A preliminary investigation of neonatal SUDI in NSW 1996-2008: opportunities for prevention

NSW Child Death Review Team

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Previous special reports published by the NSW Child Death Review Team include:

- Systemic issues arising from child deaths involving parental substance dependence (Part C of the Child Death Review Team Annual Report, 1998–1999)
- Fatal Assault of Children and Young People (2002)
- Suicide & Risk-taking Deaths of Children & Young People (2003)
- Fatal Assault and Neglect of Children and Young People (2003)
- Sudden Unexpected Deaths in Infancy: the NSW Experience (2005)
- Trends in the Fatal Assault of Children in NSW: 1996–2005 (2008)
- Trends in Child Deaths in NSW 1996-2005 (2008)

Further information on past reports and research can be found at www.kids.nsw.gov.au.

Convenor's foreword

Since its 1999-2000 Annual Report, the NSW Child Death Review Team has examined infants who die suddenly and unexpectedly (SUDI). In 2005 the Team reported the findings of several studies it undertook to determine current parental practises regarding known risk factors that contribute to sudden unexpected deaths and to describe the policies, guidelines and practices in relation ot these deaths. At the time, the Team also made recommendations on the policies, guidelines and practices in relation of these child deaths.

In 2009, the Team obtained the approval of the then-Minister for Youth to undertake a further study, this time with a focus on neonatal infants (the first 28 days after birth), so that prevention of deaths in this age group could be further examined.

This report details the demographic profile, risk factors, cause of death and circumstances of the 123 neonatal sudden unexpected deaths that occurred in the period 1996-2008. The results highlight the modifiable risk factors for sudden unexpected infant deaths that are evident in the deaths of neonatal infants.

The Team have made three recommendations aimed at focusing prevention efforts on neonatal infants and strengthening the response to sudden unexpected deaths in infancy. In particular they reinforce the urgency of communicating to parents that safe sleeping practices are as relevant for very young babies as for those over 28 days.

The death of every child is tragic and on behalf of the Team, I extend my sympathy to the families and friends of these children, and to the professionals who provided care for these infants.

I thank my colleagues on the Child Death Review Team for the knowledge and expertise they brought to the Team's deliberations.

The Team hopes that the information contained in this report will assist to reduce the number of preventable child deaths in NSW.

Megan Mitchell

Convenor, NSW Child Death Review Team

Commissioner for Children and Young People

6 October 2010

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Professor John Christodoulou who provided expert opinion on metabolic disorders.

Professor Heather Jeffery, who with the assistance of Ms Lucia Wang and Ms Angela Carberry, The University of Sydney undertook the study on behalf of the Team.

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The staff at the NSW Commission for Children and Young People for their skill and expertise in preparing this report.

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Findings and recommendations

- There were 3,727 deaths that occurred in the neonatal period (<28 days of life) over the period 1996-2008; 123 (3.3%) of these deaths were sudden and unexpected (SUD).
- Sudden and Unexpected Deaths in Infancy (SUDI) including Sudden Infant Death Syndrome (SIDS) exist in the neonatal period (<28 days of life). Neonates account for 15 per cent of all SUDI.
- Eighty-one per cent of the neonates died after being placed for sleep.
- Many of the deaths where a disease or morbid condition was evident had the potential for prevention including infections, and cardiovascular disorders.
- Ninety per cent of the neonatal infants had at least one SUDI risk factor present in their sleep environment:
    - 57% were placed for sleep in a position other than on their back
    - 73% had smoking evident in their household or during pregnancy
    - 60% were in unsafe sleep environments (co-sleeping: 36% of these infants also had evidence of exposure to tobacco smoke).
- For 25 (20.3%) of the 123 neonates the death incident occurred in hospital. Fifteen of these 25 infants died after being placed for sleep in an unsafe position or unsafe sleeping environment (co-sleeping).
- In 27 of the infants' families there was evidence of drug abuse, alcohol abuse, criminal behaviour, violence, and mental illness. Fourteen of the infants were born with neonatal abstinence syndrome resulting from methadone withdrawal.
- The causes of SUDI are varied and include SIDS, undetermined cause, and diseases and morbid conditions. These causes peak at different ages.
- There is little difference between the demographic and modifiable risk profiles of the neonatal and post neonatal SUDI groups, co-sleeping being the exception with neonates more likely to die in these circumstances compared with post-neonates.

In response to these findings the Team makes the following recommendations:

Recommendation 1: NSW Health consider these findings in a review of *Death - Management of Sudden Unexpected Death in Infancy*.

Recommendation 2: NSW Health assess compliance with the *Babies Safe Sleeping in NSW Heath Maternity Facilities* policy.

Recommendation 3: *SIDS and Kids* emphasise the risks to neonatal infants of unsafe sleeping environments, particularly the potential for this when a mother is tired and may unintentionally fall asleep.

1.0 Introduction

The NSW Child Death Review Team (the Team) was established under Part 7A of the C*ommission for Children and Young People Act 1998* (the Act). The purpose of the Child Death Review Team is to help prevent or reduce the number of deaths in NSW of children and young people aged 0-17 years.

The Team has the following functions:

- to maintain the register of child deaths occurring in NSW that has recorded such deaths since 1 January 1996 (the Child Death Register; the Register)
- to classify those deaths according to cause, demographic criteria, and other relevant factors
- to analyse data to identify patterns and trends relating to those deaths
- with the approval of the Minister, to undertake, alone or with others, research that aims to help prevent or reduce the likelihood of child deaths
- to make recommendations, arising from the Team's maintenance of the Register and from its research, as to legislation, policies, practices, and services for implementation by government and non-government agencies and the community to prevent or reduce the likelihood of child deaths
- to identify areas requiring further research by the Team or other agencies or persons.

In 2009, the Team obtained approval from the Minister to undertake a research study to examine the demography and risk factors, causes of death and circumstances of neonatal sudden unexpected deaths in order to consider prevention in greater depth. The research follows from the Team's previous reports *Sudden Unexpected Deaths in Infancy: the New South Wales experience (2005)* and *Trends in Child Deaths in New South Wales 1996-2005 (2008)* which included an examination of sudden unexpected deaths in infancy.

The Team has examined infants who die suddenly and unexpectedly (SUDI) since its 1999-2000 Annual Report. The Team identifies a death as SUDI when an infant less than one year of age dies suddenly and unexpectedly. Included in SUDI are:

- deaths that were unexpected, and unexplained at autopsy (i.e. those meeting the criteria for sudden infant death syndrome – SIDS)
- deaths occurring in the course of an acute illness that was not recognised by carers and/or by health professionals as potentially life threatening
- deaths arising from a pre-existing condition that had not been previously recognised by heath professionals

- deaths resulting from accident, trauma or poisoning where the cause of death was not known at the time of death.

The term SUDI includes deaths due to SIDS and other undetermined or ill-defined causes.

The term 'undetermined' indicates that there were insufficient findings in the history or at the scene examination, or autopsy to support a particular diagnosis but sufficient abnormal features were found that were not typical of SIDS. The term 'unexpected' indicates that the cause of death was not recognised before the event, as in cases of a pre-existing condition that had previously not been recognised.

The circumstances and causes of death for this group are diverse and include deaths:

- where infants suffocate whilst sleeping
- due to faulty or unsafe cots
- due to suffocation while co-sleeping[1] with adults (some of whom are affected by drugs and/or alcohol or who smoke)
- where infants are fatally assaulted
- where there was a pre-existing disease process or congenital abnormality.

This definition differs from the definition of SUDI used by the *Confidential Enquiry into Stillbirths and Deaths in Infancy* (Fleming et al, 2000) by extending the age range to include infants from birth. Further, infants who died unexpectedly in misadventures due to external injury where the cause was known at the time of death (such as transport incidents and accidental drownings), and deaths that occurred in the course of a known sudden acute illness in a previously healthy infant are excluded.

Agreement was reached at the Coroners' and Pathologists' meeting in Canberra, Australia in 2005 to accept the definition for SIDS starts at day 21, based on the definition of Krous HF et al (Krous, 2004). The exclusion of the deaths of the young infants is argued on the basis that the causes and therefore prevention are different from the older groups.

The purpose of this paper is to describe SUDI that occur in the neonatal period (0 to <28 days) and to determine what if any difference exists between the neonatal and post-neonatal groups in relation to demographic profile and risk factors. The Team hopes that this report will assist both prevention efforts and current understanding.

1. Co-sleeping is distinguished from bed-sharing, where a carer and infant share a bed for the purposes of feeding and settling.

2.0 Description of neonatal sudden unexpected death in infancy

Over the 13 year period 1996 to 2008, there were 829 infants usually resident in NSW who died suddenly and unexpectedly (15.5% of infant deaths). One hundred and twenty three of the 828 SUDI concerned neonatal infants (3.3% of all neonatal deaths) and 706 concerned post-neonatal infants (42.6% of all post-neonatal deaths). The number of deaths for each year is shown in Table 1.

TABLE 1. Number of SUDI neonatal & post neonatal by year, NSW 1996-2008

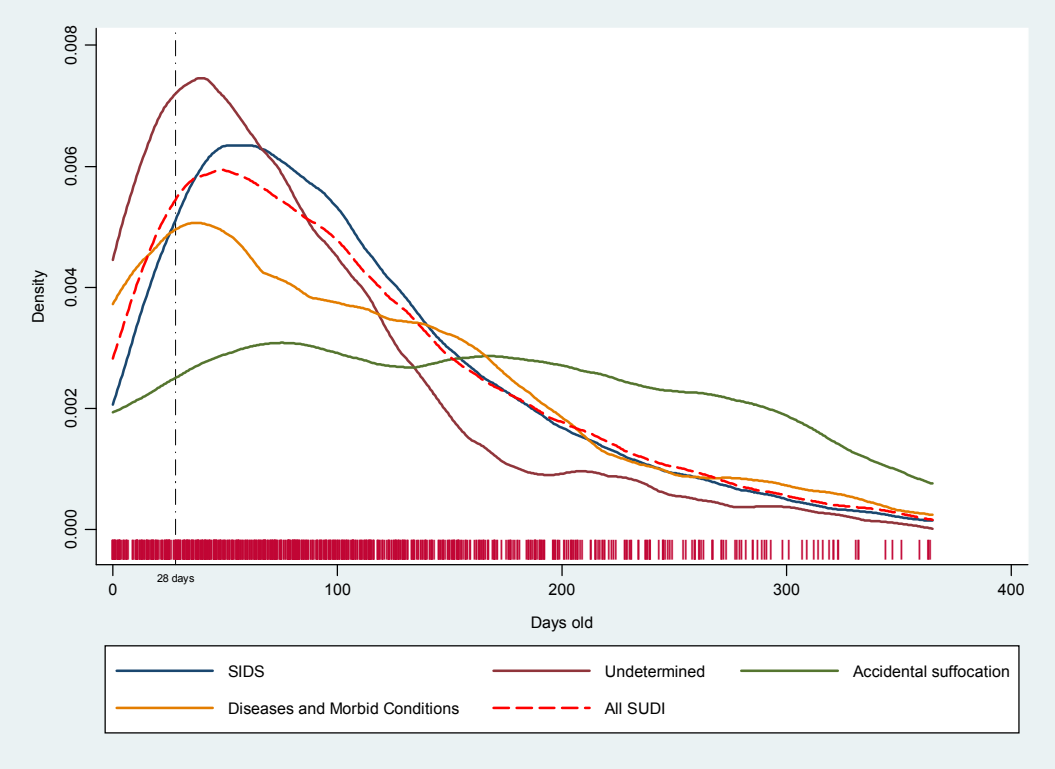
	Neonates	Post-neonates
Year		
1996	15	89
1997	12	53
1998	10	48
1999	8	60
2000	9	67
2001	12	50
2002	6	54
2003	12	47
2004	4	46
2005	10	45
2006	6	52
2007	11	57
2008	8	38
Total SUDI	123	706
Total deaths	3,727	5,290
% SUDI	**3.3**	**13.3**

During the 13-year period, the number of SUDI fell from 104 deaths in 1996 to 46 deaths in 2008. The high number of SUDI in 1996 compared with the following years is likely due to the introduction of successful public health campaigns aimed at reducing the incidence of SIDS, notably the *Kids and SIDS: Three ways to reduce the risk* program in 1997. The most important message of this campaign was to 'place baby on the back for sleep'.

Figure 1 shows the distribution of the average proportion of SUDI and the major SUDI cause of death categories by the age at death in days. The black reference line indicates 28 days. Comparing SUDI in terms of age at death, SUDI is evident from the first day of life peaking at about 40 days and gradually declining.

The major cause of death categories including *SIDS, undetermined, accidental suffocation,* and *diseases and morbid conditions* show considerable variation and peak at different ages. In the neonatal group an undetermined cause is much more likely than any other cause; an undetermined outcome peaks just after the neonatal period and then rapidly declines. Death found to occur in the context of a disease or morbid condition also peaks just after the neonatal period and, along with SIDS is more likely to occur in the neonatal period than accidental suffocation.

FIGURE 1. Kernal density distributions of SUDI by major category[1]



2.1 Demographic characteristics

Demographic information on all SUDI for the combined period 1996-2008 is presented in Table 2. The analysis presented is descriptive only. The demographic factors might not be independent of one another and this needs to be considered when interpreting the results.

Of the 123 neonatal SUDI, 37 were early (<7 days old) and 86 were late neonatal deaths (7 days to <28 days old); 21 (17.1%) were Aboriginal infants; eight (6.5%) lived in areas where the proportion of parents with post-school qualifications were in the bottom 10 per cent of areas; and 19 (15.4%) lived in outer regional, remote or very remote areas. This latter finding suggests that the majority of these infants were located close to medical services.

Information was available on the ethnicity of 72 of the 123 neonates (58.5%). Nearly 10 per cent of these neonates were identified as Asian (Chinese, Vietnamese or Indian), and seven per cent as Maori/Polynesian.[2] This finding is consistent with New Zealand research which found higher SIDS mortality in post-neonatal Maori infants when compared with non-Maori infants (Mitchell & Scragg, 2004).

1. Jann, B. (2005). kdens: Stata module for univariate kernel density estimation. Available from http://ideas.repec.org/c/boc/bocode/s456410.html
2. In 2006, mothers from Polynesia, Micronesia, and Melanesia made up 1.7 per cent of all confinements and all births in NSW (NSW Health, 2009).

TABLE 2. Demographic information of neonatal and post-neonatal infants who died suddenly and unexpectedly, NSW 1996-2008

	Neonatal		Post-neonatal			
	Number	Per cent	Number	Per cent	Chi-Sq	P-value
Aboriginality					0.0430	0.836
Non-Aboriginal	102	82.90	580	82.20		
Aboriginal	21	17.07	126	17.90		
Proportion with post school qualification					0.5632	0.755
Bottom 10 per cent	8	6.50	43	6.09		
Middle	106	86.18	623	88.24		
Top 10 per cent	9	7.32	40	5.67		
Remoteness					2.5074	0.474
Major city	59	47.97	307	43.48		
Inner regional	45	36.59	263	37.25		
Outer regional	14	11.38	115	16.29		
Remote/very remote	5	4.07	21	2.97		

Analysis was undertaken to determine if there were any differences between the neonatal and post-neonatal groups in terms of Aboriginal identity, proportion living in households with post-school qualifications and geographic remoteness. No differences were found in relation to each of these factors (at $p<0.05$). Furthermore, no trends were found in relation to remoteness (chiSq=0.81, p= 0.3687) or proportion with post-school qualifications (chiSq=0.13, p=0.7154).

3.0 Non-modifiable risk factors

This section of the report describes some of the non modifiable risk factors for SUDI identified in the literature for SUDI. These factors include being male, being born preterm (<37 completed weeks), born with low birth weight (<2,500 grams), and growth reduction. Also provided is a comparison of neonatal and post-neonatal SUDI on these factors to determine if the two groups share the same characteristics.

3.1 Neonatal SUDI

Sex, birth weight and gestational age for the 13-year period are presented in Table 3. As with the demographic information provided earlier, the analysis presented is descriptive only. The factors might not be independent of one another and this needs to be considered in interpreting the results.

As seen in Table 3, 75 (61.1%) of the neonatal infants were male; 17(13.9%) had a gestational age less than 37 weeks; and 20 (16.3%) had a birth weight less than 2,500 grams.

For 25 (20.3%) of the neonatal infants the death incident occurred in hospital; 23 in the early neonatal and two in the late neonatal period. Five of these infants had a birth weight less than 2,500 grams, and one infant had a gestational age of less than 37 weeks.

Information on growth reduction (defined by <0th percentile weight for gestational age on NSW growth charts (Beeby, 1996)) was available for 111 of the 121 neonatal infants. Growth reduction was apparent for 19 (17%) of these 111 neonates.

TABLE 3. Non-modifiable risk factors for neonatal and post-neonatal infants who died suddenly and unexpectedly, NSW 1996-2008

	Neonatal		Post-neonatal			
	Number	Per cent	Number	Per cent	Chi-Sq	P-value
Sex					0.0787	0.779
Male	75	61.10	421	59.60		
Female	48	39.00	285	40.40		
Gestational age					5.5656	0.018
<37 weeks	17	13.93	154	23.58		
37+ weeks	105	85.07	499	76.42		
Information not available	*1*		*53*			
Birth weight					4.2865	0.038
Low birth weight	20	16.26	164	24.89		
Other birth weight	103	83.74	495	75.11		
Information not available	*0*		*47*			

3.2 Comparison of neonatal and post-neonatal SUDI

Analysis was undertaken to determine if there was any difference between the neonatal and post-neonatal groups when sex, gestational age and birth weight were separately considered. Statistically significant differences were found – post-neonatal infants were more likely to be preterm than the

neonatal infants (p=0.018), and were more likely to have a lower birth weight than neonates (p=0.038). These findings may not persist when all factors are considered together.

4.0 Modifiable risk factors

This section of the report describes some of the modifiable risk factors for SIDS and SUDI that have been identified in the literature for neonatal SUDI. These factors include sleeping positions other than the back-down position, exposure to tobacco smoke, and unsafe sleeping environments (including co-sleeping, particularly in the context of exposure to tobacco smoke). Also provided is a comparison between neonatal and post-neonatal SUDI on these factors for the period 2003-2008 to determine if the two groups share the same characteristics.

4.1 Neonatal SUDI

Table 4 lists the risk factors for the 123 neonates where the strongest evidence has been provided. The information is descriptive only and does not consider any relationship between the factors.

TABLE 4. Modifiable risk factors for neonatal SUDI, NSW 1996-2008[1]

	Neonatal infants	
	Number	Per cent
Postion placed for sleep		
On back	34	43.04
Other position	45	56.96
Information not available	*21*	
Co-sleeping		
No	39	40.21
Yes	58	59.79
Information not available	*3*	
Exposure to tobacco smoke		
No	23	26.74
Yes	63	73.26
Information not available	*37*	

Information on risk factors was available for 111 of the neonatal SUDI. Ninety-seven (87.4%) had evidence of at least one of the three risk factors reported present in their environment – 67.0 per cent having more than one risk factor.

The back-down position has been shown to be the safest sleeping position for infants (see CDRT, 2005). The face-down position has been repeatedly found to be strongly associated with SIDS. Side-sleeping has also been identified as a risk factor, partly because the position is unstable and infants are more likely to roll to the face-down position. Forty-five (56.96%) of the 79 neonatal infants where information on sleeping position was available, were placed for sleep in an unsafe position.

To provide further understanding on sleeping position, the lividity pattern of neonatal infants was examined. Lividity refers to the pooling of blood in dependant areas of the body after death has

1. *Position place for sleep* and *unsafe sleeping environment (co-sleeping)* are only relevant for the 100 infants who were placed for sleep.

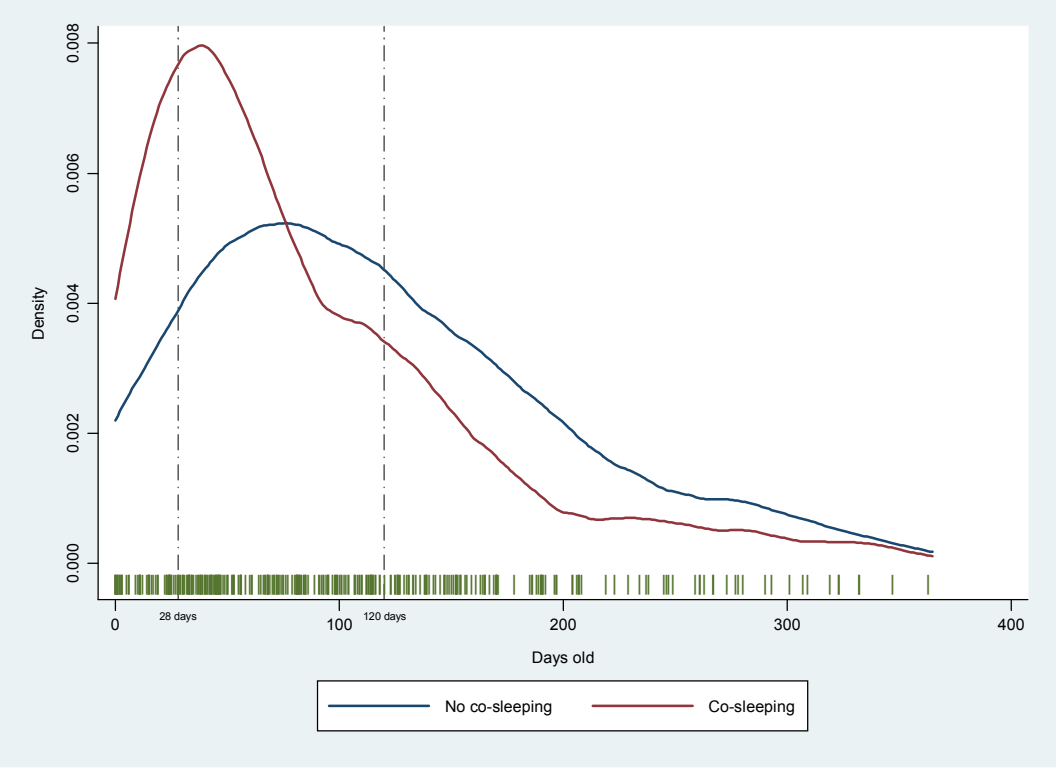
occurred. Lividity is set by about 2-3 hours after death; so even if an infant is moved from front to back during transport, pooling will still be evident on the front of the body if death occurred 2-3 hours earlier before discovery.

Lividity was described for 104 neonates and in 65 (63%) the nonsupine position (infant was not on their back) was deduced (this is likely to under-represent the position of the infants who died shortly before they were found). This finding is at odds with the position placed for sleep reported by parents which indicates that very few infants were placed for sleep in the face-down position. The reasons for this anomaly are unclear but might include the infant moving during sleep, parents' reluctance to report unsafe sleeping positions, limited investigation or inaccurate recording.

Fifty-eight (59.8%) of the 97 neonatal infants, where information was available, were found to be in an unsafe sleeping environment (co-sleeping: where an adult, usually a mother/parent and infant sleep together in bed). Thirty-five of these infants were known to have been exposed to tobacco smoke. A further four neonates were found to have been bed-sharing prior to death. In all these incidents, the parent appears to have accidently fallen asleep. Bed-sharing is where an adult and infant share a bed for the purpose of feeding and settling without the intention of sleeping in the same bed. In effect, 61 per cent of the infants where information was available were found sleeping with an adult.

Figure 2 shows the relationship between co-sleeping and the age of death for all SUDI over the period 1996-2008. The co-sleeping group is significantly different from the non co-sleeping group ($p<0.001$). SUDI peaks in the co-sleeping group at about 50 days and then drops dramatically. By contrast, the non co-sleeping group peaks at about 80 days and falls away more gradually. This supports recent research that suggests co-sleeping presents the highest risk in the neonatal period, decreasing in the second month and eliminated by the fourth month of age (Ruys, 2007).

FIGURE 2. Kernal density distributions, all SUDI by co-sleeping, NSW 1996-2008[1]



As noted earlier, the death incident for 25 neonates occurred in hospital. Fifteen of these deaths occurred after the infant was placed for sleep. Risk factors were evident in the majority of these deaths including placement for sleep in an unsafe position (5 of the 10 infants where this information was available) and unsafe sleep environments (co-sleeping: 8 of the 15 infants). Deaths in these circumstances occurred as recently as 2007.

Exposure to tobacco smoke has been identified as increasing the risk of SUDI. During the period, 63 (73.3%) of the 86 neonates where information was available were exposed to tobacco smoke either during pregnancy, after birth or both.

4.2 Comparison of neonatal and post-neonatal SUDI

Table 5 shows the comparison between neonatal and post-neonatal SUDI on the risk factors analysed for the period 2003-2008.[2] During this period, there were 51 neonatal deaths and 285 post-neonatal deaths.

1. Jann, B. (2005). kdens: Stata module for univariate kernel density estimation. Available from http://ideas.repec.org/c/boc/bocode/s456410.html.
2. Information on SUDI risk factors has not been consistently recorded for post-neonatal infants prior to 2003.

TABLE 5. Modifiable risk factors for neonatal and post-neonatal infants who died suddenly and unexpectedly, NSW 2003-2008[1]

	Neonatal		Post-neonatal			
	Number	Per cent	Number	Per cent	Chi-Sq	P-value
Postion placed for sleep					0.5564	0.456
On back	19	61.29	153	68.00		
Other position	12	38.71	72	32.00		
Information not available	*8*		*30*			
Co-sleeping					7.8816	0.005
No	15	38.46	158	62.20		
Yes	24	61.54	94	37.80		
Information not available	*0*		*16*			
Exposure to tobacco smoke					2.0292	0.154
No	13	29.55	40	19.80		
Yes	31	70.45	162	80.20		
Information not available	*7*		*83*			

There is no statistically significant difference (at $p<0.05$) between the neonatal and post-neonatal SUDI in terms of placement for sleep or exposure to tobacco smoke. However the extent of missing data for the post-neonatal group makes this finding unreliable.

There is a statistically significant difference between neonatal and post-neonatal SUDI in terms of co-sleeping ($p=0.005$). A greater proportion of neonates died suddenly and unexpectedly where co-sleeping was present than post-neonates.

1. *Position placed for sleep* and *unsafe sleep environments (co-sleeping)* were only relevant for the 39 neonatal infants and 255 post-neonatal infants who were placed for sleep

5.0 Family and personal history

Examination of the information held by the Team at the time of reporting revealed evidence of family and personal factors in 27 of the 123 infants' families (21.95%); all but two of these families had multiple factors. Drug abuse was evident in 20 families; 10 families had problems with alcohol; 10 had a history of criminal behaviour; history of domestic violence was evident in eight families; and mental illness was evident in five families. Fourteen infants were born with neonatal abstinence syndrome resulting from methadone withdrawal; the majority of these infants were born after 2000.

It is likely that not all the issues in the families of these children were evident to the investigating officers. It is reasonable to assume that the factors identified undercount the extent of difficulties in the families of these infants.

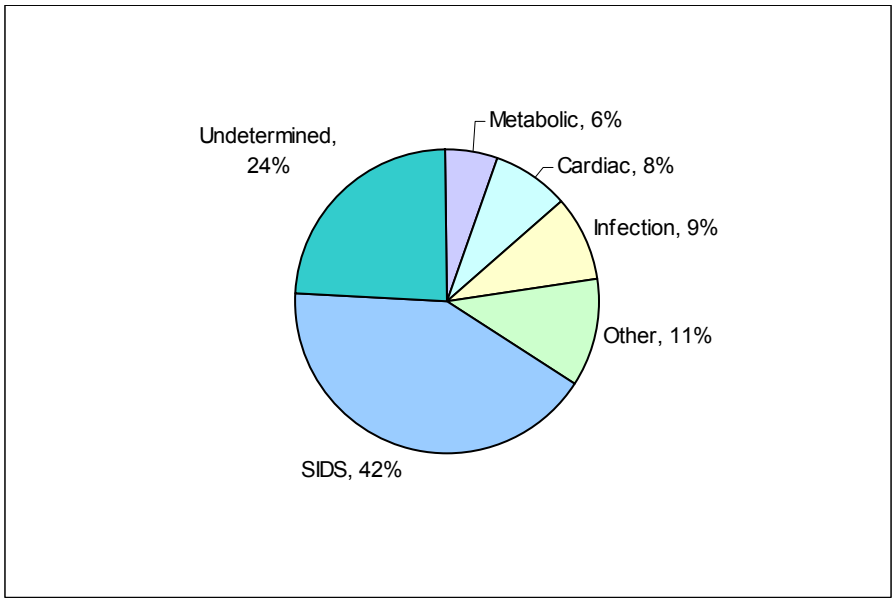
Twenty-six of the infants were identified as vulnerable – they had been reported to the Department of Human Services, Community Services before their death or a sibling had been reported in the three years prior to their death. One of these infants was living in foster care at the time of death.

6.0 Causes of death for neonatal SUDI from 1996-2008

6.1 Causes of death

Figure 3 shows the underlying cause of death for the 123 neonatal SUDI that occurred in the period 1996–2008. SIDS or an undetermined cause was evident in 65.8 per cent of infants.

FIGURE 3. Underlying cause of death for neonatal SUDI, NSW 1996-2008



The distribution is largely characteristic of all SUDI both in NSW and other population-based studies in the literature (Leach 1999; Cote 1999). The only differences reside with increased cardiovascular and metabolic causes in the neonatal SUDI. This is expected, since these conditions that are potentially life threatening classically present in the neonatal period.

Many of the infants who died as a result of a disease or morbid condition died of conditions that are preventable. The most common cause for deaths found was infection (11 infants; 8.94%). Sixty per cent of these were vertically transmitted, early onset, ascending infection with a diagnosis of pneumonia/sepsis.

The cardiovascular causes were the next most common cause of death (10 infants; 8.13%) and included eight neonates with congenital heart disease with or without congestive cardiac failure. Four neonates with coarctation would have been detected by screening for oxygen saturation by pulse oximetry in the early neonatal period and one with anomalous venous drainage. Expert advice indicated that no congenital heart abnormality may have been detected at the ultrasound scan for detection of anomalies, usually performed at 18-20 weeks gestation.

Metabolic disorders were evident in seven of the neonates (7.69%). For five of these infants the causes for death were definite and two non-specific. All but one that occurred on day one, occurred on days three or four usually before newborn screening results were available. Screening occurs on day three for optimal detection of the most common conditions, for example phenylketonuria and thyroid abnormalities, so prevention was not possible.

The 14 neonatal infants in the “other” cause of death category included infants who died with the following causes: *Other preterm infants (28 completed weeks or more but less than 37 completed weeks); Intrauterine hypoxia, unspecified; Rh isoimmunization of fetus and newborn; Neonatal cerebral ischaemia; Congenital absence, atresia and stenosis of rectum without fistula; Other specified drowning and submersion; Accidental suffocation and strangulation in bed;* and *Barbiturates, not elsewhere classified*. The Australian Modification (ICD-10-AM) of the International Classification of Diseases, developed by the World Health Organisation (WHO, 1992) was used identify these causes.

6.2 Explained and unexplained SUDI

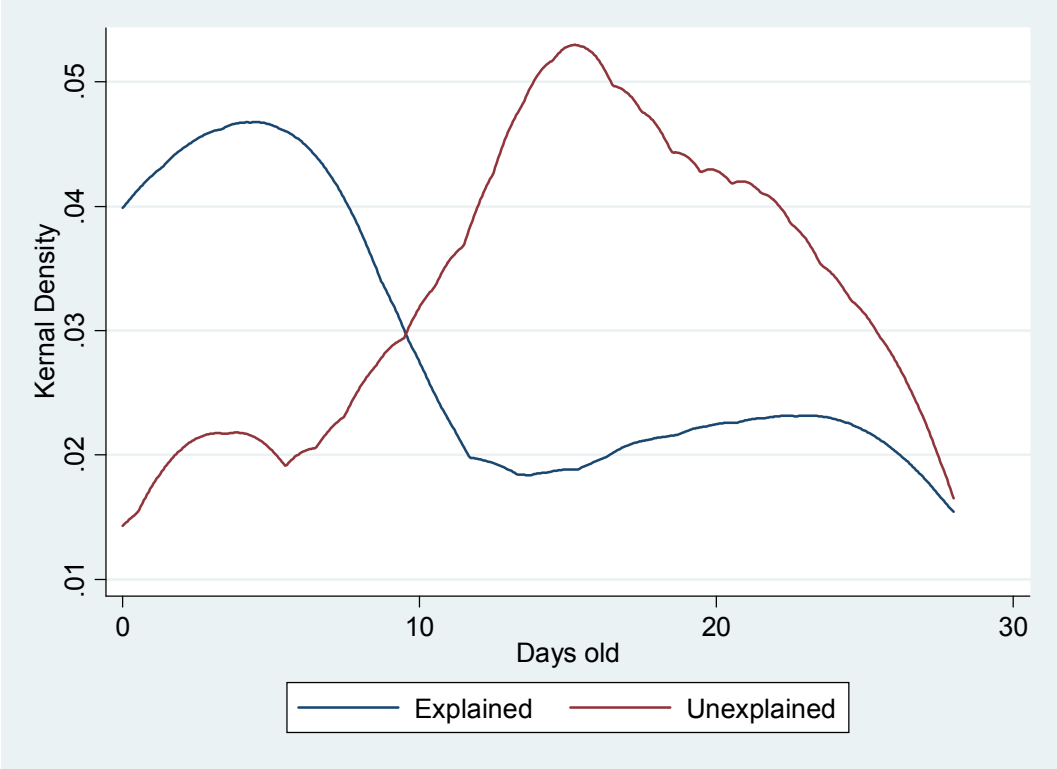
Over the period 1996 to 2008, 81 (65.9%) of the neonatal SUDI remained unexplained after autopsy (see Table 6). The proportion of unexplained deaths was greater among the late neonatal category compared with the early neonatal category (80% compared with 51%). Of the 42 neonatal deaths that were explained, causes of death included infections, cardiovascular disorders, metabolic, and others which included a range of miscellaneous causes.

TABLE 6. Explained and unexplained SUDI, NSW 1996-2008

	Neonatal		Post-neonatal			
	Number	Per cent	Number	Per cent	Chi-Sq	P-value
					8.7244	0.013
Explained	42	34.15	155	21.95		
Unexplained	81	65.85	550	77.90		
Pending			1			

Comparing the neonatal explained and unexplained SUDI groups in terms of age, explained SUDI is more likely to occur if death occurs in the first week of life declining at about five days. Figure 4 shows that an explained cause of death peaks at about five days. Unexplained SUDI peaks when death occurs at about day 15 and then declines.

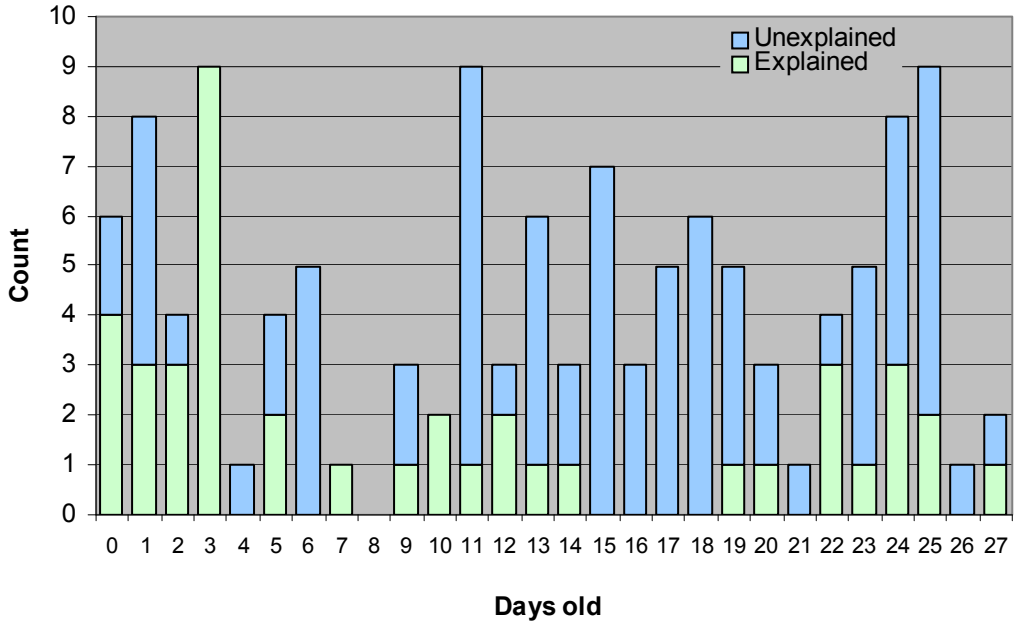
FIGURE 4. Kernal Density, explained and unexplained neonatal SUDI, by days old 1996-2008, NSW[1]



1. Jann, B. (2005). kdens: Stata module for univariate kernel density estimation. Available from http://ideas.repec.org/c/boc/bocode/s456410.html.

Figure 5 shows the distribution of explained and unexplained neonatal SUDI on each day of the neonatal period. Neonatal SUDI occurred on all but day eight. Unexplained SUDI were evident on all but days three, seven, eight and 10.

FIGURE 5. Explained and unexplained neonatal SUDI, NSW 1996-2008



7.0 Conclusion

This preliminary investigation of the deaths of neonatal infants that occur suddenly and unexpectedly revealed that neonates are not “immune” to either SUDI or SIDS, there is little difference in the demographic and modifiable risk factors of the neonatal and post-neonatal groups, and that there is opportunity for prevention.

While SUDI makes up a small proportion of all neonatal deaths that occurred over the period 1996-2008 in NSW, neonates comprise 15 per cent of all SUDI. This is a significant proportion.

Modifiable risk factors for SUDI including unsafe sleeping positions, exposure to tobacco smoke and unsafe sleep environments (co-sleeping) were evident in the sleeping environments of 90 per cent of the neonatal infants. The high proportion of deaths occurring in the context of these risk factors (including incidents that occur in hospitals), and the greater likelihood of death from co-sleeping during and immediately following the neonatal period suggests that prevention strategies need to address the risks to neonatal infants. Included in this are the risks associated with unsafe sleep environments particularly the risks associated with co-sleeping and bed-sharing where the mother may accidently fall asleep. The finding that SUDI occurs from the first day of life suggests that these strategies need to target mothers at or before the birth of their infant, and staff working in maternity facilities.

The Team has previously made recommendations to address the issue of unsafe sleeping practices (see Recommendations 1, 2 & 4, CDRT, 2005). The NSW Heath policy *Babies Safe Sleeping in NSW Heath Maternity Facilities* now explicitly describes the role of health professionals in modelling and promoting safe sleeping behaviours in maternity units and community-based child and family health work. The findings suggest that there may be difficulties in at least some locations in implementing this policy. A post-implementation evaluation could assist in determining the uptake of this policy. Broader prevention efforts are also required so that the community is informed of the risk of unsafe sleeping practices for neonatal infants.

The identification of cause of death is important for prevention efforts and the Team has also made recommendations to address the issue (see Recommendations 6, 8 and 9, CDRT 2005). In 2008, NSW Health released the policy directive, *Death - Management of Sudden Unexpected Death in Infancy*. This directive details NSW Health's and other agencies' role in the SUDI response. A compliance review of the Protocol was conducted by NSW Health in 2009. This review found ‘little change in the practices of forensic pathologists in the pre- and post-implementation phases’. Five recommendations were made to address this. The NSW Forensic Pathology Services Committee has requested another audit to be conducted at the start of 2011 to ensure that the recommendations and that the Protocol are being successfully implemented.

Finally, some of the infant deaths that occurred in the context of a disease or morbid condition died of conditions that are preventable. Early detection is critical if these deaths are to be prevented.

8.0 Methods

8.1 Aim

The aim of the research project was to study the population of all neonatal deaths that occurred suddenly and unexpectedly in NSW over the period 1996-2008, with a view to addressing the following questions:

1. What is the demographic profile of neonatal SUDI?
2. What are the risk factors associated with neonatal SUDI?
3. What can be done to further prevent neonatal SUDI?

8.2 Identification of cases

All infant deaths that are referred to the Coroner were assessed against the Team's definition. This assessment is completed by a Team member and an Expert Advisor appointed under Section 45O of the Commission for Children and Young People Act 1998.

All SUDI were further classified into two groups: explained SUDI, where a cause was found after a comprehensive autopsy and examination of the circumstances of the death; and unexplained SUDI, where the death was classified as SIDS or undetermined. This classification was undertaken independently by a member of the Team with extensive experience in forensic pathology.

8.3 Research method

A retrospective, population-based, descriptive study was undertaken. This consisted of a case file review of government and other official records held by the NSW Child Death Review Team. A chart audit was also completed including:

- assessment of availability of critical documents
- examination of 51 fields from each case file.

All neonatal infants identified as SUDI were included in the study.

Ethics permission was obtained from the Royal Prince Alfred Hospital, the institution most closely associated with the clinical issues and implications.

8.4 Data sources

Since 1996 the Team has maintained a Child Death Register (the Register) of the deaths of all children and young people aged 0-17 years registered in NSW. The Team has access to extensive information about the deaths of these children and young people.

Section 45T of the *Commission for Children and Young People Act 1998* imposes a duty on departments, agencies and individuals in NSW to provide the Team with 'full and unrestricted access' to records that the Team reasonably requires for the purpose of exercising its functions. This includes all government departments, statutory bodies or local authorities, the Commissioner of Police, the State Coroner, medical practitioners or health care professionals or heads of bodies which deliver health services to children. It also includes a person who, and the head of a body which, delivers welfare services to children (including family support services, children's services, foster care or residential out-of-home care, and disability services), and the principals of non-government schools (within the meaning of the Education Act 1990).

The Team also has access to the National Coroners' Information System (NCIS), an online computerised data storage facility that holds information on deaths reported to coroners within Australia. The NCIS is managed by the Victorian Institute of Forensic Medicine.

8.5 The population of children and young people

The data used for this report is of all deaths of infants usually resident in NSW who died suddenly and unexpectedly where the date of the death was in the 13 year period inclusively from 1996 to 2008.

8.5.1 Aboriginal and Torres Strait Islander infants

In this report the term 'Aboriginal' refers to all people indigenous to Australia, whether Aboriginal or Torres Strait Islander.

The identification of Aboriginal children and young people has been of ongoing concern for the Team and substantial efforts have been made over the years to improve coverage.

To improve the identification of deceased children as Aboriginal, two sources were used to identify Aboriginal and Torres Strait Islander infants:

- Aboriginal status of the child recorded on their death registration
- Aboriginal status of the mother, father or child recorded with the child's birth registration.

While noting possible deficiencies in the data, the judgement of the Team was that the coverage achieved through these methods was sufficient to undertake the planned analysis.

8.5.2 Geographic remoteness

The Accessibility/Remoteness Index of Australia (ARIA) was used to code remoteness. This was developed by the National Centre for Social Applications of Geographical Information Systems (GISCA, 2006). ARIA measures the remoteness of a location based on the physical road distance to the nearest urban centre (ASGC 1996), and classifies areas into five classes based on that measure. The Australian Bureau of Statistics is clear that the rules for separating areas into these classes can

be relatively arbitrary, though the members of each class are more like one another in terms of their distances to urban centres than they are to members of other classes.

The latest version of ARIA, commonly referred to as ARIA+ (ARIA Plus), was used (GISCA, 2006). Using the ABS labelling convention, these five categories are:

1. Major cities
2. Inner regional areas
3. Outer regional areas
4. Remote
5. Very remote.

See the Glossary for examples of locations coded to the various levels.

FIGURE 6. Distribution of geographic remoteness for base population

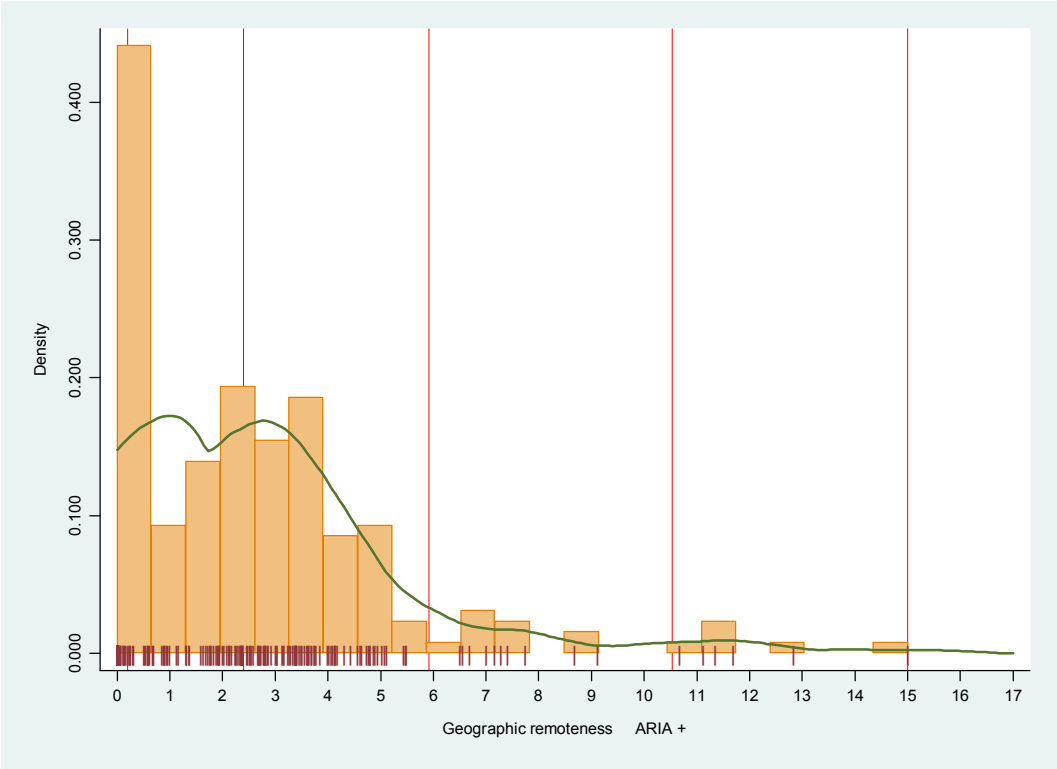


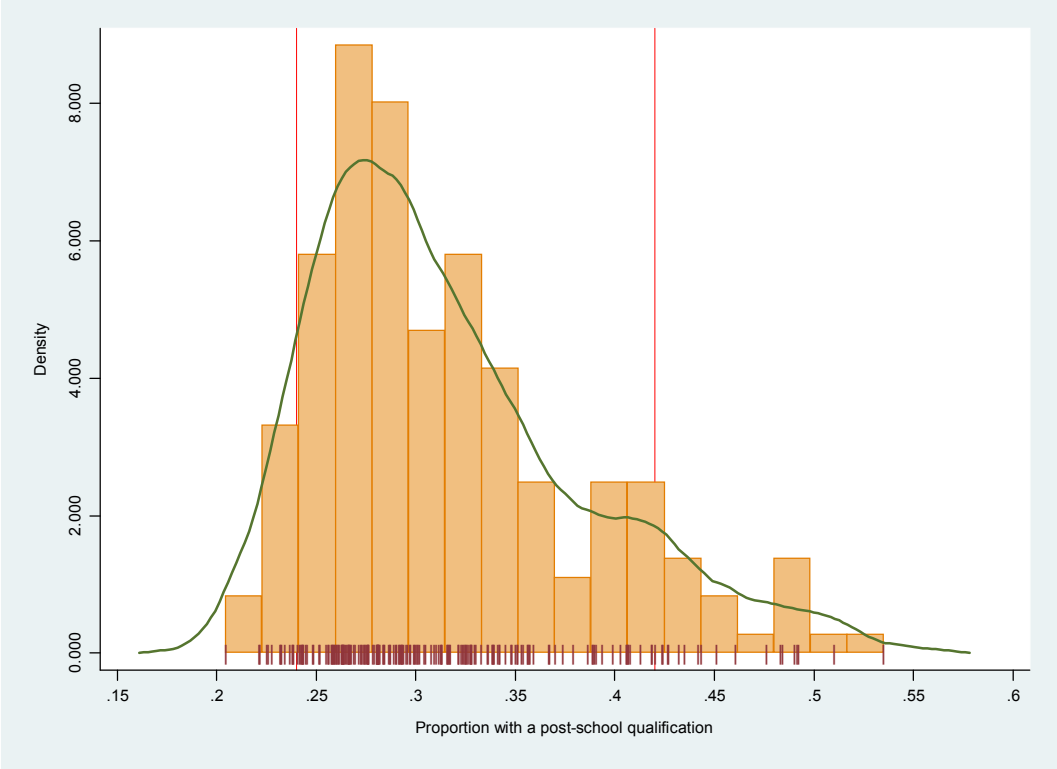
Figure 6 shows the distribution of the Statistical Local Area (SLAs) across the full ARIA+ index. The cut-scores for the remoteness groups used in analysis and reporting are indicated by the red reference lines. Those in major cities have an ARIA score of zero. The next group is the inner regional group, followed by outer regional, remote and very remote areas.

8.5.3 The proportion of the population with a post-school qualification

Post-school qualification is an ABS measure of educational level which is also a general measure of occupation and can be indicative of income — the smaller the proportion with post-school qualifications, the greater the socioeconomic disadvantage. A post-school qualification is defined as a qualifi-

cation above the Higher School Certificate or an Australian Qualifications Framework Certificate II qualification, i.e. university and higher vocational qualifications.

FIGURE 7. Distribution of proportion with a post-school qualification at the SLA level



One of the most striking results of the analysis of the Child Health Survey, 2001 undertaken for the 2005 study was the consistent relationship between the mother's level of education and risk factors for SIDS and SUDI. Figure 7 shows the distribution of the average proportion with post-school qualifications from 1996-2008 for each SLA. Some averaged close to only 22 per cent qualified, while at the other end are SLAs with averages in excess of 50 per cent. In comparing mortality rates across the distribution of post-school qualifications three comparison groups where created, using the 10th and 90th percentiles as cut-points. On average, at the 10th percentile 26 per cent of the population have post-school qualifications (95% CI: 0.364–0.388); while at the 90th percentile 42 per cent of the population have post-school qualifications (95% CI: 0.412–0.448).

8.6 Cause of death

The International Classification of Diseases, developed by the World Health Organisation (WHO, 1992), is the international standard diagnostic classification for mortality, including external causes of death. The Australian Modification (ICD-10-AM) of the fourth version of this coding system was used for this report.

The underlying cause of death was coded according to the WHO definition as the “disease or injury which initiated the train of morbid events leading directly to death or the circumstances of the accident or violence which produced the fatal injury”. Other associated causes following the underlying causes, including the primary cause of death or that which lead directly to the death, were also coded.

Coding of deaths was undertaken by the *National Centre for the Classification of Health, Brisbane* (NCCH). The NCCH is an internationally recognised Australian centre of expertise in the classification of morbidity and mortality data.

For the perinatal group the WHO rules were also used to determine multiple causes of death. Where the causes of death were not entered onto the *Medical Certificate of Cause of Perinatal Death: NSW Perinatal Death Certificate* in accordance with the WHO guidelines, the *Perinatal Selection Rules* were applied to reorganise the main and other conditions of the newborn and the main and other conditions of the mother into more appropriate fields. Where the main condition in the newborn was the mode of death, or prematurity and other conditions of the infant were entered, the first mentioned of these was assigned as the underlying cause of death and the other conditions as associated causes. Where the strict application of the perinatal rules resulted in an ill-defined underlying cause of death being assigned, other information held by the Team, such as hospital medical records, police reports and pathology reports, were used to add specificity to what was documented on the certificate.

This report includes information on the underlying cause of death (“the first in a train of events”) . It does not include information on any associated causes.

8.7 Analysis

Stata MP v11.1 was used for all analysis undertaken in this study.

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Glossary

Aboriginal

A child who has been identified as either Aboriginal or Torres Strait Islander on their NSW Births, Deaths and Marriages death certificate or a child or their parent/s who have been identified as Aboriginal or Torres Strait Islander on the NSW Births, Deaths and Marriages birth certificate.

Bed-sharing

An adult, usually a mother/parent and infant share a bed for the purposes of feeding and settling,

Underlying cause of death

The first cause in the chain of events leading to death.

Co-sleeping

Where an adult, usually a mother/parent and infant sleep together in bed.

Diseases and morbid conditions

Natural causes of death generally resulting from disease. Examples include epilepsy, pneumonia, and leukaemia.

Early neonatal death

Death from zero up to 7 days.

External cause of death

External causes of death are those external to the body. Examples include suicide, transport incidents, drownings, assaults, and poisoning.

Gestational age

The duration of pregnancy in completed weeks from the first day of the last normal menstrual period. Where accurate information on the date of the last menstrual period is not available, a clinical estimate of gestational age may be obtained from ultrasound during the first half of pregnancy or by examination of the newborn infant.

Geographic remoteness

Geographic remoteness is a measure of location, using the Accessibility/Remoteness Index of Australia (ARIA) developed by the National Centre for Social Applications of Geographical Information Systems (GISCA, 2006). ARIA measures the remoteness of a location based on the physical road distance to the nearest urban centre (ASGC, 1996) and classifies areas into five classes based on that measure. The latest version of ARIA is ARIA+ (ARIA Plus). Using the ABS labelling convention, the five remoteness categories are major cities, inner regional areas, outer regional areas, remote areas and very remote areas.

International Classification of Diseases (ICD)

The international standard diagnostic classification for mortality developed by the World Health Organisation. The purpose of the ICD is to permit the systematic recording, analysis, interpretation and

comparison of mortality and morbidity data collected in different countries or areas and at different times.

ICD-10-AM

ICD-10-AM is the Australian Modification of the 10th revision of the ICD.

Infant

Children under one year of age.

Inner regions

A category of geographic remoteness in ARIA. Examples of SLAs coded as inner regions include Hawkesbury, Lake Macquarie, Maitland, Tamworth, Lismore, Albury, Wagga Wagga and Ballina.

Late neonatal death

Death from 7 up to 28 days.

Lividity

Lividity is a settling of the blood in the lower (dependent) portion of the body, causing a purplish red discoloration of the skin: when the heart is no longer agitating the blood, heavy red blood cells sink through the serum by action of gravity.

Major cities

A category of geographic remoteness in ARIA. Examples of SLAs coded as mostly as major cities include most capital cities, as well as major urban areas such as Queanbeyan and Newcastle.

Neonatal period

A newborn infant aged under 28 days.

Outer regions

A category of geographic remoteness in ARIA. Examples of SLAs coded as outer regions include Gunnedah, Kempsey, Inverell, Cooma-Monaro, Parkes and Coonabarabran.

Post-neonatal period

An infant aged 28 days to less than 365 days.

Remote regions

A category of geographic remoteness in ARIA. Examples of SLAs coded as remote include Balranald, Warren, Walgett, Hay and Moree Plains.

SLA

Statistical local area.

Statistical significance

Statistical significance only has meaning in relation to some predetermined level of confidence regarding the certainty needed that a finding is not a result of chance.

It is an estimate only, based on a range of assumptions about the information being analysed. The level of certainty needed (the level of

confidence), depends largely on the consequences if a finding were determined to be true when it was actually false.

Vertical transmission

The transmission of an infection or other disease from mother to child immediately before and after birth during the perinatal period.

Very remote regions

A category of geographic remoteness in ARIA. Examples of SLAs coded as very remote include Bourke, Lord Howe Island, Brewarrina and Cobar.

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