10. EXTREMELY PRE-TERM FOLLOW-UP

Introduction

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 137 shows the Health Area of mother's residence at birth of the 2,327 infants who were born between 1/1/1998 and 31/12/2003. The majority of live born infants were admitted to a neonatal intensive care unit in all Health Areas.

Overall 2,659/3,839 (69.3 per cent) infants were live born, 2,327/2,659 (87.5 per cent) were admitted to a neonatal intensive care unit, 1,803/2,327 (77.5 per cent) survived to hospital discharge, 32/1,803 (1.8 per cent) died post-discharge. Live births increased with increasing gestational age from 38.9 per cent at 22 weeks gestation to 87.1 per cent at 28 weeks gestation. Similarly admission to a neonatal intensive care unit increased from 2.6 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 92.3 per cent at 28 weeks gestation (Table 138).

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 1,771 children available for follow-up at 2–3 years of age, corrected for prematurity, of these 379 children were not followed up (19 families moved overseas, 32 families moved interstate, and 328 were either lost to follow-up or refused the appointment). The follow-up rate at 2–3 years of age, corrected for prematurity was 1,392/1,771 (78.6 per cent) children (Table 138).

TABLE 137

NICUS REGISTRATIONS BY HEALTH AREA OF RESIDENCE, NSW & ACT 1998–2003

Health Area	Total NICUS registrants		Total NSW & ACT Live births#	Registrants per 1,000 live births
	No.	%.	No.	
Sydney South West	529	22.7	597	886.1
South Eastern Sydney & Illawarra	321	13.8	363	884.3
Sydney West	393	16.9	445	883.1
Northern Sydney & Central Coast	320	13.8	356	898.9
Hunter & New England	336	14.4	356	943.8
North Coast	56	2.4	56	636.4
Greater Southern	133	5.7	157	847.1
Greater Western	115	4.9	135	851.9
ACT	110	4.7	141	780.1
Overseas	2	0.1	2	–
Interstate	12	0.5	12	–
TOTAL	2327	100.0	2659	875.1

Source: NICUS Data Collection. NICUS Follow-up Data Collection. NSW Centre for Perinatal Health Services Research. NSW Midwives Data Collection 1998–2003. Centre for Epidemiology and Research, NSW Department of Health. ACT Maternal Perinatal Data Collection 1998–2003, ACT Health.
Excludes 159 babies for whom postcode (*n*=144) and/or birth outcome (*n*=15) was not known.

TABLE 138

BIRTHS BY NICUS REGISTRATION HOSPITAL, HOSPITAL SURVIVAL AND GESTATIONAL AGE, NSW & ACT 1998-2003

Gestational age (weeks)	Total births	NSW & ACT Stillbirths		Live births		NICUS registrations		Hospital survival		Died post-discharge		Available 2–3 years	Refused/ lost	Assessed 2–3 years	
	No.	No.	%	No.	%	No.	%	No.	%	No.	%	No.	No.	No.	%
22	491	300	61.1	191	38.9	5	2.6	0	0.0	0	0.0	0	0	0	0.0
23	392	224	57.1	168	42.9	90	53.6	27	30.0	1	3.7	26	4	22	84.6
24	502	185	36.9	317	63.1	260	82.0	124	47.7	1	0.8	123	16	107	87.0
25	472	123	26.1	349	73.9	340	97.4	220	64.7	0	0.0	220	25	195	88.6
26	615	143	23.3	472	76.7	479	–	378	78.9	11	2.9	367	75	292	79.6
27	608	107	17.6	501	82.4	491	98.0	443	90.2	10	2.3	433	96	337	77.8
28	759	98	12.9	661	87.1	662	–	611	92.3	9	1.5	602	163	439	72.9
TOTAL	3839	1180	30.7	2659	69.3	2327	87.5	1803	77.5	32	1.8	1771	379	1392	78.6

Source: NICUS Data Collection. NICUS Follow-up Data Collection. NSW Centre for Perinatal Health Services Research. NSW Midwives Data Collection 1998–2003. Centre for Epidemiology and Research, NSW Department of Health. ACT Maternal Perinatal Data Collection 1998–2003, ACT Health.
Excludes 159 babies for whom postcode (*n*=144) and/or birth outcome (*n*=15) was not known.

Assessment and tools

Children were assessed by the developmental assessment team (92.5 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 (5.5 per cent) or general practitioner (0.2 per cent) examined the child. The median (25th, 75th) age of assessment was 35.5 (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 performed by a psychologist or a developmental paediatrician.

Developmental outcome

Of the 1,392 children with information at 2-3 years of age, corrected for prematurity, 1,372 (98.6 per cent) had a neurological examination performed. Of these 145 (10.6 per cent) had cerebral palsy. A further 112 (8.2 per cent) children had motor incoordination. The proportion of children with cerebral palsy (minimal/mild *n*=46, moderate n=44 or severe *n*=43) and motor incoordination decreased with increasing gestational age (Table 139).

Of the 1,392 children with information at 2–3 years of age, corrected for prematurity, 1,134 (81.5 per cent) had their eyes examined by an ophthalmologist or optometrist post discharge from hospital. Of these 9 (0.8 per cent) children were bilaterally blind with a visual acuity of less than 6/60 in the better eye. Another 130 (11.5 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 140).

TABLE 139

NEUROLOGICAL STATUS AT 2–3 YEAR FOLLOW-UP BY GESTATIONAL AGE, NSW & ACT 1998–2003

Gestational age (weeks)	Neurological examination				Motor incoordination		Cerebral palsy		Total infants	
	Performed		Normal							
	No.	%	No.	%	No.	%	No.	%	No.	%
23	22	100.0	12	54.5	6	27.3	4	18.2	22	100.0
24	107	100.0	83	77.6	13	12.1	11	10.3	107	100.0
25	195	100.0	143	73.3	27	13.8	25	12.8	195	100.0
26	285	97.6	230	80.7	20	7.0	42	14.7	292	100.0
27	332	98.5	294	88.6	16	4.8	27	8.1	337	100.0
28	431	98.2	364	84.5	30	7.0	36	8.4	439	100.0
TOTAL	1372	98.6	1126	82.1	112	8.2	145	10.6	1392	100.0

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

TABLE 140

VISUAL STATUS AT 2–3 YEAR FOLLOW-UP BY GESTATIONAL AGE, NSW & ACT 1998–2003

Gestational age (weeks)	Visual examination performed		Visual problems		Bilateral blindness		Total infants	
	No.	%	No.	%	No.	%	No.	%
23	20	90.9	8	40.0	2	10.0	22	100.0
24	97	90.7	21	21.6	1	1.0	107	100.0
25	170	87.2	30	17.6	2	1.2	195	100.0
26	245	83.9	31	12.7	1	0.4	292	100.0
27	264	78.3	18	6.8	0	0.0	337	100.0
28	338	77.0	21	6.2	3	0.9	439	100.0
TOTAL	1134	81.5	130	11.5	9	0.8	1392	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, corrective lenses.

Of the 1,392 children with information at 2–3 years of age, corrected for prematurity, 1,164 (83.6 per cent) had their hearing tested by an audiologist post discharge from hospital. Of these 57 (4.9 per cent) required bilateral hearing aids or unilateral/bilateral cochlear implants. Another 215 (18.5 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 141).

Of the 1,392 children with information at 2–3 years of age, corrected for prematurity, 1,242 (89.2 per cent) had a standardised psychological test performed. The majority of children, 1,123 (80.6 per cent) were assessed using the Griffiths Mental Development Scales, 39 (2.8 per cent) using the Bayley Scales of Development-II and 80 using the Reynell-Zinkin Scales for Visually Impaired Children, Vineland Adaptive Behaviour Scales, Denver Developmental Scales, or Peabody Picture Vocabulary Test. The proportion of children with a mild (n=160, 12.9 per cent), moderate (n=71, 5.7 per cent) or severe (n=65, 5.2 percent) developmental delay decreased with increasing gestational age (Table 142).

Table 143 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=187, 13.4 per cent), moderate (n=139, 10.0 per cent) or severe (n=102, 7.3 per cent) functional disability decreased and concomitantly the proportion of children with no apparent disability increased. Of the 1392 children with information at 2–3 years of age, corrected for prematurity, 241 (17.3 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.

TABLE 141

HEARING STATUS AT 2–3 YEAR FOLLOW-UP BY GESTATIONAL AGE, NSW & ACT 1998–2003

Gestational age (weeks)	Hearing examination performed		Hearing problems		Bilateral deafness		Total infants	
	No.	%	No.	%	No.	%	No.	%
23	19	86.4	5	26.3	2	10.5	22	100.0
24	98	91.6	19	19.4	12	12.2	107	100.0
25	171	87.7	34	19.9	7	4.1	195	100.0
26	246	84.2	51	20.7	17	6.9	292	100.0
27	274	81.3	50	18.2	9	3.3	337	100.0
28	356	81.0	56	15.7	10	2.8	439	100.0
TOTAL	1164	83.6	215	18.5	57	4.9	1392	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 142

DEVELOPMENTAL STATUS AT 2–3 YEAR FOLLOW-UP BY GESTATIONAL AGE, NSW & ACT 1998–2003

Gestational age (weeks)	Psychological assessment				Developmental delay								Total infants	
	Performed		No scores		None		Mild		Moderate		Severe			
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
23	19	86.4	2	10.5	9	47.4	1	5.3	5	26.3	2	10.5	22	100.0
24	96	89.8	3	3.1	50	52.1	22	22.9	8	8.3	13	13.5	107	100.0
25	182	93.3	17	9.3	100	54.9	34	18.7	14	7.7	17	9.3	195	100.0
26	261	89.4	14	5.4	186	71.3	27	10.3	20	7.7	14	5.4	292	100.0
27	299	88.7	18	6.0	221	73.9	38	12.7	12	4.0	10	3.3	337	100.0
28	385	87.7	24	6.2	303	78.7	37	9.6	12	3.1	9	2.3	439	100.0
TOTAL	1242	89.2	78	6.3	868	69.9	160	12.9	71	5.7	65	5.2	1392	100.0

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

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 (13.4 per cent v 2 per cent), moderate (10 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 (6.5 times higher), moderate (10 times higher) or severe (15 times higher) functional disability in 23-28 week prematurely born children.[1]

Weight for age

Of the children with a weight recorded 129 (10.2 per cent) were less than 3rd centile, 157 (12.5 per cent) were between the 3rd and 9th centile, 855 (67.8 per cent) were appropriately grown and 120 (9.5 per cent) had a weight above the 90th centile for sex and age (Table 144).

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: PSANZ, 2001.

TABLE 143

SEVERITY OF FUNCTIONAL DISABILITY AT 2–3 YEAR FOLLOW-UP BY GESTATIONAL AGE, NSW & ACT 1998–2003

Gestational age (weeks)	Severity of functional disability									
	None		Mild		Moderate		Severe		TOTAL	
	No.	%	No.	%	No.	%	No.	%	No.	%
23	9	40.9	2	9.1	4	18.2	7	31.8	22	100.0
24	54	50.0	18	16.8	15	13.9	20	18.5	107	100.0
25	112	57.4	43	22.1	19	9.7	21	10.8	195	100.0
26	192	65.8	38	13.0	37	12.7	25	8.6	292	100.0
27	253	75.1	43	12.8	27	8.0	14	4.2	337	100.0
28	344	78.4	43	9.8	37	8.4	15	3.4	439	100.0
TOTAL	964	69.3	187	13.4	139	10.0	102	7.3	1392	100.0

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

TABLE 144

WEIGHT FOR AGE AT 2–3 YEAR FOLLOW-UP BY GESTATIONAL AGE, NSW & ACT 1998–2003

Gestational age (weeks)	Weight for age centile									
	<3		3–9		10–90		>90		Total	
	No.	%	No.	%	No.	%	No.	%	No.	% with weight
23	1	5.6	3	16.7	12	66.7	2	11.1	18	81.8
24	12	13.2	19	20.9	55	60.4	5	5.5	91	85.0
25	23	12.8	29	16.2	113	63.1	14	7.8	179	91.8
26	42	15.6	42	15.6	164	60.7	22	8.1	270	92.5
27	19	6.4	32	10.8	217	73.3	28	9.5	296	87.8
28	32	7.9	32	7.9	294	72.2	49	12.0	407	92.7
TOTAL	129	10.2	157	12.5	855	67.8	120	9.5	1261	90.6

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