPMENTAL STATUS AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2001

Gestational age	Psychological assessment Performed		Normal		Developmental delay Mild		Moderate		Severe		Total Infants	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
23	12	85.7	6	50.0	2	16.7	3	25.0	1	8.3	14	100.0
24	66	84.6	40	60.6	11	16.7	7	10.6	8	12.1	78	100.0
25	115	89.8	74	64.3	18	15.7	7	6.1	16	13.9	128	100.0
26	167	83.1	132	79.0	17	10.2	13	7.8	5	3.0	201	100.0
27	193	83.2	154	79.8	25	13.0	8	4.1	6	3.1	232	100.0
28	256	82.1	217	84.8	26	10.2	8	3.1	5	2.0	312	100.0
TOTAL	809	83.8	623	77.0	99	12.2	46	5.7	41	5.1	965	100.0

Source: NICUS Follow-up Data Collection. NSW Centre for Perinatal Health Services Research.

Of the 965 children with information at 2-3 years of age, corrected for prematurity, 153 (15.9 per cent) had a moderate or severe functional disability due to cerebral palsy, bilateral blindness, deafness requiring bilateral hearing aids or unilateral/bilateral cochlear implants or developmental delay more than 2 standard deviations below the mean.

When children 23–28 weeks gestation were compared to a group of 460 randomly selected singleton term infants without a major congenital anomaly born during 1996 in NSW and assessed at 3 years of age using the same assessments methods, the extremely premature children were more likely to have had a mild (11.8 per cent versus 2 per cent), moderate (8.6 per cent versus 1 per cent) or severe (7.2 per cent versus 0.5 per cent) functional disability than the term control children. This represented an increased risk of mild (6 times higher), moderate (9 times higher) or severe (14 times higher) functional disability in 23–28 week prematurely born children.

Weight for age

Of the children with a weight recorded 116 (13.4 per cent) were less than 3rd centile, 113 (13.1 per cent) were between the 3rd and 9th centile, 558 (64.5 per cent) were appropriately grown and 78 (9.0 per cent) had a weight above the 90th centile for sex and age (Table 113).

Reference

1. Vincent T, Bajuk B, Sutton L, Berry G, Henderson-Smart DJ. Study of antecedents and outcomes of severe morbidity in term neonates in New South Wales: A comparison of major disability at 1 and 3 years. *Proceedings of the 5th Annual Congress of the Perinatal Society of Australia and New Zealand.* Canberra, Australia. 2001: P139).

TABLE 112

SEVERITY OF FUNCTIONAL DISABILITY AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2001

Gestational age (weeks)	Severity of functional disability									
	None		Mild		Moderate		Severe		TOTAL	
	No.	%	No.	%	No.	%	No.	%	No.	%
23	5	35.7	2	14.3	2	14.3	5	35.7	14	100.0
24	40	51.3	11	14.1	12	15.4	15	19.2	78	100.0
25	81	63.3	20	15.6	10	7.8	17	13.3	128	100.0
26	145	72.5	19	9.5	22	11.0	15	7.0	201	100.0
27	174	75.0	33	14.2	16	6.9	9	3.9	232	100.0
28	253	81.1	29	9.3	21	6.7	9	2.9	312	100.0
TOTAL	698	72.4	114	11.8	83	8.6	70	7.2	965	100.0

Source: NICUS Follow-up Data Collection. NSW Centre for Perinatal Health Services Research.

TABLE 113

WEIGHT FOR AGE AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2001

Gestational age (weeks)	Weight for age centile									
	<3		3–9		10–90		>90		TOTAL	
	No.	%	No.	%	No.	%	No.	%	No.	% with weight
23	1	8.3	1	8.3	8	66.7	2	16.7	12	85.7
24	10	15.2	17	25.8	36	54.6	3	4.6	66	84.6
25	23	19.8	18	15.5	66	56.9	9	7.8	116	90.6
26	32	17.4	30	16.3	105	57.1	17	9.2	184	91.5
27	19	9.4	23	11.4	146	72.3	14	6.9	202	87.1
28	31	10.9	24	8.4	197	69.1	33	11.6	285	91.3
TOTAL	116	13.4	113	13.1	558	64.5	78	9.0	865	89.6

Source: NICUS Follow-up Data Collection. NSW Centre for Perinatal Health Services Research.