

## 9. EXTREMELY PRE-TERM FOLLOW UP

This is the second 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 New South Wales (NSW) or the Australian Capital Territory (ACT) who survived to hospital discharge were enrolled in the follow up clinic at their registration hospital. Table 104 shows the Health Area of mother's residence at birth of the 1964 infants who were born between 1998 and 2002. The majority of liveborn infants were admitted to a neonatal intensive care unit in all Health Areas.

Overall 2217/3201 (69.3 per cent) infants were liveborn, 1964/2217 (88.6 per cent) were admitted to a neonatal intensive care unit, 1516/1964 (77.2 per cent) survived to hospital discharge, 26/1516 (1.7 per cent)

died post-discharge. Live births increased with increasing gestational age from 36.8 per cent at 22 weeks gestation to 87.3 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 nearly 100.0 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 91.7 per cent at 28 weeks gestation (Table 105).

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 1490 children available for follow up at 2–3 years of age, corrected for prematurity, of these 308 children were not followed up (17 families moved overseas, 24 families moved interstate, and 267 were either lost to follow up or refused the appointment). The follow up rate at 2–3 years of age, corrected for prematurity was 1182 (79.3 per cent) children (Table 105).

**TABLE 104**

#### NICUS REGISTRATIONS BY HEALTH AREA OF RESIDENCE, NSW & ACT 1998–2002

Health Area	Total NICUS Registrants		Total NSW & ACT Live births No.	Registrants per 1,000 live births
	No.	%		
Sydney South West	446	22.7	501	890.2
South Eastern Sydney & Illawarra	266	13.5	299	889.6
Sydney West	326	16.6	364	895.6
Northern Sydney & Central Coast	279	14.2	304	917.8
Hunter & New England	284	14.5	300	946.7
North Coast	48	2.4	73	657.5
Greater Southern	110	5.6	129	852.7
Greater Western	97	4.9	115	843.5
ACT	96	4.9	114	842.1
Overseas	2	0.1	0	0.0
Interstate	10	0.5	18	555.6
TOTAL	1964	100.0	2217#	885.9

Source: NICUS Data Collection. NICUS Follow-up Data Collection. NSW Centre for Perinatal Health Services Research. NSW Midwives Data Collection 1998–2002. Centre for Epidemiology and Research, NSW Department of Health. ACT Maternal Perinatal Data Collection 1998–2002, ACT Health.  
# Excludes 21 babies for whom the birth outcome was not known.

**TABLE 105**

#### BIRTHS BY NICUS REGISTRATION, HOSPITAL SURVIVAL AND GESTATIONAL AGE, NSW & ACT 1998–2002

Gestational age (weeks)	Total births		NSW & ACT Stillbirths		Live births		NICUS Registrations		Hospital Survival		Died Post-discharge		Available 2–3 years No.	Refused/ Lost No.	Assessed Available No.
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%			
22	391	247	63.2	144	36.8	5	3.5	0	0.0	0	0.0	0	0	0	0.0
23	330	186	56.4	144	43.6	77	53.5	23	29.9	1	4.3	22	4	18	81.8
24	422	158	37.4	264	62.6	229	86.7	111	48.5	1	0.9	110	14	96	87.3
25	395	104	26.3	291	73.7	281	96.6	179	63.7	0	0.0	179	15	164	91.6
26	510	119	23.3	391	76.7	399	101.8	316	79.2	10	3.2	306	57	249	81.4
27	524	90	17.2	434	82.8	419	96.5	379	90.5	8	2.1	371	85	286	77.1
28	629	80	12.7	549	87.3	554	101.3	508	91.7	6	1.2	502	133	369	73.5
TOTAL	3201	984	30.7	2217#	69.3	1964	88.6	1516	77.2	26	1.7	1490	308	1182	79.3

Source: NICUS Data Collection. NSW Centre for Perinatal Health Services Research. NSW Midwives Data Collection 1998–2002. Centre for Epidemiology and Research, NSW Department of Health. ACT Maternal Perinatal Data Collection 1998–2002, ACT Health.  
# Excludes 21 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 (0.2 per cent) examined the child. The median (25th, 75th) age of assessment was 35.6 (29.5, 36.8) 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 1182 children with information at 2–3 years of age, corrected for prematurity, 1167 (98.7 per cent) had a neurological examination performed. Of these 126 (10.8 per cent) had cerebral palsy. A further 85 (7.3 per cent) children had motor incoordination. The proportion of children with cerebral palsy (minimal/mild n=55, moderate n=34 or severe n=37) and motor incoordination decreased with increasing gestational age (Table 106). Of the 1182 children with information at 2–3 years of age, corrected for prematurity, 950 (80.4 per cent) had their eyes examined by an ophthalmologist or optometrist post discharge from hospital. Of these 9 (0.9 per cent) children were bilaterally blind with a visual acuity of less than 6/60 in the better eye. Another 101 (10.6 per cent) 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 107).

**TABLE 106**

### NEUROLOGICAL STATUS AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2002

Gestational age (weeks)	Neurological examination Performed		Normal		Motor Incoordination		Cerebral Palsy		Total Infants	
	No.	%	No.	%	No.	%	No.	%	No.	%
23	18	100.0	10	55.6	5	27.8	3	16.7	18	100.0
24	96	100.0	73	76.0	12	12.5	11	11.5	96	100.0
25	164	100.0	120	73.2	18	11.0	26	15.9	164	100.0
26	246	98.8	193	78.5	19	7.7	34	13.8	249	100.0
27	280	97.9	248	88.6	11	3.9	21	7.5	286	100.0
28	363	98.4	312	86.0	20	5.5	31	8.5	369	100.0
TOTAL	1167	98.7	956	81.9	85	7.3	126	10.8	1182	100.0

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

**TABLE 107**

### VISUAL STATUS AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2002

Gestational age (weeks)	Visual examination Performed		Visual Problems <sup>#</sup>		Bilateral Blind		Total Infants	
	No.	%	No.	%	No.	%	No.	%
23	17	94.4	5	29.4	2	1.2	18	100.0
24	88	91.7	18	20.5	1	1.1	96	100.0
25	141	86.0	25	17.7	2	1.4	164	100.0
26	207	83.1	23	11.1	1	0.5	249	100.0
27	218	76.2	13	6.0	0	0.0	286	100.0
28	279	75.6	17	6.1	3	1.1	369	100.0
TOTAL	950	80.4	101	10.6	9	0.9	1182	100.0

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

<sup>#</sup> Visual problems include unilateral blindness, eye surgery, eye patching, eye drops, and corrective lenses

Of the 1182 children with information at 2–3 years of age, corrected for prematurity, 992 (83.9 per cent) had their hearing tested by an audiologist post discharge from hospital. Of these 53 (5.3 per cent) required bilateral hearing aids or unilateral/bilateral cochlear implants. Another 97 (9.8 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 108).

Of the 1182 children with information at 2–3 years of age, corrected for prematurity, 1062 (89.8 per cent) had a standardised psychological test performed. The majority of children, 990 (83.8 per cent) were assessed using the Griffiths Mental Development Scales, 27 (2.0 per cent) using the Bayley Scales of Development-II and 48 using the Reynell-Zinkin Scales for Visually Impaired

Children, Vineland Adaptive Behaviour Scales, Denver Developmental Scales, Peabody. The proportion of children with a mild (n=138, 13 per cent), moderate (n=61, 5.7 per cent) or severe (n=54, 5.1 per cent) developmental delay decreased with increasing gestational age (Table 109).

Table 110 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=150, 12.7 per cent), moderate (113, n=9.6 per cent) or severe (n=86, 7.3 per cent) functional disability decreased and concomitantly the proportion of children with no apparent disability increased.

**TABLE 108**

**HEARING STATUS AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2002**

Gestational age (weeks)	Hearing examination Performed		Hearing Problems <sup>#</sup>		Bilateral Deafness		Total Infants	
	No.	%	No.	%	No.	%	No.	%
23	16	88.9	1	6.3	1	6.3	18	100.0
24	88	91.7	10	11.4	13	14.8	96	100.0
25	145	88.4	16	11.0	6	4.1	164	100.0
26	211	84.7	28	13.3	17	8.1	249	100.0
27	234	81.8	19	8.1	8	3.4	286	100.0
28	298	80.8	23	7.7	8	2.7	369	100.0
TOTAL	992	83.9	97	9.8	53	5.3	1182	100.0

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

<sup>#</sup> Hearing problems include unilateral deafness, insertion of grommets, high frequency hearing loss, abnormal hearing test.

**TABLE 109**

**DEVELOPMENTAL STATUS AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2002**

Gestational age (weeks)	Psychological assessment Performed		No Scores		None		Mild		Moderate		Severe		Total Infants	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
23	15	83.3	1	6.7	8	53.3	1	6.7	4	26.7	1	6.7	18	100.0
24	89	92.7	3	3.4	47	52.8	19	21.3	8	9.0	12	13.5	96	100.0
25	155	94.5	10	6.5	88	56.8	30	19.4	11	7.1	16	10.3	164	100.0
26	223	89.6	13	5.8	161	72.2	21	9.4	17	7.6	11	4.9	249	100.0
27	254	88.8	16	6.3	187	73.6	34	13.4	10	3.9	7	2.8	286	100.0
28	326	88.3	17	5.2	258	79.1	33	10.1	11	3.4	7	2.1	369	100.0
TOTAL	1062	89.8	60	5.6	749	70.5	138	13.0	61	5.7	54	5.1	1182	100.0

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

Of the 1182 children with information at 2–3 years of age, corrected for prematurity, 199 (16.8 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 (12.7 per cent v 2 per cent), moderate (9.6 per cent v 1 per cent) or severe (7.3 per cent v 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 101 (9.4 per cent) were less than 3rd centile, 120 (11.2 per cent) were between the 3rd and 9th centile, 727 (67.9 per cent) were appropriately grown and 122 (11.4 per cent) had a weight above the 90th centile for sex and age (Table 111).

### 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 110**

**SEVERITY OF FUNCTIONAL DISABILITY AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2002**

Gestational age (weeks)	None		Mild		Severity of functional disability				TOTAL	
	No.	%	No.	%	Moderate		Severe		No.	%
23	8	44.4	2	11.1	2	11.1	6	33.3	18	100.0
24	49	51.0	14	14.6	15	15.6	18	18.8	96	100.0
25	98	59.8	32	19.5	15	9.1	19	11.6	164	100.0
26	169	67.9	26	10.4	33	13.3	21	8.4	249	100.0
27	217	75.9	39	13.6	19	6.6	11	3.8	286	100.0
28	292	79.1	37	10.0	29	7.9	11	3.0	369	100.0
TOTAL	833	70.5	150	12.7	113	9.6	86	7.3	1182	100.0

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

**TABLE 111**

**WEIGHT FOR AGE AT 2–3 YEAR FOLLOW UP BY GESTATIONAL AGE, NSW & ACT 1998–2002**

Gestational age (weeks)	<3		3–9		Weight for age centile				TOTAL	
	No.	%	No.	%	10–90		>90		No.	% with weight
23	1	7.1	2	14.3	9	64.3	2	14.3	14	1.3
24	11	13.3	16	19.3	52	62.7	4	4.8	83	7.8
25	20	13.2	22	14.6	96	63.6	13	8.6	151	14.1
26	30	13.1	34	14.8	140	61.1	25	10.9	229	21.4
27	14	5.6	24	9.6	182	72.8	30	12.0	250	23.4
28	25	7.3	22	6.4	248	72.3	48	14.0	343	32.1
TOTAL	101	9.4	120	11.2	727	67.9	122	11.4	1070	100.0

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